

SARCOIDOSIS NETWORKING

Volume XIII

Spring 2006

PATIENT ORGANIZATIONS COLLABORATE at 2005 WASOG CONFERENCE

Three members of SNA attended the first Patient Conference Day held in conjunction with the 8th meeting of the World Association of Sarcoidosis and other Granulomatous Disorders (WASOG). Theresa Lirette, vice president of the SNA Board of Directors; Kristi Anderson, Secretary of the SNA Board of Directors, Coordinator of the Sarcoidosis Registry, and Facilitator of the two Sarcoidosis support groups in Oregon. Also in attendance was Dolores O’Leary, Executive Director of SNA.

More than 120 patients, family members and caregivers attended the Patient Conference Day, held in Denver Colorado June 2005. This collaborative effort by the National Sarcoidosis Society (NSS), Sarcoid Networking Association (SNA), Sarcoidosis Awareness Network (SAN), Sarcoidosis Health and Wellness Support Center (SHWSC) Sarcoidosis Network Foundation (SNF) and Sarcoidosis Research Institute (SRI) with the guidance of WASOG came together for this historical event of patient education about Sarcoidosis.

Paula Yvette Polite, President and founder of SRI, welcomed the conferees. She thanked WASOG and Conference coordinators, Robert Baughman, M.D., Lee Newman, M.D., Julie Barnard, Ph.D. and Mya Sadler, CMP, and the National Jewish Medical and Research Center (hosting institution). All assisted in making the event a reality. She acknowledged the united efforts of patient organizations, who had worked with her over the past year to bring about the informative effort to develop a better understanding of sarcoidosis patients. She spoke of the common goal of the groups: “Improved diagnosis, improved methods of treatment, prevention, and ultimately a cure of the debilitating and complex disease.” To each of the working members, Kristi Anderson (SNA), Brenda Harris (SHWSC), Ruth Jacobs (SNF), Linda Lanier (SAN) and Dolores O’Leary (SNA), Polite presented a key ring symbolizing the opening of new doors and new frontiers. The item was engraved with the united objective: “to cure sarcoidosis”.

Specialists Address Patients at International Sarcoidosis Conference

Leading the agenda of the day was Om P. Sharma, M.D, of the University of Southern California, Los Angeles. He spoke of the unusual presentations of Sarcoidosis. In his opening remarks, Dr. Sharma thanked the attendees and patients for being so motivated in wanting to change the course of their illness and their desire to learn as much as they can. He went on to say: “We, the physicians, learn from you. When you tell us of unusual symptoms, we are forced to investigate. Keep your doctors informed, in the loop.” Dr. Sharma emphasized that physicians try to keep their patients as comfortable as possible when dealing with unusual presentations of sarcoidosis. He offered that multisystem disease means more than one organ; “any organ” could be involved. The disease can affect us as differently as the features on our faces.

Dr. Lee Newman, National Jewish Medical and Research Center, Denver, Colorado, reported on “What we know and don’t know about Sarcoidosis.” The genetic component of Sarcoidosis “is like a loaded gun; then something in the environment pulls the trigger.” Science has shown there are certain genes (antigens) that tell our body’s cells to identify & attack foreign invaders. In Sarcoidosis, the immune system begins to work overtime fighting against the trigger (cause or causes). Not everyone has the same pattern of the disease (phenotype). “I predict that multiple causes will be found over time.”

IN THIS ISSUE

<i>Organizations Collaborate</i>	1
<i>Specialists Speak</i>	1
<i>Reader Alert</i>	2
<i>Reader Survey</i>	3
<i>WASOG Q & A’s</i>	3
<i>Sarcoidosis Registry</i>	5
<i>Integrating Healthcare</i>	6

REGULAR FEATURES

<i>Fallen Snowflake</i>	2
<i>Golden Oldies</i>	
<i>Good Medicine</i>	
<i>Going Bad</i>	7
<i>Protect Largest Organ</i>	7
<i>Healthwise Patient</i>	
<i>Worried Sick</i>	5
<i>Fact:</i>	
<i>Sarcoidosis in Worldwide Population</i>	7

(Continued on page 2)

(Continued from page 1)



FALLEN SNOWFLAKE

Long-time SNA Board Member and Sarcoid activist, Theodore "Ted" Riley of Wichita KS passed away January 12, 2006. He also served on the Sarcoidosis Support of Kansas Board of Directors and assisted his spouse, Marge Riley, Sarcoidian with the Wichita support group and other national efforts. He will be remembered for his innovative arrangements for Marge's extensive travels and her need for continuous oxygen. She succumbed to Sarcoidosis and its complications in October 2004.

