

Spring 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.

A MESSAGE FROM FSR'S EXECUTIVE DIRECTOR

FSR Celebrates 15 Years with Change

FSR celebrates its 15th year! On this 15th anniversary, FSR welcomes a new Board of Directors President, Mr. Anjan Chatterji, MBA, J.D., LL.M. Andrea Wilson will continue her active leadership as Co-Founder and Chairwoman of FSR. Mr. Chatterji is the EVP of Corporate Development for EnGeneIC, an emerging biopharmaceutical oncology and autoimmune platform therapeutics company, where he has helped run over three successful rare oncology-based clinical trials in the last 12 months. Previously, he ran successful law and consulting practices at Foley & Lardner LLP and Deloitte Financial Advisory Services, respectively. In

summary, Anjan is a financial engineer and lawyer with more than 10 years of biopharmaceutical business, including a very successful venture and angel investment syndicate focused on next generation drug discovery. He is truly dedicated to the advancement of medicine in diseases with unmet needs. Mr. Chatterji has served on the FSR Board of Directors for over three years. As a sarcoidosis patient, he knows first-hand the struggles of finding information and therapies, and has a passion for the FSR mission and the family of sarcoidosis patients. FSR is thrilled to welcome Mr. Chatterji.

A MESSAGE FROM FSR'S NEW PRESIDENT

A Movement Toward Venture Philanthropy



Anjan Chatterji

I often refer to myself as a "sarcoidosis patient" when prefacing my introduction as to why I have focused my life to helping (myself and) others in this rare disease field. However, I don't think that this term is true or fair - instead, I would like to be known as a "sarcoidosis activist". As someone who refuses to sit down and be told to die, I don't feel comfortable in the fold of complacency; I prefer to live on the thin line between revolution and sedition. I am and have always been a fighter. Even on the day of my diagnosis as my parents and loved ones cried, I didn't permit the thought that this wrinkle in my life, this sarcoidosis, would ever take a day away from me. And it hasn't thus far - it has made life different than I had ever expected, but I will take it down before it takes me.

I recently filled out the sarcoidosis registry that this wonderful foundation has put together. While I have summoned courage that has allowed me to succeed, be it dealing with sarcoidosis or investing in disease therapies, for once I was hesitant to move forward. The truth is - I was very apprehensive to relive the experiences of the past and present by memorializing them in the registry. It was very hard for me - one of the most difficult things I have done in my life. However, entering patient information into the registry holds such great importance. With the help of FSR and the brothers and sisters that I have gained in this activist battle, I was able to add my valuable experiences and history into the registry to help research move faster.

As a sarcoidosis activist, I share the experiences of many in our FSR family - I feel the same anger, frustration, impatience, and disbelief that after 150 years of being a known disease, so few therapies exist and so little is being done to find answers. However, as an activist with education in this field, I also recognize that a gap such as this is an opportunity to make a fundamental change that will benefit many. It is also an opportunity to find a proper solution, and as a neutral, patient-centric foundation, FSR

can make sure the needs of the patients will come first.

FSR will merge its advocacy roots with a venture philanthropy capital ("VPC") and an activist-investing philosophy. We will work with our donors to ultimately become co-financiers and developers with fledgling entities and scientists with promising therapeutic leads in this field. Like many investors and even pharmaceutical companies, the process of commercializing successful therapies and monetizing such investments comes from creating incentive for all stakeholders. This incentive will allow the ecosystem to embrace and nurture development of pipelines that hold true promise. With VPC, we will be able to truly accelerate and provide much needed scientific attention to this field. We will also introduce novel ways to further enhance donors' benefits - by providing an opportunity to share in our expected returns, a donation becomes more than just an act of compassion and holds more value than just a tax return enhancement.

FSR recognizes our unique position to use VPC to de-risk and accelerate the sarcoidosis research field. As an active philanthropic investor, we will take positions in public and/or private companies that hold interest in this field to help ensure follow-through and alignment of the socio-economics of our patient population and that of managed care in the U.S. and globally.

While not everyone sees this approach as a priority, I know that as an activist and President, I share the feelings of thousands of other sarcoidosis activists around the world. And that is this: I don't have time to wait for the current system to bring me answers. My family and my business need me now, so I am working to extend the "now" by committing my capabilities toward a solution. I am inspired by the FSR family and the triumphant work and courage of Andrea and Reading Wilson, without whom I would not have this forum to share my vision. I pledge to work tirelessly to advance the science of sarcoidosis research and create an engine of discovery thereunder such that we can finally receive treatment. Join me as we begin this new journey and take matters into our own hands - not letting the disease control a single nano-moment of our special lives any longer.

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RESOURCES

Building A Network to Accelerate and De-risk Research



FSR received over 20 proposals in response to our Request for Proposals to select participants for the FSR Clinical Studies Network (FSR-CSN). After a final selection process which includes external reviewers, the CSN will determine its first study and will launch its initial phase.

This consortium brings together an international partnership of world-renowned medical institutes and researchers for unprecedented collaboration in studies and drug trials toward the treatment of sarcoidosis. The goals of the network will be to collaborate for studies, test the efficacies of treatment approaches, measure the impact of repurposed 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.

