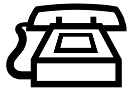

SARCOIDOSIS NETWORKING

VOLUME X Issue 3 May/June 2002

"Through Unity and Knowledge Comes Truth"

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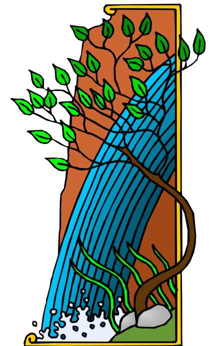

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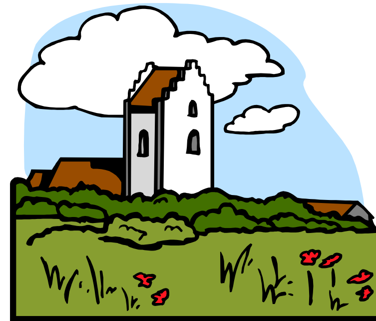

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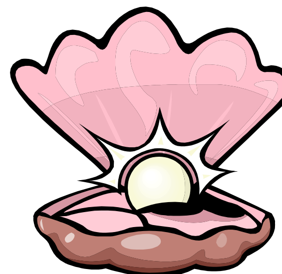


OSTEOPOROSIS
A Complication in Sarcoidosis

Have you or your physician checked your adult height lately? If you have lost more than an inch in height, it could be the signs of early Osteoporosis. Ask your doctor to run a bone density study on you. This simple, non-evasive scan will give you and your physician an evaluation of how well your bones are holding up as your body constantly ages.

Osteoporosis, medically defined as loss of bone mass, silently depletes bone. This makes for more brittle bones that are more susceptible to fracture. The spine and hip bones, which directly support your body, are the most common sites of fracture. Prevention of osteoporosis can save you from a lot of pain and discomfort in your later years. Early detection and treatment can halt the disease and give you better quality of life.

Weakened bones especially in the spine (vertebrae), hips or wrists can fracture easily. Osteoporosis should be suspect in a person who fractures any of these bones with little or no apparent stress.

Women, after menopause, are at the greatest risk of developing osteoporosis. But MEN DEVELOP OSTEOPOROSIS TOO! Caucasians and Asians have a higher incidence than Black and Hispanics, as reported in the NIH Consensus Conference Statement 2000. Other risk factors which elevate your chances of developing osteoporosis at any age include:

- Medications that hasten bone loss, including corticosteroids (i.e., commonly prescribed Prednisone for Sarcoidosis)
- A calcium-poor diet
- Smoking or exposure to second-hand smoke
- A sedentary lifestyle
- Glandular problems such as thyroid dysfunction
- Being underweight or having an eating disorder

Risk factors that cannot be controlled are: gender, family history, ethnicity and bone size. Factors that can be controlled are: a good diet, exercise, weight management and posture, go a long way in prevention and treatment of osteoporosis. Eating a balanced diet with adequate amounts of calcium and Vitamin D can assist your body in preventing bone loss.

The best exercises focus on the weight-bearing bones such as walking or stair-climbing. After you have had a thorough physical examination, follow your doctor's recommendations regarding exercises such as jogging or running. This includes light weightlifting which can strengthen muscles and bones in the upper body.

Maintaining a healthy weight is an important part of any health program. If you are underweight you have a greater risk of developing osteoporosis. The only positive point if one is overweight, is that the bones do more work with the extra weight, there is more estrogen in fat cells and one has more padding to protect bones in a fall.

Remember being told to "stand/sit up tall"? Good posture helps maintain muscle strength in your back, neck and head.

Calcium supplements and Vitamin D are recommended for both prevention and treatment.. The vitamin is necessary in the metabolism of the calcium. Experts recommend that as much calcium as possible should be obtained from daily food intake.

Estrogen (a hormone) is the most widely used drug for prevention of osteoporosis in women. Due to it's undesirable side effects it is not used in men. This drug replaces the female sex hormone levels, which diminish after menopause, slowing the rate of bone loss.

The non-hormonal class of drugs, bisphosphonates such as Fosamax, Didronel and Actonel, stick permanently to the surface of bone, slowing but not halting bone loss. Strict precautions MUST be taken to prevent serious stomach problems. New drugs coming show promise of rebuilding some of the bone lost as people age, said Dr. Michael McClung, director of the Oregon Osteoporosis Center in Portland, Oregon.

Drugs work on the preservation of existing bone but do little to restore bone density or lessen the likelyhood of fractures.

The process leading to osteoporosis occurs gradually. It may not be detected until there is pain or thin bone is noticed on a routine x-ray. Every adult should have an accurate height recorded in his/her medical records. Documentation of stature is a check point if osteoporosis is suspect in later years. The disease can be prevented, delayed or arrested at any age. The earlier you make appropriate lifestyle changes the better your chances of minimal bone loss as you age.

BONE SARCOIDOSIS

Sarcoidosis of the bone (osseus) was described in medical literature in the late 19th Century shortly after the discovery of x-rays by Wilhelm C. Roentgen and articles describing skin lesions by Cesar Boeck.

It usually affects the small bones of the hands and feet but reports have been made where the vertebrae and iliac bone are involved.

As technology improves, so too, do the images of bone lesions and more accurate diagnoses, such was reported in 1992 Prashant K. Rohatgi, M.D. of George Washington University Medical Center, Washington D.C. in Seminars in Respiratory Medicine (Volume 13, Number 6).

In Current Opinion Rheumatology July 2000, Drs. A. Wilcox, P. Bharadwa and OP Sharma write that "diagnosis and recognition of osseous (bone) sarcoidosis is easy but the therapy is disappointing.

Rohatgi reports "skeletal lesions may develop and resolve spontaneously at any stage during the course of sarcoidosis and therefore repeated skeletal survey or radioisotopic bone scanning would be necessary to detect osseus lesions of sarcoidosis."

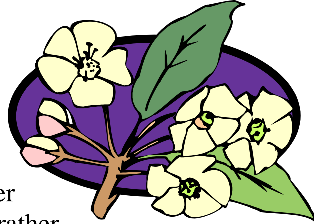
TALK WITH DEE

DEECARESFORU@AOL.COM

Hi! From beautiful Arizona.