The National Heart, Lung and Blood Institutes, (NHLBI) Herbert Reynolds, M.D. reported on the progress of Sarcoidosis research. (See *Sarcoidosis Networking*, May/June 2004.) As a clinician, who cares for patients with interstitial lung disease, which is often secondary to Sarcoidosis, he recognized that multi-organ involvement makes it a very complex picture. With the establishment of NHLBI in 1971, the then head of the division, Dr. Claude Lafontaine, included a commitment to study the interstitial lung diseases. Over the past 30 years, studies on treatment and initiatives continue to look into the causative factor(s) of sarcoidosis and genetic studies remains high among the research community. Most recent is the initiative to investigate the inflammatory process of the granuloma tissue. A coalition of Sarcoid-focused patient organizations - many of whom are represented at this conference - approached NIH Administration for a better coordination and organization of research. As a result, an internal working group of 11 institutes was established to identify gaps and collaborated in the sharing of research regarding multiple organ involvement.

Focusing on fatigue, as related to Sarcoidosis was Marjorein Drent, M.D., University Hospital, Maastricht, The Netherlands. "The cause of fatigue can be anything. Defining what kind of fatigue is necessary. A hypothesis was developed that small fiber neuropathy is related to fatigue. The many complications, including pain, must be investigated to get to the bottom of the cause of fatigue. Current testing really does not explain fatigue so it is very difficult to treat the fatigue. The patient must be aware that fatigue is a very important problem and should not be ignored. Listen to your body. Learn to recognize the signals of dysfunction. Prepare a plan to cope with possible problems. Don't be ashamed that you need to take a rest."

Professor of Medicine, Marc Judson, M.D. Division of Pulmonary and Critical Care Medicine at the Medical University of South Carolina, Charleston SC spoke of the neurological aspects of Sarcoidosis. He remarked that a form of Bell's palsy (drooping of one side of the face) can predate the actual diagnosis of Sarcoidosis, often by several months. He described inflammatory meningitis as another form of neurosarcoidosis with a headache, stiff neck and fever. Such can be diagnosed with a spinal tap when lymphocytes, a type of white blood cells are present. Treatment of Neurosarcoidosis is the same as for any form of Sarcoid. Patients need to be informed of the risks and side effects of any variety of Sarcoidosis.

Dr. Elyse Lower, M.D. University of Cincinnati Medical Center explored skin and eye manifestations of Sarcoid for the conferees. She opened her remarks with the fact that ocular sarcoidosis could be painful, vision threatening and without symptoms. Dr. Lower encourages all Sarcoidosis patients to be examined by an ophthalmologist. Skin (cutaneous) sarcoid ranges from acute and self-limiting to chronic and disfiguring. The treatment depends on the location and severity of the disease.

The Conference was taped by Dr. Julie Barnard, National Jewish Medical & Research Center, Denver. It can be obtained by contacting the Sarcoid Networking Association. (See address on last page.) Kindly specify VHS or DVD format.

TO OUR READERS

Due to circumstances beyond the control of the Sarcoidosis Networking Association and the staff of the Sarcoidosis Newsletter (SN), no issue of the SN was published in 2005.

Because of continually increasing costs, the SNA must consider changes not only to the publication schedule, but also to the method of production and delivery of the SN. A survey is being conducted to determine if subscribers with computer access would read the newsletter on-line, where it has been published for 3 years now. (Go to: www.sarcoidosisnetwork.org) Said subscribers would decline delivery of the printed version.

Those subscribers without computer access would notify us of such and continue to receive the printed version. A larger print edition, for those with compromised eyesight, would continue to be available in either on-line or print versions.

We would greatly appreciate your participation in the survey.

