



Spring 2011

The Foundation for Sarcoidosis Research is the nation's leading nonprofit organization dedicated to improving care for sarcoidosis patients and to finding a cure for this disease.

## PRESIDENT'S MESSAGE



Dear Friends:

The Foundation for Sarcoidosis Research has celebrated many successes and exciting developments since our inaugural newsletter in the fall. Our Hike for

Lung Health team was the largest and highest fundraising team for the fourth consecutive year. Our patient conference, held in Chicago in November, brought in the country's best researchers to educate patients from across North America. Finally, our signature K.I.S.S. Chicago event was a success with hundreds in attendance and more than \$100,000 raised.

On behalf of the Board of Directors, the staff and the volunteers of FSR, we applaud the National Heart, Lung and Blood Institute for their \$12 million investment in sarcoidosis research. (See page 3.) FSR feels strongly that rigorous scientific research will uncover new treatments and one day a cure.

I am honored to have heard from so many of you that you were touched by the "But You Don't Look Sick" video that we unveiled in February. I think it is critical for patients to share our personal experiences with others and to build a network of support. I am proud that FSR is able to provide an opportunity for thousands of patients nationwide to connect with each other and learn from each others' experiences.

I look forward to hearing about your successes in planning events and raising awareness during Sarcoidosis Awareness Month.

With hope for a cure,

Andrea Wilson  
President and Co-Founder

## FSR's annual K.I.S.S. Campaign reaches new levels of success



**K.I.S.S. Chicago 2011 kicked off the annual weeklong K.I.S.S. Campaign and featured the release of an awareness-raising video. The week ended with the exciting announcement of a major federal research investment.**

On Saturday, February 5th, the Foundation for Sarcoidosis Research (FSR) launched our annual education and awareness campaign, Kick In to Stop Sarcoidosis® (K.I.S.S.) at K.I.S.S. Chicago 2011. This event brought together hundreds of supporters to raise awareness and more than \$100,000 to Stop Sarcoidosis. Pictured above are (from left) Frantz Osse, Marv and Kim Dyson and FSR Board member, McGhee Osse.

Introducing the night's program, FSR President and Co-Founder Andrea Wilson expressed her gratitude to the hundreds of guests who braved the aftermath of a Chicago blizzard to attend. "That there are so many people here tonight is a testament to the success of the Foundation in raising support for this little known and hard to pronounce disease. When I was diagnosed

there was not a resource for answers. Today FSR is that resource," said Mrs. Wilson, alluding to the hundreds of requests for information received by the Foundation each month.

NBC-5 Sports Anchor and event emcee Peggy Kusinski shared, "This is a cause that means a great deal to all of us at NBC-5." In 2002, NBC's Chicago Affiliate WMAQ lost well-known sports anchor Darrian Chapman to undiagnosed sarcoidosis.

Guests at K.I.S.S. Chicago 2011 were the first to see a new video designed to raise awareness about the serious consequences of sarcoidosis. Darrian Chapman was featured in the video along with others who lost their battle with sarcoidosis including the late comedian, Bernie Mac.

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## K.I.S.S. Chicago 2011

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Those living with the disease, including Karen Duffy and former Boston Celtics great Bill Russell and his daughter, Karen, were featured with other patients who had submitted their photographs. “FSR frequently hears from patients who have been hurt by comments suggesting they don’t look sick. We hope this new video provides a clearer understanding of what it is like to struggle with this disease,” said FSR Executive Director Debbie Durrer. Since its release on YouTube February 7th, the video has been viewed more than 4,200 times. We encourage you to view the video online at [stopsarcoidosis.org/videos](http://stopsarcoidosis.org/videos).

On February 9, Dr. Dan Culver of the Cleveland Clinic, a former recipient of an FSR research award and a renowned sarcoidosis expert, presented a webinar entitled “What have we learned about sarcoidosis in the 21st century?” The webinar, which was offered in partnership with the American Thoracic Society Sarcoidosis Week, was attended by more than 170 individuals.

The 2011 K.I.S.S. Campaign concluded with the much anticipated announcement that the National Heart, Lung and Blood Institute of the National Institutes of Health plans to invest \$12 million in a three-year study of two serious conditions that affect the lungs: Alpha-1 Antitrypsin Deficiency and Sarcoidosis.

“After more than a decade of awareness, education and advocacy efforts, we are pleased that FSR’s investment in research is being furthered by federal funding. FSR remains committed to funding the research of early investigators and for encouraging them to stay in the field of sarcoidosis research,” said Ms. Durrer.

