



# SARCOIDOSIS NETWORKING



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*"Through Unity and Knowledge Comes Truth"*

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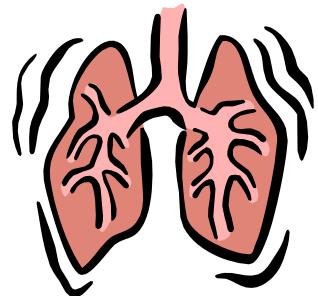
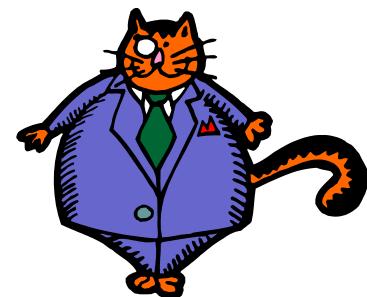
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## NOTICE!

Sarcoid Networking  
Association  
has a new website!  
[www.sarcoidosismetwork.org](http://www.sarcoidosismetwork.org)

## PULMONARY SARCOIDOSIS

By Dolores O'Leary, RN

It was the advent of soft tissue x-rays that facilitated the diagnosis of Pulmonary Sarcoidosis. Until that time the skin presentation of sarcoidosis noted in medical literature as early as 1877 was thought to be the most common form of the disease. Today's progress in understanding the unique immunological and pathological features of Sarcoidosis brings us closer to uncovering the cause and better treatment of Sarcoidosis. Investigators are gradually learning more about the epidemiology and genetic factors that contribute to the development and appearance of the disease.<sup>1</sup> Although significant impairment of pulmonary function is found in about 1/3 of patients, in less than 1% of those Sarcoidians it is the major cause of disability and death.

Onset of pulmonary sarcoidosis is rarely violent, most often insidious and only detected through routine or incidental x-ray. The lungs are the most commonly affected organ, but other parts of the airways (larynx, trachea and bronchi) may be involved, leading to airway obstruction and bronchiectasis.<sup>2</sup>

In the United States, clinical studies seem to indicate there is a higher incidence of Sarcoidosis in Afro-Americans and women in particular, while in other parts of the world, Northern Europeans appear to be at higher risk. Probably the ethnic difference in incidence of Sarcoidosis is due to genetic rather than environmental factors.<sup>3</sup> It is found to be more common in adults - age 20-40 years - but it does occur in those under 10 years and over 60 years as well.

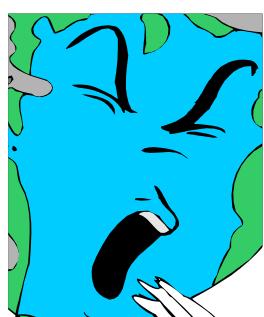
Sarcoidosis is a multisystem disease, that can present in more than one organ, but not necessarily in every patient. However , in over 90% of patients, it is primarily in the lungs and/or intrathoracic (inside the chest cavity) lymph nodes at some time during the course of the disease. About 20-30% of these patients will develop lung fibrosis with permanent loss of function. But only 2-3% will succumb to disease with related complications such as heart failure or thromboembolisms (blood clots).

A mimic of other diseases, Tuberculosis, Valley Fever, Hodgkin's Disease, Wegener's Granulomatosis, Lyme Disease, Fungal and Mycobacterial Lung Disease, to mention of few, makes it very important that all other possible causes of the patients symptoms be ruled out. The fact that it has been found to co-exist with other disorders, requires the patient to be under strict medical supervision to prevent irreversible and possibly fatal complications.

Sarcoidosis has been known to be asymptomatic - without symptoms - only to be detected through routine or incidental examinations. While a physician has been treating the patient for another reason such as preoperative surgical evaluation, or in the aftermath of an auto accident, an abnormal chest x-ray might alert the medical practitioner of something amiss. The patient may not have had any of the usual symptoms of fatigue, malaise, weight loss, low-grade fever, night sweats, or any respiratory symptoms such as cough, shortness of breath (SOB), or chest pain (usually located behind the sternum [breast bone]. This may be as slight as a vague tightness of the chest to as severe and undistinguishable as cardiac pain<sup>4</sup> requiring a complete heart evaluation.

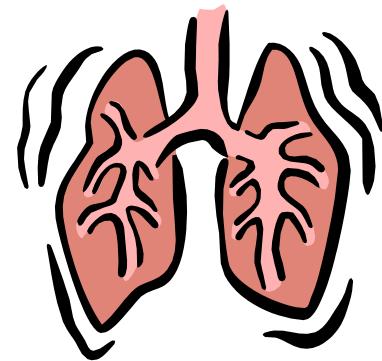
Upon taking a history, the physician might uncover other symptoms commonly associated with Sarcoidosis such as Uveitis (inflammation in the eyes); lachrymal and salivary gland enlargement much like that seen with mumps, a contagious disease; lymph node swelling; or Erythema Nodosum. It is not unusual to have spleen enlargement and/or liver symptoms, much like those found in advanced alcoholism, leading a physician to the misunderstanding that his/her patient is, or has been, a "silent" drinker.

Diagnosis and management of Sarcoidosis has been controversial over the years. General consensus emerged in recent years<sup>5</sup> with the advancement of medical science. The advent of Prednisone and the enhancement of radiological techniques, especially in the last decade, have given the medical community more expansive and less invasive ways to diagnosis and follow disease progression.



These diagnostic tests help the physician understand why and how the patient is affected. It is therefore important that a complete medical history be taken, followed by a thorough physical examination. A patient's cooperation and understanding of what the physician is doing is very important. Knowledge of what various tests and their ramifications has often lead to misunderstanding and unreasonable fears. The classification of chest x-rays is a point-in-question.

A physician will often tell his/her patients that they have a specific stage of the disease. This refers to the classification of the chest x-ray itself, not of Sarcoidosis (which has no such classification), or other disease progression. In this instance this is the terminology used in the medical community to explain what a chest film means: **Stage 0** is a normal x-ray, there are no visible chest changes or abnormalities.



<sup>1</sup> ATS/ERS/WASOG Statement on Sarcoidosis; Gary W. Hunninghake, M.D. et al; Sarcoidosis Vasculitis and Diffuse Lung Diseases; 1999; 16:149-173

<sup>2</sup> ATS/ERS/WASOG Statement on Sarcoidosis; Gary W. Hunninghake, M.D. et al; Sarcoidosis Vasculitis and Diffuse Lung Diseases; 1999; 16:149-173

<sup>3</sup> Basics of Sarcoidosis; Harold Israel, M.D. M.P.H.; G.W. Atkinson, M.D.

