

MULTIPLE SCLEROSIS NEWSLETTER

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

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CIRCULATION - Ruth Selby

PRODUCTION - Ruth Stewart

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HAPPY NEW YEAR!

Many contributions have been received and we would like to thank you for your support.

In this issue of the newsletter we initiate a series of discussions of factors which influence the clinical course of multiple sclerosis. Ground will be broken with a consideration of DIVORCE and its effects on the patient.

Divorce has become an ever increasing problem for multiple sclerosis patients. This has not always been the case. In Montreal from 1948 to 1954, divorces were rare. I can recall only two in 150 patients during this period. Divorces were also unusual from 1954 to 1970, here in Portland, but since then they have rapidly become commonplace. Hardly a week goes by without new cases coming to light. Often these have been announced by the spouse without warning, and without evident cause.

We are discussing the problem, because it is an important cause of increased activity and exacerbation of multiple sclerosis. The feelings of rejection and of financial insecurity which develops in women being divorced lead to emotional tensions, comparable to and in some cases exceeding that which results from death of a loved one. Men suffer the same feeling of rejection, which can be complicated by preceding job and financial insecurity. We have also observed divorce proceedings in which women patients were financially secure. In these few cases the tension from rejection alone has usually been well handled and significant aggravation of the disease has not occurred. In still others in which the marriage had been unsatisfactory for some time, the patients seemed to tolerate the divorce proceedings without hazard to their health, provided they were not subjected to severe financial deprivation.

We have also observed the flicker-fusion scores of patients during pending divorces and the period of rehabilitation which follows. Almost always these scores progressively decrease during the three to six months preceding finalization of the divorce and then slowly recover usually in about six months. Recovery may not be complete. The total period of depressed flicker-fusion scores is usually about one year, which agrees fairly well with the clinical evidence of aggravation of the multiple sclerosis.

The bad effects of divorce are increased disability which is sometimes permanent. One would expect something good in return at such a price, but my observations over the years convinces me that the gains are short lived, limited and largely ethereal. In the long run, the spouse usually trades one burden for an equally unpleasant one, and if there are children, their respect and love are lost.

Despite the above considerations there are cases in which divorce is practically unavoidable. In such cases, understanding, compassion and consideration can smooth the transition.

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Michael Brezack would like to correspond with other patients in his area. If you live near Michael, drop him a line at 178 Sprague Street; Dedham, Massachusetts 02026

## OUT DIET-----

**Vitamin C** - In 1750, it was shown that scurvy could be cured and prevented if fresh or preserved juices of oranges and lemons were eaten. In 1933, the antiscorbutic factor was identified as Vit. C, and since then has been produced in its synthetic form. Scurvy is no longer an important disease in any part of the world. Scurvy in adults is associated with poverty, alcoholism, famine and nutritional ignorance. There has, however, been a continued use of Vitamin C for treatment and prevention of the common cold, treatment of cancer, mental retardation and a variety of other diseases and disorders.

The FOOD AND NUTRITION BOARD feels that many of these claims are not sufficiently substantiated, or the effects are not of significant magnitude, and that routine consumption of large amounts of ascorbic acid is not advisable without medical advice.

**FOOD SOURCES** - Citrus fruits (oranges, grapefruit, lemons, limes), berries, melons, tropical fruits, such as pineapple & guavas, leafy green vegetables, broccoli, green peppers, cabbage and tomatoes are all good sources of Vitamin C. In northern areas, potatoes are often the basic natural source of Vitamin C.

**RECOMMENDED DIETARY ALLOWANCE** - The RDA for adults of both sexes is 45-60 mg. per day. Cigarette smokers require a higher intake.

**TOXICITY** - There is no evidence to show that large doses of Vitamin C serves any useful purpose. Prolonged ingestion of massive doses of Ascorbic Acid (5,000-15,000 mg/day) can produce toxic effects such as: development of kidney and bladder stones, studies have shown infertility or abortion or adverse effects on the fetus, alterations in some lab tests, Vitamin B12 destruction. It is also of interest that pregnant women taking large amounts of Vitamin C will have babies born with symptoms of scurvy. Large doses are sometimes also followed by withdrawal symptoms of addiction.

