

SARCOIDOSIS NETWORKING

Volume XII Issue 6 November/December 2004

Current and Future Directions in Sarcoidosis

Synopsis of Presentation by Dr. Ganesh Raghu

Dr. Raghu opened his presentation with remarks regarding the invaluable involvement of the Sarcoid Networking Association (SNA), its Executive Director and all the other volunteers, who provide resources, education and outreach to the Sarcoidian community.

According to Dr. Raghu, the SNA's focus on networking with those affected by Sarcoidosis, and the clinical and research professionals; the development of a sarcoidosis registry; the exchange of information regarding the possible causative (etiology) factors, diagnosis and treatment of the disease—all attest to the mission of the organization and staying well-connected.

The Doctor briefly reviewed the history of the development of Sarcoidosis as a significant disease and differential diagnosis from 1869 to 2004. The status of the disorder is that after nearly 140 years since the first case description.

- A cause has yet to be determined.
- Considerable progress in pathogenesis; cytokines, T-cell repertoire, predominately CD4+ and express α/β T-cell antigen (receptors)
- Several problems in clinical management
- No cure, but spontaneous regression occurs in a subgroup of patients.
(A cure will be found, when the cause is found.)
- Treatment: Corticosteroids mainstay (a double-edged sword due to side effects).
- Dosage and question of duration arbitrary.

It is noted that Sarcoidosis is a multi-system disease that is found globally. Its hallmark is the presence of non-caseating granulomatous tissue. Sarcoid is often a diagnosis of exclusion.

A Case Controlled Etiologic Study of Sarcoidosis (ACCESS) Findings

- ◆ Heterogeneous population (53.5 % White, 44.5% Black)
- ◆ Gender (64 %, female, 36%,male)
- ◆ Age (46.5 to less than 40 yr and 54.5 to greater than 40 yr)
- ◆ Women: greater incidence of eye, neurological , erythema nodosum (EN), over 40 yr
- ◆ Men: greater incidence of hypercalcemia
- ◆ Black subjects: increased skin involvement (other than EN), eye, liver, and bone marrow involvement, extrathoracic lymph node

Clinical Presentations of Sarcoidosis

- 49% in good health, no symptoms (Evidence usually found incidentally on x-rays ordered for other reasons.)
- 20%-30% cough, shortness of breath (SOB) , chest pain, sputum production, hemoptysis (expectorate with fresh blood)

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From The Editor's Desk

Very few readers ever notice a sentence on the last page of every newsletter – a “thank you” to the printer for the current issue. For the past 10 years, Good Samaritan Hospital Print Shop in Puyallup WA has been printing the *Sarcoidosis Networking* for us at the cost of the paper upon which it is printed. This issue is the last issue that will be printed by Good Sam's print shop staff. They have worked diligently with SN's staff, with early and late deadlines, printing all of SNA's projects. We greatly appreciate the many donated hours of dedication and quality work.

You may have noticed that the newsletter has not been reaching you in a timely manner, and this issue is no exception. We understand how important accurate and timely information about Sarcoidosis and related health issues is to each of you. It has been a struggle for our people to prepare the bi-monthly newsletter. In 2004, poor health has made it nearly impossible for us to go to press with regularity. We have lost staff and not been able to replace the volunteers who functioned so valiantly. Facing this very real problem and now losing a reliable printer, *Sarcoidosis Networking*, will be published quarterly, (four times instead of six times a year).

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- 25% complain of constitutional symptoms, i.e., fever, fatigue, anorexia, weight loss
- 5% present with fever, EN, arthralgias, hilar adenopathy, uveitis or iritis (Lofgren's Syndrome much more prevalent in White population.)
- 7% present with involvement of other organs

Clinical Manifestations of Sarcoid

| | | | | | |
|------------------|---------|-----------------|------|--------------------|------|
| Lungs | 35-100% | Salivary gland | 6.1% | Skeletal muscle | 1.3% |
| Lymphadenopathy | 73% | Joints | 5.7% | Larynx | 1.3% |
| Skin | 32% | Heart | 5% | Breast | 1.1% |
| Erythema Nodosum | 8% | Nervous system | 4.5% | Stomach/Intestines | 0.7% |
| Liver | 21% | Kidneys | 4% | Uterus | 0.7% |
| Eye | 21% | Nose/Mouth | 3.4% | Hypercalcemia | 17% |
| Spleen | 18% | Lachrymal gland | 2.4% | As per ACCESS | |
| Bone | 14% | Tonsil | 2.4% | | |