<sup>4</sup> ATS/ERS/WASOG Statement on Sarcoidosis; Gary W. Hunninghake, M.D. et al; Sarcoidosis Vasculitis and Diffuse Lung Diseases; 1999; 16:149-173

<sup>5</sup> The Management and Treatment of Pulmonary Sarcoidosis; Carol J. Johns, M.D. American College of Chest Physicians, Pulmonary Perspectives 1992; 9(2)

**Stage I** designates Bilateral hilar lymphadenopathy (BHL), the lung fields are clear, only the lymph nodes are enlarged; **Stage II** will show both BHL and lung involvement; **Stage III** has abnormalities/disease only in the lung fields - BHL; **Stage IV** indicates Pulmonary Fibrosis or scaring of the lung. Review of periodic chest x-rays can give information on the progression or regression of disease such as Sarcoidosis.

Another common diagnostic and evaluation tool for a physician is the pulmonary function test (PFT). Like the x-ray it can be a tool to assess disease impairment. This measurement of lung function is the simplest and most useful guide in assessing the severity of pulmonary damage as disease progresses and is the most practical means of evaluating the response to therapy.<sup>6</sup>

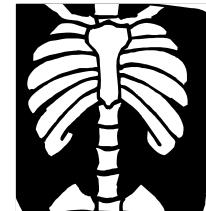
Arterial blood gases (ABGs) determine the amount of oxygen and other elements available to the whole body with exercise or at rest.

Blood tests are many and varied. Serum Antigens-Converting Enzyme (SACE) has been used by some practitioners as a guide to the extent and intensity<sup>7</sup> of disease activity. It is not, however, Sarcoid specific. Elevations may be found in other pulmonary and systemic disorders. Nor is it a reliable guide to the need for treatment<sup>8</sup> as it may reflect activity and total mass of granulomas throughout the body.

Hypercalcemia, high erythrocyte count, elevated sedimentation rate (Sed Rate), raised alkaline phosphatase are other aspects to be evaluated. It is not uncommon for a tuberculin test to be given in order to rule out contagious factors of this mimicking disease.

Electrocardiogram, especially with a complaint of chest pain, should be included among the diagnostic tests. It is valuable when conduction and rhythmic disturbances are present.

The best confirmation of the presence of sarcoidosis is a biopsy. When non-caseating granulomas, the hallmark of sarcoidosis, are present, the disease is almost always a certainty. A granuloma is an organized collection of inflammatory cells; in the center are macrophages, epithelioid cells, multinucleated giant cells; on the periphery are T-lymphocytes, B-lymphocytes, fibroblasts, and polymorphonuclear leukocytes.<sup>9</sup> When a biopsy site outside the lung or chest cavity - such as the skin, mouth or external lymph node- confirms the presence of granulomatous tissue, there may be no need for an invasive procedure such as a bronchoalveolar lavage (BAL) or a mediastinoscopy. An open lung procedure is rarely necessary.



Exact treatment and management of Sarcoidosis, be it pulmonary or any other organ, has not been well defined for all patients. No therapy is necessary in about 50% of cases with no symptoms or even mild symptoms. A physician often chooses the more conservative approach - watch and wait for 24 months.<sup>10</sup> The patient is monitored through PFT's and X-rays. Progressive or incapacitating symptoms require treatment if there is severe discomfort or inability to work. However, with eye, cardiac, or neurological involvement and/or hypercalcemia, treatment is indicated even when symptoms are slight, because in these cases, severe vision loss, fatal arrhythmias or irreversible kidney damage may result<sup>11</sup>

Since first used in the treatment of Sarcoidosis, the initial prompt response after short course corticosteroids has been well documented. Corticosteroid therapy is not curative and has not proved to avert fibrosis.<sup>12</sup> The benefit of this drug is that it minimizes suffering, permits gainful work, prevents eye and kidney damage, also fatal arrhythmias caused by Sarcoidosis.<sup>13</sup> Treatment varies with each patient, some go into remission, while others must have long term maintenance (for many years or a lifetime) to control the disease. On-going therapy may include anti-malarial drugs and cytotoxic (chemotherapy) agents. Radiation has been used in some selected cases, while lung transplantation has been used when there is organ failure.<sup>14</sup>

Complications, caused by sarcoidosis, that have caused lung damage might include hypoxia or low oxygen levels and require supplemental oxygen - nightly or all the time. Fibrocystic Pulmonary (stiff lung) Sarcoidosis usually occurs after a prolonged period without treatment. When coughing is severe, cough suppressants and rest is usually recommended. Chronic lung infections require management with antibacterial agents and may include the oral rotation of these drugs. About 8% succumb to Sarcoidosis, most frequently from pulmonary insufficiency

The nature of disease dictates there should be trusting relationship between doctor and patient. Life patterns change with reduced lung function. The patient should remain as active as possible, adjusting the pace and extent of daily activities without causing shortness of breath. She/he should maintain consistent and ongoing relationships. Sarcoidosis is not contagious and education of the patient's support network is extremely important.

Advances in the research of Sarcoidosis may ultimately result in quicker diagnosis. Better management and treatment of the disease and further investigation may reveal the cause and ultimate cure of Sarcoidosis

<sup>6</sup> Basics of Sarcoidosis; Harold Israel, M.D. M.P.H.; G.W. Atkinson, M.D.

<sup>7</sup> Deciphering The Signs Of Pulmonary Sarcoidosis; Prashant K. Rohatgi, M.D. and Robert A. Goldstein, M.D., Ph.D.

<sup>8</sup> The Management and Treatment of Pulmonary Sarcoidosis; Carol J. Johns, M.D. *American College of Chest Physicians, Pulmonary Perspectives* 1992; 9(2)

<sup>9</sup> Deciphering The Signs Of Pulmonary Sarcoidosis; Prashant K. Rohatgi, M.D. and Robert A. Goldstein, M.D., Ph.D.

