

**STATEMENT OF MARY BETH RIEDNER
SCHAUMBURG, ILLINOIS
for**

**SOCIAL SECURITY ADMINISTRATION'S COMPASSIONATE
ALLOWANCE INITIATIVE HEARING ON
YOUNGER-ONSET ALZHEIMER'S DISEASE AND OTHER DEMENTIAS**

JULY 29, 2009

I would like to thank Commissioner Astrue, other social security officials and distinguished guests for this opportunity to address you on behalf of the families who have a loved one stricken with the devastating illness of Primary Progressive Aphasia (PPA). My name is Mary Beth Riedner. Steve, my husband of 36 years, was diagnosed with PPA in the fall of 2006.

PPA is a disease of continuous losses. At this point in Steve's disease, these losses are primarily manifested in the language centers of his brain. Even just a few years ago, I never would have imagined that my formerly articulate husband would no longer be able to name the months of the year or would make a shaking motion over an imaginary bowl to demonstrate the word "cereal" that he wasn't able to say. I never would have predicted that my intelligent husband would stumble over the words to the "Birthday Song" at our granddaughter's birthday party, but would courageously continue singing anyway or that he would have to ask me how to spell his friend Jim's name and when I said "J" would write the letter "G". I never would have thought that my mechanically inclined husband would not be able to perform the simple addition problem of adding a tip to a restaurant bill or be confused by the symbols on our new barbecue that use a $\frac{1}{4}$ circle for low heat, a $\frac{1}{2}$ circle for medium heat, and $\frac{3}{4}$ of a circle for high heat. I never would have dreamt that my confident husband would worry about the day when he will no longer be able to tell me that he loves me. But these are the day-to-day realities of living with PPA.

Just looking at my husband, you would think he was the picture of health. At 60 years old, he is strong and muscular. He works out at the gym several times a week lifting weights. Just looking at him, most people would never believe that he has a terminal illness that is unrelentingly destroying his neurons and shrinking the size of his brain. When you begin a conversation with him, however, his obvious difficulty with speaking becomes apparent. But his losses are not limited to speech. He is losing the ability to read, write, spell, type, and do simple arithmetic. He can no longer compose an email and hesitates to answer the telephone because he can't write down a message. He cannot write a check or follow multi-step instructions. He has difficulty remembering his social security number and phone number. New losses are revealed almost every day. What is most heart-breaking of all is that he is fully aware of his situation and will likely continue to be aware of it long after he has lost the ability to communicate with any kind of language. I have the greatest admiration for his strength of character to continue smiling despite these losses and for his tenacity and determination to continue living his life despite what the future might hold.

I'd like to give you some brief background about our lives prior to the PPA diagnosis. After high school, Steve enlisted in the U. S. Air Force and proudly served as an aircraft mechanic for four years, including one year in Vietnam. We met shortly after he was honorably discharged from the Air Force. I had just received my Masters of Library Science degree from the University of Illinois in Champaign/Urbana. Steve found a job in the quality control department of a manufacturing corporation and I began working for the Chicago Public Library. After we were married in May, 1973, Steve started a tool and die apprenticeship and concurrently worked towards an Associate Degree from Triton College which he received in 1977. After becoming a journeyman tool and die maker, Steve continued working for the same company until it was sold in 1989. Wisely foreseeing the many layoffs that would follow, Steve left that company to pursue a job in middle management in a manufacturing environment. From 1989 to 1994 he worked first as a machine shop foreman and then as a production superintendent, eventually supervising over 70 people. While successful in these endeavors, he decided to return to tool and die work in 1994. After raising our three children, I had returned to work in 1988 as a librarian for a local private university where I eventually advanced to the position of University Librarian. Our children all completed college degrees and were living independently on their own. Our lives were productive and fulfilling.

However, beginning around 2002, when Steve was 54 years old, he became aware that something was wrong as he began experiencing difficulty performing his job. Tool and die making is a high-precision job that requires great attention to detail and uses sophisticated math including trigonometry. While he was still able to make accurate calculations using a calculator, he noticed that by the time he walked a few feet to the appropriate machine he had forgotten what numbers should be entered. He found that he had to write down the numbers and take them to the machine. He found other ways to adapt and mask the increasing number of mistakes that he had never made before.

Over the years, Steve had been an active participant in local government and he often went to village board meetings to express his concerns about current issues. He was an eloquent speaker and could make logical arguments with ease, often extemporaneously. However, he has vivid memories of the embarrassment of giving a faltering speech at one board meeting in the summer of 2002, even though he had written out his comments.

At his annual physical the next year, the doctor noticed his speech difficulties. He directed him to a neurologist and ordered a number of tests to see if he had had a stroke. An echocardiogram came back negative. A neuropsychologist observed speech and language problems but indicated that "naming and comprehension skills were intact". Although an MRI also came back negative for stroke, both the neurologist and internist decided to treat him as if he had had a stroke anyway. Cholesterol lowering medications and a daily aspirin were prescribed.