Interstitial Lung Disease: Sarcoid Pulmonary Involvement:

The interstitium of the lungs is another site for pulmonary involvement. Restrictive lung disease, such as interstitial pulmonary fibrosis (IPF) prevents the lungs from expanding to maximum because of fibroid (scar) tissue. Obstructive lung defects involve endobronchial lesions, which affect the diffusing capacity. Forced Vital Capacity (FVC) tests demonstrate limits of that function. The latter is sometimes erroneously diagnosed as asthma. Restrictive and obstructive lung disorders can occur concurrently. Plural involvement is uncommon.

Dr. Raghu explained in detail, for the Conferees, the chronological radiographic stages of chest x-rays (Stages I through IV), which have been recently published in the *Sarcoid Networking* newsletter. He also mentioned the question that often arises when a person, who appears perfectly healthy, yet, demonstrates hilar adenopathy upon incidental X-ray for insurance, or other purposes. The guideline in such a case was established in a milestone study conducted at Johns Hopkins: asymptomatic hilar adenopathy with negative lymph gland involvement and a negative clinical exam, does not necessitate lung biopsy for Sarcoidosis.

Cutaneous Manifestations:

Evidence of skin involvement is usually painless and does not itch. Examples of such are papules, plaques, nodules, ulcers, erythema, hyper or hypopigmentation, and lupus pernio, which mimics systemic lupus erythematosus (SLE). The exception to pain-free cutaneous manifestations is EN.

Erythema nodosum are red, tender nodules, several centimeters in diameter, commonly on the lower extremities. Hilar adenopathy is usually present. It has an abrupt onset and good prognosis for spontaneous resolution in 6 to 12 weeks. Treatment is with salicylates (aspirin), bedrest and steroids. Sarcoidosis is responsible for about 25% of the EN cases.

Lofgren's Syndrome:

This syndrome usually presents with a constellation of classic symptoms, which includes bilateral hilar adenopathy (BHA), EN, polyarticular arthritis and arthralgias, and can be accompanied by high fevers. Lofgren's has an excellent prognosis and complete resolution is likely within one year. Biopsy is not needed to make the diagnosis.

Dr. Raghu also addressed the histological features of the granulomas of Sarcoid; the manifestations of cardiac involvement; and the differential diagnostic considerations for Sarcoidosis.

Absolute Indications for Treatment:

- Active ocular disease (uveitis)
- Progressive pulmonary impairment
- Persistent hypercalcemia/hypercalcaemia
- Central nervous system involvement
- Myocardial sarcoid

(continued on page three)

About the Presenter :

Dr. Ganesh Raghu is Professor of Medicine, University of Washington, Seattle WA. Chief Chest Clinic, Director of Interstitial Lung Disease, Sarcoidosis and Pulmonary Fibrosis Program. Director Bronchoalveolar Lavage Laboratory. Director of Lung and Transplant Program, University of Washington Medical Center.

Dr. Raghu has been a Medical Advisor with the Sarcoid Networking Association since its formation in 1992.



(continued from page two)

- Disfiguring cutaneous lesions
- With question of liver involvement

Despite the side effects, corticosteroids are the mainstay of treatment for Sarcoidosis. They are effective in about 85% of the patients. No consensus regarding dosage and duration.

Treatments Other Than Corticosteroids:

- ❖ Inhaled corticosteroids (controversial)
- ❖ Immunosuppressant agents: azathioprine, cyclophosphamide, cyclosporine
- ❖ Anti-inflammatory: methotrexate
- ❖ Other agents: chlorambucil, chloroquine, hydroxychloroquine
- ❖ Recent treatments: pentoxifylline, thalidomide, infliximab
- ❖ Surgical treatments: lung or heart transplant.

(Latest studies note that Sarcoid recurs in the transplanted organ (allograft)).

Details regarding the treatment of neuro and cardio-sarcoidosis were given.

Resolution Rates Based on Chest Radiographs:

Patients with Stage I have a resolution rate of 85%. Those with Stage II have a rate of 70%. Stage III patients have a rate of 37%. Five-ten% of the patients who have overall progression to Stage IV experience resolution. The aforementioned stages do not denote a chronological progression, but a radiographically demonstrated involvement of symptoms.