Over doses of any essential nutrient may result in a "conditioned deficiency," a relative lack of responsiveness to normal doses.

**CHEESE** - Many patients have been eating the skim milk cheeses now available. Remember, this is not an exchange diet. The nutritional benefit you receive from the one slice of cheese containing 3-5 grams of saturated fat is minimal. Use your saturated fat allowance wisely.

**FABRICATED POTATO** - Have you seen the new fabricated potato? If you are served a half-baked potato check it out carefully. This is a new product in the U. S. The skin comes from an industry that makes the instant potatoes or french fries. The skins are ground up and mixed with modified starch to act as glue and shaped into skins that are then filled with instant mashed potatoes. They are listed on the menu as baked potatoes. This information was passed on to us from the Finegold Association for hyperactive children.

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Following are two letters to "Dear Abby" which one of our patients thought might be of interest to other multiple sclerosis patients.

Dear Abby: I must comment about the letter from the woman with multiple sclerosis. I speak from experience as a woman who has had "MS" for about 23 years. (the first 10 years I didn't even know I had it.)

I have been in a wheelchair for nine years, but it hasn't curtailed my activities. It's electric, and I zip around everywhere. I drive a van with a wheelchair lift, so I'm fairly mobile.

First, that woman should tell ALL her children that she has MS without making a big deal out of it. When I was finally diagnosed, our three boys were 2, 5 and 6. My husband said from the very onset that I should do only what I wanted to do and save my energy for family fun.

Continued -

She's packed me up five flights in temples in Japan and carried me on and off Mexican airplanes, without once hinting that being married to me was at times inconvenient. Our boys grew up sharing this attitude, and her children will, too. In return she'd better try to keep her weight down. She should also thank God it is she, not her husband, who has MS, because it would be harder for HER to get HIM up and down stairs. As for it being a "heavy burden" for her 13-year old to help at home, it won't be. By the time my eldest was 8, he could go to the bank, cash a check for \$100, do the grocery shopping from my list and come home with the correct change. All my sons can cook, sew, do the laundry, make beds and manage money. At first I used to lament to myself, "Poor boys, their mother can't play baseball with them," but I soon stopped after seeing how much more self-sufficient they were than other boys. My eldest, Kurt is now in his second year of college - 2000 miles from home. Our middle son, Dirk, is a super cook and baker, and the youngest (Clark) does the home repairs. They're just ordinary boys, now 19, 18 and 15. But they're very special to me. MS has brought our family closer together. We tend to do things NOW rather than postponing them; because things may get worse, we're having our fun while we can. If everyone lived that way, the world would be a happier place. MS is no fun, but there are worse things. I consider myself very lucky. I am only inconvenienced -- not handicapped.

Becky Zeller in Portland

Dear Becky: Yours is one of the most heartwarming letters I've ever printed. Thanks for the "upper."

Dear Abby: I'm happy for that woman with multiple sclerosis who was carried up five flights of stairs in a Japanese temple and on and off airplanes by a husband who not once hinted that being married to a disabled woman was at times inconvenient. I wasn't that lucky. After I got MS and became less able to function, my husband divorced me and left me with two teen-agers to raise alone. Unusual? Not really. Statistics show that approximately 80 percent of the women with MS end up divorced, as compared to 15 percent when the husband develops it. That doesn't say much for the American male, does it? It's good to know that the words "in sickness and in health" actually mean something to some people, but as for me, so do the words,

"I'LL WALK ALONE

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Many of you have inquired about the "snake venom treatment" or "cure." Please read on. The following article was taken from the Victoria and Vancouver Island Multiple Sclerosis Society newsletter.

#### THE SIXTY MINUTE CURE

Medical Post editorial questions snake venom claims

The following editorial which appeared in the January 15, 1980 issue of the Medical Post is reprinted with permission.

One of the few pleasures left in television for those of us lucky enough to receive it, is a documentary called 60 Minutes which is produced in New York by the Columbia Broadcasting System (CBS).

