#### MULTIPLE SCLEROSIS NEWSLETTER



From the office of Roy L. Swank, M. D. Oregon Health Sciences University, Portland, Oregon 97201

#### EFFECTS OF HIGH FAT INTAKE: WHAT AND WHY

We started treating patients with low fat diet in 1948 after a literature search indicated that multiple sclerosis occurred where much fat was consumed and was rare to absent where very little fat was consumed. We later confirmed this by epidemiological work in Norway and a survey of diet and multiple sclerosis in Denmark and Holland. It has also been independently confirmed.

Our subsequent laboratory studies showed that high fat diets caused clumping of blood cells , slowing of the circulation and a reduction in oxygen in the brain of animals. The changes in circulation were confirmed by others in man. Although so far unproved, I have suggested that these clumped blood cells plug small blood vessels in the brain and increase the permeability of these vessels. This allows toxic materials in the blood to invade brain tissues and cause destruction of nerve cells and fibers. It has now been shown by special x-ray studies called the cat scan that acute attacks of multiple sclerosis are indeed accompanied by leakage from the blood vessels in damaged areas of the brain. Several weeks later these damaged vessels are repaired and further leakage is prevented.

On low fat diet this clumping of blood cells is controlled to a large extent. Patients also experience decreased activity of disease. When diet is started early, the disease is usually controlled and disability does not develop. When started later, the control of the dimase is less complete.

When patients go off diet they eventually get into trouble. When the diet is poorly owed, a patient may not have a clear cut exacerbation. Disability will develop slowly and the patient may not be aware of it until it is too late. If, on the other hand, the diet is totally disregarded, a serious exacerbation will usually eventually occur, usually after six months to several years.

Other factors such as emotional and traumatic stress can also bring on relapses of multiple sclerosis. Usually, though, these develop slowly and are not as disabling as attacks due to going off diet.

#### OTHER FACTORS CAUSING ACTIVITY OF DISEASE:

Patients often complain of slowly increasing, or of recurring numbness and/or weakness. Usually, these symptoms are accompanied by increasing fatigue and fatigability. In addition to departing from the low fat diet regime, these symptoms can and usually are due to nervous tension, overactivity, heat of summer, or a fever. We will discuss each of these causes briefly.

You can tolerate a reasonable amount of nervous tension, and indeed, a certain amount increases the joy of life. However, when the nervousness is severe and prolonged, as it is during an impending divorce, loss of employment and sickness or death in the family, increasing fatigue and then re-appearance or intensification of old symptoms occurs. Upon release from the stress, slow recovery follows and is complete unless the stress has been prolonged and severe. In that case, recovery can be incomplete.

Physical activity which produces mild fatigue from which the patient quickly recovers can be therapeutic and helpful. On the other hand, intensive physical activity resulting in exhaustion can also cause recurrence or intensification of symptoms from which one will only recover with rest. Moderation in activity is the rule to follow; avoid fatigue.

Most of you know of the effects of heat or hot weather on the disease. Most patients me very tired and symptoms are exaggerated. This effect of heat can be neutralized by

Ling. Air conditioning, a plunge into a cool swimming pool, or plunging hands into cold water and placing a wet towel around the neck are effective ways of receiving relief. Very cold weather also leads to similar exaggeration of symptoms in many patients. Cool weather, especially if dry, is a comfort to most patients.

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Fever, from whatever cause, also can cause marked fatigue and intensification or reappearance of symptoms. Urinary infections are a common cause of this complication, but colds and "flu" are also causes to be taken seriously.

#### INTERFERON

We have heard much about interferon of late. This is an anti-virus material which is normally produced in the body in small amounts. It has been given intramuscularly without effect in multiple sclerosis presumably because the material does not permeate the blood vessels of the brain and get to the affected tissues. The recent study reported in Science magazine utilized the intrathecal route of injection. The material was injected into the spinal fluid which surrounds the spinal cord. The study was of short duration and the number of subjects much too small. The results are of interest, but not astoundingly so. All previous therapeutic trials have reported good results (approximately 50% doing well for one to two years). Yet, subsequent studies have been much less encouraging and eventually have been discarded.

I would urge caution at present. Give the investigators a fair chance to establish the usefulness or lack of usefulness of the medicine.

#### **HEADACHES**

Headaches are a common complaint and at this time of year most everyone seems to ve one. We are constantly deluged with requests for pain medicine for our patients. I find, however, that the usual headache medications are relatively ineffective. Usually, headaches are due to nervous tension and it is therefore not surprising that mild sedation three to four times a day for a month or so will either control the pain entirely or reduce the intensity of the pain to a level that the patient can handle. Do not be surprised if I discourage the use of analgesics (Codeine, Percodan, etc., or any preparation containing these drugs). There is a definite danger attached to their use since headaches tend to become chronic and everlasting, and therefore these drugs will have a tendency to be used for a long time. Addiction, therefore, is a constant possibility.

