

## Clinical Trials

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### Barbara and Dan Johnson, Brookfield, WI

Barbara was diagnosed with Alzheimer’s disease in 2012 and she and her husband Dan became very involved with the community surrounding her diagnosis. “You get so much out of talking to people who are familiar with your journey,” says Dan.

### Clinical Trial

Upon a recommendation, the couple volunteered for a clinical trial led by the Wisconsin Alzheimer’s Disease Research Center at the University of Wisconsin-Madison. Since 2012, they have participated in a **Longitudinal Study** where the purpose is to measure changes over time with an individual who has the diagnosis. This type of study looks at repeated observations of the same variables over time.

Unlike some trials with medications or drugs, this study, in 12-month increments, tracks how Barbara is progressing. Results are shared with the Johnson’s, which they share with Barbara’s doctor in Milwaukee. The study also tracks the caregiver’s journey.



### Importance of Research

“Because Alzheimer’s disease impacts millions of people around the world, there’s a tendency for just one family to feel powerless,” says Dan. “But by participating in research, it can give you a sense of power and doing something good that might help others. Even though we know the research will likely not have any impact for us, it might help our children.”

Alzheimer’s disease is the 6<sup>th</sup> leading cause of death in America affecting more than 5 million Americans. Only through increased research, with advocates like the Johnson’s, can we discover new ways to treat and eventually prevent Alzheimer’s and other dementias.

The Johnson’s continue to seek out opportunities for Barbara to participate in research studies. With the current pandemic, they volunteered for a potential clinical trial looking at the impact of COVID-19 on those with an Alzheimer’s diagnosis. Both Dan and Barbara contracted and recovered from COVID-19. “You want to be the type of person who is willing to plant an oak tree even though you know you will never experience the shade from that tree. You do it for future generations.”

### Taking Advantage of Resources

After Barbara's diagnosis, the Johnson's immediately sought out resources to support them. Over the year's they have participated in Alzheimer's Association support groups, social engagement opportunities and attended several Advocacy Forums. "We were plugged in right away to the Alzheimer's Association and immediately had a community," Dan shares. "While medically everyone may be at a separate place, we had a community to support us." They also participate in the Amazing Grace Chorus, a Milwaukee-based group of the Wisconsin Alzheimer's Institute that is made up of people living with dementia and their caregivers.

Dan and Barbara live in Brookfield and have two adult children. They enjoy swimming, walking, cooking, singing and hanging out with their grandchildren.