



FOUNDATION FOR  
SARCOIDOSIS RESEARCH

# UPDATE

Fall 2010

*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:

FSR's anniversary year began with the welcome news that Dr. Ed Chen, a grant recipient at Johns Hopkins University, made a discovery that could soon lead to new treatments for

those of us living with sarcoidosis. I am energized by Dr. Chen's results and proud that FSR's grants program has now awarded \$850,000+ to support innovative research. I'm even more excited that this 'seed' investment has led to over \$1.2 million in subsequent grants. Support from FSR's many friends makes these achievements possible.

As President, I have been uniquely fortunate to meet many generous people. I want to gratefully acknowledge the Russell family for their years of support (see page 2). As Bill famously quipped in an FSR video, "some things shouldn't run in the family." We could not agree more and our focus remains on improving care for patients and advancing research to discover a cure.

This newsletter is intended to inform you about our research, education and support programs. Twice each year, you will receive updates from researchers, information on upcoming events, profiles of our volunteers and ways that you too can become more involved. Your opinion matters, so please contact us if there are people or stories that you think we should feature in future issues.

With hope for a cure,

Andrea Wilson  
President and Co-Founder

## FSR celebrates 10 years of progress and looks forward to continued success



**KISS Chicago 2010 was a celebration of an important milestone in FSR history. As the 10th anniversary year continues, FSR will expand programs to empower patients and advance research.**

Valentine's Day in 1994 marked the end of an eight year search to identify the cause of Andrea Wilson's dizziness, muscle weakness, extreme fatigue and other seemingly unrelated symptoms. After years of misdiagnosis, doctors confirmed she had sarcoidosis. In the eyes of many medical professionals, she did not fit the traditional sarcoidosis patient model. "For years I was told that everything from MS to a brain tumor and even stress were causing my symptoms," said Mrs. Wilson.

As her symptoms weakened her physically, they strengthened her resolve to help others who suffer. "At that time, the lack of awareness and understanding of this disease among the medical professionals and the public was very frustrating." In 2000, she established the Foundation for Sarcoidosis Research offering other

patients a reputable resource for up-to-date information and the promise of new hope through better research.

On February 6, 2010, hundreds joined her at KISS Chicago to celebrate FSR's 10th anniversary. "We look back on our first decade with pride and look forward with hope for what the next years will bring," she said. (Pictured above, KISS Chicago Chair Anne Heekin, FSR Executive Director Debbie Durrer, FSR President Andrea Wilson, FSR Board Member Dr. Louis Hondros)

Under the direction of Mrs. Wilson and FSR's volunteer Board of Directors and Advisors, the Foundation has made great strides in raising awareness of and research support for this devastating disease, including the establishment of six

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## Celebrating 10 years of progress

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new research partnerships. FSR remains the only private organization funding sarcoidosis specific research, and we continue to advocate for additional federal investments in sarcoidosis research.

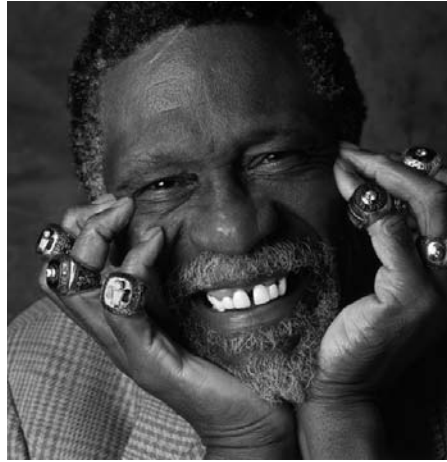
FSR strives to address the needs of people living with sarcoidosis. Patients often endure months and even years of doctor's visits before they are ultimately diagnosed. "Because we know how important early diagnosis is and because sarcoidosis can affect different individuals differently, FSR is dedicated to providing free comprehensive education for patients, family members and caregivers", said Mrs. Wilson. Since 2006, more than 25,000 copies of *Sarcoidosis and the Body*, *Sarcoidosis and the Heart* or *Sarcoidosis and the Nervous System* have been distributed to patients around the world. FSR plans to create additional materials in the future to further supplement these offerings.

FSR has also established several programs to provide people affected by sarcoidosis with the support they need to successfully cope with this disease. Nearly 7,000 members from all 50 states and 66 countries find daily information and support online through the Stop Sarcoidosis Support Community. Thousands more are helped through our in-person network of groups.

These programs and services are made possible through successful fundraising efforts like KISS Chicago. In the remaining months of our anniversary year, we hope you will make an effort to get involved. FSR will have teams at both the Hike for Lung Health and the Bank of America Chicago Marathon in October. Our patient conference will be held in Chicago this November. If you cannot attend these events, please consider working with us to plan something in your community.

