



The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

Thank you for your past support of the work we do here at The Association for Frontotemporal Degeneration (AFTD). As we celebrate 10 years of dedication to our mission, I am pleased to report that we continue to gain momentum in our quest to address the needs of our community. However, there is still much work to be done for there are far too many heart-wrenching stories about FTD. Far too many of you, like me, can relate to Katie and Mike's story.

I have been thinking a lot about the summer of 2002. A recent college graduate, I was energized, idealistic, and hopeful. And, I was planning a wedding. Mike and I were married that August. After a quick honeymoon in Vermont we moved into a one-bedroom apartment, planning and plotting for our future, bright with the promise of a house of our own, a family, and successful careers.



Now it is 2012. I should be planning our 10-year anniversary, booking a road trip to Vermont and checking to see if I can still zip up my wedding gown. Instead, I am procrastinating on choosing a headstone for Mike's grave. Mike's life was taken at the age of 33 by FTD.

FTD made its first appearance during my pregnancy with Noah. Mike's behavior became erratic and unpredictable. He was having trouble at work. By the time Noah was six months old, Mike's executive functioning was so poor that I didn't feel comfortable leaving the two of them alone together.

In September of 2008, I accompanied Mike to a routine physical appointment with his primary care physician. I asked her, "My husband is acting so weird, does he have a brain tumor?" She was the first of eight medical professionals to misdiagnose him with depression.



I kept searching for a better answer to Mike's changes and rapid decline. In February of 2009, Mike was seen by the Chief of Cognitive Neurology at the Beth Israel Deaconess Medical Center in Boston. I suspect that Dr. Galaburda knew Mike had FTD within 20 minutes of meeting us. Dr. Galaburda had something that the previous physicians and mental health professionals lacked: experience with FTD.

I quit my job to care for my family and we lost our house to foreclosure. Noah and I moved in with Dad. Social Security, food stamps and Medicaid helped us get by. Mike's parents helped care for him until his needs became too great. He spent the last two years of his life at a neuro rehabilitation center. He lost his ability to speak, walk and swallow. But, he still had a voice.

I was Mike's biggest advocate. Ensuring his comfort and dignity while preserving our story became one of my most important roles. In Mike's final moments it was just the two of us, holding hands and listening to our wedding song, reliving our beginning while we faced our end. Mike passed away on April 19, 2012. Just over 3 years from his diagnosis, 21 days after Noah turned 4 and only months before we might have celebrated a decade of marriage.

The reality of that nightmare coming true made me even more determined that FTD would not have the final word in Mike's life and in our family's story. I have just joined AFTD as the organization's lead volunteer for the Northeast Region. I invite you to join the cause as well, so the next young family faced with this diagnosis will have a brighter future.

Join AFTD, Katie and all those affected by this devastating disease as we strive to provide the support and advocacy they need today, while funding the research that will produce a cure for tomorrow. Your tax-deductible donation today will make this happen.

Sincerely,



Beth Walter
Chair

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