TESTIMONY OF

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Regarding

The New Face of Alzheimer's: Living With Alzheimer's Disease

Before The
Aging & Older Adult Services Committee
Pennsylvania House of Representatives

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The New Face of Alzheimer's

Thank you very much for giving me the opportunity to speak to this committee about my experience with Alzheimer's Disease. I am eighty one years old and was diagnosed with Early Stage Alzheimer's three years ago.

This morning I want to present two thoughts. First what is Early Stage Alzheimer's? Second, my serendipitous finding of the Best Practices of treating Alzheimer's

Early Stage, as the name implies, is the first step of a long journey downward. In Early Stage, those, like me and Alan, are indistinguishable from the general population. A few, like me, can live completely alone. Others need some help from a caregiver, usually a spouse or other family member. Some are restricted from or no longer able to drive. Some need help in keeping track of appointments or medications; have trouble remembering or organizing. Early Stage, or even before, are the places where I feel the most can be done to prolong a person's ability to have a meaningful life.

If people thought ... they recognized that one did not awake one day in the mid stage of Alzheimer's disease, unable to remember or speak coherently. But it was at this stage that most were brought to the attention of the family doctor. People believed there was little to be done to stop the course of the disease, so why rush to judgment.

Recognizing that the disease must be detected earlier received scant attention. I had been going to a neurologist for a few years for a different neurological disorder, Myasthenia Gravis. At almost every visit I complained about my perceived memory loss. My complaints were noted but ignored. After all, I lived by myself and seemed normal. Then one day as the doctor and I sat chatting I said Highlights instead of the intended Highlands. I was corrected. It happened again. The third time I misspoke, the doctor began the mini-mental test, a screening test for memory disorders. I flunked the three item immediate recall tests. So I was advised to get a neuro-psychological exam which resulted in a diagnosis of Mild Alzheimer's Disease. It was suggested I immediately get on **medication** and I did.

After the initial shock I made two resolutions. First, the diagnosis was not to be a secret. Friends and relatives would need to understand what was happening to me.

And second, I accepted the diagnosis but would fight the outcome as best I could.

Shortly thereafter I found a neurologist who was knowledgeable about both diseases. The myasthenia disrupts the connections between nerves and muscles. As a result I was becoming increasingly fatigued and unsteady in my movements. I used a cane for stability. At my first appointment I failed all sorts of neurological tests and physical therapy was prescribed. Who knew, certainly not I, that this **exercise** would also help my Alzheimer's?

I had heard many news bits that **mental exercise** might help delay Alzheimer's. Well, for me it was too late, but why not give it a try, I thought. I had been writing a quarterly column for the Wayne County Historical Society so I continued with that. I did Sudoku's and crossword puzzles. There soon came a point when I couldn't do them any more, so stopped.. After I had been on my regime awhile, I thought I was doing better, so tried the Sudoku book again. I could now solve them. I'm now almost finished a Will Shortz book. The ones I'm solving are labeled, "Beware! Very Challenging."

My involvement with the Alzheimer's Association has led to many, many new friendships. **Socialization** is another facet of my regime.

One of the people I have been privileged to meet is Dr. Mario Cornacchione, who is the Director of the Northeastern Pennsylvania Memory & Alzheimer's Center. I feel he is my guru. I've learned so much from him. It was he who steered me to the **Mediterranean Diet** and the importance of dietary supplements such as Omega 3.

As I was becoming aware that both my physical condition and cognition were **improving**, I was puzzled. It's not supposed to happen. Was I some kind of an anomaly?

I'm one of those people who like to read research. Many of the articles lend credence to each part of the regime I had adopted: **medication**, **vigorous physical activity**, **vigorous mental stimulation**, **diet and socialization**. I was finding articles saying although each of the above activities was good; the combination had a multiplying effect.

A year ago, I was retested on the neuro psych. I knew I was doing better memory wise, but would it show up on a standardized test? Would my recall be fast enough to make a difference on a timed test? When it was over I knew I'd done better, but was unprepared for the evaluation. My lowest scores had improved 10 percent!

I still had trouble believing that such a result was possible. The psychologist's reply was that he wished more doctors would have their patients follow the regime I was following. The results **were possible**.

This year for the first time, I have felt able to participate in the Alzheimer's Association Memory Walks. Most of the walkers are walking in memory of a loved one who is suffering from, or who has died from the disease. I am walking with the **hope** that my **memory** and that of untold thousands of others will be preserved through the **research** that is producing so many hopeful results and the **best practices** which will make each Alzheimer patient achieve the best possible outcome.

On my wrist is always the Alzheimer's Bracelet which reads: a reason to hope. That is my mantra: the words I live by. Hope for myself and hope that the general population and particularly the medical profession will become aware of the major benefits of Early Diagnosis and a proactive regime.

Thank you for the opportunity to speak with you.