Looking Up Lupus On-Line

Everyone with an illness thinks about doing informational research on-line about it. This can be extremely valuable, but can also be misleading.

Physicians know that some websites are very reliable for patients, but others have an agenda, a strong point of view, and are not really evidence- or science-based.

If you think of reputable institutions such as the Mayo Clinic, Johns Hopkins, Harvard, Cleveland Clinic, UCLA Medical Center, just to name a few, you can usually find reliable information on their websites. I often recommend mayoclinic.com for patients because I think it provides useful and accurate information, but I am sure that is true of many other hospital and university websites. WebMD is also good.

Some patients are looking for information that is just not really obtainable, such as a lupus diet or an exercise program or fitness information specifically for lupus patients. Other than what is common sense, there is not much scientific support for a particular diet or lifestyle for treating lupus. Obviously you would like your blood pressure, cholesterol and triglycerides, and blood sugar normal and your weight under control. That goes for everyone.

When some patients write a comment or a blog about how they overcame lupus using natural remedies, one can be somewhat skeptical whether that same approach will be helpful for someone else. I did a study of reliable websites in lupus and had myself and other professionals in my office evaluating the quality of these websites based on multiple factors. Readability, reliability, the amount of information, etc., were some of the factors. There were quite a few very well done websites, but that list is an old one so it is not applicable to the current moment.

The Lupus Society of Illinois website is a good one, and looking through it in depth can provide you the information that you need:

“Learn about lupus” click here

“Clinical Trials” click here
Another source of the latest information is by reading medical journals. Searching the latest literature, the names of the articles and the short abstract summary, through journals such as Lupus or other rheumatology journals such as Arthritis Care and Research, the Journal of Rheumatology, the Annals of Rheumatic Disease, and others can show you what researchers are investigating currently. The website clinicaltrials.gov permits you to see ongoing studies of new drugs for lupus; just search for lupus.

The Web is a very helpful tool, but you must be careful in navigating it.

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