

Advocate Q&A

Brandon Barkwell

Brandon Barkwell, 15, has attended two Advocacy Forums. His father, Brian, was diagnosed with younger-onset Alzheimer's in his late '40s, when Brandon was 5.

What impact has your father's Alzheimer's disease had on you and your family?

My dad having Alzheimer's is all I've ever known. As I get older, it actually gets harder in some ways, but acceptance also starts to set in. My dad has lived in several different residential facilities, and it's a really tough thing to watch as a child. You want to look up to your dad and not see Alzheimer's take everything from him and me, but it did. It's not easy to balance that reality while striving to excel in high school and activities in order to get the grades and scholarships for college.

My dad's Alzheimer's is an open wound that you have to deal with every day, as it has no closure for years and years. I have a strong network of friends and family that have encouraged me to use this adversity to make a difference and never stop fighting for a cure, so one day no one will ever experience this again.

What have your Forum experiences been like?

Although my circumstances for being there are difficult, attending the Forum gives me a feeling of making a difference. I also get to meet so many interesting people affected by Alzheimer's disease that are also passionate about the future. The Forum events and networking are really inspirational and get me pumped up. Going to the representatives' and senators' offices on Capitol Hill with my story and asking for more funding makes me feel empowered. It's an opportunity that has been life-changing for me.

You spoke during the Roll Call of the States at the 2014 Forum. What was that like? Were you nervous?

The experience of speaking at the Roll Call was amazing. I practiced in the actual ballroom ahead of time, as I wanted to get of feel for what the stage and mic would be like during the event. I wasn't nervous at all, as I'm grateful for any and all opportunities to speak out on the fight against Alzheimer's.

How do you feel your advocacy efforts help the cause?

Advocacy efforts are so powerful. I don't think you really understand it until you go Washington, D.C., and spend a day in those buildings going from office to office with your story and trying to explain the urgency for more funding.

How important do you feel young advocates are to the cause?

It's super important for young advocates like me to be involved in the cause. There's a misperception that it only affects old people and, therefore, only old people must be involved. This makes no sense, but I see it all the time. By advocating, I'm also raising awareness for the cause. I can tell you that most of my friends in high school aren't familiar with Alzheimer's and aren't even comfortable talking about it. There's something so wrong with that and also very hard for me.

We need a grassroots effort to change the perception of what Alzheimer's is, and that's going to come from young people getting involved. When I say young, I mean high school and college students. It needs to start at this age level.

What do you think you might do to continue your advocacy efforts?

I'll continue to go to Washington, D.C., annually and be involved with my own representative. I've asked for a greater role in the Forum if anything ever comes up for me. I'm also a member of the steering committee of the Phoenix Walk to End Alzheimer's® and have my own Walk team.

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