It is my prayer that you have a lovely spring. Spring represents "renewal". Let's pray that all people fighting sarcoidosis and other chronic illness will have a healthy spring and will feel—and be—better. We must hold onto this hope. For many, spring can mean change – and this can have positive and negative implications. Change is difficult. Let's face it; there is something safe in the familiar, and letting go is stressful.

Mother's move into assisted living was tough for us, because it represented separation. For over 17 years, due to the sarcoidosis which I fight, we'd lived together. Dealing with change such as assisted living was scary and filled with more questions than answers. What we found was that once Mother settled into an assistive living facility, we could look at the situation from a clearer perspective. We soon realized that the arrangement became a positive in our lives. Mother did not lose her independence, but rather she gained it.

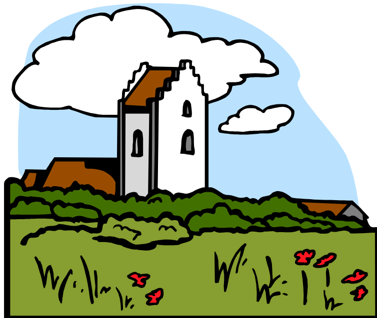


With her own apartment, Mother can maintain the independence that is so important not only to her, but to anyone facing this. If need be, she also has the care of a wonderful nursing staff. This gives us both a sense of peace. I have heard from many people who have told me stories, where the care in assistive living was less than satisfactory. Always this puts a lump in my throat. Before I continue, I want to stress that before you make a move such as this, ask questions … lots of questions. If a red flag goes up, you need to look further until you find the right place. I wish Mother could share with you just one day at her new home, so that you could see that assistive living can be a wonderful way to live. There are days when Mother is so busy with activities, that she makes me tired. The facility welcomes family and even pets. Missy, our cat, and I spent Easter with Mother. As I write this, I'm smiling because the day was so special and so filled with love.

Now it's my turn and I'm facing a new chapter in my life. Due to the ups and downs of sarcoidosis and other related medical problems, I'm selling my home and will be making the same move that Mother made. Do I have any reservations? Maybe a few, but I've learned by traveling this road with Mother, that it will be okay. Losing or giving up what one had, or things that are comfortable in our lives, is not easy.

The bottom line to all this is that the outcome as to how I live will be up to me. I'm determined to follow my mother's example and let this chapter in my life be rich and full. If you face this decision, it is my prayer that you, too, will choose to make the move.

Until next time, God bless you. Love Dee



DRUG RECALLS

Ten drugs approved since 1993 have been withdrawn from the market after reports of deaths and severe side effects. According to the Los Angeles Times, doctors, hospitals and others implicated the drugs as a possible cause in at least 1,000 deaths reported to the FDA. It is believed the number of deaths may be higher because many deaths are not officially reported.

Most of the drugs were not life saving medications. They were for heartburn, weight reduction, pain, infections, diabetes, and blood pressure, among other things. Also in 1988, only four percent of new drugs introduced in the world were first approved in the United States. In 1988, the FDA approved 66 percent of the world's drugs before marketing was allowed in other nations. At the beginning of the last decade, the FDA approved about 60 percent of new drug applications, but today it is approving more than 80 percent of the industry's applications. Critics charge that pushing these drugs quickly through the FDA review process is having a negative public health impact.

The drugs represented at least $5 billion in sales before they were withdrawn from the market. The United States was the last industrialized country in the world to withdraw several of these drugs. In 1994, the FDA reviewed 55 percent of new drug applications on time. In 1998, the FDA reviewed 100 percent of the applications on time. The agency is reviewing about 40 percent more applications today than it did before 1993, and it had fewer resources to do its job.

The FDA Modernization Act (FDAMA), and the Prescription Drug User Fee Act (PDUFA) are responsible for these major changes. Many believe these laws have seriously weakened the FDA. The National Organization For Rare Disorders (NORD) is doing its utmost to remind the government that the FDA is supposed to be a consumer protection agency, and rushing drugs through the approval process sometimes means they are not adequately tested. Erosion of public trust (and the compromising of public health) is the price the agency is paying for faulty drug approvals. Congress also deserves a large part of the blame because it has not provided appropriate funds to the agency. Additonally politicians have continued to apply considerable pressure for the FDA to approve drugs more quickly than is scientifically responsible. It is time to fix the system.

Source: NORD, Orphan Disease UPDATE, Vol 19, Ed 2, Spring 2001

OXYGENATED WATER

Don't waste your money on "oxygenated" water, selling for about $2 per half-liter in health-food stores and gyms. The makers claim that the water is infused with five to ten times as much oxygen as regular water, which will supposedly help your muscles and improve performance. One recent study found that such water did not improve aerobic performance; another found that it did not increase oxygen levels in the blood. The only way to get oxygen into the blood and to the muscles is through your lungs. And even if you could get a little more oxygen into your blood, it wouldn't help—our red blood cells are already saturated with all the oxygen we can use.

Source: U of Calif, Berkeley, Wellness Letter, Wellness made easy, Vol 18, Issue 4, Jan 2002

AGING AND VISION LOSS: STROKE

The news is often sprinkled with articles about the importance of responding immediately to the first signs of stroke as the American Heart Association continues its campaign to get folks to think of a stroke as a brain attack. As with the heart attack, a stroke or brain attack is now considered a medical emergency, in part, because a new clot-dissolving therapy can in many cases dramatically reduce the impact of a stroke if administered within three hours of the attack.

Each year more than half a million Americans suffer a stroke. The American Heart Association recommends immediately calling your doctor or 911 if any of these symptoms occur:

- Sudden dimness, loss of vision, or sudden double vision
- Sudden weakness or numbness of the face, arm or leg on one side of the body
- Sudden, severe headache with no known or apparent cause
- Unexplained dizziness, unsteadiness or sudden falls, especially along with any of the other symptoms

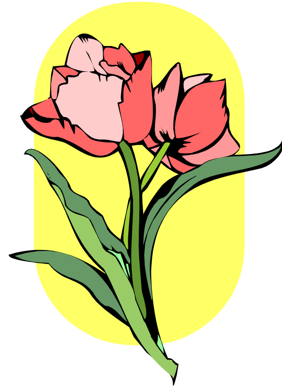
But beyond the urgency of responding to these initial symptoms, we want to take a little closer look at the longer term vision loss that might follow a stroke, how to recognize it and what can be done to better live with such vision loss.