Mild sedation is therefore preferred since it abolishes the cause. Although headaches tend to re-appear, mild sedation used periodically will repeatedly abolish them and at the same time not lead to addiction. However, heavier sedation (exceeding the prescribed amount of sedation) can lead to addiction. This is to be avoided.

#### LET'S TALK ABOUT DIET:

LABEL READING: Do not be fooled by those labels which indicate a very low saturated fat content, particularly when the listed ingredients include hydrogenated oils. Most likely the amount of saturated fat prior to hydrongenation is what is being listed. The following was taken from a soya margarine label:

> Total Fat - 11 grams Unsaturated Fat - 2 grams Saturated Fat - 1 gram

Not listed was probably 8 grams of hydrogenated oils. The ingredients were as follows: Soybean oil, partially hydrogenated soybean oil, lecithin.

UNLESS WE HAVE TOLD YOU THE PRODUCT IS PERMISSIBLE, DO NOT USE IT IF IT CONTAINS ANY HYDROGENATED OIL. ANY OIL IN A SOLID STATE HAS BEEN PROCESSED.

COD LIVER OIL: Cod liver oil capsules are available in our office or by mail. The cost is \$10.00/800 at the office - \$12.50/800 when mailed.

RABBIT: Rabbit is now permissible and can be eaten like white meat of chicken or turkey. Rabbits which are fed high forage, low grain diets produce very low fat meat. You will be seeing more rabbit meat in the market.

PLEASE REMEMBER TO BRING ONE WEEK WRITTEN DIET WITH YOU AT THE TIME OF YOUR APPOINTMENT. MANY OF YOU ARE FAILING TO DO THIS.

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- We have always indicated that sugar should be used in moderation only. Some of the i tipes in the diet book contain large amounts of sugar. The sugar in these recipes can be cut back as much as you desire. Many of the recipes were developed several years ago before sugar was considered a problem. Several patients have complained of an increase in their symptoms when eating sugar. Nervousness and frequency and urgency of urination seem to be more noticeable. We are not suggesting that sugar be eliminated from your diet; however, it is advisable to keep your intake to moderation.

CAMBRIDGE DIET - The Cambridge Diet for "quick weight loss" has become very popular in the Portland area. The diet consists of only 330 calories per day and claims to provide all the essential nutrients that the body needs. This program is extreme and can be potentially dangerous without close supervision from your doctor. If you have thoughts about trying the Cambridge Diet, please check with our office first.

#### NOTES FROM ENGINEERING LABORATORY

Since the last newsletter, we have made some practical progress in the effort to further understand multiple sclerosis. First, with the help of our friends in Salem (Shirley Smith), Vancouver (Marie Sork) and Eugene (Martha Dacar) and the valuable support of several members of the Multiple Sclerosis Society, over 2000 survey forms were mailed out. Unfortunately, only a little over 700 have been returned. We have coded most of the questions involving location. Please complete a questionnaire if you have not done so. These data are needed for the project in which we are attempting to document the existence of the many cases of multiple sclerosis in the Pacific Northwest and also attempting to unravel some common threads of this disease in this area.

A second example of practical progess concerns the work with the balance board. Despite the eful lack of space in the clinic area, we have managed to continue using the apparatus. W now able to continue monitoring changes in both balance and vision over time. The f. over fusion measure provides us with a good indication of short-term changes which can occur, while the use of the balance measures reflect long-term and gradual influences of the disease. In this regard, the balance measure shows promise as an objective measure of the overall progress of the disease and might be a very useful tool for the evaluation of any therapy as well as a means of alerting us to new factors which influence the disease.

#### SPECIAL ANNOUNCEMENT

Most of you know of the activities of the local MS Society (Multiple Sclerosis Society of Portland). For more than 30 years they have been helping disabled MS patients confined to their homes. At present they are giving assistance to about 120 patients and throughout the years have made it possible for an untold number of patients to continue to live in their home rather than in nursing homes.

In the beginning the organization raised their own funds and were independent. About 1960, the United Fund took over their fund raising and the MSC Society of Portland became one of the agencies which they supported. Those agencies and individuals who had helped the MS Society no longer were needed and these sources of funds dried up.

As of June 30, 1982, just a little over 2 months from now the United Fund will no longer support the local MS Society. The Society is now forced to go out on their own and raise the needed funds. They have 5 therapists which call on these 120 people weekly and often more frequently. They also have an office and a secretary to be paid. To keep the organization functioning will require a minimum of \$70,000.00/year.

