



SARCOIDOSIS NETWORKING

Volume XI Issue 4

July/August 2003

Skin Sarcoidosis

When the Sarcoid granuloma attacks the largest organ of the body - the SKIN - the disease gives credence to its description as a "Mimic Disease". The hallmark of Sarcoidosis, the non-caseating granuloma described in microscopic examination of suspect tissue, is the best way to give title to the diagnosis. In Sarcoidosis of the skin, visible markings may not have a classic presentation. Without a patient history of Sarcoidosis and biopsy report, sarcoidosis of the skin can be confused with other disorders (e.g. psoriasis, warts, blisters, rashes of various types, hair loss, irregular nail growth, or abnormal scar tissue) - the list only gets longer. Imagine the anguish when skin eruptions are misdiagnosed as a form of syphilis and the lifestyle of the patient gives no rise to such a conclusion. Skin Sarcoidosis is classified as specific or non-specific, the latter being when no evidence of granuloma is found in tissue biopsy.

According to D.G. James, M.D., purple lupus or lupus pernio was reported by Ernest Besnier, MD, as early as 1889. Besnier described it as a chronic, persistent violaceous skin lesion. Most commonly found on the nose, cheeks, lips, ears or fingers, it can be a very disfiguring form of the disease. It is not limited to the upper areas of the body but can be found in extreme cases in other regions including the buttocks and the thighs. It is twice as common in females and more often among Afro-ethnic populations throughout the world. When present, it is often associated with other systemic forms of Sarcoidosis including the upper respiratory track, bone cysts, lacrimal gland involvement and renal sarcoidosis.¹ It develops slowly and progressively over the years.

Allen Kayne, MD, Dermatologist at Virginia Mason Medical Center in

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PLAN NOW TO ATTEND

THE 11th ANNUAL CONFERENCE ON SARCOIDOSIS.

September 26-27, 2003

Wyndham Seattle - Tacoma Airport Hotel

18118 Pacific Highway South

Seattle WA

Contacts

Hotel Reservations: 800.Wyndham or 800.996.3426

Conference Information: 253.891.6886

WATCH FOR CONFERENCE BROCHURE IN YOUR MAIL BOX.

(Continued from page 1)

Seattle WA explains that erythema nodosum (EN) is a perfect example of non-specific lesions. This inflammatory process of fatty tissue is seen in many other disorders besides Sarcoidosis. "When EN and hilar adenopathy are both present in Sarcoidosis, the prognosis tends to be good, especially when the onset is sudden," said Dr. Kayne. EN appears as red, hot, tender, symmetrical bumps, usually on the shins, but can be seen on other body areas, including the arms and trunk.

Papule lesions (pimples) are classified as specific. Waxy or translucent, rounded, brownish or reddish brown clusters of lesions with granuloma formation on microscopic examination, are sarcoid lesions. At the 5th Conference on Sarcoidosis in Seattle, Dr. Kayne explained: "By pressing down on a lesion with a clear glass slide (diascopy) and restricting the normal blood flow in the tissue, the lesion looks yellow and in many instances, you can actually see the granuloma and can better understand how granulomas are responsible for infiltration of the skin." Thick papules are called nodules and when areas coalesce (fuse, run, grow together) they are known as plaque, a medical term for patch on the skin.² When areas are large enough they can break down the skin causing ulcers to form. Usually chronic sarcoidosis skin lesions do not cause pain or itch.³

A little understood manifestation of Sarcoid in some patients is "...Inflammation in old scars and/or tattoos... Scarring from EN or earlier biopsies and/or sites used for inoculation or skin testing, are also susceptible to this inflammatory involvement."⁴

Treatment for skin involvement depends upon the type and extent of the lesions. A corticosteroid is usually the primary drug prescribed when there is other organ involvement. Thick lesions may best respond to injection at the lesion site, when delivery of a concentrated dose with minimal systemic dosing is desired. Such is the case when thicker lesions do not respond to steroid-based creams and/or systemic therapy. Topical corticosteroid creams are most effective on thin skin lesions. Sometimes the skin can be encouraged to absorb more ointment medication by covering the lesions with plastic wrap (e.g. Saran Wrap, etc.) or using a body wrap, advised Dr. Kayne. This is referred to as occlusion therapy.

There is always the concern of side effects with systemic therapy. Such a treatment plan might include steroids, immunosuppressant drugs like methotrexate or azathioprine, TNF (tumor necrosis factor) inhibitors, or anti-malaria drugs such as hydroxychloroquine, especially when there is other organ involvement.

¹ James, D.G. Sarcoidosis of the Skin, *Seminars in Respiratory Medicine*, Vol. 13 No. 6; 432-441.