To conclude the successful K.I.S.S. Campaign with such an exciting announcement feeds our passion to educate others about sarcoidosis and to fund research. ■

## SUPPORTER HIGHLIGHT: Patients find unique ways to support Foundation



FSR frequently receives calls from patients and family members inquiring about how they can help. Three patients in particular have found ways to do just that using their strengths.

**Mary Godfrey** (above left), an artist, musician and mentor in Phoenix, Arizona, held the Breathe Festival Annual Lung Benefit on November 21, 2010. Proceeds were generously donated to FSR. The second annual festival, which raised more than \$2,000, featured 13 hours of musical performances, vendors and artisans and a silent auction. FSR is so appreciative of Mary’s dedication to using her talents to help others.

**Robbie Darden** (above center), member of the Support Group Advisory Council and FSR’s Board of Directors, asked others to support FSR during the annual K.I.S.S. Campaign. Robbie asked

her friends and family to help her “KISS sarcoidosis good-bye” by making a donation in her honor. She wrote a letter requesting support, created forms for them to fill out and even designed note cards to use for her thank you notes. The passion fueling her request was evident— and more than \$1,200 was donated in her name.

**Alice Minyard** (above right) of Rainbow City, Alabama, and her family hold an annual rummage sale to sell items donated by their family and other community members. The sale, which has raised nearly \$3,000 since its first year, has gotten so big that it is now held in a community center.

FSR is grateful to all of the creative patients and family members who support FSR each year by planning a fundraising event. Thank you! ■

## DONATE: Host an event to benefit FSR

Raise awareness in your community while supporting the Foundation for Sarcoidosis Research. Host a Benefit Event or join FSR’s Hike for Lung Health team as a “virtual” member.

If you would like to plan a walk, golf outing, community picnic or another event to support FSR, we have developed a tool kit that will guide you through the process.

If you want to raise awareness through an event but you are not ready to plan your own, consider participating “virtually” in the Hike for Lung Health. The Hike for Lung Health is a one- or three-mile walk that will take place in Chicago on Sunday, September 25. You can be a part of the Hike even if you aren’t able to travel to Chicago. Sign up to walk “virtually” in your own neighborhood or community – or even on a treadmill.

For more information about planning an event or participating as a “virtual” team member in the Hike for Lung Health, call Julie Catalano at (866) 358-KISS. ■

## MEDICAL NEWS: Find an expert

‘How can I find a doctor who treats sarcoidosis?’ is one of the most common questions we are asked. To address this need, FSR is starting an online directory of physicians who diagnose and treat sarcoidosis. This service will allow patients to find local medical professionals and rate their experiences. If you are, or you know a physician who should be listed, please forward contact information (name, address, phone number) to [info@stopsarcoidosis.org](mailto:info@stopsarcoidosis.org). Visit [stopsarcoidosis.org](http://stopsarcoidosis.org) to check it out. ■

## RESEARCH: FSR applauds \$12 million investment in research

Recently, FSR joined with the Alpha-1 Foundation in praising the National Heart, Lung and Blood Institute of the National Institutes of Health for a planned three-year study of two serious conditions that affect the lungs: Alpha-1 Antitrypsin Deficiency (Alpha-1) and Sarcoidosis.

In the last six years, FSR has awarded more than \$850,000 to support sarcoidosis research. However, as a private organization, our resources are more limited than

those of federal health agencies.

The announced \$12 million of funding will establish research centers to “conduct state-of-the-art genomic, microbiomics and phenotypic studies” of the two conditions. The study, called the Genomic Research in Alpha-1 Antitrypsin Deficiency and Sarcoidosis (GRADS) program, will assemble a multidisciplinary team of investigators.

Alpha-1 is a genetic condition that can cause lung and liver disease. It is the

most common known genetic cause of emphysema, which affects millions of Americans. Although sarcoidosis can affect any organ in the body, sarcoidosis most commonly targets the lungs and lymph nodes in people in the United States.

You can learn more about FSR-funded research projects and ways to become involved in clinical studies that are currently enrolling patients by visiting the Research Section of [stopsarcoidosis.org](http://stopsarcoidosis.org). ■

## AWARENESS: Volunteers plan activities for Sarcoidosis Awareness Month in April



FSR's Support Group Advisory Council (SGAC), a group of experienced leaders who advise the Foundation and provide resources to support groups, has planned three exciting awareness, advocacy and education activities for Sarcoidosis Awareness Month in April. Pictured above are SGAC members (from left) Patricia Coleman, Brenda Harris, Ruth Jacobs and Gwen Mitchell. We invite you to join us in celebrating!

### Raise awareness in your community!

Purple has long been associated with raising awareness of sarcoidosis, and the SGAC is encouraging everyone to wear the colors purple and white on Wednesday, April 13.

