

lupus  **FACT SHEET**

Lupus Canada

Lupus research: What you can do and what the medical community is doing

Learning about systemic lupus erythematosus (SLE or lupus) can help you become aware of specific symptoms and the steps you can take to improve your health. Information can be found in books, on reliable websites and through support groups.

By far, the most immediate resource is the Internet. In fact, the Internet has changed how people learn about lupus. Type the word “lupus” in the Google search engine, for example, and it reveals millions of hits in a fraction of a second. With so many hits, you have to wonder about the reliability of the information. How do you know which sites to trust?

Anyone can set up a website and publish anything they want about lupus, truth or bunk, so before you soar into cyberspace, you need to know how to evaluate the information you find. The Health on the Net Foundation (www.hon.ch) and the Internet Healthcare Coalition (www.ihealthcoalition.org) offer these suggestions for safe surfing:

- Click on websites created by major medical centres, national organizations, universities and government departments. They provide unbiased information based on major research studies.
- Steer clear of sites that rely on personal testimonials, push a single viewpoint or sell “miracle” cures. If something

sounds too good to be true, it probably is.

- Visit several sites and compare the information before forming your own conclusions.
- Check the dates. The date when the page was first published or last modified should be clearly displayed. Medical knowledge is always evolving, so look for the most recent information you can find.
- Look for documentation and attribution. Sites should list their information sources, and contributors should be identified along with their affiliations. Authors should stand by their material by providing their e-mail address and other contact information.
- Make sure that the advertisers and sponsors of the site are separate from the editorial content. If you’re not sure whether an advertiser has influenced the content, ask: Does the advertiser have anything to gain from supporting one viewpoint? If it’s your credit card number they have to gain, recognize that the content may be biased.
- Don’t let a comprehensive list of links fool you into thinking that several organizations back the site’s claims. A website can link to any site the creator wants. A link to Health Canada, for example, in no way implies endorsement from Health Canada.
- Recognize the limitations of an e-doctor. Online healthcare professionals cannot recommend a treatment without a physical exam and lab tests. However, they may offer insights that you can discuss with your physician at your next appointment.

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QUESTIONS TO ASK ABOUT A CLINICAL TRIAL

- What is the main purpose of this study?
- How will the study affect my daily life?
- Can I continue to take my usual prescription or over-the-counter medications?
- How many office visits are required and how long does each take?
- What kind of medication is involved and is there a chance I will get a placebo (a product with no active medicinal ingredients) instead?
- What type of procedures are involved (e.g., blood tests, x-rays)?
- What are the possible benefits?
- What are the possible risks and side effects?

Finding out about current research

Surfing the Internet is an excellent way to learn more about research in progress. Scientists are beginning to unravel some of the elements involved in lupus, including genetic, environmental and hormonal factors. During the past decade, there has been a tremendous amount of progress, and the number of studies on this disease has increased exponentially.

Many researchers are investigating the causes of lupus and are looking for a cure. At medical centres worldwide, including centres in Canada, research has led to improved tests and techniques for diagnosis and better methods for predicting flares. These allow doctors to start treatment sooner, which improves patient health.

As part of research, many centres collect and store patient information and statistics. This data can help both doctors and people with lupus make better-informed decisions about treatment of a wide range of symptoms. The Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS) unites Canadian lupus investigators across the country through collaborative research. CaNIOS has

several research projects underway, including:

• Genetic and Environmental Factors in Systemic Lupus Erythematosus (GenES Study)

The goal of this study is to identify genes, environmental factors and gene-environment interactions that influence the risk of SLE. Researchers are collecting a large set of patient cases and information from siblings and random controls. Once the data have been collected and the groundwork completed, future studies will be able to examine interactions between genes and environmental risk factors.

• Learning to Live Better with Lupus: The Health Improvement and Prevention Program (HIPP) in Systemic Lupus Erythematosus

The goal of this program is to improve health status, decrease cardiovascular risk and improve endothelial function in people with lupus. (The endothelium is the layer of flat cells lining the closed spaces of the body, such as the inside of blood vessels, the heart and body cavities.) Researchers are conducting a randomized controlled trial of HIPP versus usual care with a crossover of the usual-care group to the HIPP intervention at one year.

