

Leaving a Legacy

One Family's Commitment to Research for Nearly Two Decades

Margaret Albus lived with Alzheimer's disease for 10 years before she passed away. Her husband cared for her at home with the help of their seven children, and eventually with outside care. At the time, the Albus family participated in the Walk to End Alzheimer's in Ladysmith, Wisconsin to support, and eventually to honor their mother. At the Walk, the family was given information about the Wisconsin Registry for Alzheimer's Prevention (WRAP) study. Due to the family history with Alzheimer's disease, the family felt compelled to get involved. "It was hard to see mom go through this," says one of Margaret's daughter's, Elaine. "We all discussed it, and wanted to be a part of any research that may eventually help us if we developed Alzheimer's."

Margaret's seven children all signed up for the WRAP study and have participated since 2003 (sibling ages ranged from early 30's-40's at the start of the study). While the siblings are geographically scattered – 2 live in Ladysmith, WI, 1 lives in New Richmond, WI and 4 live in the Twin Cities area – they have all stayed engaged in the research. Every two years the University Hospital in Madison contacts them and they report for a series of tests that the study benchmarks.

"I'll be honest, it gets harder to go each year," shares Elaine. "It's very stressful to do the tests wondering if you are declining." The researchers share any significant decline with participants, but no one in the Albus family has seen that decline.

Largest Family History Study

The Wisconsin Alzheimer's Institute (WAI) is the home to the WRAP, which is the largest family history study of Alzheimer's disease in the world. Today the study follows more than 1,500 participants, nearly three-fourths of them with a parental history of the disease. Participants visit every two years to answer questions about lifestyle factors such as diet, fitness and stress; have vital signs measured and participate in cognitive testing. The Alzheimer's Association Wisconsin Chapter is a community partner to the WAI and proudly supports this critical research initiative.

Advancing Research

Alzheimer's disease research can only progress with the help of volunteers who participate in valuable research. Because of volunteers, researchers are making great strides in early diagnosis of memory problems and in identifying potential new interventions to help treat, delay the onset, and possibly prevent Alzheimer's disease entirely. They are also learning more about how to identify the disease and the variety of different lifestyle, environmental and genetic factors that contribute to disease risk. "It's a big commitment, but we want to do it for mom and now ourselves," says Elaine. "If you have children or nieces and nephews, it's something we can do to find a cure, or at least a better treatment."