**Complete and send the Reader Survey form on page 3
to continue to receive this newsletter in preferred format.**

SYNOPSIS OF 2005 WASOG Conference Q and A's

Talmadge King, M.D., San Francisco General Hospital, San Francisco, CA was the moderator. The Physician Panel included: Marjorein Drent, M.D., University Hospital, Maastricht, The Netherlands; Mark Judson, M.D., Medical University of South Carolina, Columbia, SC; Elyse Lower, M.D., University of Cincinnati, Cincinnati, OH; and Herbert Reynolds, M.D., National Heart, Lung, and Blood Institute, National Institutes of Health (NIH), Bethesda, MD.

Q: How do you explain Sarcoidosis to the patient, the family and friends?

A: Dr. Judson: As a physician, I tell my patient, "You have a condition called Sarcoidosis. It is found all over the world. No one knows the cause. It can occur in any part of the body, but basically – it is not a cancer. We don't know if it is an infection." "What we do know, is that patients are diagnosed with Sarcoidosis because white blood cells are leaving (or have left) the blood stream and forming (or have formed) balls in various tissues of the body. The balls are called granulomas, which are determined to be "non-caseating granulomas". When the person is diagnosed as having Sarcoidosis in the lungs, coughing and wheezing are usually part of the symptoms. I explain the prognosis according to the tests results. It is very important to answer the patient's questions regarding this mysterious disease, in order to assist the individual to better understand the condition."

"One of the problems that we have as doctors is that we don't listen closely enough to the patient. We can give a good explanation ... but sometimes, we don't really get to know the depth of what the patient understands or feels. We are not in tune with the patient."

"The physician needs to assess the patient's quality of life." "... [P]hysicians too often focus on the tests results. Patients do not care about the quality of air flow, or what the CT scan shows. Patients do care about breathing more easily; the loss of energy; or the capacity to participate in their usual life activities." "That's their focus." "I also provide educational materials to the patient and family." "That is my basic approach."

A: Dr. King: "We, the physicians, have the same problems as the patients have in answering the question ... What is Sarcoidosis? ... [P]atients seem to be unable or unwilling to respond when others ask them about the disorder."

"To further illustrate my point: people who have Diabetes Mellitus (DM) do not usually hesitate to say so. Despite the fact that neither the medical profession, nor the diabetics know what causes DM, the patients are not uncomfortable saying that they have DM. So why should patients with Sarcoidosis hesitate to say that they have Sarcoidosis? The situations are the same. Science does not know the cause for either disorder. In both cases treatment is currently based on symptoms."

Patients can explain Sarcoidosis by simply stating that: Sarcoidosis is a multisystemic

(Continued on page 4)

SARCOIDOSIS NETWORKING STAFF:

EDITOR-IN-CHIEF

Dolores O'Leary

COPY EDITOR

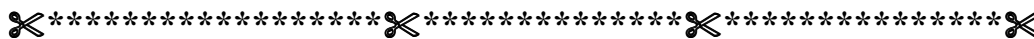
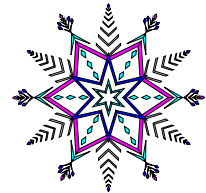
Rita Plourde

STAFF

Don O'Leary

WEBMASTER

Michael Lafrenière



READER SURVEY FORM

Name: _____

Notify me by email regarding **on-line** version.

My e-mail:

Respond to: sarcoidosis_network@prodigy.net



Send **printed** version. Name: _____

Street address, city, state, zip: _____



Respond to: Sarcoidosis Networking Association
6424 151st Avenue East Sumner, WA 98390-2601



Nothing is impossible to a willing heart.

John Haywood

14TH SARCOIDOSIS
CONFERENCE

*Improving Your
Quality of Life*

Sept. 30 – Oct. 1, 2006
Radisson Hotel Gateway
Seatac WA

Keynote speaker:
Om P. Sharma, M.D.

Save the Dates!
See Insert.



(Continued from page 3)

granulomatous disease. It can affect one or multiple organs at the same time. Usually the lymph nodes are enlarged. Often the lungs are involved. Sarcoidosis can create inflammation and scarred tissue in the lungs. It is not the result of smoking. Symptoms are usually manifested based on which area(s) or organ(s) are affected.’

Q: What about doctor-patient relationships?

A: Dr. Reynolds: “Some very helpful discussions have been held regarding how the younger physicians are instructed to interact with people. ... [I] have learned that it is very important we establish a rapport, or bonding with each other and that we have good open communication. I am delighted when patients are much more informed when they come to see me. I encourage them to seek articles on the Internet, bring them to me, and let me judge what things might be good or deceptive. ... [T]here is anxiety on both sides, doctors as well as patients. Nurses and other people can help so much with this.

