Five Empowering Facts About Lupus

by AVA MEENA

Lupus Facts

When I talk about lupus with people, sometimes I get a perplexed look because it's not a very well understood condition. There are many misunderstandings and misconceptions about lupus, that people living with the condition may feel isolated and alone.

However, I want to change that. Here are five empowering facts about lupus that many people don't know:

1. If You Have Lupus, You Are Not Alone

There are an estimated five million people throughout the world living with lupus, and approximately 30 percent of them are Americans. So if you have lupus, you also have up to five million fellow lupus warriors who understand what you're going through.

A benefit to having lupus during a time where social media is so popular is that we can easily connect. Simply scrolling through the #lupus or #lupuswarrior hashtags on Instagram has provided me with inspiration and support throughout my lupus journey.

Whenever I have a reason or opportunity to tell someone I have lupus, they often respond with, "My [cousin/daughter/friend] has lupus." I'm encouraged to know there is a huge lupus community that includes caregivers as well as friends or family of people with lupus. In fact, you are likely to have other people with lupus in your family. Up to 20 percent of people with lupus will have a close family member that also has the disease.

2. Your Lupus Is Unique

If you know another person with lupus, then you probably know that their symptoms are different from yours in some way – perhaps in tremendous ways. It is rare to find two people with lupus that have the same disease manifestations.

While my lupus primarily causes aching joints, rashes, dry eye, and fatigue, a friend of mine with lupus experiences fluid in her joints, unexplained fever, and hair loss. We may have the same disease, but we have to deal with it in very different ways.

Lupus tends to be inconsistent, and it can attack nearly any part of the body, which is why it can be tough to diagnose. As a highly individualized disease, it may seem to imitate other conditions and lead to confusion or delays in receiving a diagnosis.

Even when inflammation is causing issues with lupus, unique treatments must be used for the same root problem. For example, flare-ups of pleurisy (lung inflammation) may be treated with different anti-inflammatory medication than flare-ups of joint inflammation.

3. Attitudes About Lupus Are Changing

Historically, people have been afraid of lupus. Medical historians have theorized lupus may have played a role in vampire folklore, due to photosensitivity and facial scarring that's associated with lupus (specifically discoid lupus).

People used masks to hide lesions, scars, and rashes. These skin manifestations made others afraid of catching the illness, and physicians weren't able to determine that lupus was not contagious until the mid-19th century.

However, there is still a lot of misinformation about lupus today. For example, some people still think that lupus could be contagious. A recent survey, published by Lupus UK, found that up to 41 percent of people in the UK said they would not be comfortable shaking hands with someone who has lupus.

Huge strides have been made in the past several decades to normalize lupus and develop medications to help people with lupus live better and longer lives. Increasing education about lupus has been vital in this effort. Fortunately, we can all play a role in disputing myths about lupus by sharing our story and bringing awareness to others.

4. It's Easier Than Ever to Become an Advocate

You can be a lupus advocate – it's likely a lot easier than you think. With the internet at your fingertips, you can easily share lupus facts and give others an idea of what your life is like with an autoimmune condition.

As a lupus warrior, you are likely very well educated about your illness, and your experience with lupus is invaluable. By sharing information about lupus and glimpses into my flare days, I have received countless messages on my Instagram account where someone will tell me how much it helps to know we struggle with the same issues.

Empowering others by advocating for lupus may very well save lives. Lupus can be devastating, and the life expectancy rates improve significantly with earlier treatment. Many of the people who are at risk for developing lupus may not know anything about it.

It can be hard for people to understand why their body would attack itself – it is certainly a confusing concept, especially since we don't fully understand why lupus does this. Recently diagnosed people greatly benefit by hearing from others with lupus. You can help validate their health concerns, inform them of essential lupus facts they may not know yet, and ultimately enable them to seek the treatment they need.

5. There Are Many New Treatments on the Horizon

It wasn't until 1948 that a diagnostic test was discovered for lupus, enabling better diagnosis and treatment. Shortly afterward, doctors began using Plaquenil (hydroxychloroquine), prednisone, and aspirin to treat lupus, but it wasn't until 2011 (a staggering 63 years later) that the drug targeted to treat lupus was approved.

Benlysta (belimumab) has been phenomenal for many people with lupus, but it doesn't work for everyone, and many are frustrated that there's only one medication created for lupus while other rheumatic diseases have a lot more options.

Hopefully, we won't have to be frustrated for much longer. According to Amy Yalden, the CEO of the Florida chapter of the Lupus Foundation of America, there are currently 71 companies working on targeted drugs for lupus, compared to 12-15 years ago when there were only two companies doing that kind of research. Many of these drugs are nearing the end of their clinical trials, are showing high efficacy rates, and could be available within the next year.

Amy also emphasized that a huge part of this initiative is in response to patient advocacy. For the past decade, lupus patients have been speaking out and saying that available treatments are not sufficient. It's encouraging to

know that lupus advocacy has been a driving force behind new treatments and that all of us can help by spreading awareness about lupus.