A stroke occurs when there is a sudden disturbance in the blood supply to the brain; in most cases, this is caused by a blocked blood vessel. The other major cause of stroke is a leaking blood vessel. Sometimes warning signs, such as changes in vision, last only briefly. These episodes are often called TIAs, transient ischemic attacks, or mini-strokes. Experts encourage people not to ignore these, but to contact their physician. In some cases, a more severe stroke may be prevented if TIAs are identified and the person subsequently makes certain lifestyle changes and works with their physician to establish an appropriate health care regimen.

Most stroke-related vision loss takes the form of ***hemianopia*** (sometimes called hemianopsia) or blindness ***in one half of the visual field***. Depending on where the stroke occurs within the brain, other forms of vision loss may result, but here we'll focus on hemianopia. While hemianopia can be caused by a variety of medical conditions, stroke is among the most common.

Hemianopia is a functional defect that can affect the right or left side. For example, stroke patients with weakness of the right arm and leg may also have poor vision on the right side. Some people lose sight mostly in the upper or lower part of (the visual field) on the affected side; others lose complete sight on the affected side. Hemianopia will affect both eyes and vision loss can be severe or so slight that many people do not really notice. Most stroke-related hemianopia is ***homonymous***, which means vision loss in the nasal (inner) half of one eye and the temporal (outer) half of the other. In other words, if you draw a vertical line through the visual field, each eye can't see right or each eye can't see left of that line depending on the area of the brain impacted by the stroke.

Such vision loss is also commonly referred to as ***visual field cuts***. Again, the challenge is that people often don't notice these cuts because often it's not completely black on the impacted side, but may fill in with gray.



While there is no specific medical or surgical treatment for stroke-related vision loss, vision may show improvement over time in some patients. But it is still very important to diagnose the loss in order to help patients adjust to how they use their remaining sight.

Careful assessment of vision following a stroke is key to maximizing the success of rehabilitation and long-term adaptation. For example, following a low vision evaluation, some people find that field-expanding prisms can be most helpful. Low vision rehabilitation specialists teach patients how to maximize the use of remaining sight.

If a patient realizes that he/she sees to one side only, the patient might be able to learn to turn to the other side in order to see everything in a room, or on a table. If it is too difficult for the patient to remember to turn, living areas can be rearranged to help that individual to see important details. In the bedroom of a person with a left-hemispheric stroke and right vision loss, the bed can be moved to the left. Similar accommodations can be made in serving a meal; food can be put on the side of the plate where vision remains.

As for reading, materials can be marked to help the reader know where to stop or start. For example, if the patient has right vision loss, a red line drawn down along the right margin would be the signal that the reader has completed the line. If the vision loss were on the left, a red line drawn down along the left margin would help the reader find where to start reading. Another option that works for some patients is to turn a book on its side and read from top to bottom using the visual field that remains.

There are many ways to adapt to stroke-related vision loss. The patient will be most successful if his/her loss is fully identified and if family, friends and caregivers also understand the parameters of the loss so that adjustments can be made accordingly. For more information about how to respond to stroke and stroke-related vision loss, contact the American Heart Association's Stroke Connection hotline at (800) 553-6321.

Source: Comm. Services for the Blind and Partial Sighted, 1998, Reprinted from the CSBPS newsletter Prism, VI. 2, Summer 1997

FYI

How Does A Knee With Osteoarthritis Differ From A Healthy Knee?

In a normal, healthy knee there is fluid. This fluid acts as both a cushion and a lubricant. In a knee with osteoarthritis, however, the fluid may have lost these features. This can be one of the reasons you or someone you know feels pain in the knee.
Source: SYNVISC HYLAN G-F 20

Social Security

CHRONIC FATIGUE SYNDROME RECOGNIZED

At long last, recognizing the legitimacy of Chronic Fatigue Syndrome (CFS), the Social Security Administration has just issued a new ruling on this illness. There have been frequent instances of cases being denied by decision-makers who do not believe in the existence of CFS. The new ruling sets out careful criteria for establishing disability based on CFS.

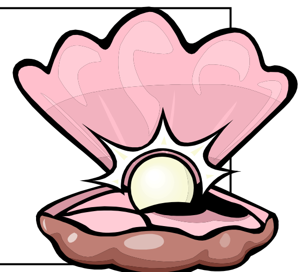
- CFS will be evaluated as any other impairment, on the basis of severity and interference with capacity to work. If fatigue, pain or other symptoms are found to have more than a minimal effect on ability to work, the decision-maker must consider this as a severe impairment and consider pursuing additional medical development.
- For SSA eligibility, any disability must last, or be expected to last, for a consecutive twelve month period. CFS must not only be documented to meet the medical requirement, it must be documented that the severity level prevented full-time work for the entire period. As is the case with any disabling condition, a diagnosis alone is not enough. The clinical signs and lab work must support the diagnosis.
- Medical documentation is required. Although there are no specific laboratory findings for CFS, the following "may be relied upon" by adjudicators: elevated Epstein Barr antibody titres; an abnormal MRI brain scan; neurally mediated hypotension, or any other laboratory findings that are "consistent with accepted clinical practice."
- Third party information will be considered from non-medical sources. Under the regulations, these would include nurse practitioners, naturopathic physicians, social workers, and also neighbors, friends, clergy and rehabilitation counselors.
- Information from a claimant's diary will be considered in assessing credibility.

The new regulation recognizes that the Center for Disease Control (CDC) definition of CFS is in conflict with the SSA definition. The CDC diagnosis requires only patient complaints and reports to make the diagnosis, while Social Security requires medical indications and laboratory findings.

