Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Scott Mack

Medicare

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My Mom was diagnosed more than two years ago with this horrible disease. I moved back to Michigan from Minnesota two years ago for a career opportunity and to be closer to family during a time of need. My father's health took a turn for the worse while he was caring for my mother and his brother in Florida. My father had a mental breakdown from all the stress. After my father started to get better, my mother's Alzheimer's started to get worse. After two years of being a caregiver, I could not imagine doing anything else. It has been a rewarding experience for me to be here for my family. I want to do everything that I can so that my parents can enjoy life and have great experiences, during the best years of their lives.

Medicare

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Bob Lemley

Medicare

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karen stickney

Medicare

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Vincent Patti

Medicare

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Pastor Thomas Humphrey

Medicare

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Mary Baker

Medicare

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Perhaps it will help to eliminate fears if the results are negative. My husband had Alzheimer's and my two children worry constantly that they might too. If the scan can give them a little more time to prepare their lives if symptoms are found, they need that.:

Medicare

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My Mother was diagnosed with Dementia and she went downhill fast. We didn't know what to do to help her. Please don't put any obstacles in the way in terms of diagnosing and treating this horrible disease!!!

Medicare

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Paul Ordway

Medicare

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My husband has been diagnosed with Dementia NOS (Not Otherwise Specified) and Parkinsonism. His neurologists at Mount Sinai Hospital in NYC think he does not have Alzheimer's disease but are not sure what kind of dementia he has. Dr. Gandy, the head of the Alzheimer's Research Project at Mount Sinai, wanted to do a PET scan to better determine the type of dementia my husband has but Medicare will not pay for it and we cannot afford it. Although getting a more accurate diagnosis for my husband isn't likely to affect his treatment options, it would be helpful for us to know the cause of his dementia since some forms of dementia are more likely to be genetically caused than others. Since our adult children have not yet had children of their own, it would be very helpful to know whether they are likely to pass on genes to their children which would make them likely to develop dementia. If they had that information, they might choose to adopt rather than have their own biological children. A more accurate diagnosis might also mean that we would be better able to plan for my husband's future care. Lastly, testing of this kind might give researchers more information that would help them to find a way to prevent or more effectively treat these devastating diseases.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care as soon as possible. I want to tell you how difficult this is -- here is my story:

Both of my parents died with dementia, as well as my mother in law. If they could have been diagnosed earlier, they could have taken advantage of current medications and had a better quality of life for a longer period.
My mother might even have been able to enjoy her first great-grandchildren, and not have taken the car keys, only to be found hours later, 100 miles away, going the wrong way on a divided highway. Only sheer luck prevented her killing or dying in that situation.
Delaying this new diagnosis tool will harm thousands of families. That is just plain wrong!

Medicare

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Information is power.

R May

Medicare

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Medicare

Today, I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My response to this email couldn't have been more timely! I just returned from the City that I have worked for the last 24 years. Today I had to relay to my Department Head and our Human Resources Manager that I have been diagnosed with the early onset of Alzheimer's. It is going to require that I retire early with a 15 year old son depending on me at the young age of 57.

Fortunately, for me thanks to PET imaging, I had warning so I can prepare for the inevitable. Preparation is not something many parents are able to provide for their children. To negate American families the opportunity to plan for this devastating disease is a sin and a true American tragedy. Our country is blessed with remarkable research and our citizens deserve the opportunity to plan and decide for their future. If you take this away from us you are taking away our freedom!

Respectfully,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
I wish that I had the opportunity of receiving Beta Amyloid Positron Imaging test but I could not afford it.i am I so different or deserving then someone who afford the test? Don't I have the right to take advantage of such a diagnostic tool.

Deb Standard

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: I am an RN and every time I took my Dad to the neurologist I asked if his dementia was Alzheimers and was never given a definitive answer. For one year Dad progressively lost his everyday abilities and parts of his personality. Thru out that final year his neurologist would never say it was Alzheimer's or not, even to this day I cannot say his dx was Alzheimer's, even tho from what I know of this disease, it was. Wouldn't it be nice for me and my siblings know for sure what our genes could possibly hold for us. Please allow for earlier PET scanning for definitive diagnoses. Thank you for your consideration.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My stepfather was treated successfully for colon cancer at age 80, had three more good years followed by a so-so year, and four increasingly bad years of dying with some sort of senile dementia. I do NOT want to end p like hm.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My Mother recently died and had Alheimers. Had she beeen diagnosed earlier, she would have lived much longer and had been healther!! Her other siblings are still alive and in their early 90"s as healthy as can be. My mother died at 88 and she was far more active, beautiful, and had a zest for life that was admirable. Everone said she would live the longest and she diedied first! She had so much zest for living and looked 20 yers younger than she was.
Pleas provide us with Dementia Diagnosis so we can all live long and healthy lives!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My older sister, a bright, well educated woman, (msters Columbia University), retired Director of a leading Geriactic Hospital in New York City, has been afflicted with severe memory and motor skills loss. She is now a resident in the alzheimers unit of a continuing care facility. As a single person she depends on her nearby family members for emotional support. The weight of the responsibility those of us who atempt to provide a connection to reallty for is heavy and we fear we are not doing enough. It is heart bracking to see her slipping away and not getting any thing to counter act the deseases progression. Anything that might prolong her useful life would be a pluss for society and her petsonnally.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother is in the late stages of Alzheimer's. In the beginning when we began to realize that something was very wrong, we experienced a very frustrating YEAR before the doctor would make a diagnosis. The doctor required that my mother go through a battery of tests that she did not show any symptoms for in spite of the fact that she was showing symptoms of Alzheimer's. By the end of that YEAR, I believe it was too late for the typical medications to have any true effect on the course of the disease. If this test is approved for coverage by Medicare, I believe that many other people would not be subjected to this type of diagnosis procedure and it might actually save Medicare money by avoiding unnecessary testing.

Please reconsider your stand and approve Medicare coverage for this technology.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My mother worked in the Navy department in a high pressure job during World War II. She married my dad, raised two daughters, worked in business for many years, volunteered at the church, and was active in her community. She began to show signs of Dementia at age 78. When she was 84, my dad died, and she continued to live in their home, and during that first year she began requiring more oversight than my sister and I could manage with jobs and families of our own. She no longer recognized a picture of her husband of 57 years or recognized his name. She spent 4 years in an assisted living center, and then 4 in an Alzheimer's facility. Year by year her world grew smaller and she became less able to do basic care for herself or recognize those around her or her surroundings. For the last 2 months of her life, she did not even remember how to swallow. This is a terrible end for a capable, intellegent woman, and it was a toll on her family. The cost of care can crush many families. A timely diagnosis of these patients may quickly lead to therapies that stave off the terrible end so many millions will face. Please support diagnostic testing and research for this terrible disease.

Medicare

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My mother of blessed memory died because of complications from altzheimers. She was diagnosed 10 years ago, but looking back, if she had had a proper diagnosis when earlier signs began to manifest, she may have a better life during her very difficult years with Alzheimers.
Since the cure seems to be in the distance, proper and early diagnosis will radically change the lives for many patients. Money and time will be focused and directed properly. Please consider the trmendous boost it will be for all of us, you and me, to have a reliable diagnostic tool to combat a disease that took my mother's life too early. The goal is to extend our lives in the face of Alzheimers with the porper daignostic tool. This tool may be the key for a btter life for the patient and for the caregivers. Thank you.

Medicare

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My mother was well into her dementia before a diagnosis could be made. Knowing the real nature of her problem would have saved her a great deal of suffering. From a purely practical perspective, it would have saved Medicare money by not having her take unnecessary medications. Postponing action on this much needed testing procedure does not serve patients, places unnecessary burdens on families, and costs the Medicare administration and private supplemental insurance ecomoanies money. Thank you for making the right choice.

Medicare

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Mr Randy Owens

Medicare

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My aunt fell over a concrete block in a supermarket parking lot and was out cold for a brief period of time. She was somewhat addled after that, but we didn't think it was Alzheimer's. My sisters took her to a couple of different doctors for diagnosis, and my aunt's intelligent replies about earlier periods of her life fooled them. It was only after my sister got her to a specialist for brain scanning that it was finally determined that she did have Alzheimer's.The delay certainly did not help her to get the right treatment in a timely fashion.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I have seen the progression of this condition in my family. The memory issues that gradually worsen until the dementia becomes severe and out of control. A very sad state! A wait and see....or with the seriousness and demands this disease commands, would not a diagnostic tool like the Beta Amyloid Positron Emission Tomography be worth the effort to achieve a diagnosis and hopefully better end results??

Please, give this serious consideration. The projected incidence is expected to be very high. I am 75 and this issue concerns me. The elderly population continues to increase. This PET imaging is needed.

Gratefully,
Iole LeTissier
Michigan

Medicare

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My wife has had alzheimer's for three years. So far, I have been able to take care of her in our home despite my own heart problems. She has a good disposition, but ask me the same questions over and over and I pray for patience every night and try and respond to her. One day a week, I have a professional caretaker come in so can play golf and have lunch with my friends. Unfortunately, she can no longer drive and the only thing she likes to do is eat out six days and nights a week. I barbecue on Monday nights and she says she is glad we only have to stay home one night a week. She no longer plays golf, and hasn't one lady friend that ever calls her to have lunch. We have been married fifty five years and I want to take care of her as long as I can. We still love each other very much.

Medicare

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My mother, who almost died and was on total life support from a heart attack & pneumonia has what is called vascular dementia.

I am now my mother's caregiver and I see the dementia getting worse and worse. I would like her tested for Alzheimer's disease ASAP so that I know what I am dealing with.

It is heart breaking to see and be with just a shadow of my mother.

Please, made PET imaging available to my mother, me and my family.

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I have had the HIV virus for 34 years. While I look perfectly healthy, I have had memory problems for several years. I have complained to my doctor, but it's difficult for me to prove the necessity and urgency of a proper diagnosis. There seems to be few resources for diagnosis. I need to know what direction my health is taking, and the complication of years of HIV infection makes this difficult.

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In 1997 my mother at age 79 was diagnosed with dementia and told it most likely was Alzheimer's. Although there were some medications thought to help if it was Alzheimer's, there were others that would be better should the dementia be a different disease. Our family was told that there wasn't really a confirmed diagnosis until a postmortem autopsy would be done. Mother passed away in 2007. The autopsy revealed it had been Alzheimer's. For 10 years we wondered if we were providing her the best chance with medications for Alzheimer's. Had the Beta Amyloid Positron Emission Tomography been available, we could have made decisions based on real knowledge rather than supposition.

Hopefully the decision to make the breakthrough in diagnostic testing will not be delayed by Medicare imposing additional barriers, delays and costs.

Because others in my family have died from Alzheimer's, I have a higher risk to develop it. That doesn't mean should I develop another form of dementia that I want to assume that it is Alzheimer's. I would like to have a Beta Amyloid PET scan to confirm an Alzheimer's diagnosis earlier than having an autopsy done.

Respectfully,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My wife was diagnosed with early onset dementia at age 52, she is now 55, and it's Alzheimer's. No one should have to go through this. Anything that could help should be tried, not dismissed.

Medicare

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My mom was 46 years old when I started noticing something seemed wrong. It took me a year to convince my parents to seek medical attention. There wasn't a lot of information out there about Alzheimer's, and especially about early-onset Alzheimer's. It seemed impossible to even consider that might be what was going on. Finally, the testing began, and it took over a year of agonizing tests, including a spinal tap, to get a diagnosis of early-onset Alzheimer's, and even then it was still inconceivable.

My mom courageously submitted herself to tests and experimental medicine to try to slow down the deterioration of her brain. Nothing worked. Within a few years, at the young age of 52, my vibrant, steadfast mom passed away.

If there was a way to detect the beginning of Alzheimer's far sooner, we might be able to do more to halt or slow it's progress. I'm now almost 32, planning on having children with my husband within the next few years, and I try not to think about how young my children will be if I were to die from early-onset Alzheimer's, which is hereditary. I try not to think about how young they'll be if I begin to deteriorate at the age she did, and if they'll remember me as who I am, instead of the person Alzheimer's transforms our loved ones into. I try not to think about the financial and emotional strain caring for me will place on my family. I try not to think about feeling myself disappear little by little.

And I'm only one person out of many.

The cost of providing timely and accurate diagnosis is nothing compared to the cost of not providing it--on individuals, on our nation as a whole. Nobody deserves to die, or see their loved ones die like that. You could easily be Alzheimer's next victim, and if not you, someone you love. Think about what you would like to have done if that were the case.

Thank you for hearing my story.

Medicare

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I am a successful 57-year old woman seriously impacted by this health risk. My mother has dementia and I have been told that I have a genetic variation that puts me at very high risk of developing Alzheimer's.

We need every possible new tool to enhance diagnosis and develop better treatment options.

PLEASE ENSURE THAT MEDICARE FUNDING IS PROVIDED TO ENABLE THIS PROMISING NEW TECHNOLOGY!

Medicare

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I have started to be forgetful and sometimes confused. My mother had Alsheimers and it appears to me and my f amily that I am mid way in the morass of this terrible disease. As it is, I am giving up my home and driving my car, as I am in the nether world of what may be this disease. Until recently I was a contributing member of this community, and feel an obligation not to waste my years of education and commitment to others. My future is undetermined by my symptoms. If I knew what I have going on in my brain, I could deal with it. Not knowing is really a hardship and a waste.

Medicare

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This trrible disease runs in my family, grandmum, mum, aunt (diagnosed at 56), three uncles. Ladies and gentlemen I live in terror of this disease, I would appreciate the opportunity to know as early as possible when it is starting. You see I have no family so I could make arrangements for my care, I would know if I should sell my property now to finance that care. I would make arrangements for my pets care. I believe in being prepared. Waiting until I show obvious signs is too late.....Do you understand? If I have to wait until I show obvious signs, I will not be mentally capable of making these preparations for the final phase of my life. I am begging you please make this PET imaging available to us. Respectfully submitted. Laura Layton

Medicare

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I have been caring for my Mother, who has slowly disappeared and with hind site it started in 1999 and now in 2013 she doesn't know me or anyone else. I feel anything that could diagnosis this earlier would be a God send.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

It was finally determined after almost three years that my mother did indeed have Alzheimer's not dementia that her doctor insisted she had. She was not given any medication that could have slowed the process which meant we lost her as a person much sooner than had she been on medication.

An early diagnosis helps everybody plan ahead

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother in law has Alzheimers. But in the 70s she also had a brain tumor, which was removed. When she began to show signs of memory lapse and a retreat into more childish behavior, there was no way of telling if this was Alzheimers or damage from the surgery, or if the tumor was coming back.

Now, of course, it is too late. She is suffering from Alzheimers Senile Dementia. And there is no way of turning back the clock.

A diagnostic tool would have enabled us to get the right treatments for her and slow the progression of this hideous disease.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My Mother has dementia..assumed to be Alzheimer's Disease. Mom always stayed active and ate healthfully, so her body is pretty healthy. But though she tried very hard to hang on to the memory of me, about a year ago, it was clear that she no longer knew who I was. For the whole time she was in facilities she would call everyone by my name. Mom lived up north and my daughter arranged for a place near her, as my disabled husband was requiring more and more care from me. The consequence of that was, that I seldom could leave to go and visit my mother. My Mother and I were so very close..joined at the hip..as they say. I just recently lost my husband of 36 years and if I ever needed my Mom....it would be now. She is 91, but for this disease she would have been living a fairly normal life...maybe some back problems. I am now feeling very alone in the world...my kids are very busy with their lives and are not near by. I miss the closeness my Mom and I had. It was so healing for both of us. We have been separated by a thief called Dementia or Alzheimer's Disease. If Mom had had a diagnostic tool to determine whether or not it was really Alzheimer's, I can't help wondering if things might have been a little different. She started showing marked signs of memory problems about 2003...came to live with me after having a psychotic episode(2006), where she didn't know where she was when there was a power failure, and escaped out of the house through a first floor window, but got knocked out as she fell out...so for 2 years I was caring for my husband and my Mom who was getting progressively worse...hostile temperament...she wanted to go back to her home and have me come and visit a lot, so we tried with 24 hour care...she escaped again and didn't recognize the house as hers anymore with a stranger living there with her. My daughter then found a place near by her in 2008. In 2011, the large facility felt they were not staffed enough to deal with her without heavy sedation which was making her unresponsive...and recommended a converted 6 bed home...we found a wonderful one that has been able to get her off all but 2 medications with their wonderful 1 on 1 relationship with their residents. Could a lot of this have been avoided? Perhaps delayed? Could I have a Mom now that, while perhaps a little confused or memory compromised... would still know me as her daughter that she loves so...and I could tell her of my loss and she could hold me and tell me that it's going to be ok?

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: There are precious few diagnostic tests that can be definitive either as a positive test or a negative test regarding Alzheimer's. It is important to me that I have access to all the diagnostic testing that has been proven to yield useful results to my doctors.

Dennis Matthies

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My mother had Alzheimer's before there was a way to diagnose the disease. Living with a parent with Alzheimer's is terrible. With some treatments available today, we need to know as soon as possible what the diagnosis is.   Then, action can be taken.

My mother's mind died years before her body gave up. She had taught school for years and was very intelligent. Such a shame. If anything can be done, it should be done.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Rosia Johnson

Medicare

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Barbara Layne

Columbus, OH 43209

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My lovely Mother was originally diagnosed with Alzheimer's in 2003 but looking back now we realized memory issues were
present at least 4 years earlier.

She became very vulnerable and after 20 yrs of marriage to my step dad my older sister in another state convinced her to start
divorce proceeding and leave him to live with her. She went back and forth from her in Oregon and me in Washington state each time when she went back to Oregon my sister would tell her lies about my step dad and me. My sister was after control of her portion of their estate. After a few years of debating over the settlement of their divorce, she called my step dad and told her Terry was controlling her. He picked her up they cancelled divorce proceedings and they spent one year together before she needed full time care. My step dad brought her from California to Washington State where I live and we put her in a memory care facility of 36 residents. It was a wonderful place and I spent every day with her watching her fade away. She sucumed to the disease 18 months after entering the facility and I was with her as she passed. The sad part is in the beginning to the moderate phase of the disease the patients know their memories are fading and it gets very stressful.

