

# Fall 2013 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

## A Strategic Approach to Advancing Research

We have all been there – facing a daunting task that threatens to overwhelm us. Regardless of the size of the project, the first step is to assess what you have and what you need to do to make the most progress. Once you have the right tools, the project can advance, but not until then.

While pushing for therapies and a cure for sarcoidosis is a huge undertaking, FSR approaches this goal in the same sequential way. We assessed what we have and don't have in the field. Our Scientific Advisory Board has identified the major gaps or missing tools that are critical to finding new treatments and a cure. These gaps are priorities on which FSR will focus – the FSR Research Agenda.

If FSR can facilitate the development of these essential elements, then researchers and doctors can reach the ultimate goal faster. Without the resources of an animal model, a patient registry, endpoints, a clinical trial network,

etc., research will remain stalled. These are essential “tools” currently missing in sarcoidosis research which FSR seeks to provide.

Sarcoidosis has been a known disease for about 125 years with still very little movement toward improved understanding and development of treatments. FSR is not willing to wait another 125 years, or even a few years, before patients receive answers. In these pages, you will find information about FSR's plans to ensure we reach our goal of changing and saving lives.

Helping to push that plan forward, we brought on two new staff members that will facilitate major connections and enhance our outreach: Senior Development Officer **Sarah Ayers**, and Philanthropic Communications Coordinator **Kimmia Forouzes**. We are excited to bring these very talented professionals on board!



GINGER SPITZER

## Patient Registry



One of the major needs to find treatments in sarcoidosis is a

longitudinal collection of patient information that can inform doctors and researchers about aspects of the disease. How many people have it? How does it manifest in various patients? What are its long term effects and mortality rate?

All that information can be discerned through a large anonymous patient registry, which FSR is launching in collaboration with the National Institutes of Health (NIH). However, it will be imperative that patients enter their information - the value of this highly needed tool is dependent on the involvement of patients! **This is an impactful way for patients to contribute to finding treatments and a cure!**

The Patient Registry does not cost the patient anything and offers incredibly valuable information to help researchers find answers. Announcements with the link to the registry will be coming soon!

## Conferences

FSR will attend CHEST 2013, a conference held by the American College of Chest Physicians, October 26 - 31 in Chicago. The conference is open to all physicians, nurses, and other health professionals with an interest in critical care or emergency medicine, and will feature hundreds of sessions focusing on relevant pulmonary topics. In addition to attending the sessions, FSR will exhibit our Physicians' Protocol, Research Agenda, and Patient Registry to those in attendance.

As part of the CHEST conference, FSR will attend the American Association of Sarcoidosis and Other Granulomatous Disorders (AASOG) meeting, “What is New in Sarcoidosis” on October 26.

Topics for discussion include genetics, epidemiology, diagnosis, and treatment. Many members of our SAB will present their latest findings, and our Executive Director Ginger Spitzer will give a short presentation on the Patient Registry (see left).



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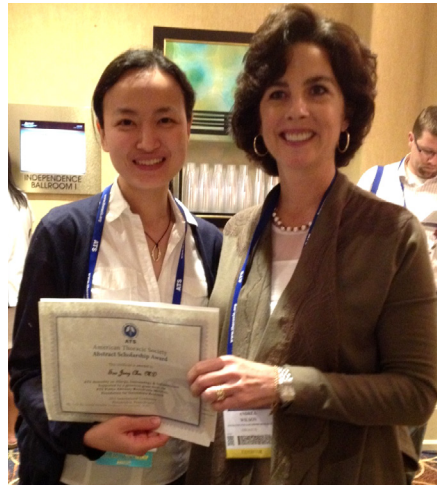
# RESOURCES

## SGAC Forum

FSR's first annual Support Group Advisory Council (SGAC) Forum will be held on October 25, 2013. FSR is bringing our valuable SGAC members from across the nation to Chicago to provide input for current and prospective initiatives in FSR's newly designed Patient Resource & Education Program (PREP). The members of this council serve as a link between FSR and our patients, and their input on these matters will be invaluable! This crucial meeting will enhance the role of the SGAC to help guide FSR patient initiatives. After the forum, our SGAC members will have the opportunity to meet the head of our Scientific Advisory Board, Dr. Dan Culver. We look forward to reporting on this event!

## Grants at ATS

FSR is proud to announce the recipients of the ATS 2013 Abstract Scholarship Awards! Dr. Soo Jung Cho (pictured below with Andrea Wilson), Dr. Caroline Broos, and Dr. Richard Su received grants from FSR at the American Thoracic Society Conference on May 20, 2013 to support their ongoing research in the field of sarcoidosis. FSR is excited to help fund new researchers to support the advancement of more research!