The ACCESS report of September 2004 noted environmental and occupational risk factors for Sarcoidosis. Results indicated a positive association between Sarcoidosis and agricultural employment; exposure to insecticide at work; and a work environment with moldy/mildew exposures and microbial aerosols.

Specialists for Sarcoid Investigation and Care

Physicians to whom a patient may first appeal, should be based on the site(s) of symptoms or organs involved. The specialists are listed in no particular order.

| | | | |
|----------------|-------------------|-----------------|--------------------|
| Sarcoidologist | General Internist | Pulmonologist | Neurologist |
| Rheumatologist | Psychiatrist | Endocrinologist | Cardiologist |
| Allergist | Gynecologist | Hematologist | Gastroenterologist |
| Immunologist | Dermatologist | Urologist | Ophthalmologist |

Sarcoidosis: Definition and summary

Dr. Raghu remarked that Sarcoidosis is the great imitator. It affects so many diverse systems; mimics and is mimicked by so many disorders; and has such an unpredictable progression. Sarcoidosis is:

- ✦ Idiopathic (unknown cause) multisystemic disorder
- ✦ Has a histological characteristic of non-caseating epitheloid granuloma
- ✦ Absence of infection, neoplasm, foreign body
- ✦ Most commonly in young adults (Second highest onset group is women aged 45-60 years)
- ✦ Histology in more than one organ
- ✦ Positive Kveim test

Sarcoidosis: Future Directions

As reported by Dr. Ganesh Raghu of WASOG and Dr. James Kiley of NIH:

- ★ Pathogenesis: tissue bank of lung tissue from broncho-alveolar lavage (BAL) and lymph tissue
- ★ Genetic factors: humans, animals, gene-gene and gene-enviro interactions
- ★ Identify targets for potentially novel treatment
- ★ Improve management of patient primary care; M.D. referrals to specialists
- ★ Newer approaches to doctors' value of patient registry
- ★ New therapies; randomized continued clinical trials

NIH is very much on-board with patients, sarcoidologists and researchers regarding such studies and directions.

Editor's Note: Doctor Raghu's complete presentation is available on video, which can be obtained by contacting the SNA. See contact information on page 12 of this issue. Also available on video, are the presentations of other conference speakers, including Dr. James Kiley's keynote address.

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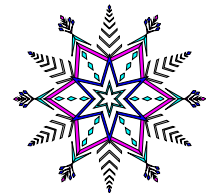
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SARCOIDOSIS RESEARCH COORDINATING COMMITTEE FORMED

The announcement of the formation of the Trans-NIH* Sarcoidosis Research Coordinating Committee was made by Dr. James Kiley. The naming of the committee was made at the 12th Annual Conference on Sarcoidosis held in Seattle, October 1-4, 2004. Dr. Kiley is the Director of Lung Diseases, NHLBI**. He will serve as Co-Chairperson of the newly formed committee along with Dr. Herbert Reynolds, Leader of Immunology/Fibrosis Scientific Research Group.

Other SRCC members and institutes include:

National Institute of Allergy and Infectious Diseases – Dr. Richard Sawyer
 National Institute of Diabetes, Digestive and Kidney Disease – Dr. Stephen James
 National Institute of Environmental Health Sciences – Dr. Sally Tinkle
 National Eye Institute – Dr. Richard Fisher
 National Heart, Lung and Blood Institute – Dr. Hannah Peavy
 National Human Genome Research Institute – Dr. Alan Guttmacher
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 Office of Research on Women's Health – Dr. Elizabeth Begg



SARCOIDOSIS MYTHS/ UNTRUTHS

Ganesh Raghu, M.D.

- I. Disease of Black Americans
- II. Chest radiograph is diagnostic
- III. Radiographic Staging has chronological significance
- IV. Serum angio-tensin-levels (ACE) are diagnostic and serve as guide to therapy
- V. BAL differential cell counts serve as guide to therapy
- VI. Difficult to diagnose
- VII. Sarcoidosis is tuberculosis

"The goal of this committee is to coordinate sarcoidosis activities across the National Institutes of Health, facilitate research and networking with the coordinating sciences," said Dr. Kiley. He emphasized that this committee was the direct result of concerns expressed to NIH Director, Dr. Elias Zerhouni, in a letter from several sarcoidosis organizations. "Clearly your voice is being heard," remarked Dr. Kiley, as he was given an executive directive for this committee to be formed.