A Mission Informed by Global Experts

FSR maintains a strong Scientific Advisory Board (SAB), composed of world renowned leaders in the field. The SAB helps advance FSR towards its mission dedicated to finding a cure for this disease and to improving care for sarcoidosis patients. The SAB has expanded to include three new members to better represent our international focus. Joining the SAB in 2015 will be:

Ulrich Costabel, MD, FERS

University of Duisburg-Essen
Ruhrlandklinik
Essen, Germany

Seamas Donnelly, MD

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Dublin, Ireland

Marjolein Drent, MD, PhD

President of WASOG
Maastricht University Medical Center and
University Hospital
Maastricht, Netherlands

Dominique Valeyre, MD

Assistance Publique Hôpitaux de Paris
Avicenne University Hospital
Bobigny, France

Resourcing Patients with Information on Treatment Options

The FSR mission is dual-focused, with comprehensive education and outreach efforts to patients and physicians, as well as major investments and collaborations to move the needle forward in sarcoidosis research and treatment development.



As a patient-centered organization, we recognize the importance of up-to-date, accurate information and resources for patients. We are continually collaborating and communicating with the biopharma industry as well as health care providers to identify treatment options for patients. Information on therapies, including drug type, dosages, focus, efficacy, etc. are changing based on studies and practice, and FSR works to inform patients as well as physicians of all their options to treat sarcoidosis. Please continue to check our website at www.stopsarcoidosis.org for ongoing updates.

AWARENESS



April is Sarcoidosis Awareness Month!

In recognition of Sarcoidosis Awareness Month in April, the CHEST Foundation and the Foundation for Sarcoidosis Research have launched a national sarcoidosis awareness campaign entitled "*Sarcoidosis: Seek Answers. Inspire Results.*" The goal of the campaign is to educate patients, doctors, government organizations, the healthcare industry, and the general public

about sarcoidosis. The campaign, supported by in part by a grant from Mallinckrodt Pharmaceuticals Autoimmune and Rare Diseases, will address the current lack of knowledge and access of information around sarcoidosis. Patients are often misdiagnosed and may wait years for a correct diagnosis, and also struggle with knowledge of and access to current treatment options. In addition, it is critical that all stakeholders learn about the true burden of the disease so that more research and information can be produced to help patients counter their struggle.

Beginning this April, FSR and the CHEST Foundation will host patient conferences, events, and educational activities throughout the year to build awareness and power advocacy efforts.

Upcoming FSR Events

Webinar with Dr. Bob Baughman

Wednesday, April 1
www.stopsarcoidosis.org

KISS Fundraiser

Thursday, April 16
New York, NY

Patient Conference Chicago

Saturday, April 25
Chicago, IL

KISS 5K Run/Walk

Saturday, April 25
Chicago, IL (or virtually!)

Meet the Experts at ATS

Saturday, May 23
Denver, CO

FSR Patient Conference

September 2015 (TBD)
Denver, CO

Hike for Lung Health

Sunday, September 20
Chicago, IL



JOIN THE PATIENT REGISTRY SHARE YOUR VOICE

Register today at www.stopsarcoidosis.org

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, 2014 to December 31, 2014.**

\$25,000-\$100,000

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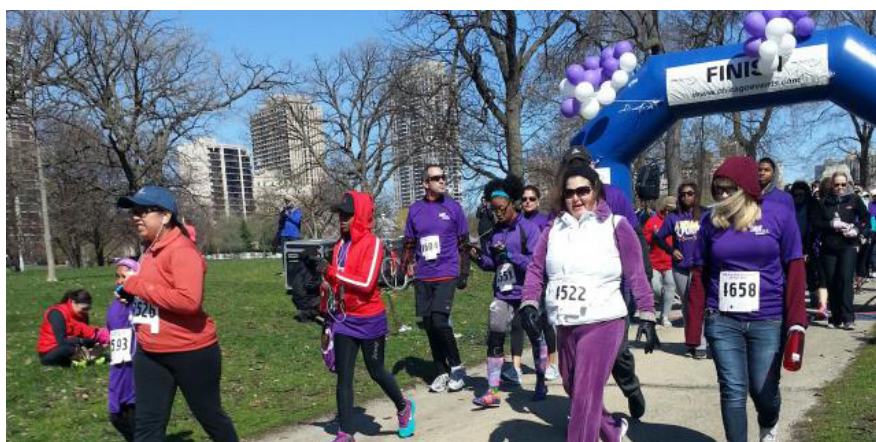
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Register now for the Kick In to Stop Sarcoidosis 5K Run/Walk!



**Kick In to Stop Sarcoidosis
5K Run/Walk
Saturday, April 25, 2015
10:00am
Lincoln Park, Chicago, IL
(or virtually around the world)**

Celebrate Sarcoidosis Awareness Month with FSR at the second annual Kick In to Stop Sarcoidosis 5K Run/Walk. Join us on Saturday, April 25 in Chicago, or join us in spirit as a virtual participant from around the world. Register today at www.stopsarcoidosis.org!

Registration is \$25, and includes a race-day tech T-shirt, refreshments after the race, and the chance to meet and celebrate with other sarcoidosis patients. Virtual participants are encouraged to hold runs in their communities and join us in spirit! Create your own fundraising page and help FSR raise funds for sarcoidosis research and raise sarcoidosis awareness. Check out more details at www.stopsarcoidosis.org

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.

FEEDBACK