The earlier the diagnosis the better as patients can get treatment earlier and perhaps give them years of better memories.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: When my daughter married James they moved into his house and she said he would frequently ask where she had moved dishes in the cupboards or other things of his that she had not moved at all. He often times seemed confused about things he should know. As the years passed he often forgot appointments and meetings with friends. I remember her telling me on their 5th anniversary that she was very concerned and she suspected he was having trouble at work. She said they had made an appointment with his doctor to talk to him about the problems he was having. The doctor said to him, well your grandmother had Alzheimers so I suspect you do too and put him on one of the Alzheimers meds. Shortly after, some of James' co-workers talked to my daughter at a company picnic and she found out that he was indeed having problems and they had been trying to cover for him. When they went back to the doctor, for some reason he said he thought they should take him off the medicine. They found a new doctor who decided he was just stressed from the job and he put him on an anti-depressant. It helped a bit with his mood swings and his paranoia, but did nothing for the memory problems. At work he was unable to do his job as a bus mechanic. Finally they decided that they were going to insist that he be seen by a neurologist to find out if this really was dementia or some other problem. It was affecting their marriage badly. The doctor did not agree with the decision, but referred him. He was given some tests and did poorly. When it was all done the neurologist diagnosed him with Early-onset Alzheimers disease. By this time 11 years of misery had passed. This was a middle class family with a home and cars and a life and now they are struggling to hang in. They have no insurance, because what they could get paid nothing anyway. She has 1st stage kidney disease and a clotting disorder. She has gone back to work to help, but he is soon going to be unable to stay alone while she is gone to work. Anyway that they can diagnose this disease early for the young patients needs to be done. They have had years of confusion about what was happening and by the time they finally get to a diagnosis they are financially destroyed. I am very proud of the way they are handling what they are dealing with, but it would be wonderful for young people to not have to go through such a long agonizing wait.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:my mother was diagnostic with Alzheimer's the doctor could not help her because they did not have the treatment to help her get well,I don't want that to happen to me this is a scare feeling but you don't suppose to live in fear but this is one of it's we deserve the right diagnostic and early treatment to get well for our grandchildren to be around see our grandchildren graduate from college .please don't take that away from us break the barriers.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother, her father and two of her brothers had Alzheimer's. I cared for her to the very end and it was horrible. I am afraid that my children and/or my sister's children will face this same ordeal if a cure is not found as soon as possible.

Medicare

I am a 66 year old woman with three wonderful children and seven wonderful grandchildren. I was diagnosed with Alzheimer's disease about two years ago after my children forced me to see the doctor because it was obvious to them that I was becoming very repetitive and my memory was failing me. I would go to the grocery store like I did in the past and several days later would find all of the groceries that I bought in the trunk of my car. I would spend an evening with friends that I have known for 40 years and with minutes after they left forget who I had been with. I am now having trouble with names and could not recall the name of a Nephew who I love very much and who is soon going to be a father. I torment myself regularly by misplacing my handbag and house keys. But I am lucky. I have a loving husband and loving children who are witnessing my life changing before their eyes and around to support me. Many people of my age and older do not have the support group that I do and I feel very bad for them. This awful disease is predicted to hit more and more people over the next few years. If it is ignored it will cause great pain to families and people beyond count. It will end up costing Medicare more than anything else because of the need of those who cannot afford to have caretakers and who do not have family caretakers. For both humanitarian reasons and financial reasons Medicare must support every opportunity to diagnose and eventually cure Alzheimer's disease. My husband has helped me write this letter but the thoughts are my own.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My Aunt was diagnosed with Alzheimer's but I took her to several Doctors who diagnosed her with Dementia due to a stroke. I only wish the first Dr had the PET imaging available which would have saved her from going to numerous Dr's before getting a final diagnose. My mother later was diagnosed with Dementia also and then Alzheimer's. If the PET imaging had been available maybe the diagnose would have been different. My mother-in-law was diagnosed with Alzheimer's and to this day we are not sure she has Alzheimer's or Dementia or even if she had a stroke which may have caused her memory lose. Perhaps with this new technology, she could get the correct diagnosis.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Our late mother, , who was diagnosed with dementia, suffered all the way to the end of her life, in a nursing home etc.. Medicare - assisted her care and treatment too.. thank you..

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I once had a vibrant and inquisitive wife, who now cannot function in any but the simplest way. Please revise your decision.

Thank you,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My family was impacted by physicians' lack of knowledge about Alzheimer's. Because appropriate treatment was unavailable my family lost approximately 2.7 millions to con artists targeting a family member who had this form of dementia. Neither federal nor state laws protected my family from the actions of crminals focusing on persons disabled with Alzheimer's. If there had been sufficient access to treatment these attacks would not have had resulted in the monetary and health losses we suffered from.

Mr Craig Alvord

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother was diagnosed in her 50s with early onset Alzheimer's. It is thought that she had probably had it for 5 years at that time. There were no known treatments, presciption or otherwise for Alzheimer's, so she agreed to take part in a trial drug study for the first drug that was ever offered for Alzheimer's, Tacrine. She died in 1996 at the age of 61.

Although there are now more drugs available than when my mother is alive, there is still no treatment and no cure for this disease. PET scans will allow the doctor's to better track Alzheimer's from its onset to its completion and hopefully develop better treatments and eventually a cure. Please help current and future Alzheimer patients so that may have a better prognosis than my mother.

Thank you.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Crystal Tomaino

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Ms A van der Hoogt

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother began her journey into Alzheimer's in 1998, though as I was in denial, she showed symptoms earlier. She began to forget simple things, like putting paper plates in an oven, which as so out of character as she was a top skilled cook. Her doctor asked her some questions, gave her a "repeat" my sentences, which she failed and embarrased her. Thus began the long, slow heart breaking journey to her death on 1/11/2011 at the age of 89. For years she was bed bound, mute, could not move, requiring 24 hour round the clock care, which she received in her on home, not at a nursing home. This is a disease far worse than cancer, as you loose them long before they die.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Both my mother and brother died from some form of dementia that was diagnosed as Alzeheimer´s. My brother began to have dementia symptoms as young as the age of 63. Both of them had inadequate diagnostic testing, and I was not their primary caretaker and had an impossible task of trying to determine what tests they actually had. Both of them had dementia and aphasia, but also other symptoms that were inconsistent with Alzeheimer's. I strongly feel they were MIS-diagnosed, and therefore improperly treated. Both became worse on the medications they were prescribed, and better when taken off the medications, but their caretakers/doctors kept putting them back on the medications when I left town. I am still trying to track down what other diseases they could have had, so that the very many offspring of my brothers large family can try to get better preventative care and correct treatment if needed.

I implore you to not make the already poor US healthcare system even weaker, and subject even more seniors to inadequate and improper care by denying them this new diagnostic tool. Better diagnosis will allow those with dementia symptoms caused by possibly treatable conditions (and there are many) to have a productive life, and will prevent the extreme suffering caused by an Alzeheimer´s misdiagnosis.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I am a Hospice volunteer and have worked with Alzheimer's patient for many years.
PLEASE, make this PET imaging available for all the people who may be at risk of this disease !!! Do you have any idea just how devastating this disease is for these people?
Suppose it was one of your relatives!!!
Let's do all we can to save people from this suffering.......

Ronee Henson

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My husband was just told he may have Alzheimer's. We don't know for sure because there is no test to help us know. How can I plan for the future if I do not know. Should I move in with my children. Can I care for him at home . How can I do what is best if I do not know for sure. We have always tried to do what is best and you need the correct information to do that. I can not tell you how hard this is. The pain of not knowing has paralyzed me. Please make PET imaging available so we can get our house in order and I can plan for caring for my husband.
Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother died last year because her Alzheimer's was not diagnosed early enough to get any medical treatment.
Not having an early diagnose took years from my otherwise healthy mother! Please help others not lose a lived one because of failure to diagnosis this TERRIBLE disease!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I lost my husband, my home and my way of life to Alzheimers. My husband was diagnosed at age 45 with "Alzheimer's or related dementia". He died two years later. We lived for months with his deteriorating condition--job loss, foreclosure on the home we built together, divorce, going on welfare for the children and myself all the while not knowing what was "going on with him". An earlier diagnosis would have saved untold pain and guilt. Please be supportive of the advancing technology which will assist in diagnosis and thus follow-up care.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My grandmother, her sister, my mother, and her three siblings all have either died of AD or are presently in the last stages of the disease. We NEED the diagnostic tools, including the Beta Amyloid PET imaging to intervene sooner and provide the necessary medication to stall AD as we continue to search for interventions that will make a real difference in halting this disease.

Please make this tool available NOW to ALL who need it!!!

Sincerely,

Medicare

I have lost two aunts, my mother, and this past May, my brother to Alzheimer's disease. It is predicted within the next two decades to be our nations #1 killer. Yet research is on the decline. While cancer deaths are declining, 92% of available funds go towards cancer research, six scientists for every one devoted toward Alzheimer's research. Alzheimer's is age driven, the Silver Tsunami is washing over us.....and we need your help and LEADERSHIP!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
I'm 78 years old. I have been a nurse in the geriatric field. I have worked to implement care for those with memory problems. With all this experience it has still been astounding to me the number of close friends and relatives who have this disease. The pain of experiencing non recognition from close friends and relatives is distressing. Please allow coverage for this technology.

Medicare

Your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's, you will be killing people, but only after they have a slow torturous decline and their families are torn apart.

as not my only experience. From1985 until the development of the Protease Inhibitors, the AIDS therapies that have made it possible for PWA's to live with the disease, I have worked in the field and have founded two international agencies, so I knew dementia well as it ravaged the minds of so many; many of whom were among the country's most talented artists, writers, Broadway performers, film makers. I think you get my point. We lost our best and brightest.

Your decision as it stands is wrong headed and cruel. We´ve got FDA approved technology that I want to be able to take advantage of. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. My Medicare is designed to allow me to have health care and yet these barriers, wasted time, and additional expenses you would impose on me and my children´s happy lives is unconscionable. This policy must not be exercised.

Ms Sally Fisher

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I watched my mom slowly progress from a bright coherent college educated woman through the various stages of memory loss! This is not easy and was very tough on me personally.Please support dementia tools that are appropriate. THANKYOU

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Bill Bryan

Medicare

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Mrs Sarah Vanderwaall

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My family has already faced barriers, delays and immense (nearly impossible) costs related to belated diagnosis and implementation of appropriate productive therapy. If we could have known prior to when the symptoms became apparent, we might have been able to take some cost saving measures and advanced preparation instead of having to race around and make abrupt decisions without having been able to seed valuable advice, which became available only after the fact and far too late. It has all but bankrupted us and forced us to put or jobs on hold and in jeopardy long before its time in order of react instead of to act. Anything that will give families some advantage of foresight is significant. Take it from one who has been there, done that and will suffer for it for the remainder of my life.

Larry Rafey

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Victor Monjaras

Medicare

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Mrs Carol DenTandt

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
I've been Studying Alzheimer's disease for the last 15 years. i also do a lot of tree research and this disease has affected a lot of people. They need the tools available to them in order to make an easier diagnosis. I urge you to act on this piece of legislation.

Professor Troy Rohn

Medicare

I was the sole care-giver for my mother for 8 years, as she fell deeper and deeper into a state of total dependance due to Alzheimer's disease. Had she had access to a PET scan when her first symptoms of forgetfulness began to present themselves it is highly possible that the advancement could have been slowed down considerably, by medication.

I am now the sole care-giver for my husband who has Parkinson's disease. Dementia symptoms are increasing. Had insurance covered access to a PET scan been available several years ago I am convinced his progress could have been slowed.

Consider this: For a total now, (and ongoing) I have, for all intents and purposes, been a prisoner in my own home, since neither my mother nor my husband are safe if they were/are unattended. Why should care-givers end up in such a position if a PET scan could have, at the very least, postponed such a constricting situation???

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Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
I lost my grandfather to Alzheimer's. I was only a teenager at the time so I didn't thoroughly understand what was going on but I will always remember watching him slowly deteriorate until he couldn't speak, or feed himself and finally couldn't breathe. It was terrible to watch my grandma's hopes rise when he had days and moments of lucidity only to have him slip back into dementia. My cousins were just babies when he died and since then I have had my first child whom I would have loved for him to meet. It is a shame that this disease stole the time they could have had with him. He was a wonderful grandfather.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mom had always exercised every day and she always read a lot. Now she can't remember what happened a few minutes; she can't read like she use to, as I suspect she has trouble concentrating; has trouble walking; cries easily; I watch her 24 hours a day and I have to wash her bed clothes and pajamas every day; she has trouble pulling up her own pants. It is so sad to see her dementia take such a hold on her. She danced, exercised; had a lot of friends that she associated with and now she doesn't say much after being so outgoing. It has completely changed my life, as I care for her all the time and don't have a life of my own. And she falls asleep all the time.. I wouldn't have it any other way. But people don't realize what the care givers go through. You have to tell her something between 5 - 10 times in order for her to do it. It is very frustrating for both of us. Anything you can to for dementia or altziheimers would really be appreciated by all of us caregivers, especially. The parent turns into the child again and is very hard to watch happen. Plus are we next?.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

This hellish disease is taking the life of one with whom I have loved for sixty years. She is no longer a mother, grandmother, or wife. At this time she has becomes more child like every day. In addition to the general memory problems there is a very serious vision problem and hallucination. It is almost impossible to share the wonderful memories we have had because there is no recollection of what we have discussed from one moment to the next. It is living a life of wondering when the next "shoe" will fall.

The question is: Why should we living in the wealthiest country in the world, and paying twice as much for medical care, continue to tolerate the statuesque?

I served as on the IRB of a major university and was dismayed at the power of the pharmaceutical industry to promote their product without adequate evidence to insure patient care. This is another instance of having a system where medical care is no longer a service institution, but an economic model that neither serves the patient or our nation.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My girlfriend's mother has early onset Alzheimer's. I see the pain in her eyes every time she talks about the woman who was always her pillar of strength and a role model. Please support this new technology.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Kristen Baker-Fletcher

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

People in my family who were diagnosed with Alzheimer's disease....
1998, my father, my aunt, my uncle, and then in 2000 my other Uncle...and then my Mother in law who was diagnosed in 2007.....all now deceased.
For my family members who were diagnosed in the late 90's, there was no treatment at the time, my mother in law was on some medication for Alzheimer's, but it never really worked, this disease progresses quickly....VERY quickly, treatment needs to be done at the first sign of the disease....this is not fair to delay treatment....I bet who ever is making the decision to hold back treatment, has never had to care for a person with the disease, it's heartbreaking my husband and I both have, as well as my cousins who's parents were affected.
Thank you.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: I am a psychotherapist, and I have watched my patients grapple with the uncertainty as to whether their loved ones are afflicted with dementia. Because they couldn't get some definitive proof, this helped them stay in denial and thus prevented them from getting help for themselves and their family members. They suffered needlessly longer than they had to. It is unconscionable to withhold testing which could alleviate emotional pain and lead to the proper treatment protocol.

Margot Osborne

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My mother almost died, living alone and with Alzheimer's, until we discovered her condition. Now my sister is living with her 24/7, with all the stress involved in that. My mother does not recognise her, nor does she know that she is living in her own house. She cannot do anything for herself at all and it is sad to see her in such a condition.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I have participated in a couple of clinical rials where I have received a pet scan. This could tell me if I have the tangles and plaques that confirm Alzheimers. But the terms of the clinical trials prevent the doctors from telling the participants what the tests show or don't show. Obviously, I don't want to take medications if I don't actually have Alzheimers and I do want to take what ever might help if I do. The tests for amyloid are the proof. As you know, this is a terrifying disease. Please don't exclude the test from Medicare benefits.
Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I don;t really have a story, but worry that I am on track to
Alzheimers, as my mother was diagnosed in her early 1970s,
the age I am now . I refuse to take the sort of question and answer memory and other cognitive
tests commonly given to people suspected of having dementia for fear that my nervousness could skew the results.
Pet imaging sounds like a far more accurate and unbiased diagnostic tool, unaffected by a person's emotional state.

Medicare

My father suffered from Alzheimer's, and it was devastating for him. This was many years ago, long before this current discussion was even thought of, or conceptualized. To see him go from lucid to dementia was hard to take. I would not wish that on anyone, and all efforts to end this, or at least catch it earlier before it becomes so ravaging is of the utmost importance. As hard as it was for me to see, it was even harder for him to endure. To see a virile man be reduced to tears in his states of lucidity was too much to experience, especially as a child, as I was at that time. And the thought that I might go through the same torture is very disconcerting. We need to stop this now.

Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved the technology, and people who face a diagnosis of Alzheimer's deserve to have it brought to their care.

I lost my mother to dementia this past December at age 76. She suffered terribly for many years. If PET imaging had been available when she began to show early signs, it may have led to a more definitive diagnosis sooner. With that, perhaps we could have started her on a more appropriate course of care much earlier.

Having lived this nightmare - and now worrying about my own future - I can't stress enough the importance of doing whatever we can to support early diagnosis. This should include introducing PET imaging sooner in the process than later.

Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My husband was diagnosed with Early Onset Alzheimer"s at the age of 64 and lost his battle at age 70. I am quite sure his symptoms began in his late 50s to early 60s. The years with this disease were absolutely horrible. If anyone can find help for any patient with any form of dementia that person or persons is morally bound to do so. I am convinced that once an answer for any form of dementia is found, all of the dementias will benefit. If an insurance does not support this, it's just WRONG.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My wife was getting very forgetful and constantly repeating herself about 2002. She was misdiagnosed locally as having vascular dementia since she had suffered a few TIAs. Finally in the spring of 2005 it was obviously getting worse and our local doctor was able to get us an appointment at Mayo Clinic that fall in Rochester, Minnesota. There she diagnosed as "having dementia of the Alzheimer's variety". Fortunately our local doctor had "guessed" right and had put her on Aricept "off label" in the months preceding our appointment at Mayo. We have no way of knowing if an earlier diagnosis, back in 2002, would have made a difference in the course her disease has taken. I took care of her at home from 2005 until June of 2013. Now we are searching for an appropriate nursing home. She is almost 88 years old and we have been married almost 6o years.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother and first cousins were victims of Alzheimer's Disease. I am now 66 years old, involved in Trial Match research, and terrified that I, too, will develop this disease. Diagnosis, treatment, research, are crucial to dealing with this disease which will be the scourge of my generation.

Please make PET imaging available NOW!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Mr CHRIS GILL

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care.

I am not going to write my personal story in a public forum for people to see. However, I will comment on how it seems government would rather pay the costlier expenses of caring for people long-term, rather than the cheaper expenses of prevention and early diagnosis so people can live without Medicare assistance longer.

Think about it. If people are able to live better, healthier lives because something is found and treated earlier, isn't that better for everyone?

Please think about it.

Dana Garlick

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

was my friend and I watched her sink into Alzheimer. I'd take her to the store and it was like I had a little kid with me...she was into everything because it was "new" every time we walked past it. Her dear husband had to put her in an institution because at 84 he couldn't do everything she needed at the end. She had been a Nurse Anesthetist and became totally dependent on others. so very sad. Knowing earlier would have allowed the meds to put it off longer. It was a waste of a beautiful woman.

Mrs Cynthia Stevenson

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I wish I could have known sooner that my mother had Altzheimer's, but she lived on the West coast and I, the East. As soon as I heard her say that driving to Florida from NY would take at least 3 hours, I knew something was wrong and made arrangements to fly out at Christmas. A trip to the doctor's and some questions gave a "probable diagnosis" that my mother's worst fear had come to pass. It was already in full swing, but like so many others, she had learned to hide the symptoms. Please make this testing available - early.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is --here is my story:

I suffer from mental illness--bipolar to be exact. I just celebrated my 70th birthday. My memory is deteriorating--I don't remember the names of my close neighbors, I can't tell you what I did during my day, perhaps after five minutes after it was accomplished. I look at my dogs and have to think what their name is because it is lost for moments. Throughout the day I have to ask my wife what was I talking about because I've lost the connection to the immediate conversation.

I'm not the person I used to be--my last job was as an Associate Professor of Educational Leadership/Dept. Chair. I worked under pressure and had to be highly organized to get the job done.

Now I wonder each day what I'm I going to face next week, next month, next year. Currently, my doctors say not to worry, but I know deep inside I am not the person I used to be and it brings much sadness to my everyday living.