It is hard-hitting television journalism--hard-nosed and iconoclastic.

But we have come across a story which indicates that the power of the program may have corrupted it. 60 Minutes might under certain circumstances be a subject for itself. In the late months of last year, the program started work on a segment centred on the possibility that Multiple Sclerosis (MS) might be helped by the administration of snake venom.

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 m therapy consists of injecting a mixture of cobra and krait venoms on the  
 is cocktail cor ins nerve-growth factor (NGF). The theory has been for-

by Miami pediatrician Dr. Ben Sheppard and snake handler William Haast.  
 Dr. Sheppard says that 20 per cent of patients treated with the venom show lasting  
 improvement of symptoms, particularly bladder incontinence.

Dr. Sheppard has not offered records to substantiate his claims. He says he does not  
 examine patients routinely nor does he confirm the diagnosis which experts say may be  
 incorrect in as high as 20 per cent of cases. Dr. Sheppard injects the diluted venom  
 into more than 1,000 patients a year.

Haast, who runs the Miami Serpentarium, says though he thinks that NGF is the active  
 ingredient, he has never tested the preparation which is being used clinically for  
 the factor. Some fractions are eliminated in processing.

One odd fact is that NGF is not found in cobra or krait venom, but only in viper poison.  
 Neurologists have pointed out that even if it were present, the factor is active only  
 in stimulating the sympathetic nervous system. Multiple Sclerosis has its devastating  
 effect on white matter. And NGF acts on neurons and MS affects oligodendrocytes which  
 produce myelin.

Until 60 Minutes started work on its segment, the Multiple Sclerosis Society (USA) had  
 no plans to launch a clinical trial on the grounds that snake venom is not a likely  
 solution nor a reasonable approach to the problem.

But the power of television--and particularly a program like 60 Minutes--is so strong  
 that the MS Society has buckled.

Dr. Byron Waksman, a member of the Society's research program committee, says bluntly:  
 "It is straight media pressure." Yet he says, perhaps with a backward glance at Laetrile,  
 that the MS establishment would "be insane to ignore" the 60 Minutes story.

The MS Society is reported to have gone to considerable trouble to find good clinical  
 neurologists willing to test the treatment in double-blind trials. Dr. Waksman says  
 half the investigators he approached "wouldn't touch it with a 10 foot pole." However,  
 two neurologists with considerable reputations have said they might take part in trials.  
 They are Dr. Barry Arnason, who is professor and chairman of neurology at the University  
 of Chicago and Dr. William Sibley, who is professor and chairman of the same specialty  
 at the University of Arizona in Tuscon.

Apparently, there is no shortage of snake venom. One reported reason for this is that in  
 1974, Haast supplied dilute reconstituted venom to a Maryland firm which sold it to help  
 a wide variety of disorders. The preparation was removed from the market after the Food  
 and Drug Administration and National Academy of Sciences Research Council found claims  
 made on its behalf could not be substantiated.

What disturbs us most in all of this is the attitude of 60 Minutes producer Drew Philips,  
 who is quoted as saying quite correctly that he doesn't know if snake venom works. "I  
 just want to give hope to MS patients," he said, adding that there is no such thing as  
 false hope.

And in a naked display of media power Philips boasts he has "enough clout" to get FDA  
 approval for any trials the MS Society wants to organize. "I am 60 Minutes."

The point to be made to Philips is that what makes good television is not necessarily  
 good medicine. The very nature of MS is puzzling. No physician tells a patient he, or  
 she, has MS until the evidence for the diagnosis is overwhelming.

*Muscle*

RESEARCH IN MUSCLE THERAPY— Barbara Runnels, a student at Western State Chiropractic College, has recently contacted Dr. Swank with two research proposals for work in muscle therapy. She has been working for some time with two patients of Dr. Swank's both of whom are experiencing some help.

The first project is a Self-Help Program. The program will feature four massages (one per week for four weeks), exercises (non-stress) and self massage. The purpose of the program is to relieve muscle tension, aid in defecation, control urine leakage, aid in circulation and in general teach patients with multiple sclerosis to do things that will make them feel better. There is room for four people in the first group. They will be monitored by Dr. Michael Daley and by Barbara Runnels. This will be a pilot study for possible further expansion.

