arch, 1984

# MULTIPLE SCLEROSIS NEWSLETTER From the office of Roy L. Swank, M. D.

No. 19

FATIGUE is the subject of a comprehensive discussion in this newsletter. It is the most common (frequent) and persistent symptom of multiple sclerosis. It develops very early in the disease, and often preceeds the first neurological symptoms. In a few patients fatigue prevades their entire life from early childhood, then intensifies when the actual clinical disease appears.

Fatigue is persistent, but this is not to say that it does not vary. In fact it varies a great deal, more or less spontaneously. Early in the disease patients may have days, weeks, and even months in which they are not conscious of being fatigued, but these periods are usually followed by re-appearance of their old unwelcomed "friend". In long standing or more advanced cases there is little let up from the fatigue.

Periodically a deeper fatigue may develop, which I have called lassitude. These spells may develop quickly, and apparently without cause, and last for days or weeks, but rarely longer. They may describe the fatigue as almost painful. During these periods patients often find it difficult to get out of bed, or do the simplest chores. These spells usually lift or disappear abruptly leaving the underlying persistent fatigue.

I have already stated that the intensity of the fatigue may vary spontaneously, or for to known reason. Its itensity can also be increased or decreased by different cirimstances or events.

Fatigue can be, and almost always is intensified by illnesses such as the common cold or "flu". If these illnesses are accompanied by fever, severe intensification of the fatigue almost always occurs, and at the same time many of the neurological symptoms of the disease increase or reappear. Urinary infections with fever are noteworthy for causing extreme severity of fatigue, general weakness, and intensification of neurological symptoms. Once the fever subsides the condition of the patient improves. It is fortunate that our patients develop the common cold or "flu" less frequently than normal members of their family, and if they are involved the illness in patients is much less severe.

Fatigue accompanied by increased generalized weakness and deterioration of the neurological state usually follows the development of anxiety and mental agitation. If the stress causing the anxiety is of short duration a quick recovery (1 or 2 days) can be expected. If the stress is severe the fatigue and accompanied neurological symptoms are more marked and recovery can be delayed for months. Sometimes recovery is only partial or fails to occur under these circumstances.

Excessive work, or exercise to exhaustion may also cause the fatigue to be increased. The degree of change and its duraton will depend upon how excessive the physical and mental activity were. However, it has been our observation that as a rule physical excesses are less apt to lead to severe prolonged fatigue than are anxieties.

Anxieties tend to be self-propelling once they have been set in motion. Thus car cidents in which the patient viewed the potentially devastating accident, yet was not riously injured, are apt to lead to a growing or increasing anxiety reaction, and thereby to increasing fatigue, weakness and neurological deterioration. On the other hand, a more serious accident, which was not observed by the patient, and in which the patient was rendered unconscious for some minutes by a non-bleeding head injury, may result in very little increase in anxiety and to insignificant weakness and neurological changes. Patients are exceedingly (unbelievably) sensitive to weather changes and to exposure to very warm or very cold weather. Marked changes in the daily temperature will be followed within a week by deepening of fatigue and weakness in many patients. For this reason we will see many patients in October-November and again in April-May who complain of fatigue and weakness. The symptoms last for about 2 to 4 weeks, then disappear. Fatigue also occurs during the hot summer days. Fatigue from overwork, concern, and frustration develop in most women following the Christmas holidays.

The only effective treatment for fatigue in multiple sclerosis not due to an infection with fever is rest by lying down. Rest by sitting up is much less helpful. If the fatigue is severe go to bed for several days. If not severe be sure to take your daily naps, or increase these naps to twice daily.

Mild sedation is helpful for those whose fatigue has resulted from anxiety.

In other newsletters we have discussed the treatment for fatigue resulting from overheating during hot weather or from a hot bath. Treatment of urinary infections and their prevention have also been described in earlier newsletters.

I have frequently observed that patients do very well when away from home on vacation. The fatigue may lift and the patient will return rejuvenated.

There is one more aspect of the fatigue that needs to be mentioned. Fatigue seems to be much more evident and is complained of more by patients who are actively ambulant, than by those who are inactive. Fatigue is complained of most vehemently early in the disease when the patients are most active. On the other hand, patients in wheel chairs register this complaint infrequently and with little rancour. Perhaps what we are dealing with is "easy fatigueability". Prior to the clinical onset of M. S. most patients are very active and energetic. Many jog, others are active hikers, and in general most are high physical and mental producers. The onset of M. S. brings with it reduced physical ability and endurance. Increasing fatigueability is the result. Even the act of ambulation through an 8 hour week shift causes persistent fatigue.