This diagnosis would help people like me to know whether it is just old age or the beginning of a long road of a total non-functioning brain.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My husband's aunt was remanded to our care since there were no closer relatives to care for her. She did not have an Alzheimer's diagnosis and we struggled to find the proper living arrangements for her - Independent Living? She quickly flunked out of that as she was not able to remember how to get to the dining room, take her meds, etc., so the next step was Assisted Care. Even though the facility had a great reputation they did not have supervision from 9PM-8AM and Aunt Millie could and did go walking. We finally found a wonderful "Memory Care" facility but of course it was horribly expensive. However, she lived there for several months and got incredible care and was as "happy" as she was able to be. When her money ran out we had to move her yet again to a facility that she could afford with the help of Medicare. If we had been able to determine a positive diagnosis of Alzheimer's we might have been able to spare her the stress and frustration of moving and having to adapt to new people and surroundings.

We are now in our mid-70's and worry that we will have the same experiences if something isn't found to determine a definite diagnosis. I hope this technology is available in time to help our families avoid the type of experience we had in attempting to provide the best care for a loved one. We need a definite diagnosis in order to qualify for services. Please don't make it harder for us and others like us to live with dignity.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother was an intelligent, very well-read, strong woman. She was caring, open, & never met a stranger. She had a wonderful, albeit odd, sense of humor. She loved crossword puzzles and her beautiful flower garden. She loved her pets, whom she treated like family. She beat breast cancer and has been in remission for 25 years. She survived a stroke. Through all of that, she never lost her love for life and her family.

Today, however, she is nothing like the woman she was. She can't speak intelligibly. She can't tell you when she's hungry or has to use the restroom. She can get violent when you have to "change" her, because she doesn't understand what you are doing. She refuses to get into the shower or tub. My father has to sponge bathe her. Yet, portions of her still remain. She still laughs, although we don't always know why. She gets silly every now and then. She knows that she loves us, but she doesn't know why. She still never meets a stranger, frequently walking up to people in the grocery store, restaurant, etc, which results in odd looks and people pulling their children in the opposite direction. People think she's weird, sometimes scary. All because she no longer has control over her mind. Alzheimer's has control of her.

My grandmother also suffered from Alzheimer's disease, and my aunt is already in the beginning stages. Earlier detection would mean a better, more appropriate treatment for my sister and I as we get older. The thought of putting our families through what we're going through with my mom and aunt terrifies us. Please, PLEASE help put an end to this terrifying, life altering, life destroying disease. Thank you for taking the time to read my letter.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

When I was 32 Alzheimer's disease took my dad. Today, i am 55 and it is here to take my mom. She is still healthy but dementia has her. Please make PET imaging available now. What are we waiting for. as a women i know that I have. 72% chance of getting this disease and with it already in the family my chances are even greater. With carefiving for my mom, I cannot risk thIs. The time tomact is now.

Thank you.
S. Clark

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mom is my best friend. Since about 2003 my sister and I suspected something was wrong with my mom's memory. We were unable to get any type of diagnosis. Many people, including my mom, are afraid of losing their independence. For a while, my mom was able to fool my brother, her friends and her sister that there was nothing wrong with her memory. My mom lived with me for just over 6 years. I saw her day to day and I noticed the subtle changes with her memory, mood and speech problems. Other than my sister, no one believed me.

Finally, in 2010, my mom's doctor sent her for a CT Scan. She was diagnosed with Dementia like Alzheimer's. We were told there was definitely shrinkage of her brain. Since 2010, my mom has had to be placed into an assisted living facility. She had declined, mentally, greatly.

She was given the generic, Aricept, but it was too late to do any good for her, in 2011. In fact, it was a waste of her money and the insurance. The pharmaceuticals made out in the deal but my mom did not. Had my mom had the use of the Amyloid Positron Emission Tomography we could have slowed down the progress of her Alzheimer's sooner where the medication might have helped. Now, along with my siblings, we must visit my mom and slowly watch the memories she once had fade to nothing. We must watch the zest she once had for life, fade. We must watch the inside of her being disappear. Fade into nothingness because we are not doing enough to cure/help these people.

I am scared to death that I, too, will end up with Alzheimer's. Since 1906, this disease has had a name. And over one hundred (100) years later, we still do NOT have a cure or the ability to properly diagnosis this dreadful disease soon enough without having to die and have an autopsy. People are NOT given the opportunity to make arrangements prior to this memory robbing disease because it is NOT detected soon enough or with the accuracy to develop the research to cure this damned disease. It is heartbreaking to watch my mom/best friend become someone I no longer know. Act no more like she used to. Not even know what the words "shopping mall" means. Unable to tell you if she hurts, tickles or any other list of feelings or emotions.

I implore you to PLEASE, rethink your stance on using the PET scan. It can benefit thousands of people so that they may have a quality of life that they deserve. Think about how you or a loved one of yours would benefit from being properly or timely diagnosed.

I was shocked that there is, yet , no cure or even the ability to properly diagnose what isn't clear without an autopsy. How many people must die and have autopsies of their brains to give a definitive diagnosis of Alzheimer's?

A couple years ago in a Communications class I had to write a poem. Not a long poem but one that had strong heartfelt feelings without listing those feelings within the poem. My poem went like this;

Doctor´s voice
Blank stares
Total disbelief.
No cure, very little help.
The mind´s eye is fading away.
Mentally gone but physically here.

The tens of people at my mom's facility range from quite functional to totally dysfunctional. Those that you look into their eyes and there is no one in there anymore. Just a shell of what they used to be.

PLEASE help make it easier for the people to be diagnosed sooner and generate funds for research to end the suffering of family caregivers, patients, and all of us that end up watching our loved ones mentally disappear but are physically here!

Medicare

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Mrs Sunny Clark

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Five years ago my aunt, Patsy, on my mother's side passed away after having Alzheimer's for years. I was with her daughter, Nancy, throughout the years as it progressed and it was heartbreaking to experience. Now I am going it through it again only this time with my mom. I hate this disease I can't think of any thing more cruel then Dementia/Alzheimer's. It started with mom not remember names, then she started having problems remembering how to cook for my dad, soon after that she forgot how to go up and down steps. Now she can't feed herself and she doesn't know us, her own children. Some days she if fine and will sit and listen while we talk but other days she is angry and wants you to leave. She can't wait any more so she is in a wheel chair. She feels no pain and doesn't know when she has filled her pants. Her sister, in Kansas City, Kansas, has Alzheimer's. I have a mom but don't have a mom. I can't go and talk to her about anything because she doesn't remember the past. Can't remember my siblings. I just hold her hand and smile at her. Tell her I love her. But my heart is breaking. I can't write this without crying. I miss my mom. This is MY MOM!!! I always cry on my way out the door after seeing her and all the way home but I refuse to let her see me cry. My dad who has been married to her for 66 years is lost he doesn't understand Alzheimer's. She still looks like his wife why don't you try harder he asks. She says hurtful thing to him and to all of us - but has no idea what she is saying. She still looks like my mom and like grandma to the grandkids. This could be your daughter, mom, wife, grandma or sister! PLEASE - PLEASE - PLEASE remove the barriers, delays and extra costs to the patients and doctors so someone can find a CURE. What chance do my three sisters have when my mom and her two sisters all got Alzheimer's it's a slow miserable death that's why it is called the long goodbye. Without your help our families are looking at three more women who will end up with Alzheimer's unless a cure is found. We need more research and we need to have earlier diagnosis. I have instructed my husband if I get this horrible disease to not come and visit me very often once I'm in a home. Just check every so often that I'm being taken care of, clean, fed, and getting my meds. I want him to continue to have a life even if mine has been robbed. Unless you have experienced this with your family member there is no way you could understand the pain for the families of the one who has Alzheimer's but I am praying you will try really hard. Thank you.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
I have had first hand experience with dementia. My husband suffered with it for about l0 years, ending up in a nursing facility for two years
and passing away 2 1/2 years ago. My husbands doctor said nothing
was wrong with him when I approached the subject of him possibly
having early stages of dementia. This went on for sometime until my
husband was exhibiting actions that where not in his character. My
daughters pushed for taking him to a place that could possibly test him
so we would know what we were dealing with. Eventually we by passed his primary care physician and went to a clinic that was dealing with this disease. They did tests and an MRI and determined that he had dementia.

Medicare

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Darlene Nichols

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Alzheimer's is an insidious disease. The people who suffer from it have many falls resulting in ER visits and hospital stays due to fractured or broken bones.
My mother died at the age of 86 from Alzheimer's but the actual process took six years from diagnosis to death. She and I had been discussing this topic for 40 years. It's time something really positive is done.
She once stepped into someone's home when she was out walking (which she was not supposed to be doing but she didn't remember not to go outside alone).
She took meds which were supposed to help stave off dementia but they gave her hallucinations.
Had we known earlier, or I as her daughter, could know earlier what we were or are facing, we could have received different treatment and care for an improved quality of life.
One test vs. thousands of people made demented and possibly bankrupt by this disease.
Is this the way you would want to live? I strongly doubt it.
I know I do not.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: I was told by my PCP 4 months ago that I have early Alz. I'm having problems with short term memory, and have had to make a checklist for my visits with my patients in order not to miss anything. This is horrifying. I won't tell my 85 year old father or my siblings until I know for sure. I'm 53, lean, athletic, a singer and F-horn player. We hike and parrtner dance. I'm a registered dietitian and don't eat beef or pork. Do I really have this? No good way to know.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: This diagnosis affects every aspect of your life and your families. We need to know for sure if one has it or not so that it can be treated properly or if it is something else to treat that.. I don't know of anything that is worse for everyone concerned and people don't need to go thru this diagnosis that affects everything in your life unnecessarily. It is so sad. Nothing has ever come close to being so horrible as this diagnosis.

Joseph Hudgins

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My husband suffered with the disease...nothing they did seemed to help him. I think that is the worst thing you could possible have..it is terrible. It takes everything from you before it takes your life,Please back every effort to find a prevention or cure for the disease...ASAP.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother had this but the diagnosis was to late to help here during the early stages no body really understood the problems an treatment was not available.
But with new medical advances more can be done--an has to be done for the sake of all.
We are talking about human lives being wasted because no body care to help. Let me tell you this its time to act an now.
.Not Later

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
As a skilled nursing facility social worker for 12 years, multi year facilitator for a local Alz Support Group, among the 34 total years I have worked in the S W Colorado 'aging services network', I have encountered numerous circumstances of need for clearer dx of the dementia status of patient after patient, in order to develop treatment plans, design effective plans of care, and assist families in facing and managing this sad disease process. Every enhancement in dx and care makes a difference in the acceptance, approach, care and cost effectiveness of caring and living with this devastating disease.

charlie speno

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother had Alzheimer's...she passed away January 6th, 2013, the day before her 75th birthday. She died from cancer! I never thought I would be grateful to hear that someone I love had cancer, but it was a much quicker, kinder death than it would have been than watching her slowly, oh so slowly, die from Alzheimer's!! Had my mother had better treatment & diagnosis in the early stages of Alzheimer's/dementia, who knows how much longer & better her life could have been. By the time she got cancer, she had lost her language skills, she couldn't communicate at all that she was feeling bad. By the time we figured out that something was wrong & had her checked out, the cancer was so far advanced that we were told on Wednesday night she had cancer & she died before noon on Sunday! We didn't even have 4 full days to say goodbye! Early diagnosis is so important!! The quality of life for not only the person with the disease, but for the care givers must be considered! The right treatment & care can make such a difference. I miss my mom everyday...
Please give everyone effected by this horrible disease the best chance possible for the best treatment.
Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My beloved 82-year-old ex-Superman is in stage 5 of 7. Were he less brave, we would all be suffering far more. HAD HE HAD THE BENEFIT OF AN EARLIER DIAGNOSIS BY AS LITTLE AS 3 YEARS, we would still be able to enjoy life about 9 times as much. However, between the demands of caring for his first wife (of over 50 years) during the latter stages of COPD/lung cancer, he failed to get examined or tested and diagnosed. When he came to live w/ me (we were all close friends for over 20 years), I saw right away that there was more than mourning afoot. Alas, the very conservative local neurologist didn't do much at first, and more ground was lost. With better early diagnosis......... Well, please try to imagine how much tragedy and suffering might be spared with having a means to treat appropriately and aggressively. For millions of victims and Care Givers. Maybe many could then readonably hope to stay reasonably whole until a cure is found.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

One of my family members had Alzheimer's. She was so smart that we were unable to realize her situation until treatment was too late.

Catherine Hunt

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My father died in 2011 after a 13 year deterioration with Alzheimer's. However, he was lucky enough to have excellent resources and to prepare for his incapacity because of early diagnosis. Not everyone has access to such a timely diagnosis, or the time to prepare for long term care, and I worry that I may not have that opportunity, should I fall victim to Alzheimer's as well.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I lost both my parents to Alzheimers. Enough already.

Medicare

My husband has been diagnosed with Dementia/Alzheimer's? This is used interchangeably and becomes confusing. Not all have the same experience and it is heartbreaking to see that NOTHING is done to help us with this disease. Dementia or Alzheimer's is not something that happens to a few people who are elderly! Every family that has an elderly mom/dad or relative is experiencing the heartbreak of non-treatment. If you, who are working and making the decisions to fund this help, deny help, you are a candidate for dementia or Alzheimer's all one has to do is become old. I now read that this is beginning to happen to people in their 50's! Does this not frighten any of you. DON'T THINK IT WILL NOT HAPPEN TO YOU.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care.
I am a caregiver who works with Alzheimers' patients. One of my patients died recently after 15 years of suffering. Her daughter told me that the first 7 of those years, she was estranged from her mother, who accused her of all kinds of awful things. Neither of them knew that Alzheimers' was robbing her of her ability for logical thought. All those years lost, when she still knew her children, all because of the length of time it took to get an accurate diagnosis so the family could get her the help she needed, and did not receive.
If this technology could save one family that kind of pain, isn't that the humane thing to do?

Mrs L Segel

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

We took my mother to various doctors and specialists and each one of them told us the same thing-your moms test results are normal-there is nothing wrong with her but my family and I knew different.We could tell mom was not acting like herself.By the time we received an accurate diagnosis-she was already well into moderate stages of alzheimers disease.This made it impossible for her to qualify for clinical trials because she could not render a high enough score on the mms test to be considered.This was both frustrating and devastating to all of us.It took away my moms chance at trying out a potential new treatment.A better way to diagnose would mean a huge difference and mean a better overall chance for a person with alzheimers to live a longer and more productive life.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care.

alissa fields

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

When my brother died, my sister-in- law could no longer live outside of a care facility. She had to move away to live near her daughter . She no longer recognizes me. When my brother died, I lost them both.

Medicare

I am responding to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care.

Both my father and my grandmother suffered from Alzheimer's. Early diagnosis is crucial. From what I have seen of how little there is to quality of life, I would rather kill myself than let myself be put through the barriers that Medicare raises. Life with Alzheimer's is difficult. Don't make it impossible.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My mother started having some memory loss at least 10 years ago at age 79 although i saw some major personality changes several years prior. My father was, of course, in denial of this all -- about 6 years ago he did acknowledge something was amiss and wrote a trust putting my brother and i in charge in case something happened to him. He then did have my mother see a doctor who prescribed several medications to slow the progression of her disease -- It may have staved off her rapid decline a bit, but at this point, they are not working at all and she has been removed from those drugs. My father has since passed and my brother and I are left to deal with our mother who no longer knows that her husband is gone, cannot remember friends(but does know my brother and me) and is a very lonely, depressed person without any will to live --- and i cannot blame her. I t is a depressing illness for everyone involved. I now have some concern that I , my brother and my offspring could develop this life altering disease and I would think it advantageous to develop an antidote -- not just to relieve the suffering it causes but to save us all a considerable amount of money to care for people with this condition

Medicare

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My 59 year old husband has been diagnosed with Alzheimer's . As you can imagine our whole family is devastated, especially me and my teen-age daughter. To be in the prime of your life and handed this diagnosis is a death sentence . Thank god for the Pet-scan which helped the doctors determine, with certainty, my husbands diagnosis. Although its a horrible tradgedy, at least they can treat him with medication to slow the disease and put him up for trials. Believe me if you or your family were faced with this you would be enraged I'd you couldn't get a pet- scan which is imperative to diagnose Alzheimer's.
My insurance refused to pay for the Pet-scan, so I paid cash. The last thing I should have to do right now is fight my insurance company. Although the results were not what we wanted to hear, at least we know the monster we're facing.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I care for my mother in the final stage of dementia. I work nights and hire people to be here at night, I don't have much time for the luxury of sleep. I believe she has Alzheimer's disease, but not sure. We have arranged a brain autopsy for the end. It would have been nice to have had better testing than 20years ago with mayo saying "I believe this is Alzheimer's disease". It's been a long road for her, first my father took care of her and now it's been my family and hired care people.for 8years.
We tried a nursing hom Mn veterans home and this certainly wasn't a good option. better testing I believe would help in caring for many. my mother is a sweet lady whom is never combative, compared with many whom are.

thanks for listening.
jean

Medicare

Your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's is disheartening to say the least. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

The evaluation of my "memory loss" by a well-meaning and caring neuropsychologist was certainly not comprehensive and the resulting diagnosis left my wife and me with little comfort and no real sense of what to expect. A casual suggestion of one of two medications that my primary doctor might prescribe didn't give us any more sense of what I was facing. Certainly an Amyloid PET scan would present us with measurable data that then could be translated into specific treatment. Don't we deserve that? If the end of life can be met with more confidence as a result of the most positive diagnosis and thus the best treatment
available. This is what is best not only for patients but for their families, too.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

byung-joon joo

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother is 82 years old and has had Alzheimer's for about 8 years - atleast that's what the doctors can tell us. Diagnosing ALZ is difficult for the doctors and even tougher for the families. If there are tools out there that can further the research and make ALZ easier to diagnose, we may be heading in the direction of prevention or cure. Right now, THERE IS NO PREVENTION and NO CURE. We are desperate for help in these areas. Please reconsider, the life you save might be your own.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Every time I bring up my concerns about the potential of having Alzheimers/dementia with my PCP he basically ignores the topic completely. Without a definitive tool for patients: doctors; the AMA; and, Healthcare insurers with avoid the topic and allow patients to undiagnosed dementia and senility.

