

MULTIPLE SCLEROSIS NEWSLETTER

March, 1985 From the office of Roy L. Swank, M.D.

No. 22

Editor-Barbara Dugan Typist-Suzy Wood Production-Ruth Stewart

COMMENTS ON EARLY DIAGNOSIS OF M.S.

We have frequently stated that early diagnosis of M.S. is essential to obtain the best possible result from treatment. Because of the nature of the pathological changes of the disease it is unlikely that more than prevention of further disability or deterioration with moderate improvement can be accomplished by any therapy. It is true that during remission remarkable recoveries often occur early in the disease. Later when the disability has been present for long periods of time, remarkable recoveries are rare. It is therefore important that we do our very best to make a diagnosis as early as possible, and follow this promptly with therapy. Our experience has been almost entirely with the low fat diet to which we have added plasma infusion the last 5 years. The low fat diet has been very effective in preventing disability for 35 years in cases diagnosed relatively early. The plasma, as many of you know from experience, has been effective in restoring energy and endurance especially in early cases.

The diagnosis of multiple sclerosis continues to be a problem. Because of "grapevine communications" between patients and friends the diagnosis or awareness of a possible diagnosis of M.S. by potential victims often precedes a diagnosis by the physician. The physician lacks a laboratory test specific for M.S. so must depend on his clinical skills plus supportive tests. A complete history supported by neurological findings is still the most reliable evidence on which to base a diagnosis. The history should reveal evidence of an exacerbating - remitting neurological illness, supported by findings indicating the presence in the central nervous system of multiple lesions disseminated in time and in space.

It is helpful and reassuring to have supportive, objective test evidence of CNS lesions. The tests, now available furnish evidence of CNS lesions, but do not identify their cause. The objective tests to which I am referring include the visual, auditory and sensory evoked responses and the Computed Tomography scan with enhancement. These tests indicate areas of the CNS which are involved and can often confirm what one already suspects from the history and examination. The cerebrospinal fluid examination for oligoclonal bands also confirms the presence of damage to the CNS, but does not identify the cause and fails to locate the lesions. This test, which requires a lumbar puncture, has the added disadvantage of often being followed for prolonged periods by aggravation of the disease and severe headaches. The flicker-fusion (1) and balance (2) tests used by your writer are also not specific for M.S., but they also

point to the areas of nervous system which are involved. We have also found these tests useful in evaluating progress of the disease.

A relatively new test, the red cell mobility test (3) (4), was for a time considered specific for M.S., but as we have gained experience we have found that patients with amyotrophic lateral sclerosis, cerebral vascular disease, or brain tumor occasionally exhibit reduced red cell mobility characteristic of M.S. However, this test probably correlates more highly with M.S. than any of the other tests mentioned before and when associated with an exacerbating-remitting neurological disease it is rarely misleading. As performed in the Biocolloid Laboratory of Providence Medical Center (headed by Dr. G.V.F. Seaman of the Department of Neurology at the Oregon Health Sciences University) the mobility test confirms the diagnosis of multiple sclerosis in about 95% of cases. The test may have a lower than 95% correlation with M.S. during the very early stage of the disease when the patient is often in complete remission, and in late phases of the disease when the patient is disabled and non-ambulant. Yet early in the disease and often during remission, when the other tests usually fail to confirm the diagnosis, the red cell mobility test gives valuable support.

The red cell mobility test depends on a decrease in electrical charge on M.S. red cells which occurs when they are treated with Linoleic acid. Reliable determinations of the electrical charge on red cells are painstaking and difficult to make. Consequently only a few laboratories perform the test. Dr. Seaman's laboratories at the Medical School and the Biocolloid Laboratory at Providence Medical Center are the only laboratories doing the test in North America. The tests are also done in several laboratories in England and in Europe.

Symptoms which are not specific for M.S. but which are often associated with it are cold hands and feet, periodic multiple subcutaneous hemorrhages, intolerance to heat and occasionally to extreme cold, and severe, easy fatiguability. These symptoms often precede the clinical onset of M.S. and usually are present during the disease. Specific very early symptoms and signs of M.S. include vague alterations of sensitivity to pain and touch. The patient recognizes these modalities but states that they feel abnormal or unusual. Other early "unconvincing" symptoms are slight unsteadiness of the upper and lower extremities causing patients to drop objects, or to walk into furniture and door frames without drawing the attention of casual observers; vague visual problems without loss of visual acuity; and urgency and frequency of urination without adequate cause. Also common, but usually missed early symptom because of its vagueness, is impaired memory and mild confusion. At these times clinical evaluation often fails to confirm neurological involvement because of the vagueness of the signs and symptoms. It is in this early phase that a test such as the red cell mobility test can be helpful.

