What Can You Do to Raise Awareness of Lupus?

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Raising Awareness of Lupus

Prior to my diagnosis, back when the word “lupus” was just an unfamiliar, harmless jumble of letters, I found myself watching my very first lupus awareness commercial.

*“*Lupus: the disease with a thousand faces” flashed across my television screen and for the briefest moment, I was intrigued. *A disease with a thousand faces? What does that even mean?*

And then the flicker of curiosity was gone, lost as I switched the channel, unaware that my face would soon be counted among the millions of lupus sufferers around the world.

The commercial made me wonder, but ultimately, personal stakes draw you in. Cancer, arguably the most visible disease out there, touts the tagline, *“*Everyone knows someone with cancer.” It’s that personal connection, the stories and human faces that we can care about and relate to that create the best platform for disease awareness.

Lupus patients are of a lesser number, but still add up to an estimated five million people around the world — more than AIDS, cerebral palsy, multiple sclerosis, and cystic fibrosis combined. Knowing this, I wondered, "Then why do I feel so invisible?”

In fact, more often than not, my disease *was* invisible; inflammation wreaked havoc and caused pain on the inside, while leaving my outer appearance largely unchanged. Most of the people in my life had no idea they knew someone with lupus.

I wondered if I was doing enough to create awareness around the disease I was struggling with. Managing my disease was consuming all of my energy — why would I want lupus to take over more of my life than necessary?

Why Should I Play a Part in Raising Lupus Awareness?

The choice to promote awareness for the disease(s) you're living with isn’t for everyone. Most often, but not always, those who do make this choice have had their illness for a number of years.

They’ve had the time to process and accept that they’ve entered into a life long process of understanding and managing their chronic illness. They’ve learned hard lessons from poor health decisions and would like to help others avoid their mistakes.

They’ve gathered a lot of useful information from their experiences with medication and health care providers, and want to share this knowledge with newly diagnosed lupus patients.

This expands into a desire to enlist others in the fight for a quality life for every person with lupus. Regardless of

when a person starts to ponder the patient's role in disease awareness, there tends to be three main reasons an individual chooses to engage in it:

1. **Personal validation:** Having an invisible illness like lupus can be a mind game. People say you look well, when in reality, you are gravely ill. Your body tells you that yes, you are in physical pain, but each comment plants a seed of doubt. Sometimes, lupus symptoms can debilitate you for days and other times just for the morning, but not in the afternoon. People in your life are confused by the random nature of your illness and you constantly feel on the defensive. Spreading awareness is a way for you to validate your experiences and say, "Hey, it's real, what I'm experiencing is legitimate!"
2. **Getting the personal support you need:** By spreading awareness, you are also educating the people in your life. It exposes them to the facts and information that can help them understand your daily struggles and provide the support that you need.
3. **Getting public support for everyone with lupus:** The moment you engage in the lupus community, whether it be online or within your local lupus support group, your lupus bubble is pierced. Suddenly, you see beyond your own symptoms and problems, and you want all of your fellow lupus warriors to get the support that they need. Spreading awareness in the public sphere ranges from general education, seeking donations for research, and enlisting others to share their stories.

What Can One Person Do to Make a Difference?

Raising awareness and funds can feel like a daunting task, especially when there are so many campaigns out there asking for people's attention and donations.

There are many different ways to spread awareness of lupus, and some are much easier than you think. Here are ten ideas to get your awareness mojo going:

1. **Share your story:** This is the easiest way to spread awareness and it can be done in many different ways every single day! If you like to write, start a blog, and if you don't, tweet or Instagram different aspects of your lupus story. Social media gives us the ability to reach more people than ever before. Looking for a place to start? Challenge yourself to tweet something lupus-related once a week!
2. **Join your local lupus organization:** This is a great way to contribute by assisting with support groups, outreach, and fundraisers.
3. **Organize a lupus walk for your workplace:** Every year, lupus societies, foundations, and organizations hold lupus walks to raise money for research. Encourage your coworkers to sign up and walk with you as a lupus-fighting team.
4. **Organize a lupus lunch and learn:** Ask a representative from your local lupus organization (or present a lunch and learn yourself) to your workplace or any other group you are involved in. In fact, you could plan a lunch and learn for your family and friends as well.
5. **Swear jar at work or at home:** Donate the proceeds of your coworkers' or housemates' slips of the tongue to lupus research. During lupus awareness months (October and May), put up lupus facts near the swear jar.

6. **The gift of giving:** On birthdays, anniversaries, and holidays, consider asking for donations to the lupus organization of your choice in lieu of gifts.
7. **Kisses for lupus:** Planning on getting married? Instead of guests clinking their glasses for the bride and groom to kiss, ask for lupus donations instead. No donation, no kisses!
8. **Garage sale:** De-clutter your home and while you're at it, donate some of the proceeds to lupus research. Have a sign visible at your cash register with some fast facts on lupus and how it has affected your life.
9. **Donate your skills:** Do you teach yoga? Paint? Great with handy work around the house? Think about the skills that you have and consider offering services to others in exchange for lupus donations.
10. **Wear awareness on your sleeve:** Create your own lupus awareness slogans or sayings and create t-shirts for casual or work out wear. They make great conversation starters — you'll be creating awareness without saying a word!