In addition to fatigue patients note that they recover slowly from increased fatigue due to physical or psychological stress. This becomes progressively more marked when the M. S. progresses.

The fatigue is usually not visible or obvious to the casual or even professional examiner. It is noticed and remembered by close friends, and by members of the family. Deep fatigue however, frequently is accompanied by a drawn and pale countenance, which is readily recognized by an interested observer.

<u>CHOLESTEROL</u> levels have an interest for many of you. This is due to the reported relationship of blood cholesterol to heart disease and stroke. The low fat diet you are on has been used in this study of M. S. since 1948 (for 36 years). This diet has been very effective in lowering blood cholesterol to levels consistent with good heart health. Except for a few patients who have problems with cholesterol metabolism the cholesterol levels in patients on our diet regularly fall below 200 mgs. and usually between 140 and 170 mgs. In younger patients the cholesterol levels are often below 160 mgs. and then tend to rise by about 10% with age.

A recent study from Northwestern Medical School has shown that the incidence of heart deaths is reduced by 75 to 90% in patients whose blood cholesterol levels are similar to the levels attained by patients who follow our low fat diet.

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Lecent studies have also shown that many cancers are in all probability due to a high fat intake. Low fat diets such as the one you are following are now being advocated to prevent these cancers.

The knowledge that the high fat diets, usually consumed in the Western Industrialized countries, are important causes of heart disease, strokes and cancer as well as multiple sclerosis should help to motivate not only you, the patient, but also your entire family to endorse and follow the low fat diet. Many families have already done so. Common sense and a desire to stay healthy and vigorous should motivate the remaining stragglers to follow suit. It would make life more pleasant and simpler, and the cost of groceries less painful, if all members of the family were to consume the same basic foods.

Cooking two different meals is not only time consuming and costly, it also suggests a lack of cooperation with the patient. We have patients who have slowly gone off diet and deteriorated neurologically because of a lack of cooperation from the family which led to the cooking fo two separate meals. This in turn caused excessive fatigue and a loss of adequate motivation to continue.

### PHYSICAL THERAPY PROGRAM

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A new physical therapy program has been developed at Portland Aventist Medical Center, 10123 S.E. Market St., Portland, OR. The program is designed for only multiple sclerosis patients. There will be 3 staff members available to our patients. Group therapy and individual therapy, depending on the need of the patient will be available.

The sessions will be one hour twice each week, Tuesday and Thursday at 11:00 for four weeks. There will be no more than six patients per group. The cost per session will be \$15.00. Insurance can be billed. We have arranged for 3 levels: 1. newly diagnosed; 2. ambulatory with mild disability; and 3. disabled.

In the future we would like to develop aerobic exercise classes and support groups run by the patients.

We would like to see those of you who are able to take advantage of this new program. Please contact Barbara if you are interested.

SUPPORT GROUP - Susan Shadburn is interested in developing a support group in the Portland area. She would like anyone interested to contact her at 3436 NW Thurman, Portland, OR. 97210.

#### Let's Talk About Diet

For those patients we have not seen for a long time, there has been a change in the amount of red meat allowed on diet. RED MEAT IS NOW ALLOWED ONLY ONCE PER WEEK IN THE AMOUNT OF 4 OUNCES.

# Recipes

# Flavorful, Low-fat Sauces

S reduce the fat content of sauces that call for cream, but still retain the velvety, creamy goodness, substitute reconstituted nonfat dry milk made extra strength. Use one-half cup of milk powder to make one cup of milk. Butter is often called for in sauce recipes, as are meat drippings and chicken fat. But you can make a sauce without added fat. Simply combine liquid with a thickening agent, add flavoring and cook.

To make a low-fat lump-free basic white sauce, combine one cup milk, two tablespoons wholewheat pastry flour, and a dash each of cayenne pepper and nutmeg in a blender and whiz briefly just until smooth; or place the ingredients in a screw-lid jar, put on the lid and shake vigorously. Pour mixture into a saucepan and cook over medium heat, creating constantly until thickened to the consistency of cream.

Vegetable purees make superb low-calorie, high nutrition thickeners. Use cooked vegetables such as onions, turnips, potatoes and rutabagas pureed in a blender and stirred into your sauce until thick.

Other thickening agents are: Cornstarch and arrowroot (about twice the thickening power of wheat flour - use half as much)

Potato starch - twice the thickening power of wheat flour - Potato starch sauces are wonderfully light and smooth.

SUPPORT GROUP - Alice Baughman is interested in developing a support group in the Gladstone, West Linn, Oregon City and Beavercreek areas. Anyone interested should contact her at 927 Madison St., Oregon City, OR 97045.