Medicare

-- here is my story

Dear Mr. George Vradenburg
According to the World Health Organization´s statistics, up to 80% of working-age population suffer from vertebra diseases. Falling down is major cause of accidental death of elder people; children and adults die while sleeping, sportsmen in sports ground, students at classes in schools.
My research is basic knowledge on dizziness and balance, nausea and air disease of not only spacemen, seamen, drivers and workers dealing with different devices, but also for common citizens and passengers using any vehicles, such as lift, car, and tram.
Dizziness is not a disease, it is state which one can´t get used to; at present it can´t be cured, there is no medicine for it, it exhausts a human who is ready to fulfill any requirements to be free of it. In fact to be free of this state does not require any charges, this is pure self-care. It takes only several seconds. This problem is not medical, it is of social character. It is finding it difficult to diagnose dizzy patients; causes span various subspecialties, including internal medicine, neurology, otology, ophthalmology and psychiatry. Basis science aspects are limited. ´What to do if you haven´t a clue´.
Promise to create fast-acting drug to suppress stroke of dizziness in naupathia with no bad effect for health in the nearest future still remains a promise. Theoretical papers in physiology and pathology are not a decision for search of cause and means to normalize vestibular system of a human. The problem requires conceptually different approach, clear understanding of vertebra activity. I do use only my common sense while applying it.
On conducting my personal research of vertebra organization and physiology I empirically and practically succeeded to prove safe influence of my method onto vertebra. Composite joint of vertebra is upper part of a body, which consists of head, shoulder bone, collar bone and shoulder joint. In this part of vertebra I´ve discovered previously unknown phenomenon of inborn reflex.
A human is able to get free of backache, lumbago, dizziness due to simple method and physiological availability of the abovementioned reflex. It produces positive effect on life quality and longevity. Main point is ultimate availability and excellent result. In this case medical problem transfers into social necessity without any contraindications.
Sincerely,
Vitalii Kravchenko
07.31.2013

Academician Glyshko Str.11, apt.56
A/C-18, City of Odessa
65113, Ukraine
E-mail: vitaliy_62@list.ru
Tel. mob. +380671540199

Vitalii Kravchenko
Academician Glyshko Str.11, apt.56
A/C-18
City of Odessa, Ukraine, 65113 , ot 65113, Ukr

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My Mother and my husband both have types of dementia. Right now I am trying to take the best care of my husband as possible but there are days I just want to sit down and cry. He was a truck driver for over 25 years now he can not drive at all and to deal with his heartbreak over that is trying to say the least. I have told my dad if my husband goes before my mom I will move near to her and help take care of her. Both of them have been giving people all there life's and now they can . Its heart breaking to see them this way. We also have one niece take care of her older sister with it. Peggy has put her life on hold for her sister. The older sister is only 4 years older but she used to be a very active person. Now she will not leave the house unless you almost have to make her. She will not bath until made to, Nor will she eat, change clothes none of the everyday thing a normal person will do. Peggy has been taking care of her for almost 5 years and its taking a toll on her.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My Mother suffered for years with this horrible disease and there is no way to describe how awful it was to her and all our family...We need a cure!!!!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother was diagnosed with dementia several years ago. The exact cause of her dementia remains unclear. She had a horrible reaction to a psychotropic medication given to her because the doctor assumed she had Alzheimer's. The neurologist we consulted afterward told us that if she took that medication again she could die. I believe that a diagnostic tool to assist families and physicians in understanding the root causes of dementia is essential not only to provide appropriate treatment but to avoid fatalities that would not otherwise occur.

We love our mother and want to not only to get the best possible care, but to suffer as little as possible.

Please approve this diagnostic testing.

Medicare

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Mrs S D

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother was a smart, energetic nurse practitioner, one of the first in the state of Massachusetts. In her late 50s she began to behave strangely, repeating herself, forgetting things, becoming a little paranoid.

Frightened by the prospect of Alzheimers Disease she wanted nothing more than to deny there was anything wrong. We, however, wanted to fight this disease aggressively. This entailed hour long drives into the convoluted maze of Boston streets, parking fees, MRIs, memory tests, blood draws and questionnaires - only to be repeated again in 6 months or a year. And our answer? Mom MAY have Alzheimers - since there was nothing else they could find.

The theory today is the drugs we have may need to be started at a much earlier stage in order to produce any benefit. Delaying diagnosis will do nothing but hurt the patient and ultimately cost so much more, both in emotional pain and real dollars. It is expensive to care for someone who can no longer dress themselves, go to the bathroom unassisted or be trusted not to wander.

I, myself, carry the genetic flaw which makes this my likely destiny. I would prefer to fight for my life. Please help me and others do exactly this.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother had early onset Alzheimer's as well as her brother. There is a genetic influence apparent in my family. I have seen first hand how a bad diagnosis or a late diagnosis can make this devastating disease even more destructive. Please reconsider and allow PET imaging now. PET imaging is a powerful and helpful tool.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

In reference to the availability of PET Amyloid scans.
I think it is very important to the outcome of people like me to these tools.
For me it took 9 years to get a diagnoses. It was not until I received the PET scan that it confirmed that something was truly wrong. Many insurance companies still do not pay for that test. I cannot begin to tell you how many times I had repeat many of the test hoping for an answer. I even had 3 Neuropsychological tests that cost over $2500.00 each during that time.
Because of this diagnose.
I was able to start my medications.
Start my end of life planning and make plans to live life to the fullest in the short time I had left.
Able to get in Clinical trials
Apply for disability
Able to now focus my effort to being an advocate for the disease which had now given me a new life´s purpose.
When I need surgery the doctor was able to avoid anesthetics contraindicated in AD.
The delay in my diagnose led to being fired from my job and losing the very benefits I had contributed to that would have taken care of me for the rest of my life. It would have even simplified it for my caregiver. Now we both suffer. I lost it all and must rely on social security.

Medicare

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toni lubka

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My father-in-law was stricken with Alzheimer's disease and suffered with the disease for 14 years before it finally took him from us. At the time he was diagnosed, there wee only a handful of medications approved for treatment withl limited success. We watched this brilliant man, a decorated Naval pilot, the holder of two Masters Degrees and head of design staff for General Motors slowly disappear to be replaced by someone unable to care for his basic needs. It broke our hearts and resulted in us losing his wife just three short years after we list dad because of the toll caring for him took on her health. Please approve payment for this testing for a definitive diagnosis for Alzheimer's disease so that patients can get the correct medications to help them

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Dr. Pilar G. Cabrera

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Hi my name is George and I had a chance to watch this dredded disease take hold of my mothers life. Over the span of 8 yrs I watched slowly how this disease took my mothers life and turned it upside down. Her retirement turned to constant visits to doctors to hear the bad news that it will never get any better only worse. My mom worked hard all her life as she was a single mom tring to support herself and me, keep a roof over our heads, food on the table, clothes on my back, and shoes on my feet. She deserved better and I tried to be the best son that I could be. I live in Florida and for a good part of the last 5 yrs of her life I traveled up to New York to visit every 3 months to spend a short 4 days with her and watched first hand how this disease slowed took her into the abyss. I felt helpless and my stepfather took good care of for the whole time but finally her heart started to fail and it was recommened she be placed in a nursing home where she finally sucumed to the disease and passed 08/29/05 while my wife and I were visiting her. Though it was a sad experience I was gratful to be there for her in her last moments on this earth and to be able say I love U for the last time. This is why it is so important for you the health care system to give people access to this new technology s that other familys don't have to experience the pain of watching a loved one with Alzheimers/Diementia... GS

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Angelica Estrada

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My mother started to show signs of not being able to hold a job in her late 50's. She came to live with us - and our 3 teenaged children. The doctor diagnosed a mental disorder - not certain what exactly was diagnosis. Over the next 15 years she was cared for by many different family members. Upon her death, her brain was sent to the Harvard Brain research center - where the diagnosis of stage 6 Alzheimers was finally confirmed. I have to ask why a person has to die to find out the exact disorder. Had my mother had the correct diagnosis, she/we could have had help for her, and us, earlier.

I urge you to allow the doctors and patients the tools available today to find this disease earlier.

Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My beautiful, vivacious Mother (and my best friend) had Alzheimer's disease for about 14years. I owned a business at that time taking over from my younger brother after his sudden. My Mother died in 2011. Since then and during the time I was my Mom's full time caregiver, I 've had major depression. I lost the business in order to take care of my Mom so I am financially ruined I am haunted by nightmares of the horrific life my Mother and I lived with Alzheimer's disease. There are hundreds of details I could relate, but I don't have the strength. No one came to visit us. No one wanted to help us. It was like she had leprosy. And no one came to be with me. My Mother thought the people on TV were in the room. She did not want to get up, and when I couldn't get her up, all of her clothes and bedding were soaked with urine. She didn't want to go to bed at nite so I went through this every day and night. I had to call the paramedics to get her up out of her chair. She was miserable and was aware of all of this misery but didn't know why contrary to what most people think. It is so frustrating, I tried so hard to help her, but nothing much worked, and no one, especially doctors could help us.

In the end, I had to put her in a nursing home. She was devastated about this and so was I. She was not able to do anything. She wouldn't even smile at me,and I was always the light of her life. I am in tears now. I layed beside my Mom until she took her last breath . What a horrible way to leave your Mother. I struggle every day to keep going on..69 years old, financially strapped, completely alone. No one understands. I' m in a world of my own. Please do something to help us!

Medicare

TO PEOPLE WHO CARE:

I am writing in response to the proposed decision to require more evidence development before PET imaging is available to people who may have Alzheimer's. This decision needs to be rescinded.

The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have this technology to support a documented diagnosis. Getting a diagnosis for my mother was cruel and unusual punishment for her and for our family and here is why ....

Our mother's PCP refused to link my mother's symptoms with Alzheimer and months went by while her condition worsened. When the PCP finally referred her for psychological testing, the results were not surpirsing - she had early stage dementia.

The testing that our mother had to undergo was 4-6 hours of questions and tired her out; when more testing was required as 'follow-up', she was visibly upset about being 'forced' to take tests she didn't want to take. These later tests confirmed that her condition had worsened and that the medication she was put on after the first test series was no longer deflecting the decline in her mental status.

My grandmother had Alzheimer's, now my mother. Does it stand to reason that any one of my siblings (7) may also suffer from this disease? YES. Would it be less of an agonizing journey to diagnosis if PET scans were readily available? YES.

Please reconsider the decision and make this technology available. We all know that there are registries out there that can collect real-time data if the only reason that Medicare is denying the application is that more evidence is needed. Several registries have provided much needed data and more such as the SPORT registry, the Framingham Heart etc. etc.

For those of us who may face a diagnosis in the future and for those of us who need a diagnosis now in order to get medications that are effective at certain stages of the disease, please make this technology available.

Thank you.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I have been in a volunteer research study for Alzheimer's for 20 years which includes MRI's & PET scans and to not use the results of this ongoing research and FDA approved diagnosis to help the people who face Alzhiemer's would be a travesty.
My mother died from the results of Alzheimer's nearly 30 years ago and if today's knowledge was available then it would have been God sent for her. Please fund the diagnostic testing.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My wife age 82 has been showing signs of dementia for about two years. Altzheimer's disease runs in her family, and we naturally are alarmed. Anything that can be instrumental in diagnosing her case must be made available to us--and anyone else in our situation.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Alesia McCarthy

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Sam Runyon

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My wife's family has a strong history of Alzheimer affecting several generations.

James Franklin

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My grandmother gradually had onset of dementia/Alzheimer's for the past 7 years or so. It started with all of her bills snowballing and being in a bad spot. I tried to speak on her behalf to all of her accounts but they wouldn't speak to me unless I had P.O.A. so I obtained that and have taken care of her finances, her social issues with neighbors and medical issues that come up. I am a single mom with two children and a full-time job and home to take care of, and while my grandmother is the one with the disease, it's myself and my other family members it's taken a huge toll on in caring for her to the best of our abilities. I personally, have been in a depressive state, with panic and anxiety for the past several months and I am pretty sure it is due to all of the stress inolved with her needs compounding all of my other obligations and duties. It has been a scary time. If others didn't have to go through this at some point with help of this diagnostic testing then please, I urge you, I beg of you, allow it to happen without the extra hardships. Thank you for any consideration and understanding.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I will say this. My deceased grandma suffered from Alzheimer's before she left this world, and it was truly painstaking on my uncle to watch her wither away from the disease, especially being handicapped himself. People who suffer from the disease should not have to endure more hardship/delays/inhibitions than need be, in order to be treated properly. Enough said.

Medicare

Dear Sir or Madam,

As the daughter of a mother who died from Alzheimer's, I can assure you the trail to her death was difficult and painful. The drugs that were aimed a calming her, made her docile, lethargic and unable to communicate. Or maybe they did nothing to her brain.

I do know that for those who do not have Alzheimer's, it would be a tragedy to be subjected to these medications and care.

If the FDA has approved of making PET imaging available to those facing the prospect of Alzheimer's, why not use it to give the patient and the family the assurance that they are making the right decisions, and sparing those who do not have the condition the pain of going through unnecessary and debilitating treatment.

Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: I watched my paternal Grandmother slip away mentally late in her life. Then years later, I watched my father mentally fade away, but much sooner in his life. This horrible disease begin to take him in his mid to late 60s. It is so sad to watch someone you know and love disappear before your eyes. They are still there physically, you can see that face you know, but behind those eyes, they are gone. They no longer know you, or know anything they knew before this terrible disease takes them away mentally. All we can do is be there for them, continue to love and care for them, even when they no longer know us. I hope and pray that my body does not outlive my mind. But, with my family history, it could be my dark destiny too. Please reconsider you decision.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I watched my beloved maternal grandmother, my great-aunt Ida, and my mother-in-law suffer and die from Alzheimer's. It is a horrible way to die, and I support anything that will improve care for the victims of this disease.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My 93 year old Mom has Dementia and her brother and sisters have all had dementia. I strongly feel that the science community needs to do all it can to help us live with and survive dementia. Please help us!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: as early as 2001, my husband, who was very intelligent and well educated, began telling his GP that he was experiencing difficulties with his memory. The GP was sympathetic and administered a test that is still being used today involving several tasks of mental function. My husband easily fulfilled the test. This was repeated over the years several times until finally, in 2004 the GP referred Victor to a psychiatrist. The psychiatrist listened to my husband's concerns, administered the same test and hypothesized that because of my husband's intelligence, the decline is his mental ability was not yet showing up on the test. Finally, in 2007, a brain scan revealed that my husband did have Alzheimer's and a prescription for Aricept was given.

In those days, there wasn't anything better available for diagnosis or treatment. Now there are both new medications and a new diagnostic test approved by the FDA. Please don't cause others like my husband to have to wait so long for a proper diagnosis.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

It broke my heart to watch my father progress with Alzheimer's disease...and there are some dementia diagnoses that are wrong...and to this day, I'm not sure if my father could have been helped if there hadn't been more choices for us to have to help him...we are going to have more and more baby boomers diagnosed with this horrible disease,and we need things to be easier, not harder for us to try and choose the right course of action for our loved one!

Shame on this country for letting the lobbyists with the deep pockets keep calling the shots in pretty much all aspects of our lives! My father fought in WWII for this great country and came back to get married and raise his family only to be left to whither up and die with us by his side, but our government shunning their responsibility to him instead working the hardest they can with coming up with new courses of action to fight this!

No one should have to go through what my dad went through while Alzheimer's progressed through his brain and robbed him of his twilight years!

Medicare

Your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's is not helpful. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
Several family members have declined and died because of Alzheimer's. I hope that you do not have to share that experience with me and my family. It is beyond sad.
Anything you can do to improve or prevent this wrecking disease from devastating people's lives is important. Please act.

Victoria Beardsley

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

ELIZABETH CLAY

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My Mother, Father, Brother, Husband, and Great Aunt have all been told they have dementia. How many more people have to suffer? I am only one who has to watch my loved ones go through this and I am one too many. Multiply my number (5) times many others that may share my pain.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

When my husband was diagnosed 4 years ago, the Neurologist from Oregon Health and Science University told me "to go home and get a support group." I received no direction nor was I informed about Namenda or Aricept. We began using Neuro-transmitters based upon a study out of University of Minnesota and Dr. Marty Hinz. and although, not a cure, it has helped to slow the progression of the disease. We need help to diagnose this disease earlier so we can at least slow it's progression.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My father began his dementia at age 50. I watched him decline and disappear. He died when he was 88 years old, not being able to care for himself or know anyone for over 10 years. Title 19. Now I'm 62 and am in the position of wondering if my strange acts and declining brain scans and MRI's are due to this dreaded disease. Should I begin taking brain altering drugs to try to delay it's onset? There's no way to know if I need it, if it will benefit me or if it works. I have had Type 1 Diabetes for 45 years. How do I deal with the complications of Alzheimers in managing my diabetes??? HELP ME TO KNOW!!!

Medicare

I am writing to support making PET imaging available to people who may have Alzheimer's. Not to provide coverage for this important tool is the wrong decision.

My grandmother suffered tremendously trying to get an appropriate diagnosis for her dementia. This is an important tool in a field severely lacking tools.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My father had three siblings with Alzheimers, and when he began to exhibit symptoms, it would have been helpful to be able to confirm that he also had it, so he could have enjoyed the time he had left before the disease became severe. It's hardest on the family to suspect a loved ones condition and not know for sure.

Please allow this process to move forward.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Ashley Smith
Consultant

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Lisa Hammermeister

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My paternal grandmother began losing her memory very quickly. It seemed that over night she forgot recipes that she had been preparing for over fifty years and shared with her daughter's. She lost her way in her own home. My grandfather did not have the strength to care for her himself.

She was sent to a local nursing home where she spent the next thirteen years suffering with Alzheimer's disease. She could not communicate. She could not feed herself. She did not recognize her husband or her children, grandchildren, or great grandchildren.

She developed diabetes and gradually lost the her legs which were amputated to save her life. But what life did she really have laying in a hospital bed day after day. When my grandfather became ill, he occupied the bed next to her. He died by her side, but she didn't even know she was there.

By the time my own father turned fifty, he began to show signs of memory loss. As the years went by, he developed speech problems. He would forget words in mid-sentence and be unable to complete his thought. The doctors said he had impaired cognition from what appeared to be early onset dementia. Fortunately, my father died from emphysema before the dementia could take full control over his life. To suffer his mother's fate would have been too cruel. However, his at least one other of his surviving siblings has developed similar symptoms.

I am an attorney. I worked long and hard to put myself through law school. My eldest son is preparing to follow my footsteps. What is our fate? Will be be spared this horrible disease, or will we suffer its same cruel effects and lose the most precious resource we possess, our minds?

Barriers and roadblocks to health tools is cruel and inhumane. Help us help ourselves. Allow every diagnostic tool available to those who need it. Stand for the justice thing to do. Be on the right side of history.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My Grandmother suffered for years. She lived alone as Alzheimers took her mind, her personality, and her independence. Years later, my mother, her daughter, suffered the same fate. Learning that my uncle, her brother had died the same way, I now face a life of uncertainty and fear, wondering... am I next? Hardly a day passes that I don't think about this. You can't imagine what this is like for me. And my sister. Please support this diagnostic breakthrough before it takes another generation of my family.
After 3 generations of tragedy, isn't it time to move forward?forward. please help us.
Before

Medicare

Dear Sirs;

I live in Saltville, VA. According to the former Director of our Medical Center, we have more than twice the national average of Alzheimer's cases. It could be, because we have a NPL Superfund Site because of mercury pollution. My sister and I were the caregivers for our Mother, and now our older brother has been diagnosed as having early onset Alzheimer's. Frankly, if stem cell research had begun years ago, we might have a cure by now. Any thing we can do test wise, has to help. We also need to increase funding for Alzheimer's research, before it becomes even more of a national catastrophe! Thank you!

Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Both my mother and my mother-in-law suffered from dementia of some kind. Various causes were suggested, such as strokes or medications, as well as Alzheimer's.

Both my husband and I are, of course, concerned that we are vulnerable. It would mean so much to us and our families to have a firm diagnosis in order to plan for care in order to use resources efficiently.

Thank you for your consideration.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My brother was diagnosed at 54 and died shortly before his 62nd birthday. I watched him rapidly age and deteriorate and at his death he looked to be a man of 85; unable to communicate, focus, swallow, express himself, or retain his dignity. Please do whatever is in your power to stop this from happening to anyone else. My only solace is in the fact that he now rests in the arms of his Savior Jesus Christ as a perfect child of God.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My father suffered with Dementia for 11 years and my mother in law suffered with Alzheimer's for 10 years. We as their family members suffered along with them as they lost the ability to do things for themselves, lost the ability to interact with their loved ones, lost their sense of security and their personality. They lost their sense of dignity and their physical health as well.