Considering the fact that they now make it possible for 20 patients to live in their own homes and avoid the \$10,000 to \$15,000 yearly cost of a nursing home, a total savings in excess of \$200,000.00 to society, the \$70,000.00 looks like a bargain. There are also the inditional 100 patients some of whom will have to be added to the list of those requiri ursing home care if they are no longer cared for at home.

Individual donations can be helpful and may be the answer. However, it is possible that some of you have relatives or friends who could help. Perhaps you might find some person or organization which could give a big boost. Remember, the final date is June 30, 1982. Call the Society at 503-223-8532 if you can help.

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RECIPE CORNER:

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1 Yos can tuna(drained)
1/2 can cream of chicken soup
1 1/2 tsp. lemon juice
1 T mayonnaise
2 T chopped onion (optional)
4 English muffins (split)

Airst 5 ingredients - Airst XiM
 Toast on muffins in oven.

### Bread

3 cups self-rising flour 3 T sugar 1 can room temp. beer

Stir together first 2 ingred. Add beer and make dough. Put into one loaf pan and let raise for 15 min. Bake at 425 degrees for 45

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1 can tuna drained and flaked
1 1/2 cups bread crumbs
1 egg
2 T grated onion
1 tsp. lemon juice
1/4 tsp. pepper
1/4 tsp. pepper
Finely shred zucchini with nex
Fowels. Mix zucchini with nex

l med. zucchini

Summer Tuna Cakes

Finely shred zucchini; pat dry with par towels. Mix zucchini with next 7 ingre Shape into patties. Brown in small amo of oil. Fix like a hamburger on toaste wheat bread or bun.

TO:

Roy L. Swank, M.D. 3181 S.W. Sam Jackson Park Rd, Portland, Oregon 97201 MULTIPLE SCLEROSIS NEWSLETTER From the office of Roy L. Swank, M. D.

y, 1982

In April, 1980, I was invited to visit London and speak at the annual open meeting of the society, <u>ARMS</u> (Action for Research into Multiple Sclerosis). At that time, <u>ARMS</u> was organizing its first multiple sclerosis clinic. By April, 1982, when Barbara and I visited London for the annual meeting, the clinic in London had received, processed and was treating over 300 patients. In addition, nine satellite clinics had been established in different parts of Great Britain and others were being established.

<u>ARMS</u> is a privately financed organization in Great Britain dedicated to vigorous research to solve the problem of multiple sclerosis. The organization was formed in 1974, by a small group of multiple sclerosis patients and other interested persons. The original group of thirty members started the first year with an income of £32 (about \$50.00). Spearheaded by John Simkins, the membership grew to 1800 by 1980, with a research budget of over £120,000 (about \$220,000.00). The original small group set as their aim a broad based research effort and a better informed public. Among their fundamental aims was to fund a variety of different programs. This arose from their perception that the Federal government and the multiple sclerosis society of Great Britain, since its inception twenty-five years prior, had sunk untold amounts of money into projects, which from the point of view of patients with multiple sclerosis had been unproductive. The multiple sclerosis society had spent nearly two million dollars in research in the past two years and had invested this money along the same lines supported by the Federal granting agencies. <u>ARMS</u> felt that greater diversification was called for and set out to accomplish this.

The Society, therefore, supported a number of projects which were previously refused ancial support by the two major funding agencies in England. One of these projects led. to the development of the Field and Joyce early diagnostic method for multiple sclerosis which we are now using routinely. As mentioned previously, we have been investigating this method and have produced two modifications which have led to confirmation of blood plasma abnormalities in patients with multiple sclerosis. One of these modifications is being used in London by Dr. Forrester in the ARMS program.

For the last three to four years, <u>ARMS</u> has invested heavily in the influence of nutrition on multiple sclerosis; approximately the same approach we have used for thirty-three years. Their program is on a much greater scale than our program, but otherwise the two are similar.

ARMS clinical unit is located at Central Middlesex Hospital which is approximately five miles from the center of London. Their staff is composed of five highly qualified personnel. Dr. Alec Forti, Neurological Registrar, Judy Harding, Nutritionist, Ann Ashburn, Physiotherapist, Steve Cauendar, Counselor and Stella Dobson, Counselor.

The procedure for evaluating and caring for the patient is similar to our own. They are examined by Dr. Forti and then referred to the other staff members. If necessary they are referred to the hospital for further studies. They are fortunate to have the funds to be able to maintain a complete service for the multiple sclerosis patients.

