



Spring 2014 NEWSLETTER

The Foundation for Sarcoidosis Research (FSR) is the nation's leading nonprofit organization dedicated to finding a cure for sarcoidosis and improving care for patients with this disease.

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Join the Kick In to Stop Sarcoidosis 5k Run/Walk!



Let's all Kick In to Stop Sarcoidosis! Just in time for Sarcoidosis Awareness Month, the Foundation for Sarcoidosis Research is proud to announce

that we will host a 5k run/walk on April 26, 2014 in Chicago. The family-friendly run will bring awareness to sarcoidosis, and also raise funds for continued sarcoidosis research. Join us as we run (or walk) 5 kilometers (about 3 miles) along Chicago's beautiful lakeshore in Lincoln Park.

Not up for the course? Encourage your family and friends to participate in your honor, and cheer them on from the sidelines! Not able to make it to Lincoln Park with us? Sign up as a "virtual walker"! Participants around the country are encouraged to sign up and create their own teams to run with friends and family in their communities. Registration is only \$20, and includes a race-day tech T-shirt, refreshments after the race, and

the chance to meet and celebrate with other sarcoidosis patients. Log on to www.stopsarcoidosis.org for more information on how to register, create a team, and start fundraising for research today!



A MESSAGE FROM FSR'S EXECUTIVE DIRECTOR

Serving Patients - Igniting Research



GINGER SPITZER

Success feels good! Over the past year, FSR has more than doubled our resources for patients and has forged partnerships with multiple stakeholders to build drug development pathways. We know that engaging the patient is critical to the research-advancement mission.

One way to do this is to supply patients with tools to find answers and get involved. FSR proudly introduces P.R.E.P. – our Patient Resource and Education Program which provides these tools for patients. See the next page for details!

In addition, FSR has created the Physicians Outreach Program - P.O.P. (I guess we LOVE acronyms!) One of the biggest challenges for patients is when their primary physician doesn't have the most current research or answers to best aid the patient. This initiative provides frequent outreach to hundreds of physicians everywhere to share updates on sarcoidosis and treatment options.

FSR will continue to consistently connect with doctors to ensure up-to-date information is shared.

FSR also made progress in addressing a major gap in sarcoidosis research – the lack of information about the disease from patients. The FSR Patient Registry will collect information from thousands of patients to share with researchers for a better understanding of sarcoidosis. This will help create an epidemiology much needed for research.

And finally, FSR established many new and valuable partners! We have connected with companies and physicians for drug repurposing projects, and will share the results soon! We also are continuing our work with companies, hospitals, and academic research institutes to identify clinical trials, educate and link patients, and explore projects that need funding.

We've had a busy year, but have much more to do. Thank you for your continued belief in and support of this important mission!

RESOURCES

Meet the Experts



FSR is proud to partner with the American Thoracic Society for their annual conference in May 2014! The conference, ATS 2014 San Diego, will offer the latest information on clinical, basic, and translational science in pulmonary, critical care, and sleep medicine. FSR will participate in the many seminars and workshops as well as present FSR Grants in partnership with ATS. In addition, FSR will host a Meet the Experts Panel facilitating patient-to-doctor discussions with some of the best researchers and physicians in sarcoidosis. PATIENTS ARE ENCOURAGED TO ATTEND!! Please RSVP to info@stopsarcoidosis.org.

Potential experts who will be answering your questions include:

Robert Baughman, MD
University of Cincinnati

Daniel Culver, DO
Cleveland Clinic

Nabeel Hamzeh, MD, FCCP
National Jewish Health

Marc Judson, MD
Albany Medical College

Lisa Maier, MD
National Jewish Health

Karen Patterson, MD
Penn Medicine –University of Pennsylvania

P.R.E.P. Program

FSR's P.R.E.P. is inspired by the belief that engaging the patient is critical to the research-advancement mission. The program includes:

- Patient Advocacy and Education Materials provide disease-specific information about sarcoidosis, providing knowledge to patients and increasing awareness and support.
- Physicians Directory connects patients to physicians all over the globe (searchable).
- Patient Network Center connects patients to patients for networking and knowledge-sharing.
- Support Group Directory identifies formal support groups across the globe (searchable).
- Clinical Trial Interest Indicator enables patients to indicate clinical trial interest and maps where potential patients are located for researchers.
- Clinical Trial Connector lists open trials recruiting for patient engagement.
- Treatment Protocol presents treatment guidelines developed by physicians in a mobile app and PDF file.
- Patient Registry gathers and provides data to help researchers further understand the disease and develop treatments on a web-based platform.
- Patient Conferences and Workshops engage the patient at events developed through collaborations with medical providers, educational institutes, industry, patient groups, etc.

EVENTS



Thursday, March 27th, 2014

7th Annual Public Health Care Conference & Expo
Bowie, Maryland
www.mcquireglobalrecruitment.com

Saturday, April 5th, 2014

Sarcoidosis Awareness Purple Tie
Dinner and Dance
Boynton Beach, FL
mvoce@bellsouth.net

Saturday, April 5th, 2014

Marilyn's Fight for Life Sarcoidosis Awareness
Balloon Release Event
New Castle, DE
<http://mommielynns.com/sarcoidosis>

Friday, April 11th, 2014

Sarcoidosis Meet and Greet
Rainbow City Community Center
www.Sarcoidosisoutreachsos.com

Saturday, April 12th, 2014

Candlelight Vigil and Walk-a-Thon
Quincy, FL
mvoce@bellsouth.net

Saturday, April 12th, 2013

Sarcoidosis Hope Walk 2014
Vivian Lee Maddox Sports Complex
www.Sarcoidosisoutreachsos.com

