Lupus Awareness Month

by BARBARA LEECH

Invisible Me: May Is Lupus Awareness Month

Chivalry and Lupus Awareness Month feel similar to me, strange as it may sound. Both bring attention to me or my disease in a way I am not accustomed to quite yet. I am a work in progress. Lupus Awareness Month stirs a similarly unreasonable gut reaction. Because of my past, I am accustomed to being as invisible as the disease I battle.

It remains foreign to me, unnerving down to my core, to be granted a moment that I come first or that talking about my disease is acceptable and even encouraged. Essentially, it's like when someone demonstrates that they "see" me, to stop, wait, hold open a door and smile, and suddenly I am unnerved. And when I am asked to spread Lupus awareness, I feel awkward, like I am complaining to people who hate complainers. I realize I need to accept that I am visible to others and I am worthy of being heard.

Having Lupus and talking about it for public awareness is attention that is needed and deserved. Nobody seems to know what it is, which is why we have Lupus Awareness Month. I mean, how can we ever get to a point of finding a cure, better treatments or even general understanding and compassion from coworkers, employers, family and friends if nobody knows what Lupus is? Say that you have cancer, and you get endless support. Say you have Lupus, which can also take your life, and you get a confused, blank stare. "I've heard of it, but what is it?"

Invisibility

Lupus is invisible. Nobody can see that my immune system mistakes parts of my body for invaders it is supposed to battle against. Instead of protecting me, it is attacking me, having gone after my heart, lungs, pancreas and several other human mechanisms required to keep me going.

People don't see my struggle to endure all I have been dealt with, and only the ones who truly care about me ask how I am, how I **really** am. Many forget anything I have told them regarding what this disease does. That is frustrating. I mean they asked me about it, right? I never just randomly pour out my heart about it.

"Hello. I have Lupus, and at this moment, it is causing pleurisy, which is swelling of the lining around my lungs. It hurts to fully inhale and to move too much, and I feel like I am being smothered 24/7."

So, there you go. I don't do that. But when asked, I take the time to explain what Lupus is doing to me. But for some reason, a month later, those same people seem completely surprised to realize I am in a daily battle with this relentless foe.

"It can affect your breathing? Oh wow. I didn't know it could do that. You should take this herb I take, which boosts the immune system."

So much is wrong with that statement. The last thing I should do is boost an immune system that is in hyper-overdrive and on attack. It makes me feel invisible to be given advice that so clearly shows they never listened to me in the first place. People need to be aware of what Lupus is, even if they don't have it themselves. This month serves as a voice for all of us seeking a broader understanding of our battle for survival. For a wealth of information, the Lupus Foundation of America (www.lupus.org) is a great resource.

To a handful of people, I am not invisible. My children can see me even when I am trying to hide. (Can I at least take a shower without interruption?) And I am married now to someone who takes the time to understand this disease and supports me through it all. In this relationship, doors are opened for me out of respect, and I feel cherished, even with Lupus. I deserve to be seen and heard. It is time to speak up.