People who are diagnosed with this disease are basically dying a slow and tortuous death. It is so difficult to watch your loved ones struggle and not be able to help them. As they suffer, you as a family member suffers as well. I am fighting depression and anxiety issues due to the stress of being a caregiver. This disease is relentless and being a caregiver is very stressful.

Please help millions of people and their families get help by being tested earlier and receiving treatment that could improve the quality of their lives. Billions of dollars will be needed in the next 10 years to care for all of the people afflicted with this disease if there are not more diagnostic tools made available.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I don't have a direct story, but one that involves a lot of people. I am an Emergency Medicine physician and I see the confusion and pain that family goes through trying to make decisions about the care of their loved one who is not really diagnosed. It seems as though the patient has Alzheimers, and their doctor doesn't know whether to start them on treatment, treatment that if the person has Alzheimers could give them a few more years of a more productive and responsive life. Please give these patients and their families the time that they deserve to have by getting a proper diagnosis and then treatment plan.

Dr June McMillin

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Sheila Swindle

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My Mom is her high school Junior Prom Queen, bright, talented, woman. Now, she barely recognizes her own children and has a loose grip on reality. If she had an accurate early diagnosis this would have meant the right treatment to improve her quality of life.

She will always be the Best Mother in the World. Help me and others be the best children to them.

j leslie

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My mother was already losing her mental capacity before she received any medicine, so that the medicine ultimately did little to slow her decline, which took almost a decade until the end. Since my father also had dementia of faster development toward the end of his life, I have serious concerns about my own mental capacity and its deterioration. I need tests like this.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Barbara Babbitt

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My husband, Richard, had to stop working in July 2004, at age 56 because he "was not doing his job anymore." Nobody can see from the outside that a person is developing dementia on the inside. I believe this is especially true of highly intelligent people because they can sort of make-up for deficiencies in other ways. When Richard stopped working, I knew something seemed to be wrong with him, however, I had no idea what. I sent him to the doctor for a physical. The doctor could not find anything obviously wrong with him. In the meantime, Richard told me he needed to have a job that did not require reading. I couldn't believe that, my husband who read everything, all the time. So to help him with his reading, I took him for eye exams; about 4 in a year because nobody could seem to find the correction he needed. Finally, an eye doctor told us there was something wrong inside of his head and referred him back to our PCP. PCP referred him to a neurologist. A year and a half after he stopped working, after a PET, a neurologist told us that Richard had dementia. It was just before his 57 birthday, I was 49. Even then I don't believe the diagnosis was accurate as to what type of dementia. Finally, last year, while on hospice, a doctor told me Richard had fronto-temporal dementia. All the proceeding years, Richard had been receiving treatment for Alzheimer's Disease. I think that some of the medication he took did nothing to help him, and was a waste of money, time, and hope. Richard died on May 8, 2013. Please do everything within human power to assist in better diagnosis, treatment, and care for all dementias. For the patients and the caregivers. We are all victims of dementia.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Ms Janet Garcia

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother died in the advanced stages of Alzheimer's from a heart attack, but the most difficult time was getting a clear diagnosis of the disease in it's early stages. If there is anything that helps early diagnosis it is sorely needed! I urge, no I demand, you to approve PET imaging as an early diagnostic tool. Too many heartbreaks and too much suffering and too many dollars are spent dealing with this disease and caring for its sufferers!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother died from Alzheimer's in 2008. An official diagnosis was a painfully arduous journey, from doctor to doctor as more and more precious time sped by. When a consensus was reached, it was much too late for the treatment available at that time. Mama lived out her remaining years as a frightened, anxious shell of herself; essentially one of the walking dead. Anything and everything must be done to provide a concise and early diagnosis. Monies should be allocated at this time; otherwise you are "penny-wise and pound-foolish". Give our loved ones a chance of quality of life instead of tragically wasting away in the throes of astronomically expensive caregiving facilities. There but for the grace of God go you! May you never be touched by this evil disease.

Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother was diagnosed, several years ago, with Alzheimer's but by the time she received her diagnosis she could no longer talk or walk. It was too late for any treatment even had it been available then.
My husband spent a more than a year going from test to test and doctor to doctor. He was diagnosed just in time to prevent the wrong drugs from causing him harm. He does not have Alzheimer's, but has Lewy Body Dementia. With this diagnosis he was saved, just in the nick of time, from Alzheimer's drugs which could have killed him.
Don't shortchange dementia patients!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Ten years ago, at age 70, my mother noticed lapses in her memory. Her primary care doctor ignored her complaint. Months later when she confided in me (I am a nurse), I attended an appointment with her. She was referred to a neurologist who also told her " You do not have Alzheimer's. I think you are depressed." Blood tests and an MRI ruled out any other physical issue and she was placed on an antidepressant.

When she continued to experience memory problems, she finally was prescribed an approved Alzheimer's medication, which did help stableize her memory.

I know there is no cure for Alzheimer's. But it would have been helpful if from the very beginning, Mother could have been tested and treatment could have begun.

Her memory is gone, but her body lives. My father, my sister and I take care of her at home with a lot of outside help. I hope that our country can continue to be willing to do what it takes to defeat this terrible disease.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My Mother has Parkinson's dementia. Her mobility is under control but her dementia is getting worse even with medicine. It is very hard to live with this and to see a loved one slowly lose touch. Getting her to accept an assisted living arrangement is hard and looking to the future is even worse. Please do all you can to study and treat this disease for all of us who know this pain.

Medicare

My husband has Alzheimers. He was fortunate enough to get an early diagnosis and begin early treatment which included participation in Clinical trials at Georgetown Medical Hospital. He will have been diagnosed 9 years ago in September. He is still functional today. He attends an exercise class, walks regularly, and participates in social activities. An early diagnosis has meant the difference in many more years of being able to enjoy family and friends.

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care.

Please help others to get an early diagnosis!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My family and I are navigating our way through the difficult passages of caring for an Alzheimer's patient. It has been more than 10 years since my mom began to have trouble remembering things or where she had put things like her glasses. At the time she was a piano teacher and was the chairman of the Refugee Committee at our church. My dad is a retired public school teacher and they live in my childhood home across the street from where I chose to buy my home when my dad had a major heart attack many years ago. Clearly I thought our family challenge was going to be my dad's heart condition. Now, with my two sisters living in Northern California, Dad and I are busily caring for my mother and meeting the daily challenges.
Had my dad not been the consummate saver, we would be in deep trouble. He is paying for a team of 4 women whom we found through our church to help with the daily care of my mother.After Mom was hospitalized with what turned out to be a serious urinary tract infection during which one caretaker and I spent every day and night in the hospital room with my mother since she was not able to be cooperative at all and constantly tried to remove her i.v. and to get out of bed, it has become necessary to have the caretaker with Mom every night. She lives in the same home where she has lived since I was 2 (I am 57 years old now). My sister recently found her in the laundry room sobbing because she thought that that was the bathroom and she couldn't find the toilet. After almost 66 years of marriage, my dad is crushed that the love of his life is so confused and lost. We rejoice every day when she sits down to play the piano and does so so very well. Somewhere deep down inside, our mom is still there. Our family is doing much more than the average family does or is able to do for our mom--this is what Mom's doctor in the hospital told us, but it is very costly financially and emotionally. My sisters make as many trips down to visit and help with my parents' care, but much of the burden falls on me and my dad is literally wearing out. At 89, he is doing much better than any 89 year old I have ever known, but the caretaking process has dragged us all down. Now is certainly not the time to begin withdrawing funding and support for the many, many families who are dealing with Alzheimer's Disease as well as the many other types of dementia. My sister's in-laws both recently passed away after a comparatively quick mental decline due to Lewie-Body Dementia. Our story is not unique. Many, many families are caring for a parent who has Alzheimer's Disease. Our entire family is vegetarian and has been for many years, but Alzheimer's is one cruel joke. You can't diet your way out of it. My parents have outlived every single family member and this is probably due to their healthy lifestyle, now our country needs to devote the funding and time to find the cure to this horrendous disease.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother has worked all her life since very young. She has been a wedding planner, baked wedding cakes and handled the whole wedding. She worked many hard jobs through her life but this was the one she loved. Later she would do dinners in her new dinning room.

Always busy, bright and alert through her life, she swam at the YMCA and took trips with the group. She enjoyed a full life. Took care of a husband dying of cancer and was made a widow four times.

The first time I knew some thing was wrong, she drove down a center line of a high way. She made like it was a joke. My mom just wasn't like this. Later on I'd notice more and talked to family. I took her to a Dr. who tested her and said, dementia. The Dr. wasn't very nice, laughing when mom made mistakes, I didn't take mom back, just got another Dr.

She stayed home, alone awhile but left her stove on, lost things, put food together you wouldn't give a stray dog. Her house was becoming un kept as well as her self.

We tried a nice place where she had an apartment but people were there to care for her. Later, we moved her to what is called A Memory Ward, just for people with her problems. At first she was pretty alert, she enjoyed the people and us visiting. Then it got to she couldn't remember anyone visiting. They help her with bathing and soon with eating as she is starting to play in her food like a child.

I want you to reconsider funding this program. It might have helped her if they'd had it earlier. Think how you'd feel in her place, not understanding half of what's going on around you. When you forget even who you are, wouldn't you want to know funds and places to live safely would be there for you? what if it was your mom or aunt? Wouldn't you want her to have the right tools to help? Please pass this very soon.

Thank you for your consideration.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My father was diagnosed with Alzheimers 5 years ago. Some people with Alzheimers wander, which my Dad did. It is very dangerous, as he was walking outside in the middle of the night and crossing busy streets. In order to keep him safe, we placed him in assisted living on a alheimers wing of the center. It breaks my heart to see him there in his own room when he should be living with his wife of 60 years, my mother. My father is a wonderful father and has been a good man all of his life. I hate that he is spending the last years of his life apart from my mother. He is disappearing in front of our eyes and I don't want to lose him.

If this tool could lead to quicker and more accurate diagnoses and earlier treatment, I'm all for it.

Thank you.
Sincerely,

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My mom is suffering from Alzheimer's disease. She got this at a very young age - in her early 60s. We could have had a diagnosis 1 year earlier and started treatment 1 year earlier, but insurance would not pay for a PET scan. After going back and forth and getting rejected and rejected, as a family, we made a decision to pay out of pocket for the PET scan which confirmed our worst fears: that my mom has Alzheimer's. This is by far the worst disease that exists today. No one ever beats Alzheimer's, you only lose. And this disease doesn't just affect 90 year old women in nursing homes. My mom is now 66 and she probably won't live to see 68 unfortunately. Please please please take this seriously.
Thanks!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Karla Cook

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mom was diagnosed with Alzheimer's back in 2011 and her diagnosis was confirmed using a PET scan. The ability to get a fairly early diagnosis allowed us to provide my mom with medication that may have helped slow the progression and give us more time with her before she moved into a more advanced stage. I think it's unconscionable to even consider requiring people to provide more evidence before appoving a PET scan. Dealing with and facing this disease is hard enough as it is then to have to worry about convincing Medicare of the need to test is simply not right. Please consider the evidence and don't place another barrier to diagnosis & ultimately treatment.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

Kevin McCoy

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My mother suffered for years with the beginning signs of dementia - no one in our family realized this was the case, however, until she suddenly died at the relatively "young" age of 79. Her mother and grandparents all lived well into their 80's. If we had the ability to test her, we could still have her with us. She has 4 children, 17 grandchildren and 10 great-grandchildren who all loved her and miss her.

Besides, I fear the disease will be in my future - and already have signs of some cognitive impairment that has recently developed. I am only 55! What a relief it would be to know how to plan my future, rather than dread it as I fear sinking into confusion and pain and depression as my mother did.

PLEASE reconsider making early detection a possibility through this test.

Medicare

My wife has been a diagnosis of Alzheimer Disease. It was done using some form of neurological test. Her memory in all forms appears and disappears and communication can be frustrating and painfull. We do not know if she suffers from a different form of dementia. It has been suggested she receive a Beta Amyloid Pet scan. Why are barriers being erected to receiving this technology? Who profits from the delays? It is frustrating , filled with tension when there is not a definitive approach to diagnosis.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My Dad has cognitive impairment, but the neurologist does not know if it it due to his normal pressure hydrocephlus or Alzheimer's; he did get the PET scan but it was hard and costly. It turned out he did not have Alheimer's drug, so he was able to save the cost and possible side effects of the Alzheimer's drugs. Another positive was the piece of mind this gave him. Please help to make it easier and less costly for patients like my Dad. The science is there--it is important that the aging population get access. It will end up costing our system less in the end.
Thanks for yur consideration.
Denise Dickson

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My wife was diagnosed with a PET Scan in January, 2011 with Alzheimer's Disease. She was only 63 years old at the time. Even though I had insurance through CIGNA, it was not approved, and I had to pay for the PET Scan out-of-pocket. Now she is Medicare eligible, and I believe that this is an essential service that needs to available to people that have Alzheimer's Disease, and other Dementias. It is imperitive that families not have to suffer with this diagnosis, if it can be readily available, so that they can have their loved ones treated with medications that make life with Alzheimer's and related dementia more tolerable.

Thank you for your consideration of this important subject in a timely basis.......

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My family and I started to notice my mother would repeat a story she told over and over, as if we had not heard it already. The truth is we heard it, but she did not remember she had told it, so it was the first time for her each time. As time passed, we realized there were important things she could not remember, like did she eat breakfast that morning. If we reminded her that she had, there would be a big argument, because she clearly did not remember. We mentioned this to her doctor who took what we said with a grain of salt. Over valuable time, we insisted she be tested. She was diagnoised with alzheimers. I tell this story in short order, but the devistation of the disease was anything but a short period of time. She and my dad had been married for 60 years at that time and as my mother lost her memory of their wonderful days together he was losing the best friend he ever had. My Mom past away in 2008, my Dad died 8 months later of a broken heart. I realized I has lost my Mom long before her physical body died.

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My best friend was suffering from memory loss and confusion when he was in his late 40's. It continued to get worse over the following years, and he was advised to get a PET scan to rule out Alzhiemers and Dementia, however his insurance at that time would not cover it. Several years later, when his condition had worsened, he paid out of pocket to have the PET scan. The results showed that he had early onset Alzheimer Disease. At the stage he was diagnosed (through the PET Scan) it was already to late to start progressive treatments as the disease had progressed quickly. He was just 58 years old.

I believe that our Government has the control and should exercise that control over insurance companies and especially through Medicare, for early diagnosis and treatment of Alzhiemers and Dementia. My friend is now totally disabled at age 62 and on Medicare. He has been denied into treatment studies because of the progression of this disease at diagnosis.

This life, this mind, could have been saving through early diagnosis. Please clear the red tape, and delays in providing Medicare coverage for this type of early diagnosis through PET Scan. It will save many lives, hearts, and families.

Thank you from the bottom of my heart.

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Mr Jim Sheridan

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My father is a 74 year old veteran. He has top notch healthcare with medicare and tricare. His case is complicated by all accounts. It has taken 4 years and many different doctor's to get a diagnosis and we are still not sure if we are right. To be able to have a test, looking for something specific and definitive like amyloid plaque, would make all the difference in the world. We could be sure of the right course of therapy and be able to have an actual test to show my father and get him to better accept his diagnosis and comply with his treatment. He would be able to accept and comply if he saw the proof. He has a right to know. Diseases of the brain are so taxing on the patient and the caregiver, sparing us some of the 4 years of appointments and tests would have been life altering. We have spun our wheels with no answers long enough. I have a hard time when I compare how different this experience has been than when he had a heart attack. Doctor's and insurance don't blink an eye at the proper tests for the proper diagnosis and proper treatment. All was done rapidly and effectively. What I don't understand is why is the heart more important than the brain? I am sure the cost of his heart care far exceeded the cost of this test that could bring my family some answers and reassurance in the proper course of therapy. Please consider reversing the stance on the new diagnostic testing.
Thank you,

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After taking care of my Mom for over ten years and watching her suffer, I now am having the same problems she and her mother had. It's hard to believe I have to fight so hard just to verify what I already know. They are deliberately refusing to help me. No one could be so stupid and I have to trust these fools to help me?

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My only sister has Alzheimer's. I only got to see her because an old friend from Wisconsin met her plane in Chicago. Then the two of them took the train to Seattle, where I met them and brought them to our home in Port Townsend. Between this kind friend and an understanding porter, she survived two nights on the train. I am so happy for that visit. I don't think she would know me any longer.

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When my mother (RIP) was diagnosed with Lewy Body Dementia 2 years before she died, we learned about the signs and symptoms of this dementia that not many were familiar with (even doctors). It was a hard 2 years leading up to her death. Hard because we had to watch her suffer and watch our once vital, vibrant mother turn into a complete stranger (both physically and mentally) before our eyes. If we would have had an earlier diagnosis, we would have been prepared to help her more. We would have known HOW to help her. And, in turn, we could have helped others going through the same thing. Please allow PET scans to be covered. They are an imperative part of the diagnosis of any form of dementia.

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Douglas Holbroo

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My husband was an executive chef. talented, creative, and as a husband, kind and considerate. He retired in 2006. I wasn't eligible for medicare for several years, so decided to keep working. I was looking forward to our retirement together. It didn't happen. He is 72 years old, and severe vascular dementia which has become Alzheimer's. He has been in a care facility for over a year now. I cared for him at home, took early retirement and am now spending my days without my husband. Early diagnosis may have prolonged the effects of this terrible disease. Please , please help. S many of us will be afflicted by Alzheimer's. So many families ruined because of it. Until a cure is found, early diagnosis is the only thing. PLEASE help.

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My husband died from ALZ in October. His dad and mom both died of the disease. If he had a PET scan early on he might,could have started treatment earlier and live a better last few years. If there is not more research done on the disease I don't know what is going to happen as the baby boomers age and more and more people get ALZ. It is a terrible disease both for the victim and the family, especially the care giver. There is no help in our area. What is going to happen to all those people that get the disease as time goes on?? Death panels?? Obamacare is not going to help, in fact I think it will make it worse for victims of ALZ. Death panels are not the answer. This country is better than that, at least it always has been. Help the helpless!

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My Dad was not just showing signs of aging but something seemed really off. We ended up having so many different tests done before his diagnosis. This was not only costly to Medicare but delayed a diagnosis and delayed medication that could help slow it down.

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I am the primary caregiver for my 85 y.o. Dad who was diagnosed with Alzheimer's over a year ago. It was a struggle to get a diagnosis because most of his behavior was chalked up to "old age". If I did not advocate for my Dad, he probably still would not be diagnosed. Even though there is no true diagnosis until after death, why take away this test from people who deserve to know and prepare for what is happening to their bodies? There was a time when mammograms were not given as a routine part of a person's care. We learned that was not a good approach. People should be able to find out as far ahead as possible, at the earliest signs of this disease, what they (and their families) are up against. If people had access to this test it would give them more time (with their memory) to prepare for their care rather than burdening the nursing home system with people who have no pre-planning in place. This disease is growing and taking the lives of our loved ones everyday. Once my Dad was diagnosed, he was already in the moderate stages and we had to rush to sell his house, move him in with me and adjust his finances. It was a burden to our family. If we had access to this test when his signs first presented themselves, our situation would have been different and he would have had more time to do all his "last things" in his life before he was robbed of his memories. Please don't take this chance away from our loved ones. And to be completely honest....if this is a money issue than you should heighten your fraud investigations and stop the fraud that causes so much waste and apply it to this test. It disturbs me everyday to see how much fraud occurs within your system. Disgrace.

