

Giving a Hand to Our Helping Hands!

AFTD Volunteer: Mary Black

Advancing AFTD's mission requires the engagement of a growing number of wonderful volunteers across the United States. Based on individual interest, skill and availability, AFTD works diligently to match each volunteer with the work that needs to be done.

One of our many valued volunteers is Mary Black. Mary, currently residing in Philadelphia, lost her husband, Bernie (64), to FTD in 2012. She recalls that she was first introduced to AFTD as she struggled with the knowledge that Bernie's illness was growing progressively worse, and that keeping him at home was becoming less and less of an option. "I would call the AFTD Helpline, mainly to ask questions about nursing home placement," Mary recalled. Mary's journey with FTD was difficult on its own, but adding the stress of finding placement made it even harder. "It took two years. I did finally manage to get Bernie into a stellar facility that took Medicaid. I wrote them several letters, and never gave up hope, even after being rejected three different times," stated Mary.



Mary Black with grandson Daniel

Because Mary encountered such resistance from the nursing homes, she is now volunteering in AFTD's facility outreach program, which strives to educate staff at facilities about FTD. "Some facilities don't accept anyone under 65," Mary said. "I want to advocate for nursing homes to be open to taking these much younger clients." Mary also provides office support when there are special projects and plans to represent AFTD as a community awareness representative at the upcoming Brain Health Fair in Philadelphia.

Working closely with Mary, Kerri Barthel, volunteer manager, explains that "Mary is always flexible and willing to make herself available to help. She is truly dedicated to advancing the mission of AFTD."

Mary's experience with FTD has been "a soul stretching journey. Watching it take over someone you love requires reserves of courage that you didn't know you had, but somehow, that courage will be there when you need it."

Rachel Baffa, whose father is affected with FTD, is a volunteer writer for AFTD.