

**Written Testimony of Eleanor M. Perfetto, Ph.D., M.S.**

Wife of Ralph R. Wenzel Former NFL Offensive Lineman  
and Senior Director, Pfizer Inc.

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Chairman Conyers and Committee Members, thank you for inviting me to appear before you today. My name is Doctor Eleanor Perfetto. I am a pharmacist with a Ph.D. degree in public health, having concentrated my work in health policy and epidemiology. I currently am employed by Pfizer Inc. I tell you that because I wear two hats today, predominately one as a wife and caregiver, but also one as a health researcher who understands the study of disease and treatments in populations and who understands research methods and study biases.

The topic of “the lasting impact of head injuries suffered by National Football League (NFL) players” is very important to me and has been for almost 15 years. I want to tell you about my personal experience and provide suggestions about urgent actions that need to be taken by the NFL to help disabled retired players, current players, and children involved in sports today.

My husband, Ralph Wenzel played as an offensive guard in the NFL for seven seasons. He retired in 1974 and became a high school- and college-level physical education teacher and football coach. In 1995 -- over 20 years after his retirement from the NFL -- my husband began having vague and disconnected symptoms: depression, general uneasiness and anxiety, always losing things like his wallet or checkbook. Today we recognize those symptoms as resulting from chronic traumatic encephalopathy (CTE). In the following years, Ralph began to suffer obvious memory loss and confusion. In the fall of 1999, ten years ago, at the age of 56, Ralph was diagnosed with mild cognitive impairment, or MCI, a condition known to progress to Alzheimer’s disease.

Ralph’s condition did progress over the last 10 years to full dementia related to CTE. I can’t tell you on what day his condition flipped from MCI to dementia. However, in those 10 years, he lost his ability to work, drive a car, play golf, read the biographies he loved, cook gourmet meals, and enjoy a glass of wine. He can no longer dress, bathe, or feed himself. He lost his dry sense of humor. He lost his warm, quiet personality. He lost it all. Almost three years ago, I had to place my husband in an assisted living facility for dementia patients and he still resides there today. But frankly, my husband no longer has a life, certainly not one he’d want for himself.

I don’t want to see this happen to anyone else.

In the almost 15 years since our ordeal began, Ralph and I went through many ups and downs. In those first few years, we had no idea what was wrong. You have a spouse who is aloof, disconnected, irresponsible, whose personality is changing, who may be hostile and you don’t know why. It made life difficult and I admit that before Ralph’s diagnosis, I considered divorce. The diagnosis was frightening, but it also was a relief. I finally understood why these things were happening; it’s not me, it’s not him, it’s an illness.

After the diagnosis, I cared for Ralph at home for over 7 years and I learned. I learned about living wills, power of attorney, guardianship, social security, home care, adult

medical day care, psychiatric hospital admissions, assisted living, etc., etc. I was on my own.

While these experiences are similar to those of any family member caring for someone with dementia, I also learned that our country's current infrastructure in adult day care and long-term care facilities are based on providing services for your grandmother, not for a 6 foot 2 inch, 225 pound man. For example, I bought a full size bed for Ralph because he did not fit in the twin bed his facility provided. He has caregivers that I have hired, in addition to those who work for the facility, to insure he gets individual attention and extra exercise during the day to keep him from jogging around the halls and jeopardizing other residents' safety. Old habits die hard. And what is particularly hard to overcome is that staff at these facilities are afraid, and in some cases rightly so.

My husband was lucky in one way. He has a wife who is educated, a wife who works in healthcare and can battle the healthcare system, one that has a very good job with a company that offers excellent health benefits, and she also happens to be a very pushy broad. So, Ralph has fared well because he has a strong advocate.

But, there are many players out there in the situation Ralph and I were in 15 years ago, ten years ago, five years ago, and they need help. They need the relief of understanding what is going on and help wading through the system. I speak with many NFL retired player spouses on a regular basis and I work to help them find doctors, assisted living facilities, and other services. Often, I simply just talk to distraught women at the end of their rope and help them get through it. They turn to people like me because they have no place to go and they are finding their way the same way I did years ago.

