

Fall 2015

NEWSLETTER

FOUNDATION FOR SARCOIDOSIS RESEARCH



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.

BOARD

A MESSAGE FROM FSR'S EXECUTIVE DIRECTOR

Focusing on Patient Empowerment

"Empower: to promote the self-actualization or influence of"

In considering the Webster definition above, the term "empower" can be applied to how FSR promotes the ability of patients to influence their own lives. FSR believes strongly in empowering patients within their disease – but what does this actually mean? In battling a rare, complicated, and oft-misunderstood disease like sarcoidosis, patients are often left feeling victimized, not only by the disease, itself but also by the system around them that has no answers or help. Patients and their families need to be heard, included, and valued within considerations of treatment, care, and research. By providing specific information, networking, and forums for engagement, FSR enables patients to influence the course of their disease, both from a short term focus (treatment options, doctor selection, etc.) and a long term one (research).

Our Patient Resource & Education Program (PREP) is designed to provide the tools patients need to understand and manage their disease, as well as opportunities to get involved in accelerating research towards a cure.

For example, the FSR Physician Directory is an excellent tool for patients to identify and locate a sarcoidosis expert. Our online Inspire community connects patients together to share knowledge, experiences, and emotional support.



GINGER SPITZER

The FSR Sarcoidosis Patient Registry provides patients with an easy way to influence research by providing their data to a study that will help researchers understand sarcoidosis. FSR's Clinical Trial Connector allows patients to easily identify trials and studies both to help themselves and to help the course of the disease field. FSR also organizes multiple highly empowering forums that enable the patient voice to be included in discussions around desirable outcomes for treatment and the true burden of the disease.

Patients are tired of the status quo, of no answers, of limited options, of a public who doesn't understand this disease – they are tired of being victims. FSR is committed to making sure patients can influence their own health and their own lives, which is true empowerment.

Clinical Studies Network



Sarcoidosis remains relatively under-studied and under-funded, resulting in a lack of inter-institutional structure and support

needed to address basic questions. For example, there is little data regarding the magnitude of change after treatment with medical therapies, despite their use for several decades. In addition, there is no data assessing minimal important clinical differences for most of the metrics used to assess sarcoidosis, and there is a striking absence of

information about long-term morbidity of the disease.

FSR addresses these and other needs with the newly launched FSR Clinical Studies Network, an eight-member consortium that brings together an international partnership of world-renowned medical institutes and researchers for unprecedented collaboration in studies and trials toward the treatment of sarcoidosis. The FSR Clinical Studies Network addresses a range of important but unanswered questions in sarcoidosis, facilitates a move towards broader consensus about clinical endpoints, and enables the pharmaceutical industry entrance into the sarcoidosis space with less perceived risk.

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FSR- CSN Sites: Steering Committee

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Coline Van Moorsel, PhD	St. Antonius Hospital
Marjolein Drent, MD, PhD - CSN Steering Committee Chair	ILD Care Foundation (not a site)

RESEARCH

FasterCures

FSR was honored to be selected as part of The Research Acceleration and Innovation Network (TRAIN), a program of FasterCures. Through this elite network (including organizations such as the Cystic Fibrosis Foundation, Michael J. Fox Foundation, and the Leukemia & Lymphoma Society), innovation in one disease area is translated to another in order to achieve treatment breakthroughs for all.



TRAIN organizations are recognized for being collaborative, mission-driven, results-oriented, and strategic in the use of capital. FSR is thrilled to join the ranks of these stellar organizations who all hold the mission to rapidly move promising therapies from the laboratory bench to the patient's bedside. Like our new colleagues in TRAIN, FSR is dedicated to supporting translational research to ensure therapies reach the patient as quickly as possible. We are grateful for inclusion into this group of medical research innovators as we all help each other tackle challenges that cut across diseases.

ATS Grants

FSR is committed to funding emerging researchers, and we were pleased to present the 2015 Abstract Scholarship Awards at the American Thoracic Society Conference in May. Grants were given to four young investigators for their ongoing work in the field of sarcoidosis research, including Caroline Broos, M.Sc. and Lindsay Celada, Ph.D. (pictured below with FSR staff member Kimmia Forouzesh). FSR applauds these researchers on their commitment to sarcoidosis!