• The Role of Thrombophilic Factors in Persons with Systemic Lupus Erythematosus (ThromboFIL)

This research evaluates the risk of thrombosis (blood clot formation) in people with SLE at the time of diagnosis and yearly afterwards. Researchers first conduct a descriptive study of patients with a new diagnosis of SLE in the past five years to determine the proportion who have thrombosis at presentation as well as the rate of thrombotic events afterwards. Subsequently, they will perform a case-control study using the same patients.

• The 1,000 Canadian Faces of Lupus (1,000 Faces)

This research program creates a long-term, multi-ethnic Canadian database of more than 1,000 lupus patients that characterizes ethnic differences in clinical manifestations of lupus and disease outcome. It identifies socioeconomic, cultural and environmental factors influencing the course and outcome of lupus in different ethnic groups, and it will determine the prognostic value of anti-Smith (anti-Sm) antibody in these patients. Particular emphasis will be placed on Asian Canadians and First Nations Canadians, as these population groups are both growing rapidly, have genetic



GLOSSARY OF TERMS

endothelial function – endothelial cells line the interior surface of an artery and other closed spaces of the body

thrombosis – the formation or presence of a blood clot within a blood vessel

antibody – any of a large number of proteins produced as an immune response

nephritis – acute or chronic inflammation of the kidney

glomerulonephritis – nephritis marked by inflammation of the renal

glomeruli – small functional units in the kidney

links to lupus, are more frequently anti-Sm positive, and are generally thought to have more severe lupus.

• Lupus Nephritis New Emerging Team (LuNNET)

Glomerulonephritis, a type of kidney disease, is a common manifestation of SLE and a major cause of morbidity and mortality. To better understand why some patients develop kidney disease, this study creates a national collaborative platform that unites lupus researchers with expertise in kidney diseases and methodologists. This

network of experts is working toward the discovery and definition of the mechanisms that lead to the onset of lupus and cause kidney damage.

Enrolling in a clinical trial

You or someone you know with lupus may want to participate in a clinical trial. A clinical trial is a scientific study that tests the safety and effectiveness of a treatment in patients with specific medical conditions. Every clinical trial attempts to answer one or more specific research questions. To do this, each trial has eligibility requirements that determine who can participate, including parameters around age, sex, disease status, other medications being taken, etc.

You may decide to participate in a clinical trial for the personal satisfaction that comes from being part of scientific research. Participating in a clinical research trial is very much like a regular doctor's visit, but usually involves extra time commitment and/or extra testing (for example, providing more blood or urine samples than usual).

Before enrolling in any clinical trial, you will be provided with an informed consent document, which you should read carefully. The consent form explains the purpose of the trial, the possible risks and benefits of treatment, and all the procedures involved in the trial. Your witnessed signature is required. It is important that any questions or concerns you have about the research trial are addressed to your satisfaction before you sign the consent form.

Research trials have risks and benefits. It is possible that the treatment could improve your health or quality of life, but there may be side effects, which can vary from person to person. Be sure to read about them in the consent form.

Clinical trial participants also have responsibilities, which you must understand before beginning. You need to attend all your appointments, follow instructions carefully, and take medications exactly as prescribed. All of these are vital if the information from the trial is to be valid.

Deciding to participate in a clinical trial is your decision. Even after signing the consent form, you don't have to continue if you feel uncomfortable about it. You have the right to leave the study at any time.



FOR MORE INFORMATION

- Lupus Canada: www.lupuscanada.org. This site includes electronic versions of the *Living Well with Lupus* fact sheets.
- *Lupus: The Disease with a Thousand Faces*, edited by Dr. Sasha Bernatsky and Dr. Jean-Luc Senécal, Key Porter Books (2004) ISBN 1-55263-603-8. Contact Lupus Canada to order this book.
- Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus: www.CanIOS.ca
- Arthritis & Autoimmunity Research Centre Foundation: www.uhn.ca/foundations/aarc/site. One of the three foundations at University Health Network (UHN) in Toronto.
- www.ClinicalTrials.gov Although this site is American, search "lupus, Canada" for links to trials being conducted in this country.
- Alliance for Lupus Research: www.lupusresearch.org. A voluntary health organization based in New York City that funds lupus research.

Disclaimer

Systemic lupus erythematosus is an autoimmune disease that affects thousands of Canadians, mostly women in their childbearing years. Symptoms vary greatly from person to person and treatment is highly individualized. Patients are urged to contact their physician or healthcare professional with any questions or concerns they might have.

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