These early symptoms should alert one to the possibility that the patient has M.S. Serious consideration of this possibility, if followed up, can often prevent the severe disability which results from late diagnosis of the disease.

References:

- (1) Daley, M. & Swank, R.L. Flicker fusion threshold in multiple sclerosis - a functional measure of neurological damage. Arch. Neurol. vol 36:292-295, 1979
 - (2) Daley, M. & Swank, R.L. Quantitative posturography: use in multiple sclerosis, IEEE Transactions on Biomedical Eng. Vol. BME-28 No. 9:668-671, 1981
 - (3) Field, E.J. & Joyce, G. Simplified laboratory test for multiple sclerosis. Lancet ii:367-368, 1976
 - (4) Tamblin, C. H., Swank, R.L., Seaman, G.V.F. & Zukoski, C.F. IV Red cell electrophoretic mobility test for early diagnosis of multiple sclerosis. Neurol. Rel. 2:69-83,1980
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It has been some time since we have solicited funds to defray the cost of publishing and mailing the newsletter. We are now asking those of you who can afford to do so to remit \$10.00 for this purpose. Those of you to whom this would be a hardship are not asked to contribute. The newsletter will continue to be mailed to one and all of you whether you do or do not contribute.

If you have suggestions for improving the letter or would like for us to discuss aspects of M.S. which we have overlooked, do not hesitate to send in your suggestions.

I am also reminding those of you who have planned to contribute to our research and so far have failed to do so that you send in your contribution as soon as possible.

THE DIAGNOSIS

I called upon my doctor
And he checked me end to end.
The many flaws he found in me
shouldn't happen to a friend.
He drew my blood, he checked my lungs
And probed in personal places,
Showed knowledge of my grievous lot
With frequent sad grimaces.
Then he prescribed a hapless list
Of joys untolerated
Now I'm drinkless, saltless, sugar free
And fully decaffeinated.

By our poet J. D. Manley Treece

The phone problem has greatly improved in that we receive many fewer calls which are not necessary. Even so the phone is sometimes busy continuously for hours.

We still have one problem. Many people call requesting letters. We are not willing to write a letter without a written request from you, describing briefly what you want. A self-addressed and stamped envelope will facilitate and hasten a response. A phone call will cause our response to be delayed. Also, when ordering cod liver oil, please send in a note with a check for \$12.50 for each package. There is no need to call for the cod liver oil.

LET'S TALK ABOUT DIET

We are in the process of revising the low fat diet book and would like your favorite recipes. Any suggestions you might have as to those recipes that should be omitted or changed would be appreciated. Please send your recipes to the office, attention Barbara. We plan to have the rough draft completed by August, 1985.

Roy L. Swank, M.D.
Department of Neurology
Oregon Health Sciences University
3181 SW Sam Jackson Park Rd.
Portland, OR 97201

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From the office of Roy L. Swank, M.D.

No. 24

Editor-Barbara Dugan Typist-Suzy Wood Production-Ruth Stewart

It is difficult for people who have been very active and aggressive all their life to slow down to the speed of the average person. To have been driven all your life by some poorly understood mechanism in your body - a biological gyroscope - and then be asked to cut the speed by 1/2 or 2/3 is asking a great deal. Obviously the slow down cannot be done suddenly, and in practice most patients have found it very difficult to reduce their "crusing speed" the necessary amount even slowly. Yet this adjustment is necessary if you are going to live a comfortable, exacerbation free life, with minimum fatigue and no exhaustion.

I have stated to you individually and by means of our newsletter that fatigue and easy fatiguability are the most persistent of all M.S. symptoms. These symptoms can be mild and not disabling or severe and disabling, to a very large extent due to the way that you have managed your own life, and in particular managed your diet. Two essential personal qualities are necessary if one is to avoid disability. First, you must understand the diet, and other directions such as the necessity of rest when tired, and the necessity of avoiding nervous tension (physical and psychological stress), Second, you must be able to discipline yourself sufficiently to follow the rules. In other words follow diet carefully and listen to your body. When it is tired rest; when you are nervous and agitated do whatever is necessary to correct the situation.

When you overdo frequently or for long periods, or go through a long period of nervous tension you are apt to drain or lose much of your energy reserve (your endurance is reduced). You may feel that you recover to your former self in a few days, but you are apt to discover that your endurance has decreased. If you do not allow time to rebuild your reserves by cautious conservation which includes avoiding fatigue and nervousness for anywhere up to several months, and an event occurs which usually causes you only temporary discomfort and fatigue, you may find yourself deeply fatigued and in relapse (exacerbation). Those unexpected events to which I refer include prolonged exposure to the sun, or to very hot weather or water which causes blood to pool under the skin; the pre-menstrual period which normally causes some fatigue and depression, but which when you are tired can cause severe symptoms and fatigue, due to pooling of blood in the pelvis; fever from any cause which brings blood to the surface of the body and to the area of the infection; and severe or fatiguing exercises which cause blood to pool in the muscles.