Patient Registry

The FSR Sarcoidosis Patient Registry, currently has close to 2,000 sarcoidosis patients registered. By registering, patients can be actively engaged in the movement to find therapies and a cure for the disease. Patients hold the key to unlocking solutions — your information, your history, your body holds the answers toward a cure! The registry is user-friendly and understandable. It takes only a small amount of time to complete, and will allow patients to continually update their information. All information is secured with full privacy ensured. Please join the fight against the disease by directly contributing to research! Go to www.stopsarcoidosis.org to register today!



Sarcoidosis: Seek Answers. Inspire Results.

Through collaboration with the CHEST Foundation, FSR proudly presents *Sarcoidosis: Seek Answers. Inspire Results.*, a campaign designed to raise awareness for sarcoidosis. Working together, we educate patients, doctors, government, the healthcare industry, and the general public about this disease throughout the year.

EVENTS

Hike for Lung Health

Join us on Sunday, September 20 for the 2015 Hike for Lung Health! Held in partnership with the Respiratory Health Association, this nationwide event promotes awareness and funding for all lung diseases, including sarcoidosis. Join us in Chicago for this family-friendly event, or sign up as a virtual walker and have a Hike in your town! The Hike consists of a 1 or 3 mile walk, or if you're not up for hiking, come and cheer us on from the sidelines. Create your own fundraising page and encourage your family and friends to donate on your behalf to help stop sarcoidosis! Join Team FSR today at www.hikeforlunghealth.org!



KISS 5K Run/Walk

The 2nd annual Kick In to Stop Sarcoidosis (KISS) 5k Run/Walk was cold, wet, and wonderful! The rain didn't stop us, with over 250 participants registered. The 5K celebrated Sarcoidosis Awareness Month with patients and supporters, increased public awareness for sarcoidosis, and raised funds for research. Save the date for April 30, 2016, and help us make the 3rd annual KISS 5K bigger and better than ever!



Clockwise, from top left: patients celebrating the 2014 Hike for Lung Health; winners of the KISS 5K Run/Walk; participants Faye, Alexis, and Carlo Postell at the 5K.

FSR Sarcoidosis Patient Conferences

CONFERENCES

FSR is pleased to produce a number of patient conferences held throughout the year. These conferences are open to patients, their families, care providers, and medical providers, and feature some of the top sarcoidosis specialists. FSR Patient Conferences provide a vital opportunity for patients to learn about sarcoidosis, current research, treatment options, and issues related to sarcoidosis.

The conferences present opportunities for patients to meet and speak to physicians and researchers who are studying the disease, and provide a forum for patients to get together as a community to network and share common experiences. Patients will also receive information about FSR resources to help educate and support them throughout their journey in living with sarcoidosis. Registration is required, and space is limited. Join us at a FSR Patient Conference near you! Sign up today!

Upcoming Patient Conferences

Denver Patient Conference

When: September 26, 2015

Where: University of Colorado
Anschutz Medical Campus
Aurora, CO

Time: 11 a.m. - 4 p.m.

Cost: \$10

St. Louis Patient Conference

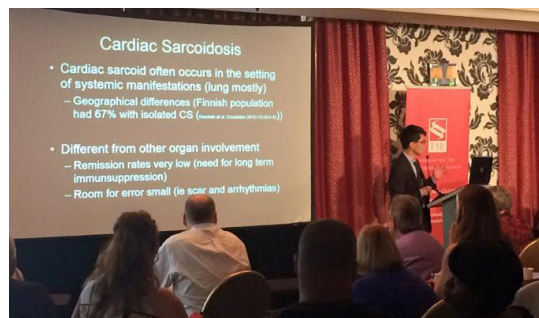
When: October 17, 2015

Where: Washington University
Medical Center
St. Louis, MO

Time: 10 a.m. - 3 p.m.

Cost: \$10

Register today at
www.stopsarcoidosis.org



Save the Date for FSR Patient Conferences 2016: February – New Orleans, LA; April – Chicago, IL; May – San Francisco, CA; August – Dallas, TX; October – TBD (All 2016 dates and locations are subject to change).

Top: Dr. Alan Cheng speaking at the Baltimore Patient Conference. Below: Patients Cathy Wick and Rodney Reese connecting at a FSR Patient Conference.

Patient Spotlight: Alan Berkelhamer, R. Ph.



At first, I didn't know I had sarcoidosis. In fact, I had never heard of it. All I knew was that I was having trouble when riding my bike with my buddies, which became trouble climbing a flight of stairs, and eventually became trouble walking to the kitchen to get a drink of water.