² *Taber's Cyclopedic Medical Dictionary*, 19th Ed., F. A. Davis Company, Philadelphia.

³ Hunninghake, Gary W. et al; ATS/ERS/WASOG Statement on Sarcoidosis; *Sarcoidosis Vasculitis And Diffuse Lung Diseases* 1999, 16:149-173.

⁴ Nat .Org. for Rare Disorders (1999). Brochure # 215, Sarcoidosis.

FYI

The skin is the largest organ in the body. It covers all organs and the skeleton in 3 distinct layers; preventing invasion by myriad organisms and foreign objects. This waterproof covering also helps regulate body temperature. It is one of the body's sensory organs. Besides its basic cell structure, it contains blood vessels, nerve tissue, sweat glands, hair follicles, oil glands and muscle fibers.

Complex Regional Pain Syndrome:

Complex Regional Pain Syndrome (CRPS) is a significant cause of chronic pain. It can arise as a result of an injury or illness, and can become a primary illness in itself. This condition was formerly known as Reflex Sympathetic Dystrophy.

A poorly understood dysfunction of the nervous system, the most significant onset characteristic of CRPS is the patient's experience of burning pain. Swelling and loss of motor function, far out of proportion to the physical findings, may follow. Skin changes, muscle spasms, tremor, and atrophy can all be present.

This pain is severe, said to be the worst pain humans can endure. Full blown CRPS disables a patient from all work, even "intellectual" work, due to the impairments in memory, concentration, persistence and pace.

The pain does not respond to conventional medication. This is a disease process of the autonomic or unconscious nervous system – the system that takes care of body functions like sweating, blood flow, pulse rate. If CRPS has been diagnosed, it is important to get clarifying information into the record for a Social Security claim.

Many people are conditioned to minimize terms like "chronic pain." Having the terminology "Complex Regional Pain Syndrome" clearly delineated and described by the treating physician takes the case out of the "run of the mill."

In a Social Security or SSI case, emphasis needs to be placed on "proving" the pain. Family and friends can testify or write letters about what their observations have been.

Records from physical therapists, information about pain injections, TENS therapy, medication, emergency room treatments, x-rays or thermograms and even pain diaries kept by the claimant can all be helpful.

As always, the psychological element of depression enters these cases. Seriously ill people are often depressed to some degree, especially so if their lives have been inescapable altered by constant pain. It is helpful to quantify pain by a battery of psychological tests and a report for Social Security.

Source: Social Security Newsletter, March 2003

ATTENTION SARCOIDIANS

To those with active or inactive disease and those in remission:

Carefully consider information regarding the interaction of Sarcoidosis, calcium, vitamin D and your particular case. Discuss these issues with your healthcare provider.

Researchers, clinicians, groups of Sarcoidians and individuals, continue to explore answers to the question as to whether or not serum levels of calcium and vitamin D (the 1,25-dihydroxyvitamin D hormone) in Sarcoidians be routinely measured.

Recent studies indicate that the granuloma, characteristic of this disease, produces a vitamin D binding protein. Such activity coupled with supplemental calcium/vitamin D compounds and exposure to natural and dietary sources of vitamin D, could precipitate vitamin D toxicity.

Consensus among concerned parties continues to be elusive.

Sarcoidosis Networking will continue to present the varying perspectives of this topic as the developments present themselves. The intent is not to promote a particular protocol but to present data so that each individual might make informed decisions in their healthcare.

Sidney M. Wolfe, M.D., et al, in their publication *Worst Pills, Best Pills*, 2nd Edition mention the following: "**Early signs** of vitamin D toxicity include: constipation, headaches, loss of appetite, metallic taste in the mouth, nausea or vomiting, dry mouth and increased thirst, tiredness and weakness, increased frequency of urination. **Late signs** of vitamin D toxicity include: bone pain, cloudy urine, weight loss, convulsions, high blood pressure, eyes easily irritated by light, irregular heart beat, itching, mood or mental changes, muscle pain, nausea and vomiting, severe stomach or flank pain."

SARCOIDOSIS
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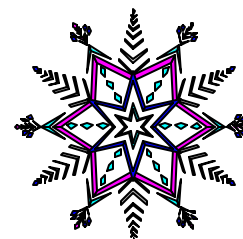
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NSAIDs & VITAMINS

Aspirin and other nonsteroidal anti-inflammatory drugs (NSAIDs) can cause vitamins, herbs and other nutritional supplements to be broken down more quickly in the body reducing absorption and rendering them less effective. According to the Arthritis Foundation, to help minimize interactions, take your supplements two to three hours before or after taking an NSAID. The idea is to wait for one to be ingested and absorbed before taking the other.