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<sup>14</sup> ATS/ERS/WASOG Statement on Sarcoidosis; Gary W. Hunninghake, M.D. et al; Sarcoidosis Vasculitis and Diffuse Lung Diseases; 1999; 16:149-173

## INSPIRATION

### THE BEST THINGS IN LIFE ARE FREE!

Happiness can't be purchased, or bought,  
Because the best things in life are freely sought.  
A good night's sleep, in a soft warm bed,  
The smells of Mama's homemade bread.  
A zillion stars twinkling in the night,  
Morning dew shimmering in the golden sunlight.  
Surprise lilies where nothing dare grow,  
Moonlight reflecting off of a fresh fallen snow.  
Leisurely strolls amid nature's best,  
Blessed with good health, and filled with zest.  
The birth of a child, the success of a friend,  
When a task, or chore, has come to its end.  
Rainbows, butterflies and ladybugs,  
Good news, love letters, and lots of hugs.  
Chirping birds, and puppies fuzzy and sweet,  
Ice cream, pizza, and of course chocolate can't be beat!  
Hearing laughter, and feeling love,  
Being right with God above.  
Extraordinary moments where the spirits connect,  
And those warm and wonderful memories where we go to reflect.  
Happy thoughts, where smiles are found,  
Having lots of loved ones, and friends around.  
Look for such treasures, and you will see,  
The best things in life are priceless and free!

Patty Hadley



### TAKE TWO FOR HEART HEALTH

Here are two ways to reduce high blood pressure:

- = Taking your medication properly
- = Following the DASH Diet

Taking your medication properly includes getting your refills on time and following your doctor's instructions. In addition to taking your medicine as prescribed, the DASH Diet (Dietary Approaches to Stop Hypertension) is an eating plan proven to reduce high blood pressure.

The DASH Diet is recommended by the National Heart, Lung, and Blood Institute. This plan has been proven to reduce blood pressure—often within 2 weeks of beginning the program.

For more information about the specifics of the DASH Diet, please visit the National Heart, Lung, and Blood Institute (NHLBI) website at [www.nhlbi.nih.gov](http://www.nhlbi.nih.gov). Talk to your doctor before beginning a new diet.

Remember to continue taking the medicine your doctor has prescribed for you. A healthy diet and your medicine can help to combat your high blood pressure.

*Source: www.nhlbi.nih.gov*

### SOSKEL TO SPEAK AT CONFERENCE

Norman T. Soskel, M.D., Director of the Sarcoidosis Center in Memphis Tennessee, will be keynote speaker, at the 10<sup>th</sup> Annual Conference on Sarcoidosis. It will be held October 11 and 12, 2002, at the Wyndham Hotel, SeaTac Washington which is just south of Seattle.

Dr. Soskel, has a clinical practice in Pulmonary and Critical Care medicine and is also an Associate Professor of Medicine at the U of Tennessee. The site, [www.sarcoidcenter.com](http://www.sarcoidcenter.com), documents his position as a caring physician open to providing information to inquiring patients.

Returning by popular request is Dr. Doug Paauw, M.D. Internal Medicine specialist at the University of Washington Medical Center and Professor of Medicine at the U of W School of Medicine. His perspective of systemic sarcoidosis is a well-received presentation.

Another popular speaker will be Mel Erickson, a counselor and coordinator of support groups. Her humorous approach of adaptive coping skills and common sense approach to everyday living always send the attendees home with a new outlook on life in general.

“Sleep Apnea” will be presented by Steve Kirtland, MD of Virginia Mason Medical Center, who is the current chief of the Pulmonary and Critical Care Division. Sleep Study Medicine is a subspecialty of this energetic physician.

Topics from Communications between Patient and the Medical Team to Nutrition and Exercise will round out the two day event.

Again this year scholarships to the conference are available, please call Dolores O’Leary, Conference Coordinator for details at 253-891-6886 or contact by email: [sarcoidosis\\_network@prodigy.net](mailto:sarcoidosis_network@prodigy.net). (See flyer for details)

A new location, the Wyndham Hotel, near the Seattle-Tacoma (SEATAC) airport, has many amenities available to their guests including shuttle service. Conference rates on accommodations if reservations are made before September 20, 2002. Call 1-800-WYNDHAM or contact them via their web site at [www.wyndham.com](http://www.wyndham.com).

**ON TO  
SEATTLE**

**October 11 & 12, 2002**

**Wyndham Hotel**



## CRITERIA FOR MENTAL IMPAIRMENTS STANDARDIZED

There have been several changes in the past year in the Social Security mental impairments regulations. The diagnoses that would entitle a claimant to benefits remain the same, but the analysis of whether the condition is severe enough to be disabling has been changed. The regulatory language has been updated to conform with the 1994 DSM-IV (Diagnostic and Statistical Manual-IV). Changes to the more recent edition of the DSM were deferred in the interest of getting the regulations through the comment period and printed.

After a diagnosis has been established, the analysis turns to evaluation of functional abilities. The previous regulations had varying requirements – the new ones standardize the functional criteria for any mental impairment at two,. To be found disabled, a person must have a diagnosis PLUS significant impairments in two of these functional areas. The only exception is mental retardation, which requires just one.

Since depression is a common basis for disability claims, it will serve as an example of how the regulations work. To be considered disabled due to depression, a claimant's records must demonstrate at least four of the following diagnostic criteria:

- Anhedonia – the pervasive loss of interest in almost all activities
- Appetite disturbance with change in weight
- Sleep disturbance
- Psychomotor agitation or retardation
- Decreased energy
- Feelings of guilt or worthlessness
- Difficulty concentrating or thinking
- Thoughts of suicide
- Hallucinations, delusions, or paranoid thinking

If a finding of depression is made, the inquiry turns to whether the depression is sufficiently severe to be disabling. To satisfy this requirement, the regulations now require that the depression result in at least two of the following:

- Marked restriction of activities of daily living.
- Marked difficulties in maintaining social functioning.
- Deficiencies of concentration, persistence, or pace resulting in frequent failure to complete tasks.
- Repeated episodes of deterioration or decompensation in work or work-like situations.

*Source: Social Security Newsletter, March 2002*



## STAY OUT OF TANNING SALONS

A new study in the *Journal of the National Cancer Institute* finds that people who use tanning lights are up to twice as likely to develop common kinds of skin cancer as those who shun them. Contrary to tanning-parlor propaganda, it's more harmful to go to the tanning parlor and get a little bit of exposure each day than to get an infrequent sunburn at the beach, according to the lead researcher. Surprisingly, 28 million Americans still use tanning parlors each year.

*Source: UC Berkeley Wellness Letter, May 2002*

## IS ACUPUNCTURE EFFECTIVE?

A 1997 consensus statement on acupuncture released by the National Institutes of Health states there is clear evidence that acupuncture helps relieve postoperative dental pain. It can also help relieve nausea caused by chemotherapy, anesthetics or pregnancy.

Acknowledging the lack of well-designed and controlled research, the report states that acupuncture may help control pain associated with menstrual cramps, tennis elbow, fibromyalgia, low back problems, osteoarthritis, headaches and other types of pain.