Many times, patients can’t remember what was said, or what they wanted to ask in clinic. Doctors can be distracted too. The follow-up is important. I send every piece of paper to my patients. You should ask your doctor for a copy of every report. Keep a complete file of pertinent information, including tests results.

Because a lot of things do not get discussed in clinic, I give patients my e-mail address and encourage them to contact me about their questions and concerns. Not all doctors choose to do so.

Sometimes when I’m away from the context of the clinic, I have more time to examine your questions. Patients must develop a rapport with the physician so that effective communication can occur. I think that physicians really appreciate that candor.’

A: Dr. Judson: Communication skills are most important for both the patient and the doctor. Establishing a common level of understanding about the clinic situation and acknowledging the many factors that create a trust, awareness and cooperation in the doctor-patient relationship, is essential to a successful alliance in managing Sarcoidosis.

Q: There were several questions about chemical and environmental exposures, and their possible relationship to Sarcoidosis.

A: Dr. Reynolds: I am convinced ‘that occupational hazards and toxic pollutants to which people are exposed, do condition the initial diagnosis and treatment plan for certain individuals.’ ‘... [F]or years, I’ve been interested in something called, *hypersensitivity pneumonitis*. This may be caused by protein antigens in the workplace such as on a dairy farm, or where pigeons are raised. The antigens might cause different forms of granulomous response, not just sarcoidosis.’

‘Variables can cloud the definition for a great number of people, who work in such occupational hazards as metal grinding, welding with solder, or exposure to beryllium. All these must be factored out, because the symptoms overlap.’

‘There are many exposures that seemed innocuous and weren’t considered to be important. However, 20 to 30 years later, they became a significant factor.’ ‘The role of occupational and environmental exposure is very important.’

A: Dr. Judson: “... I think that there are many potential causes of Sarcoidosis; some of them might be infectious, some of them environmental.” Some possibilities, such as insecticides, metal exposure such as titanium in photocopiers or aluminum, were noted in the ACCESS: (A Case Control Etiology of Sarcoidosis Study), in which I and several of the Speakers today were involved.’ ‘Another study in South Carolina indicated that wood smoke exposure might be a cause. The greater the exposure to the smoke of combustible wood products, the higher is the rate of Sarcoidosis.’ ‘This was corroborated in a study comparing the exposure rates among EMTs and Firefighters in New York City. Firefighters do indeed have a higher rate of Sarcoidosis.’ ‘My personal bias is: there are very many occupational and environmental exposures associated with Sarcoidosis. I don’t think that any one is THE cause.’

A: Dr. Lower: “We’d be remiss if we didn’t mention the word ‘genetic’ -- part of that inherited susceptibility that dictates how each body reacts to a disease such as Sarcoidosis.” Considering Dr. Judson’s list, some of you will say: “I didn’t smoke.” “I haven’t worked in a factory.” ... “Why did I get this?” [Sarcoidosis].

There are populations in which genetics play an important role in the type of Sarcoid diagnosed. Such populations are called phenotypes. An example is the incidence of Sarcoidosis of the eyes, which is much more common among the Japanese than it is in the United States. I don’t think that we can forget the fact that Sarcoidosis is probably a reaction to factors that we all have. We have to have some underlying pre-disposition. Some of us will get Sarcoid; some will not; others will have different problems.

WORRIED SICK

Many physical ailments can be traced to mental stress. Emotional problems can jeopardize your health, particularly if the problems are ongoing, unresolved matters. When stress becomes chronic, your body is tense and unable to relax. In addition, long-term depression, anger and anxiety may affect your immune system, leaving you vulnerable to illness.

A growing body of evidence suggests that our mental attitudes affect our susceptibility to disease and our ability to overcome it. Take time to evaluate your state of mind—Do you feel hopeful or dejected? Do you feel in control or at the end of your rope? Test your mental fitness by checking the statements that apply to you...