### Raise awareness among your elected officials!

Ask that April 2011 be declared Sarcoidosis Awareness Month by your city or state legislature. The goal is to have every state issue a proclamation calling for more awareness and research dollars earmarked for sarcoidosis research.

**Get educated about the latest in sarcoidosis research!** The Foundation will host the second in an ongoing webinar

series with sarcoidosis experts on April 13. The first webinar, co-hosted with the American Thoracic Society in February, featured Dr. Dan Culver from the Cleveland Clinic. The specific topic and speaker of the April webinar will be announced shortly.

To commemorate Sarcoidosis Awareness Month, groups around the country are planning garage sales, walk-a-thons, television and radio appearances, library displays and many other activities to educate their communities about sarcoidosis.

The FSR Sarcoidosis Support Group Advisory Council has developed a Sarcoidosis Awareness Month Tool Kit complete with suggestions for activities, guidance for asking for a proclamation, and graphics to advertise your activities. To download a copy of the Tool Kit and see some of the ways Sarcoidosis Awareness Month is being celebrated around the country, visit [stopsarcoidosis.org](http://stopsarcoidosis.org). Call Jan Lugibihl at (866) 358-KISS for more information. ■

## SUPPORT GROUPS:



### Meet Karen Reynolds

One year after starting the Greater North Alabama Sarcoidosis Support Group in Huntsville 25 people regularly attend the group's quarterly meetings led by Karen Reynolds.

Karen was diagnosed with sarcoidosis in 2008 and has a passion for connecting with other patients and their families. She is also an active contributor to FSR's on-line Stop Sarcoidosis Support Community. As a result of her leadership, she was recently chosen to join the FSR Support Group Advisory Council.

Robbie Darden, member of the FSR Board and Support Group Advisory Council says, “Karen gets the fact that there needs to be more education, awareness and research. She also gets the importance of raising money to make all these things happen. Plus, she's got a great sense of humor and is just plain fun!”

Karen has extensive contacts in her community, and she and her group are looking forward to holding events to raise funds for FSR's research efforts beginning with a Rummage Sale & Silent Auction held on April 9th.

Karen, FSR salutes you, and thanks you for your leadership and passion! ■



**Foundation for Sarcoidosis Research**  
122 S. Michigan Avenue  
Suite 1700  
Chicago, IL 60603  
stopsarcoidosis.org • (866) 358-KISS



April is Sarcoidosis Awareness month. Wear your Stop Sarcoidosis lapel pin to raise awareness of sarcoidosis. Two designs are available exclusively through FSR's webstore. Order yours today!

## FSR expands patient education efforts



As a result of two successful patient education programs, the 2010 Patient Conference in November and the webinar held during the recent K.I.S.S.

Campaign, FSR has committed to expanding our educational offerings. During 2011, we will host quarterly webinars and educational lecture events throughout the country. Furthermore, "Sarcoidosis and the Eyes," which will be published in the coming months, is an exciting new addition to FSR's library of comprehensive educational brochures.

FSR is dedicated to providing educational opportunities for patients and others affected by sarcoidosis. Visit our website at [stopsarcoidosis.org](http://stopsarcoidosis.org) to learn more or to order brochures! ■

## RESEARCH: Sarcoidosis tissue needed

Research into rare diseases like sarcoidosis is difficult without the generosity of patients who consent to donate tissue samples. FSR partners with the National Disease Research Interchange (NDRI) to supply tissue to researchers working on new and innovative treatments. Donations can come from surgical procedures, transplants or post mortem. There is no cost to you or your physician. The consent form takes only a few moments. Contact NDRI staff 24 hours a day at (800) 222-6374 to register today. ■

## UPCOMING EVENTS

### April 2011

#### Sarcoidosis Awareness Month

Visit our website for information about the month's activities, including an education webinar on April 13. Also, on April 13, don't forget to wear purple and white. See page 3.

### May 14, Denver, Colorado

#### American Thoracic Society Breathing Better Forum & Sarcoidosis Meet the Expert Session

The Breathing Better Forum provides an opportunity for patients and their families to learn about the latest pulmonary research and clinical care. Join FSR prior to the Forum for a morning session with leading sarcoidosis experts. The session and lunch are FREE.

### September 25, Chicago or "virtually"

#### Hike for Lung Health

FSR is pleased to partner with the Respiratory Health Association and other health organizations in raising awareness of and financial support for lung diseases. Join us.

For more information about upcoming events or to plan an event in your city, contact us at (866) 358-KISS or visit our website at [stopsarcoidosis.org](http://stopsarcoidosis.org).

Please direct all comments and questions concerning the Foundation for Sarcoidosis Research or this publication to [info@stopsarcoidosis.org](mailto:info@stopsarcoidosis.org)