Source: *Arthritis Today*, Nov/Dec 2002, pg 69



Women's Health:

PUZZLING OVER PAP

For over 50 years the PAP (Papanicolaou) smear test has been one of medicine's best success stories. Through those years as technology advanced, so too did the procedures to obtain more accurate readings for detecting disease.

The goal of Pap screening is to identify and remove any precancerous tissue and prevent invasive cancer from occurring, according to [Mayo Clinic Women's Healthsource](#), May 2003.

New guidelines set up by a panel of experts convened by the American Cancer Society (ACS) indicate Pap tests should begin about 3 years after the start of vaginal intercourse but no later than 21 years of age.

When the conventional method Pap (cervical cells smeared on a microscopic slide for examination) is used, the screening should be done every year until you are 30. If the liquid-based preparation of cervical cell smear is used, then the screen can be done every 2 years until the age of 30.

Screening can be spaced every 2 - 3 years after the age of 30 **AND** if you have 3 normal tests in a row. A test result is considered abnormal when other than cervical cells are present. ***It is important to discuss the frequency of Pap smears with your women's healthcare provider.*** The risk of missing abnormal cell changes increases when Pap smears are missed for longer than 3 year intervals reports the Mayo Clinic.

With the new guidelines, women older than 70 who have had 3 or more normal test results in the past 10 years can choose to stop cervical screening. However, you are at risk if you have: 1) a history of cervical cancer, 2) a compromised immune system* 3) or your mother was prescribed diethylstilbesterol (DES) while she was expecting you.

You need not have Pap smears if you had a hysterectomy and the cervix was removed for reasons of cancerous or precancerous conditions. Do continue them according to guidelines if the cervix was not removed.

Choosing to have Pap smears is a good tool to detect invasive cancer early. There is an increased risk of developing untreatable cancer if you have never had a Pap smear or ignored screening within the past 5 years.

Contact the ACS (800-227-2345) for more information.

***Editor's Note:** *Individuals who have sarcoidosis and are taking corticosteroids, chemotherapy (immunosuppressants) or tumor necrosing factor (TNF) inhibitors are considered to have compromised immune systems.*

ROUTINE FOOT CARE

Routine foot care commonly includes the paring, cutting, or trimming of corns, calluses of the foot, and trimming or debridement of the toenails in absence of localized illness, injury, or symptoms involving the foot. Routine foot care, unless qualified is a non-covered Medicare service.

These routine care services are usually performed by the beneficiary, a family member, friend, or designated caregiver. Medicare covers these services only when the conditions under "Indications and Limitations" (I&L) are met. {Sarcoidosis meets those I & L guidelines.

These conditions describe the systemic

diseases and their peripheral complications that may place the patient at risk for infection and/or injury if a non-professional were to provide the routine foot care services.

Medicare covers routine foot care services in the qualified "at risk" beneficiary when these services are performed by a professional, e.g., a physician, typically at a frequency no more often than once every 60 days, unless there is appropriate documentation evidencing the medical necessity for more frequent routine foot care services in individual patients (42CFR 411.15 (L) (2) (ii)).

Men's Health:

PUZZLING OVER PSA

Prostate specific antigen (PSA) blood test is a valuable diagnostic tool and recommended as a monitoring tool for men's health, especially for those over 50. On the one hand it can initiate a process that will allow you to identify cancer in its earliest and possibly most treatable stage. On the other hand, diagnosing cancer after a suspect PSA test results requires a biopsy, reports The Cleveland Clinic, Men's Health Advisory (June 2003).

The prostate is a walnut-size gland, only in men. It is located below the bladder and in front of the rectum. The prostate can also be felt upon rectal digital examination (RDE) during a routine physical exam. A PSA can be requested at the same time routine blood work is ordered as a preventative healthcare measure.

It is normal to have some PSA in the blood stream. A man is considered at risk for prostate cancer if he is Afro-American or has a family history of prostate cancer with his father and/or brother (s). Annual check-ups should then be started at the age of 40 according to the American Cancer Society (ACS).

A normal PSA level is considered 2.5 - 4.0. Conditions that can raise PSA levels include: benign prostatic hyperplasia, commonly known as enlarged prostate, (BPH); infected or inflamed prostate; biopsy or operation on the prostate; or cancer cells in the prostate gland. A relatively low PSA simply means less risk of developing cancer; however, it is not an absolute monitor and should be accompanied by other recommended diagnostic testing which can include ultrasound and/or biopsy when indicated. "Men should not have routine base-line biopsy," said Dr. John Corman, MD, Urologist and Prostate specialist at Virginia Mason Medical Center in Seattle Washington.