If you check more statements in the left column than in the right, it's time to adopt a

NEGATIVE PATTERNS

1. Ignore your body. Eat lots of high-fat foods and keep smoking and living a sedentary life. Above all, feel guilty about it.
2. Keep pushing yourself even if you are tired and overstressed
3. Do most of the things you don't like and few of the things you want
4. Fill your mind with negative pictures and obsess over them. Worry most, if not all, of the time
5. Avoid close, lasting relationships
6. Blame other people for your problems
7. Don't express your feelings or views openly and honestly. If at all possible, do not even know what your feelings are
8. Avoid making any changes that would bring you greater joy and satisfaction

WHOLESOME HABITS

- Do things that bring you a sense of fulfillment, joy and purpose. See yourself as worthy and your life as a positive one.
- Release your negative emotions—resentment, fear, envy, sadness, anger. Express your feelings appropriately.
- Carry positive images, picturing what you really want in life. When fearful images occur, focus on those that make you feel better.
- Nurture fun, loving, honest relationships. Try to heal wounds in past relationships
- Make a positive contribution to your community through some form of work or service you value and enjoy
- Make a commitment to your health and well-being, altering one behavior at a time
- Accept life as an opportunity for growth and learning. When you make mistakes, take a lesson and move on
- Keep a sense of humor

healthier state of mind. With practice you can learn to think and feel better about yourself—and that may help protect your health.

Pierce County WELLNESS WORKS, May 1997

THE SARCOIDOSIS REGISTRY HAS ARRIVED!

SNA is pleased to announce that the Sarcoidosis Registry is now online. The website is www.snaregistry.org. We are receiving significant response to the site, which is a strong positive confirmation of SNA's vision. This information permits greater patient participation in Sarcoidosis research.

We are proud to have Dr. Om P. Sharma, Dr. Ganesh Raghu, and Dr. Gopal Allada as members of our Scientific Advisory Board. Their expertise and historic commitment contribute to the search for better understanding of the enigma that is Sarcoidosis.

Multiple protective measures have been established to insure participant confidentiality. Please contact Kristi Anderson with any questions concerning the registry at admin@snaregistry.org or 541-905-2092. We look forward to your comments and concerns regarding this endeavor. Working together, we can make a difference.



I am only one, but I am still one. I cannot do everything, but still I can do something. Because I cannot do everything, I will not refuse to do the something that I can do.

- Helen Keller

INTEGRATING HEALTHCARE: A PATIENT'S RIGHT AND RESPONSIBILITY

Every patient must take an active part in one's own healthcare program. Patients have the responsibility to be well-informed about the many aspects of their diagnosis(ies), treatment plan(s), and how such might impact their health, lifestyle, family and friends. A partnership must be developed between the patient and the treating healthcare providers. The professionals, who comprise the individual's healthcare team, are responsible for keeping the patient informed about his or her condition(s), and make the person aware, at all times, of the available options.

Any and all ramifications of the recommended treatment program must also be explained to the patient. It is that patient's right.

The enigma of Sarcoidosis is still being explored. Increasingly, the medical and research communities theorize that there are possibly several causes of the disease and each must be examined accordingly. Once a cause(s) has/have been identified by researchers, then specific treatment plans can be recommended by the medico-professional community. Currently, treatment remains focused on the relief of each patient's symptoms.

Investigating the different approaches to disease management can be conducted more efficiently with today's computer technologies and testing facilities. Personal Computers (PC's) make it possible for professionals and patients to gather an inordinate amount of information and mis-information. It must all be evaluated. New data might necessitate different and/or updated testing. The results would then be examined and compared with the findings on record. (Incidentally, "base-line test" refers to the results of the first time a particular test is conducted on an individual. Future values would then be compared to the patient's "baseline".)

It is advised that every patient maintain a personal healthcare file containing copies of office notes, consultations, correspondences and tests results. Therein should also be notes regarding the diagnosis, treatment plan and list of prescribed and over-the-counter (OTC) medicines and supplements. Names and addresses of the healthcare team, their office and FAX numbers and e-mail, (if any), should be available in the personal healthcare file.

An experienced physician is aware that many medicines are available for the patient with Sarcoidosis. No longer are corticosteroids - like prednisone - the "only" drugs prescribed to control symptoms. The patient has the responsibility to ask the prescribing physician to spell the market and/or generic name(s) of the medication. Such should be compared with the medicine received from one's pharmacy of choice. Pharmacists should be questioned about possible contraindications to taking the drug, adverse reactions with other drugs and/or OTC medicines and supplements.