*National Institutes of Health

**National Heart, Lung and Blood Institutes

Social Security Disability: Understanding Terminology

The SS Disability (SSD) application often contains terms that are unclear, or have precise definitions which are evaluated for determining disability. The applicant must follow specific ground rules to be deemed eligible for compensation. To better help you understand what SS takes into consideration we repeat the following descriptions:

Disability: The law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. To meet this definition, you must have a severe impairment, which makes you unable to do your previous work or any other substantial gainful activity which exists in the national economy."

Activities of daily living: ADL include selfcare tasks like dressing and bathing. It also includes activities such as cooking, cleaning, grocery shopping and taking public transportation.

Social Function: Social Functioning means the ability to interact appropriately and communicate with others.

Completing tasks in a timely manner: This means having the sustained concentration, persistence and pace to do tasks commonly found in the workplace. A claimant must be able to perform on a sustained and predictable basis.

Degree of Limitation: "Moderate" limitation may be present when several activities or functions are impaired or even when only one is impaired. "Serious" limitations is described as interfering with the ability to function independently, appropriately and effectively.

Attorney fee: The advice of legal services may be necessary when filing appeals. The fees of most disability law specialists is on a contingency fee, which means that only if the claim is successful is the fee then allowed. The amount of the fee is subject to evaluation by the SSD administrative judge for appropriateness and then deducted from the award granted to any claimant deemed eligible for SSD benefits

Social Security Newsletter, Atty. Kenneth N. Gormly; October 2004
 Edited for publication.

PROTECT THE BODY'S LARGEST ORGAN

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

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

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

A warm shower is better for the skin than soaking in a hot bath. Some fragrant soaps have ingredients, such as alcohol, which removes the natural moisture-barrier through evaporation. Use a gentle beauty bar or cream as a cleanser instead.

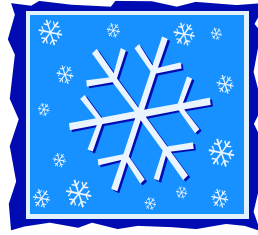
Avoid prolonged exposure to the wind and sun, and stay hydrated by drinking plenty of water daily. After all, lotions can't seal in moisture that isn't there.

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

Golden Oldie



Are you giving up chocolate because of caffeine? Believe it or not, chocolate does contain caffeine, but not much. Compare chocolate with regular-brew coffee. A one-ounce milk chocolate bar contains about 5 milligrams of caffeine compared with 115 milligrams of caffeine in 5 ounces of coffee. So if caffeine is what you are avoiding, eliminate the coffee first.



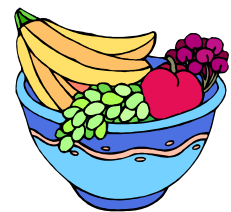
FALLEN SNOWFLAKE

Marjorie (Marge) Ellen Riley, passed away October 6, 2004. Her struggle with Sarcoidosis began in 1993, primarily with the involvement of the lungs. Eventually other organs were affected. Marge would have been 67 on October 27.

Her professional background, as a registered nurse and desire to help other Sarcoidians, prompted her to co-found Sarcoidosis Support in Kansas, with her husband Ted. A support group was established in Wichita, which she facilitated for several years. Marge was an active supporter and networker for a national sarcoid organization. She worked diligently with other leaders and the American Lung Association to organize and facilitate such groups in the late 1990's.

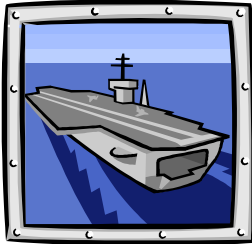
From the out-set of the Wichita group, Marge was an active member of the Sarcoid Networking Association. She constantly encouraged others and was an inspiration to everyone who met her. Her travels to many SNA conferences and elsewhere, with all the oxygen paraphernalia and mobility aides required, motivated others to expand their activities of daily life. Her infectious smile and graciousness encouraged and inspired us all. She is missed by her family, friends and the sarcoidosis community.