Early prostate cancer usually has **NO** symptoms. Once the cancer has grown it may cause discomfort or problems urinating, blood in the urine, or a variety of other symptoms, reports the ACS.

PSA alone cannot determine if cancer cells are present. Cancer diagnosis must be made by biopsy. It can be done at the time of prostate ultrasound. This causes only a small amount of discomfort. Follow-up with the physician is important.

Do not fear having the tests you need to rule out or detect cancer. The most successful treatment for cancer is to be treated in the early stages - the earlier the better.

For more information contact ACS at 800.227.2(PSA)345 and/or discuss it with your physician.

CRACKED AND IRRITATED MOUTH CORNERS

Saliva contains small amounts of yeast, which can break down skin at your mouth's moist edges, causing inflammation and fissures. To destroy the yeast, Charles Camisa, head of clinical dermatology at the Cleveland Clinic Foundation, suggest dabbing an over-the-counter antifungal cream onto the raw areas twice a day for two weeks.

After applying the antifungal, pat a bit of zinc oxide cream onto the raw spots to prevent saliva from lingering on your skin as it heals.

If the cracking is really on your lips, slick on a lubricating lip balm such as to keep your pucker soft. Constantly licking your lips will only make the chapping worse.

If your skin doesn't improve after two weeks, call your doctor; you may need a prescription drug to control the yeast.

Source: HEALTH magazine, Nov/Dec 1999

Note: Edited for publication.



TEA A Good Friend

All teas—green, black, and red (but not herb teas)—contain a range of beneficial chemicals that may reduce the risk of many cancers and that act as antioxidants. Drinking tea regularly may protect arteries from plaque build-up. Tea does not, as was once believed, promote bone loss.

Source: University of California, Berkeley WellnessLetter Healthy Eating

AROUND THE COUNTRY

EVENTS



September 20, 2003

ILLINOIS and

MANY OTHER STATES

Annual Walk-A-Thon, in many areas coordinated by the National Sarcoidosis Society, Inc. For information about this in your area, call. 773.536.7756



September 26-27, 2003

WASHINGTON

Seattle—11th Annual Conference on Sarcoidosis at the Wyndham Sea-Tac Hotel. For conference information. Call 253.891.6886 For hotel reservations call 800.996.3426. To share a room, call Lynn 253.471.0423



October 24-25, 2003

FLORIDA

Orlando—Sarcoidosis Patient Conference will be at the Hyatt Orlando Hotel. Hotel Reservations must be made by October 2, 2003. To make reservations call 800.233.1234

For more detailed information call 901.766.6951

SKIN CANCER ... THE ABCDs

Malignant melanoma is a deadly form of skin cancer. However, when it is found early, treatment can be very successful. Monthly self-examination is the best way to become familiar with the moles, freckles, and spots on your skin. A change in a mole or spot may be the first sign of skin cancer.

Malignant melanomas do not look like normal moles. A handy way to remember the features of melanoma is to think of ABCD:

- A. **ASYMMETRY** – One side of the mole doesn't match the other side. Normal moles are round or oval.
- B. **BORDER IRREGULARITY** – The edges of the mole are uneven, scalloped, or notched. The edge can look blurred. Normal moles have smooth, even borders.
- C. **COLOR** – The mole may have different shades of brown or black, and possibly spots of red or blue. Normal moles are usually a single shade of brown.
- D. **DIAMETER** – Any mole or growth larger than 6 millimeters (about the size of a pencil eraser or ¼") is a matter of concern. Normal moles are usually smaller.

If in doubt, please contact your dermatologist.

How To Examine Your Skin

Careful examination of your skin every month will improve your chances of finding early warning signs of skin cancer. This is especially

important if:

- you have fair skin and sunburn easily
- you have had several blistering sunburns
- you have a lot of moles on your body

Examine your skin in a well-lighted room using a full length mirror and a smaller hand mirror. Undress completely and examine every inch of your skin, including hard to see places. You may want to have someone help you.

1. Examine your entire face, lips and eyelids, scalp, neck, and tops of your ears.
2. Examine the front and back of your body. Raise your arms and look at your sides. Check the skin under your breasts.
3. Check all sides of your arms and hands, between your fingers and your fingernails.
4. Examine back and front of your legs. Use hand mirror, scan buttocks and genitals.
5. Sit down to check your ankles and feet, including the soles and between your toes.

Contact your healthcare provider right away if you notice any changes in your skin such as a new mole or change in an existing mole.