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My mother passed away may 2012 from Alzheimers. She was 80 years young. Her mother s still alive and s 102 and has no dementia. I wanted my mom to ave diagnostic tests but the doctors would not saying there s no cure so there s no use doing them. I am convinced that mom had something other than Alzheimer's as her symptoms were in the neurologist opinion atypical. It was tho met heart reaching thing to see my mother deteriorate. In 1994 my mother fell and hit her head. the MRII and said there was something on the scan and did no further testing. Shortly after that she started to decline. She lived for 9 years with the Agnes of Alzheimer's and. Believe a PET scan could have found the real reason for her illness. Please don't deny other families seeking the best treatment and hope possible for their loved one. Sincerely, Tamara Singer, Outreach Specialist for Dementia Care.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: I have been an LPN nurse for 38 yrs. 25 were in Nursing homes. I have seen many with this horrible disease. Now my husband of almost 37 years also has Alzheimers. Being a nurse I know what comes next with this disease. Someday I know he will wake up and not know who I am. Please help! At present time he receives Medicare. I am at the present time unemployed. Please give me some more years with him.

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It happens to people that are above average intelligence, more often than not. Imagine seeing your loved ones thinking they are going mad, rather than being the brilliant engineer they were or multi-tasking mother, wife, career person that cant remember family members. The most SINISTER thing is, that the illness has begun long before it is diagnosed and medications to retard the progress of it could have made ever so much difference to both the patient and family members. Government programmes should NOT be able to dictate the grade of care given to the sick...what ever happened to medicine having to do w/ the Oath of Hippocrates?????? We will be lost as a race if you keep up this modus opperendi.

Deborah Koss

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have every chance available to identify this disease as early as possible. Only through early and accurate diagnosis of Alzheimer's is an individual given the opportunity to maximize their remaining time to fight the disease.

The country son "Live like you are dying" could be applied to individuals with Alzheimer's because this disease takes away everything- even the most precious things. The disease slowly erodes your mental, physical and emotional abilities, stealing away the essence of your individuality. Your most precious memories are stolen by this disease. At this time there is no cure for the disease, but with early diagnosis there are treatments and interventions that help improve the quality of the patients life. Yes, with the diagnosis of Alzheimer's I realize what the end game will be; however, with early diagnosis through PET imaging I will have a better chance to fight the disease. To maximize my remaining time, yes to "Live like you are dying". To make the most of every day and to relish every memory because I know it will be taken from me.

I encourage you to reconsider your position and support diagnostic testing. Eliminate the imposed barriers, delays and cost so that our country can support all the citizens facing this terrible disease.

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Three years ago my father passed away, leaving my mother with at that time in moderate to early Alzheimer's. At the hospital he asked me to move home to help take care of them because he couldnt anymore. I lice states away and am 59 so I have to work. The hardship this has placed is almost overbearing and how long is equally hard. I have been priced himes up to 9100.00 per month. There isnt any way to afford this or to work more to pay. Had this test been performed years ago I might be more situated to handle this. We need help. Cancer and heary problems are NOT the only health issues. W

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Joanne Hill

Medicare

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My husband was diagnosed with early onset Alzheimer's in 2003 and should have been given a PET imaging early on so we could do more for him. It I difficult to know exactly what a person has if there is not evidence such as a PET imaging scan.

Let's do the most so our loved one can have a better quality of life and we know more definitely if they have Alzheimer's and how much it has progressed.

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More than 10 years ago my husband began showing signs of dementia. I could see it, he could feel it, and the doctors suspected it, but dementia is hard to pin down. I child proofed the house, learned to cook with only one knife hidden in the kitchen, took the knobs off of the gas stove and removed everything toxic from my house. I tricked him out of his car keys and installed an alarm system in case he wandered.

And still there was no test available to help with diagnosis. Until the seventh year.

One afternoon I found him crouched in a corner, flailing about, in the throes of a terrifying episode of acute psychosis, the first of many to come. Can you imagine believing you were in a Mayan ceremony, being punished because you could not perform all of the rituals?

For three days he was in the hospital where they administered Haldol. He had always been a cooperative patient but after the Haldol, he swung at two nurses. So they gave him more and strapped him to his bed. He got worse with every Haldol injection until they could give him no more.

He was misdiagnosed with Picks Disease, because of his agitation. I was told he would never come home and we would have to manage his behavior. Future episodes were, thankfully less terrifying, just as disabling and became more and more frequent.

Finally, after much effort his Neurologist at Cleveland Clinic, Lou Ruvo Brain Center managed to get approval for a PET scan, which we could not have afforded on our own. This at least allowed us to narrow down the diagnosis.

He did not have Picks disease or Alzheimer's (it came two years later). He was a victim of Dementia with Lewy Bodies. Important because the medications used for this type of dementia are frequently different than what is used for others. For instance, Haldol makes symptoms worse and could have killed him. His misdiagnosis led to an extra three days in the hospital and almost three weeks more in a rehab facility. At what cost?

He had, for years become restless and defensive around Veteran's Day and Memorial Day. I wrote it off to his past service to his country in the 11th Airborne during the Korean War. I hid and locked up his guns and anything else that could be used as, or viewed as a weapon. Not for my safety only, but because when you call and tell 911 that you need help with someone who is in psychosis, the first people who come are the police. I wanted to make sure he did not have anything in his hands that could make him look like a threat to himself or others. I could tell them, all I wanted, that he was not violent, because we now knew to avoid the wrong medications!

Look around you, please. If there are three people reviewing this, one of you will someday have dementia. Will it be you? If there are three older adults in your family, at least one is probably showing signs now. If you have three children, at least one will age into dementia - unless we stop it soon! This is not a small thing.

Correct diagnosis is so important. If we are wasting time and money on inaccurately diagnosed dementia patients we are making the problem worse and more expensive, inaccurately prescribing, causing more complications, racking up avoidable hospitalization costs and squandering funds that could be used elsewhere.

Please approve this test. It will pay for itself over and over again with more accurate diagnosis and treatment. It could help determine whether you end up a caregiver, or Heaven forbid, end up under the care of one of your children because no one quite understands what is wrong. They future of our society and how we deal with this epidemic depends on providing accurate diagnosis for all diseases.

Today is July 31, 2013 and I respectfully submit this plea in memory of my husband, Christopher R. Sgambati who died, of end stage debility due to Dementia With Lewy Bodies, on August 11, 2013. May this cause of death disappear from future death certificates, just as smallpox has. May families of the future never have to write a letter such as this through their tears.

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My grandmother is my second mother, and we have been close my entire life. They used to call us "the clones" because we were so similar. When she got the early diagnosis, my sister and I made sure that she got the care she needed by way of Aricept and support groups, trying to engage her mind. The rest of the family was in denial. In the beginning, it was a good excuse to see grandma - take her to the doctor, to the grocery, etc. but that was when we could actually communicate.

Over time, her condition worsened and when we realized that she was letting strange men into her apartment, we moved her immediately. That's when all hell broke loose, and she took a nosedive into her dementia. No more conversations. she doesn't remember anything. even who I am, her grand-daughter. and now she cannot even talk with any sense. she has no control over her body or her mind. it often seems as if she is watching angels in the air above my head. she is living in a facility and the whole family is convinced she will outlive us all, as nature can be so cruel. She is a shell of her former self. I have spent years grieving the loss of my "second mother" and deal with guilt and sadness around visiting her.

My mother struggles with her feelings about grandma (history) but is the only child to take care of her affairs. I see how much this has affected her. It is not fair.

And I am so incredibly fearful of getting it, I have resorted to doing puzzles like mad every day, trying to stay engaged. The future looks bleak to me, with an incredible amount of elderly dementia patients roaming the streets without care. It took YEARS of persistence to get grandma the aid she needed. and there is no guarantee there will be anything for my generation. And I have no children to fight on my behalf.

The situation is so bad that my mother and I have discussed investing in a gun instead of an IRA. If either of us get the diagnosis, we don't plan on sticking around to be a burden on society and family. Morbid but true.

We must as a society figure out how to cope with this epidemic and try to find a cure, especially since the projections are terrifying on how many people will be affected. That or a lot more social assistance.

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My father was finally diagnosed with Alzheimer's at the age of 56 after going through many, many tests and fights with insurance companies to cover the exams. He is now 62, and is institutionalized. Alzheimer's is affecting more and more people, and is starting at younger ages. It is imperative that we offer as much testing , evaluation & support to those that may be affected.
Sincerely,

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My Name Is Kenna, My Daddy Has Dementia, He Is 83. I Had Without Choice Had To Put Him I n. A Nursing Home . To Watch Your Daddy Fade Is The Most Saddest Thing I Had To Experience .   My Daddy Had Always Been So Sharp . Loved His Bible . Now He Doesn't Remember How To Pick It Up Read The Word Of God , But He Still Knows Who He Is .. He Confused My Daughter For Me . He Sometimes Has Child Like Symptoms . He Speaks Of Family Members Who Have Been Passed For 20Years He Always Ask of His Mother Whom Had Been Gone For 21 years Does Not Remember Going To HER Funeral .. I KNOW THAT IT IS JUST A MATTER OF TIME BEFORE HE FORGETS WHO I AM . THE THOUGH BRINGS TEARS TO MY EYES .. YESTERDAY I HAD TO DO THE MOST HARDEST THING ANY CHILD WOULD AVE TO DO . PRE FUNERAL ARRANGEMENTS .. HAVING THIS DISEASE MAKES LIFE FOR THE LOVE ONE JUST AS HARD AND STRESSFUL .. I PRAY YOU WILL ALLOW THESE TO MOVE FORWARD WITHOUT FUTURE EVIDENCE DEVELOPMENT LET'S GET THIS STARTED THANK YOU KENNA Brown

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My grandma was diagnosed with Alzheimer's in her 60's, she was one of the most important people in mine and so many others lives. This disease really hits home with me because it doesn't kill you, it deteriorates you. And your family has to watch as the person you love slowly falls apart. It's not fair and it is an awful disease as many out there. My family and I participate in a walk and I throw a benefit every year to help raise money, I just only hope one day it will help and no one will have to go through the effects of this horrible disease.

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Bessie Hornbeck

Medicare

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My mother was diagnosed with Alzheimer's in 1993. It was by far the worst ordeal my sister and I ever went through. She had such bad dementia that she thought her husband was constantly trying to kill her and her dog. We watched her turn from an intelligent lively person into a person that could not say or do much of anything. We were both there fir her last three days of hospice until she finally passed away.

My sister's now all worry about getting the disease and how we all will deal with that. Any prior notice or test that can help with this horribly disease is something we all need. Great strides have been made since our mother passed away in 2007. Please don't take away anything that can help.

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I believe that ANYTHING that we can do that could help to diagnose Alzheimer"s earlier or help in the treatment of it should be explored. This is truly a horrible disease, to me, much worse than cancer or any other disease, due to the fact that at least with the others you at least know what is wrong with you and are mentally aware of what is going on and are familiar with those around you.! My Mom, who is now 84 was diagnosed with Alzheimer"s a few years back ,and although, Thank God that she still knows who we all are and physically she is still here with us, in a lot of ways we have already "lost her"! Here once was a woman who raised 5 children and helped in raising grandchildren, loved cooking, baking, sewing, crafts ,daily walking, and is now pretty much limited to sitting in her favorite chair watching tv. I used to spend the whole day with her shopping and just talking for hours; of which now, I usually spend an hour basically just having her repeating the same questions over and over--"how are you"?, "how are the kids"?, "are you hungry"?. She, also lost 2 sisters to this same disease, and we worry because this disease can also be hereditary. I don"t want for my children or grandchildren to have to go through the pain of watching me one day deteriorate; we need to end this disease now!

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By the time my Mom was finally diagnosed the meds that slow it down did little! Now she is sitting in a nursing home and doesn't know any of us! New technology is needed to prevent it from getting too far advanced that nothing can help them Dementia ruins the lives of family members and although our loved ones are still here they are totally unaware of us and their surroundings! Please allow any new technology to help!

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Kaye Klassen

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I am a 51 yr old daughter, taking care 24/7 as a Sole caregiver, for the last 6 1/2 years of my NOW 75 yr old Mom...Margie with Alzheimers diagnosed Dec 2006 although we think she had it WAY BEFORE!!! No one knows untilits too late to start ARICEPT or NAMENDA or EXALON PATCHES! The Drs don't know which medicines exacerbate the anxiety, agrresiveness etc... The hospital Nurses don't know how to care for my Mom when she goes to the hospital! I get called witin 2 hours of going home to feed her cats!!!! EVERYTIME!!
My MOM HAD THE BEGINNINGS OF ALZHEIMERS WAY BEFORE SHE WAS DIAGNOSED! One out of every 2 patients will be diagnosed with DEMENTIA/ALZHEIMERS in the year 2050! Huge problem coming our way! HUGE!!! GET WITH IT NOW, WHILE YOU CAN!!! Our MEDICAL WORLD will need ALL THE HELP THEY CAN GET before it's too overwhelming and we all are trying to play CATCH UP!! It will be too late! Please GET ON BOARD SOMEBODY and help with this AWFUL DISEASE! NOW NOT LATER!!! Sincerely, Suzanne Baber

Medicare

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Leslie Scanlon

Medicare

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My husband was diagnosed 4 years ago at age 60 with Dementia. He is 64 years of age and can not tie his shoes, feed himself, have a conversation, clean himself. These are things that we all take for granted. I have had him in a facility to control his anger and agitation during sundown, it did not work. He lives at home with me and I take care of him 24/7. He needs round the clock care. Had there been a test prior to his diagnosis, he may have been able to do things longer.

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My papaw, was diagnosed with this disease and it has been so hard for my family. To watch someone you love literally lose their mind to the point of wandering away from home so you have to put them in a nursing center or to visit them and they look at you not knowing who you are! It is heartbreaking! I pray for a cure for this disease and for others as well because I know it isn't easy for anyone. To have the gift to be able to spend more time with a loved one, to tell them you love them, forgive them or have them forgive you, to let them know your proud of them, or just to say I love you and thank you means the world to every single soul I know! Please do not ignore our crying pleas for any and all help that we need and deserve. May God bless whoever reads this, and your family. May you be blessed to not ever have to endure this kind of heartbreak.

Medicare

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My name is Bakhus Saba
I was a caregiver for my mom from 2004 to 2011, it was then I placed my mom in Long term care for Alzheimer's. That was the most difficult decision I had to make. I Knew somehow that I would need to be a voice for all of our loved ones that are not being heard so this was the only way I could do that, Through song a song called Still a Child and through a video Called Alzheimer;s Knows no Borders There are over 15 million Caregivers in the USA so what you see in this video is important please watch and I ask you Do ALL YOU CAN TO FIND A CURE FOR THIS DISEASE 250,000 EARLY ONSET DIAGNOSIS IN THE US
hope you can watch and please share on your site so others can share their story and journey with their loved one with Alzheimer's with 10,000 baby boomer turning 65 everyday in the USA from 2011-2030 and a ratio of 2/3 women affected by alzheimer's/dementia,This is a special video with very personal stories.
Alzheimer's/Dementia has no borders and we must always remember with every person living with dementia there is a story, there is a life full of families, friends, work, careers, activities, hobbies, social engagement, emotions and memories - an individual - a person.
thank you please share on you FB site
http://www.youtube.com/watch?v=mj_2Q9jzmlE

Medicare

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In 2008 my husband quit working a part time job. He is retired after 23 years in the USAF. During his last year working I noticed he had more difficulty at work, but thought it was just him being so Conservative in nature and getting older. Mainly just a grumpy old man (at 61). He turned 62 and he decided we would sell our home and hit the road in our RV. We did- Sept 1 we started out on a trip unknown. Such a change can be daunting at best as you go different places unknown and for the first time in your life feel untied down. As time went by he would get lost and not understand directions and blamed it on me as a woman who couldn't read maps. Then his anger got bad, it was beyond anger when he yelled at me and called me names in public. He became very reckless driving. I was at my wits end and I was in such anguish dealing with him. I researched on the internet a lot and entered a lot of the symptoms he showed. * Severe, unwarranted anger; confusion; nightmares; he sometimes didn't know where he was; one time he did not recognize me looking me right in the face asking someone to help him find his wife. He cried; he became bitter about everything; turned very selfish; used very poor judgement on money spending and many other things; used bad language in public; became aggressive to strangers.

We finally went home to our doctors and I convinced him that something was wrong and I was going with him. I told the doctor all of the things that had been happening and he immediately started evaluating him. He put him on Aricept and raised his dosage of Zoloft. In no time I started seeing my old husband returning some. He has been on it since 2009 and even though I still see the differences in him, most days I totally forget that there was ever anything wrong with him. But I recently went on vacation for a week and saw such a big difference in him when I returned. I could go on and on. But my goal was just to let you know how noticing his behavior changes and getting him to a doctor quickly, I feel, has helped him tremendously. I only wish it would go away and not just be masked by the medications. But I will always be close and watch for any changes. Not everyone has that opportunity. Please help us and all the people who are struggling with symptoms not knowing what they indicate. Someone has to notice and diagnose Dementia and Alzheimer's.
Thank you for listening.

Medicare

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My father is currently living with Alzheimers and it is very hard to get any help unless that is, if he has nothing, no home, no bank account, etc. How can we expect to help all of the people living with Alzheimer's if we do not take care of them. Please, I beg of you to help get this treatment out to patients immediately. WE need help!!!

Thank you-

Medicare

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Abbye Caudle

Medicare

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Medicare

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My mother was diagnosed just last may, 2012. She has progressed so fast with this horrible disease. I desperately wish I had been given more options for her treatment. She has had a downward spiral in just one year! my heart is so heavy, words can't even express!

Medicare

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My uncle passed away 3 yrs ago from Alzheimer's. It was the worst time in my life to see him melt away to nothing. I can't even write this letter without crying. Please help these older people who have worked hard all their lives & end up not being able to enjoy growing old together with spouse. Would you want to die like that?

Medicare

As I said on Twitter. My uncle has been a preacher longer than I've been alive. Although my Uncle suffer's from Dementia there was nothing more scarier to my Aunt Pamela Magee then realizing something was wrong with him when he couldn't remember things he'd preached for years.

That is no way to discover somethings wrong. The heartache to loved ones can not be undone. To watch the person you love and spent 30, 40 plus years with to mentally disappear.

That is a fate worse than death! My mother in law was diagnosed about a year ago. She's was a nurse. Responsible for others care. Luckily she realized what was going on and took early retirement. But that could easily have gone another way.

My father is another example of why early detection would be important. Although it too is not Alzheimer's if we had known sooner that he was having mental capacity issues I wouldn't be going through this hell right now. Steps and actions could have been taken and it would be such constant battles.

There are consequences for not approving early detection. It doesn't just affect the individual with the disease but others as well. It also leads to the potential to help with so many other issue as well. Is anyone really willing to take those kind of risks? Is it all about the bottom dollar?