SUPPORT GROUP - A new support group has begun in the Woodburn area. If you are interested please contact Karen Griffith at 678-5405.

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June, 1984

# MULTIPLE SCLEROSIS NEWSLETTER From the office of Roy L. Swank, M. D.

No. 20

<u>ABOUT PREGNANCY</u>. We receive a steady flow of queries from younger women with M. S. concerning the effect of <u>pregnancy</u> on their disease. We have referred to this problem before, but in this newsletter I will try to clarify our position and be more comprehensive. The cause of the many questions is the conflicting opinions which have reached the ears of the patients.

A recent M.S. newsletter release, dated April 12, 1984, suggests that the course of the disease is not affected adversely by pregnancies. They stated that patients did well during pregnancy and were apt to have more trouble after delivery but that <u>invalidity</u> was not changed by pregnancy. The studies referred to were based on hospital records and neurological examinations of patients. It is not stated, but your present writer wonders if the majority of these patients were already seriously disabled when they became pregnant. Our limited experience with seriously disabled patients is "also" that the degree of disability is not significantly altered.

With active ambulant patients, however, our experience has been different. The <u>quality</u> of life is affected adversely by frequent pregnancies. Although M.S. patients do very well during the pregnancy, in approximately 50% the disease exacerbates during the first 3 months following delivery. This causes 6 to 12 months of deep fatigue and general eakness, and often leads to lingering neurological symptoms. Subsequently the disease tabilizes, usually resulting in a diminished level of patient activity.

The conclusion we have reached based upon observation of many patients before, during and after pregnancy is that invalidity may not be significantly affected by pregnancy, but the quality of life is frequently adversely affected by pregnancy.

I first became aware of this relationship about 1951 while still in Montreal. Dr. Primrose, head of Obstetrics and Gynecology at McGill Medical School told me that he had had bad luck with pregnant M.S. patients shortly after delivery. At that time they frequently suffered severe exacerbations although they had done very well during the pregnancy. He had also witnessed severe relapses of M.S. after major surgical procedures. This agreed with a limited experience that I had had during my first 3 years running an M.S. clinic and with observations by Ghezzi and Caputo (Pregnancy: a factor influencing the course of multiple sclerosis? Eur. Neurol. 20 (2):115-117;1981).

Shorlty before, it had been reported by Alexander that blood transfusions prolonged remissions (see newsletter #17). Acting on this information I suggested that we transfuse patients with 1 or 2 units of whole blood immediately after delivery (and also after major operations). This led to disappearance of the post-delivery and postoperative exacerbations, and promoted rapid recoveries from both.

I continued to transfuse patients with whole blood following delivery and operations until about 4 years ago when we learned that similar results were obtained by infusion of 2 units of fresh frozen plasma instead of the 1 unit of whole blood. Our entire experience with whole blood or plasma has shown that when given post-delivery while itients are still in the recovery room, exacerbations of their disease do not occur. In patients fail to receive the blood or plasma a high percentage of exacerbations do occur (approximately 50%). Although blood or plasma is advised in all cases, for a variety of reasons some patients have not received an infusion. These patients have frequently suffered from relapses. We have also noted that delaying infusions for several days is less effective in preventing aggravation of disease than are infusion given promptly. The type of exacerbations which occur in ambulant patients when blood or plasma is not given after delivery can be described as follows: either the patient has intensification of old symptoms, or new symptoms appear which take months to clear satisfactorily if at all, or they develop deep fatigue and generalized weakness which lasts for 6 months to a year or longer.

My advice to patients with M.S. who plan to become pregnant depends on the severity of their disease and the number of children which they already have. If they have 2 or more children I usually advise against further expansion of their family. Also if their financial situation is precarious my advice is the same, and if the disease is disabling and long standing, my advice is still the same. Although patients in each category have no difficulty carrying and having the baby if plasma is given after delivery, but caring for, and raising the baby requires energy which many patients lack. It is because of this lack of energy that I usually recommend against additional pregnancies in these cases. Needless to say, unplanned pregnancies occur, or patients willfully do not follow my advice.

I recommend that patients be on diet at least one year before attempting to get pregnant; that they rest during pregnancy by lying down daily as originally advised; and that they receive an infusion of 2 units of fresh frozen plasma immediately after delivery while still in the recovery room. If undue fatigue develops in the next 2 weeks, the plasma infusion should be repeated.