With your continued support, in the years ahead, the promise of a cure may be within our reach! ■

## SUPPORTER HIGHLIGHT: Russell family helps Foundation



Legendary Boston Celtics basketball player Bill Russell and his daughter Karen, both living with sarcoidosis, have a long history of helping FSR raise national awareness of sarcoidosis. Beginning in 2005 when they recorded a Public Service Announcement and were featured in an interview about sarcoidosis on the Today Show, the Russells have consistently supported the Foundation's awareness activities. Karen has also been one of our most energetic walkers at the annual Hike for Lung Health along Chicago's lake front and has leant her voice and star-power as emcee to our KISS Chicago gala events.

Their dedication and commitment are apparent, and FSR is grateful for their support.

"While everyone knows my father as a great basketball champion, he truly is a champion for his daughter and all those who struggle with this disease," said Karen earlier this year as she worked with FSR to launch an online auction of one-of-a-kind sports memorabilia and unique VIP opportunities using the auction site CharityBuzz.com. The online auction which concluded in the spring raised more than \$8,000 for the Foundation for Sarcoidosis Research.

Packages ranged from VIP tickets to a taping of *The Daily Show: With Jon Stewart* in New York and a chance to meet Jon Stewart to Boston Celtics memorabilia signed by Bill Russell. The top selling item was two tickets to attend all of the exciting NBA All Star Weekend activities. Karen has already reached out to more celebrity friends like Dr. J for donations for future auctions.

Fundraising, whether it's an online auction, a garage sale or a bowl-a-thon, helps generate important funds to support FSR. If you would like to plan a fundraiser to benefit the Foundation for Sarcoidosis Research, call Julie Catalano at (866) 358-KISS. ■

## DONATE: Increase the impact of your gifts

You can stay active in the fight against sarcoidosis all year long with a monthly contribution of \$10, \$20, \$100 or more to the Foundation for Sarcoidosis Research. Recurring gifts provide FSR with solid, predictable income without the administrative expense of mailings or other outreach — allowing us to allocate more of every dollar to funding research and supporting sarcoidosis patients. You only have to sign up once!

With a monthly recurring gift, supporting an important cause is as easy as paying a household bill. And, you maintain complete control:

- You choose the frequency of your gift, down to the day of the month you would like your credit card charged.

- You will receive an annual statement summarizing your charitable gifts to FSR and your credit card (or bank) statements serve as an additional record of your contribution.
- You can cancel any time by simply calling or emailing the Foundation.

Most importantly, recurring giving allows you to express your support of the Foundation's mission more fully than might otherwise be possible. Monthly gifts of \$15, \$25, \$50 or \$100 are sustainable within many household budgets, but to FSR, those gifts add up quickly to have a significant impact in support of our mission!

To set up a recurring contribution, call Julie Catalano at (866) 358-KISS. ■

## RESEARCH: FSR awards new \$100,000 grant

There is still much to be discovered by researchers about sarcoidosis, and FSR believes strongly in collaborating with experts from around the world to advance the understanding of sarcoidosis. In 2005, FSR partnered with the American Thoracic Society, one of the largest medical societies focused on pulmonary medicine, to offer an annual \$100,000 grant to support sarcoidosis research.

Over the last five years more than \$850,000 has been awarded to support innovative research projects through this

partnership. We are very proud that these young investigators have gone on to receive an additional \$1.2 million to further their research.

FSR is pleased to announce our 2010 ATS-FSR Grant Recipient is Kyra Richter, PhD, MS from Vanderbilt University. Her innovative project "The Role of Differential Cytokine Production in Sarcoidosis Disease Pathogenesis" will evaluate specific immune cell function with the goal to determine why some patients face a more challenging prognosis. This

information might lead to a better understanding of what causes sarcoidosis and suggest new treatments.

You can learn more about FSR funded research projects and ways to become involved in clinical studies like the one Dr. Richter is planning by visiting the Research Section of the FSR Web site. ■

## EDUCATION: FSR to host patient conference in Chicago

FSR is hosting a day-long educational meeting for patients and their families on November 13, 2010 at the Hilton Rosemont, near Chicago's O'Hare airport.

The 2010 Patient Conference will provide patients and their families access to cutting-edge information about this disease through presentations from leading experts in the sarcoidosis field. Attendees will be joined for lunch by physicians with sarcoidosis expertise and by support group leaders. This was a very popular component of last year's conference, and as one 2009 Conference attendee said, "The additional one-on-one time with doctors [at lunch] is golden."

