SWANK FOUNDATION

JANUARY 1997

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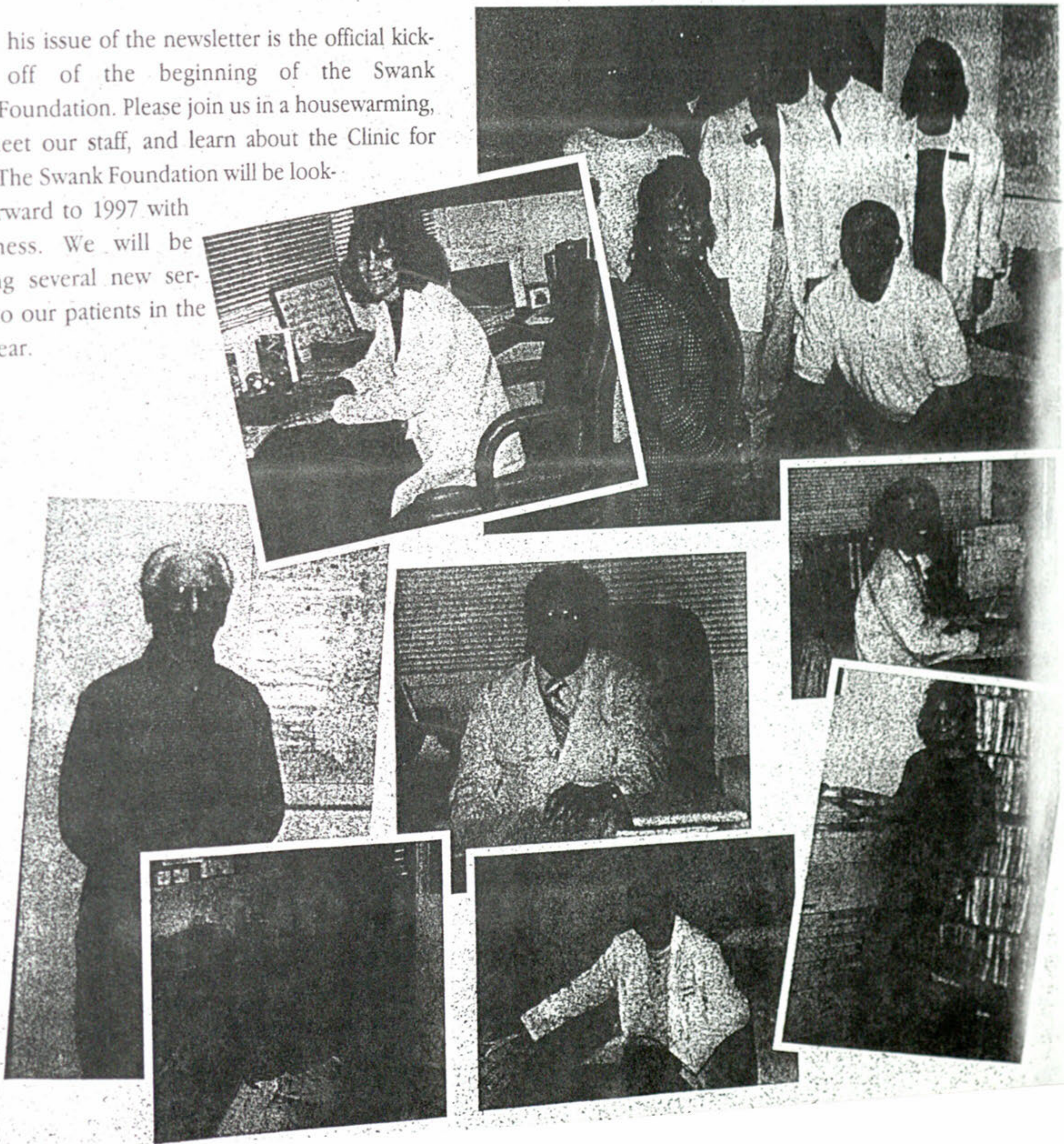
EDITION #72

This issue of the newsletter is the official kick-off of the beginning of the Swank Clinic/Foundation. Please join us in a housewarming, and meet our staff, and learn about the Clinic for 1997. The Swank Foundation will be looking forward to 1997 with eagerness. We will be offering several new services to our patients in the [illegible] year.