Since we have been giving blood or plasma following delivery, our patients on diet have done well during pregnancy and have continued to do well after the baby is born. They have had very few minor fluctuations of disease and very little fatigue. The care of the baby (and of growing children), however, can be a real problem. If the mother has a relative or friend, or can hire help to assist in the daily chores and care of growing children, or if the children are old enough to help and are well trained and willing, one can feel secure in recommending pregnancy, if the other rules prior to and just after delivery are followed.

Our main goal in the case of M.S. patients is to maintain a satisfactory quality of life. Obviously this is not possible in all patients, but it remains our goal nonetheless. Invalidity is a sign of failure and is to be avoided or prevented as long as possible. Exacerbations or aggravations of the disease, regardless of cause, push patients toward invalidity, and should therefore be avoided if at all possible (Swank and Bourdellon, Multiple Sclerosis: Assessment of treatment with a modified low-fat diet. J. New. Ment. Dis., 131:468-488, 1960).

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#### LET'S TALK ABOUT DIET

VACATION - EATING OUT - It is vacation time and all of you are faced with the problem of eating out. I hope the following recommendations will make your travels easier.

The low-fat diet allows 15 grams of saturated fat each day after the first year. We have found that patients have less difficulty if they remain below the 15 grams. During vacation (2-3 weeks) you may increase your saturated fat intake to <u>20 grams</u> maximum. The increase in saturated fat for this short period of time should not alter the disease and will give you a little more flexibility while traveling.

#### TRAVELING BY AIR

If you call the airlines in advance, they will prepare a vegetarian selection for you. This may come with a slice of cheese. This should <u>not</u> be eaten. You can also have the restaurant in your hotel prepare a lunch for you to take on the plane. If you will be in the air for several hours, plan ahead and bring food with you. Do not go without eating. You will become fatigued and not enjoy your vacation. If you can afford to travel first class, the selection of food is much better. Check with the airlines.

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# IVING ACROSS COUNTRY

raveling by car can be fun with little problems if you keep the following suggestions in mind.

# Breakfast

Your breakfast meal should not be difficult to find in any restaurant. If you are tempted to order the usual, hashbrowns and eggs or a plain waffle, thinking there is not much saturated fat, please think again. The following list will give you some idea how much fat is packed into these common foods.

l egg – 5 grams saturated fat	1/2 cup hashbrowns - 11.7 grams
l piece french toast - 3.3 grams	1 cup 3 percent milk - 5 grams
1 average pancake - 3-4 grams	l baking powder biscuit – 6 grams
l waffle - 7.4 grams	l buttermilk biscuit - 4.1 grams

As you can see, it would not be difficult to reach the maximum 20 grams just at breakfast. If you are ordering cereal and cannot find non-fat milk, use 1/2 cup of the 2 percent and count as 2.5 grams.

# Lunch

Delicatessens are terrific for non-fat, inexpensive lunches on the road. You can find a Deli in most towns. When ordering a turkey or tuna sandwich, do not be concerned about the kind of mayonnaise used. The amount will be minimal. (This applies only on vacation.) Usually you can find pasta, fruit and vegetable salads. These can be eaten in the Deli or packed to take along for a picnic.

a Deli is not available, most restaurants will serve sandwiches and salads. When choosing a restaurant for lunch it is best to look for those that are moderately expensive. The more expensive restaurants tend to serve gourmet type entrees for lunch which contain cheese and high fat sauces.

The grocery store is always available when you grow tired of restaurants. Carry along a small cooler - ice can be found in your hotel each day. Fresh fruit, smoked or canned fish, fresh vegetables, french bread and something cool to drink. This is less expensive and a welcome change from restaurant food.

For those of you who might stray to the fast food places such as Burger King or Mac Donalds, be careful. If you have been following diet carefully, the amount of saturated fat in one small order of french fries could mean many restroom stops. You will not be able to tolerate these foods any longer. The following list will give you some idea of the saturated fat, sodium and caloric content of junk foods.

MACDONALDS	Calories	Sodium	Sat. Fat
Filet-O-Fish	373	519	22.7
Fries-regular	268	45.	10.6
Big Mac	587	888	31.4
BURGER KING			
Whaler	502	466	46.0
Fries-regular	158	56	10.0
Whopper	663	1081	32.0
TUCKY FRIED CHICKEN			
Original Recipe 2 pc.	720	1445	46.0
TACO BELL			
Taco	194	213	8.0
Bean Burrito	343		12.0

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Dinner

Unlike lunch, your evening meal should be eaten at the more expensive restaurants. You will find the choices will be much greater. The better restaurants will be happy to accommodate your needs. If you have been careful during the day and not exceeded 5-10 grams of fat you should be able to order without problems.

