

MULTIPLE SCLEROSIS NEWSLETTER

May, 1986 From the Office of Roy L. Swank, M.D. No. 26
Editor-Barbara Dugan Assistant Editor-Barb Kalkhoven
Production-Ruth Stewart

In previous newsletters we have emphasized the necessity for patients to remain on diet. In the newsletter of July 1985 (No. 24), we stated that "cheating on diet is very dangerous. We now know that an additional 8 grams (1½ teaspoons) of saturated fat can lead to slow deterioration over the years. There may not be warning signs until it is too late and the disease has slipped into a progressive phase." This should be modified as follows: ("The addition of 8 grams of fat often may appear to allow stabilization of the disease but this lasts for no longer than 7 years. Then the disease becomes rapidly progressive, from which there is no recovery.")

This should be a warning to patients receiving plasma, as well as all others. The chance that you can tolerate more than 15 grams of fat daily is no more, and probably less, than 4 percent. Ninety-six percent of patients who have exceeded their diet by 10 grams or more have ended up deteriorating rapidly and suffered a high death rate. To emphasize this point, we are including in this letter a graph showing the relationship of deterioration and deaths to the daily intakes of fat. You will note the sharp increase in disability and deaths upon addition of 8 grams or more fat to your diet.

It is important that the patient understands that a saturated fat intake of 20-25 grams will not usually produce apparent increased disability in a short period of time. A slow, silent deterioration occurs, and in a few years increased activity of the disease surfaces. To exceed this level repeatedly will result in the inability of leading the active life all of you are striving toward.

Some patients receiving plasma or its fraction have assumed that this is a substitute for following diet closely, and have increased their fat intake. For a time this seemed to work, but in succeeding years it became evident that infusions of plasma were required more often, and finally failed to benefit patients altogether. At that point the patient is faced with a prolonged recovery period of a year or more on a strict low-fat regime augmented with rest. The patient is fortunate if he is able to return to his former well controlled state. We have been, and will continue to check your cholesterol and triglyceride levels prior to your appointment. This helps us determine how closely you are following diet. Those patients receiving plasma on a regular maintenance program will be checked even more closely. Those not adhering to diet will not be given plasma. Plasma therapy must be accompanied by strict adherence to the low fat diet in order to be completely effective.

permissible in limited amount. You are allowed one serving equalling one-half cup per day. Weight Watchers Ice Cream Bars (not the sandwich) are permissible in limited amount. You are allowed one bar per day.

Cola Drinkers - Did you know that there are 10 teaspoons of sugar in a 12-ounce can of Pepsi. Many patients are drinking too much cola. Cola contains more sugar than candy. Diet cola is not as good as it sounds. It contains high amounts of sodium. Fruit juices and ice water with lemon are good summer substitutes.

Chocolate/Carob - Carob candy bars and chips contain as much saturated fat as a chocolate bar. In a chocolate bar the fat comes from cocoa butter. In the carob bar the fat is usually palm or coconut oil. Carob powder only is permissible.

Ice Bean - There are two types of Ice Bean Frozen Desert. The tofu flavors are not permissible as they contain coconut oil. Because of the high oil content you are allowed no more than one-half cup per day.

Natural - Don't be fooled by the word Natural on a label. The Food & Drug Administration has great difficulty defining the word Natural. A food can be called natural and still contain artificial ingredients. Products indicating "No Artificial Flavors" often contain artificial colors and preservatives. Products indicating "Sugar Free" may be free only of sucrose and contain other high calorie sweeteners such as honey or corn syrup.

MISCELLANEOUS OFFICE NEWS

We have 2 new secretaries in the office. Barbara Kalkhoven replaced Rusty and will work from 8:30-3:30. Marlene Brandt will join the staff working part time from 1:00-4:00.

As many of you know, getting through to the office on the telephone can be difficult, at best. On an average day, our office receives approximately 80-90 telephone calls. This may be a low estimate. And, then when you count the outgoing calls we need to make, you can understand why the most familiar sound you hear when you call is a busy signal. Something else you may hear is; "Hello, you have reached Dr. Swank's office . . ." The main reason for these encouraging words is there is usually only one person to answer the telephone, and, that's me. Whenever I leave the office, I put on the answering machine. I return all the messages that are left on the answering machine as soon as I can. At times, however, the name and/or telephone number in the message cannot be understood. It is very important that you speak clearly when leaving a message. This will guarantee you a return call from me. To help keep the telephone clear for emergencies, write your request down and mail it to the office. With the busy telephone situation in mind, you could possibly get a faster response by using the mail. The exception to this, of course, is if you are having increased activity of your disease, call the office.

