

## **Helene Decoste**Research Participant

Timing is everything! Helene DeCoste had just cleaned out her sister's condo and was driving home when she heard an advertisement on the radio about getting involved with Alzheimer's research. That was Fall of 2014 and Helene's sister Judith, who had Alzheimer's, had just moved into an assisted living facility since it was no longer safe for her to live at home alone.

Having already lost her mother and an aunt to Alzheimer's, Helene says the ad prompted her to call the Center for Alzheimer Research and Treatment (CART) at Brigham and Women's Hospital where she made an appointment and "the rest is history."

Helene soon enrolled in the A4 study where she met Dr. Reisa Sperling on the day of her first infusion. Helene says "the atmosphere in CART was one of peace and happiness" and she has become friends with several staff members as well as other research participants and their study partners.

Helene participated in the A4 study for about five years and traveled to CART every four weeks during that time. She says as she was reaching the end of the study she was wondering what she was going to do with herself once it was done. "Luckily, the Open Label phase started up and I have continued participating," states Helene.

According to Kirsten Glennon, Clinical Trials Nurse at CART, "Helene's positive can-do attitude inspires our research staff every day; we often say she is one of Alzheimer's clinical trials greatest cheerleaders. Helene has repeatedly said that she participates in Alzheimer clinical trials so that her family won't have to. She is committed to playing an active role in finding a cure for Alzheimer's so that her children and grandchildren will not have to carry the burden of worrying about Alzheimer's disease."

In addition to Helene's own support of science, both her mother and sister Judith (who eventually passed from Alzheimer's), donated their brain tissue for research.

Helene says the friendships she has made through research participation have been especially helpful during COVID isolation. "There are several of us who keep in touch via email and share news about not only our research experiences, but our personal interests and everyday life."

Adhering to COVID safety protocols, Helene continues her study participation and recently had her first home infusion. She says, "Being in the study has been one of the best things I could have done. How lucky am I?"