If it is about the bottom dollar consider this early detection of any disease reduces the long term costs of dealing with the complications of the disease. Maybe they get to stay home longer before going to a $6k a month nursing home.

Medicare

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i believe the testing be available now i watched my dad fight with this disease befor passing away a year and a half ago he didn't know he had it until his work addressed his forgetting to do his job correctly and i took a test for the disease by reading a story and immediately telling it back im scared i will develop it and not know until its to late like my dad and if there's a test that can tell me before its to late then please don't lengthen it's use until however long you deem necessary also my grandmother passed away from dementia she also had no warning until she forgot where she was going and police took her drivers license so long story short 2 family members have passed away with this cruel disease with no warning so any early notice would help thank you

Medicare

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My father was diagnosed with 'dementia' with no PET scan or anything. Just details of his medical condition and they called it what they thought it was. He later suffered a major stroke and brain hemorrhage that we believe could have been avoided if he had had a proper scan. He didn't live very long after this but what quality of life he had was nil.
I am worried that I may have the beginnings of Alzheimer's, but there is no way of knowing unless the proper testing is allowed. Please, work this out so that quality testing is made available for all people, not just seniors !

Medicare

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My husband was diagnosed with dementia exactly 1 year and 12 days ago. Due to his medical history, and his abuse of alcohol, getting him treatment was damn near impossible. For weeks and weeks, he begged the hospital to admit him and help him find out what was wrong. He could feel himself slipping away. He spent days and nights crying and telling me he needed to find himself before he was lost forever. The only diagnostic tool offered him, after a complete mental breakdown at his place of employment was an MRI and a psychiatrist who wanted to dope him up and send him home. It took 3 weeks of research and study on MY part to get a diagnosis out of the doctor. It has taken nearly the entire time since his diagnosis to figure out what he needs as far as help in our living space, contact with others, mental stimulation to keep his faculties sharp, etc. My firm belief is that if he had had access to better diagnostic tools, better medical care, and resources that did not limit him due to his age, he would be in much better shape to face the next 50 years of his life. Oh yes--my husband? He's 52 now. Time stopped for him on June 27, 2012. In his mind, he will always be 51 and getting ready to go to work. The struggle to get him proper care and treatment hasn't ended. His age seems to exclude him from everything. So for the next 13 years, the only expert in dementia that will be working with him is me. His disabled wife. Health care professionals who hear when a patient says something is wrong, and diagnostic tools such as PET scans, are crucial to early diagnosis. Early diagnosis is the key to slowing down and possibly reversing the damage done to a person's life. Don't let another person lose themselves, and their entire lives, due to the lack of one small test. PLEASE!

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my husband cant take the meds on the market now. he has terrible reactions to them, his blood sugar will drop to the40s and then, we go to the hospital. yes he is als a diebectic. hard to control when on any of these meds. we need another way to help them.PLEASE find us some help.

Medicare

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As for you people in Washington thinking that making your money is more important than helping our elderly citizens you are sadly mistaken. They are the reasons why we have some of the programs that we have. The medications are to expensive and some of the elderly have to choose between medicine, food or utilities. I hope none of you have to have this experience. You should cover all the medical costs of this disease or increase their cost of living.

Medicare

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My dad died of Alzheimer's at the young age of 77. His body was healthy but his mind was gone. This is one of the most horrible diseases EVER!!! I'm the youngest of 7 kids...what are our chances of developing Alzheimers? What should we do to help detect early stages? How will this affect our children and grandchildren?

If we don't do something NOW to help early detection...this disease will wind up being the #1 killer of people in the world.

Medicare

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I lost my husband 2 years ago to Alzheimer's. I just find it impossible to believe that you would want to do anything to delay the diagnosis of this terrible issness. David lost his ability to communicate with us and did things toward the end of his life that if had realized what he was doing bould have so upset. Early diagnosis is so important. Please do everything in your power to maie this possible.
Thank you!

Medicare

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My family is suffering the effects of this awful disease! Both my Mother and Father had dementia. They are living in an assisted living and we are trying to keep them together! They have been married for 64 yrs. This family has been fighting it for about 18 yrs with my Dad and around 10 yrs with my Mom! It has devastated our lives! My parents were the glue that held this family together. I also have a older brother who has it also. I am thinking my youngest brother has it also! Please give us a little peace of mind!!

Medicare

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My father was recently diagnosed with Lewy Body Dementia and I believe that this tool canl more accurately diagnose his condition far better as well as the other millions suffering from other Dementias. I say that because you cannot 100% get an official diagnosis of Alzheimer`s Disease until after an autopsy.

More money is spend on cosmetic breast surgery and viagra than Alzheimer`s Disease research!!!

You truly can not KNOW how devestating this disease unttil it strikes you or someone you love and the problem is only going to get worse with less funding.

Please consider this diagnostic testing method!

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I LOST MY MOM TO DEMENTIA AND ALZHEIMERS IT WILL BE AZ YEAR IN AUGUST THAT I LOST HER . PLEASE PLEASE REALLY THINK ABOUT YOUR DECISSION BECAUSE NOT ONLY FOR THE PATIENTS BUT IT CONCERNS TO FAMILYS . PLEASE IT REALLY BOTHERED MY MOM TO HAVE THIS IT DESTORYED HER LIFE . PLEASE HELP

Medicare

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You havent seen sadness until you watch a loved one deteriate from alzheimers and have to stand by and watch helpless to do anything I watched a lady go from independent to a person who didnt know her own name She was very dear to me and my heart breaks just to think of how she suffered and her family that loved her could do nothing to help except try to make her comfortable Money did no good as that was not an issue Her son a strong man used to being in control crumbled watching the mother he loved go from taking care of everyone to having to be led to the bathroom and reminded to use it Her teeth were never unbrushed and her own at 80 yrs of age began to decay as so many other parts of her body due to not enough people to take care of a very special lady There need to be something done to prevent this happening to another person no matter the cost Alzheimers takes so much from a person and their family so please do what it takes to stop this unfairness

Darla Ellis

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: My husband has Alzeimer's Desease and because his diagnosis was delayed by about 10/12 yrs. An early diagnosis would have given us time as a family, time to make better plans, time to made better financial decision and time for him to have had a better quality of life. Please provide every available means possible for advancement of early diagnosis.

Medicare

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Linda Coffman

Medicare

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My husband is in a nursing home now because I couldn,t take care of him by myself.He can,t walk nor talk or feed himself.He is in diapers all the time.They put him in bed or wheelchair and he has fell out of both of them befor.We been married 53 years and he didn,t retire till he was 72 and he is 76 now.He started working when he was 15 and got this terrible disease now.It,s so hard to see him this way I go over everyday and feed him his lunch and I am 72.I have heart pacemaker and total joints in hip,2 knees, and shoulder plus back surgery.They need to do more research on this deadly disease now.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:
My mother had Alzheimer's which alone is a story in itself . How much more evidence do you people want? How can you not see how important it is to use these diagnostic tools with the staggering number of people with this disease. It!s the most expensive disease to have even more so than cancer,it destroys families that have to leave their jobs to become caregivers because they can't afford to pay for full time help. Time to wake up Medicare and give these people the care they deserve and have paid into!!!!

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. When there is demonstrable and proven technology that can assist in a diagnosis it means that treatment happens sooner.

My mother was diagnosed, finally, with Alzheimer's--but not until she had suffered more than needed. She not only suffered from the disease but she suffered a loss of dignity because no one knew what was wrong with her and medications could not be titrated in the most effective manner.

My mother was fortunate in that her form of dementia meant that she didn't suffer long. Within a year from a correct diagnosis she was gone. If only we had known earlier she may have retained some dignity and been with us longer.

Don't deny someone the ability to get a correct diagnosis and to utilize every tool that is available to do so. Allow PET scans in diagnosing dementia. You would want it available for your diagnosis. Wouldn't you?

Medicare

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I recently lost my Father, By recently I mean 2 weeks ago. He was only 75 years young. I sat by and watched my mother lose the love of her life to this disease. Watching my father wither away was painful for him, and for us to watch. Early diagnostics is very important.

That's not bad enough, My Grandfather died from it in 2001. And looking back this is more than likely the same disease that killed my Great Grandmother. Hum My siblings or i could be next..

So yeah I would say it is very important. Early treatment and a cure. get off your butts and get it done!

We protect other countries, feed them, give them health supplies,.
I severed this country.. I guess we the people are not important enough to treat and cure

Medicare

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Ms Anne Brusca

Medicare

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Diana Melton

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My beautiful sweet mom passed from this dreaded disease. Her father had passed from Alzheimer's so she knew what was ahead of her. We promised to keep her at home always and with love, courage and guts we did. My father basically gave up his life to care for her. No one should watch or die themselves from Alzheimer's.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My husband started having strange symptoms.... Blood pressure dropping...was his autonomic nervous system.... .driving he was getting lost.....didn't know which door to go out if going to the car..

He was only 53 years old.   He was checked for every thing that could cause this except MRI. And spinal tap.....we lost 1 &1/2 years on correct treatment.   (Because HE WAS TOO YOUNG TO SUSPECT ALZHEIMER'S)

Was already approximately 4 years into the Disease before correct treatment........ within 1 year of correct diagnosis he was not able to dress himself......HELL ON EARTH TO WATCH.....

Medicare

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my husband is facing this diagnosis so we need all the help we can get. he has gone from an 82 yr man who did everything to one that needs help to remember what to do after his morning shower it is so sad to watch this and there a lot of people who are like this. so please what ever you can do will be helpful. tahnk you

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story. I lost my Mother to Alzheimer's disease in 2000. I went along with the physicians and placed her in a rehab center but due to Medicare's guide lines, she was not progressing far enough, such as a child in kinder garden so she was taken out of the program. I am an only child and was not going to leave my Mother there in that home that didn't love her no where near as much as I did. I worked with her at home taking an early retirement from my job with the state, after all you only have one Mother and she was all I had. I wish there had been more that could have been done for her and I pray that I do not get this dreaded disease and my Children have to watch me suffer like I watched her. Thank you.....

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My father suffered from dementia and the diagnosis came very late.We had had an MRI of his brian and were told he did not have dementia. That ended up being untrue.

Any tool that can help in an earlier diagnosis is critical to all the poor souls who will become victim to this disease.

PLEASE no more delays!

Medicare

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Sherrie Durell

Medicare

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Perla Castro

Medicare

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My grandfather, was a great guitrrist. He knew a million of songs and could play and sing the melody as any part of the harmony. As years went by he started to forget some of his favorite tunes until he completely stop playing the guitar out of frustration. We did not know that it was the beginning of his war with alzheimers. He forgot how to carry a conversation. He forgot all our names. It was so painfull for all the members and friends of our family to see him lost in silence. His life would have been easier if he had been diagnosticated with it when the symptoms started.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story: I watched both my mother and my mother-in-law suffer from Alzheimer's. It really hit home when my mom looked at me and said "We've known each other a long time haven't we?".
I knew the rest of her life we would never be able to share day to day events, and laugh with each other.

Medicare

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My husband, now 57 years old, participated in UCSF research study regarding this PET SCAN. The doctors were thrilled the PET Scan confirmed the three years of testing that he in fact did have early onset Alzheimer's Disease.

It helped us to know what we were dealing with and not always wondering if we had the right diagnosis and on the right medication rather than the endless search for answers.

There are still many unanswered questions why he has the disease and will his children get it. He was diagnosed in 2008 but problems started in 2005. He is now in the moderately sever or mid-stage Alzheimer's disease.

Please help the families of those with Alzheimer's Disease in knowing how to help their loved one with a proper diagnosis.

Medicare

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My daddy is an Alzheimer's patient & it is a terrible disease that I do not want. I try to read what I can do with alternative care to help prevent it, but it is so needful for everyone be tested so they can begin the attack against it. How much is one human life worth? We are all in this together & should love each other enough to help any way we can, that does not exclude corporations, government, medical providers, etc. Why are we all here & what is our purpose in life? To help our brother or make more money?

Medicare

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I just lost my father to this horrible disease that he lived with for about 10 years. The last few years were the worst!! For the family, it is just as bad. There needs to be more research and more financial aid put towards the cure to Alzheimer's Disease. I have a great chance of developing it myself, as both my father and grandmother had it. I know it is too late for me, but for my children's sake and for the many generations to come, I implore you to allow the PET scan to those who may have Alzheimer's so that they may have a chance to get on medications sooner and improve their quality of life, for what is left of it.

Thank you for listening!

Medicare

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This disease is slowly taking my Mother as I know her away from me. It's hurts to watch this and can't do anything. The costs for care are thru the roof. There is nothing good about this disease. We need to address this problem pronto..

Medicare

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Comparing two PhD scientists at the Smithsonian Instiution:

Early diagnosis and treatment helps. Because of treatment, my father's dementia has been slow. He is still functional and enjoying life.

Meanwhile, a dear friend and colleague (younger than my father) did not benefit as early in his symptomatic stage. He is nearly vegetative.

We have enjoyed several years of positive life experiences with my father because of early diagnosis. If technology now allows for even earlier diagnosis and treatment for other families, then PLEASE do everything possible to make that
possible. We can do SO much to improve the quality of life for so many people.
Thanks

Medicare

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I knew my mom had dementia and all the tests came back negative because they were the wrong tests .

Medicare

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The most painful part of my grandmother's diagnosis with Alzehimers was that it happened after I moved away. I would call my grandparents weekly and chat with them about my life 2500 miles away from home. Then, I called one Saturday... my grandmother playfully answered the phone like she always did (she sounded like a little girl) and I said "Hi Granny, it's me, Ashley." I'll never forget what she told me... she responded with "I'm sorry, my mother told me I can't talk to strangers," then she hung up the phone. I sorta chuckled to myself and called back, thinking this was a game. However, I had the same answer again. I called my mom to ask what was up... and she told me of the diagnosis of advanced Alzheimer's and that my grandmother was given 6 months to live. It didn't really sink in a first... but as time progressed and I had more and more issues calling and talking to my grandparents, things became clear about how heartbreaking this disease is. I wasn't able to fly home that year for Christmas. However, I went home the following year for Thanksgiving...to find that my grandfather had to admit her to a nursing home for care. She would wake up in the middle of the night, become confused, start hitting him and thinking he was going to rape her. They had been married for over 50 years. To show his dedication, he would wake up every morning before 6, get their dog ready and go to the nursing home to feed her. He then stayed all day... visiting with other patients and waiting to feed my grandmother lunch then dinner. He would go home late at night and do the things around the house that needed his attention there before repeating it all again the next day. He did this dutifully for 6 years. When I visited her in the nursing home, she was laying on a bed with her eyes closed. She wouldn't open them and would scream like someone had hit her if you touched her without speaking to her first. It was very heart breaking. I had spent so many happy years with them...

When I came back two years later, I came with my new husband. We made her favorite chocolate pie and brought it to her in the nursing home. My grandmother, much to my surprise, was sitting in a wheelchair.... and, most importantly, she recognized me. It wasn't the happy surprised look you normally get when your granny sees you after a long absence... but rather, she looked like Munch's painting of The Scream. She literally put her hands to her face and screamed like someone was pulling her hair out. It was painful, because I knew she was happy, but when she expressed it, it came across as frightening. The nurse (thankfully) reminded me that her brain was confusing her signals or I might have just ran out of the room. I introduced my husband, who fed her the pie as she sat and lovingly stroked his arm. So, what was the difference in the two years? Why did she have such marked improvement? She was put on the trials for Aricept. I am very thankful for that medication... for it allowed my grandmother to interact with her family before she passed. It allowed me to have my last memories of her be ones of happiness instead of bleak despair.

Medicare

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joe ireland

Medicare

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My mother, grandmother, great-grandmother and great-great grandmother have all suffered with this awful curse called dementia/ Alzheimers. This pretty much tells me what my fate will be within the next 30 years. Thats a terrible realization.
I have taken care of my mom for the last 2.5 years in my home (one of the hardest jobs I've ever done in my life and I've been a nurse for over 25 yrs!!) but unfortunately I recently had to admit her to a nursing home which has completely broken my heart and my spirit. I thought I could care for her till the very end, but once she stopped walking, it became impossible.
We must find a cure soon or at least be able to confirm the diagnosis. By the year of 2030 Alzheimers will be considered an epidemic... the statics are astronomical.... Someone in every family will be affected!!!!!!!! Even yours. Think about that.

My mother in law has also recently became a victim of this curse, her mind is slipping day by day. It want be much longer before she completely loses her memory also. She is the only parent my husband has ever had... Not sure how he will be able to handle it. Honestly, I'd much rather die of a heart attack or another type of disease than to cause my children the pain I've had to go through with my mom. Death is usually quick and final.... dementia is long and tortorous! To hear the person that raised from you birth, no longer know your name or tells you to get away from them is gut-wrenching!

It breaks my heart and makes me cringe to think I too may oneday look at my children and grandchildren and not even realize they are my family.... whats even worse is to think my daughters may eventually receive the same diagnosis, thats a thought that haunts me daily!
I BEG for your help in doing what ever possible for early detection of this horrible disease. It not only destroys the effected patients brain, it destroys the hearts of their family!!!! My father absolutely died with a broken heart because his wife of 58 yrs considered him a total stranger. Please do whatever is necessary to diagnose this disease early, so preparations can be made while we still have our sanity. That is the least that can be done.

Thank you,

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Over 5 years ago my husband began showing signs of something going wrong. He had behavioral changes and a once empathetic person became very self-centered. When our psychiatrist no longer felt he was able to help we turned to a neurologist. Unfortunately, the neurologist dismissed my concerns as being an overly nagging wife. There was no test to validate my concerns. We went to a new neurologist and eventually we received the diagnosis of Pick's disease -- a form of fronto temporal dementia. The agony of no diagnosis and people telling me it was my problem was almost as unbearable as living with dementia.

A test which would help to make this diagnosis period easier would be a godsend to both the patient and the caregiver. Please reconsider permitting this test.

Medicare

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Medicare

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I am the caretaker for my husband who is a victim of this terrible disease. It has taken some time to receive a diagnosis. It was diagnosed as mild cognitive impairment but it was obvious that my husband definitely has dimentia and his behaviors fall under Alzheimer's. We should have become aware of this disease much sooner as the medications have not made any difference in the progression. If an earlier diagnosis had been made, perhaps the medication would have delayed the progression. Planning for the onslaught would have been easier than to find out at this late date.

Sincerely

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

My maternal grandmother suffered from Alzheimers disease as did all 3 of her siblings. When I use the word 'suffer' I mean it in every sense of the word. We watched her detoriate slowly at first, forgotten names, numbers and faces to the point where she was convinced we, her family, were kidnapping her from the family farm of her youth. She did not know her husband, chlidren or grandchildren.

Knowing there is a sifnificant hereditary factor we now watch my mother very carefully, just waiting for the first signs show. At this time it's difficult to tell if my mother is actually in the initial stages or if those things that slip by are just evidence of an aging parent.

We know that early diagnosis and treatment is the only way to keep this horriffic disease at bay. It is the only way that we can live our lives with dignity, saying what needs to be said, teaching each other what we can before the monster moves in. On behalf of my grandmother, mother, myself and, yes, my children I beg you to reconsider.

We should not serve only the young in our society but the seniors as well.

Sincerely,

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my mother has Alzheimer's she has had it for about 8 years and of course not getting better its so sad to see my mother in this situation I wish we could get medicine for her that will help her with her Alzheimer's she still recognize who I am but there is times she plays it off and don't remember who I am it hurts my heart to see her this way wish we could have a medication that we need for that would help her remember.please people I want my mother back.