Pain specialists at Mayo Clinic have used acupuncture since 1974. It's one of several options in Mayo's pain treatment program.

Depending on the reasons for seeking acupuncture, you'll have one or several hair-thin needles inserted under your skin. How deeply they're inserted depends on the style of acupuncture (for example, Chinese, Japanese or Korean), where the needles are placed and the reason for treatment .. Needles are sometimes stimulated with an electrical current (electroacupuncture).

To find a qualified practitioner, ask for a referral from your doctor or contact the American Academy of Medical Acupuncture (AAMA). Visit the AAMA Web site at [www.medicalacupuncture.org](http://www.medicalacupuncture.org) or call 323-937-5514. AAMA's members are all licensed physicians with more than 200 hours of special training in acupuncture.

*Source: MAYO CLINIC magazine, Special Report: Alternative Medicine*

## SUPREME COURT NARROWS DISABILITY LAW

On January 8, 2002, the U.S. Supreme Court unanimously ruled that a person who is "disabled" under the Americans With Disabilities Act (ADA) must have substantial limitations in daily functional abilities, not only limitations that affect job performance.

The ADA is the 1990 federal law that protects the civil rights of people with disabilities. Employers are required to make "reasonable accommodations" for disabled workers so they will be able to do their jobs. The law defines disability as "a physical or mental impairment that substantially limits one or more of the major life activities", plus "a record of such impairment," or "being regarded as having such an impairment."

The Court's decision defined the definition of substantial limitations to major life activities as "needs to be interpreted strictly". Therefore a person is not disabled if the condition does not prevent the performance of daily tasks such as dressing, walking, and toileting.

The case involved a woman with a repetitive motion injury who asked her employer (Toyota) to assign her to a job involving minimal use of her arms. The decision, made in favor of the employer, means that, in the future, Courts will have to consider whether a person's disability affects one's functioning in daily living activities, along with the ability to do the job held prior to the disability. Thus, people who do not have serious impairments that interfere with daily functional activities may not qualify for the protection of the ADA law.

*Source: Orphan Disease Update, Spring 2002, Vol XX, Ed 2*

## A MEDICATION SIDE EFFECT THAT MAY BE OVERLOOKED: UNWANTED WEIGHT LOSS

For anyone struggling to lose a few pounds, an unexpected weight loss that occurs without cutting calories may sound like a pleasant surprise. But weight loss isn't always desirable, especially for older people. An involuntary drop in pounds can depress the immune system, diminish valuable muscle tissue, and complicate recovery from illness or surgery. Many studies have also linked it with greater risk for illness and death.

Ironically, a number of medications used to improve health can contribute to unwanted weight loss, mostly via side effects that can turn a person "off" his or her normal eating habits. For example, the bone-building medication Fosamax can cause difficulty swallowing, along with nausea or even vomiting. Some antidepressants can dull appetite. Likewise, cholesterol-lowering medications and anti-histamines can alter a person's sense of taste. Taking several drugs for different conditions only complicates the potential problem. Granted, medications are not the most common cause of unintentional weight loss. Depression, GI disturbances such as ulcers, and cancer are fingered more often. But medicines are frequently overlooked.

Fortunately, the problem can be readily addressed. Doctors may be able to discontinue a medication or substitute one with a different side effect profile, says Grace Brooke Huffman, MD, associate medical director at Brooke Grove Foundation, a long-term care facility in Maryland. A doctor may also recommend weight-gain strategies to counteract the effects of a drug or a combination of drugs. For instance, a patient may be advised to snack on calorie-dense but nutritious foods like cheese, nuts, and dried fruit—or sip fruit smoothies and milkshakes if swallowing is difficult.

Unintended weight loss needs investigating when you've dropped 5 to 10 percent of your body weight in a year or less, or lost 5 pounds in 3 months. If that sounds like you, make an appointment for a work-up.

*"WE MUST TAKE CARE TO LIVE NOT MERELY A LONG LIFE, BUT A FULL ONE; FOR LIVING A LONG LIFE REQUIRES ONLY GOOD FORTUNE, BUT LIVING A FULL LIFE REQUIRES CHARACTER. LONG IS THE LIFE THAT IS FULLY LIVED; IT IS FULFILLED ONLY WHEN THE MIND SUPPLIES IT OWN GOOD QUALITIES AND EMPOWERS ITSELF FROM WITHIN."* - SENECA

## BONING UP

The North American Spine Society has a Back to Health theme this month, is offering two new handouts about the causes of osteoporosis and simple steps individuals can take to prevent it. For "Preventing Osteoporosis" and "Are You at Risk for Osteoporosis?" call 877-774-6337 or go to [www.spine.org](http://www.spine.org).



## Drugs That Can Cause Weight Loss – And How\*

| Drug Name                            | Appetite Loss | Taste Change | Swallow | Nausea/Vomiting |
|--------------------------------------|---------------|--------------|---------|-----------------|
| Dilantin (anticonvulsant)            |               | ✓            |         | ✓               |
| Flagyl (antibiotic)                  |               | ✓            |         | ✓               |
| Fosamax (for osteoporosis)           |               |              | ✓       | ✓               |
| Glucophage (lowers blood sugar)      | ✓             | ✓            |         | ✓               |
| Iron Supplements                     |               | ✓            | ✓       | ✓               |
| Lanoxin (controls heart arrhythmias) | ✓             |              |         | ✓               |
| Levodopa (anti-Parkinson's)          | ✓             | ✓            | ✓       | ✓               |
| Symmetrel (anti-Parkinson)           | ✓             |              |         | ✓               |
| Ventolin (bronchodilator)            |               | ✓            |         | ✓               |
| Zyloprim (anti-gout)                 |               | ✓            |         | ✓               |

Some entire classes of drugs have weight-loss inducing side effects.

| Drug Class                              | Appetite Loss | Taste Change | Swallow | Nausea/Vomiting |
|---|---------------|--------------|---------|-----------------|
| ACE inhibitors (lower blood pressure)   |               | ✓            |         |                 |
| Antibiotics                             | ✓             | ✓            | ✓       | ✓               |
| Anticholinergics (inhibit secretions)   |               | ✓            | ✓       |                 |
| Antihistamines                          |               | ✓            |         |                 |
| Benzodiazepines (sedatives)             | ✓             |              |         | ✓               |
| Lipid-lowering drugs (lower blood fats) |               | ✓            |         | ✓               |
| NSAIDs (pain relievers)                 |               |              | ✓       | ✓               |
| Opioids (pain relievers)                | ✓             |              |         | ✓               |
| SSRIs (antidepressants)                 | ✓             |              |         | ✓               |
| Tricyclic antidepressants               |               | ✓            |         |                 |

\*Adapted from Huffman G, "Evaluating and Treating Unintentional Weight Loss in the Elderly," *American Family Physician*, February 15, 2002.