The second project will be measuring the results of a muscle-relaxing technique. Briefly, a sore spot will be identified within a muscle and pressure applied to it to release the pain. Hopefully, this will result in the ability to move more easily. There is room for twenty people in this project. Participants will be measured twice in one week and measured and treated twice a week for two weeks (a total of six sessions). The results of this research project may be published.

The first project will start as soon as possible. The second project will start in April or May.

Barbara Runnels will come to your home for the first project. For the second project, participants will be asked to provide their own transportation to the treatment center. There is no fee involved in either of the projects.

If you are interested in being a participant in either of these projects, please contact our office - 225-8370.

and now for some new recipes from our patients:

CHICKEN BROCCOLI

Brown chicken in 1 T. oil  
 Mix 1 can chicken broth  
 2 T. soy sauce  
 ¼ cup sherry  
 ¼ t sugar  
 Pour all of the above ingredients over chicken; add broccoli flowerets, mushrooms (sliced), 1 can water chestnuts (sliced) and some chopped onion tops. Cook about 7 minutes.  
 Mix 2 T. Cornstarch with ¼ cup water  
 Thicken broth & cook 2 min. more.  
 You can add celery or pea pods if you want

CHICKEN CHASSUR

1 lb. boneless & skinless chicken breast cut in strips  
 1/3 c. corn starch  
 ¼ t. Tarragon  
 ¼ t. pepper  
 2 c. chicken broth  
 3/4 c. sherry  
 3 tomatoes-cut in 1/8's  
 3-4 c hot cooked rice  
 Most people prefer more chicken & mushrooms  
 You can also add celery or pea pods.  
 Dredge chicken in corn starch, brown in lg. skillet the coated chicken in oil. Stir in seasonings and onion tops. Cook 2 min. longer, add broth & sherry. Cover, simmer for 10 min. Gently stir in mushrooms and tomatoes. Cover, simmer 5 min. Serve over rice.

¼ c veg. oil  
 ¼ t. Thyme  
 1 c. sliced onion tops  
 1 c. sliced mushrooms-fresh or canned

the two batches with the lemon peel, vanilla and sugar. Pour into crust. Bake at 325 degrees for 1 hour.  
1. Do the same with the other 1/2 of the tofu, 1 egg and 1 t lemon juice. Mix  
out 1/2 of tofu (let the tofu) sit a few minutes after taking it out of the water it  
res in), 1 egg and 1 t lemon juice in blender. Blend until smooth. Pour into a

- 1 graham cracker crust
- 1 1/3 lbs of Tofu
- 1 t lemon peel
- 1/2 cup sugar
- 2 T lemon juice
- 1 t. vanilla
- 2 eggs

TOFU CHEESE CAKE

Can make and store up to 5 days in refrigerator. To use after storage; shake or stir  
Makes lots of pancakes.

Add 1 rounded Tablespoon baking powder  
Beat in 1/2 cup oil and 1 tsp. real vanilla or 1 Tablespoon artificial vanilla  
Add 2 1/2 to 3 cups flour; make smooth again  
Add 1 can skinned condensed milk and 1 can water - whip until smooth  
Add 1/2 cup sugar and 1 tsp. salt; beat until stiffens  
3 eggs - beat until fluffy

UNCLE LOUIE'S PANCAKES

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TO:

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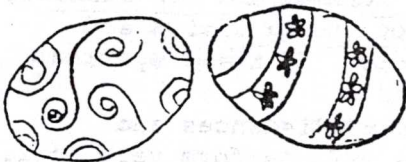
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HAPPY EASTER AND HAPPY SPRING



In our last newsletter, we talked about divorce and the effects it has on the multiple sclerosis patient. We would like to make it clear that the incidence of divorce among our patients is no more than twenty percent and these usually occur before disability is severe. IT IS NOT THE HIGH EIGHTY PERCENT WHICH ABIGAIL VAN BUREN (DEAR ABBY) INDICATED IN HER ARTICLE LIVING WITH M.S.