If the chicken is not available without the skin, remove the skin and count this as 5 grams of saturated fat. Avoid red meat. This will help compensate for the hidden fats you have had to consume throughout the day.

Remember this increase in saturated fat is to be used only when on vacation once each year and if possible stay below the 20 grams.

# ALCOHOL

Alcohol should be used in moderation while on vacation. We consider moderation to be two drinks. Alcohol to excess (for most patients this is over 2 drinks) can lead to increased fatigue the following day (refer to newsletter #9).

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MS SUPPORT GROUP - EASTERN WA. - Walt Gray has started a support group. If you live in the area and have an interest, call Walt at 509-646-3482.

MS SUPPORT GROUP - PUYALLUP, WA. - Ken Cupp and his wife have started a new support group. If you live in the area and have an interest, call Ken at 206-848-3779.

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Rhubarb Sorbet 1 1b. fresh rhubarb cut in 1" pieces (3 cups) or 1 package (16 oz.) frozen cut rhubarb, thawed 2 to 3 tablespoons water 3/4 cup sugar, or to taste 1 teaspoon vanilla 2 to 3 drops red food coloring (optional) 1 egg white

In blender or food processor, puree rhubarb with water. Transfer to medium saucepan; add sugar. Cook over medium heat 5 minutes, stirring often. Remove from heat; stir in vanilla and food coloring. Cool to room temperature. Meanwhile beat egg white until stiff but not dry. Fold into rhubarb mixture until well blended. Pour into shallow metal pan or ice-cube tray; freeze about 1 hour or until firm around edges. Turn into chilled bowl; beat until smooth. Freeze partially; beat again. Freeze about 2 hours or until firm. Makes 8 servings.

Strawberry Ice
1 pint strawberries, rinsed, drained and hulled
1 cup water
3 tablespoons honey
3 tablespoons orange juice
2 tablespoons lemon juice

Reserve 4 whole strawberries for garnish. Puree remaining strawberries in a food processor or blender. Blend in water, honey and juices. Freeze in ice-cream maker following manufacturer's directions or pour into 8" square metal pan; partially freeze; stir, then freeze about 2 hours longer until firm. Serve ice in goblets or glass bowls; garnish with the reserved berries. Makes 4 servings.

MULTIPLE SCLEROSIS NEWSLETTER From the office of Roy L. Swank, M. D.

vember, 1984

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

Former newsletters have discussed anxiety (nervous tension or nervousness) and its effects on patients with multiple sclerosis. That nervous tension may lead to irritability has also received attention. In this letter we will concentrate on irritability, its causes, and its effects on the patient and family. We will also discuss how to control or diminish irritability and the value to all concerned when this can be accomplished.

Every individual is possessed of some anwiety which I will refer to as "free floating" anxiety. A certain amount is stimulating and zestful. It encourages alertness, promotes striving for perfection and/or increased productivity. Anxiety of this degree is usually not detected by others, and is well controlled. However, this anxiety may be so near the surface in some individuals that without an obvious cause, it often becomes evident to members of the family and to friends. When these individuals are exposed to real stress the anxiety may become blatant. It is this sensitivity to stress which characterizes many patients with multiple sclerosis; few M.S. patients seem able to keep their anxieties under control.

Serious anxieties are usually due to recognizable stress. The stress may be due to many things, but usually one basic factor is at the root of the matter - ones security is threatened. One becomes financially insecure if one loses his or her job and has no other means of support, or if one is threatened with divorce, and support is uncertain. Can be emotionally insecure upon loss of a loved one, in particular the loss of a ld. One can be physically insecure as the result of an accident or diagnosis of a rious disease. In each case, however, dwelling on the insecurity intensifies the anxiety and leads to irritability. Unfortunately in a number of people the source of the stress need not be real, it can be fabricated in the mind of the patient and amplified to the point that irritability results. Fortunately, when the stress is reduced or removed the anxieties lessen and patients usually recover their poise while the symptoms subside.

As the anxiety increases a characteristic series of symptoms develop which can forewarn the patient of the impending problem. The first symptom is usually a feeling of nervousness and difficulty sleeping. The most common somatic (bodily) complaints which then appear are headache, abdominal distress with heartburn, and/or backache. Less frequently palpitation, shortness of breath sometimes leading to hyperventilation, and night sweats occur. At some point in the development of these symptoms the patient gets irritable and "emotional" to the point of frequent tears and frequent shouting at the children. The patient refuses to compromise, and insists that he or she is always right, and everyone else is wrong. The patient is near exhaustion from lack of sleep and now worries that another disease is the basis of the many complaints. Hospitalization may result but usually the work-up is more tiring and stressful than the benefits.