At that time you may liken yourself to an automobile with less than 1 gallon of gasoline in the tank. You can travel fast for but a few miles, then stutter and stop.

The most practical and sensible way to avoid this low energy state, and also to build up your reserves is to "pace" yourself. Don't rush; don't attempt to be busy all the time; spend time relaxing and even meditating; avoid confrontations; and if you have a major task to perform avoid the unimportant, tiring pranks, even if desirable. In other words listen to your body, and very carefully monitor and control your desires. If you plan a major event prepare for it by taking it easy for several weeks before and after the event.

With patients who are already to some extent disabled the problem is somewhat different. Their endurance is already so low that they cannot extend themselves for more than a very short time. In order to do even a little they are forced to be almost continuously conserving their energy. Prolonged exertion will often precipitate an exacerbation and remissions from this are only partial.

Summer is here and it is necessary for most of you to keep cool. I have explained how you can temporarily do this by putting hands or feet in cold water and wrapping a wet towel around your neck.

A new method of cooling your body was recently told me by a patient. This patient uses a fine spray to mist her plants, and finds that she can use the mister to mist herself. She mists her arms, head and neck.

LET'S TALK ABOUT DIET

Cheating on diet is very dangerous. We now know that an additional 8 grams (1 1/2) tsp. of saturated fat can lead to slow deterioration over the years. There may not be any warning signs until it is too late and the disease has slipped into a progressive phase.

It is imperative that your saturated fat intake always remain below 15 grams per day.

TOFU DESSERTS

Tofu desserts have become the new health craze. They look and taste much like ice cream and have become popular as a non-dairy alternative because they lack butterfat. These products are extremely high in oils, saturated or unsaturated. They range from 40-64 percent depending on the flavor.

They are also very high in calories. Even though they are made from Tofu the protein content is very low, about 1-4 grams per serving.

Many products have been labeled tofu frozen desserts and are found to contain not tofu but isolated soy protein or soy isolates, which are derived from soybeans using a chemical, water or acid process. Soy isolates have a long shelf life and are tasteless. Tofu, in contrast, is perishable and leaves a beany after taste that is difficult to disguise.

Because there are no present standards set for tofu or its labeling we are NOT PERMITTING ANY TOFU DESSERTS, INCLUDING TOFUTTI.

LYNDEN FARM CHICKENS - Bob and Jerry Belozar, owners of Lynden Farms, have assured us that their chickens are not fed hormones of any kind. These are Oregon grown chickens and are available in most markets.

EMERGENCY CALLS - Because we have been so busy it has been difficult to get through on the phone. If you are having an attack or an increase in symptoms please let Suzy know and she will put your call through or notify Dr. Swank or Barbara and one will return the call as soon as possible.

Finally - If you spend a day in the sun, particularly if active in a boat, be prepared to spend a few days in bed and take cold baths several times daily.

DIET NOTE: Juanita's Tortilla Chips - ARE NO LONGER ALLOWED - These chips have been fried in soybean oil and contain much fat.

Some of you have contemplated donating to our research but have delayed doing so. Now is a very good time to make this donation. At present our budget is overdrawn and badly in need of resuscitation.

Make check payable to: The Oregon Health Sciences University Foundation for Dr. Swank's Research

Send check to: Dr. Roy L. Swank, Dept. of Neurology
Oregon Health Sciences University
3181 SW Sam Jackson Park Rd.
Portland, OR. 97201

CONTRIBUTOR'S NAME: _____

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MULTIPLE SCLEROSIS NEWSLETTER

December, 1985 From the office of Roy L. Swank, MD No. 25
Editor-Barbara Dugan Typist-Rustie Production-Ruth Stewart

This is our Xmas newsletter and progress report. One of our newsletters was omitted this year because of the press of research and the need for relief from some of our duties to rewrite the diet book, both of which will be discussed later in this letter. We will first consider the problems of the rapidly approaching winter and holiday season.

Winter rules of Multiple Sclerosis patients need to be observed. These are:

1. You have probably received some benefit from the very nice fall weather which now seems to be on the wane. The wet chilly or cold weather of winter may not be so kind to you. Keep your home or room you live in warm (70 to 72 F) or dress extra warmly at home. Wear warm underwear, preferably full length during the day and wear warm bed clothing. Avoid becoming overheated, however, by an electric blanket, but feel free to use local heat for aching muscles and joints.
2. If this advice does not give you some relief from aching muscles and joints, quinine sulfate, lioresol, or a new medicine called trental may help.
3. Above all, avoid getting caught in cold rainy or snowy weather without adequate clothing.
4. Remember the problems you have faced in the past with Thanksgiving and Xmas. In addition to the dietary problems, there are additional problems facing women with children. The entire season is a drain on you, it leaves you exhausted and suffering from fatigue for some weeks after. Pace yourself and avoid nervous tension and fatigue. Do not do all your Xmas shopping on one day- do a little each day, and rest after each shopping trip.

