Great Books and Websites for People Living With Lupus

by ANNA SCANLON

The Best Lupus Resources

Living with lupus can seem incredibly isolating, especially if you don't know anyone else around you with the disease. However, there are tons of lupus resources and websites you can use to gain information on lupus and connect with others who are going through the same thing you are.

Websites

Lupus.org

Lupus.org is run by the Lupus Foundation of America and provides tons of great resources for both lupus patients and caregivers. The website has a wealth of information, including hundreds of questions lupus patients have asked and the website (and their on staff doctors) has answered.

This includes everything from questions about diet and lupus to having a robust sex life with the disease. It even answers questions such about what can be done to counteract the dreaded weight gain from prednisone.

Additionally, the website offers information for local chapters so you can meet others with lupus, participate in lupus walks and find clinical trials in order to help doctors with new medication.

Lupus.org is absolutely invaluable and one of the first websites I look to when finding information out about lupus. It is also a great place to refer family and friends when they are curious about various aspects of the disease and will always give a clear, concise, easy to understand scientifically based answer.

St. Thomas Lupus Trust

Although based in the UK, the St. Thomas Lupus Trust offers great information for people all over the world. The St. Thomas Trust gives a comprehensive list of lupus specialists in not only the UK, but also in mainland Europe and the USA, making it a little bit easier to select a doctor to help with your diagnosis.

In addition, they do tons of fundraising events (including skydiving!) that allow lupus patients and friends and family of lupus patients to get involved and raise money for the cause.

Medical professionals can also log onto the site and get up to date on the latest information pertaining to lupus. Patients can scroll through profiles of other patients and read their stories, helping them feel a little less alone (my story is on there!).

And lastly, if you want to purchase a knick-knack to benefit lupus research, St. Thomas is the place to stop. They have loads of adorable gifts, including special edition and exclusive Beatles paraphernalia — Julian Lennon, John Lennon's eldest son, is their patron.

His childhood friend, Lucy Vodden, was the inspiration for the song “Lucy in the Sky with Diamonds.” Lucy would later die from complications of lupus SLE, which inspired him to support the charity.

Books

Looking for a book on lupus can be particularly daunting, as many of them claim cures by doing different things such as eating certain foods or abstaining from certain foods. Although it is up to you to explore whether or not a certain diet will work for you (I definitely don’t advocate anything in particular), there are other books you can check out that do not claim to cure, but simply help you better understand your disease.

The First Year — Lupus: An Essential Guide for the Newly Diagnosed **by Nancy C. Hanger**

The best thing about this book is that a doctor or a professional who only has clinical experience with the disease did not write it. Instead, it was written by a lupus patient herself, with guidance on some portions from a doctor. It attempts to include everything you’ll need to know in your first year of navigating the illness.

In addition, Hanger discusses topics like lupus and pregnancy and overlapping disorders like Sjogren’s, chronic fatigue syndrome and everything else in between. Additionally, Hanger gives her top tips for finding the right doctor, explaining lupus to other people and coming to terms with the condition.

By the time the book had been published, Hanger had been battling lupus for over 10 years. In her “other life” Hanger has worked in the book publishing industry, making her writing all the more readable for patients.

Instead of being cold and clinical, the book is actually pretty engaging and makes it really easy for people to understand. Although the book is pushing 12 years old at this point, it is still a valuable piece to invest in, especially if your diagnosis has been relatively recent. All of these years later, the book is still a best seller, meaning that there is definitely something in it that keeps people coming back.

The Lupus Encyclopedia: A Comprehensive Guide for Patients and Families **by Donald E. Thomas Jr.**

If you’re looking for something a little more up-to-date, *The Lupus Encyclopedia* recently made its debut in 2014. Although written by a doctor and not a lupus patient, Dr. Thomas has scads of credentials that make him the perfect candidate to write this book.

With a selection of tables and diagrams, the book not only outlines what lupus is and how it is treated, but also seeks to give patients advice on how to maximize their lives with lupus. Like Hanger’s book, *The Lupus Encyclopedia* also gives tips on working with lupus, navigating disability in the United States and giving women who intend to get pregnant advice on doing so safely.

Although the word “encyclopedia” can be daunting, it is still pretty readable and a great resource to those looking for answers to their questions. Plus, it is a bit more updated than Hanger’s book, making it a better pick for those who want only the cutting edge research on their bookshelves.

Lupus Q&A Revised and Updated, Third Edition: Everything You Need to Know **by Dr. Robert G. Lahita and Dr. Robert H. Phillips**

If you prefer your Q&A in a book format, this is the perfect book for you. Again written by doctors instead of patients, this book has been a bestseller for several years.

Newly revised in December of 2014, it offers patients answers to an abundance of questions, including advice on new drugs and complementary and alternative treatments.

The interesting thing about this book is that it is written by both a rheumatologist and a psychiatrist, meaning that the book seeks to take aim at both your physical and mental wellbeing. This is definitely one to keep on your bookshelf to help answer some of your most burning lupus questions.