

Dear Mrs. Joanne Knight and Family,

I would like to take this opportunity to thank you for your generous donation and support of the Knight ADRC at Washington University and the DIAN Network. It was because of you and your husband's philanthropy that I was able to attend the DIAD Family Conference. As an at-risk carrier for an early-onset Alzheimer's disease mutation, no words can express the gratitude I feel for having had the opportunity to participate in such a unique event.

My dad was 49 years old when he was diagnosed with early onset Alzheimer's disease. I was eighteen and had just graduated from high school. I remember sitting at the kitchen table when my mom broke the news. We had been noticing symptoms for a while, but I think we were all in denial. I just couldn't imagine the strongest, most generous, most intelligent guy I knew could have Alzheimer's. The next day I went to the library and checked out every single book on Alzheimer's disease; in the following months, I signed up for every neuroscience class on campus; and when that wasn't enough I joined a lab studying Alzheimer's disease. That was over 10 years ago and despite the heartbreak this disease has brought, it has also led me on a wonderful journey of discovery; discovery of self, inner passion, and an un-ending drive for research. With every turn, every frustration that is getting a PhD, every confusing result, I have pushed forward, all the while pursuing the dream of finding that one key that would solve all of my family's problems.

Despite my day-to-day pursuit of better understanding the biological component of Alzheimer's, coming to terms with the other facets of this disease continually eludes me. Watching your parent slowing deteriorate, losing their memory of you, themselves, and their dignity. Then losing your parent. The grief. The sorrow. The anger. You can't understand what kind of world lets this happen to the best person you ever knew. The unfairness of it all. The grief never leaves you, but then something new presents itself. The thought that you carry the mutation too. Something grips your heart and you are never the same. Every relationship, every long-term goal, every plan becomes tainted by this looming dread. Then you find someone who you let in and who can't live without you, even if it means only having you for a few years. Then you start talking about having a family and again that stupid mutation presents itself. To say that Alzheimer's disease is a part of my life is an extreme understatement. Not only is it my job, but it is my past, my present, and my future.

Throughout your life you run into people who have experienced loss, who have also lost parents at a young age, who have also watched this disease wreak havoc on their loved ones. But you never meet someone who knows the deepest darkest thoughts that comes with early-onset Alzheimer's disease. That is until you go to a DIAD Family Conference. Suddenly, you're in a room surrounded by people who have all been there. There are no words to express what that feels like. Like coming home. Like becoming part of a family that gets you the moment you speak. Suddenly you have 10 brothers and sisters who all have the same thoughts and worries. All motivated to make a difference. No one looks at you with pity. It is just acceptance and warmth.

The ADAD and DIAN Network is a unique group of individuals that I am so grateful to have become a part of. It was with your help that I was able to join this great network of individuals; and it was with their help that I finally mustered up the courage to join a clinical trial and contribute in a very personal way to the field of Alzheimer's. Dr. Bateman and his staff have been nothing but wonderful and I believe that together we'll be able to make tremendous strides in the field.

Thank you again for efforts on behalf of this devastating disease. I hope this letter helps explain how grateful and appreciative I am, that we all are, of your generosity to our families and to the field of Alzheimer's disease. I wish all the best for you and your family.

Sincerely,
A grateful family member