SWEEPSTAKES - BON VOYAGE

Warm those cold hands and feet! Enter to win our Grand Prize of a $1,000 gift certificate to take the vacation of your dreams. The choice of your destination is up to you. You may visit Hawaii, Bermuda, Disneyland, Etc. - the choice is yours. You may even upgrade your ticket. That trip of a lifetime you have always dreamed about, now can be a reality. The second prize is $500.00 in cash. The third prize is $250.00 in cash. We are mailing approximately 15,000 tickets - so enter early and often.

You will find five (5) raffle tickets waiting for you in the enclosed envelope. Sell them to your friends and save one for yourself. Each ticket costs $10.00 and will be entered into the drawing. The drawing will take place March 20th, 1997, at the monthly meeting of the CMS Group (Control, Management and Support), at the Swank Clinic, 13655 SW Jenkins Rd., Beaverton, OR (503) 520-1050.

The winners will be notified by telephone the following day of the drawing, March 21st, 1997.

Don't forget to place your name, address and telephone number on each ticket to be entered in the drawing. This is an exciting way to start out the new year and also help the Swank Foundation in its critical research.

RESEARCH

Dr. Steffin is starting the early phase of neurorehabilitation with the bladder training program. Don't forget to sign up if you are having problems with bladder frequency, urgency and incontinence. Be sure and read Dr. Steffin's article in this edition of the newsletter regarding our bladder management program.

BLADDER MANAGEMENT PROGRAM

A frequent problem for people with Multiple Sclerosis is deterioration of bladder control. This may take one or several forms:

Urgency/frequency/incontinence - Because of loss of cerebral control mechanisms, bladder reflexes become exaggerated. The major bladder muscle responsible for voiding, the detrusor is stimulated to contract when the bladder wall is distended. Sensory nerves activate nerve cells within the spinal cord to initiate the voiding reflex. In some MS patients, this happens too much, too vigorously, and too suddenly.

Patients can learn to manage the problem. Because normal bladder sensation may be altered by MS, patients need independent measurement of bladder fullness. This is done using and ultrasonic probe to measure bladder volume without catheterization. Using this independent measurement, patients can learn to recognize the urge to urinate and to correlate it better with actual amount of urine in the bladder. This helps to gauge how much time a patient has before she/he needs to urinate.

By going through urination cycles with the aid of the probe patients should be able to retrain themselves in bladder control through a process of biofeedback. We will be working with patients having urgency, frequency, and incontinence to develop an individualized program, using medication if necessary to reduce the discomfort and incidence of incontinence. We will be conducting trials of a new instrument available for the purpose here at the Clinic.

Retention. The urethral sphincter is a muscular ring at the base of the bladder that acts as a valve to prevent urine leakage. Like the detrusor, it can become abnormally active in MS, and in fact can go into spasm. When this happens, normal detrusor action cannot adequately expel the urine. Because residual urine remains in the bladder, urinary tract infections are likely. Medication can help, but in some cases catheterization is necessary.

But catheterization can also cause infections. It is important to be sure that catheterizations are not used inappropriately or too often.

It is often difficult for patients to tell whether frequency is due to excessive detrusor action or to retention. The bladder probe can help with this problem, so that patients with retention can be placed on an optimum schedule to reduce the likelihood of infection.

Urinary tract infections are major complications of MS, and can cause severe illness including kidney damage. Therefore, management of retention is an important part of the management of MS.

Who should be in the program? We are offering the bladder training program to all patients who suffer from urgency, frequency incontinence, retention symptoms, and frequent urinary tract infections. Our program will begin in January.

Please contact the Clinic for further information.

ARE YOU RESTING ENOUGH

Those of you frequenting our Clinic know the emphasis we place on resting daily. Diet alone is not as beneficial as diet and rest together.

Despite our frequent advice concerning rest and the dangers of overdoing, the same complaints have a tendency to recur yearly, and now are on the verge of showing their ugly heads.

January is a month of complaints about numbness, tingling, muscle aching, fatigue, etc. Exhausted, the patients retire to bed.

Complaints are noted primarily by young women with or without children. They work very hard during Thanksgiving, and worry through the entire period before and during the Christmas season. This leads to exhaustion.