## New Patient Resources/ PREP

FSR is pleased to introduce our new Patient Resource & Education Program (PREP), which will provide specialized services and information for sarcoidosis patients. This dynamic online patient-centered program offers resources specifically for PATIENTS, and is the foremost provider of sarcoidosis information and support worldwide. This incredible opportunity to reach and serve the patient is inspired by our passionate belief in keeping the patient front and center, even while we focus our work on advancing research. We know that engaging the patient is critical to the research-advancement mission; the two elements are inseparable. The elements of PREP include: FSR Patient Registry, Physician Directory, Patient Network Center, Support Group Directory, educational material, and other valuable services. Many features included in the program currently exist on our website, with other elements still in development. We will soon launch this comprehensive program online at [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org)!

# TEAM KISS

We would like to thank everyone who has participated in our Team KISS events! These events are held all over the country, fundraise for FSR, and bring awareness to sarcoidosis. Below are just a few photos of the fun times had at Team KISS events this summer. Clockwise from top left: mothers and daughters enjoying ice cream after the Sarcoidosis 5k Fun Run in Long Island, two runners fist bumping for some friendly competition before the Sarcoidosis 5k Fun Run, Jessie White Tumbling Team at the Hike for Lung Health, a group of friends celebrating a birthday at the Hike for Lung Health, Sheila's Warriors stand together to walk at the Deloris D. Mayo Walk in Virginia Beach. Did you host a Team KISS event this year? Share your photos with us on Facebook! [www.facebook.com/StopSarcoidosis](http://www.facebook.com/StopSarcoidosis)



## FSR Announces New Research Agenda

*The following areas, set forth by our Scientific Advisory Board, are priorities for FSR, which we will support in order to fill the gaps in sarcoidosis research. When these voids are filled, more researchers will be drawn to the field, better therapies can be developed, scientists can develop new drugs, and more focus will be drawn to the disease.*

### Animal Model <sup>1</sup>



Transform the landscape of sarcoidosis research by financing the development of an animal model. This will propel preclinical drug development and reshape the future of sarcoidosis.

### GRDR <sup>2</sup> Patient Registry

Facilitate a large scale repository of patient information to increase sarcoidosis understanding and provide longitudinal data for research.

### End Points <sup>3</sup>



Establish endpoint measurements for use in clinical trials to determine the appropriate qualifiers for effective treatments.

### Clinical Trial Network <sup>4</sup>



Develop a database of patients interested in participation, promote the importance of patient involvement and connect researchers with patient locations.

### Patient Resource Education Program <sup>5</sup>



Increase sarcoidosis awareness and engagement through the Patient Resource Education Program. This multifaceted endeavor includes a physician directory, patient networking, treatment protocol, support group links, and education material.

## Team KISS: 26.2 miles ran, \$6,000 raised for FSR!



Meghan and Bridget Baxter

Sisters Meghan and Bridget Baxter ran their first marathon for an important cause – their brother, Brian. “As soon as we made the decision to commit to the marathon, we immediately knew this would be a great opportunity to raise awareness and funds for a foundation near and dear to our hearts – the Foundation for Sarcoidosis Research. In 2010, our brother Brian was diagnosed with cardiac sarcoidosis. Since Brian’s diagnosis, with the help of experts in sarcoidosis and family support, our brother is feeling strong, healthy and doing very well!” said Meghan.

As advocates of FSR, Meghan and Bridget ran 26.2 miles in the Chicago Marathon on October 13. Through this they raised over \$6,000, “to continue to bring to support to Brian and others battling the disease.” Both

## DONOR HIGHLIGHT

FSR and the Baxters have been overwhelmed by the support of their community – close to 100 of their family and friends have donated to their team!

The Baxters made supporting FSR a family affair – Brian’s wife Lesley aids the FSR office with administrative support and research.

Join us in wishing Meghan and Bridget congratulations on a well-run race and a well-run fundraiser!

This is just one example of the many different ways to fundraise for FSR. Events like the marathon help not only to raise funds for research, but to raise awareness as well. If you would like to start a Team KISS fundraiser, please contact us at [info@stop sarcoidosis.org](mailto:info@stop sarcoidosis.org)



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SARCOIDOSIS RESEARCH

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Participate in our silent auction! Visit [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org)!



**Memominee River Rafting**



**Stay in San Miguel, Mexico!**

**Silent Auction: November 3-10!**

The Foundation for Sarcoidosis Research will host an online-only silent auction from Sunday, November 3rd to Sunday, November 10th, just in time for holiday shopping!

The silent auction has traditionally been one of the biggest hits of our KISS events and this year we want to extend the opportunity to everybody! The auction will be visible to the public and is expected to reach over 10,000 participants. Current silent auction items up for bid include fabulous resort getaways, private catering parties, lunch with the founder of FSR, sports memorabilia, event tickets, and more!

All contributions are tax-deductible to the extent provided by law, and all proceeds benefit FSR directly. For more details about the auction, please visit our website:

**[www.stopsarcoidosis.org](http://www.stopsarcoidosis.org)**

Be sure to check out the auction starting November 3rd!

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](mailto:info@stopsarcoidosis.org).

