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An Interview With

Dr. Robert Levin

CAREGIVERS AND LUPUS

AN INTERVIEW WITH

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Robert W Levin, MD, is in private practice in rheumatology in Clearwater, FL. He is involved in clinical research in the areas of SLE, novel biologics for treatment of osteoarthritis and novel treatments for rheumatoid arthritis, chronic pain, gout and osteoporosis.

Dr. Levin has consulted and speaks for several pharmaceutical companies on topics of RA, osteoporosis, gout and osteoarthritis. He is an Assistant Affiliate Professor of Medicine at the University of South Florida. He serves as the President of the Florida Society of Rheumatology and the President of the Alliance for Transparent and Affordable Prescriptions.

Gary Barg: Dr. Levin, could you define lupus, SLE and tell me what the symptoms are?

Dr. Levin: Lupus is an autoimmune disease and what that means is that the immune system goes awry. So instead of protecting you, it starts to recognize your own tissues as foreign. Patients with lupus typically complain of fatigue, especially if they have systemic lupus. The most common physical manifestations are skin rashes and arthritis, but there are many other areas of the body that can be affected by lupus.

Gary Barg: How is it diagnosed?

Dr. Levin: A diagnosis of lupus is based on a constellation of symptoms, physical exam and laboratory findings. The symptoms that make up the diagnoses include certain types of skin rashes. Another criteria that we use is abnormal sensitivity to the sun. Arthritis caused by lupus usually is in the small joints of the hands, feet and wrists, but it can be in multiple joints, which can be tender to the touch. The lab studies include what's called an ANA, (Antinuclear Antibody) test. With an ANA you're detecting antibodies that are circulating against proteins that are in the nucleus of cells. Just about every patient

with systemic lupus has positive ANA tests. Generally patients can be any age, but the disease affects females much more than males, on the order of nine to ten to one. Patients can be any age, but the biggest group of patients is in their twenties to fifties.

Gary Barg: Do you recommend any lifestyle changes people can adapt to help ease their symptoms?

Dr. Levin: While I don't think you can adequately treat lupus with just lifestyle changes, there are certain things that are important. First, a very common symptom of this disease is fatigue. Driving yourself through fatigue is not a healthy thing to do. Also, ultraviolet light can activate the disease, so wearing good sunscreen, avoiding sunbathing and wearing a hat and sunglasses can be helpful in controlling these symptoms.

Gary Barg: What would you say some of the typical treatment regimens are for the condition?

Dr. Levin: One of the most common medications that's used for a lot of patients diagnosed with lupus is a corticosteroid called prednisone. Steroids are highly effective medicines to treat inflammation, although there are a lot of side effects that can occur. The longer that you're

on this medicine and the higher the dose that you take, the more likely problems are to occur. The drug can cause the elevation of blood pressure or blood sugar, salt and water retention, bruising or even osteoporosis. Not to mention an increased susceptibility to infection.

In addition to prednisone, there are a number of other drugs that are commonly used to treat patients with lupus. One of the classes used are antimalarial drugs, such as hydroxychloroquine, Plaquenil, or Quinacrine. Another class of medicines is what we call immunosuppressant drugs. These include, azathioprine or Imuran, mycophenolate, mofetil, or CellCept and methotrexate. These are drugs used to suppress disease activity as well, often when the antimalarial class isn't tolerated or isn't completely effective.

And there are drugs used only in patients with very severe kidney involvement or neurological involvement with lupus. These drugs include Cyclophosphamide, which is used for patients with more serious kidney disorders.

Every medication has downsides and we try to identify better medications all the time. Our drugs are not perfect and there are clinical trials right now to develop new medications for lupus. One of the clinical trials that I'm involved with is using a new product called a BTK inhibitor for specific individuals with confirmed lupus, who aren't adequately responding to standard treatments.

Gary Barg: Can you help us understand what a clinical trial is?

Dr. Levin: A clinical trial is a research project. It may be studying a drug in development, an FDA- approved drug to further our understanding, or to evaluate the drug for a different use. Once the patient meets the entry criteria through the screening process, they are assigned to a treatment. Most clinical trials involve different doses of the study medicine and they may include a placebo. The reason for this is that the goal of the study is to prove that the drug or treatment is effective. To do that, you

must have a group of randomly assigned people in the study who are not getting active treatment, and that's called a placebo.

All these studies are very carefully monitored by an investigator like me. I make sure that the patients are safe and that the study protocol is being followed where the patients are being evaluated and treated in the proper way.

If you're interested in looking into a lupus trial, there's a website that you should look at, it's called lupusstudy.com and that will put you in contact with the folks who can find an investigator in your area. Or you can call 877-888-9764.

Gary Barg: What role do you see we, as family caregivers, should play for people living with lupus?

Dr. Levin: People living with lupus need support and help from their family, who need to understand that the person actually has a medical illness. A lot of the lupus patients I see don't look sick necessarily, but they complain of fatigue and have real legitimate physical complaints. Understanding that, and being able to pick up some of those responsibilities that the lupus patient has, is extremely helpful.

Gary Barg: What is the most important piece of advice that you'd like to share with people who think they may have lupus?

Dr. Levin: If you have symptoms that are consistent with having lupus, it is important to get to a rheumatologist to guide therapy and make treatment decisions. Rheumatologists know how to diagnose the condition and really understand what the options are for those living with lupus. My second piece of advice is to listen to your body. If you're fatigued, make sure you get adequate rest. Also, being open in your dialogue with your physician is really important, so that we can tailor your therapy to make sure that it's the right stuff to control this disease.



Find an investigator in your area
LupusStudy.com or call 877-888-9764

LUPUS SUFFERERS ARE NOT ALONE



▶▶▶ *Lupus is an autoimmune disease that may cause painful and frustrating symptoms like swelling, chronic fatigue and pain.*



BTKi-SLE
clinical study

Currently, there is a clinical research study seeking people who have been diagnosed with SLE (a type of lupus) for 6 months or more, and are looking to modify their treatment plans or try a new approach to control their lupus diagnosis.

The investigational medication tested in the study works differently than other standard medicines used to treat lupus. People who participate in the BTKi-SLE Study can continue taking their current lupus medications in addition to the investigational medication. Participating in this study will help researchers better understand the effectiveness of the investigational medication in reducing the symptoms of lupus.

LEARN MORE ABOUT THE BTKi-SLE CLINICAL RESEARCH STUDY AT

LupusStudy.com