A mid-day rest aids the patient in avoiding fatigue. Longstanding fatigue eventually can lead to exacerbation of disease.

What constitutes rest - If you are a working patient, find a quiet area and elevate your legs. If possible, it is best to lie down. The rest period should be a minimum of 15 minutes and preferably one-half hour. If you are not working, go to a quiet area and lie down for a minimum of one-half hour.

You may feel as though the rest break is unnecessary. To wait until you have problems is risking disability.

If symptoms develop, fluctuations of disease, begin a concentrated rest program immediately. If working, take a few days off work. Decrease all activities and stop exercise until your energy level returns.

Early signs of increased trouble are: Increased fatigue, cold hands and feet, slow mentation or memory loss, irritability, weepiness, gray of color to complexion and a look of weariness. Sensible management of your illness can prevent increased disability.

CLINIC NEWS

JOIN THE SWANK CMS GROUP

All Oregon and Washington subscribers please note - the third Thursday of February 1997, and each month thereafter, we are commencing our CMS (Control, Management and Support) Group .

Let's start the new year off right. Take charge and control of y[illegible] illness. Become a participant in the CMS Support Group. Space is limited to a total of 25 participants. The charge for each meeting is $5.00 per participant or an annual fee of $55.00. The meetings will be held at the Swank Clinic, 13655 SW Jenkins Road, Beaverton, OR., 6:30-8:00pm. Beverages will be provided.

The goal of CMS is more than just a support effort, it is a chance to take charge of your illness and help decrease the chance of disability.

Remember, this is YOUR group. Any items of particular interest or concern should be relayed to our office so we can address them at our meetings. Our staff will be prepared to answer your questions.

Since space is limited be sure and make your reservations now by calling (503) 520-1050. We are looking forward to seeing you.

EXERCISE FOR FITNESS AND FUN

Welcome Kris Hughes to our staff. Kris is a graduate of Gonzaga University with a degree in Physical Education with emphas[illegible] Exercise Science. Our Clinic will soon be offering individual as well as group programs to those interested in safely keeping fit.

The level of fatigue you are experiencing and your physical limitations will be addressed and you will be placed in the group that best fits your needs. Kris will also be offering individual programs for those interested. Please contact Kris at the Clinic to sign up. We will also be offering water exercise. Please specify your preference when you call. The classes will be held in the Beaverton area. Details will be mailed to you after signing up. Join the fun and improve your physical health. We are planning on the first class to begin mid February. Don't delay - Call Kris - Space is limited.

INTERNET

Watch for the Swank Foundation Web Page. Dr. Steffin has been working very hard to complete our Web Page. You should be able to surf the net and find us around January 1st.

Our e-mail addresses are:

