I am Lou - My name is Megan Mishork and Marilyn Silva

"To change the world, you start with one step. And no matter how small, the first step is hardest of all." ~ Dave Matthews Band

When you first think of the word "family", one tends to do so in the most basic terms- "all the members of a household under one roof or a group of persons sharing common ancestry". Beyond that definition, there is much room for debate and discussion. Families can share many common belief systems, physical characteristics, personality traits, and personal histories. But, they can also hold vast differences in interests and experiences.

Megan Mishork and Marilyn Silva are a living definition of all of these interpretations. They have many things in common- their wit, their love of travel, and, sadly, a shared history and genetic commonality. They come from a family that has had been fighting and living with ALS for over five generations.

And now, they each are living with it too.

Marilyn Silva was diagnosed in May of 2009 at the age of 51. She had lost her father and grandmother to ALS, both died at age 42. Her aunt died at the age of 19. This disease has also taken the lives of her three brothers.

"My last brother died just three years ago", she shared. "It has not skipped a generation in our family from as far back as we have researched."

Within a month of her diagnosis, Marilyn had decided to move on to hospice.

"Now it has hit our family hard, both myself and my 25 year old niece are dying from it at the same time." Marilyn said.

Marilyn is receives her care and treatment at The ALS Treatment and Research Center at UCSF. Marilyn's sister, Mari Betti is actively involved in her care. "Although it is a very difficult job, I am very fortunate to be here to help with such wonderful, brave people." Mari said.

Megan Mishork was only 24 when she was diagnosed November 12, 2008.

"I had dealt with ALS for the past 17 years. My father died when I was six from this disease," Megan shared. "Since then, my Uncle Johnny and Uncle Jimmy have passed. Also, my great grandmother, my grandpa and great aunt

"About four months prior to being diagnosed with ALS, I was about to celebrate six years with my boyfriend and was wishing to get married. There was nothing more in life that wanted than being a mom. I was saving money to build up my nest egg in hopes to buy my first home. I was at the beginning of the rest of my adult life and excited for my future. "At 24 years old, you can imagine the shock I felt when my doctor turned to me and said 'You have ALS'. I always knew it was a possibility, now it was a certainty."
Once a resident of Orange County, Megan began receiving her care and treatment and worked with the Orange County chapter. She has since relocated to Northern California, to be closer to her family, and is currently receiving her care and treatment at The Forbes Norris ALS Center.

Megan’s mother Linda Bracciotti feels an incredible blend of agony and pride for her daughter’s fight with ALS. “I lived knowing that I was going to have to bury one of my kids in my lifetime.” she says. “It has been like the ticking time bomb in the room. My son has fortunately tested negative, but that doesn't help my brave daughter. The craziness and the headaches with just trying to navigate the health care system for just the basics to cope with the disease are a constant challenge.”

Life has had many other changes and disappointments for Megan since her diagnosis. But she has maintained her sense of humor and sense of optimism. “Sure-I am no longer with the man I thought I wanted to spend the rest of my life with. I'll never walk down the aisle on my wedding day and that's if someone would marry me. I will never experience being a mom.”

"I had to sell or give away all of my things and moved back in with my parents. All so someone could spoon-feed me, dress me, bathe me, and yes, wipe my butt." she said, with a chuckle in her voice. "Which by the way, there is a very small, but prestigious list of those who are allowed to wipe my royal caboose." she jokes.

"But I am pretty lucky to have the opportunity of knowing how and approximately when I am going to die," she shares. "I have learned there is no reason to ever worry. It is an incredible freedom to do whatever I want as long as it makes me happy and I am not hurting anyone. I don’t feel guilty about not going to the gym or spending too much money on things I enjoy doing. I don’t worry about the extra calories in eating dessert, or being lazy, or getting tattooed."

"It is a privilege to know, and to work with Marilyn and Megan", says Madelon Thomson, Director of Patient and Family Services for the Greater Bay Area Chapter. "They have such great senses of humor. I admire their perspectives and focus on living in the now, while taking advantage of medical opportunities for treatment. Their extended family is absolutely amazing in the depth and scope of the support and love for Megan and Marilyn"

Mari Betti, also shared her thoughts. "In working on this article, I again realized how strong these two women are. They are my sister, my niece, and they are my 'bestest' friends."

The Mishork family are passionate advocates in doing everything that they can to help in the fight. Whether it is traveling to Washington DC to participate in Advocacy efforts, or help to raise funds for research. But, they also recognize that there are families that facing incredible challenges with the disease now. So, they were proud to participate in the 2009 East Bay Walk to Defeat ALS to help to support the chapter and it’s Patient and Family Services and Programs. Megan is also very active in the social media community, on Twitter and Facebook. She also writes a well known blog- www.gimpgirladventures.blogspot.com

Mari Betti shares, "I know the months ahead are going to be difficult, watching my two ladies progress. They both do indeed have a great support system which I hope and pray will carry us all through this terrible disease once again. I do hope I live to see a cure and definitely hope I do not live to see another member of my family die from this," she said.

Marilyn shares her point of view. "My niece Megan, and I each struggle everyday to keep our quality of life as' normal' as possible. With everyday, we hope to hear a cure will be found but in our lifetime we know that is not
possible."
"We both hope that through research and public awareness of this disease that someday there will be a cure or at least a treatment for our children and future generations." Marilyn says.

"I have four children of my own, so if I can or could do anything to help fight this disease I will do it."

Megan offers a similar perspective. "For me, just bringing this disease to public attention would be truly a gift I would leave in the hopes that, someday, no one else would have to suffer with such a horrible disease.

"I have 15 cousins who are at risk and odds are half of them will suffer and die from ALS. Most patients get two to five years after diagnosis, looking at my family history, we get less than a year. I would never want anyone to feel sorry for me. I knew I had a 50/50 chance of dying from ALS, but never thought I would endure it at 25 years old. This is my reality, my life, and I just accept it.

"I do not believe I will live to see a cure." Megan said. "But I hope in sharing my story I will bring some awareness to this disease and my efforts will make me the last one of my family to die from it."

- Written by Jenica Lancy
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