After diagnosis, I had a special kind of pacemaker implanted in my chest to prevent a certain type of heartbeat that could kill me, as my sarcoidosis interfered with my heart's ability to beat properly. A few months after surgery, I received a letter from my insurance company telling me that I did not need this type of pacemaker because there was no clinical proof that it was necessary; there were no studies that spelled out that sarcoidosis patients need this type of pacemaker.

The good news is that my heart beats are starting to be more normal. I found a doctor who has experience with sarcoidosis and treats me with a great deal of compassion. We have experimented with different drugs in different quantities, checking my blood for signs of improvement and taking special scans of my chest.

When my doctor wanted to try a stronger (and therefore more expensive) drug, my insurance company once again denied the treatment, stating that the drug was not used for sarcoidosis and there were no clinical studies. You see, in order to do clinical studies, you need a fair number of patients, and sarcoidosis is rare, especially sarcoidosis that is just in your heart.

After being newly diagnosed, the thoracic surgeon provided me with a journal article on cardiac sarcoidosis, and an online search for additional information led me to FSR. An upcoming event in Chicago (KISS) prompted me to volunteer and hopefully meet someone else who had sarcoidosis. At the FSR office I met Andrea Wilson, the Co-Founder and Chairwoman of FSR, who recognized that

FSR ADVOCATES

I was a patient. I shared my story and she, in turn, shared her story. Her courage and willingness to make a difference was inspiring. I did not have to be a victim – I decided that day to take action.

The Foundation for Sarcoidosis Research gives me, as a patient, a voice.

The Foundation for Sarcoidosis Research has a registry where patients can identify when they were diagnosed, where the granulomas are in their body, and which medications they take. Patients can also ask to be part of clinical studies.

The Foundation for Sarcoidosis Research provides funds for clinical studies so researchers can look for causes of this condition and determine how best to treat it. FSR also provides important tools and resources to help educate, empower, and engage patients like me.

Whether you are a patient like me, or you love or take care of a patient, or you are just interested in learning more about sarcoidosis, I thank you for your interest and support for the Foundation for Sarcoidosis Research.



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Taking an Active Role in Your Disease



Through the following programs, FSR educates and informs patients, physicians, and other stakeholders:

<p>Patient Registry</p> <p>Web-based patient registry including ongoing history, medical reports, diagnostics, and treatment information. This anonymous data helps researchers further understand the disease, treatment options, diagnostic capabilities, etc.</p>	<p>Support Group Directory</p> <p>A searchable directory of over 70 formal patient led sarcoidosis support groups around the world.</p>	<p>Clinical Trial Connector</p> <p>Lists open trials recruiting patients; provides links for applications for inclusion.</p>	<p>Patient Network Center</p> <p>Connects patients via the internet, phone, and in-person for networking and knowledge-sharing.</p>	<p>Clinical Trial Interest Indicator</p> <p>Enables patients to indicate clinical trial interest and maps where potential patients are located for researchers.</p>
<p>Treatment Protocol</p> <p>A mobile app as well as a printable, web-based tool presenting treatment guidelines developed by physicians.</p>	<p>Physician Directory</p> <p>A searchable tool to connect patients to sarcoidosis experts of varying specialties across the globe.</p>	<p>Patient Conferences & Workshops</p> <p>Launched through collaborations and connections with medical providers, educational institutions, industry, and patient groups. See inside for more details!</p>	<p>Treatment Options</p> <p>A comprehensive list of commonly used drugs to treat sarcoidosis. Please consult your physician for an individualized treatment plan.</p>	<p>Patient Advocacy & Education Materials</p> <p>Disease-specific information about sarcoidosis that provides knowledge to patients and increases awareness and support.</p>

Informed, engaged patients are critical to breakthroughs in disease research. We are focusing our efforts on educating patients about the fundamental value they bring to clinical research, and connecting patients to the many opportunities to be key participants in the sarcoidosis research field.

The FSR Patient Resource & Education Program (PREP) provides a specialized service to sarcoidosis patients.

All of these resources can be found on our website at www.stopsarcoidosis.org.

Thank you for your interest in FSR! We are committed to providing information in our newsletter to help you stay connected with our work. If you have ideas on how we can further accomplish this, please send an email to: info@stopsarcoidosis.org.