The nutritional program is also similar to the Swank program. Their diet, known as "Diet Rich in Essential Fatty Acids," is low in saturated fat and high in essential fatty acids. Their guidelines, however, are not as rigid as ours. Even so, the saturated fat intake is not more than five grams greater than we advocate. They believe that essential fatty acids are deficient in multiple sclerosis patients. They recommend that one-half pound of liver be eaten each week because of the high essential fatty acid content, "rticularly arachidonic acid. In addition to the fish, legumes and nuts which are also

h in essential fatty acids, they supplement the diet with evening primrose oil to .sure a good intake of gamma-linolenic acid. We supplement our low fat diet with Cod liver oil for similar reasons and advise raw linseed oil, which contains linolenic acid when Cod liver oil is poorly tolerated.

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Even though we use almost identical treatments, we attribute the benefits differently. We believe the primary benefits derive from the low fat diet; the oils make the diet more palatable, and nutritionally more complete. (Newsletter No. 12 discusses some of the abnormalities produced by high fat intake.) The point of view of <u>ARMS</u> is that the oils are essential. The low fat diet is necessary so that the oils will be efficiently digested and metabolized. In other words, they consider the disease due to a deficiency of essential fatty acids. Giving the oils alone is not sufficient. A low fat diet is necessary so that the oils can be utilized efficiently. Their point of view like our own cannot be proved at this point. Regardless of the theory or explanation, the therapy is beneficial. For that we can be thankful.

In addition to the clinical program, <u>ARMS</u> is supporting research in other aspects of nutrition. Dr. Michael Crawford and his group are studying essential fatty acid metabolism. This program is aimed at clarifying the function of essential fatty acide hypothesis, is continuing his work along similar, the Father of the essential fatty acide hypothesis, is continuing his work along similar, but more clinical lines. Dr. Tony Forrester is continuing his work with early diagnosis using a method developed in Dr. Seaman's laboratory here in Oregon and Dr. E. J. Field and his associate Ms. Joyce are continuing with their work. On the clinical side at Charing Cross Hospital Dr. Clifford Rose and Dr. Rudy Capildeo are continuing other related studies. Dr. Rosemary Jones is working in the Charing Cross Hospital and is working with Forrester and amplifying our knowledge of the role of plasma in multiple sclerosis, a new avenue of research initiated by our laboratory here in Portland.

Finally, I would like to pay tribute to the power behind <u>ARMS</u>, John Simkins. It is largely his guidance which has developed <u>ARMS</u> and continues to keep it growing. He has devoted endless hours to fund raising and maintaining tranquility within the society. We have hopes to have the opportunity to honor him in our country.

I regret the necessity to solicit research funds at this time. As you know we have done this yearly in December. In the last year, however, research costs have far exceeded our income making this request necessary. I am asking those of you able to do so to contribute as before by making your checks payable to the Oregon Health Sciences University Foundation and sending them to me.

For your convenience and to facilitate the Foundation's work of responding to your gift we have attached the following form. Those of you who contribute should complete this form and include it with your donation.

# DEPARTMENT OF NEUROLOGY Area Code 503 225-8370

Portland, Oregon 97201

## UNIVERSITY OF OREGON HEALTH SCIENCES CENTER

December 1, 1982

This is our annual Christmas progress report and appeal for funds to assist in our research.

You have all become acquainted with the red cell mobility test for multiple sclerosis. It was noted on our report to you of December 1, 1981 that the test was very sensitive and highly predictable for multiple sclerosis. In the course of our work, Dr. Seaman's laboratory found that the red cells could be fixed in glutaraldehyde and could then be stored at room temperature and even shipped long distances. When used in the test these fixed cells were still reliable indicators of the disease. This variation of the test is now being used in London by ARMS group.

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It was also shown that the test can be done in the absence of red blood cells by agitating small plastic beads in plasma. After adding the linoleic acid, beads soaked in multiple sclerosis plasma migrate more slowly than those treated with normal plasma. These studies appear to us to establish that different mobilities of the red cells are acquired from the plasma. This work is in the process of publication.

- Tamblyn, C. H., Swank, R. L., Seaman, F. V. F.and Zukoski, C. F. IV. Red cell electrophoretic mobility test for early diagnosis of multiple sclerosis. Neurol. Res. Vol. 2:69-83, 1980.
- Zukoski, C. F., Tamblyn, C. H., Swank, R. L. and Seaman, G. V. F. The basis for the unsaturated fatty acid red cell electrophoretic mobility test for multiple sclerosis. In cell electrophoresis: Clinical application and methodology. 1979.
- Tamblyn, C. H., Swank, R. L. and Seaman, G. V. F. Use of polystyrene latex particles in an electrophoretic mobility test for multiple sclerosis (in process of publication).