The conference agenda was developed by FSR's Sarcoidosis Support Group Advisory Council and Conference Director, Milton Rossman, MD, a renowned expert from the University of Pennsylvania and member of the FSR Board of Directors. Speakers will cover a range of topics from disease causes to current research and future treatments. Dr.

Ed Chen from Johns Hopkins University will also provide an update on his recent research discoveries.

The afternoon session will offer participants the opportunity to attend education sessions which address issues of interest to patients in smaller group settings.

The conference will open with an optional evening Networking Reception on Friday, November 12th to provide attendees with the chance to meet and socialize with each other and with support group leaders. This reception will be hosted by the Support Group Advisory Council, a group of volunteer support group leaders and sarcoidosis advocates from around the country.

The full agenda and registration information for the FSR Sarcoidosis Patient Conference including information about location and accommodations is available at [www.stopsarcoidosis.org/conference](http://www.stopsarcoidosis.org/conference) or by calling the Foundation for Sarcoidosis Research at (866) 358-KISS. ■

## CLINICAL TRIALS: Multi-Center Trial

Clinical trials are medical research studies in which people participate as volunteers and are one way of developing new treatments for diseases like sarcoidosis. Two investigational drugs are currently being tested to see if they may be useful in treating chronic sarcoidosis. This study will compare the effects (both good and bad) of the two investigational drugs to those of

placebo. The purpose of this study is to evaluate the safety and effectiveness of the two investigational drugs (administered as individual treatments) in patients with chronic sarcoidosis with lung and/or skin involvement who still have symptoms even though receiving current therapy. To learn more, visit the Clinical Trials Section of the FSR Website. ■

## SUPPORT GROUPS: Meet Shirley Holley



FSR Board Member Karen Duffy ('Duff') recently teamed with FSR to honor support group leader Shirley Holley on a television special produced by Fine Living Network (FLN) and Walt Disney World. As leader of the Denver Sarcoidosis Awareness Support Group, Shirley has made a difference in the lives of many people living with sarcoidosis, including her son Lenny. Duff surprised Shirley during one of her support group meetings with the announcement of a trip to Disney World to reward her efforts.

Shirley works tirelessly to raise awareness of sarcoidosis and through her service as a founding member of FSR's Support Group Advisory Council she has mentored several new support group leaders.

Following Shirley's example, other Denver support group members have been inspired to do more to help others. Member Kirk Mease's annual "Golf in the Darc for Sarc" glo-ball golf tournament has raised more than \$45,000 to benefit neurosarcoidosis programs at FSR and member Robin Mulroney has given talks to local medical students to raise professional awareness of sarcoidosis.

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





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**Kick In to Stop Sarcoidosis (K.I.S.S.)** by wearing the Sarcoidosis Awareness t-shirt. This 100% cotton embroidered white t-shirt is available exclusively through FSR's webstore. Order yours today!

## FSR celebrates the Year of the Lung

FSR has joined with the American Thoracic Society and other international groups to proclaim 2010 The Year of the Lung. This global effort unites health advocates to raise awareness and encourage increased funding for lung disease research. Lung disease and lung health concerns cost the United States billions of dollars in lost productivity and increased health care expenses each year— to say nothing of diminished lives. Yet public demand and political commitment remain inadequate.

“Although sarcoidosis is one of the most common causes of fibrotic lung disease in the U.S., the cause remains unknown, and there are virtually no safe, effective treatments. We hope that the year's effort will highlight the need for an expanded investment in research for all lung disease,” said FSR Executive Director Debbie Durrer. ■

## UPCOMING EVENTS

### October 3, Chicago

#### Hike for Lung Health

FSR is pleased to partner with the Respiratory Health Association of Metropolitan Chicago and other community health organizations in raising awareness of and financial support for lung diseases. Join us for this walk along Chicago's lakefront.

### October 10, 2010, Chicago

#### Bank of America Chicago Marathon

The 2010 Bank of America Chicago Marathon is sold out, but please contact us to receive information about next year's event. If you are already registered, consider joining Team Sarcoidosis.

### November 13, Rosemont (Chicago)

#### FSR Patient Conference

This one-day conference will feature updates on research and treatment, breakout sessions and lunch. See page 3 for more information.

### February 5, Chicago

#### KISS Chicago 2011

FSR supporters and friends celebrate FSR honorees and enjoy cocktails and dinner while bidding on fabulous auction prizes, playing wine roulette and enjoying the KISSino.

**For more information about upcoming events or to plan an event in your city, contact us at (866) 358-KISS.**

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