Also, in the last newsletter we indicated that we were going to discuss factors which have a deleterious effect on patients with multiple sclerosis. In that letter we discussed divorces. Today we would like to discuss the general problem of litigation in which the differences between the patient and his or her adversary is to be settled by a judge or jury. This often takes place during divorces, but it is also involved in damage suits, accidents, requests for pensions, etc. In each instance the verdict is uncertain, often for months. This uncertainty is the real stress factor. Once the lawsuit or hearing has been settled regardless of whether the patient wins or loses, the tension is released and the patient feels better. Of course, if he wins he feels better than if he loses, but none the less the decision, good or bad, is welcome.

This indecision and mounting tension and often agitation can lead to definite increase in disability, some of which can be permanent if the agitation is prolonged. It is therefore important to settle such cases quickly and avoid them if possible.

Social security hearings have been experienced by many of you, and in some instances they have been traumatic. The hearings have been the source of serious agitation and increased disability, and delays for added opinions can be frustrating.

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Detroit, Michigan area patients: I would like to get together to talk about our experiences with the Detroit area medical community, good or bad. Some of us may have more support than others. Let's trade information. Please contact me, and I'll set up a meeting (maybe over a "legal" pot luck). Wendy Watson Cheyfitz, 19939 Lichfield, Detroit, Michigan 48221. Telephone number 313-342-4797.

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COD LIVER OIL - Our office has received many requests to mail the Cod liver oil capsules. We are sorry, but at the present time we are not mailing the capsules. They are available in the office only.

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For those of you in need of some legal help in the area of disability contact Mr. Mike Haines, 1083 Wallace Road N. W., Salem, Oregon 97304. His office telephone number is 503-370-7414. He is the attorney who handled many social security hearings so expertly for so many of you. He is now living in Salem, Oregon.

DISABILITY AND LIMITATIONS - Disability is well understood by most patients with multiple sclerosis. In early cases it may be temporary, but in advanced cases it is apt to be permanent. In other cases periods of disability alternate with periods in which the patient is free of disability. It is relatively easy to convince patients to avoid fatigue when disability is present, but much more difficult once they have recovered from that state.

When free of disability almost all patients are limited to some extent in what they can do. However, many do not recognize these limitations and often exceed their tolerance for both physical and emotional stress. All too often this leads to aggravation of disease and sometimes to clear cut exacerbations. Symptoms such as increased fatigue and nervousness, increased numbness and leg weakness, painful muscles, double vision, foggy vision and dizziness may re-appear and force the patient to slow down and rest. If these symptoms are ignored disability or increase disability may become permanent.

A few examples may be helpful. A patient can walk normally for short distances and when examined in my office after a few minutes in the waiting area will perform very well. His gait and coordination are normal. At that time he displays no disability. However after walking a few blocks his legs become weak and feel like rubber and he starts to stagger and perhaps drag one leg. He then displays disability. Another patient may be able to walk for distances, but no longer can run or jog without numbness and weakness developing in the legs. When he rests he can again run, but again develops the same symptoms.

Both of these patients are limited in what they can do. In the first case the limitations are quite severe, in the second they are slight. In both cases, however, persistently exceeding these limits or limitations will result in increased disability.

THE RULE TO FOLLOW IS: AVOID EXCEEDING YOUR PHYSICAL AND EMOTIONAL LIMITATIONS!

I have observed over the years that in the early phase of multiple sclerosis, patients who have followed diet carefully gradually increase their tolerance for physical and emotional stress. In the beginning they are "fragile" and intolerant of excesses. By the third year of dieting their tolerance for stress significantly increases and by the fifth year they become stable and much more resilient. Those few early cases who have not done well despite following diet have persistently ignored the tell-tale warnings of excessive activity such as increasing fatigue and nervousness, re-appearance of numbness and tingling, aching and weakness usually of the legs, and fogginess of vision in one eye, double vision, or light-headedness.