As additional research is done to establish the cause and cure for CFS, SSA may revise this regulation. For now, it is a vast improvement that the agency recognizes that CFS can be genuinely disabling.
Source: Social Security Newsletter, August 1999

PEARLs *OF WISDOM*

- **P**roceed with positive thinking
- **E**xercise regularly
- **A**dopt a balanced diet
- **R**emember to take your medication every day
- **L**isten to your health care provider



Source: AppleSeeds, Aetna US Healthcare, Fall/Winter 2000

TAKE STEPS TO EAT HEALTHIER AND BE MORE ACTIVE

If you have recently been diagnosed with diabetes, you are probably overwhelmed with the lifestyle changes you need to make in order to control your blood glucose levels. Don't panic! Meet with your doctor and a qualified dietitian to set up goals and work toward them.

Eating right with diabetes is no longer about following a "diet." It's about making healthy food choices and eating similar amounts of foods at regular times. You may need to change your eating habits, but you can do so gradually. Don't expect to make quick and drastic changes just because you now have diabetes. Think about your current eating habits and food choices, then think about a few easy changes you can make: adding one more serving of vegetables a day, switching to fat-free milk, or eating smaller portions of foods high in fat or carbohydrates.

Becoming more active is a way to lower blood glucose levels. If you are not currently involved in a regular exercise routine, start with a few minutes of activity each day. Walk to the bus stop, work in the garden, clean the house or ride a bike. Gradually move up to a total of 30 minutes of activity each day. Being active not only helps your blood glucose levels, but also helps control your blood lipids (fats) and blood pressure!

Taking these "baby steps" toward a healthier lifestyle will enable you to take control of diabetes. Start with attainable goals; write them down along with the steps you will take in achieving them. Review them and redefine them as you progress!

If you would like help finding a dietitian or diabetes education program in your area, try the following organizations:

- American Diabetes Associations at 1-800-DIABETES or **www.diabetes.org**
- American Association of Diabetes Educators at 1-800-TEAMUP4 or **www.diabeteseducator.org**
- American Dietetic Association at 1-800-366-1655 or **www.eatright.org**
- Or ask your healthcare provider for a referral.

Source: HEALTHSITE, 2001

Tip To Be A Positive Person

Sometimes problems drive us to negative people who love to listen to our problems and to share their problems with us. Listening to them can make us even more unhappy. Find a group of positive friends, write down their phone numbers and call when you face problems.

Source: Be A Positive Thinker ***Happiness May 2001***

TAKING CORTICOSTEROIDS

by Debbie Holland , Judith Kay and Dolores O'Leary

There are many names for corticosteroids, which act as anti-inflammatory drugs; some are generic and some are brand names, Prednisone is the most common brand. Corticosteroids are formed naturally in the adrenal gland. They are not prescribed without due consideration to the effect they have on the body and the suppression of the body's ability to make this hormonal steroid. As a prescription drug, it is available in many forms: eye drops, eye and skin ointment, powders, nasal and oral inhalers, pills, injections (into muscles, joints or veins) etc. Do not use over-the-counter medications containing "cortisone" or similar compounds without first consulting your physician.

NEVER STOP TAKING CORTICOSTEROIDS SUDDENLY!

Before starting corticosteroids, discuss the drug and all its effects on the body with your physician. Discuss its effect(s) on all medications, regularly and occasionally taken, be they prescription or over-the-counter! Tell your doctor about unusual or allergic reactions you have had to any medications, especially to Prednisone or other adreno-corticosteroids.

Because this drug can cause glaucoma and/or cataracts with long-term use, your doctor may want to have your eyes examined by an ophthalmologist periodically during treatment. This drug can raise blood sugar levels in diabetic patients. Blood sugar should be monitored carefully with blood or urine tests when this drug is started. A Bone Density study is advised before starting corticosteroids as they contribute to osteoporosis.

You should not be vaccinated or immunized while taking this drug. This medication decreases the effectiveness of vaccines and can lead to overwhelming infection if a live-virus vaccine is administered.

Tell your doctor if you: have had TB; have thyroid, liver, kidney or bone disease; have ulcerative colitis, diabetes, seizures, history of ulcers, Myasthenia Gravis; have had clots in legs or lungs, emotional instability, heart disease, high blood pressure, or osteoporosis.

Be sure to tell your doctor if you are pregnant. Prednisone crosses the placenta. Also tell your doctor if you are breast-feeding an infant. Small amounts of this drug pass into breast milk and may cause growth suppression or decrease in natural adrenocorticosteroid production in the nursing infant.

Adverse reactions and side effects may be more frequent and severe in persons over age 60.

This drug should NOT be taken by people who have systemic fungal infection (unless told to do so by your doctor).

If you have been taking this drug for more than a week do not stop taking it suddenly. If it is stopped suddenly, you may experience abdominal or back pain, nausea, dizziness, fainting, fever, muscle or joint pain, shortness of breath or extreme weakness. It can cause you to go into shock. Your doctor may, therefore, want to reduce the dosage gradually. Never increase the dosage or take the drug for longer than the prescribed time unless you first consult with your doctor.

Tell your doctor or dentist you are taking CORTICOSTEROIDS /Prednisone prior to any treatments or surgery. It is wise to carry "Medic Alert" identification while taking the drug. Your dosage may need to be adjusted if you are subjected to stress such as serious infections, injury or surgery. Discuss this with your doctor.

Don't take extra doses or skip a dose without talking with your doctor. Take it at the beginning of your activity day, and take it at the same time every day, or every other day as directed by your doctor. Eat something before taking this drug to help prevent stomach upset. Stomach X-rays are advised if you have an ulcer and will be on this drug for any length of time. Alcohol, aspirin and anti-inflammatory medications (such as diflunisal, ibuprofen, indomethacin, ketoprofen, meclofenamate, mefenamic acid, naproxen, piroxicam, sulindac, suprofen and tolmetin) aggravate the stomach problems that are common with the use of this drug.

The dosage of oral anticoagulants (blood thinners such as Coumadin) oral anti-diabetic drugs or insulin may need to be adjusted when this medication is being taken.

Anticonvulsants, such as phenobarbitaland, Dilantin, rifampin, and ephedrine can increase the elimination of Prednisone from the body, thereby decreasing its effectiveness. Oral contraceptives and estrogen-containing drugs may decrease the elimination of corticosteroids from the body, leading to an increase in side effects. Prednisone can increase the elimination of aspirin and isoniazid, thereby decreasing the effectiveness of these two drugs. Cholestyramine and colestipal can chemically bind to this medication in the stomach and gastro-intestinal tract, preventing its absorption.

