

Young advocate honors father with fight against Alzheimer's



Elizabeth Gelfand Stearns and Alzheimer's Association Ambassador Brandon Barkwell.

One of the youngest advocates at the 2014 Advocacy Forum was Brandon Barkwell, 15, of Scottsdale, Arizona. Brandon's father, Brian, was diagnosed with younger-onset Alzheimer's disease in his late 40s, when Brandon was 5.

This year's Forum was Brandon's second time at the gathering. In addition to providing an update on the Alzheimer's Association Desert Southwest Chapter's legislative victories, Brandon — an Alzheimer's Association Ambassador and an already seasoned advocate — was part of the chapter delegation that spoke to lawmakers on Capitol Hill. He called the event "an amazing experience."

"Although my circumstances for being at the Forum are difficult, attending gives me a feeling of making a difference," Brandon said. "I also get to meet so many interesting people affected by the disease who are passionate about the future. Going to Capitol Hill with my story and asking for more funding makes me feel empowered. It's been a life-changing opportunity for me."

Back in Arizona, Brandon will again captain his Walk to End Alzheimer's® team in Phoenix — he recruited 40 team members last year and raised \$3,000 — and serve on the Walk's planning committee. A particular focus of his ongoing Alzheimer's activism is recruiting other young people to engage with the cause.

"There's a misperception that Alzheimer's disease only affects old people and that only old people must be involved," Barkwell said. "This makes no sense, but I see it all the time. Most of my friends in high school aren't familiar with Alzheimer's and aren't even comfortable talking about it. 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."

Brian's battle with Alzheimer's is essentially all Brandon has ever known about his father, who has resided for the last year and a half in an assisted living facility. Though the disease has become increasingly difficult to deal with, Brandon has accepted his reality — and he pledges to continue attending the Forum and serving as an advocate for as long as necessary.

"You want to look up to your dad, but Alzheimer's took everything from him and me," he said. "It's an open wound that you have to deal with every day... but I have a strong network of friends and family that has encouraged me to use this adversity to make a difference and never stop fighting for a cure, so one day no one will ever have to experience this."