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msteffin@involved.com

SWANK MS
FOUNDATION

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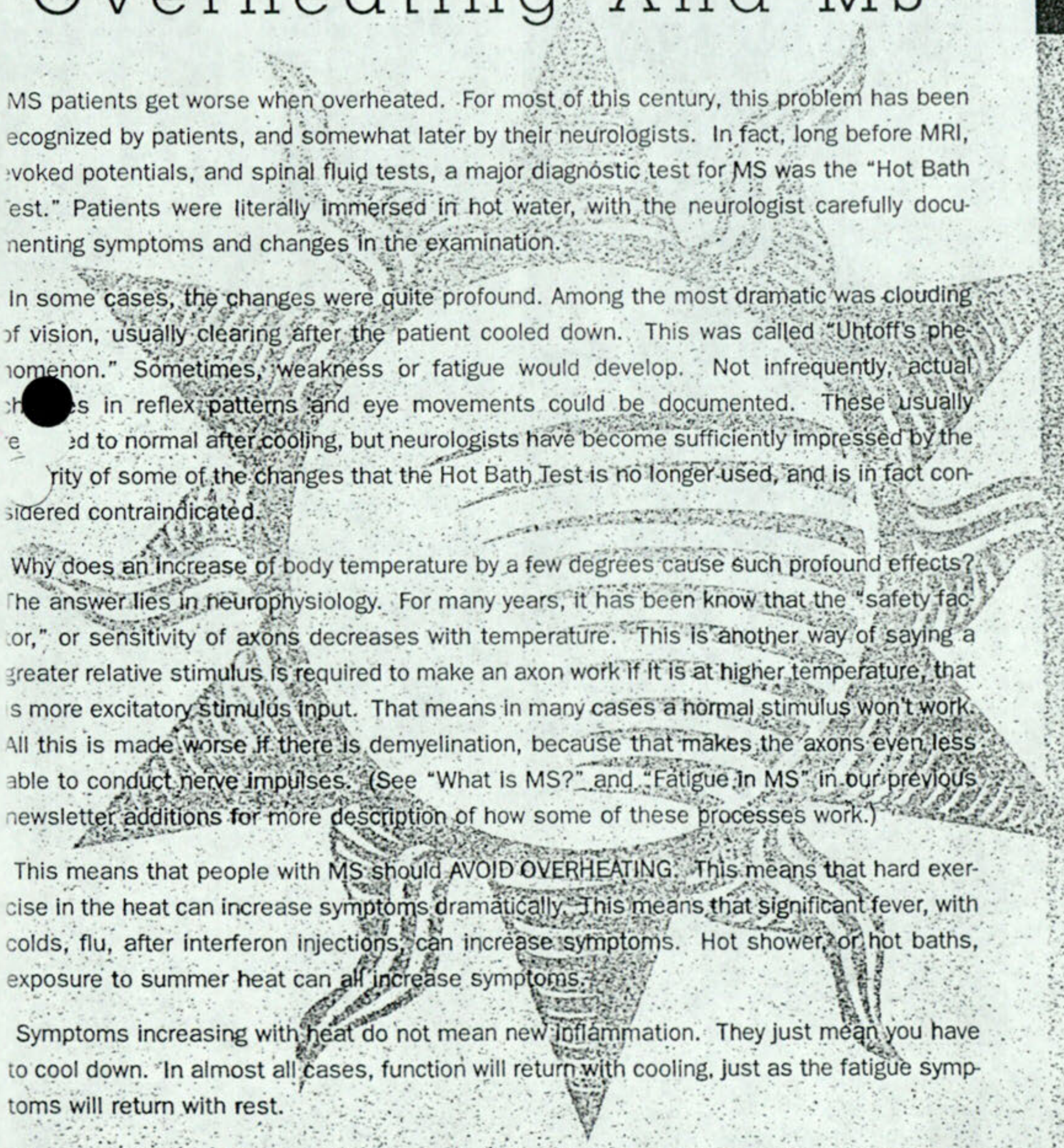
Overheating And MS



MS patients get worse when overheated. For most of this century, this problem has been ecognized by patients, and somewhat later by their neurologists. In fact, long before MRI, voked potentials, and spinal fluid tests, a major diagnostic test for MS was the "Hot Bath est." Patients were literally immersed in hot water, with the neurologist carefully documenting symptoms and changes in the examination.

In some cases, the changes were quite profound. Among the most dramatic was clouding of vision, usually clearing after the patient cooled down. This was called "Uhtoff's phenomenon." Sometimes, weakness or fatigue would develop. Not infrequently, actual ch[illegible]es in reflex patterns and eye movements could be documented. These usually e[illegible]ed to normal after cooling, but neurologists have become sufficiently impressed by the [illegible]rity of some of the changes that the Hot Bath Test is no longer used, and is in fact considered contraindicated.

Why does an increase of body temperature by a few degrees cause such profound effects? The answer lies in neurophysiology. For many years, it has been know that the "safety factor," or sensitivity of axons decreases with temperature. This is another way of saying a greater relative stimulus is required to make an axon work if it is at higher temperature, that s more excitatory stimulus input. That means in many cases a normal stimulus won't work. All this is made worse if there is demyelination, because that makes the axons even less able to conduct nerve impulses. (See "What Is MS?" and "Fatigue In MS" in our previous newsletter additions for more description of how some of these processes work.)

This means that people with MS should AVOID OVERHEATING. This means that hard exercise in the heat can increase symptoms dramatically. This means that significant fever, with colds, flu, after interferon injections, can increase symptoms. Hot showers or hot baths, exposure to summer heat can all increase symptoms.

Symptoms increasing with heat do not mean new inflammation. They just mean you have to cool down. In almost all cases, function will return with cooling, just as the fatigue symptoms will return with rest.