Source: *Health & Nutrition Letter*, Vol 20, No. 3, May 2002

## CAN DRUG ADS LEAD TO UNNECESSARY SPENDING?

Robert Goodman, M.D., assistant professor of clinical medicine at Columbia University in New York, gives a doctor's view of two competing anti-arthritis drugs: Pharmacia Corp.'s Celebrex, the first drug to make \$1 billion in 12 months on the market, and Merck's Vioxx, with sales of \$1.5 billion in 2000.



"Many people, as a result of direct-to-consumer advertising, think they're more effective at treating pain than (over-the-counter) ibuprofen. That's absolutely not true for pain," he says.

"Vioxx and Celebrex have less gastrointestinal side effects, so there's some benefit for people with ulcers and (other concerns)," Goodman adds. "But they're being prescribed (as painkillers) for everybody, even young healthy people who could be taking Tylenol."

"The only way (drug companies) are going to get physicians to prescribe Celebrex over Vioxx (or vice versa), is to out-promote the other guy, because the drugs are the same in their effectiveness."

Source: *AARP BULLETIN*, March 2002, Vol 43, No 3, Washington D.C.

## SOUNDS GOOD BUT . . .

Some foods sound healthy until you read the fine print.

- o **Fat-free cookies/cakes:** Usually have nearly as many calories as their full-fat counterparts. Calories do count.
- o **Sugar-free cookies/candy:** Just as many calories as the regular foods, just no sucrose (table sugar).
- o **Wheat bread/crackers:** "Wheat" means refined white flour (with little fiber) unless it's preceded by the word "whole."
- o **Fruit drinks, beverages, punch:** Little fruit juice. Basically sweetened water.
- o **Fruit pops:** Only distantly related to fresh fruits or their juices. Basically frozen sweetened water.
- o **Trail mix:** Its "high energy" comes from concentrated calories, largely fat.
- o **All-fruit jam:** No more nutritious than regular jam. Sugar is sugar.
- o **Reduced-fat peanut butter:** Nearly as many calories as the regular stuff (the fat is replaced by corn syrup solids).
- o **Granola bars:** Nutritionally more like candy bars than whole grains.
- o **Spinach pasta:** Very little spinach and no nutritional advantages.
- o **Chicken hot dogs:** Only a little better than pork/beef dogs, unless labeled "reduced-fat."
- o **Frozen yogurts:** Usually lots of added sugar; some have 9 grams of fat per cup. Compare labels.
- o **Bran muffins:** May contain no whole-wheat flour, but lots of eggs, butter, oil, sugar, and other sweeteners. A large one may have as much fat as a Big Mac and more than 500 calories.
- o **Packaged "air-popped" popcorn:** Some brands are loaded with fat.
- o **Banana chips:** More like potato chips than bananas or dried fruit. Lots of fat, calories, and usually sugar.
- o **Fast-food chicken or fish sandwiches:** Usually breaded and deep-fried. Nearly as many calories and as much fat as a Big Mac.

Source: UC Berkeley Wellness Letter, May 2002



### HEADACHE HELPER

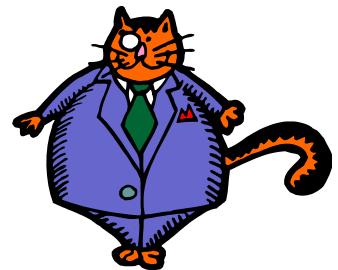
Here's a quick relaxation exercise when you have a headache or feel lot of tension in your face:

- Squeeze your eyes shut for 7 seconds
- Let your lids go limp
- Squeeze your eyes together half as tightly as before
- Relax
- Squeeze again, half as tightly as the last time
- Relax
- Repeat, each time halving the muscle tension
- Repeat this halving exercise until your entire forehead feels free of tension and stressful energy.

Source: Winning the Battle Against Pain and Stress

### WERE YOU BORN TO BE FAT?

Being overweight stems from an interaction of several factors:



- *Genetics.* Your genes affect the rate at which your body accumulates fat and where the fat is stored. A family history of obesity increases your chances of becoming obese by about 30 percent. But other obesity risk factors, such as what you eat and your activity level, are strongly influenced by your family as well.
- *Energy-dense diet.* Foods that are high in fat and sugar are energy dense. That means you're getting a relatively small amount of food but a lot of calories. Fat provides more than twice as many calories as protein or carbohydrates (9 calories per gram vs. 4 calories per gram). Foods and beverages with a high sugar content, such as soft drinks, candy and desserts, are loaded with calories but provide few, if any, nutrients. Remember that low-fat foods don't necessarily mean low-calorie.
- *Physical activity.* Overweight and obese people are usually less physically active than those who are normal weight.
- *Sex.* Muscle uses more energy than fat does. Because men have more muscle, they burn between 10 percent and 20 percent more calories than women do during rest.
- *Age.* As you get older, your metabolism slows, the amount of muscle in your body tends to decrease, and fat accounts for a greater percentage of your weight. These changes reduce your calorie needs. If you don't reduce calorie intake or maintain a good level of physical activity, you'll likely gain weight.
- *Cigarette smoking.* Smokers tend to gain weight after stopping. This may be partially due to nicotine's ability to raise metabolic rate, so when smokers stop, they burn fewer calories. Former smokers often gain weight because they eat more after they quit—food tastes and smells better. But the health benefits of stopping smoking far outweigh the risks of adding a few pounds.
- *Pregnancy.* After each pregnancy, a woman's weight increases an average of 4 to 6 pounds over her pre-pregnancy weight.
- *Medications.* Corticosteroids and tricyclic anti-depressants, in particular, can lead to weight gain.
- *Medical problems.* Less than 2 percent of all cases of obesity can be traced to a metabolic disorder or hormonal imbalances.

Although obesity arises from a combination of factors, the most notable causes are lack of proper diet and physical activity habits. That's good news, because these are things you can change.

Source: MAYO CLINIC SPECIAL REPORT: Weight Control

## EXERCISE AND HYPERTENSION

By Judi Sheppard Missett

We've known for some time that exercise helps patients control hypertension, but recent studies reveal important nuances regarding its effect on blood pressure and physical response to mental stress.