Source: Glaxo Dermatology, July 1996

SARS: A MOVING TARGET

Severe acute respiratory syndrome (SARS)—the potentially fatal respiratory infection that has hit China, Canada, and several other countries hard—is serious. Most Americans need not worry about SARS yet. As of April 29, SARS had infected 41 Americans and killed none. Experts do not yet know if certain characteristics make people more or less vulnerable, but children seem to be less severely affected than adults.

SARS is caused by a newly discovered coronavirus, other types of which cause the common cold.

SARS begins with a fever of at least 100.4 degrees Fahrenheit, that is sometimes accompanied by chills, aches, or general discomfort. At the outset, some people also experience mild respiratory symptoms. Within a week, SARS patients typically develop a dry cough, which may lead to seriously impaired breathing.

If you suspect you have SARS, visit a physician, but call ahead so healthcare personnel can take precautions against transmission. Also, remember that even if you have SARS-like symptoms, the Centers for Disease Control and Prevention says you are probably not infected *unless* you have recently had contact with a SARS patient; visited mainland China, Hong Kong, Singapore, Hanoi or Toronto; or if you have had contact with a traveler from one of those destinations.

For the latest information on this rapidly changing epidemic, visit www.cdc.gov/ncidod/sars/ and/or www.who.int/crs/sars/en/

Source: Massachusetts Medical Society: HealthNews, June 2003

Golden Oldie

How To Spot An Unproven Remedy

With all the new treatments being touted, separating what is safe and proven from what isn't may seem impossible. But it isn't as hard as you might think. Here are some guidelines.

- Be wary of any product that claims to work for all variants of a disease as well as other health problems. For example, treatments for the many forms of arthritis vary and there isn't one treatment known that works on every one.
- Be wary of any product that uses only case histories or testimonials of "satisfied users" as proof that it works. Anecdotes can't replace the assurance of effectiveness and safety that comes from scientific study.
- Only use products that come with printed directions for use or warnings about side effects. All medications approved by the FDA are required to list recommended dosages and precautions on their labels.
- Use products that list contents. Avoid products that are describe as "harmless" or "natural." Some "miracle drugs" are simply more expensive versions of common products like aspirin. Others, labeled as "natural," aren't necessarily "harmless". Many natural ingredients, such as bee venom, can be dangerous.
- Question any treatment that claims to "cure" a disorder like arthritis. Currently, there is no known cure for many diagnoses. If there were such treatment, many people would know about it, particularly your doctor.
- Avoid products that claim to contain a "secret formula" or are only available from one source. Legitimate scientists share their discoveries so that the results can be reviewed and questioned by other experts in the field. Once proven safe and effective, treatments are made available from many different medicalcare providers, not just a single person or company.

Source: Arthritis Today, Jan-Feb 89, Jan-Feb 82, Jan-Feb 97.

LEAVES OF THREE, LEAVE THEM BE

With leaves usually grouped three to a stem, poison ivy and poison oak are two common causes of a severe allergic skin reaction call allergic contact dermatitis. Other plants that can cause a reaction in some people include sumac, heliotrope (found in deserts of the Southwest), ragweed, daisies, chrysanthemums, sage-brush and wormwood.

If one of these comes in contact with your eyes, face or genital area, or if you have a severe reaction, contact a doctor or poison control center promptly. In all cases:

- Immediately wash the oily substance left by the plant (resin) off your skin, using soap and water. If done within the first 5 to 10 minutes of contact, this can help avert a reaction.
- Use soap and water to wash any clothing, including footwear and shoelaces, and any jewelry or other objects that may have come in contact with the plant—the resin may cling to the article.
- If you develop a rash, try not to scratch it. Take cool showers or use cool, damp cloths to relieve the itch.
- Cover open blister with a sterile gauze.

Over-the-counter preparations (calamine lotion or hydrocortisone cream) or a paste of baking soda or Epsom salts mixed with water can ease itching.

Source: MAYO Clinic Health Letter, May 2003

APPLYING DIFFERENT CREAMS

As long as you finish with a broad-spectrum sun block, experts say you can slather on lotions in pretty much any order you please. There's a certain logic to starting with a product - such as retinol, vitamin C, beta or alpha hydroxy lotions - so it's close enough to the skin for proper assimilation. Allow it to absorb for a few minutes before applying the next cream. This avoids diluting any of the first product's active ingredients.

If tretinoin is part of your routine, make sure the other lotions you use are labeled "Retin-A compatible," says Patricia Engasser, clinical dermatology professor at Stanford University. "Some creams can inactivate it."