Even so, be careful not to exceed your tolerance.

LET'S TALK ABOUT DIET

We have been carefully checking the patients' diet and are finding that a number of patients are pushing the saturated fat intake level above 15 grams. Part of the problem is the availability of more low-fat or so called natural products on the market. Some of these products are permissible, but the majority are not. Careful label reading continues to be important, but often label information must be backed up by writing to the manufacturer for more detailed information. A label may indicate soybean or cottonseed oil without including processing information; for example, were they hydrogenated. If you feel that you must indulge in one of the many non-dairy, non-meat products available, first check with the manufacturer or with our office.

We have had many requests for a list of new available foods. We have decided against this because of the concern in exceeding the limits on diet. Those patients visiting the clinic on a regular basis will have the advantage of being able to discuss newly available products and their limits. We do not feel that we can safely permit patients to make decisions about the large number of products now available to them. It is for this reason we must say "NO" to products indicating low-fat or non-fat on the label without checking with the company.

PRODUCT INFORMATION

Pure Vegetable Oil - Check your vegetable oil carefully. After opening always refrigerate; oils become rancid if stored at warm room temperatures once opened. A pure polyunsaturated vegetable oil remains liquid at room and refrigerator temperatures. If an oil clouds or hardens when refrigerated this is an indication that the oil has been processed or is not highly unsaturated. ~~All Wesson oil products are forbidden on diet, including the new sunflower Seed Oil, because the oils do not meet this test.~~ Remember to always test your oil by refrigeration before using.

Frozen Yogurt - Most all frozen yogurt contains 1/2-3 percent fat. This can be deceiving since most labels indicate the fat content per one ounce serving. The average serving size is 4 ounces. These products are not permissible.

Fruit Sorbet and Baskin & Robins Fruit Ice are permissible. These products contain no saturated fat. Weight Watchers Ice Cream is

As stated before, whether you are or are not receiving plasma, "it is imperative that your saturated fat intake always remains below 15 grams (3 teaspoons) per day."

MOOD SWINGS

Mood swings are common in patients with multiple sclerosis. The down-swings tend to occur after the Thanksgiving-Christmas season, and during the months of October-November and April-May. Up-swings tend to occur from June through October and again in February and March. The down-swings are usually due to increased physical and psychological stress, during changeable or unsettled weather, during problems with ones spouse or family, during infections, and during periods of unusually hot weather. Up-swings follow the down-swings and are associated with settled weather - either warm or crisp and dry.

Treatment is variable. Often more rest is effective if the cause is physical fatigue. Mild sedation is the most effective if the patient is nervous, tense, or upset. If the cause is an infection with fever appropriate treatment measures include antibiotics, rest, or both. It is important that the patient remain patient and optimistic in order to insure the best results.

NIGHT SWEATS

In recent years we have become more aware of night sweats as a symptom preceding and accompanying activity of M.S. It is not a symptom that patients describe voluntarily. We hope that those of you who experience night sweats will call our attention to them when we see you.

WEATHER

Summer will be here soon. Brush up on precautionary measures. It is necessary for most of you to keep cool. You can manage to cool off temporarily by putting hands and feet in cold water and wrapping a towel wet with cool or cold water around your neck with the ends of the towel on your upper chest and breasts.

One patient uses a fine spray to mist her arms, head and neck. Others use a cool swimming pool for frequent dips or showers, and others find air conditioners most useful. The general rule is to keep cool, or if warm, cool off as soon as possible. This is particularly important for those of you who exercise, either occasionally or frequently, and for those who have spent time in the sun.

A few patients tolerate and even seem to benefit from the sun.

26

PUBLICATIONS

Dr. Swank and Barbara Dugan have completed the new edition of the MS Diet Book. The book has been sent to Doubleday Publishers. Unfortunately, there will be a delay in publishing the book. It should be available in book stores in December or January.

SCHEDULING

We are now scheduling new patients into next year. Our available appointments for regular appointments are now booked through December. If you find it necessary to cancel your appointment, it may be hard to fit you into the schedule before December, unless we have a cancellation. Due to the full schedule, please cancel your appointment as soon as you know that you won't be able to keep your appointment. Other patients may be waiting for an appointment.