First, low-level aerobic activity appears to reduce ambulatory systolic blood pressure as effectively as does high-intensity exercise, according to a study published in the *Journal of Clinical Epidemiology*. Study participants were divided into two groups. One group exercised at 20 percent maximum work capacity. Both groups experienced comparable benefits.

This is good news, considering that low-intensity exercise may be safer for unsupervised patients and also may increase compliance to a regular fitness program, as moderate physical activity is easier to do.

Second, exercise and weight loss appear to have a positive effect on cardiovascular responses during mental stress. Researchers at Duke University in Durham, N.C. and the University of Colorado gathered individuals who were mildly to moderately overweight and had elevated blood pressure, and split them into three treatment groups:

- Aerobic exercise (45 minutes of biking and walking three to four times a week at 70 percent to 85 percent of maximum heart rate).
- Aerobic exercise and a behavioral weight-loss program.
- No intervention

The participants underwent four mental stress tests before and after a six-month treatment program. The mental stress tests included:

- Simulated public speaking
- Anger recall interviews
- Mirror image tracing, in which they had three minutes to reproduce an image, viewed in a mirror, as many times as possible.

At the conclusion of the treatment period, participants in the two active groups had lower systolic blood pressure, diastolic blood pressure and heart rates in response to the stress tests. They also experienced greater resting stroke volume—amount of blood pumped with each stroke, or beat, of the heart—and cardiac output, the amount of blood pumped by the heart each minute.

These results are notable because there is growing evidence that our response to mental stress and behavioral challenges may be a better predictor of future damage to the cardiovascular system than is resting blood pressure.

So the message is clear for individuals with hypertension: Get active! While aerobic exercise should provide the foundation of your program, it is important to include flexibility exercises to decrease your risk of injury.

The following exercise stretches the hip flexors while challenging your balance.

Kneel on the exercise mat and bring one foot forward, placing your foot flat on the floor in a lunge position. Shift your hips forward, and place your hands on the floor next to



your foot for support. Make sure your lunge is big enough so that your front heel is on the floor and your knee is aligned over your ankle, not over your toes. You can remain in this position, stretching the muscles of the hip and thigh, or raise your arms and work on balance as well. Slowly straighten your torso into an upright position and raise your arms overhead with your palms together. Breathe deeply, and focus on trying to balance without tensing your shoulders, neck or upper back muscles. Hold the stretch for at least 15 to 20 seconds before performing the stretch on the opposite leg. Repeat as desired, four to five times on each side.

*Source: Happiness magazine, Feb 28, 2002*

## HYDROXYCHLOROQUINE OCULAR TOXICITY

By D. Geraint James M.D.  
Royal Free Hospital, London England

The Royal College of Ophthalmologists and the Royal College of Physicians, London have formed a committee to provide guidelines on the safe use of hydroxychloroquine [1]. This committee includes ophthalmologists, a dermatologist and a rheumatologist since chloroquine and hydroxychloroquine are widely prescribed for rheumatoid arthritis, systemic lupus erythematosus and for cutaneous lupus. Sarcoidologists should take note of their conclusions since these quinolones have also been widely prescribed for many years for sarcoidosis, either alone or in combination with corticosteroids and methotrexate. These drugs bind to melanin and interact with nucleic acids, and large doses for many years may give rise to irreversible retinopathy. Irreversible changes include a fine granular appearance to the macula or the more sinister bull's eye maculopathy, which is associated with impaired visual acuity and central visual field disturbance. Reversible changes include corneal epithelial changes and loss of the normal focal reflex. Unfortunately there is no reliable screening test to detect early reversible toxicity before it is identified by ophthalmoscopy. Indeed, the onus is shifted to the patient, who should report visual impairment when taking hydroxychloroquine. He should always read instructions on the bottle containing the tablets and stop taking them if his vision is blurred.

Even more important are the working party's maximum daily dosage recommendations. Hydroxychloroquine should be restricted to 6.5 mg per kg body weight daily. This amounts to about 400 mg daily. Some would go even further and prescribe this dose on an alternate day basis.

The report also draws attention to the use of these drugs in children and in the elderly for the management of juvenile chronic arthritis and systemic lupus erythematosus. Sarcoidosis infrequently involves patients at these extremes of life. The elderly should certainly have a baseline assessment by an ophthalmologist since there is often ocular morbidity from cataract, glaucoma and age-related maculopathy.

### REFERENCE:

- A. Fielder, E. Graham, S. Jones, A. Silman, A. Tulls: Royal College of Ophthalmologists Guidelines: Ocular toxicity and hydroxychloroquine. Eye 1998; 12: 907-909.



## STRESS RELIEF FOR WEIGHT LOSS

By Alison Ashton, Copley News Service

Stress causes chronic overeaters to reach for fatty foods, and a behavioral psychologist at Baylor College of Medicine in Houston is studying whether monitoring body

temperature and using deep relaxation techniques curtails the urge to overeat

"One of the main reasons people give for overeating is that they are stressed, depressed or feeling insecure," says Dr. Ken Goodrick. "They choose comfort foods to feel better and soothe their feelings."

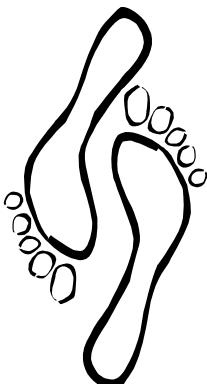
He suggests that if overeaters learn to recognize stress, by using an electric thermometer to measure skin temperature, and use relaxation techniques to cope with negative emotions, they'll be less likely to chow down.

You don't have to wait for the study's results to try it yourself. Goodrick offers these strategies to short-circuit stress and avoid pigging out:

- Devote 20 minutes a day to relaxation. Choose an enjoyable, non-work related activity, such as exercise, yoga or reading.
- In times of stress, use the "747" breathing method to relax. Inhale deeply for seven seconds, hold for four seconds, then exhale slowly for seven seconds.
- Take a five-minute break for each hour of work. Practice deep breathing, stretch or just get up and walk around.
- Pay attention to your body. Stretch sore muscles, especially in the neck, shoulders and back, to relieve tension.

"We are a stressed-out society, and few of us know how to relax," says Goodrick. "Yet we have an over-abundance of food around to comfort us. Through our study, we hope to make people more aware of the relationship between their emotions and eating, and help them learn other ways to cope."

Source: *Happiness magazine*, May 19-25, 2001



## PREVENT ATHLETE'S FOOT

To prevent athlete's foot, keep your feet clean and dry, especially in hot weather. Snug, poorly ventilated shoes and damp, sweaty socks provide an ideal breeding ground for the fungus that causes athlete's foot. Wash your feet daily with soap and water, and be sure to dry them thoroughly, especially between the toes (you can even use a hair dryer on low heat). When you can, go barefoot. The next best thing is to wear sandals. When you wear shoes, wear clean socks, too, preferably ones made of a synthetic material that "wicks" away moisture.