Remember: you are not imagining the adverse effects of heat on your nervous system. T[illegible]he appropriate precautions: use air conditioning on hot summer days, avoid exercis[illegible] a "sweat" (swimming is better: you won't overheat if the water is under 80 degrees), [illegible]oid hot showers and baths, and cool down right away if you get overheated. Some patients may actually need cooling vests, but most patients do well by following these suggestions and understanding what heat can do in MS. Remember: COOL IT! For information on Cool Vests call Microclimate Systems at 1-800-397-3004.

IN BRIEF

The Insurance Battle

We at the Swank Clinic would like to extend our sincere appreciation to our patients and friends who have stood by us during this tumultuous period. Payment of insurance premiums no longer guarantee patients coverage for their care. The insurance companies have gained control of health care. Unfortunately, physicians who become members of the large insurance groups must conform to decreasing patient care by limiting time available to patients, and tailoring their treatment options to the wishes of the insurance companies.

Our philosophy of care is currently not compatible with insurance policy. We spend a great deal of time with our patients. We form lasting relationships and provide care based on patient need and not on a required maintenance schedule. Some insurance companies feel our care is excessive and unnecessary. For you, this leads to greater out-of-pocket payments for our services. We are working very hard to control costs to our patients, and have set up our Foundation to assist us in this process.

What you can do to facilitate this process is to call your insurance carrier before your appointments. Ask them what steps are necessary to guarantee coverage for our services. You may also need to specify that we are not a participating member of their plan. Often, preauthorization or referrals are required to obtain medical services out of your network. They may also deny your request to come to our Clinic. Patient appeal can be very powerful in this situation. This is your premium money at stake. With your hard work, it may be possible to open your plan for yourself and future patients. In this way, it may also be possible to improve the current insurance climate.

We appreciate our patients and friends standing by us in this time of outside pressure, and plan to continue our quality care through the future years.

"I'm So Tired Of Being Tired." Mechanisms Of Fatigue In MS

Many people with MS are faced with skepticism early in the course of the illness because the only symptom they have is profound fatigue, with normal test and examinations. Since fatigue is a totally subjective situation, diagnosis is usually delayed until clear-cut criteria can be determined: At least two episodes of specific neurologic problems (such as numbness, weakness, vertigo, double vision, decreased visual acuity) with some neurological abnormality on examination, or alternatively abnormal laboratory studies (evoked potentials, MRI, spinal fluid examination). As the illness continues, fatigue also persists and often presents one of the more disabling aspects of completing activities of daily living and employment duties. This fact is often overlooked in the lay community, and often by disability evaluators who are programmed to demand the presence of clear objective abnormalities in determining levels of impairment.

We know that specific nerve tracts are affected by demyelination, leading to fairly specific symptoms such as weakness, spasticity, visual disturbance, and incoordination. But how does demyelination cause fatigue?

There are two mechanisms that have been suggested through basic research. These are the following:

1. Fatigue involving specific nerve tracts.

Let's take the example of weakness. Quite frequently this results from demyelination of the corticospinal tracts, the bundle of fibers called axons that, like large telephone cable, connects the controlling nerve cells (neurons) in the brain (cerebral cortex) with the muscle-activating neurons in the spinal cord. Demyelination slows conduction in these fibers, and in fact reduces the likelihood that an individual nerve impulse will get through like a partially short-circuited telephone line in the big cable. So, the percentage of impulses getting through is reduced, and as a result, the strength of muscle contraction is also weakened.

But, the interference with conduction is not totally blocked. Rather, the efficiency of conduction is reduced, and the affected nerve fibers can be shut down if stimulated too much or too often. But the shut down is temporary and recovers with rest. So the idea must be to reduce the overload of stimulation. To get the same contraction from the MS weakened muscle as from the normal muscle can produce this overload

So rest helps. This does not mean MS patients can't exercise. But it does mean that exercise has to be graded and adjusted for the level appropriate to the individual.

Similar considerations apply to other portions of their nervous system. Incoordination, sensory problems like numbness, double vision, and incoordination can also be made worse by fatigue.

Increase in body temperature also reduces the efficiency of impulse conduction in demyelinated axons. This is why heat adversely affects many MS patients.

