

Fall 2012 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



ANDREA WILSON

A MESSAGE FROM FSR'S PRESIDENT & CO-FOUNDER

Rebooted and Refocused

While many of us associate renewal, rejuvenation, and rebirth with the spring season, here at FSR we are celebrating autumn with these concepts fresh in our minds! As we enter our 13th year, FSR has re-launched with a new team of staff members and a new commitment to our mission to support research that will lead to finding a cure for this disease and to improving care for sarcoidosis patients.

Four new FSR staff members joined our team in the past few months. We welcome **Ginger Spitzer** as Executive Director, who is poised to provide leadership and initiative for mission focus. **Jeanne Douglass**, Director of Development, brings her extensive fundraising skills and creativity as we enhance our development efforts. Alongside Jeanne, **Katie Jensen** serves as our Development Associate, coordinating many projects as well as managing the administrative needs of the office. Our new Marketing and Communication intern, **Sara Nolan**, provides us with the gift of time and impressive communication skills while she attends Loyola University as a full-time student. The Board and I are thrilled to join

forces with this dynamic group as they bring forth new ideas, new energy, and a new passion to FSR.

As we "re-boot" our efforts, we are embracing our core purpose. Our 2012 redesigned K.I.S.S. Campaign "A Hug not a K.I.S.S." was hugely successful by broadening FSR's geographic reach and raising awareness about our efforts supporting sarcoidosis research.

We have many exciting initiatives and projects in the works which promote and enable innovative research in sarcoidosis by assisting the larger research community to build resources and momentum. One such project, supported by a service grant by the NIH's Office of Rare Disease Research (ORDR), is the FSR Sarcoidosis Advanced Registry (FSR-SARC Patient Registry). More details of this project and the results of other recent research grants are inside this issue!

We cannot do this without you – thank you. Our supporters and friends are invaluable as we re-invigorate our work. K.I.S.S. 2013, scheduled for Feb. 9, 2013, will be a blowout celebration of this and we look forward to seeing you there!

A MESSAGE FROM FSR'S EXECUTIVE DIRECTOR

Keeping the Mission Front and Center

I am honored and delighted to join the Foundation for Sarcoidosis Research as the new Executive Director! I am dedicated to ensuring that this organization continues towards its mission to find a cure for this disease and to improve care for sarcoidosis patients. I look forward to bringing my experiences in resource development, operational management, and fiscal responsibility to ensure we can deliver our objectives effectively and efficiently.

I am excited to bring my efforts to such a strong, dedicated team! As my husband begins to learn about the mysteries and frustrations of living with sarcoidosis, I am that much more determined to be a part of this passionate force to build and grow research opportunities. I have always believed in the power of a few to truly change the world, and here I have found an army of intensely passionate supporters from all spectrums, people who unquestionably believe in changing the world. And in this case, changing the world will literally change, and save, lives.

FSR strives to provide domestic and international funding with the direct intent of supporting research. To succeed in this, we must secure resources from events, sponsorships, grants, individuals, and other forums. In short, we have to get in order to give. We must raise revenue with the sole focus of funding cutting-edge researchers poised to advance knowledge about sarcoidosis and to ultimately find a cure.

Since its establishment in 2000, FSR has funded numerous research efforts and worked diligently to provide resources to thousands. I recognize that against this backdrop, I have much to learn and much to do. I am extremely driven to ensure FSR finds every opportunity to increase our revenues so that we may enhance our giving towards research.

I am thrilled to be a part of this wonderful effort and I promise to keep the mission of FSR front and center in every endeavor.



GINGER SPITZER

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RESEARCH

FSR SARC Patient Registry

FSR is highly committed to finding new ways we can help advance research. We are proud to announce that FSR is one of 12 rare disease organizations awarded a service grant to develop a patient registry. The FSR SARC Patient Registry is being developed through a pilot program funded by the Office of Rare Diseases Research (ORDR) and its partners to establish a Global Rare Diseases Patient Registry and Data Repository (GRDR).

