

Fall 2014 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.

A MESSAGE FROM FSR'S EXECUTIVE DIRECTOR

A Strategic Approach to Advancing Research

FSR continues to fulfill the Scientific Research Agenda, which outlines the major gaps in the field of sarcoidosis research that need to be addressed in order to lead to new treatments.

This summer we launched the new FSR Sarcoidosis Patient Registry, which will be imperative to understanding the epidemiology of this disease. The current void of collected data has, up until now, been a massive barrier to research as no longitudinal data means an empty pipeline of researchers, studies, funding, and awareness. With the information gathered in the Registry, patients help change the course of research to accelerate answers!

We also are excited to be working with various partners on development of a Clinical Trial Network to further advance

the field. Once these elements can be provided to researchers and pharma, the advent of new therapies for patients is near.

In addition, we are continuing to build resources for patients across the country and the globe, recognizing that patients everywhere face the despair of dealing with a disease with no understanding or answers.

FSR could not be more proud nor more grateful to our incredible donors and partners, for it is this selfless giving that allows us all to work on this mission TOGETHER to change science and change people's lives.

Thank you!



GINGER SPITZER

Join the FSR Sarcoidosis Patient Registry!

We are thrilled to announce that the FSR Sarcoidosis Patient Registry is open for business! The FSR Sarcoidosis Patient Registry was established in collaboration with National Institutes of Health (NIH) to provide critical data for doctors and researchers. The registry fills an imperative need that will advance research.

The Registry is an online system for collecting information from hundreds of thousands of patients and providing this to researchers so they can identify patterns, similarities and differences, and ongoing health information. The system makes each patient anonymous, and aggregates the information into reports. Reports can then be provided to researchers, without any patient-identity information, to guide their efforts to find

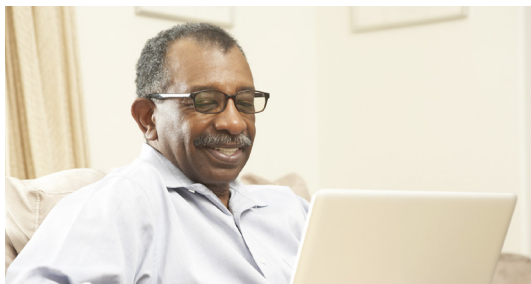


**SARCOIDOSIS
ADVANCED
REGISTRY for
CURES**

safer and more effective ways to treat the disease. This "big picture" provides a very comprehensive overview of what this disease looks like across the country and across the world. This knowledge will lead to targeted hypotheses which can then lead to answers.

The registry is in itself a global "clinical trial" that patients can do right from their living room, helping researchers find answers. To make sure that patient identity is fully protected, we have partnered with a HIPAA-compliant hosting facility to make sure patients' information is de-identified (anonymous) and completely secure.

The registry will lead to groundbreaking changes in the field of sarcoidosis, as patient information will help researchers understand this disease and find answers. To make the registry as effective as possible, we need patients to sign up. Without large quantities of patient data, we will not be able to see the full scope of this disease.



The FSR website has a series of how-to videos to walk patients through registering step-by-step and answer questions along the way. We hope patients will share this registry with other patients - we need thousands of patients to register to let researchers and drug companies see the HUGE need for help in sarcoidosis.

Now is the time for patients to join the fight against this disease by directly contributing to research! Registering is easy, and it's free. Please register today at www.stopsarcoidosis.org and help us find a cure!

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RESEARCH

FSR - Sarcoidosis Clinical Trial Network (FSR-CTN)

In 2015, the Foundation for Sarcoidosis Research will launch the world's only Sarcoidosis Clinical Trial Network (FSR-CTN), bringing together an international partnership of world-renowned medical institutes and researchers for unprecedented collaboration in drug trials toward the treatment of sarcoidosis. The FSR-CTN will serve as a collaboration of treatment and research centers that specialize in conducting clinical trials of research and pharmaceutical treatments for sarcoidosis.