Much of what you have already read in this letter refers largely to the average or so called normal person as well as to you. Those of you with M.S. have a number of unique stresses to contend with. You fatigue quickly and have reduced stamina. You can therefore not always accomplish what you would like. This is particularly frustrating

ause most of you were once energetic, aggressive and doers rather than observers. ddition you suffer from aching muscles and joints especially when on your feet a sat deal. You are also apt to have urgency and frequency of urination, and occasionally loss of control of your bowels, which can lead to very embarrassing situations. Some of you have lost your sex drive or are impotent which is demeaning and cause for discontent in your spouse, as well as yourself.

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Furthermore, you are an intense, sensitive, basically nervous group of people and you have more than the usual problems in controlling your anxiety in the face of stressful situations both those generally experienced by the average normal person and those peculiar to you.

Stresses are poorly controlled as a rule, but your reaction and accommodation to stress can be improved. It is first necessary that you understand what is happening. You must understand that the problem is yours to be resolved. Your spouse and family can help, but only if they understand the problem. If you are attempting to do too much physically your family can pitch in and help. It is especially helpful and rewarding to patients when children cooperate, both by being condiderate, and by helping with the home chores. At the same time you need to cooperate and help as much as you are able.

Take daily naps as often as necessary, but be sure to rest every mid-day. Consciously do your best to slow down - do not hurry. Plan your daily work so that you are not exhausted by the end of the day. Tell your family what you are experiencing, but do not dwell on it for if you do they will get bored and avoid you. Do not be a complainer and do not brag about not complaining. You must in every way seek the cooperation of your family, and they must try to help you.

When anxious there is the inclination to become isolated with ones own problems. This merely intensifies and justifies the anxiety and the suspicion of those close to you. It helps to have interests which take your thoughts from yourself. Yet you are trapped by your own lack of energy. If religious, you can seek help within your church. If not so inclined you need to find some other activity in which you can become interested. Meditation while practicing Yoga has been used successfully by many patients to ease tensions. Counseling and vacations away from home are also often helpful.

Finally, it is often necessary to resort to the use of tranquilizers. It would be better if this were not necessary, but more often than not tranquilizers are necessary. Sometimes for sleep alone, and often during the day. In either case tranquilizers and antidepressants should be used as sparingly as possible, but in sufficient doses to control the anxiety. Remember above all that recovery from severe anxiety is slow, and measured in months rather than days.

If not controlled, the irritability which accompanies the anxiety can result in the loss of cooperation by the family, and unimately in constantion and even divorce. Problems are then amplified, and fatigue, general weakness, intensification of symptoms already present, and even the development of new symptoms result. Without question if anxiety plus irritability are not controlled they lead to estrangement of the patient from the family and ultimately to an increase in the seriousness of the disease.

#### Seasonal Suggestions

We are approaching Winter and the Christmas holiday season. This calls for several measures which we have previously discussed.

- 1. Dress more warmly. If you have leg pains, wear long underwear. You can also apply localized heat to the painful area, but avoid overheating your body which may occur in a hot bath or in overheated rooms.
- 2. The Christmas season is fatiguing and stressful. Do not exhaust yourself on any one day; in other words pace yourself so that you distribute work, shopping, and other fatiguing activities on a succession of days rather than on one day. Take your daily rest, as usual by lying down. Many patients note increased fatigue and aggravation of their disease during and after Christmas. Avoid lotting this happen to you.

#### T'S TALK ABOUT DIET

Thanksgiving is just around the corner. If you are planning to prepare a turkey it is important to find one not injected with an undesirable oil or butter. Some fresh turkeys are also injected. Check with the market and order ahead.

The following list of foods contain 1 gram or less of saturated fat and can be added to your diet.

Weight Watchers Frozen Dessert Weight Watchers Orange Vanilla Treat	l cup/day 1/day
Weight Watchers Chocolate Mint Treat (only one of the above per day)	1/day
Blue Bell Pretzel	unlimited
Fred Meyer Pretzel	unlimited
Heinz Vegetarian Beans	unlimited
Van Camp Vegetarian Beans	unlimited
Health Valley Spicy Vegetarian Chili	unlimited
Hain Natural Jalapeno Bean Dip	unlimited
Rosarita Vegetarian Refried Beans	1/2 cup serving
Carnation 70-Calorie Hot Chocolate Mix	unlimited
Alba 66 Hot Chocolate Mix	unlimited
Swiss Miss Non-Fat Hot Chocolate Mix	unlimited
Fearn Spice Cake Mix	unlimited
Krusteaz All Purpose Bake and Fry Mix	unlimited
Oil Free Italian Dressing (Kraft)	unlimited
in Natural Tapioca Pudding	unlimited
ell-O Pudding and Pie Filling	unlimited
(all flavors indicating a fat content of 1 gram or less)	
Soy Lecithin Spread	2  tsp. = 1  tsp.
Butter Buds	unlimited
Tofu Ravioli	unlimited
Juanita's Tortilla Chips	unlimited
Progresso Soup (Tomato, Vegetable, Minestrone, Lentel)	unlimited
Amaratti Sorono Cookies	unlimited