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As many of you know we have been treating a number of patients with infusions of normal plasma. This has been very effective in early stages of multiple sclerosis during exacerbation, but much less helpful in chronic severely disabled patients. We have also looked at the effects of fresh frozen plasma infusions on the red cell mobility tests in a number of patients. Before infusion the red cell mobility in these cases was slow to very slow. After infusions of plasma the mobility increased to normal and remained there for four to eight weeks. It then slowly decreased and became abnormal again. Repeat infusions again returned the mobility to normal and the cycle of events was repeated. We feel that this series of experiments demonstrates that the plasma of multiple sclerosis patients is deficient in components which can be supplied by normal plasma. The nature of these components is not known. It was shown in 1952 by your writer (RLS) that multiple sclerosis plasma differed from normal plasma. This was confirmed recently by a group of English investigators and finally established in collaboration with Dr. Seaman's laboratory and the Red Cross Blood Services (Dr. Peetoon).

In the past year your writer finished a book "PLATELET AND PLATELET-NEUTROPHIL AGGREGATES: THEIR GENESIS AND PATHOPHYSIOLOGICAL EFFECTS." This book will be officially published in January, 1983. It is the result of study and experimentation between 1960 and 1972. It was a spin off from our multiple sclerosis work. From this work came the first microemboli blood filter which is in use throughout the world. There are now many competing filters. Large volume filters for continuous blood filtration during cardiovascular surgery were the first to be used. Later smaller filters were designed for blood transfusion.

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Late in September we had our second Multiple Sclerosis Seminar. The attendance was very good and the program varied by the presence of two visitors from ARMS in England. John Simkins, one of the organizers and who is the present chairman of ARMS gave a very interesting description of the formation and development of ARMS. From a small group of fifteen to twenty individuals and less than \$50.00 in donations the first year, the organization has swelled in five years to a membership of several thousand and an income for research of more than \$300,000.00. Dr. Alec Forti talked about the clinical side of their program and outlined the various avenues of research being financed by ARMS.

From our own staff, Dr. Seaman spoke of the diagnostic test and importance of plasma. Dr. John Hale discussed nervous tension and how to control it. Rusty Hale interviewed the children and summarized her impressions for the group.

It was the impression of the staff of this office that the meeting went very well. God willing, we will organize another meeting next year.

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We have recently purchased an automated electrophoresis apparatus which will greatly increase the number of blood samples we can analyze daily. It will probably also increase our accuracy since it will remove the "human element" from the test and improve the objectivity of the measurements. Dr. Preece from Bristol, England who developed this machine, spent a week with us in September checking out the apparatus. We can look forward to another three to six months before the machine will be in active use. We need to hire and train another technician for this job. Cherry Tamblyn will then be released to pursue the factor or substance which is missing from multiple sclerosis plasma.

The machine has already cost us \$23,000.00 and we have on loan a unit from the manufacturer worth \$5,000.00 to \$10,000.00 which we must eventually purchase. Another cost will be the technician. This is only one of the reasons we are requesting from you financial assistance for our work. Don't forget that our work is intended to benefit you. A very long study of the cerebral blood flow in multiple sclerosis was completed a year or so ago and is to appear soon. It shows that the blood flow to the brain in multiple sclerosis progressively decreases with increase in disability. Patients on diet (low-fat) show much less of a fall in blood flow and also far less disability.

Swank, R. L., Roth, J., Woody, D. C. Cerebral blood flow and red cell delivery in normal subjects and in multiple sclerosis. Neurological Research (to appear).

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As in years past, I am asking you to help finance studies on the disease which you have so patiently endured. I hope that those of you in a position to help will give generously. Last year's response was gratifying, but more is needed. Make all checks payable to the Oregon Health Sciences University Foundation, Portland, Oregon 97201. I will direct the gifts to the correct address and you will receive a receipt. The funds are tax deductible.

Barbara and Ruth join me in wishing you a pleasant and prosperous future.

Sincerely yours,

Koy V. Awank

Roy L. Swank, M. D.

RLS:rs

For your convenience and to facilitate the Foundation's work of responding to your gift we have attached the following form. Those of you who contribute should complete this form and include it with your donation.

Make ch <b>ecks</b> payable to:	The Oregon Health Sciences University Foundation for Dr. Swank's Research
Send ch <b>ecks to:</b>	Dr. Roy L. Swank Department of Neurology Oregon Health Sciences University Portland, Oregon 97201

CONTRIBUTOR'S NAME:
CONTRIBUTOR'S ADDRESS:
AMOUNT OF DONATION: \$\_\_\_\_\_\_

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