

Volume 1, Issue 2**Special points of interest:**

- **100 Voices**
- **Awareness**
- **Celebrations**

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Editor

Kirsten Searby, mother of a son with sarcoidosis, relays what she has learned from support group meetings, Karen M. White, emails, flyers, and others.

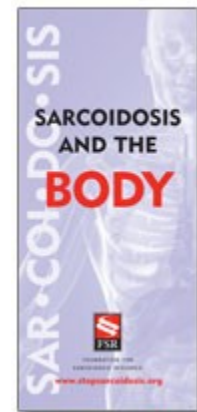
Sarcoidosis Newsletter Of Northern California

What is Sarcoidosis?

According to the Foundation for Sarcoidosis Research, “Sarcoidosis is an inflammatory disease that can affect almost any organ in the body. It causes heightened immunity, which means that a person’s immune system, which normally protects the body from infection and disease, overreacts and damages the body’s own tissues. The classic feature of sarcoidosis is the formation of granulomas, microscopic clumps of inflammatory cells that group together. When too many of these clumps form in an or-

gan, they can interfere with how that organ functions. It most often affects the lungs and lymph nodes, but the disease can affect other organs, too, including the skin, eyes, liver, sinuses, kidneys, heart, bones, brain and nervous system. It is often serious and can even be life-threatening.”

Sarcoidosis and the Body

**The Evolution of 100 Voices**

When Dr. Laura Koth, a researcher from the UCSF Medical Center, visited the Northern California Sarcoidosis Awareness Foundation support group a few months ago, she informed the participants of the latest research. She also asked them to write their personal stories about living with sarcoidosis and

the need for research. Many did immediately; others wrote them during a support group meeting; and others were asked to write from other support groups as well. Dustin Hollingsworth compiled it.

He has compiled 100 stories into a 148 page booklet titled

100 Voices: (A plea for more funding, better research, and global awareness for Sarcoidosis). Dustin found the stories “intriguing, inspiring, educational, touching, and in many ways terrifying.” He felt that these stories would be of “value to many different people for many different reasons.”

The Evolvement of 100 Voices .Continued

Dustin further stated that there are many “insights as to how people have dealt with this disease.” He asked the writers of the narratives to give him permission to post it on the Sarcoidosis Awareness website at [http://](http://www.sancsupport.org)

www.sancsupport.org. This way it would be available for any one to read it and/or download it.

Dr. Laura Koth from UCSF presented the booklet to Dr. Kiley, Director of the Division of Lung Disease at the National Institute of Health. He was very impressed with it and mentioned that the organization likes to keep in touch with issues that patients are experiencing; in fact, he expressed frustration with the lack of scientific progress in the field of sarcoidosis. Later he told Dr. Koth that he was impressed with the work that we are doing in the Bay Area, and that the studies are cutting edge and very important.

Guest Speakers

Dr. James Stewart and his wife Cindy shared their personal story. As a Physician Assistant, Critical Care Specialist, and sarcoidosis patient, Dr. Stewart has learned first hand the frustrations of living with the disease. Currently he is on disability and has a

guide dog to wake him up in case of an emergency.

He made several suggestions to the sarcoidosis members:

1. Keep a journal and look for patterns.
2. Make sure to have open communication with the doctor
3. Bring someone with you to the doctor.
4. Use the same pharmacy if possible to prevent drug interaction.
5. Monitor kidney and liver closely if on pain medication.
6. Men must check for hormonal level for fatigue.
7. Use alternatives for pain control: massage, etc.

Guest speaker Lou DeVille from Mental Health America in Sacramento offered suggestions on how to cope with depression. He used the acronym W.R.A.P. which stands for Wellness, Recovery, Action, Plan.

*Knowing is not
enough;*

We must apply.

*Willing is not
enough;*

We must do.

Goethe



Suggestions Welcome

Please contact kwhite@sancsupport.org or ksearby@sonic.net for suggestions for newsletter. We plan to publish four times a year. Should we include a section on questions and answers, suggested health notes related to sarcoidosis, personal stories, and others? Let us know.

Support Group Meetings:

- **Sacramento:** Mercy Medical Group (American River Conference Room, 6th floor), 3000 Q Street, 95816: **Feb. 26 and April 30 from 10 A.M. to 12 noon**
- **Concord:** John Muir Lung Health Services (Classroom A), 2730 Grant Street, 94520: **Jan. 8, March 12, May 14, July 9, Sept. 10, Nov. 12 from 10 to 12 A. M.**

Sarcoidosis Research Study:

If you are interested in participating in sarcoidosis research studies, call 415-476-5896 for more information or email laura.koth@ucsf.edu or agomez@medsfgh.ucsf.edu. Be sure to say you're calling about the "Sarcoid Study with Drs. Koth and Gomez."