Air out your shoes between wearings—don't wear the same pair day in, and day out. Powder, or even a spray antiperspirant, can help keep feet dry; if you already have athlete's foot, try an over-the-counter antifungal product. Don't use powder containing cornstarch, which may actually encourage fungal growth.

Source: *UC Berkeley Wellness Letter*, March 2002



## NEWS AND VIEWS

### Ibuprofen May Hinder Aspirin's Effects on the Heart

A recent study raises questions about how pain relievers interact with aspirin, and indicates ibuprofen may blunt the property in aspirin that's useful in protecting against heart attack and stroke.

The study results published in the Dec. 20, 2001, *New England Journal of Medicine* looked at how aspirin's blood-thinning ability is affected when other pain-killing medications also are taken. The pain relievers used in the study were acetaminophen (Tylenol, others) and three nonsteroidal anti-inflammatory drugs (NSAIDs) -- ibuprofen (Advil, Motrin, others), rofecoxib (Vioxx) and delayed-release diclofenac (Voltaren, other). For 6 days, each group in the study took an 81-milligram (mg) aspirin in the morning and then one of the other pain relievers 2 hours later. Then for 6 more days, each group took the NSAID pain relievers first, followed 2 hours later by aspirin.

Laboratory tests showed that aspirin's blood-thinning benefit was blunted when ibuprofen was taken before the aspirin. In addition, researchers found that taking three daily doses of ibuprofen undermined aspirin's benefits even when aspirin was taken first. The other painkillers had no effect on the aspirin.

Mayo Clinic physicians caution these are preliminary laboratory results. There's no certainty that concurrent use of ibuprofen and aspirin would negatively affect the incidence of heart attack and stroke. Mayo doctors say it may be wise for people who take aspirin daily for cardiovascular health and regularly take ibuprofen for pain relief to consider, with their doctor, a different NSAID might be appropriate until further studies are done. Mayo doctors also note that the data from the study can't be expanded to adult-strength aspirin (325 mg).

### Thiazide Diuretics and Osteoporosis

A class of medications commonly used to treat high blood pressure may have some positive effect in preventing or helping to treat osteoporosis, according to a study published in the Oct. 3, 2000, *Annals of Internal Medicine*.

People ages 60 to 79 without high blood pressure were randomly assigned to one of three groups. Groups were assigned to take either a 25-milligram (mg) dose or a 12.5-mg dose of a diuretic also used as a blood pressure medication (hydrochlorothiazide), or a placebo.

Researchers found that bone density levels in the hip and the spine increased at higher rates in the people taking hydrochlorothiazide than in those taking the placebo. People taking the higher dose experienced the highest rate of increase in bone density.

Mayo Clinic doctors say that thiazide diuretics show promise as an additional therapy to other osteoporosis medications. The improvements in bone density reported in this study are relatively modest, so these medications generally wouldn't be considered as the sole treatment for osteoporosis. Longer-term studies are needed.

Source: *Mayo Clinic Health Letter*, May 2002

**The soul needs friendship, the heart needs love.**

**Ed Habib**

## Excessive Drinking Raises Risk of Diabetes

Proving once again that moderation is the key to health, a study in the October 15 *American Journal of Epidemiology* suggests that excessive drinking increases the risk of type 2 diabetes (the type that usually develops in adulthood). Ironically, abstinence may also increase that risk (see HN, November), but when it comes to alcohol, more is not necessarily better.

Researchers questioned 12,261 middle-aged people who did not have diabetes about their drinking habits and followed them for three to six years. Compared with men who reported drinking less than one alcoholic beverage a week, men who reported drinking more than 21 alcoholic beverages a week were 50 percent more likely to develop type 2 diabetes. This increased risk was linked largely to the consumption of spirits (such as gin or scotch), rather than beer or wine. Men who drank more than 14 servings of spirits were 82 percent more likely than men who did not drink to develop diabetes. By contrast, the same number of servings of beer or wine did not significantly increase diabetes risk. No similar effects were found in women, but few women drank 14 or more drinks a week, making a comparison of the effects of excessive drinking impossible.

"Avoid excessive drinking, particularly of spirits," advises *HealthNews* Editor Holly G. Atkinson, MD, "but there's no need to stay away from alcohol completely. When consumed in moderation, alcohol appears to reduce the risk of heart disease, stroke, and diabetes."

*Source: HealthNews, January 2002*

## FYI

Companies that pass muster in ConsumerLab's testing for contents may purchase from the firm the right to place this seal on their product. Keep in mind, however, that the seal does not guarantee any label claims. Wordings on the labels of herbal and other supplements often imply health benefits that have not been clinically proven. There's not even any guarantee that what's considered the "standard" dose is necessarily an effective dose. Herbs are not held to the same standards as prescription drugs.

*Source: Tufts University Health & Nutrition Letter, October 2001*

## SLEEP TIGHT



If you want to sleep well, don't drink beverages containing caffeine or alcohol within three to six hours of bedtime.

Alcohol is a depressant, and while it can speed the onset of sleep, you'll wake up again, and you'll sleep poorly the second half of the night.

Caffeine is a stimulant. It's in coffee, black tea, cocoa, and most soft drinks.

The adult liver needs three to six hours to metabolize caffeine (up to 24 hours for older adults). One cup of coffee two hours before bedtime can double the time it takes to fall asleep.

*Source: National Sleep Foundation*

## SMOKING-CESSATION AIDS

|  |   |
|--|---|
| <b>Nicotine Patch</b>                        | Provides stable dose of nicotine for 16 to 24 hours but does not produce peak level until 2 to 4 hours after application.               |
| <b>Nicotine Gum</b>                          | Increases blood level of nicotine within 20 minutes of use, but level begins to decline within 2 hours.                                 |
| <b>Nicotine Nasal Spray*</b>                 | Increases blood level of nicotine within 5 to 10 minutes of application, but it can irritate the nose, throat, and mouth.               |
| <b>Nicotine Vapor Inhaler*</b>               | Similar to nicotine gum in rapidity of effect but is also irritating and requires frequent puffing.                                     |
| <b>Bupropion*<br/>(Zyban, Wellbutrin)</b>    | Must be started 1 to 2 weeks before target cessation date. Should not be used by people with a history of seizures or eating disorders. |
| <b>Nortriptyline*<br/>(Aventyl, Pamelor)</b> | Must be started 2 to 4 weeks before target cessation date. May be problematic in people with heart disease.                             |
| <b>Counseling</b>                            | Especially useful when combined with other smoking-cessation aids. Efficacy increases with time spent in counseling.                    |
| <b>Hypnosis</b>                              | Remains largely unstudied. Anecdotal reports of success unproven.   |
| <b>Acupuncture</b>                           | Does not appear to improve smoking-cessation success rate in randomized trials.   |

\*Requires a prescription.