2. Fatigue involving central pathways.

There are complex connections within the nervous system whose effects are not evident by easily observable external problems. The process of thinking, for example, is very complex and not well localizable to a specific nerve bundle. We talked about this in our last newsletter on changes in cognitive function in MS. A similar type of activity is responsible in areas of the brain responsible for general alertness. As we become more aroused and stressed, these circuits become more active. Like the tracts, they can become overloaded and partially shut down. Also like the corticospinal tracts, they can recover with rest.

The important point here is that the symptoms of brain circuit overload are not as definite as those from overload of the specific nerve tracts. We can try to ignore the fatigue, to "push on through it." This is generally a mistake, and a quite common one for people with MS who tend to be hard-driving from the start. This behavior tends to have a cumulative effect and often results in an increase in fatigue to the point of a "crash" and sometimes a frank exacerbation.

So the neurophysiology of MS is much more complicated than just the occurrence of demyelination. One of the most fascinating aspects of MS is the remission, or even the day-to-day recovery from rest and proper management. Some recovery may be d actual remyelination, or regeneration, but this te be a slower process. More rapid improvements ably result from the effects of rest in "recharging" the fatigued axons.

There is experimental work to support this idea of "recharging." For example, we know that axons stripped of their myelin generate new "sodium conductance channels," which are the electrical switches that turn on the conduction of nerve impulses. It is also possible to alter the impulse generation mechanism by taking into account the "Hodgkin-Huxley" properties of the axon nerve membrane. These were two British investigators who won the Nobel Prize in the 1950's for showing the principles behind what we are discussing. Use of this information is helping in the development of new drugs, such as the experimental 4-aminopyridine, which affects potassium conductance in axons, that can increase the ability of fatigued axons to conduct impulses more efficiently. (This drug has side effects and is not yet available, but has undergone some clinical testing).

Other drugs, like amantadine and pemoline, ar vous system stimulants and can temporarily re fatigue, but too much stimulation can be deleterious by producing circuit overload. So every patient is different, and medications must be adjusted individually.

We try to use these neurophysiologic principles in our day-to-day management of the fatigue problems of people with MS. If you would like more information please contact the Clinic.

How Much Fat Is Too Much

Patients often ask the question: "What happens when I eat a large volume of saturated fat at one meal"?

The following brief history and explanation follows:

Early on in my research at the Montreal Neurological Institute my peers suggested that patients be administered large amounts of saturated fat as a real test of [illegible] theory.

[illegible]olunteer patients were given only 30 grams (6 of highly saturated fat. Two patients experienced exacerbation of their illness. In one, paralysis of the lower extremities with subsequent slight recovery, and in the other generalized weakness of the extremities developed with very little recovery. The remaining four patients developed no more than severe fatigue.

As the work progressed, we learned that patients could not eat more than 15 grams of fat per day and remain well and free of added disability. Finally, at the end of 35 years, it was evident that 10-15 grams were the outside safe limits of fat intake. If this were exceeded by no more than 8 to 10 grams of fat per day, patients deteriorated as fast as patients who were not on the low fat diet. They deteriorated rapidly and expired early (79 to 81%). Patients who stayed on low fat diet (15 grams saturated fat) had a death rate (31%), much of which was due to aging (average 65-70 years).

In experiments in which humans and dogs were fed [illegible] meals of cream fat (2 grams per kilogram of [illegible]t) small fat globules most of which were [illegible]mped together were found in the blood. At the [illegible]e time, red blood cells had become adhesive and also tightly packed in clumps. Observation of the actual circulation in small blood vessels, principally capillaries showed slowing down of the blood flow. These clumps managed to slowly squeeze through the vessels. The slow squeeze through capillaries stretched the lining cells and separated them from one another to cause leaking, which is known as break-down of the blood-brain-barrier.