For these reasons, I recommend that patients carefully observe their limitations during the first and second year on diet. During the second year, I recommend increasing activity, but still observe the rule - avoid exceeding your limitations. When this rule is followed considerable increase in the ability to tolerate physical and emotional stress usually develops.

"A word to the wise is sufficient" - pay attention to the subtle warnings from your body and obey them.

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In an earlier newsletter we stated that patients who smoke run a high risk of experiencing persistent problems with vision. To more accurately evaluate the influence of smoking on disease, we have been studying immediate effects of a single cigarette on the balance and vision of regular smokers. Vision and balance are first tested as usual. Next, the patient smokes a cigarette and these tests are repeated a few minutes later. If time permits we repeat the test a few more times during the ensuing hour.

Of the twelve patients given the vision test, nine (75%) exhibited a deterioration of vision immediately following smoking. Of the ten patients given the balance test, four (40%) showed a deterioration of balance following smoking.

The onset of the deterioration occurs within ten minutes of the first puff and lasts for nearly an hour. Because of the speed in which the effect takes place, it makes us suspect that its cause is a reduction in the blood supply to the areas of injury due to contraction of the blood vessels.



T'S TALK ABOUT DIET -

Lean Strips - For those of you wondering about Lean Strips - THEY ARE NOT PERMISSIBLE ON DIET - SORRY.

SOY LECITHIN SPREAD - Soy lecithin spread which is very much like margarine, is available at the Fred Meyer Nutrition Centers. It is counted as an oil - two tsp. equals one tsp. oil. INGREDIENTS INCLUDE: Soybean oil, lecithin, honey, carrot oil, salt. I have checked with the company and the oil is not hydrogenated.

VITAMINS - PLEASE CHECK YOUR VITAMIN LABEL.

If any of you are taking extremely potent vitamins, i. e., Radiance Timed Release Magna II vitamins, we are concerned that you are getting too much Vitamin D. These vitamins are mega potency and are far above the RDA for all vitamins and minerals. The RDA for Vitamin D is 400 I. U. These vitamins contain 1,000 I. U. If you combine this with your Cod liver oil and the vitamin D in the foods you are eating, you could be exceeding a safe level. If you have questions place a call to the office. Excessive amounts of Vitamin D (above 2,000 I. U./day) are potentially dangerous. Some of the symptoms you might experience from excessive levels of Vitamin D would be loss of appetite, thirst, nausea, vomiting diarrhea, abdominal discomfort and loss of weight. The blood calcium level is elevated, leading to increased calcium excretion in the urine; calcium may be deposited in the kidney, resulting in damage to that organ and impaired function.

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REMINDER

The dinner commemorating Dr. Swank's more than thirty years in the treatment of multiple sclerosis is to be held Saturday, May 16, 1981, at the Red Lion/Jantzen Beach. There will be no host cocktails at 7:00 P. M. and then dinner at 8:00 P. M. (Ballroom East). Tickets per person are \$13.00. Any amount above will be used as part of the group donation. Make checks payable to Oregon Trail Savings & Loan - Dr. Swank Dinner. Mail your check with the following information to: Kay Yasutome; 3900 SE Henry; Portland, Oregon 97202.

NAME \_\_\_\_\_  
ADDRESS \_\_\_\_\_ ZIP \_\_\_\_\_  
PHONE \_\_\_\_\_ NUMBER OF TICKETS \_\_\_\_\_

Anyone interested (attending or not attending) is welcome to join in the celebration by sharing in the making of a scrapbook gift. Include a picture of yourself and a letter to Dr. Swank. You can review your MS history with him and it would be a wonderful opportunity to say "Thank you."

- OREGONIANS: Send your scrapbook materials to: Tracy Kelly; 21625 SW Koehler Rd; Beaverton, Oregon 97007.
- OUT OF STATE PATIENTS: Send your scrapbook materials to: Norma Atkins; 5608 NE 45th Street; Vancouver, WA 98661.

The evening promises to be a gala event! It is not too late to join the people already coming from England, Canada, Seattle, San Francisco and the coast, in addition to those from Portland and Salem.