According to a recent study, a diet rich in fruit and vegetables may help prevent age-related mental decline. Fruit and vegetables contain antioxidants, which are nutrients that prevent damage from harmful molecules called free radicals. Free radicals are believed to play a leading role in certain diseases and age-related changes



SOME VETERANS NEED RE-EVALUATION

The Naval Assessment Final Report, published February 18, 2004, was the result of Congressional hearings. This gave rise to concerns that occupational lung disease may have been misdiagnosed among Navy personnel. As a result, a Public Policy Advisory Committee Recommendation was published stating that: "...military personnel, who have worked aboard ships and acquired a diagnosis of sarcoidosis," should be informed that U.S. government medical personnel would conduct free medical evaluations, to better clarify their lung disease, if they knew or suspected that they had been exposed to dusts, such as generated by dock-grinding while aboard ship, or if they had a history or symptoms of lung disease." For more information, contact Jerry Cochran in Atlanta GA at 229-889-1533.



One of the deep
secrets of life
Is that all that is
worth the doing
Is what
we do for others.

Lewis Carrol

A 27-Year Historical Prospective Study, 1975-2001¹ was published in *Chest*, November 2004. "Higher prevalence of sarcoidosis among Blacks remains unexplained, but a disproportionate exposure to environmental or infectious agents, or a genetic predisposition has been suggested." The article reported the present study findings were consistent with the study made by Philip Jajowski, M.D. in 1998. The latest study used "a cohort study design rather than a case-control approach." The report looks at naval service assignments on "clean" and "dirty" ships, finding a higher incident of sarcoidosis in the aviation mechanic occupation area.

In the May/June 1998 *Sarcoidosis Networking* reported the increased incidence of Sarcoidosis among U.S. Navy personnel, in an article by Jajowski. His article: "Sarcoidosis Diagnoses among U.S. Military Personnel: Trends and Ship Assignments" (*American Journal of Preventive Medicine*, April 1998) raised many concerns and questions.

The more recent study cites the same issues. Veterans diagnosed with lung disorders, especially those serving on aircraft carriers, are to be re-evaluated for possible misdiagnosis. It is the affected veteran's responsibility to contact their local VA medical center for re-evaluation.

Conclusions: There was a steep decline in incidence of hospitalized sarcoidosis in Blacks in the Navy. Occupational associations suggest the possibility that a dust or moisture-related lung disease may have been erroneously classified as sarcoid, or, alternatively, that sarcoidosis had a previously unrecognized occupational component.¹

1. Edward D. Gorham, M.P.H.PhD; et al; *Trends and Occupational Associations of Incidence of Hospitalized Pulmonary Sarcoidosis and Other Lung Diseases in Navy Personnel*; *Chest*. 2004; 126:1431-1438.

Medicine Chest

FAT ABSORPTION BLOCKERS.

What are fat-absorption blockers? Do they work?

Fat blockers are chemical medicines sold in pharmacies with a physician's prescription. When taken by mouth, they bind to an enzyme known as lipase, which is made by the pancreas and released into the small bowel. These drugs are approved by the U.S. Food and Drug Administration (FDA) for weight control. The fat-absorption blockers have been tested carefully and proven to help reduce weight by 10 to 12 percent over a year's period---and to maintain the reduced weight for another year.

The enzyme lipase normally digests the fat taken with food into smaller units that can be absorbed from the bowel into the blood where they become distributed to all body organs. Intake of these blockers could prevent breakdown of fat and its absorption. The undigested fat is passed into the stool. These blockers, taken regularly – particularly when consuming a low-fat diet – can eliminate up to 30 % of fat intake and pass it into the stools. That is the reason for the weight loss.

The side effect of this treatment is that the undigested fat, at body temperature, is transformed into liquid oils that in some individuals can cause strong bowel movements and gas. It is also difficult to prevent its accidental leakage and the resulting soiling of clothing.

In addition, the fat-soluble vitamins like vitamins A, D, E, and K, which are essential for health, are lost with the fat in the stools. It is therefore recommended, that individuals on these medications should take these vitamins in the form of supplements^[1]

[1] Dr. Ahmed Kisebah, Professor of Medicine and Pharmacology; Director of the General Clinic Research Center, Medical College of Wisconsin; Director, Take Off Pounds Sensibly TOPS[®] funded research at the medical college; and serves as TOPS medical advisor.