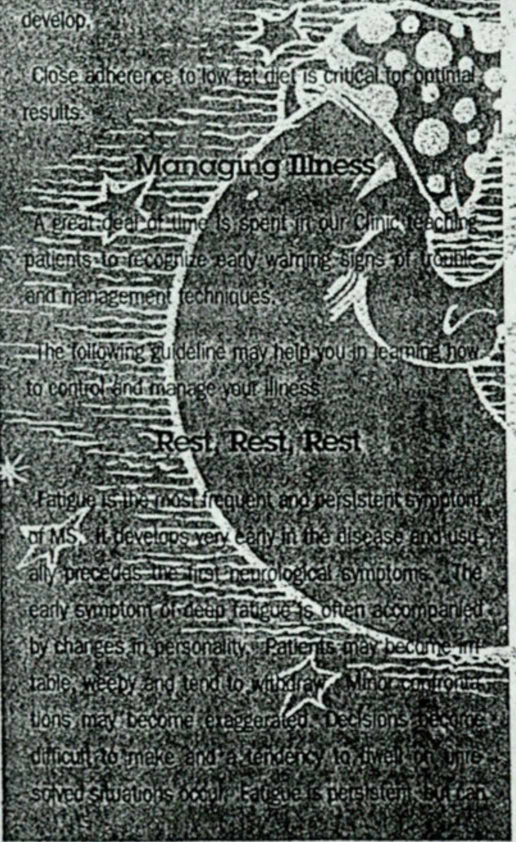
Blood capillaries throughout the body are porous and allow large amounts of plasma and its contents to pass through the walls into the tissue. Thus, whenever a colored dye such as trypan blue is injected the entire body become colored by the dye, with the single exception of the brain which is protected by the "blood brain barrier." Only if the barrier is injured does it become porous. This simple barrier protects the brain from toxins which injure and destroy areas of the brain. Some toxins are in the blood normally, others are there by chance, but the barrier protects the brain from all toxins.

If a dye (trypan blue) were injected at the time of damage to the blood-brain-barrier, it would leak through the blood vessels and strain the brain.

The importance of the blood-brain-barrier has been known for more than 60 years, and now it is being investigated seriously.

The significance of this message is that your saturated fat should always remain below 15 grams daily. A large bolus of saturated fat can produce increase in symptoms or exacerbation of disease, because it causes red cells to clump together and thereby damage brain capillaries.

Straying from diet of only 8-10 grams will slow the exacerbation rate, but continued deterioration will develop.



Close adherence to low fat diet is critical for optimal results.

Managing Illness

A great deal of time is spent in our Clinic teaching patients to recognize early warning signs of trouble and management techniques.

The following guideline may help you in learning how to control and manage your illness.

Rest, Rest, Rest

Fatigue is the most frequent and persistent symptom of MS. It develops very early in the disease and usually precedes the first neurological symptoms. The early symptom of deep fatigue is often accompanied by changes in personality. Patients may become irritable, weepy and tend to withdraw. Minor confrontations may become exaggerated. Decisions become difficult to make and a tendency to dwell on unresolved situations occur. Fatigue is persistent, but can vary a great deal. The onset of MS brings with it reduced physical ability and endurance. Increasing fatiguability is the result. It is difficult for people who have been active and aggressive all their lives to slow down to the speed of an average person. To have been driven all one's life by some poorly understood mechanism in one's body, and then be asked to cut speed by a half or two-thirds is asking a great deal. In practice most patients have found it very difficult to slow down, even gradually. Yet this adjustment is necessary for living a comfortable exacerbation free life. When you overexert frequently or for long periods and fail to allow sufficient time for recovery, deep fatigue may be prolonged. The most practical advice is to pace yourself. Don't rush; don't attempt to be busy all the time; and spend time relaxing and even meditating. Listen to your body, and very carefully monitor and control your desires. The only effective treatment for fatigue in MS is adherence to the diet and rest by lying down. Resting by sitting up is less helpful. If the fatigue is severe, be sure to take daily naps (one hour lying down) or increase these naps to twice daily. STOP BEFORE YOU HIT THE WALL!

Look, Listen & Feel

If you have a grayish look to the skin, hollow eyes, and you are weepy, fearful, and possibly paranoid - then it is time for some help. Oftentimes this can be provided by a spouse or family member. You might be experiencing tight bands, vision problems, a feeling of heaviness, and irritability. The fatigue is not usually visible or obvious to the casual or even professional examiner. It is noticed and remembered by close friends and members of the family. Deep fatigue, however, frequently is accompanied by drawn and pale countenance, which is readily recognized by an interested observer. These are early warning signs of trouble. Your spouse, family member or friends must level with you and convince you to begin resting immediately.