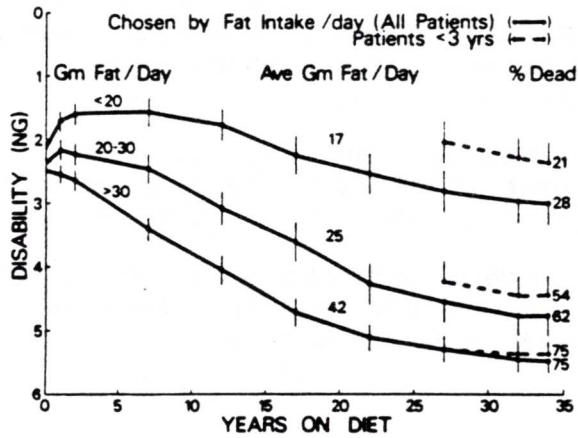
When mailing in your checks for Cod Liver Oil, please indicate if you have already received your order or would like to have it mailed. Please note the charge for Cod Liver Oil is \$16.50 if we mail it to you.

Include your telephone number with the area code on all correspondence. This will help update our records, and if I have any questions concerning your request, I will be able to contact you. Also, if your address has changed, let us know.

DIET STUDY ILLUSTRATION

This figure illustrates the relationship of fat intake to the progress of disability and number of deaths in the 35 year study of 150 patients with M.S. in the original study in Montreal. The disability grades (N.G.) range from 0 which is normal to 6 which is deceased. 2 and 3 indicate difficulty walking, 4 in wheel chair and 5 in bed. From the total group of 150 patients, those who had M.S. for less than 3 years when placed on diet were analyzed separately. Their death rates are indicated by () at the ends of the dashed lines. Those patients on less than (<) 20 grams of fat a day, those consuming between 20-30 grams of fat daily, and those who consumed more than (>) 30 grams of fat daily are graphed. The dashed lines to the right are for patients who had M.S. less than ---3 years when placed on diet. Note that patients consuming less than 20 grams of fat daily had 28 or---21% deaths by the end of the study. A slight increase of no more than an average of 8 grams of fat per day, more than doubled both the death rate to 62---54%. An additional 17 grams of fat was attended by a modest further increase in death rates and deterioration.

Swank Multiple Sclerosis Study



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No 27

July 21, 1986

The enclosed reprint is from my hometown newspaper. Because of many requests, my staff suggested (!) that we obtain copies and include them in our newsletter. I objected, but staff won. To make this newsletter more than a total loss, a few remarks about the value of the MRI and other diagnostic methods are included, together with our mid-year appeal for funds.

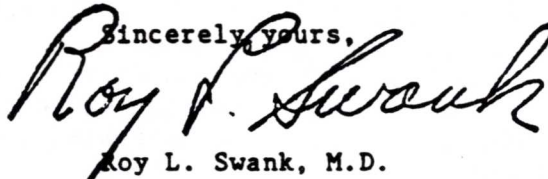
As many of you are aware, the MRI (Magnetic Resonance Imaging) test has been advertised as the last word for diagnosis of Multiple Sclerosis. The impression gained is that it is the most reliable of diagnostic tests, and that if this test is negative, the patient does not have Multiple Sclerosis. This attitude is reflected by many practitioners of Neurological Medicine, and has assumed major importance in the minds of some patients.

Our experience has not confirmed this point of view. We have seen a number of patients, most with early disease, whose MRI was normal, but the history and neurological examination plus the red cell mobility test indicated that the patient had Multiple Sclerosis. We have not observed the opposite; patients with a positive MRI test who do not have Multiple Sclerosis, although, this is a possibility. Several other diseases of the brain do produce positive MRI pictures.

We are not alone in our position. A recent prestigious neurological text written by neurologists in England with broad experience in this field, indicates that all tests, including the MRI and the CT Scan, although very useful supports for the diagnosis, may yield negative results, especially in early cases, and that the diagnosis of Multiple Sclerosis is still primarily clinical.

It is important to realize that the MRI test is very helpful in confirming the disease, but falls short of diagnosing it alone. The diagnosis of Multiple Sclerosis is primarily a clinical diagnosis. The MRI and other tests are valuable for confirmation, but can be very misleading if used to rule out the disease.

Sincerely yours,



Roy L. Swank, M.D.