To keep from feeling trapped under a layer of emulsions, split your creams or lotions between A.M. and P.M. routines to give your skin some room to breathe.

Source: HEALTH, Nov/Dec 1999

Daily Living Skills for Sarcoidosis

10th Annual Conference on Sarcoidosis, Round Table

Eddie Glenn, PhD., Sarcoidian and

Professor of Counselor Education, Illinois State University

Report on Q's, A's and Hints by a Sarcoidian

DRY-EYE DISCOMFORT

- Pause often to rest your eyes and blink when reading, watching TV, or working for long periods at a computer.
- Do NOT use eye drops for reducing redness. These can make dry eyes symptoms worse.
- Use only "preservative free" artificial tears.
- Ask your doctor about special shields that attach to the side of eyeglasses or sunglasses. These reduce air circulation over the eyeballs to cut down on evaporation.
- Use a humidifier in the room you spend the most time in during the day and in your bedroom at night. This may decrease tear film evaporation.
- If you wear contacts, take them out when you don't need them and lubricate your eyes.

Source: The Cleveland Clinic Men's Health Advisor, vol 5 No 5, May 2003

Q: I try to loosen-up in the morning; what should I do on the days when I can't even get dressed?

A: The body is not a machine. It is not designed to produce endlessly. Engage in daily activities, whenever you can. Keep your cardiovascular system healthy and the muscles toned with exercise. Even when lying down or reclining, one can move parts of the body [to maintain range of motion and] tone. On days you feel fatigued, do what you can.

Q: I never had to stay in bed. Lately, I have gone from my bed to the couch. I have routine rising and bedtimes. I often don't sleep all night and even then, I don't sleep well. On a good day, it takes about an hour before I can get around. I work on the computer a lot. I take the prescribed medications and have meals about 7:30am and 3:00pm

A: That's not good for you. It is too long to wait between meals. You're current meal patterns place your body into the fasting mode, similar to the mode that the body enters during sleep. It's not a healthy regime. You aren't giving your body the food it needs to function consistently and effectively. Adjust your mealtimes to a schedule of more frequent, small meals about 3 to 4 hours apart. Drink fluids at least every 2 hours. Reasonably spaced food and beverage intake will hopefully maintain your energy levels. Note your environment, your work habits and the day's previous activities. Divide activities into shorter sessions.

Q: I have Sarcoid in the eyes, lungs, hands and feet. Under my doctor's supervision, I'm on prednisone, but titrating downward [slowly reducing the amount], with the intent of discontinuing the steroid. I have diabetes and that's a battle. My blood sugar is always high. I've tried to manage that with proper nutrition and medication. It seems to help. I've also done some fasting.

A: Fasting can be good, but it needs to be monitored. Fasting does not lower glucose levels. It can be tricky trying to manage diabetes along with Sarcoidosis. You need a supportive prime care physician (PCP) to coordinate the management of your healthcare. The PCP could refer you to specialists such as an ophthalmologist (eyes), a pulmonologist (lungs), a rheumatologist (immune system disorders) and an endocrinologist (diabetes). Initially, bring copies of your medical records and lab results to each of the physicians. Advise them that you would like each of them to be a part of your healthcare team. The cooperative healthcare arrangement, with you as an integral member, would be in your best interest.

Hints from Dr. Glenn:

Seek informed and concerned physicians. Ask doctors specific questions about how the Sarcoid has affected your lungs, eyes, or other body systems. Take someone with you to record the information. You could then more easily relate to your loved ones and care providers what has been learned. It is important to keep every appointment even if it might be physically or emotionally difficult at times.

Dr. Glenn advised that the keeping of a journal and mental health counseling are important. She reflects on what she doesn't miss, like stress.

Evaluating one's priorities is absolutely necessary. She shared that for her, the managing of her personal health is more important than when she will return to work or the state of her finances. According to Dr. Glenn, lifestyle adjustments are paramount in accomplishing the goal of doing and enjoying what one can do and not focus on the losses of health and identity that one has experienced.

Medicine is an art and a science, though not an exact science like mathematics, observed Dr. Glenn.

Sarcoidosis is not a high priority disease for researchers. We, as patients, must continue to share information and participate with the healthcare community of researchers, clinicians, academics and providers in the quest to know and cope with this enigmatic disease. This collaboration is a partnership.

Note: Edited for publication.