By observing these rules you will avoid being irritable and cross with your family. Xmas will then mean so much more to you and your family.

We have frequently talked about exacerbations of Multiple Sclerosis but have not discussed what you, yourself, can do for them. Patients not on low fat diets will have between 0.2 to 5.0 exacerbations (average 1 to 2 exacerbations) per year. On low fat diet the frequency of exacerbations decreases to less than 1 exacerbation in 20 years. However, minor fluctuations may occur which are recovered from quickly, and leave no trace. These may occur several times a year and are usually due to weather changes, nervous tension, severe fatigue, hot weather or hot baths, and infections. These usually respond to rest and mild sedation, or in the

case of heat, respond to a cold bath.

The best treatment for the fluctuations, if they are mild, is bed rest several times a day (or total bed rest if they are more severe) until the symptoms clear. Mild sedation is also very helpful in most cases. The sedation should be taken 3 to 4 times a day. It is important that the patient sleep well at night and that all sources of agitation be removed.

In more severe aggravations of disease, with increase of symptoms and appearance of new ones, it may be necessary to resort to plasma infusions.

Practically, however, I advise the patient to quit work if possible and go to bed. If you have fever, call this office immediately. If nervous, start taking your sedatives. If you are no better in 2 or 3 days, or worse than before, call this office and explain your problem to Rustie. She will see to it that Barbara or Dr. Swank will contact you as quickly as possible.

As already alluded to, Barbara and I are rewriting the diet book. By the time you receive this letter the manuscript should be finished and in the hands of Doubleday and Co., the publisher. The diet instructions have been clarified, recipes added, and others removed. Barbara had done much to make the recipes easier and more practical for Multiple Sclerosis patients. Because early diagnosis is so important, the early symptoms have been described in detail. Also much is added concerning fatigue, nervousness, childbirth, operations, etc. with descriptions of how each can be successfully treated. We hope you will find it interesting and helpful. We will let you know when it is published and is available.

Research has continued on the effects of normal blood plasma on patients with Multiple Sclerosis. The treatment has continued to be successful. In the past 3 years we have given more than 900 infusions at the medical school and additional infusions have been given to our patients by other physicians. The great majority of these patients have been significantly helped by these infusions.

These studies include the long term double blind study which is nearing the 2/3 point of completion. We have also started a maintenance program, the aim of which is to more closely determine the correct dosage of fresh plasma and plasma fraction. This study is promising and hopefully will determine how frequently we must give single infusions to maintain a stable, smooth course of the disease.

We are also attempting to statistically determine the value of the red cell mobility diagnostic test.

Our analysis of 35 years experience with low fat diet with

the Montreal patients is nearing completion, and some of this information will appear in the book.

We are not quite finished collecting data of temperatures extremities in Multiple Sclerosis patients and control subjects.

ONE LAST BIT OF NEWS:

Barbara and Dr. Swank have talked to large groups of Multiple Sclerosis patients in three cities in Washington this fall. We spoke first in Yakima, then Spokane and finally on November 9, 1985 in Seattle. They were well received in each city.

LET'S TALK ABOUT DIET

Scholl's Thriftway, 12880 SW Scholls Ferry Rd., Portland now has skinned smoked turkey breasts available. These can be sliced for you on request. To order, call the Meat Department, 620-7717.

NEW PRODUCT: Cassava Crackers, an Indonesian product, similar to a potato chip when fried, are permissible and available at Scholl's Thriftway and other markets carrying specialty items.

Count Down Cheese is now available at Health Mart in the Hillsdale Shopping Center, 6326 SW Capital Hwy. The cost is \$5.45.

Soy Lecithin Spread is also available.

This is the season when we solicit funds from those of you able to help our research. This year our financial situation is acute as always, only more so.

Suzy Wood, former secretary is no longer with us. We are happy to introduce Rustie Dokelsky, our new secretary to you. She is presently busy reorganizing the office, and otherwise getting acquainted with procedures and attitudes. You will find her pleasant, courteous and helpful.

In the change over since Suzy Wood left, we have found a number of double and triple appointments. If any of you have had confusing or double appointments, please let us know. This will open spaces for both new patients and old patients who need to be seen. We are now taking new patients, one each week. We will add patients as space becomes available. Also re-appointments are not delayed as they were before.