RLS/blk



LET'S TALK ABOUT DIET

We receive numerous letters daily about the many new products on the market. Most of the products in question are not permissible. We are finding that many patients are allowing their fat intake to rise above the allowable levels because of misleading packaging (100% natural, low-fat, etc.). As a result, they are exceeding 15 grams of fat per day. In order to incorporate these new products into the diet a number of the patients have attempted to exchange one food for another. This can be harmful not only because of the possibility of exceeding the 15 grams of allowable fat, but also removing valuable food groups from the diet and replacing them with processed foods will add to loss of energy and reduced feeling of wellness in the patient. We are beginning to see patients who had previously been stable, now becoming slowly progressive (refer to last newsletter). Once this happens the patient may not return to their previous stable condition. It is very important that our patients are aware that the original Montreal group (started 38 years ago) did not eat prepackaged, specialty foods. They were very disciplined when it came to staying on diet. Their diet consisted of basic foods prepared according to diet. This group, after 38 years has done very well.

We hesitate to say no to all the new products that have become available. Although most of these products are not allowed on diet, the few that are can help make the diet easier to follow. We cannot monitor what you are eating, you, the patient must take responsibility for your own health. One way of looking at this is--would a person with diabetes eat sugar?

When you come into the office for your appointment, we will help you determine if a product you are interested in is permissible. To help check on your diet, we are asking that all patients go to the Biocolloid Lab at Providence Hospital in Portland for a Total Profile blood test every year. We suggest that each patient schedule their own appointment for this test one week before seeing us. If this is inconvenient, the appointment can be made at another time, or be discussed with us and made on that same day. You will need to fast from midnight the night before your test. The number of the Biocolloid Laboratory at Providence Hospital in Portland is (503) 230-6137.

PRODUCT AWARENESS AND LABEL READING

For years we have always told the patient not to use a product indicating hydrogenation or processing of the oil. If the label indicated the type of oil with no indication of processing the product was generally permissible, with the exception of those using palm or coconut oil. This rule no longer applies. Many companies are not indicating hydrogenation on the label. A product may look very innocent and contain large amounts of saturated fat. The new rule for label reading is as follows:

ANY LABEL INDICATING PALM, COCONUT, OR HYDROGENATED OIL INDICATES THE PRODUCT CONTAINS HIGH AMOUNTS OF SATURATED FAT AND MUST BE AVOIDED. IF THE LABEL INDICATES THE TYPE OF OIL SUCH AS SOYBEAN OIL, OR COTTENSEED OIL, WITH NO INDICATION OF PROCESSING, IT IS NECESSARY TO CONTACT THE COMPANY TO VERIFY THAT THE OIL USED HAS NOT BEEN PROCESSED.

PRODUCT INFORMATION

Rosserita Vegetarian Refried Beans - This product was permissible, but because the soybean oil is hydrogenated, and not indicated on the label, we have removed it from the permissible list.

Chips - Many patients are snacking on a handful of potato chips thinking just a few won't hurt. The following listing of saturated fat will surprise those sneaking a chip or two.

Corn Chips - 1 ounce = 10.4 grams fat
 Tortilla Chips - 1 ounce = 6.8 grams fat
 Potato Chips - 10 pieces (2 inch diameter) = 8.0 grams of fat
 Potato Chips - 3½ ounces = 39.8 grams of fat
 Potato Chips - 1 ounce = 10.5 grams of fat
 BBQ Flavor

Ground Turkey - Because dark meat and fat are added to ground turkey, it is **NOT** permissible on diet. Most meat markets will be glad to grind chicken breasts for you, without added skin and fat.

MISCELLANEOUS OFFICE NEWS

If you are receiving more than one newsletter, please contact the office so that we can delete the extra mailing address from our records.

When mailing in your checks for cod liver oil, please indicate if you have already received your order, or if you would like to have it mailed. The cost for the cod liver oil mailed is \$16.50, if picked up in the office the cost is \$14.00.

Please remember to write down what you eat for one week before your appointment, and bring this with you.

Six month regular appointments are now being scheduled into March and April of 1987. New patient appointments are now filled through May, 1987. Please cancel your appointment as soon as you know you are not able to keep it. This will help patients who are waiting for appointments.

Dr. Swank and Barbara will be on a much deserved vacation the first three weeks in August, and they will be in Europe the last two weeks in September. Barb and Tony will be in the office during regular office hours.

MULTIPLE SCLEROSIS NEWSLETTER

September, 1986--From the Office of Roy L. Swank, M.D. No. 28
Editor-Barbara Brewer Dugan Assistant Editor-Barb Kalkhoven
Production-Tony Leckband

SHORT REPORTS--

The season of variable weather is upon us. It usually includes October and November, but can include the month before and after. During this period you may experience more fatigue, and minor flare-ups of former symptoms than usual. Those of you carefully on diet for some years will have far less trouble than those who follow diet poorly.