TOPSnews; Aug/Sept 2004.

IS IT CHRONIC FATIGUE?

Chronic Fatigue Syndrome (CFS) may be diagnosed if your fatigue has lasted at least 6 months and you have four or more of these symptoms:

- ◆ Short-term memory loss
- ◆ Severely impaired concentration
- ◆ Sore throat
- ◆ Swollen lymph nodes
- ◆ Muscle pain
- ◆ Joint pain (without swelling or redness)
- ◆ Headaches
- ◆ Non-restorative sleep
- ◆ Malaise (a vague sense of uneasiness or discomfort) for more than 24 hours after exertion.

Looking at Fatigue

The body has a built-in protective mechanism called fatigue. This is a normal response to physical or mental overexertion; but if it is a constant situation, it needs to be explored. Raul Seballos, M.D. of The Cleveland Clinic says that patients who complain of weakness, tiredness, lack of energy or lack of motivation, should have a thorough medical evaluation. "We take a full medical history and ask about their daily routine, work habits and environment. If the physical exam is normal, we do some blood work to rule out other medical causes."

There are disorders that can cause fatigue: thyroid disease, infection, anemia or diabetes are a few medical reasons for feeling tired all of the time. Sleep study should be done to rule out any of a number of problems that keeps one from getting restful sleep. In addition, damage to the heart and brain can occur from repeated episodes of sleep apnea. Chronic diseases such as asthma, kidney or liver disease may also be responsible for fatigue. Depression, grieving, loneliness or chronic stress can also contribute.

Medications, prescribed and over-the-counter, can cause fatigue: sleeping pills, antihistamines, antidepressants, blood pressure meds and corticosteroids (like Prednisone) complicating the health profile. Sometimes simply switching to another medication that also controls the health problem will restore a patient's energy levels.

CFS is a specific illness. Its cause is unknown. No infectious agent has been associated with CFS. Research continues in the quest to identify the possible cause(s). Even the National Institutes of Health (NIH) are involved in such studies.

Lifestyle Changes

Dr. Seballos recommends that patients with ongoing fatigue may need to make some changes in their lifestyle, as the first step in dealing with their fatigue problems. These include:

- ✗ Get more sleep
- ✗ Keep to a regular sleep schedule
- ✗ Improve the nutritional quality of your diet
- ✗ Drink plenty of water during the day
- ✗ Lose weight if you are over-weight
- ✗ Exercise 15-30 minutes at least 4 days per week
- ✗ Stop smoking
- ✗ Eliminate alcohol
- ✗ Watch your caffeine intake
- ✗ Take some rest breaks during the day
- ✗ Try to reduce the stress in your life
- ✗ Learn relaxation techniques, such as deep breathing, yoga or meditation
- ✗ Make time for activities that you really enjoy
- ✗ Pace your activities to your energy level
- ✗ Do not over-exert; stop before you become too tired.

Feeling tired all the time is not normal. With a full medical evaluation and some self-help measures, you do not have to feel tired all the time.

Men's Health Advisor, July 2004
Edited for publication.



Most folks are
about as happy
as they make up
their mind
to be.

Abraham Lincoln

PLAYING THE NUMBERS GAME

By Christine Miller

A common mistake is repeatedly checking blood glucose levels at the same time, day after day. In order to know if your diabetes is in good control, check your glucose at varying times. For example, if your doctor has suggested checking once per day, be sure to select different testing times. Monday you could check before breakfast, Tuesday check one or two hours after the start of breakfast, Wednesday before lunch, and so forth. The table below lists the recommended glucose levels:

American Diabetes Association (ADA)

Before Meals: 90-130 mg/dl After Meals*: Less than 180 mg/dl

American Association of Clinical Endocrinologists (ACE)

Before Meals: <110 mg/dl After Meals*: Less than 140 mg/dl

*ADA defines this as 1-2 hr after the start of the meal.

It is essential that your doctor or healthcare team have a way of reviewing your numbers at medical appointments. Keeping a written log or providing a computer-generated report using software provided by your machine's manufacturer will do the trick.