Use of corticosteroids can result in any of the following:

1. Increase in sodium and water retention which can lead to edema (swelling).
2. Interferes with the body's ability to absorb sugar which can result in a diabetes-like condition.
3. Loss of/or deficiency of: calcium, protein, potassium, zinc, Vitamin B-6, Vitamin C.
4. Abnormal hair growth patterns.
5. Decreases resistance or ability to localize infection; may mask signs of or cause new infections to develop.
6. Use of tobacco increases the effect of the drug including possible toxicity.
7. Enhances appetite which results in dramatic weight gain.
8. Contributes to mood swings, very minor to severe psychotic episodes.

Minor side effects of CORTICOSTEROIDS: Dizziness, false sense of well-being, increased appetite, increased sweating and/or "hot flashes", indigestion, menstrual irregularities, reddening of the skin on the face, restlessness, sleep disorders, weight gain and/or fatty tissue deposits in unusual places. Tell your doctor about any side effects that are persistent or particularly bothersome.

DO NOT CHANGE OR STOP MEDICATION WITHOUT FIRST TALKING WITH YOUR DOCTOR.

To help the body eliminate fluid and reduce generalized swelling, your physician may place you on diuretics, often referred to as "water pills". To avoid potassium loss while using diuretics, take your dose with a glass of fresh or frozen orange juice, or eat a banana each day.

Check with your doctor before making any dietary changes. The loss of potassium caused by Prednisone can lead to serious side effects in individuals taking digoxin (heart medication).

IT IS IMPORTANT TO TELL YOUR DOCTOR about abdominal enlargement, abdominal pain, acne or other skin problems, back or rib pain, blurred vision, eye pain, headaches, increased thirst and/or urination, mood changes, muscle wasting or weakness, nightmares, nosebleeds, thinning of the skin, or abnormal bruising or bleeding, or unusual weakness. ***Bloody or black, tarry stools or convulsions should be reported immediately to your doctor***

TALK WITH YOUR DOCTOR OR PHARMACIST IF YOU HAVE ANY QUESTIONS ABOUT YOUR MEDICATION!

Starting and stopping treatment of any disorder with corticosteroids can be life threatening. This is not a drug to be taken lightly. It is a drug that can be very effective in the treatment of Sarcoidosis, alone and in combination with other drugs. Discuss it thoroughly with ALL your health care providers including your pharmacist.

(The authors first discussed this topic in 1993 on the Prodigy Bulletin Board. The pros and cons for taking Corticosteroids continues to be an important subject matter for all patients.)

BONE-WEARY

Women suffering from depression often say that they can feel it in their bones—and they may be right. Low bone-mineral density (BMD), the hallmark of osteoporosis, is more common in depressed people than in the general population.

To better understand a possible link, the National Institute of Mental Health (NIMH) has launched a study to monitor stress hormones and bone loss in 160 depressed women ages 21 to 45. "We know that depression is a disease not just of the soul and mind but also of the body," explains lead researcher Giovanni Cizza, M.D., Ph.D. "The question is if there is something intrinsic to depression that might affect bones." One hypothesis is that cortisol, the "fight or flight" hormone known to be elevated in depressed people, may contribute to bone loss. Depression is also associated with decreased estrogen and human growth hormone levels, which may weaken bones.

These findings do not mean depression is an osteoporosis sentence—it's only one risk factor. But women who suffer from depression should be aware of the extra risk and take a few preventive steps. For those under age 50, making sure to get 1,000 milligrams of calcium a day and cutting out other risk factors, such as smoking, can help. So can starting to exercise, especially since depressed women tend to be less active, says Suzette Evans, Ph.D., associate professor of clinical neuroscience in psychiatry at Columbia University.

If you suffer from depression and have other osteoporosis risk factors, such as menopause or maternal history of the disease, ask your doctor for a bone-density test, the most reliable predictor of osteoporosis. The good news is that depression and osteoporosis are very treatable, especially when caught early. "The key is to be aware of the connections and make the diagnosis," Cizza says. - *Eva Marer*

Source: Health magazine, April 2002

Inspiration Corner

STRIVE FOR PERFECTION… OR ELSE!

If 99.9 percent is "good enough," then…

- The IRS will lose two million documents this year.
- 811,00 faulty rolls of 35mm film will be loaded this year.
- 22,000 checks will be deducted from the wrong bank accounts in the next 60 minutes.
- 1,314 phone calls will be misplaced by telecommunication services every minute.
- 12 babies will be given to the wrong parents each day.
- 268,500 defective tires will be shipped this year alone.
- 14,208 defective personal computers will be shipped this year.
- 103,260 income tax returns will be processed incorrectly this year.
- 2,488,200 books will be shipped in the next 12 months with the wrong cover.
- 3,056 copies of tomorrow's Wall Street Journal will be missing one of the three sections.
- 18,322 pieces of mail will be mishandled in the next hours.
- 291 pacemaker operations will be performed incorrectly this year.
- 880,000 credit cards in circulation will turn out to have incorrect cardholder information on their magnetic strips.
- 55 malfunctioning automatic teller machines will be installed during the next 12 months.
- 20,000 incorrect drug prescriptions will be written in the next 12 months.
- 315 entries in Webster's Third New International Dictionary of the English Language will turn out to be misspelled.

Something to consider…

Source: Reprinted from InSight, Sept 1996

THERE ARE NO ENDINGS

This I have found among the twisted ways,
The narrow paths converging into one,
Somewhere beyond the setting of the sun,
When dusk lends softness to the web of days,
And weary hours sink to blend among
The quiet peace, where a silver star
Reminds me heaven isn't all that far,
Whose ladder Hope has fashioned,
Rung by rung,
Where reason seeks the meaning of a man,
Hearts can sense the things eyes cannot see,
Though life remains the great mystery,
Love holds the clue within a gentle hand,
"There are no endings, only pauses when
We look for new beginnings once again."

Grace E. Estery

IT DOESN'T TAKE A LOT OF MUSCLE TO GIVE THE HEART A LIFT.