Tofutti Ice Cream - we have been unable to find out if the oil in the ice cream has been processed. Please do not eat this product until you check with the office.

oil

I will continue to add to this list as new products become available.

#### IN TIME FOR THE HOLIDAYS

"Make It Easy" - A new low-fat cookbook containing M.S. diet recipes for the whole family with an introduction by Dr. Roy Swank is now available. If you would like to order this new addition to your low-fat library send \$10.00 plus \$2.50 per copy for shipping and handling to: The Latham Group, 12570 SW Glacier Lily Circle, Tigard, OR. 97223. Satisfaction guaranteed or your money will be promptly returned.

We are still having telephone difficulties. The calls to this office are too numerous to be handled as expeditiously as you would desire. When leaving your name do not forget area code as well as local number. State your business as briefly as possible. If you are requesting a letter or prescription, to be mailed, it would be best if you wrote

letter, again with specifics as briefly written as possible.

We have received our Cod Liver Oil. We ordered an extra shipment so we now have enough for all.

We will be closed the Friday after Thanksgiving.

HAVE A HAPPY THANKSGIVING!

# THE OREGON HEALTH SCIENCES UNIVERSITY

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November 15, 1984

## CHRISTMAS PROGRESS REPORT

It has become customary at this time to report our research progress for the year. This same letter is also an appeal for financial support from those of you able to help. You will note that our research, directed toward therapy, has been and is being expanded. This has led to increased expenditures and to a need for additional financial assistance. I urge you to do your best to help us finish the studies discussed below in this report.

#### A. Plasma Studies:

In an earlier communication I described the effects of infusions of normal hyman plasma on the aggravated symptoms of M.S. This work was published last year in the Journal of Plasma Therapy (Roy L. Swank, Frans Peetoom, Michael Daley, Cherry Tamblyn, and Geoffrey Seaman; Plasma in Multiple Sclerosis: A Possible Abnormality, Plasma & Transfus. Technol. 1983, 4:301-311). In early cases in acute exacerbation plasma infusions were followed by rapid subsidance of symptoms and a return of energy. In severely disabled patients, the response to plasma was less impressive. It was also shown that the red cell mobility which is abnormally slow in M.S. patients, increased to normal after plasma infusions, remained normal for 6 to 8 weeks, and then slowed to become abnormal again. The patients symptoms also improved after infusion and later returned to the previous severity as the red cell mobility slowed. The figure below illustrates these changes.





These results suggested that an abnormality existed in the blood of M.S. patients. This had been suggested earlier, since incubating M.S. red cells in normal plasma caused their mobility to be increased, whereas incubating normal red cells in M.S. plasma caused the mobility of the red cells to decrease (Seaman, Swank, Tamblyn; Plasma Origin of Red-Cell-Membrane Changes in Multiple Sclerosis, Lancet, 1980;1:938). It was later confirmed that the plasma rather than red cells was abnormal. Plastic beads incubated in normal plasma migrated differently than when incubated in M.S. plasma (Seaman, Swank, and Tamblyn; Polystyrene Latex Particles as Indicators of Abnormal Plasma Properties in Multiple Sclerosis; Neurology 34:547-549, 1984).

It is your writer's impression that the abnormality consists of a deficiency since adding normal plasma to the blood of M.S. patients corrected the abnormality for several months. The question arises: What is missing from M.S. plasma? We are attempting to answer this question by a series of steps. The first is to test several different portions or fractions of normal plasma to determine which are most effective in restoring e mobility of M.S. red cells to normal. A low molecular weight fraction is veriffective, no others have been. The second step was to purchase an apparatus for producing this fraction in volumes sufficiently large for testing in patients. This fraction is then tested for toxicity, pyrogenicity and sterility to satisfy FDA requirements before it is infused into patients.

The plasma fraction is prepared under sterile conditions in a dust free atmosphere by Annette Steury in Dr. Seaman's laboratory. Cherry Tamblyn in the same laboratory does the red cell mobility tests.