Medicare

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Medicare

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I come from good "stock", my Mom is 87 and doing well, but she has outlived family and friends younger than her for this disease. I am married for 25 years and my Mother-in-law is 84, she has now outlived 1 sibling for this disease and is living among 2 sisters who have it. For her history, I would love her to be able to prevent herself from this, she is active and capable of being a subject to keep herself from it by testing. Both of my "Moms" are healthy, they could live longer and be so valuable for this. I, along with other family members can help those who suffer and help prevent this terrible place in our elders lives. We must do all we can to protect and preserve their lives with dignity.

Medicare

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My great-grandfather, my grandfather, my uncle on my father's side and my father have all passed away from Alzhiemers. At one time when I was pregnant with my last child, we had the University of Florida take samples of the blood from me, my 3 sisters, my father, and all over our children. When my father passed away, we let his brain go to Alzheimers research. But we never heard anything back regarding the research. My father was diagnosed with Alzheimers at the age of 47 and died at the age of 55. We all thought that was a bit fast. My father never got to meet and know any of my children other then my oldest daughter.. when he forgot who she was, it was the worst thing for her and for me. And watching my father slowly leave us and him no longer know who he family was.. about killed me.. To this day I still cry when I think of him.. I am crying right now..

There are not enough places for our loved ones to stay and be taken care of the proper way.. My father ran away from 2 different homes that supposedly knew how to care for my father. The last time it was late fall/early winter and my father was found walking down a major highway in flipflops, shorts and no shirt. He had no idea where he was or who I was til I said my name. He also tried to cook for himself twice and caught 2 stoves on fire. That is when we had to put him somewhere that we thought he would be taken care of. We did not want to do that but we had 3 children, 1 was an infant to take care of also.

Please Please. do what can be done to help the people with Alzheimers and those of the families who have to deal with everything.. God Bless You All

Medicare

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I was diagnosed almost 2years agom with Alsheiker's I am now 63 so I was 61, I had to quit work, can not drive I am still a viable person willing to work & do more but we need all the help from organisations like the FDA & othe Government agencies. This illness has to be brought incoontrol before it become the number 1 killer in the World, please reconcider your decesion.
Reguards

Medicare

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my dad was afflicted and spent many years in a nursing home.the familys pain seeing him struggle to think clearly was terrible. think of the money the government can save by helping these people early.Help now or pay later.

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care.

Alzheimer's is one of the most debilitating diseases that we face and impacts almost everyone in this country. We all have family, friends or acquaintances who have or are currently suffering from this terrible and fatal condition. The cost...financial, physical, mental and emotional are without equal and literally distroy not only the patient but entire families. To make it worse, the predominant age group affected are our senior citizens who in many cases lack the financial means to diagnose and treat this disease. Medicare is a primary source of medical care for many sufferers and it is unconscionable that you are considering reduced efforts and investment in this rapidly growing population instead of taking the lead in proactively dealing with it and contributing to early diagnosis and treatment. Short term savings will result in long term greater costs and immeasurable suffering for those who must depend on Medicare for their health care. Please reconsider and do the right thing.

Ron Dean

Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

I don't have anyone in my family w/ a dx of AD; however I know many people that do and the incidences are going to increase exponentially as people continue to live longer and the 80+ population continues to increase. Early detection & dx can lead to early treatment and (hopefully) help to prolong a good quality of life.

A dx of AD is much like one of cancer was in the not too distant past. People look at it as a death sentence. We now know what a difference early detection and treatment of a cancer dx can make. A 98% cure rate is not unusual. Presently, too many people are in denia and won't even discus the possibility that there might be a problems when symptoms indicate some dementia.. Families and friends are essential as a support system.

People need to be informed. Those w/ AD need our help and support. They, like anyone else w/a chronic condition have both good & bad days; they aren't always "out there" and need to be treated as people, not as a disease. Families also need lots of support; caregivers face deal w/ incredible stress, don't take enough time for themselves and all too often, die before their family member.

Finally, if it's just the bottom line being considered, the cost for diagnostic testing will be much less than the costs of caring for someone w/AD for an extended period as itreatment can help to delay cognitive deterioration

Kathy Urquhart

Medicare

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My mother developed early-onset Alzheimer's twenty years ago - it took three years for doctors to diagnose her illness. She died at 56. I am now 50 and am terrified of going through the same nightmare. Every time I have a memory lapse, I wonder, "Is this it? Has it begun?" While we do not have a cure yet, I would want to have every opportunity to try whatever treatment is available to at least slow the progression of the disease if I have it. I am a teacher, a mother, a grandmother, a wife - I still have purpose and desire to contribute to others' lives and to my community for as long as possible. I KNOW there are many, many others who are in similar situations. Please give us hope - give us this one more tool to fight this horrible, debilitating, nightmare of a disease. Think to yourself, "What if it were me?"

Medicare

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My Dad had A.D. It took YEARS (over 3) to get a diagnosis! If we had the proof that he had A.D we could have had him on medicine much sooner and it would have made his life and ours much better. We could have had a lot more help in dealing with this horrible disease.

If we have the ability NOW to diagnose and treat patients with medicine that would really make a difference then why should we have to wait????

Medicare

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Kim Vaadia

Medicare

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Ken Kroon

Medicare

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My father was diagnosed with early onset of Alzheimer's and he passed away at age 66. I saw him deteriorate at a rapid pace. If I would have known earlier about this awful disease my family could have provided him with improved assistance. My brother who is now 56 was diagnosed with vascular dementia. I am sure he will be ultimately diagnosed with Alzheimer's. I believe I am at risk along with my four other siblings. Please approve this diagnostic testing for my family and for all others who will eventually experience this awful disease. Thank you from the heart.

Medicare

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With Dementia on the rise it is imperative to that more accurate test need to be available to help diagnose this horrible disease ..as I was my mother's caretaker ..who knows first hand what happens to alz. patients ..please push for this to be allowed now .

An Advocate for A Cure ALZ.

Medicare

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My mother was labeled with Alzheimer's Disease over 8 years ago. No treatment was recommended. She continues to decline and is currently in an Assisted Living facility following a crisis. Could we have done more to help her? She is a lovely 81 year old Native American woman, mother, grandmother, wife, neighbor. She was once incredibily artistic and an avid reader. Today, she may not know her family, she can't read a book or do simple crafts. She can't order from a menu or turn on the TV. She became at risk due to wandering, excessive weight loss and mixing up her medications.

There is technology to have helped her and our family understand what is happening to her and the impacts it has on all of her care givers as well as getting her the appropriate medication for the specific area of the brain affected.

One of the most important aspects of a human being is our collective memories and our abiity to function independently. ALZ robs us all of this as a loved one is attacked randomly. Better understanding can lead to better treatment and a cure. Untreated or misunderstood the burden will fall onto local emergency services to assist in medical crisis, violent episodes, or locating the lost that are all part of the progression of this disease.

We need more care, not less, for this growing problem.

Medicare

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We all know Alzheimers is not reversable but I really missed out on the quality time my husband and I had left before he had to go into a nursing home because it was really never detected or treated early enough. He had signs of dementia 4 years ago and was told it was probably his type 2 diabetes. He just had been losing his cognition but it increased so quickly that it just hit us like a ton of bricks. It was almost like he woke up one morning and knew nothing and was in a fog. Doctor sent him for CAT scan and said no stroke, no Alzheimers showing so we continued on in a semi fog. Now he is in a nursing home, I could no longer take care of him at home and I spend everyday with him. The hardest thing is getting some photos together to put on his wall and to see how just 3 years ago he was so vibrant and fun laughing and always wanting to be involved in anything. When he couldn't remember how to make his chili for his competitions we were in I knew something was really wrong. He still knows me and the dog but others he draws blanks. Knows faces but can not communicate to say names. When the time comes, I have made a decision to have his body donated to science for the research on Alzheimers and the possibility of it being a risk factor with his type 2 diabetes. Our doctor said it is probably because there was not enough nutrients going into the brain. I hope this is read and understanded by what I said. It is hard to get it out on paper. Thank you - Diana

Medicare

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Medicare

I am writing in response to your proposed decision to require more evidence development before you make PET imaging available to people who may have Alzheimer's. This is the wrong decision. The FDA has approved this technology. People who face a diagnosis of Alzheimer's deserve to have it brought to their care. I want to tell you how difficult this is -- here is my story:

my daddy died of alzthemeirs,it tored my family into peices. we had no idea he had it. my daddy remarried after my mother died in 88. he married a woman 10 years his senior, she died in octocber of 2008. my daddy was in his early 90's. out of five childreni volunteered to move in with my dad and help him out through his grieving time. the first night i was alone with my dad i realized something wasn't right. i don't even know if i can share this cause its still too painful. i will have to skip this part. i called one of my brothers and said daddy isn't acting himself, we took his actions as to his grieving. well as days past, he started getting frustrated with simple things that he did daily. as time went by he became more angry, which is NOT part of my daddy's personality. he became more demanding, he wanted every bit of my time, my attention and even then it wasn't enough, i couldn't even go to the bathroom without him getting anxious. i have 4 siblings and each one of us thought we knew what was best for my dad. well, let me back up for a year, i had him to myself most of the time. i was working at the time and drove 1 1/2 hours each way to work and might i say a very demanding job, it got to the point, that i had to go out on FMLA just to take care of my dad. he would forget things, where places were and ALWAYS wanted to drive somewhere. scary! he didn't have a cell phone or even remember his own home phone number, but he wanted to drive. it was a full time of care giving, not to count the endless sleepless nights he couldn't sleep, and then i got sick, real sick. i had no buisness trying to take care of him at this time, BUT i wouldn't give up, you see , i know he would never give up on me, so i hung in there and did the best i could. now, in the meantime my siblings thought they knew what was best for me and my daddy, put him in a nursing home or a senior living, but he was against that and i promised him i would NEVER do that to him and i would always be there for him no matter what. and i tried and i failed.he left on october 7th 2010 and went to one of my brother's house, shortly after a memory loss facility. my father was more than a handful, he would say things that was inapproriate, he was like a deliquent child out of hand. my brother was in shock, i think after he got to him he realize a small part of what i went through. but all my brothers got together and place him in one of the finest memory loss care you could get. and my brother took on the responsiblity of his caregiver, him and his family. one of my brothers the oldest was and is in iraq, i called him every day, he was the only support i had that didn't judge me. so let me move on, i would go to visit me daddy and it was the most painful, heart wrecthing experince in my life, everytime he saw me, he thought i was taking him home, it was like everytime he saw me he took 10 steps back on getting adjusted to his new surroundings, so, i didn't go back for awhile, i mean awhile, i loved him so much and i thought that when he saw me i was hurting him in some kind of way, thats love, but so hurtful i have no words to explain. i moved to arizona from texas, i would see pictures of him and he was adjusting, but his mind wasnt there. he soon forgot his grandchildren, his wife, my mother and some of his kids from time to time. i went back to visit him in february 2011, my siblings told me to be prepared because he probably won't know who you are, but, i said oh no i will be the last one he forgets, you can count on that. so, i went to visit and he said, where have you been, i have been waiting for you. oh, i was so happy he remembere me, but he keep asking me questions, the same ones over and over and over again, he couldn't remember his last sentence. he told me i won't be in here long, how will you find me? i said daddy you know me, i will find you anywhere. he said ok and i kissed him goodbye and that was the last time i saw my daddy consious. i got a called november 2012 and he was in a coma, i flew home and was by his side when he died he never came out of the coma. i want to be tested for this horrible disease, for any prevention. this is just a small part of my family's story.

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WE NEED MORE HELP with this area of illness! How can we stop it if we can't diagnose it? The only way to stem the costs of this disease is to cure it or manage it better. PLEASE DO NOT STOP us from MANAGING this disease!

My mom suffers from Dementia - PLEASE HELP.

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My father, and his mother both suffered from it, I work in health care and see a lot of it. It is a most devastating disease, not just for the patient, but for the families, not to mention the expense of care for the patients. Before you get to a certain point, you are aware that there are things going wrong with both mind and body, and are unable to do anything about it, please don't let this illness go unchecked until it is too late, if we can find ways to stave it off, or stop it, and dare I say, hope to reverse some of the damage, it will help with costs to families, in terms of mental anguish and emotional suffering as well as monitary costs long term.

Thank you for reading this, if you do, I am 61, so I'm not yet eligible for Medicare, but I am not far away either, and the possibility exists for myself and my 3 brothers, and my sister for us to develop this devastating and draining disease.

Sincerely,

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My grandmother developed this disease and within 2 years, she'd fogrgotten who we all were (her 7 children, 20 grandchildren and 8 great grand children. This disease is hard to atch as the person you loves fogets who you are. Can you imagine? The ONLY person she remembered was her husband, my grandfather. PLEASE do something for this disease. It hurts everyone who touches it.

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My loving Mother came down with this life sucking disease. She got to where she was confused and I took her to her Dr.and he diagnosed her with Alzheimer's and for the next short five years she had left ,she knew hardly anyone she became my child. I love her so much and during this terrible trauma,we had to put different locks on the doors.We also had alarm bells on her bed to alert us. She would wonder off and get lost. She always went back to the childhood she had. This made me sick, and angry. I do t want this disease. It was hard work for my family though would do it again. We tried putting photos on the walls with names below to help her recognize her family. Some times it did but three-fourths it did not. Thanks for listening. Oh yes her two sisters also had this and passed away

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My father has been diagnosed with Alzheimer's. My mom said it stared when he was in his early 60's but it did not advance until he was in his middle 70's. My father is now 80 years old and although he is getting around and can communicate he doesn't recognized his children their spouses or his grandchildren. I am not sure he really knows who his wife is but he relies on her alot for reassurance and assistance with his daily entertainment although tomorrow he won't remember what he did today. It is very difficulty as a daughter to watch my parents go through this. It affects the entire family and my mom has taken care of him and kept him active. My concern is will my sister, my brother or myself have this same fate? The only way to test this is a brain biopsy after death. It would be helpful to be able to know if we have inherited this trait. Please
reconsider your decision to not allow medicare to pay for this test. It could be very valuable to determine early intervention and treatment for this terrible neurological disease.

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Both my grandmothers had alzheimers. Lue Anna was the grandma who did it all: canning, apple-core dolls, quilting, tating, etc. Had a doctor who recognised that she had Alzheimers. She ending up helpless and veggative state before passing away when I was 20. Lucille was the grandlady who could chair committees so opposing sides would at least listen and try to work out their differences. She became angry, combative and paranoid before passing on. Lucille was given Alzheimers dianogse post mortern.

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My father and his only sibling died from complications of Alzheimer's after becoming debilitated for 1-2 years. Their father did the same. Their mother, luckily, didn't develop Alzheimer's. However, two of her brothers and many of her uncles did develop this horrible disease. As you can imagine, my brother, my sister, and I are terrified. Please help!!

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9 years ago, I watched my able-bodied grandfather's mind just die. He could still build a house if he wanted to, but he didn't remember my name. Yesterday? I got my 23andme genome typing kit back, and despite being a relatively healthy 34 year old who leads a healthy lifestyle, my genome type is HIGHLY likely to develop Alzheimer's.

I work in healthcare. I work for patients. I live for my family and their health. Please allow my family access to technologies that improve our quality of life as we age.

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Both my grandmother and my mother suffered from dementia ., so much so, that we had to say goodbye to them earlier than was necessary. Im 70 years old and dementia related issues were prevalent among my older siblings. I have a higher chance of developing dementia myself and my husband had two people in his family with Alzheimers. I think if the PET scanning can be done early enough, there are ways to slow down the disease whereas if one waits for the onset, there is no hope. Please reconsider your ideas, and help us live a longer and more productive life.. It's not fun getting old..please don't make it worse for us..Thank you..

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My mother was diagnosed to late and was in total denial of the disease. It was too late to plan her finances. She lost everything she had, along with her mind. Everyjhing her and my father saved and scraped to have something to give their own children. One sibling died and now I am left with her debt. So now my own family struggles constantly. If she could have been diagnosed before the disease had her confused maybe things would have turned out differently.

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My father had this (Alzheimer's): when it first began, he would forget the name of objects{pencil, bowl, stove,ect.}. Dad thought he was losing his mind. That he was going crazy. Then he forgot how to get places. He was so upset with himself. Once he was diagnoised, he was able to except the medical aspect of what was happening to him. I saw him go from extreme anger to acceptance. Had he been able to get a diagnosis earlier, he could have had some more time with his family. Due to the late diagnosis, he had about eight months where he recognized us. This is a horrible, long, and trying death. Everyone should have as early as possible a dianosis, so the family can have their time to say goodbye.

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My husband was diagnosed in November, 2008 with early onset Alzheimer's at the age of 61 years old. He was a 28 year veteran of the Foreign Service, retiring from the State Department after his last posting as Ambassador to Cyprus. After retiring he continued to worked privately in International Consulting until the State Department asked him to come back into diplomatic service and move to Israel to serve as Tony Blair's Head of Mission for the Quartet project to bring financial stability to the Palestinians. My husband could not say no to serving his country. We packed up our house, I took a leave of absence from my job and Don left a fulfilling job as a consultant with a private firm. We rented out our house and moved to Jerusalem. Unbeknownst to me, Don had been talking to his Internist off and on over the last few years about his concern about his memory. The Doctor dismissed his concerns/worries and chalked it up to his age, his many responsibilities and said his memory issues were normal. Once in Israel, it became clear that, very uncharacteristicly, Don was not able to remember all the new and difficult names of the important people involved in the project and was having trouble managing the team under his supervision. After 3 months on the job he was not able to fulfill his job description and we had to leave Israel. This had never happened to Don in his 30 years of professional work. He had always taken the bull by the horns, jumped into difficult situations and successfully negotiated his way through many international crises. He had many honors, including the French Legion of Honor, which was the first time the French ever awarded it to an American below Ambassador level. At the point when Don was told that he needed to leave, I encouraged my husband to seek medical attention with a neurologist at Hebrew University to see what was causing Don's cognitive difficulties. I had noticed that Don was struggling with his memory and was not functioning professionally in a manner that was familiar to me. The renowned Dr. at the University ruled out a brain tumor and after a few tests and blood work he dismissed any medical diagnosis. He gave Don a xanax prescription and said stress can make one forgetful. We left Israel but spent another 6 months away from home without a diagnosis but living with an unresolved mystery of why Don was not able to manage the job in Israel. When we arrived back in the Washington area in August of 2008, we began the long and agonizing journey to figure out what was ailing Don. Despite the fact that my mother died of Alzheimer's disease in 1998, neither of us suspected such a strong, healthy man of 61 would be diagnosed with Alzheimer's. And yet, he was. If his Internist had taken him seriously in those few years before we were asked to dismantled our life to serve our country once again, and been able to turn to a diagnostic test that would have told us of Don's medical prognosis, our life would have been so much less stressful, so much less embarrassing and difficult. Timely and accurate diagnosis, now that it has finally become a reality, must be made available to all patients who are struggling with memory concerns. Don is still feeling the humiliation of trying to fulfill a professional role that he would never have attempted if he had been aware of his dementia diagnosis. We could have slowly begun to reduce Don's work load and expectations and begun to figure out our financial situation for the future. Don never worked again in a salaried position and that is not a situation anyone would want without careful financial planning.