*Source: HEALTHNEWS, Straight Talk On The Medical Headlines, April 2002*



## HORMONE REPLACEMENT THERAPY (HRT)

### Benefits & Risks:

#### HRT Benefits ---

- Helps prevent osteoporosis.
- May reduce the risk of heart disease.
- Eliminates hot flashes.
- Decreases insomnia.
- Improves energy, mood, and sense of well-being.
- May improve longevity.

#### HRT Risks ---

- Possible increased risk of cancer of the uterus (taking progesterone keeps this risk very small).
- Possible small increased risk of breast cancer with prolonged use (more than 10 years).
- Continued menstruation or breakthrough bleeding.
- Breast swelling or pain.
- PMS with some progestin.

For more information about Women's Health resources and programs in your area, visit the Boeing Wellness Website at: <http://healthy.web.boeing.com>.

*Source: Menopause: The Silent Passage, by Gail Sheehy*

## Around the Country - Around the World

### NEW YORK

#### ENTERTAINMENT EXTRAVAGANZA

to raise money for sarcoidosis and to bring public awareness to the forefront in battling this illness. This event will be held at Adelphi University Ballroom on August 3, 2002. Contact Alicia Sutton, Sponsor & Program Coordinator, through the internet address: [Wsutton59@aol.com](mailto:Wsutton59@aol.com), or you can call (516) 876-2612 day or evening. The postal address is: Alicia Sutton, 25 Westwood Dr. Apt 97, Westbury, NY 11590.

### WASHINGTON

#### 10<sup>TH</sup> CONFERENCE ON SARCOIDOSIS

SeaTac, Washington, October 11 & 12, 2002. See article on page 3 for details. Contact the SNA office at 253-891-6886 for early registration and questions.

### ITALY

#### A PHYSICIAN COMMENTS

Sarcoidosis is diagnosed after exclusion of other diseases, and often other rare causes of granulomatous disease are not even thoroughly investigated. I think there is a lot of work to be done in this field.

One important point, at least in my area, is that people with sarcoidosis do not even often get the right and complete information about their disease, and often are induced to think that the disease is not as serious as it is or can be. Therefore, treatment is sometimes inappropriate or the patients (even nurses) try to stop therapy prematurely because of fear of side-effects.

Moreover, the disease is common in Blacks, and Italy has seen in the last decade a considerable influx of African immigrants. Most general practitioners and family doctors do not know that sarcoidosis is common in Blacks and tend to look only for tuberculosis. This leads to a waste of time and very late diagnoses.

All in all, I have realized that considerable efforts are needed to put sarcoidosis in the right perspective and such efforts must have as targets patients, physicians and also the general population.

Living in Italy, I cannot attend meetings in the States, but I do welcome any correspondence with interested patients and doctors.

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Phone: +39.347.2435479  
Fax: +39.045.917259  
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### WORDS YOU SHOULD KNOW

Generic Medicine: A drug that has the same medicine as the brand name drug. It will work in the same manner as the brand name drug, but often cost less.

Prescription Medicine: A drug that can only be bought with permission from the doctor.

Pharmacist: The person in the drug store who is trained to fill your prescription and answer questions.

Source: FDA-Office of Women's Health

### Healthwise Patient

#### WHEN SHOULD ONE GO TO THE EMERGENCY DEPARTMENT?

Summer is here and that means more activities—and sometimes more accidents and injuries. Each year, more than 40,000 of our neighbors turn to the emergency department physicians and nurses for expert care.



When a person's condition seems life-threatening or one needs the help of a paramedic, immediately call 911. One should go to the hospital if you or a family member experiences any of the following:

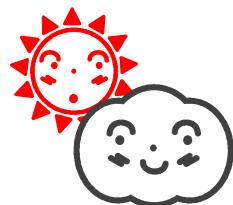
- ◆ Severe pain, especially in the chest, or pain that radiates into arms, legs or jaw; abdominal pain
- ◆ Sudden major injuries, especially to the head or neck; severe burns; or bleeding that won't stop
- ◆ Poisoning—if possible, call the 24-hour Poison Help-line at (800) 222-1222 and ask for immediate home treatment advice.
- ◆ Sudden numbness anywhere on the body, confusion, slurring of speech, loss of vision, severe headache or dizziness
- ◆ Breathing difficulties, including shortness of breath or loss of consciousness
- ◆ A bad reaction to an insect bite or sting, or to a medication, especially if breathing is difficult
- ◆ Coughing or vomiting blood, or vomiting that won't stop
- ◆ Suicidal feelings
- ◆ Bring a child to the emergency department for any of the above conditions as well as any type of head injury; severe headache; stiffness in neck, back and other extremities; signs of dehydration; animal bites; severe asthma symptoms and high fever.

We hope you never need the services of the emergency department, but if you or a family member need help, they're always there for you.

Source: St. Clare Hospital Health! Magazine, Spring 2002

### SUMMER-TIME WARNING

You don't have to have fair skin to get a sunburn! Medications can often make one more sensitive to damaging sun rays - even if you are no longer taking the drug, the residual effects can last for many months. As we age, our skin also becomes thinner and more fragile.



Use the strongest protective lotion you can find, even on an overcast day. Don't ignore the reflection of water or snow if you are out of the direct sunlight. Protective clothing is advised. Short or long exposures can cause damage.

If you notice a suspect patch of skin, do have it examined by a physician and rule out any possibility of cancer.

**SARCOID NETWORKING ASSOCIATION**  
**SARCOIDOSIS NETWORKING**  
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**SAVE THE DATES!**

**OCTOBER**  
**11 & 12, 2002**  
10<sup>TH</sup> Annual  
Conference on  
Sarcoidosis  
Seattle WA  
(see page 4)

**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.

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**(If unable to make a donation, no one is refused the newsletter.)**

*Change of Address???*

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**NEW ADDRESS BELOW**

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Phone \_\_\_\_\_  
E-Mail \_\_\_\_\_

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

**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 is 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 care.

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**COMMENTS/RESPONSES**

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