In preliminary studies it was determined that the fraction was effective in improving the patient's neurologic state, and in returning the red cell mobility to normal. It was observed that patients receiving the fraction had very few if any allergic reactions, and that fatigue was either absent after infusion or much less marked than had been experienced by the same patients after receiving fresh frozen plasma. It is also important that the fraction is free of viruses including those of hepatitis and aids.

In October we started a triple blind study in which fresh frozen plasma, the plasma fraction and a normal salt solution as a control are compared. This study will continue through the winter and possibly longer. If successful we will fractionate the plasma further, and continue the patient studies.

The clinical evaluation of patients including the balance test is done by me. Anton Pardini does the flicker fusion and temperature tests. Barbara Dugan assists in selecting patients for the study, schedules them for infusion and checks on them frequently. A comprehensive questionnaire is given to each patient so that we will be informed of his or her reaction to infusion.

Annette is notified of the name of the patient and date of infusion. From a list of random numbers she arranges for infusion of either fresh frozen plasma, plasma fraction or normal saline (control). Only Annette and the nurses in day surgery know what the patient receives. We follow the patient for a 2 month period and enter the clinical data weekly into the computer. At the end of the study the nature of the infusion is added, and analysis begins.

The aim of these experiments is to identify and isolate the active substance in the plasma responsible for improving the patients condition and returning the red cell mobility to normal. The significance of this work must be obvious to all, and especially to those of you who have received plasma or its fraction. The need for additional funds to complete this work should also be obvious.

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B. Montreal Low Fat Diet Study:

This study has been mentioned before, but today I will describe it in greater detail. The study was started in December 1948, and in August of 1984 the study was closed. We placed 153 patients with M.S. on our low fat diet between December 1948 and April 1954. These patients were followed continuously and seen periodically until the day the study was closed 35 years later in August 1984. In an earlier report at the end of 20 years (Swank, R.L., Multiple Sclerosis: Twenty Years on Low Fat Diet, Arch. Neurol. 1970: 23:460-474) it was shown that when compared with other published studies, our low fat diet patients had many fewer exacerbations of disease, fewer patients became disabled, and the death rate was lower by approximately 75%. It was also shown that the earlier after onset of disease that patients were placed on diet the better they did, and that those and others started on diet prior to becoming disabled had a very good chance of remaining without disability.

The main criticism of the study was directed at an absence of controls. Because we kept records of the fat eaten by each patient it is now possible to group the patients according to their fat intake for analysis. In the figure below three such groups are illustrated. Those who ate less than 20 mgs. of fat daily are shown in the upper line; those who ate 20 gms. or fat daily are represented by the middle line; and those that ate more than 20 gms. of fat daily are found in the lowest line. It can be seen that those who ate the least amount of fat (upper line) became less disabled than those eating more fat. The vertical line to the left of the graph indicates the degree of disability of patients. 0, indicates a normal neurological examination and performance; 1, neurological findings but normal function; 2, indicates moderate disability, such as slight difficulty walking; 3, indicates severe difficulty walking; 4, indicates confined to a wheel chair; 5, indicates confined to bed; and 6, indicates deceased. The degree of disability indicated in each line of the graph is an average of 49, 49 and 50 patients, respectively.

Some patients in each group did better and some worse than average. Also note that the duration of disease prior to going on diet varied considerably and is not shown in the graph. You are looking only at averages.



In this study it was also observed that the exacerbation rate fell by approximately 95% in each of the three groups (see illustration in M.S. Diet Book by Swank & Pullen). This gave the poor dieters a feeling of misguided security. Note that during the first 10 years the clinical course of the M.S. was nearly identical in the two better diet groups (top two graph lines). After this the clinical courses diverged, the best dieters deteriorating at a significantly slower rate than the next best diet group.

It should be clear to the thoughtful patient that fat intake should be kept as low as possible if one is to receive maximum benefit. For that reason in the past 10 years we have discouraged the use of red meat and other foods containing variable and unknown amounts of fat. We now strive for a diet containing less than 15 mgs. (3 teaspoons) of fat daily.

We are now statistically analyzing the data from this study with the help of a computer expert and a consultant in statistics. This is an added expense which is swelling our expenditures.

#### с. Added Space:

I would also like to report that we have been fortunate to receive added space. This has allowed us to separate the patint waiting area and secretarial space from the rest of the office. We no longer "run all over one another and can breathe freely." The remodeling is another expense we have had to about the breather of the remodeling is another expense we have had to about the break of the second sec