SPIRITUALITY AND CHRONIC PAIN

Spirituality is an important part of well-being that many people tend to overlook, even though most people count themselves as having a spiritual life.

Some people express their spirituality through their religion. This can take many forms, including prayer and attending church services. But religion isn't the only way to express spirituality. For some, spirituality is feeling in tune with nature and the universe. For others, spirituality is expressed through music, meditation or art.

Religious involvement and spirituality overlap in many ways. But spirituality isn't so much connected to a specific belief or form of worship as it is with the spirit or the soul. Spirituality can be about meaning, values and purpose in life.

Whatever form your spirituality takes, addressing your spiritual needs can be an effective strategy for managing chronic pain. People find it brings inner peace and added strength to deal with their pain and stress.

Spirituality and healing

Numerous studies have attempted to measure the effect of spirituality on illness and recovery. In reviewing many of these studies, researchers at Georgetown University School of Medicine found that at least 80 percent of the studies suggested that spiritual or religious beliefs have a beneficial effect on health. The researchers concluded that people who consider themselves to be spiritual enjoy better health, live longer, recover from illness more quickly and with fewer complications, suffer less depression and chemical addiction, have lower blood pressure, and cope better with serious disease, such as cardiovascular disease.

In another study, researchers found that among a group of hospitalized individuals, prayer was the second most common self-reported means of controlling pain – pain medications being the most common.

No one knows exactly how spirituality affects health. Some experts attribute the healing effect to hope, which is known to benefit your immune system. Others liken spiritual acts and beliefs to meditation, which decreases muscle tension and can lower your heart rate. Still others point to the social connectedness spirituality often provides.

An important point to keep in mind: Although spirituality is associated with healing and better health, it isn't a cure. Spirituality can help you live life more fully despite your symptoms, but studies haven't found that it actually cures health problems. View spirituality as a helpful healing force, but not a substitute for traditional medical care.

Finding spiritual well-being

The first step toward reclaiming a sense of spiritual well-being is to recognize what actions, feelings, people or circumstances are interfering with your sense of inner peace. Once you recognize what is making you angry, anxious, nervous or stressed, you can begin to respond effectively.

Using coping and problem solving can help you deal with the emotions or circumstances that are troubling you. If you decide that whatever is making you angry, anxious nervous or stressed is beyond your control, you need to recognize this and let it go.

Many people find that talking openly with a therapist, religious leader or their doctor helps them find internal peace. Other methods of gaining inner peace include relaxation techniques, inspirational writings, worship, prayer, volunteer work, art, music and spending time in the outdoors.

Source: 1998-2002 Mayo Foundation for Medical Education and Research

UNLOCKING THE MAGIC OF VEGETABLES

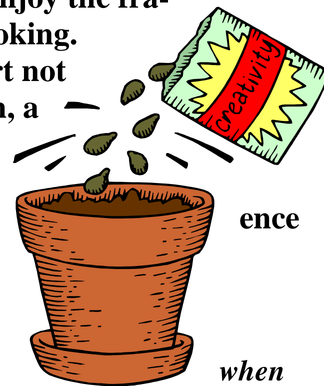
Just how do vegetables protect you from cancer? In some cases, they trigger your body's own defenses, a new study suggests. Researchers at Johns Hopkins University Bloomberg School of Public Health found that mice unable to produce a particular protein were more prone to developing stomach cancer than were normal mice. And mice that lacked the protein had higher cancer rates even if they were given a chemical known to be protective against cancer. This protein, called nrf2, spurs cells to produce enzymes that detoxify cancer-causing substances. And the best way to stimulate the production of nrf2 in the body is to eat your vegetables, says Thomas W. Kensler, Ph.D., who directed the study. "We know that the chemicals in certain plants—particularly cruciferous vegetables like broccoli, cauliflower, and Brussels sprouts—activate nrf2 production," he says. Green leafy vegetables also contain these helpful chemicals.

Increasing production of nrf2 is important whether you're woman, man, or mouse, Kensler believes. "We're beginning to understand that if we can elevate the level of these detoxifying enzymes, we can enhance the resistance to carcinogens in animals and, we believe, people."

Source: Health magazine, July/Aug 2001

FYI

The nice thing about herb gardening is even if you have very limited space, or if you are limited in mobility, you can have a few pots of herbs indoors or on the porch, to enjoy the fragrance and use them in cooking. Herbs are for the most part not fussy plants. They like sun, a well-drained soil and usually just carry on with minimal interference by the gardener.



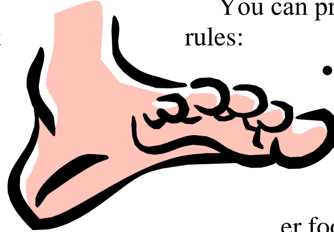
Generations, Vol 8 No.2 April/May 2002

How many cares one loses, when one decides not to do something, but to be someone.
Coco Chanel

ATHLETE'S FOOT

Athlete's foot is a very common skin condition—many people will develop it at least once in their lives. It occurs mostly among teenage and adult males. It is uncommon in women and children under the age of 12. If a child displays what appears to be the symptoms of athlete's foot, chances are it's another skin condition. Athlete's foot should not be ignored—it can be easily treated, but it also can be very resistant to treatment.

Athlete's foot is a term used to describe what really is a form of fungal infection of the feet. The correct term for athlete's foot is *tinea pedis*. The fungi that cause it are living germs, like small plants, that grow and multiply on all humans. Some people may actually have the fungus on their skin, but unless the conditions are agreeable, athlete's foot will not develop. Why some people develop athlete's foot and others don't is not clearly known.



Athlete's foot does not occur among people who traditionally go barefoot. It's moisture, sweating and lack of proper ventilation of the feet that present the perfect setting for the fungus of athlete's foot to grow.

Why does athlete's foot develop?

The fungi that cause athlete's foot like to grow in moist, damp places. Sweaty feet, not drying feet well after swimming or bathing, tight shoes and socks, and a warm climate all contribute to the development of athlete's foot.