Led by PI Dr. Leslie Serchuck, the FSR SARC Registry will contribute a subset of collected de-identified patient information into a central and common data repository to be available to (1) investigators expanding the knowledge base for rare diseases, (2) clinicians treating patients, (3) epidemiologists analyzing disease data, and (4) investigators seeking patients for new clinical trials. The objectives of the FSR SARC Patient Registry are to:

- Stimulate hypothesis driven clinical research and new drug development among academic and industry partners by making available a large longitudinal set of aggregated de-identified data on sarcoidosis patients interested in participating in clinical trials;
- Enhance the understanding of the variability, progression, and natural history of sarcoidosis with the ultimate goal of better

guiding and assessing therapeutic intervention;

- Provide the sarcoidosis medical community with recommendations for monitoring patients and to provide reports on patient outcomes to help optimize patient care;

- Connect interested patients to IRB (Institutional Review Board)-approved research opportunities.

FSR will provide ongoing updates as the project develops. General information about this ORDR project can be found at www.grdr.info.

Nicotine Treatment Improves TLR2 and TLR9 Responsiveness in Active Pulmonary Sarcoidosis

In 2008, Dr. Elliott Crouser, Director of the Sarcoidosis Specialty Clinic at the Ohio State University Medical Center, received a jointly sponsored FSR-ATS award for a novel approach to treating this disease.

Sarcoidosis is a systemic inflammatory disease, characterized by abnormal immune responses to molecules we are frequently exposed to in the environment. The identity of the disease-causing molecule(s) remains unknown, and current therapies are directed at suppressing the immune response to reduce the amount of inflammation in affected tissues.

Dr. Crouser's study sought to determine if chronic treatment with nicotine patches would normalize immune responses in patients with sarcoidosis. As expected, sarcoidosis patients with active disease had impaired immune responses, particularly to environmental molecules that promote inflammation through Toll Like Receptors (TLR) -2, -4 and -9. The more interesting finding was a normalization of TLR-2 and TLR-9 immune responses following

nicotine treatment. These results suggest that nicotine corrects the abnormal immune response in sarcoidosis patients. It remains to be determined if nicotine treatment (not smoking!) is an effective treatment for sarcoidosis.

The Effect of an Antioxidant, N-Acetyl-L-Cysteine, on Inflammatory and Oxidative Stress Markers in Pulmonary Sarcoidosis

In 2011, Dr. Nabeel Hamzeh, an Assistant Professor of Medicine at National Jewish Health, received a two-year FSR-ATS award for his research into the role of antioxidant therapy. Dr. Hamzeh's study investigates the association of oxidation (oxidative stress) with inflammation in the lungs of sarcoidosis patients to see if an anti-oxidant taken by mouth can reduce the amount of oxidative stress and inflammation in the lungs.

In the study, patients with lung sarcoidosis who are not on medications by mouth for their sarcoidosis will have a baseline bronchoscopy with a washing to extract the cells from the lungs to measure the level of oxidation and inflammation in their lungs. Then 15 patients will be randomly placed on an anti-oxidant regimen for 8 weeks and 5 will be randomly placed on a placebo. After 8 weeks, they will have another bronchoscopy with a washing to re-measure the changes in oxidation and inflammation in their lungs. Levels of oxidation and inflammation will also be measured in the blood. The anti-oxidant being used, called N-acetyl-cysteine, has been investigated in other lung diseases in addition to other non-lung diseases.

IN MEMORY



Robbie Lynn Darden
1957 - 2012

Robbie was someone that everyone loved and respected. She loved her friends, her family, and she always talked about her niece Kennedy. She never had a harsh word to say about anyone. Robbie wanted a cure for sarcoidosis more than anything and she worked tirelessly to bring awareness to the disease. She was on FSR's Board of Directors and the FSR Advisory Council. She was also President and Founder of the Central Indiana Sarcoidosis Support Group. Everything she did was done to perfection. It was done right or not at all.

Robbie knew that we had a lot of work to do to get awareness out so that one day a cure for sarcoidosis would be found, and she was willing to do the work. Even from her

sick bed she was still directing our steps and seeing that things were done and nothing left hanging. She truly believed...like the rest of us...that one day soon a cure would be found. She also believed:

“As long as you don't let a disease conquer your spirit, your sense of reason, your sense of humor, then it cannot destroy you.”

Robbie had an “aura” about her that no one could overlook. If you knew her you were drawn to her, no questions asked. Our “Angel” has gone home now and the torch has been passed. Those will be some big shoes to fill.