So what are my "asks"? What do I want to see come out of today? I have four.

First, the NFL must stop it's denial of the relationship between brain trauma and brain disease. The evidence is there. Once the denial stops, the NFL can become the proactive leader it should be. The denial is disrespectful of the players and families who are suffering and it endangers current players and children who are at risk for injury.

Second, the NFL must do more to protect current players and children so they are not faced with this travesty in later life. There is no treatment or cure for CTE. Right now there is only prevention. The NFL is in a prime position to educate on and advocate for prevention. It is a moral imperative. Specific suggestions on how sports and the game of football can be made safer I leave to experts in that area, who I am sure will make those suggestions today.

In 2007, the NFL instituted the 88 Plan, named after Baltimore Colts hall of famer, John Mackey as the result of advocacy efforts by John's wife, Sylvia. John is also in assisted living now. The 88 Plan is offered to eligible retired NFL players diagnosed with dementia and covers medical and long-term care costs up to \$88,000 per year. Ralph's long-term care costs have been covered by the 88 Plan since spring 2007.

My third ask is that the NFL go beyond the 88 Plan. It must educate players and the public about CTE, and must find players with early signs and symptoms to provide support so they and their families can better manage the ordeal that is before them. The 88 Plan assists players who are diagnosed with dementia. They and their families have suffered for years before that diagnosis comes. For former players like Mike Webster, the diagnosis came too late. The numbers indicate we are seeing the tip of the iceberg.

Lastly, I mentioned earlier that I wear a second hat as an epidemiologist. That means I have been trained to study disease and treatments in the population. I am more versed than most in the types of studies that have been and are being conducted, and the methods issues and biases encountered in doing this research. My fourth ask is that you to examine carefully the studies put before you. There will be people today who will tell you that some of the studies should be disregarded, or that some are flawed. I encourage you to consider two specific issues you may not be familiar with.

One is the issue of statistical power. This is a mathematical calculation that tells you a study is large enough, it includes enough people, to be able to find a difference between two groups. If the study is too small, a researcher can erroneously conclude that there are no differences between the two groups. In reality, not enough people were included and differences could have been seen if only more people were recruited.

The second issue is that of recruitment bias. This simply means that you may have recruited a certain type of person in your study or left out certain types of people because of the way that you recruited participants. This bias can mean that your study findings are too low or are too high, depending on the direction of the bias. But, it does not mean the study should be discounted in its entirety. I provide an example of this in my written testimony that I ask you to consider.

Allow me to provide a relevant example. If I send out a survey to retired NFL players to ask them about cognitive problems and dementia, and I use a mailing list of retirees who are members of a club, I likely will have a response bias. To belong to the club, you must be healthy enough to make the decision to join, fill out an application form, and write a check for membership. If you have dementia, it is unlikely you can do those things and it's unlikely your caregiver will take the time for you. So, you are not even a club member and are not on the mailing list at all. You have the disease I am looking for, but you are left out.

If you were well when you joined the club but developed dementia after, then you would be on the mailing list. But, when the survey comes you may no longer live at home. If you do live at home you may no longer receive the mail and you probably can't read the mail. Again, it's unlikely your caregiver who gets the mail has the time to respond. So, your response would never be sent in and, again, you will be left out.

Who is sending a response in? Those responding are retirees healthy enough to become club members, who are still well enough to live at home to receive the mailing, who are well enough to read the mail, and who are well enough to answer the questions and put

the response back in the mail. It is likely that these are not retirees with dementia or other neurological or mental health conditions.

The study has a bias because those you are trying to find, those with cognitive problems or dementia, are reached in fewer numbers due to decision to use the club list. Some people will tell you that this means the study is fatally flawed and cannot be used. In fact, the study is not flawed for just having a bias. You can interpret the data as long as you understand and recognize the direction of that bias. In this example, it means that any estimate you arrive at on the extent of cognitive problems and dementia in the population is probably too low. It means the problem is probably worse than what you have found. It means there are probably more people who need help than you thought.

I thank you for this opportunity to speak to you and I am happy to answer any questions you may have.