

Lupus Update with Dr. Robert Katz

Why is increasing lupus awareness so important?

It's Lupus Awareness Month – the perfect time to talk about the importance of lupus awareness!

Spreading the word about lupus is important because many people don't know what it is. This lack of awareness is not good for people who develop lupus – they often feel somewhat isolated and uncertain about when to mention their lupus diagnosis with employers, colleagues and friends. A lack of public awareness also impacts funding for programs and services as well as research.

The internet is a great tool to help raise awareness and educate the public about lupus but it also presents challenges. How do you find the best factual information on lupus on the internet? I did a study several years ago in which I assessed the best websites for reading about lupus. There certainly are a lot of websites, and if you Google the word “lupus” 50,100,000 results come up.

So it is important to read information, which is accurate and in which there is not a “catch.” Sometimes the catch could be the promotion of an unapproved, usually over the counter medication or a new hypothetical treatment or diet yet unproven. Most of these are simply a waste of time. On occasion they could be hazardous, particularly if your lupus is active and potentially organ damaging. I have certainly seen a number of lupus patients develop more serious problems when they neglected their lupus – not deliberately – because they simply tried to forget about it as much as possible. That is usually not a good idea.

The (www.lupus.org) and the Illinois Chapter website. LFAI website tailors information to Illinois.

Good websites include:

1. Lupus Society of Illinois website (www.lupusil.org)
2. Mayo Clinic.
3. Johns Hopkins.

4. WebMD.
5. The National Institutes of Health.
6. American College of Rheumatology

There are many good websites concerning lupus, but the ones mentioned above come to mind as the most consistent and reliable.

The LFAI tries to keep you updated with new information, current studies (some of which you can enroll in), provide education and generally assist with any lupus related concern. The foundation does its best to spread the word. Please forward any suggestions to info@lupusil.org.

When I first went into the field of rheumatology, many regarded lupus as a frequently fatal disease. That has gradually changed over the years as better treatments and earlier diagnosis have helped to improve prognosis. Now we have lots of technology to help us with diagnosis and lots of potent therapies – although we need more treatments and better targeted treatments.

Lupus remains a complicated disease because it can involve many different parts of the body and many organ systems. It can be organ threatening. It can be severe. It can come and go with flares and remissions. It is not always the same for everyone, which makes it hard to pin down a diagnosis for a lot of people. But we have come to learn more about the immunology of lupus and how to treat it over the years. We have gotten pretty successful. So without trying to pat ourselves on the back, this is Lupus Awareness Month, and we want to share the facts about lupus.