TESTIMONY OF

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TESTIMONY BEFORE

The Subcommittee on Aging, Health, Education, Labor & Pensions Committee
United States Senate

Field Hearing on
“Alzheimer’s Research & Care: Helping Patients & Families”

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Ina Dutra Savage, born in Rio de Janeiro, Brazil in 1941, came to the US for the first time to attend high school as an international exchange student in 1958. After graduating from Mineola High School, she returned to Brazil to attend the Catholic University of Rio, where she got a degree in sociology and became an associate teacher at the university. Because of her linguistic ability—she spoke Portuguese, French, English and Italian—she was hired by the US Embassy to serve as a social secretary assigned to the US Ambassador, Lincoln Gordon. In this job, she met her husband, Peter Savage, and they were married in 1967. She was assigned with her husband, a CIA officer, to Brazil and, later, Argentina, returning to the US in 1978, with her husband and three daughters. When her children were of school age, Ina enrolled in a Master's Degree program for linguistics at University of MD, graduated in 1988 and was licensed to teach French and Spanish in the Baltimore Public School system in 1990.

The first sign of any difficulty for Ina was her apparent inability to remember her teaching program in classes and her inability to maintain class discipline—both very much out of character. In 1991 she had to resign as a teacher and signed up as a translator/interpreter for Spanish, French and Portuguese. Other lapses and orientation problems appeared and, in 1993, she was referred to a neurologist. After more than a year of exams, observation, and tests it became apparent that there was a progression to her ailment and she was referred to Sheppard Pratt for more analysis. After long study, she was diagnosed with Alzheimer's disease in October, 1995. At that point, the impact on the family began to be felt.

The first problem was that Ina could no longer drive a car so that getting kids to and from school, shopping, and daily activities were shifted to her husband or older daughters, two of whom were off at college. The Alzheimer's Association was helpful in identifying support groups where others could point the way to the problems we faced. An elder care lawyer had to be identified, our wills and living wills had to be drawn up, and we had to plan for our future finances to deal with an uncertain future with an uncertain time frame.

Immediate and Pressing Problems

The immediate concerns following the diagnosis were:

- Where could Ina's husband, Peter, find a job that allowed flexible time for him to deal with the family chores Ina could no longer perform?
- How could we get health insurance that could avoid a pre- existing condition exclusion for the Alzheimer's?
- Where should we go for medical attention to the immediate manifestations of a disease that was, probably, Alzheimer's?
- What resources were available to support any of these decisions that had to be made?

Long Term Problems

Longer term problems also loomed and needed consideration in the short term:

- If institutionalization were the likely end of the line for Ina, how would she qualify for Medicare and Medicaid?
- Social Security had not recognized several years of Ina's independent contractor work and, accordingly, disqualified her time necessary to qualify for benefits. How to deal with this?
- What were the roles that each member of the family would take on as Ina's abilities declined?
- Who are the lawyers, accountants, brokers, psychologists, and support groups who can help sort out these questions?

None of these questions has a definitive answer that suits every family. Certain it is, however, that when a mainstay of a household becomes incapacitated—becomes a vegetable—the world of a family is stood on its head. And if there are insufficient financial resources to meet unexpected needs the impact can be ruinous and relationships within the family unbearable.

While some of these questions remain unresolved, there were answers for the short term pressing questions. Peter got a real estate license and became a commercial broker so that his hours were flexible and he could tailor work around family demands.

The family became an incorporated entity where all, including Ina, were salaried employees or dependents, so that, under Maryland law, a health insurer could not deny coverage by reason of pre existing conditions.

Sheppard Pratt referred us to Claudia Kawas, a neurologist conducting various tests for new drugs aimed at Alzheimer's Disease at the Bay View Neurological Center at Johns Hopkins, who introduced various courses for enrolling in new clinical trials. Staff working with Dr. Kawas were helpful in assessing how our resources should be allocated in meeting the crisis. They recommended a book, *The 36 Hour Day*, by Dr. Peter Ravens (and others). This book was indispensable reading.

In addition, Dr. Kawas was in a position to diagnose Ina's situation to see which study might be most suited to her treatment. In the end, however, Ina would have had to discontinue taking drugs which had proven beneficial (donepezil) to qualify her for several of the studies being conducted by Dr. Kawas or for other studies being considered in the field. Ina is presently involved in a long term study measuring the progression of memory disorder at the Bay View Research Center and has donated her brain on her death, to Johns Hopkins.

Her present doctor, Vassilis Koliatsos, of Sheppard Pratt Neuropsychiatry Program, has also kept us currant on new clinical trials under consideration and advised us on what courses to consider. Ina volunteered for the positron emission tomography (PET) study at Johns Hopkins but, again, she would have had to stop taking donepezil for a 6-month period prior to the study.

Dr. Constantine Lyketsos, of the Johns Hopkins Neuropsychiatry Service was very helpful in getting Ina around the gate keepers to the ELAN/EN1792 vaccine study at the Mayo Clinic last September, but her mini-mental scores were lower than the candidates permitted in the sample. This test was ended abruptly and her non-participation was probably a grace.

Most of the longer term problems have still to be resolved but the most aggravating part has been dealing with the bureaucracy at Social Security who have been so unhelpful that a lawyer has had to become involved at considerable expense.

The roles of family members are still being resolved. Ina now requires caretakers 24 hours a day, so the daughters have advertised for caretakers, interviewed them, made a schedule and coordinated it so that Peter can have his work day free to go to the office and have weekend activities out of the house. One daughter acts as a caretaker three days a week and Peter is on duty nights and weekends.

The long- term prospects are still clouded by Ina having to qualify for disability and Medicaid within the time that she may require permanent institutionalization. In addition, the family has been challenged by the difficulty in finding appropriate activities to keep Ina stimulated as the disease has progressed. Each case of Alzheimer's disease affects the family and the individual differently. Services and supports that are utilized by one family or individual may not meet the needs of another.

Senator Mikulski, I thank you for inviting me to speak at this hearing and for the opportunity to discuss how Alzheimer's disease has affected the Savage family.