It's commonly believed that athlete's foot is highly contagious—that you can easily catch it from walking barefoot in the locker room. This is not true. Experiments to infect healthy skin with athlete's foot have failed and often one family member may have it without infecting others living in the same residence.

What does athlete's foot look like?

Athlete's foot may affect different people in different ways. In some, the skin between the toes (especially the last two toes) peels, cracks and scales. In others, there is redness, scaling and even blister on the soles and along the sides of the feet. These skin changes may be accompanied by itching.

Toenail infections can also occur and can be very stubborn to treat. Toenail infections result in scaling, crumbling and thickening of the nails and even nail loss.

Not all rashes on the feet are athlete's foot. Before treating a foot rash yourself, check with your dermatologist, who can diagnose the condition and prescribe the correct medication. Using over-the-counter preparations on a rash that is not athlete's foot may make your condition worse. If athlete's foot isn't treated, it can result in skin blisters and cracks that can lead to bacterial infections.

How is athlete's foot diagnosed?

Your dermatologist will examine your feet. This examination may include a scraping of the skin on your feet. The skin scales are then examined under a microscope or placed in special substances to help identify fungal growth.

How is athlete's foot treated?

Once the fungus is diagnosed, treatment should begin immediately. For simple cases, anti-fungal creams may be prescribed. The creams can relieve the symptoms fairly quickly. In more severe cases, your dermatologist may prescribe foot soaks before applying anti-fungal creams. If your athlete's foot is stubborn, antifungal pills may be prescribed. Toenail infections are very difficult to treat. Research is ongoing to try to find effective ways to treat toenail fungal infections.

It's important to continue the use of your prescribed anti-fungal creams and medications. While your skin may look better, the infection can remain for some time afterwards and could recur.

What is the best way to prevent athlete's foot?

You can prevent athlete's foot by following some simple rules:

- Wash your feet daily.
- Dry your feet thoroughly, especially in between your toes.
- Avoid tight footwear, especially in the summer. Sandals are the best warm weather footwear.
- Wear cotton socks and change them daily or more frequently if they become damp. Don't wear socks made of synthetic materials.
- If possible, go barefoot at home.
- Dust an anti-fungal powder into your shoes in the summertime. Don't use powders containing cornstarch.

Source: 1987 American Academy of Dermatology, Revised 1991, 1993, 1994

GIVE A SWIFT RESPONSE TO STROKE

Like a heart attack, stroke is a medical emergency. Call for emergency help immediately at the signs of stroke:

- Sudden numbness or weakness of the face, arms or legs, especially on one side of the body.
- Sudden confusion, trouble speaking or understanding.
- Sudden trouble seeing with one or both eyes.
- Sudden problems with walking or balancing.
- Sudden, severe headaches with no known cause.

When a stroke strikes, the best care is at a hospital with a specialized stroke program. That's the word from HealthGrades, a highly respected health care quality firm, which rates stroke programs in each state.

Source: American Heart Association, MultiCare Health Living, Winter 2002

FOR WHAT IT'S WORTH ......

ALL U.S. PRESIDENTS HAVE WORN GLASSES. SOME JUST DIDN'T LIKE BEING SEEN WEARING THEM IN PUBLIC.

KETCHUP WAS SOLD AS A PATENT MEDICINE IN THE EARLY 19TH CENTURY - DR. MILES' COMPOUND EXTRACT OF TOMATO.

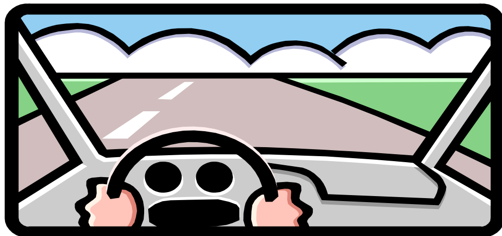
THE INSIDE TRACK ON DRIVING AND VISION LOSS

Losing vision is hard to face. For many this loss is compounded by losing their driver's license and can be emotionally devastating. However, having low vision doesn't necessarily mean losing the keys. It may take some persistence, some time and some testing, but it is worth the try.

Washington State uses the Snellen standard of testing which requires that drivers renewing their licenses pass the 20/40 acuity with both eyes, corrected or uncorrected. If individuals with low vision don't initially meet the 20/40 acuity standard, they have the option to either re-take the test, return with corrective lenses and retake the test, or complete a certificate of visual examination by a competent visual authority, as defined by the Department of Licensing (DOL)..

If a certificate of visual examination is obtained and the acuity is 20/50, 20/60, 20/70 or 20/80, the driver will be referred for re-examination (an in-vehicle test) of the driver's ability to see and drive safely in the area surrounding the licensing services office. If the acuity is worse than 20/80, or if bi-optic lenses are used, the driver will be referred for special examination licensing. Special examination licensing is an investigation of the driver's need for a license, his or her past performance and the ability to see and drive safely.

In some cases, losing the keys may mean the individual loses only part of their license and receives instead a "restricted license." A restricted license may include requirements such as the driver using corrective lenses while driving, drives only during daylight hours, drives only in certain roads posted with or below a specified speed limit, drives only on specified routes, uses bi-optic lenses or drives within a community, specified mile radius or number of blocks from the driver's residence.



Unfortunately some states do not allow any use of bi-optic devices while driving, while others allow limited use. Bioptic devices cannot be used to meet the basic vision requirements, several states allow the driver to use such devices during a special examination, after submitting a vision certificate completed by a competent visual authority.

Some states are now using the Useful View of Field Test (UFOV), a more comprehensive test, but many are just starting to re-evaluate their driver-screening programs. This research will affect testing for all age groups and disabilities.

In the near future, new technologies will help more people remain independent. For the time being there are special alternatives and options for people with partial vision who wish to drive. Speak with your doctor about the options available to you or contact your state or local drivers' licensing office to find of what types of testing and programs are available for people with low vision.

Source: PRISM, Vol 10 No 1, Spring 2002

AROUND THE COUNTRY - AROUND THE WORLD

OREGON

NEW SUPPORT GROUP! - Albany Oregon has a new support group facilitated by Kristi Griffin. Meetings are scheduled for the second Saturday of each month at Albany General Hospital; 11:00 AM - 12:30 PM. Call Kristi at 541-812-9299 for room location.