10 POWERFUL SUGGESTIONS

1. Thou shall not worry, for worry is the most unproductive of all human activities.
2. Thou shall not be fearful, for most of the things we fear never come to pass.
3. Thou shall not cross bridges before you come to them, for no one yet has succeeded in accomplishing this.
4. Thou shall face each problem as it comes. You can only handle one at a time anyway.
5. Thou shall not take problems to bed with you, for they make very poor bedfellows.
6. Thou shall not borrow other people's problems. They can better care for them than you can.
7. Thou shall not try to relive yesterday for good or ill, it is forever gone. Concentrate on what is happening in your life and be happy now.
8. Thou shall be a good listener, for only when you listen do you hear ideas different from your own. It is hard to learn something new when you are talking, and some people do know more than you do.
9. Thou shall not become bogged down by frustration, for of it is rooted in self-pity and will only interfere with positive action.
10. Thou shall count thy blessings, never overlooking the small ones, for a lot of small blessings add up to a big one.

THINK...ZINC!

Most people know that vitamin C is a powerful antioxidant and that calcium is important for strong bones. Not all vitamins and minerals are quite as well known. If you are the type of person who likes to read the cereal box while you eat breakfast, maybe you've noticed your cereal is "fortified with zinc."

What is Zinc and Why is it Important to Our Diet?

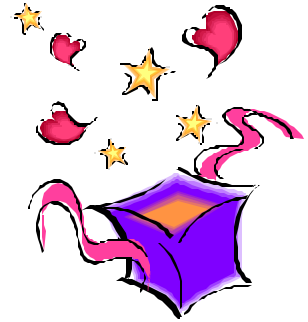
Zinc is an essential mineral found in almost every cell. Zinc supports a healthy immune system, is needed for healing, and helps maintain your sense of taste and smell. Zinc also supports normal growth and development during pregnancy, childhood, and adolescence.

Zinc is found in a wide variety of foods. Red meat and poultry provide the majority of zinc in the American diet. Oysters contain more zinc per serving than any other food. Other good food sources include beans, nuts, whole grains, fortified breakfast cereals, and dairy products.

Eating a good variety of the foods listed above, including fortified cereals, makes it easier to consume the U.S. Recommended Daily Allowance (RDA) of zinc. Anyone considering taking a zinc supplement should first see if they can meet their needs with dietary zinc sources and fortified foods.

For more information about dietary guidelines for Americans, visit
www.ars.usda.gov/dgac

Source: National Institute of Health



WHAT IS LIFE?

Life is a Challenge, meet it
 Life is a gift, accept it
 Life is an adventure, dare it
 Life is a sorrow, overcome it
 Life is a tragedy, face it
 Life is a duty, perform it
 Life is a game, play it
 Life is a mystery, unfold it
 Life is a song, sing it
 Life is an opportunity, take it
 Life is a journey, complete it
 Life is a promise, fulfill it
 Life is a beauty, praise it
 Life is a struggle, fight it
 Life is a goal, achieve it
 Life is a puzzle, solve it

--Anonymous



SKIN CARE DURING TREATMENT

Skin sensitivity is common with immunosuppressant therapy. Here are some things to gently care for your skin:

- Use appropriate skin care products that won't irritate skin, as recommended by your doctor.
- Avoid rubbing, scrubbing or scratching.
- Wash skin using lukewarm water and mild soap. Pat dry.
- Wear loose clothing.
- Limit exposure to sun and always use sunblock.
- Consult with your doctor can regarding chronic skin problems.

STRESS RELIEF: SPEND SOME QUALITY TIME ON YOURSELF

Occasional stress can help you feel more alive.

But feeling constant stress is no way to live.

Excess stress can hurt your physical and mental health. Researchers have linked stress to a variety of ailments, including asthma, ulcers, autoimmune diseases, aches and pains, depression, anxiety, and heart, sleep and skin problems.

Relieving stress may keep you from getting sick or help you recover more quickly. The American Medical Association suggests these steps.

Take care of your body. Eat healthful meals and snacks. Back off on caffeine, saturated fat, sugar and salt. Don't smoke, and know the risks of drinking alcohol.

Try to get 30 minutes of moderate exercise, such as walking, on most days.

Find a workout you enjoy so you'll stick with it. Do simple stress-reducing exercises, such as stretching at your desk. Get enough sleep. Learn to breathe deeply from your abdomen.

Give your mind a break. Visit a park, read, cook, play music, volunteer, see a movie, unplug the phone. Remember: You don't have to be perfect. Reduce your commitments and decline new ones you don't want.

Find a good ear. Talk with a friend or family member. If you're considering seeing a mental health professional such as a counselor, social worker, psychotherapist or psychiatrist, your provider may be able to make a recommendation for a referral.

Source: American Medical Association, HealthyLiving magazine, winter 2003

BECOME AN INFORMED HEALTHCARE CONSUMER

You can be a responsible health care consumer. A good way to start is by applying the following questions and criteria to any health information that you read or hear. These should help you sort fact from fiction.