A prescription is written in a specific format. Ask the prescribing professional about the purpose of the drug, its dosage, and when it can be expected to become effective. Pharmacists also have such information to share with the patient. Question if the drug is to be ordered for a short-term or long-term treatment. Why?

Through inter-disciplinary communication and evaluation - including the information and observations acquired and shared by the patient - the physicians are best able to advise the individual. If more than one system is involved, then the scope of the treatment is widened.

Should multiple health problems be affecting the person with Sarcoidosis, each challenge must be evaluated and addressed as part of the treatment program. It is the patient's right and responsibility to participate in the planning and exercise of the treatment program.

The prime care physician (PCP) is the healthcare professional responsible for the overall health of the patient. It is that physician's responsibility to coordinate the recommendations of the various specialists, who make the necessary decisions about treatment, based on their area of expertise. The patient is then empowered to make an informed decision regarding her or his healthcare.

Some patients with Sarcoidosis have the perception of being considered as a segmented entity - less than a whole person - by some or all of the treating professionals. They sense that some team members do not practice holistic medicine. Healthcare team medicine is analogous to the practice of holistic medicine in that the body and mind are viewed as a whole within the person's environment (i.e.: daily life activities, lifestyle, diet, exercise, social and cultural involvement, family values, interpersonal relationships, employment, spirituality, expectations and the support systems). Such a situation must be corrected in order to focus on the restoration of whatever degree of well-being and quality of life is possible for the patient, who happens to have Sarcoidosis.



Golden Oldies



WHEN GOOD MEDICINE GOES BAD

The expiration date on your pill bottle says: Discard after January 4. It's January 5th and the bottle's half full (or is that half empty)? Do you try to squeeze in a few more doses from the bottle or should you toss those final precious pills? In most cases, taking drugs a little bit past the expiration date won't hurt – if you have stored the medication properly, in a cool, dry and dark place.

On the other hand, a medication kept in less-than optimal conditions, such as on a sunny window sill or in a steamy bathroom medicine cabinet, can go bad even before it officially expires. "Sun exposure, heat and moisture can all affect medication", says Don Miller, Pharm.D, professor and chairman of the Department of Pharmacy Practice, at North Dakota State University, and a member of the *Arthritis Today* medical advisory board.

Fortunately, even if you take an expired medication it probably won't hurt you – at least not directly. The biggest danger of using an expired medication is that it won't help. Dr. Miller maintains that, "After the expiration date, drugs start to lose their benefit, and the potency of the medicine cannot be guaranteed."

There are exceptions to every rule, of course. Aspirin and the tetracycline antibiotics can break down into products that can be damaging to the kidneys.

If you're ever in doubt about a medication that is near or past its expiration date, or it just doesn't look right, it's best to ask your pharmacist about it or just throw it out. Better to lose to a few pills than to lose benefits of medication you need.

Arthritis Today: 2003 Drug Guide

PROTECT THE BODY'S LARGEST ORGAN

The largest organ of the body is the skin which covers it. The skin is water proof and an armor against harmful agents when we are accidentally exposed to them. Keeping skin in good condition year round is an on-going process. Most people know that over exposure to sun can damage the cell, causing burns, a serious concern. Skin is also a wonderful catalyst that manufactures vitamin D when exposed to sun light. Winter time has conditions that can also cause skin damage

The body produces essential moisture-retaining oils that protect the skin from becoming dry and itchy. These oils decrease as the body ages. Certain medications, including corticosteroids like prednisone can also dry the skin or reduce the amount of natural moisture from the inside of the body.

By using an over-the-counter moisturizing lotion every day is a good skin care habit. Some individuals who have dry skin already may need a moisturizer that contains additional protection like petroleum jelly or mineral oil. Wear loose clothing as fitted clothes can rub and agitate the skin.

A warm shower is better for the skin than soaking in a hot bath. Some fragrant soaps have ingredients that may release more skin moisture with alcohol evaporation removing the natural moisture-barrier instead of holding in moisture. Use a gentle beauty bar or cream as a cleanser instead.

Avoid prolonged exposure to the wind and sun, and stay hydrated by drinking plenty of water daily. After all, lotions can't seal in moisture that isn't there.

Get more information about your dry skin problems from your dermatologist or go to www.aad.org for one in your area.

American Academy of Dermatology

FACT

Sarcoidosis, with a worldwide occurrence of 4 per 10,000, is listed as an uncommon disease by the National Organization of Rare Disorders.