Knowing your blood glucose goals, your A1c, and checking and recording daily blood glucose readings will put you in the driver's seat of your diabetes. If you find your blood glucose or A1c remaining above goal levels, some part of your diabetes treatment plan should be adjusted. Talk with your doctor or diabetes care team about possible changes to your diet, exercise, diabetes medications or other strategies you can use to get better numbers, now!

Proper diet is an integral part of managing type 2 diabetes. If you're ready to take control - and maybe lose a few pounds along the way .

As a dietitian and diabetes educator, one of the most common questions I am asked is, "What should my blood glucose readings be?" Many people are confused because so many different numbers seem to be out there. There are the numbers they use to diagnose diabetes. To add a bit more confusion, two well-respected organizations involved in the care of people with diabetes both publish different recommendations for blood glucose goals. Finally, there is even your neighbor's opinion as to what your blood glucose should be! It is time to cut through the confusion and help you know, once and for all, what those darn numbers should be.

First, it is important to realize there are really only two ways for you and your doctor to know if your diabetes is under good control. One way is by testing your Hemoglobin A1c (A1c) and the other way is by reviewing the results of your daily home blood glucose readings. A single blood glucose check will reflect a quick snapshot while the A1c provides the big picture of your blood glucose control. The A1c is actually a measure of your blood glucose over the preceding three to four months. This test is routinely performed with a blood sample. Finger-stick versions of this test are also available for home or medical office use.

Recommendations by: A1c* Goal for Diabetes

American Diabetes Association (ADA): Less than 7.0%

Association of Clinical Endocrinologists (ACE): Less than 6.5%

*Using a DCCT-based assay. Normal ranges of A1c are 4% - 6%.

Tracking your A1c over time is an excellent way to get feedback on how your diet, exercise and medications are working.

The other way of determining if your blood glucose levels are controlled is by daily home blood glucose monitoring. Fortunately, most insurance companies cover the cost of the machine and testing supplies. If you notice that your A1c is not at goal, home blood glucose monitoring can help you pinpoint when your glucose levels are running higher.

eDiets, September 13, 2004

^Christine Miller is a Registered and Licensed dietitian, as well as a Certified Diabetes Educator. Christine moderates the Living with Diabetes support group at eDiets.com and conducts live monthly online meetings for people with diabetes. Christine received her Masters Degree in Nutrition from Texas Woman's University in 1991 and has specialized in diabetes for the last 12 years. In addition to her responsibilities at eDiets, Christine also maintains a private practice in Tampa, Florida.



High Blood Pressure

When you think of controlling diabetes, you think of keeping your blood sugar levels balanced. Controlling your blood pressure may be just as important.

Uncontrolled blood pressure may increase your risk for developing health problems related to diabetes, especially heart disease and stroke.

BETTER HEALTH AND YOU

Part II*

LOSING WEIGHT

Losing as little as 5 to 15 percent of your body weight over six months or longer can do much to improve your health. For example, if you weigh 200 pounds, losing 5 percent of your body weight means losing 10 pounds. A safe rate of weight loss is 1 to 2 pounds per week.

Try some of these ideas to support your weight loss efforts:

- ø Keep a food diary.
- ø Shop from a list and shop when you are not hungry.
- ø Store foods out of sight.
- ø Use a smaller plate with smaller servings.
- ø Eat at the table with the TV off.
- ø At restaurants, eat only half your meal and take the rest home.
- ø Take a different route if you regularly pass by a tempting fast-food place.
- ø Expect setbacks and forgive yourself.
- ø Seek support from family and friends.
- ø Be realistic about weight-loss goals. Aim for a slow modest weight loss.

Tips for healthy eating:

- ♦ Drink plenty of water. Aim for about eight, 8-ounce glasses of water each day.
- ♦ Eat breakfast every day. People who eat breakfast are less likely to overeat later in the day. Breakfast also gives you energy and helps you think and learn.
- ♦ Choose whole grains more often. Try whole-wheat breads and pastas, oatmeal, brown rice, or bulgur.
- ♦ Select a mix of colorful vegetables each day. Different colored vegetables provide different nutrients. Choose dark green, red, orange and blue most often.
- ♦ Choose fresh or canned fruit more often than fruit juice. Fruit juice has little or no fiber.
- ♦ Use fats and oils sparingly. Olive, canola, and peanut oils, avocados, nuts and nut butters, olives, and fish provide heart-healthy fats as well as vitamins and minerals.
- ♦ Eat sweets sparingly. Limit foods and beverages that are high in added sugars.
- ♦ Have low-fat, low-sugar snacks on hand at home and work to combat hunger and prevent overeating.
- ♦ Don't skip meals. Eating regularly helps keep you on a healthy-eating track.