Saturday, April 12th, 2014

10th Annual Sarcoidosis Awareness Walk
5601 S. Braeswood Blvd. Houston, TX 77096
www.jsmf.org/events

Saturday, April 19th, 2014

Shanetta's Sarcoidosis Awareness Walk
Michigan City, IN
shanettajordan@yahoo.com

Saturday, April 26th, 2014

Kick in to Stop Sarcoidosis 5k Run/Walk
Chicago, IL
Info@stopsarcoidosis.org
www.stopsarcoidosis.org

Saturday, June 21st, 2014

3rd Annual Chad Hammond Memorial Golf Outing
Charles Town, West Virginia
Dan_Conn@comcast.net



2nd Annual Sarcoidosis Awareness Fundraiser

Saturday, July 26th, 2014

3rd Annual Deloris D. Mayo Walk
Virginia Beach, VA
www.delorisdmayowalk4sarcoidosis.org

Saturday, August 16th, 2014

4th Annual Philip L. Orkin Golf Classic
Sussex, Wisconsin
jon.orkin1212@gmail.com

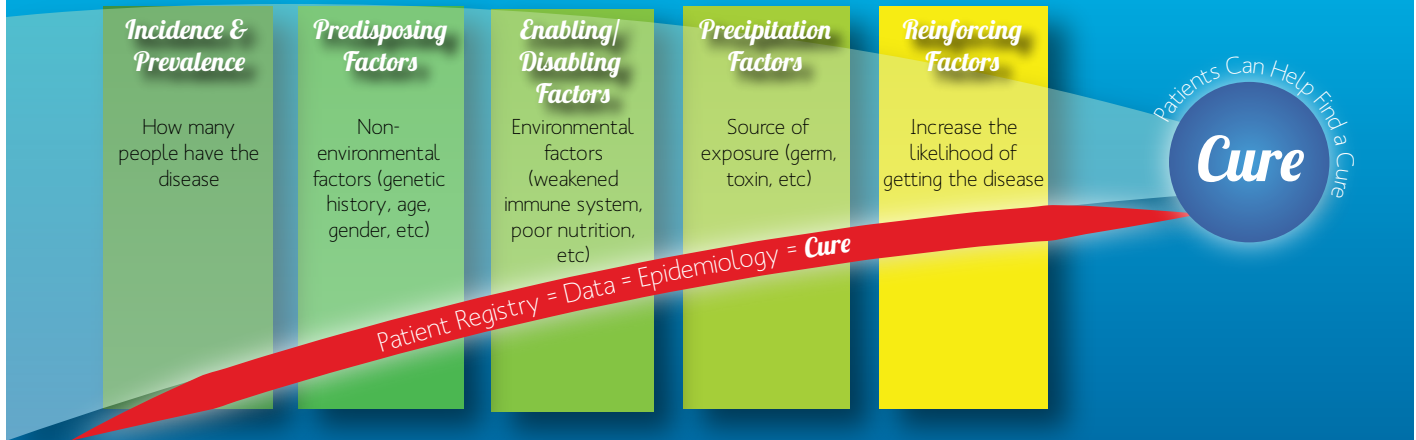
Saturday, August 23rd, 2014

Sarcoidosis 5k/ 1 mile fun run
Long Island, NJ
www.sarcoidosisofli.com

October 2014

3rd Annual Sarcoidosis Awareness Fundraiser
Manasquan, NJ
cathyscause@gmail.com

To find a cure, researchers need data about patients to build an epidemiology, which is the study of the patterns, causes, and effects of sarcoidosis. This will help increase awareness, support, and research initiatives. Participating in the FSR Patient Registry will provide answers to these questions:



Thank You to our Donors!

FSR's work is made possible through generous individuals, corporations, and private foundations who have made gifts or hosted fundraisers in support of our mission. **This list recognizes gifts of \$250 or more received from January 1, 2013 to December 31, 2013.**

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* Denotes a third party event



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Phone: (866) 358-KISS (5477)
www.stopsarcoidosis.org



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Become a monthly giver today!

Can you give \$10 a month for sarcoidosis research? How about \$20? Smaller gifts each month over the course of a year make a big impact! Our monthly giving program makes it easy to give consistently to FSR throughout the year. By using our sign-up form online, payments are automatically made on the same day each month in the denomination of your choice. These smaller gifts provide FSR with a reliable source of income, helping to fund high-impact research in an efficient way. Visit www.stopsarcoidosis.org to find the form under the Help Win the Fight tab, or call us at (312) 341-0500 to join!



Thank you for your interest in FSR! We're committed to providing information in our newsletter to help you stay connected with our work. If you have ideas on how we can do that better, please send an e-mail to: info@stopsarcoidosis.org.

Volunteer Spotlight: Wendy Pawelek



We certainly couldn't do everything we do without the help of our volunteers, including our rock star office volunteer Wendy Pawelek. Wendy was introduced to FSR when she and her partner Jonathon, who is a sarcoidosis patient, attended KISS Chicago 2013. Wendy wanted to be more involved with the organization because, "I wanted to learn everything I could about this disease and contribute in any way to finding a cure." Over the past year, Wendy has dedicated countless hours stuffing envelopes, completing data entry, securing items for our silent auction, and more. Wendy always comes in to the office in a cheerful mood and a friendly face, happy to help out wherever she is needed. Wendy and Jonathon are also part of our monthly giving program (see left). Thank you both for all that you do for FSR!

FEEDBACK