University of Iowa will be conducting research on sarcoidosis and will need participants for their focus group and website participation. They need at least 12 people for the focus group. They plan to send someone to California to meet with the group.

Awareness and Celebrations

Awareness:

With the help of a local jewelry school, Karen White created the new Cure Sarcoidosis Pin as a way to make others aware. It costs only \$5 and can be bought at the support group meetings.

Karen White set up a booth at the Pulmonary Health Fair on October 23 to make others aware of sarcoidosis. She met people whose relatives had the disease. The fair offered various speakers on topics such as sleep apnea, the surgeon's role in lung disease, and living your life with a chronic disease.

Celebrations:

Hurrah! Sarcoidosis Awareness of Northern California is celebrating its first anniversary on Saturday, November 13, 2010 at John Muir Lung Health Services. Food will be served and members will discuss and explore together how the organization and support groups have helped them. They will also make plans for the coming year.

We have a celebrity among us! Karen White was selected to train with the Sacramento Kings' Dancers for a chance to perform during half-time

shows. Unfortunately, our own Karen doesn't have the energy to participate.

What can you do to improve your lung capacity? Maybe you should take saxophone lessons like our own Karen White. We could start our own band!

Support Websites

- Foundation for Sarcoidosis Research (FSR) (Chicago): www.stopsarcoidosis.org. Will send you pamphlets on the disease and latest research. Leading nonprofit organization in sarcoidosis research.
- Sarcoidosis Awareness of Northern California: www.sancsupport.org. Will inform you of what is available regarding support, clinical trials, donations, personal stories, etc. in Northern California.
- Constructive Feedback: <http://greatnonprofits.org/reviews/write/1584052>

Special Recognition for Extraordinary Volunteers

- *Karen M. White*: She continues to find ways to bring awareness, find donations, and update us of research. She is one of a kind and our anchor.
- *Dr. Laura Koth*: We really appreciate her dedication to research and spreading the word in the medical field. She includes us in her endeavor. We revel in it.
- *Dustin Hollingsworth*: His compassion and respect for our cause is seen in his compilation of the booklet titled *100 Voices (A plea for more funding, better research, and global awareness for Sarcoidosis)*. We are so grateful.
- *Lou DeVille*: Thank you so much for coming and offering suggestions on how to cope with depression. We will always remember W.R.A.P.
- *Elizabeth Yahn*: Thank you so much for donating hours setting up the newsletter format, so we can have a professional-looking newsletter.
- *Dr. James Stewart & wife Cindy*: We're grateful for the insight to your world of living with sarcoidosis and personal medical experiences. You walk the talk.
- *Jeanne Fershleiser*: How can we ever thank you enough for contacting so many people across the U.S. to write their narratives? You are remarkable.
- *Samantha Dussell & Family*: We really appreciate your helping sell our new Cure Sarcoidosis Pins

Donations and Awareness to Help Our Organization

For the month of September, the San Francisco Giants displayed the organization's name during the pre-game scroll.

Online Shopping: If you download the Good Search - Sarcoidosis Awareness of Northern California toolbar, our cause will earn money every time you shop or search online. Add the Sarcoidosis Awareness of Northern California at <http://www.goodsearch.com/toolbar/sarcoidosis-awareness-of-northern-california>. Stores such as Amazon, Target, Gap, Best Buy, eBay, Macy's, Barnes & Noble will donate up to 30 percent of each purchase to us.

Electronics: If you'd like to donate your used electronics (laptops, cell phones, MP3 players, digital cameras, etc.) into cash to support Sarcoidosis Awareness of Northern California, go to Sarcoidosis Electronic Donation Drive (<http://sancsupport.gazelle.com>) to learn more about the drive.

American Express: www.membersproject.com, click, donate and enter Sarcoidosis Awareness of Northern California

Visa: www.visagiving.com. Cards for Causes: www.cardsforcauses.com. Support your cause: www.supportyourcause.com

Chase Chevrolet's owners, management, and staff donated and purchased our new Cure Sarcoidosis Pins.

Fundraisers Close and Far

Pin: The Cure Sarcoidosis Pin for Northern California is available for purchase for \$5 at the support group meetings.

Golf: We are planning a golf event, tentatively scheduled for October 1, 2011, at the Los Lagos Golf Course in San Jose, California in celebration of Sarcoidosis Awareness month. (<http://www.playloslagos.com/>)