In 2003 the company where Steve was working as a tool and die maker was purchased by a British company. Steve was laid off that summer as the new owners moved production to China. Initially, he made efforts to find a new job, but outsourcing was eliminating tool and die and other manufacturing jobs everywhere. Only a few telephone interviews were generated by the resumes he sent out and he knew that he was not presenting himself well at these interviews due

to his speech difficulties. As I had a full time job that provided us with health care insurance and an adequate income, Steve eventually gave up looking for work.

In 2006, my employer changed health insurance providers and Steve had to change doctors. At his initial physical with his new doctor, he casually mentioned his speech problems towards the end of the visit. The doctor then referred him to a neurologist who recommended a battery of tests including an MRI, EEG and neuropsychological testing. After reviewing the results of these tests, this neurologist gave us our first diagnosis of PPA in Dec., 2006. The neurologist told us that he had seen only one other case of PPA in his career, so he suggested that we seek further care from Dr. Mesulam at Northwestern University where significant research into PPA was being conducted.

Our first visit to Dr. Mesulam was in Feb., 2007 where he confirmed the PPA diagnosis. At that time we were introduced to all the other wonderful resources offered by Northwestern's Cognitive Neurology and Alzheimer's Disease Center (CNADC). It was one of the social worker's at the CNADC who first suggested that we apply for Social Security Disability Insurance (SSDI) benefits.

I have to admit that I had some trepidation about beginning the SSDI application process. I had heard stories from other caregivers about how difficult the process was and how frequently applications were denied. We started the application process on Aug. 26, 2007, but did not submit the completed application until two weeks later on Sept. 9. During that time I spent several evenings and the greater part of one weekend combing through my files to retrieve the information necessary to complete the application, working with Steve to formulate the narrative responses, and entering the data. The Medical History section of the Adult Disability and Work History Report was especially time consuming as we needed to include information on eight doctors and other medical professionals, six hospitals and clinics, five prescription medications, three non-prescription medicines, and seven medical tests. Some of these doctor's visits and tests went back to 2003. We wanted our responses to be as accurate and as inclusive as possible so that there would be no basis for denying it. Fortunately for us, I had been meticulous about retaining our medical records "just in case". The application process took much longer than the combined one hour and forty-five minutes estimated in the Paperwork Reduction Act statements included in the instructions for the application

After submitting the report electronically, I took a half-day vacation from work so that we could go to the local Social Security Office for the required in-person interview. We did not have an appointment as we had been advised at an earlier visit that it might take several months to get an one. We brought along the required documents as well as copies of many of the lab tests that had been conducted over the years. Dr. Mesulam had also written a letter of support that, to be honest, was very difficult for us to read, but which accurately described the prognosis for individuals with PPA. At the end of the interview, we were informed that our file would be sent to the Illinois Department of Human Services (IDHS) for further processing.

In mid-September, the IDHS sent us two questionnaires on "Activities of Daily Living" which Steve completed by himself as a demonstration of his writing abilities. On Nov. 5, a call

adjudicator from the IDHS interviewed me by telephone to find out more about how PPA had affected Steve's daily life.

Finally, in mid-December we were very pleased to receive a notice of award in the mail. While we were quite grateful that our application had been approved on the first round, the entire process had taken almost four months to complete.

PPA caused unexpected havoc in our lives at a time when we were at our top earning potential and also at a time when we could see the long-awaited years of retirement on the not-too-distant horizon. Instead we are faced with a disease for which there is no known cause or treatment and for which there is only a prognosis of continuous decline in abilities ending in total helplessness and death. The passage of time is not a friend to people with terminal illnesses. Unnecessary delays affect the quality of life for people who are already suffering. While our SSDI application was successful, we found process to be time consuming and challenging. There was also an underlying sense of anxiety while waiting for a decision and uncertainty over whether our application was going to be approved or denied. Including PPA in the Compassionate Allowance Initiative would go a long way to ameliorating some of the difficulties and delays encountered by people already in a crisis situation.

The award of SSDI benefits has made a significant difference in our lives. Because of the monetary assistance and the fact that my husband became eligible for Medicare last August, we decided that I should resign from my job last summer. My COBRA health insurance will run out in a few months and we will soon be faced with the challenge of obtaining and paying for an individual health insurance policy for me. We have already needed to start dipping into our savings, especially with the current economic climate. Despite these financial concerns, we now have time to be together and to enjoy each other's company while Steve still has the ability to do so. Being home with Steve, I can go with him to all of his doctor visits, we can participate together in research opportunities at Northwestern's CNACD, I can monitor his progress more closely, provide him with companionship instead of being away all day at work, help to maintain his dignity and independence, and encourage him to continue an active and engaged lifestyle for as long as possible. I also have time to join various support groups and to attend educational programs on caregiving. Having lived together for 36 years, I feel that I am the person most likely to understand Steve as he continues to lose his communication abilities. Hopefully, I will be able to help him continue to express his thoughts and feelings with a minimum of frustration.

While we never expected to become beneficiaries of SSDI, we are grateful that we live in a country that has created a safety net for those who can no longer work due to a disability. Including PPA in the Compassionate Allowance Initiative will help to ease the path for those in the future who are unfortunate enough to become victims of this crippling disease.

Thank you for your time and attention to my comments.