By facilitating data-sharing and multi-center trials, the goals of the network will be to test the efficacies of treatment approaches, measure the impact of re-purposed drug treatments, and rapidly screen new promising compounds that emerge from biomedical research, significantly decreasing the time and amount of money needed to develop them. The initial phase of the CTN will be 2015-2017, and is to include 6-8 national and international partners who will apply for inclusion via a competitive application process. The initiative will then expand in the next years to include additional partners as FSR continues to bridge the gaps in the field of sarcoidosis by building collaborations and tools such as the FSR-CTN.



TEAM KISS

these throughout the year. For more information on how to host your own Team KISS fundraiser, visit www.stopsarcoidosis.org, or email us at info@stopsarcoidosis.org.

Team KISS fundraisers are a vital part of FSR's mission to fund sarcoidosis research and raise awareness about this disease. We encourage patients and their supporters to host fundraisers like

Cathy's Cause

Patient Cathy Wick will be hosting her 4th annual fundraising event for Team KISS on October 18 in Manasquan, NJ. The event includes dinner and



drinks, a silent auction, and live music from Don't Know Jack and the Pipes and Drums of the Jersey Shore Shillelagh. Cathy has raised over \$25,000 for sarcoidosis research in the past three years, and is hoping to raise another \$10,000 this October.

She was inspired to start fundraising because "I didn't know what else I could do. I remember thinking that the only way to get the answers I want is through research, so I needed to raise some money." Cathy has also found hosting the fundraiser to be therapeutic for her, helping to keep her busy and feel accomplished, since her battle with sarcoidosis keeps her out of work. "I cannot tell you how wonderful it feels the night of the fundraiser to see all of the people who came out to support me and help

me raise money for research. I am so grateful for the experiences."

Over the past three years hosting her fundraiser, Cathy has met many fellow sarcoidosis sufferers, "which makes me feel less and less alone. In fact, I have met so many people in the area, I have started up a local support group!" In addition to her fundraiser and support group, Cathy also spreads sarcoidosis awareness throughout the year, hosting events such as local beach clean-ups and putting together teams for other Team KISS events in her area.

When asked for tips for others hosting fundraisers, Cathy said, "You want to find something that people will want to come to, not just other people with sarcoidosis! You will also need to make sure you have some help. It's a lot of work!" Hats off to you, Cathy!



ATS Grants

FSR was pleased to present the 2014 Abstract Scholarship Awards to young investigators at the American Thoracic Society Conference in May. Grants were given to Francesco Bonella, MD, Caroline Broos, MSc (pictured below with FSR staff Katie Jensen Simms), and Lindsay Celada, PhD for their ongoing work in the field of sarcoidosis research. FSR commends these researchers on their dedication to sarcoidosis!



Patient Competes in Half-Ironman

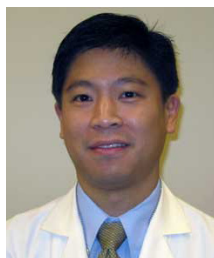
A big CONGRATULATIONS goes out to patient Tracey DuBree, who recently competed in the Eagleman Half-Ironman Triathlon to support FSR! Tracey raised over \$3,000 using the online giving platform ActiveGiving to ask for donations from her friends, family, and co-workers. Tracey did all this while training for a 1.2 mile swim, a 56 mile bike ride, and a 13.1 mile run – 70.3 miles altogether! "I certainly wasn't the fastest competitor, but I crossed the finish line and feel good knowing that I helped raise money for a cause that focuses on the research and support for those suffering with this disease." Thank you, Tracey!



From left: Cathy Wick and Amanda Cregan at the 3rd Annual Sarcoidosis Fundraiser; Cathy's Cause at a beach clean-up; Tracey DuBree preparing to race.