By Yvonne James, FSR Board Member



EVENTS

160 Donors, 70 Walkers, and \$10,000 Raised: FSR Team is Top Fundraiser!

EVERY STEP BRINGS US CLOSER TO A CURE

Big Thanks

A big thank you to the support of our ace volunteers **Rick Passaglia** and **Julie Romero**. Thank you also to **Lakeshore Sport & Fitness, Group Fitness Director Marcelo Ehrhardt**, for leading the warm-up activities, and thanks to **Chicago Cubs Charities** for donating awesome tickets to give away as incentive prizes!

We would like to take a moment to thank and celebrate the individual donors, team sponsors, walkers, and volunteers who made FSR Team Sarcoidosis the top fundraiser and largest team in the Chicago-based Hike for Lung Health this past September. It was a crisp and sunny fall day in Chicago's Lincoln Park that saw hundreds of people walking along the lakefront to raise awareness for lung health. While many FSR team members participated in the walk to honor a loved one with sarcoidosis, many others walked facing their own personal struggles with sarcoidosis.

What brought us all together from around the Midwest and beyond on September 23, 2012? The opportunity to join forces as a

community-in-spirit united in the fight to find a cure for sarcoidosis.

For **Jennifer Foronjy**, the team's top fundraiser who resides in Virginia, 2012 marked her 5th year walking in honor of her husband, Bill, who succumbed to sarcoidosis in 2007. **Amanda Nigro** did the walk in New Jersey in honor of her father Bob, who she lost five years ago. It was all in the family for **Bob Acerrano**, who brought his mother in from Michigan to join the team.

PICTURED ABOVE #1 Millie Lucero and Ginger Spitzer #2 Mary Jane Borg and Family #3 Andrea Wilson with Bob Acerrano and Family #4 Marcelo Ehrhardt leading the warm-up #5 Team Passaglia

Matching Gifts

Contact your company's Human Resources department to find out if your employer matches employee gifts to nonprofit organizations.

FundRazr

Fundraise without leaving your home! Go to FSR's Facebook page and click on FundRazr GIVE to create a personalized campaign.

Stocks/Securities

Donate stocks and/or securities to FSR in order to utilize the unique tax benefits yielded from donating to a charitable organization.

Host an Event

Consider hosting a golf outing, lemonade stand or cocktail party to raise awareness of this disease and funds for FSR.

Memorial/Honorary

Express sympathy for the loss of a loved one or honor a special person/occasion with a gift to FSR, and we will send an acknowledgement card.

Monthly Giving

Spread your gift to FSR over a period of time by designating an amount to be automatically deducted from your credit card each month.

Planned Giving

Whether your estate is large or small, you can support FSR during your lifetime and beyond. Ask your financial advisor about options.

United Way and Workplace Giving

If you contribute to a local United Way campaign or another workplace giving campaign through payroll deduction, you may be allowed to direct a portion of your contribution to FSR. To do so, indicate on your pledge form that you want to support either the "Donor Choice Program" or "Other 501c3 Organization."

GIVING

The Foundation for Sarcoidosis Research relies on the support of individuals who have been touched by sarcoidosis to fund our research grants.

Give a gift by phone, mail or online through our secure server. Donations are tax-deductible. For more information about the many ways to give to FSR, please call us at (866) 358-KISS (5477) or email us at info@stopsarcoidosis.org.

Thank you for your interest in FSR! We're committed to providing information in our newsletter to help you stay connected with the work of FSR. If you have ideas how on we can do that better, please send an email to: info@stopsarcoidosis.org or write down your notes and pop them in the enclosed envelope.

FEEDBACK



FOUNDATION FOR
SARCOIDOSIS RESEARCH

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SAVE THE DATE



k.i.s.s. chicago 2013

Join FSR supporters for an evening in Chicago of dining, dancing, and signature cocktails. Money raised from the benefit will fund research to find a cure for the disease.

SATURDAY, FEBRUARY 9, 2013

**River East Arts Center
435 East Illinois Street**

7:00 PM - 11:00 PM

CONTACT Jeanne Douglass, Director
of Development at (312) 341-0500
or jeanne@stopsarcoidosis.org

Don't miss this arabian night to remember...

LEFT TO RIGHT Kiss Host Committee Kick-Off Meeting: Jeff Johnson, Frantz Osse, McGhee Osse, Andrea Wilson, Reading Wilson, Ginger Spitzer, Greg Jagmin, Karrie McDermott, & Jeanne Douglass

**SPONSORS
TO DATE**

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Please direct all comments and questions concerning the Foundation for Sarcoidosis Research or this publication to info@stopsarcoidosis.org