Warmer clothing is advised, starting with long, light-weight underwear in the Pacific Northwest, and heavier underwear in colder climates.

Thanksgiving-Christmas follows on the heel of the unsettled Fall weather, and in turn, is followed by January, a month of fatigue in mothers, especially those of small children. This is due to the many pressures and duties that mothers of small children experience during this time of year. Outside help or help from other family members during this period of time can greatly reduce the amount of stress and pressure that these patients experience. This will help ensure an enjoyable holiday season for all members of the family.

Burning pain has received little attention in previous newsletters. It occurs infrequently, but when present, is persistent and sometimes becomes disabling. Usually sensitivity to pin and touch are retained and often intensified. The general term for this type of pain, and for other abnormal sensations, is paresthesias.

The burning can be confined to a local area, for example, the feet or hands, or be right or left sided, or involve the entire body. It may or may not be accompanied by a redness and actual warmth of the area. It seldom involves the head. It may continue to be present for years, or be periodically present during hot weather or during periods of stress.

Cooling the painful area with cold water usually gives temporary relief, but medications have generally been disappointing. We have tried Dilantin and Tegretol, both of which are therapeutic for other painful conditions, with limited success. Sedation may reduce the intensity of the burning, but give no more than limited relief.

The burning seems to be an intermediate phase of a sensory change. Normal responses to the pain of a pin prick and to touch are maintained, and usually exaggerated. Walking on "hot feet" is usually unpleasant and can be downright painful. In early cases the burning often disappears with time, but in other cases it may be dishearteningly persistent.

Family Stress - B. John Hale, DSW, MPH

Families are carefully balanced systems. When any part of this system is stressed the entire system (family) is at risk.

When an acute stress, such as an accident strikes, most families believe that they can deal with the crisis and return to normal, if given time. They usually do. When a family is threatened by a chronic illness, like Multiple Sclerosis, all parts of the system need to readjust. Stress is a naturally occurring by-product of the attempt to rebalance the family system. Values and rules are re-examined, and relationships within the family change. If an accident then occurs, the family, and especially the patient is subjected to another stress; a stress that may last for months.

The family can re-organize with little harm to itself, and in fact, be stronger. Often, however, the process is frightening, and family members fail to understand what is happening. The process of reorganization can be confounded by other life crises, such as, career problems, extended family problems, mid-life crisis, etc. The result of this psychological/family system stress is individual stress. Until a family has arrived at a new working balance and accommodation, the chronic illness of the body will be under stress.

Individual stress reduction techniques are useful, but family therapy and improved communications are usually necessary during the period of adjustment if a satisfactory balance is to be obtained.

Micellaneous Office News--

The entire office staff would like to take this opportunity to thank our patients, their families and friends, and other interested parties for your patience and understanding of our busy telephone and full schedule. With only a few exceptions, everyone has been very understanding and supportive of our very busy office, and we thank you very much.

To help cover the cost of preparing, printing, and mailing this newsletter, we are asking for a yearly contribution of \$20.00. Please make your check payable to the O.H.S.U. Foundation, Swank, M.S. Research; and mail it to our office, Roy L. Swank, M.D., O.H.S.U. L-104, 3181 S.W. Sam Jackson Park Road, Portland, OR 97201.

COMING EVENTS

In this newsletter, we are pleased to announce two future events of interest to both patients and interested readers.

The First Announcement concerns the yearly Marquam Hill Lecture Series. Of special interest in this series to patients with neurological disease is the lecture by Dr. Earl Zimmerman, Professor and Head of Neurology at the the Oregon Health Sciences University, who will talk on November 6, 1986. He will talk about brain grafts and their future in degenerative neurological diseases, such as Alzheimer's disease and Parkinsonism.

You will find the enclosed brochure very informative. In addition to describing this series of lectures and the personalities giving them, it gives background information about the Marquam Hill Society.

Our Second Announcement is addressed specifically to our, and to other, M.S. patients, their families, and friends. This is a symposium on M.S. to be held in the ballroom at the Benson Hotel on November 1, 1986. Dr. Swank, Dr. Seaman, and Dr. Hale will be speaking. They will discuss what has been accomplished, and what is being done at the Oregon Health Sciences University to benefit patients with M.S., how to diagnosis M.S. early so that it can be controlled, how to control it, and how to cope with its many frustrating features. There will be time to answer your questions concerning your own problems. The second enclosed brochure on this symposium should answer any questions you might have. If you have additional questions, please call the office.