- *Is the recommendation or treatment based on scientific studies?*
- *How effective is the recommended treatment compared to other treatments, or doing nothing at all?*
- *Have the studies been scientifically reviewed and published in respected medical journals?*
- *Do the citations provided include the name, site, and credentials of the investigator(s)?*
- *How well controlled are the studies? Were the treatment groups compared with groups not receiving the treatment?*
- *Have the studies been repeated with the same results obtained in other situations and by other investigators?*
- *What percentage of those who tried the therapy have actually been helped?*
- *Was there some other possible explanation for the results that were obtained?*
- *How safe was the treatment or remedy? Do the benefits associated with the treatment outweigh the potential risks?*
- *Are words such as "breakthrough", "miracle," and "cure" used in the advertisement? If so, it is probably too good to be true.*
- *Is the product sold only through the mail, Internet or door-to-door? Such methods are usually used by people or groups who have to "get out of town fast" when consumers discover that their product does not live up to its claims.*

These steps may seem lengthy and involved. To become an intelligent healthcare consumer, the steps are necessary. Your good health is important to a long, happy and productive life. You wouldn't take your car to the first mechanic you see on a list. Therefore, carefully evaluate all information you see, hear or consider regarding your health.

Source: Heart Matters, Vol. 2, No. 2. Your Heart, An Owner's Manual, American Heart Assoc.

CHOOSING A PHYSICIAN

How you choose a doctor may depend on your health insurance plan. Your plan may allow you to choose any doctor you wish. Some plans may assign you to a doctor or provide you with a list of participating physicians. If you don't know any doctors in your home area, ask friends and family members for their recommendations, or contact the nearest county medical association for a list.

Before making an appointment for your first visit, call the doctor's office and ask the receptionist the following questions:

- *Is the doctor accepting new patients?*
- *For routine visits, how far in advance must you make an appointment?*
 - *To which hospital (s) may the doctor admit patients?*
- *Does the office accept your health insurance plan, or assignment from Medicare?*
 - *What is the doctor's fee for an office visit?*
 - *How long has the doctor been in practice?*

If you are satisfied with what you learn, schedule an appointment with the doctor for an interview or a routine exam. Be prepared for your first visit.

- *If you're changing doctors, have your medical records sent in advance or hand-carry them to the appointment.*
- *Make a list of questions that are important to you. Don't be afraid to ask the doctor to explain further if you don't understand technical terms.*
 - *Bring along a list of your prescribed and over-the-counter medications.*

After your visit with the new doctor, evaluate your experience.

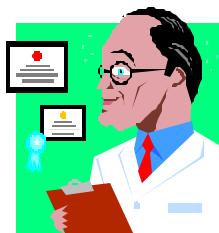
- *Was the facility clean and pleasant?*
- *Was the staff friendly and professional?*
- *Were patient education materials or programs available?*
- *Did the doctor seem to be a caring person? Agreeable to being part of a team?*
- *Did the doctor explain things in a way that was easy for you to understand?*
 - *Did the doctor encourage you to ask questions?*

If your experience was not what you wanted it to be consider your alternative. You may want to talk to the doctor about your concerns. If you are still not satisfied, you may want to learn if your health care plan allows you to choose another doctor. If it does not allow this, share your concerns with your plan administrator.

Doctors are not your only source of health information. People get health information from a variety of sources.

This includes many outside the medical care system, such as television, newspapers, magazines, friends and family members. Unfortunately, not all of the health information available from these sources is technically sound or medically accurate. You should be justifiably concerned about the reliability of new medical discoveries and treatments.

Source: *Heart Matters*, Vol. 2, No. 2.
Your Heart, An Owner's Manual, American Heart Assoc.



Disclaimer

SNA does not endorse any of the medications, treatments, or 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 physician or pharmacists.



You must be the change you wish to see in the world. Gandhi

TEMPORARILY AWAY??

Newsletters are not held by the Post Office, but returned to SNA requiring the organization to pay a first class postage fee. Newsletter service will not be resumed unless the subscriber notifies the office. Please notify the Editor when and where to deliver your newsletter after each hold.



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

Our deep appreciation to Good Samaritan Hospital, Puyallup, WA for printing this edition of Sarcoidosis Networking

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WHAT'S SARCOIDOSIS NETWORKING ABOUT ???

The newsletter SARCOIDOSIS NETWORKING is published by the Sarcoid Networking Association — individuals with Sarcoidosis and those interested in this disease — six times a year. 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 health-care professionals.

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