Why I Walk to End Lupus

by BARBARA LEECH

2014: Taking Part in the Walk to End Lupus

In March of 2014 my husband and I committed to walking in the Walk to End Lupus Now Boston fundraising event for the Lupus Foundation of America. It was something I had thought of doing for the last couple of years and this year seemed to be the right one. I was motivated. I wanted to do something that mattered and spread awareness. It was only a one-mile walk and I felt I could do it, so we created a team, Barbara's Believers and began raising sponsorship funds.

Committing to it was one thing; getting my flare-stricken body into a "let's do this" mode was another. I woke that Saturday morning at 6 a.m. (because it is about an hour and 40 minute drive to Boston) and thought, "This was a bad idea." I was exhausted and hurt everywhere. But I had committed to it and I was determined to make this happen. Lupus was not going to stop me.

My team consisted of myself, my husband (and greatest supporter), all four of my kids, my son in-law and my oldest daughter's fiancé. I realized when we were all together, all wearing our lupus walk t-shirts, what a powerful feeling it was. For that one special morning, I actually felt like I can beat this disease. I felt like what we were doing mattered. I felt loved.

And the people I met at this walk, my fellow Lupies, were so amazing and dedicated. The Boston Common was filled with families like ours tired of the struggle and the pain. My husband summed it up beautifully. As he stood in line for my youngest kids to get their faces painted, a fellow spouse of a Lupie struck up a conversation. He talked about his wife's struggles, my husband shared mine in return. There were many, many things in common. There were several replies of, "me too" and "been there".

My husband told me about it on the way home that afternoon. He said it was the first time he spoke with someone who knew what our life was like with lupus, and had been through the same challenges. It felt amazing to him to have that moment. Lupus can feel like a very lonely affliction, even for him. Nobody understands the day-to-day struggles… except at this type of event. Everyone there understood.

Our team raised more than $1,400 for the Lupus Foundation of America, but we gained a connection that we could not put a price tag on. Lupus can make you feel like everything is out of your control. Taking some of this back by taking action to fight for a cure was an empowering feeling. I encourage you to be a voice for this disease. There is power in your voice, there truly is.

What You Can Do to Raise Awareness

- Find a walk for lupus near you. Check out the Lupus Foundation of America's website for the walk scheduled that is closest to where you live. Even if you are signing up for next year, take action now.
- If someone asks about lupus be open to sharing what your experience has been and what the disease does.

- Wear lupus awareness items whenever you can. People will begin to recognize them the more they see them. The goal for the future is for all to know what lupus is and to be supporting action for greater research and a cure.
- Find new ways to advocate. Support others with this disease. Share your story. Be a voice for a cure.

2015: Turning Misery Into My Message

On October 24th, 2015, I walked with my team of lupus supporters in the Lupus Foundation of America's Walk to End Lupus Now in Boston. Frankly, I was wondering how I was going to make it through the day.

In a flare for the last several months, I feel like each day presents insurmountable challenges for me just getting through work and taking care of my family.

I have cried more times than I normally do lately, usually alone, late at night when the pain in my chest is so severe I question if I need to head to the ER or just tough it out because there is so little they can do, unless of course it is actually a heart attack.

There is always that uncertainty with lupus. My cardiologist recently found fluid around my heart, so each time the pain comes crushing in, I must wonder if it is simply pain I must live through, or if it actually is pain signaling something is about to kill me.

It is a guessing game. A cruel, ongoing battle where you don't want to go to the hospital for nothing, yet you are suffering symptoms that would cause anybody else to call 9-1-1.

I feel vulnerable and miserable, but somehow I remain determined that my misery should fuel me as I spread my message about lupus. Something must be done.

Next page: why you should participate in a walk to end lupus.

Mom on a Mission

I want there to be a cure, and most importantly, I want to live to see that day.

I want people to hear I have lupus, that you have lupus, or Selena Gomez has lupus, and automatically know what it is — what it means to our lives and what we endure. I am fed up with explaining. I am fed up with ignorance. Mostly, I am fed up with being me and all the pain and misery I must face.

So, I walk, I raise money the Lupus Foundation of America uses towards funding research and treatment development, and I continue to try and spread awareness.

I listen to all those wonderful cancer awareness campaigns and I think, "God bless them, but everyone knows about cancer and what it is and what it does. What they really need is a cure. Cancer awareness has been achieved."

But, with lupus, when you watch a talk show host as articulate and informed about important causes as Ellen DeGeneres sit down with Selena Gomez and ask what lupus is because she did not know, well it points out that awareness for this disease is pretty low.

I want to change that, and the only way I can think of is to not be silent about it. To not go quietly into the night, but to wear bright purple t-shirts and shout my warrior battle cries around Boston Common.

I will continue to petition our leaders to support lupus research funding and I will write about what it is to have lupus and to be a wife and mother who is afraid she won't be around to make all those memories she dreams of making. All of this inspires feelings I am certain many of my fellow lupus warriors can relate to:

Fear

I am scared. I developed pneumonia out of nowhere recently and on top of everything else happening with my lupus, it really felt like I might succumb to it all.

I have been through a lot with this disease, but I think there have only been a couple of times I felt so uncertain if I had the strength to make it. It made me think about the future and what could happen next. It made me worry what a flare like this might do to me when I am a bit older.

Anger

None of this is fair and none of us deserve to have our lives so brutally disrupted. To top it off, we also have a large chunk of the population unaware what lupus even is, so how can they respect our battle when they don't know what our disease can do? Lupus warriors spend their time explaining.

Resentment

I see others so blissfully healthy all around me and I cannot help feeling jealous, and at times, resentful of the ease in which they chase after their kids or proudly share they just ran 10 miles before work.

Even when I was exercising daily, it was a constant battle with pain and health setbacks. I never felt "good" or energized afterward. So, resentment can creep in. I don't like this about myself and I am trying to learn to let this go, but it is difficult when each moment is a struggle.

Grief

I mourn the loss of who I once was. Because of lupus, I no longer run. I no longer enjoy anything that happens during weather extremes.

With cold weather on the way, I have already begun my retreat inside. Lupus hates the cold and though snow used to be one of my favorite things, I no longer can play with my kids like I wish to without suffering unbearable pain for days afterwards.

I feel robbed of experiences and memory making moments on a daily basis and I grieve the death of who I once was. All of this sounds overwhelming, I know. But, if you have ever felt the same, I ask that you consider helping me spread lupus awareness.

If you can, raise money to support research and treatment development that is funded through campaigns like the Lupus Foundation of America's Walk to End Lupus Now. Do not give up in silence, but rather, fight on with your head and your voice raised high. As the campaign says, "People need to know lupus — for someday there to be no lupus."