TEXAS

NEW SUPPORT GROUP FORMING in El Paso Texas! Call Kathrine Willson-Stewart (915) 857-5285 for meeting day, time and location.

WASHINGTON

Tenth Conference on Sarcoidosis, Seattle WA, Mark your calendars for October 11 & 12, 2002. Scholarships available for the Conference. A new location this year, Wyndham Seattle-Tacoma Airport Hotel. Plan to attend, make new friends, meet old ones.

SWEDEN - STOCKHOLM, June 16-19, 2002.

VIIth WASOG Congress (World Association of Sarcoidosis and Other Granulomatous Disorders). For more information email: wasog2002@stocon.se

BACK BELTS LOSE SUPPORT

If you have to do heavy lifting, or if you're pumping iron, you may wonder if you should use one of those back belts that delivery staff or the participants at a gym sometimes wear. The answer now appears to be "no". In 1995, as we reported, the weight of evidence showed that back belts did no good, and might even instill a false sense of security, leading wearers to lift too much. But in 1997 a study showed that back belts reduced worker injury by a third. Now another study, this one in the *Journal of the American Medical Association*, finds belts don't protect people who do their lifting as part of their job—and thus, presumably, they're also no help to anyone else. What's important is to know how to lift. Stand close to the object you're lifting, with your feet a shoulder-width apart; bend your knees and squat, and lift with your legs straight. Get help when lifting really heavy things.

Source: University of California, Berkely *Wellness Letter, Vol 17, Issue 9, June 200*

HEALTH PRIVACY LAW CHANGING

Health Privacy laws change from state to state and very rapidly. With Internet access individuals can monitor them closely. Even if you do not own a computer, your local librarian can help you find the information you need through the community equipment.

For many reasons the personal and private information you share with your doctor is open to insurance companies, pharmacies, researchers and employers. Your medical records are not legally protected as is other personal information. Congress has been unable to come to a consensus agreement of a comprehensive federal law protecting the confidentiality of your health records.

Every state has different laws and only about half of them give patients the legal right to inspect and copy their health records. If you live in a state that does not give you this right, you still might be able to inspect and copy requested records. How many times have you signed a release of your health files to another physician at no cost, yet cannot get them yourself without paying a high fee for "copy" expense if at all. Before you sign any "release form" find out to whom and for what purpose, information is being released. By simple revision of a general form, you may be able to restrict distribution of the information to parties other than those designated. Always initial and date any revisions.

Your health care provider is the best resource to provide you with necessary information about yourself. He/she can help you understand what are the most current regulations about confidentiality and which information is required by law to be released to insurance companies. Some providers keep this information separate from the other parts of your record to insure confidentiality. By sharing your concerns about confidentiality with the health care providers you frequent, you are taking a big step in the area of Health Privacy.

When you seek a new health care provider, do not hesitate to ask about their policy in protecting the privacy of their clients. Ask to see the format(s) they use for release of information. Be wary of filling out "surveys," health screening or medical information. A new "collector of information" is "Web Site information". Read the privacy policies before giving any information. Know who will have access to and how will the information be used.

The web site for the Health Privacy Project is an excellent place to start investigating your state's standing on Health Privacy: www.healthprivacy.org.

The Medical Information Bureau has a membership of some 600 insurance companies where health information on insurance applicants can be obtained. If you wish to obtain a copy of your file contact: MIB, PO Box 105, Essex Station, Boston MA 12112 or **www.mib.com**.

The Department of Health and Human Services recently announced proposed changes o the HIPA medical privacy regulations giving the public a 30 day window to voice their concerns about the changes. That period ended April 26, 2002 at 5 PM. This did not give us time to alert our readership to take appropriate action according to their best interests. It is not too late to contact the HHS requesting they change this policy to a 90 day response time , or at least 60 days following announcement to the general public. Not everyone has easy access to electronic communications. Even access to printed announcements is restricted.

ONLY YOU KNOW WHAT'S IN YOUR MEDICINE CHEST

And only you can determine—in the final analysis—what goes into your body.

MYTH

"But I've been taking medications for years and nothing has ever happened."

FACT

Now that you're older, your body is more sensitive to the effects of drugs.

MYTH

"My doctor wouldn't give me drugs that are bad for me. He knows what he's doing."

FACT

Your doctor does know what he's doing. But he/she doesn't know what your other doctors are doing. Only you know what they're all doing!

MYTH

"I always read the label. I know exactly what I'm taking."

FACT

It isn't what you're taking. It's what you're taking it with.

MYTH

"Over-the-counter drugs are no problem, right?"

FACT

Wrong. Over-the-counter drugs can adversely react with prescription drugs—and with each other. They can be a big problem

MYTH

"I've been taking drugs all my life and I know I'm not allergic to anything."

FACT

Drug combinations that were safe when you were 30 could cause a problem—including an allergic reaction—when you're 50 or 60.

Take control of your health by taking control of your medications.

Source: The John Hopkins Consumer Guide to Drugs

LIFE IS WORTH LIVING ……

Anna Mary Robertson, better known as Grandma Moses, embarked on a new career when she was well into her 70's. Anna, whose first love was intricate embroidery, was so crippled with arthritis that she had difficulty holding the embroidery needle. She turned instead to the paintbrush and enjoyed more than 25 years of success in her new vocation. .

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Change of Address???

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Phone ____
E-Mail ____

NEW ADDRESS BELOW

Name ____
Address ______________________________________
City, State, Zip _________________________________
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.**

Articles are not necessarily the view of, or endorsed by, the *SN* or the Association. Ideas or items of interest, information, or inspiration presented will be published as space is available. When submitting such articles, please indicate the author's name and source of the material. If it is an original, so indicate. *SN* reserves the right to edit for publication purposes.

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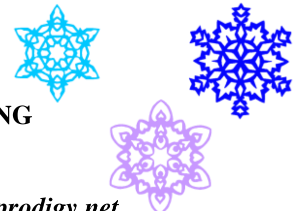

No two snowflakes are identical and no two individuals with Sarcoidosis appear to have identical symptoms. Therefore, snowflakes have been chosen to symbolize Sarcoidosis.