

How three letters transformed our lives... **ALS**

A vital letter from ALS patient Karen Delaney Shideleff

November 26, 2013

“My mother’s joy, smile and laughter will live on in all of us.... but sadly, so may the reason she had ALS.”

Karen Delaney Shideleff

I was only 16 when **ALS** entered my life.

My vibrant and loving mom, Lorraine Delaney, was diagnosed with **ALS**, or Lou Gehrig’s Disease, at the age of 46. My dad, Larry, and my sisters and I were able to care for my mom at home with the help of The ALS Association Greater Philadelphia Chapter. In 1991, after a two year struggle of watching my mom lose the ability to walk, dress, and feed herself, ALS took the heart of our family. There isn’t a day that goes by when I don’t think about her, and remember all the laughter-filled moments our family shared. I feel her presence today in the way my sisters love their children and in watching our dad with his grandchildren.

My mother’s joy, smile and laughter will live on in all of us.... but sadly, so may the reason she had ALS.

Almost 20 years after my mom lost her battle to ALS, our family went to battle again. **I was diagnosed with ALS in February 2011, at the age of 37.** I feel very strongly that every person with ALS should be encouraged to do everything in their power to help advance research. I have thrown myself headfirst into every research study that would take me. My participation in research trials and studies has been extremely rewarding and empowering. I feel like I’m able to fight back against this disease, that little by little, is taking away my independence.

At the time of my mom’s 1989 diagnosis, there was still so little known about the disease named after the great baseball player, Lou Gehrig. Researchers had discovered that the majority of ALS is

please turn over...

(L to R) Chrissie, me, Susan and Kathy at the Greater Philadelphia Walk to Defeat ALS® in November.



(Center) Mom Lorraine, (clockwise) Dad Larry, me, sisters Chrissie, Kathy and Susan.



(Center) Dad (Clockwise) Kathy, Susan, Chrissie and me today.



sporadic, with the familial form like mine accounting for about 10% of cases. My mom knew that her father was diagnosed with ALS when he was 36, but had never heard that anyone else in the family had ALS. After years of investigating our family tree, we can now trace ALS back to my mom's great-grandfather and we know at least 25 family members have had the disease. Knowing the importance of research, my mom donated her tissue in 1991. She didn't live to see the results of the studies, but we are so proud that her cells are now a part of such groundbreaking discoveries.

I have participated in promising drug trials, each one costing thousands of dollars, and will continue to do so. I have donated everything from my hair to my spinal fluid for research studies. If you know me, you know I don't have a lot of hair to spare. I like to say that I am leaving a little bit of myself everywhere!

In the years since my mom's passing our family continues to very actively fight ALS. Our involvement in the Chapter board, advocacy and events like the ALS Express and Walk to Defeat ALS® helps raise awareness and funds.

We do all of this because we truly appreciate all the programs and services provided to us by the Chapter. Your support of ALS Research will make a difference for people like me! But what really determines our fate? **This disease could happen to anyone, anywhere and at any time. But why? Research will tell us.**

You can help create a future where no one ever has to watch their spouse, parent, child, sister, brother or best friend suffer from ALS. I would give anything to have my mom back so that together we could watch my nieces and nephews grow up. Please make a generous donation to ALS research today.

With my heartfelt thanks,

Karen Delaney Shideleff

PS – PLEASE GIVE TO THE CURE – ANY amount will help families like mine. Your gift can start working today when you give online at www.alsphiladelphia.org/2013research

“...we can now trace ALS back to my mom's great-grandfather and we know at least 25 family members have had the disease.”



My amazing and supportive husband Bob finished the ALS Express Bike Ride this past summer.

“This disease could happen to anyone, anywhere and at any time. But why? Research will tell us.”



Dad and me at my wedding.

Our Hershey Walk team started by my college roommate, Kristi Menicheschi