FSR Sarcoidosis Patient Conference 2014

CONFERENCE



Expected Presenters: Dr. Robert Baughman, Dr. Edward Chen, Dr. Wonder Drake, Dr. Alicia Gerke, Dr. Elyse Lower, Dr. Lisa Maier

FSR Sarcoidosis Patient Conference 2014

When: September 20, 2014

Where: The Ohio State University
Columbus, OH

Time: 12 p.m. - 4 p.m.

Cost: Complimentary

The FSR Sarcoidosis Patient Conference will be held on Saturday, September 20, 2014, at The Ohio State University in Columbus, Ohio. The conference is a FREE half-day event open to all sarcoidosis patients, their families, care providers, and medical providers.

Held in partnership with American Association of Sarcoidosis and Other Granulomatous Disorders (AASOG) National Conference 2014, the FSR Sarcoidosis Patient Conference provides a vital opportunity for patients to learn about sarcoidosis, current research, treatment options, and issues related to sarcoidosis. The Conference will present opportunities for patients to meet and speak to physicians and researchers who are studying the illness, and provide a forum for patients to get together as a community to meet and share common experiences. Patients will also receive information on FSR resources to help educate and support them in their journey in living with sarcoidosis. Registration is required, and space is limited!

Hike for Lung Health

Join us on Sunday, September 28th for the 2014 Hike for Lung Health! Held in partnership with the Respiratory Health Association, this nation-wide 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, but if you're not up for hiking, we'd love to have you 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 hikeforlunghealth.org!



EVENTS



K.I.S.S. 5K Run/Walk

The 1st annual Kick In to Stop Sarcoidosis 5K Run/Walk was a smashing success! The race celebrated Sarcoidosis Awareness Month with patients, increased public awareness for sarcoidosis, and raised funds for research. The 5K had over 250 participants, including in-person and "virtual runners" from around the world. We had a great time celebrating with patients and their families, and are excited to host the 2nd annual 5K next year! Mark your calendars for the last weekend in April, and join us in 2015!

Clockwise, from top left: 5K winners after the race, 5K volunteers from UIC Business School, the Jessie White Tumblers performing at the 2013 Hike, and Ulysses Kirby from the Chicago Southside Support Group enjoying the 2013 Hike.



FOUNDATION FOR
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Ways to Give

Monthly Giving

Setting up a monthly gift online is simple and convenient. Your monthly gift will provide FSR with regular and reliable income, ensuring that more of each donation goes directly to our programs and services.

Stocks/Securities

Many individuals choose to donate stocks and/or securities to FSR because of the unique tax benefits yielded from donating to a charitable organization. Contact FSR to learn more about stocks and securities.

Planned Giving

Ask your financial planner about advantages of charitable gift annuities, life insurance, retirement funds, charitable trusts, and others to support FSR during your lifetime and beyond.

Major Giving

Become an investor through one of FSR's giving societies which enables us to gather the capital needed for our Scientific Research Agenda. Contact FSR to learn more about major giving.

Tribute

A gift to FSR is a thoughtful way to express sympathy for the loss of a loved one or to commemorate special occasions or holidays. FSR will mail a notification of your gift to the person you designate.

Workplace Giving

Contribute to a local United Way campaign or another workplace charitable giving campaign through a payroll deduction, and direct a portion of your contribution to FSR.

Matching Gifts

Thousands of companies offer a matching gift program for employees, doubling (or tripling!) your donation to FSR. Contact your HR department to find out if your employer matches gifts.

Team KISS

Fundraise for FSR by hosting a Team KISS event, or by using peer-to-peer fundraising networks such as CrowdRise or FundRazr. See the Team KISS article inside for more information!

GIVING

FSR relies on the support of individuals who have been touched by sarcoidosis to fund our research grants.

All contributions to FSR are tax deductible to the amount extended by law. Give a gift by phone, mail, online, or through one of the many options listed on the left. Visit www.stopsarcoidosis.org or contact us at 312-341-0500 or info@stopsarcoidosis.org for more information on ways to give. Thank you for your dedication to the mission of stopping this devastating disease.

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 email to: info@stopsarcoidosis.org.

FEEDBACK