Be Good to Yourself

Many people feel stress in their daily lives. Stress can cause you to overeat, feel tired, and not want to do anything. Regular physical activity can give you more energy.

* Part I of this article was published in the issue of *SN*, Sept./Oct. 2004

Better Health and You; TOPSnews; Aug/Sept 2004
Edited for publication



Help!

If you need it, get it. If you can't shake pessimistic or negative thinking, seek professional help.

Consider cognitive therapy which focuses on changing your unfavorable thoughts and beliefs into positive ones.

This will improve your mood

AROUND THE COUNTRY, AROUND THE WORLD

PLAN TO ATTEND NOW

Sarcoidosis Patient Forum to be held in conjunction with the World Association of Sarcoidosis and Other Granulomatous Disorders (WASOG) 8th Meeting.

Denver Colorado

Adam Mark Hotel

June 12, 2005

7:30 AM to 4:30 PM

Meet with Sarcoidosis Specialists (Sarcoidologists) from around the world.

Additional details forthcoming - Mark your calendars!

Save the date!

EDUCATE BEFORE YOU MEDICATE

Communication is the key to better healthcare. The National Council on Patient Information and Education offers these three steps you can take to help ensure safe medicine use.

Step 1: Take part in your treatment decisions.

Don't be afraid to ask questions and talk about your concerns. This means informing your doctor and pharmacist about any illnesses or problems for which another health professional is treating you. Discuss the risks and benefits of each medicine or treatment you might get and tell your doctor and pharmacist about any medicine allergies you have. Also, let them know what non-prescription medicines, supplements and herbal products you are using and if you've experienced medication or alcohol dependence or abuse in the past.

Step 2: Follow your treatment plan.

This includes contacting the doctor or pharmacist with any concerns you have about your medicine, especially during the first few days as the body is adapting to the medication. Don't let embarrassment keep you from telling your doctor or pharmacist important information.

Step 3: Watch for problems and get help in solving them.

Keep working with your health professionals while you are taking your medicine. This means don't change doses or abruptly stop a prescription without first consulting a healthcare provider. Ask for results of medical tests that indicate if the medicine is working and if the particular medicine is still needed. Tell your doctor or pharmacist about any side effects or any new problems, that may be related to the medicine.

Walgreens' and Fred Meyer's
Patient Education Series



BE AN INFORMED SARCOIDIAN

A healthwise person is a responsible patient, able to discuss with healthcare professionals every aspect of his or her health program. The diagnosis of sarcoidosis presents many challenges to the patient, the family and the caregivers. You must be aware of all choices available and how you can receive the best possible care. Hopefully, the following will provide a checklist for you to consult.

Seek the best possible healthcare available to you, know your resources.

Ask a family member or trusted friend to accompany you to your appointments

Request full information about any tests or treatments you receive

Carefully read every prescription you receive, make sure it is for you.

Opinions of one or more specialists should be consulted when you are in doubt.

Identify your health care professional, know his or her qualifications to treat you

Don't be timid in regards to your healthcare, ask questions

Obtain the results of all tests you undergo in writing, keep them in your own file

Speak up when you don't understand what your healthcare professional has said.

Inform your healthcare professional about all your health problems.

Safeguard your health. Be informed about your disease(s) and treatment(s).

Know your rights and responsibilities as a patient. Be aware of every aspect of your healthcare.

Disclaimer ...
SNA does not endorse any of the medications, treatments, or products reported in this newsletter. This information is intended only to keep you informed. We strongly advise that you check any drugs or treatments mentioned with your physicians or pharmacists.



If you have knowledge,
let others light their candles in it.

Margaret Fuller



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

*Phone Hours 8 AM-8 PM
Pacific Time
253-826-7737
or e-mail:
sarcoidosis_network@
prodigy.net
SNA Web site
www.sarcoidosisnetwork.org*

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



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

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**WHAT IS SARCOIDOSIS
NETWORKING ?**

***SARCOIDOSIS
NETWORKING***

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

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

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