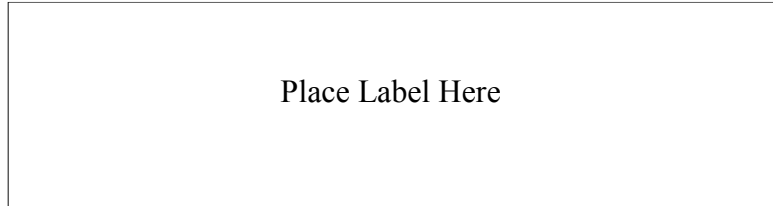
Since Sarcoidosis mimics many other diseases, the number of people who actually have Sarcoidosis is thought to be considerably higher than the number of cases reported

Phone Hours 9:00 am-5:00 pm
Pacific Time
253-826-7737
or e-mail:
sarcoidosis_network@
prodigy.net
SNA Web site
www.sarcoidosisnetwork.org

Sarcoid Networking Association
6424 151st Ave E
Sumner WA 98390-2601

NON-PROFIT ORG.
US POSTAGE
PAID
Puyallup WA
98371
Permit #93

RETURN SERVICE REQUESTED



Sarcoidosis is a multi-systemic disorder that can involve any organ of the body. There is no known cause, no known cure. Treatment is based on clinical symptoms presented by the patient. Research is ongoing throughout the world.



No two snowflakes are identical and no two individuals with Sarcoidosis appear to have identical symptoms. Therefore, snowflakes have been chosen to symbolize Sarcoidosis.

YES! I'D LIKE TO PARTICIPATE IN SARCROID NETWORKING ASSOCIATION
(A Not-For-Profit Organization) Spring 06

- An Annual Participation Gift of \$25**
- A Special Gift of _____**
- Receive Newsletter.**
- Sorry, I can't make a donation now.**

No one is refused the newsletter because of inability to make a gift.

Temporary hold ? Contact editor
Postal or e-mail address change

CURRENT INFORMATION

Name _____
Address _____
City, State, Zip _____
Phone _____
E-Mail _____

NEW INFORMATION :

Name _____
Address _____
City, State, Zip _____
Phone _____
E-Mail _____

SARCOIDOSIS NETWORKING is published by the Sarcoid Networking Association, by and for individuals with Sarcoidosis and those interested in this disease. Since 1992, its sole purpose has been to heighten awareness and form a network with each other, the medical community and the general public.

It is not intended to replace the advice and/or diagnoses by healthcare professionals.

You are advised to seek proper medical attention whenever a health problem arises requiring expert medical attention.

Disclaimer ...

SNA does not endorse any of the medications, products reported in this newsletter. This information is intended only to keep you informed.

We strongly advise that you check any drugs or treatments mentioned with your physicians or pharmacists.

EARLY BIRD REGISTRATION

Improving Your Quality of Life: 14th Annual Conference on Sarcoidosis, "FALLING INTO PLACE"
September 30 & October 1, 2006
Key Note Speaker: Om P Sharma, M.D.

NAME

ADDRESS

CITY STATE ZIP

PHONE, EMAIL or FAX

REGISTRATION

EARLY BIRD DONATION: \$40

AFTER AUGUST 29TH: \$45

AT THE DOOR: \$50

FOOD : \$15 (Continental breakfast, lunch and break snacks
are included in the food donation.)

NUMBER ATTENDING _____

AMOUNT ENCLOSED (US FUNDS) _____

Make checks payable to : Sarcoid Networking Association.

Mail to current address: Sarcoid Networking Association,
6424 151st Avenue East,
Sumner, WA 98390-2601

For scholarship application, more detailed information, diets, or special needs
please contact the SNA at least 30 days prior to the conference date.
call: 253-826-7737 or email: sarcoidosis_network@prodigy.net

Special conference hotel rates available at Radisson Hotel Gateway, (Sea-Tac Airport)
18001 International Blvd., Seatac WA 98188 1-800-333
. Call before September 1, 2006

INTERESTED IN SHARING A ROOM ? Contact the SNA Room Coordinator
at: 253-471-0423 or email the Coordinator at : lynn_short@msn.com
Sharing of lodging arrangements must be made only with the Sarcoid Networking Association
- - - NOT THE HOTEL