

Giving a Hand to Our Helping Hands!

AFTD Volunteer: Kacy Kunesh

Written by: Kathy Urban, volunteer writer for AFTD

It can feel overwhelming to navigate a disease that is met with so much unfamiliarity. Many people touched by FTD find themselves in a world where most, including medical experts, have no idea what they're up against. It can be isolating. Thankfully, volunteer efforts to raise awareness are helping to change that.

Kacy Kunesh has been an AFTD volunteer for three years. Her work to raise awareness stems from personal experience gained over the course of her family's more than nine year journey with the disease, and when talking with Kacy, her dedication and passion shine through. FTD began to impact her mother, Donna, when she was only 55.

"I volunteer to keep other patients and families from going through the stress and emotional toll of what we went through in the beginning," she said, "...and in the hope that other families can be spared from spending the amount of time, money and energy that my family did during a four-and-a-half-year misdiagnosis period."

Kacy has attended three AFTD annual education conferences so far, and has found that they are a great place to start connecting with others who share a common base of experience. At last year's conference she joined a group of younger caregivers in their 20s and 30s for a lunch discussion. Out of that meeting grew a Facebook support group for young adults, which she helped to moderate. This was just a starting point for Kacy to begin her outreach to those who needed support.

In her latest endeavor, Kacy helped to organize AFTD-Team participation in a 5K in her Austin, Texas community this spring. She encouraged others to sign up for the June 13 event, at which 27 people represented AFTD, bringing new awareness to participants, organizers, and the surrounding community. Through the event, she was also able to raise more than \$2,400 to support AFTD's mission.

Kacy was one of four volunteers across the country who piloted AFTD's facility outreach project, before we offered it to all of our volunteers as an option. "Feedback from the volunteers who piloted the project helped us create what we use today as resources and tools for our volunteers," said AFTD Volunteer Manager Kerri Barthel.

The facility outreach project now offers volunteers an opportunity to raise awareness, by arranging short visits with health providers in their communities, to ensure that administrators are aware of FTD, and inform them that AFTD is a resource for persons diagnosed, families and professionals.

Spreading FTD awareness is what drives many of us – in hopes of helping others in the future. For Kacy, volunteering has been a way deepen her connection to this community, even as she's found her own way as a caregiver. Being a volunteer doesn't require knowing all the answers. "Over these years, whether I was helping AFTD or they were helping me... it's been valuable to have an open line of participation and communication," she said.

The supportive community that the organization and volunteers like Kacy have built makes this emotional and trying journey a little easier.



Kacy Kunesh with her father, Bob



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