Final note: Careful management of this illness is absolutely necessary for continued remission of symptoms. Close adherence to low-fat diet, daily rest breaks, & avoidance of fatigue can prevent disability.

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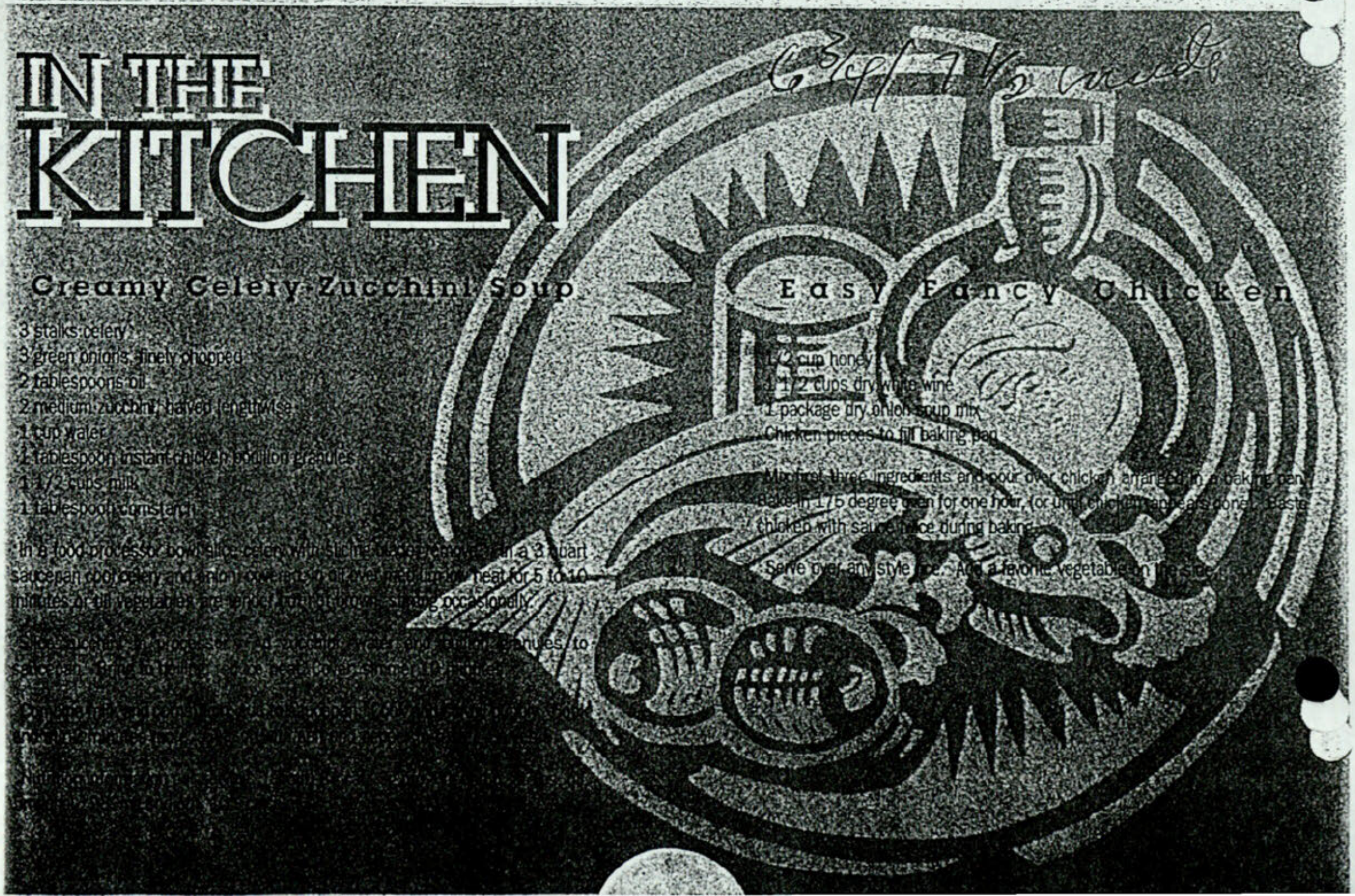

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IN THE KITCHEN

Creamy Celery Zucchini Soup

3 stalks celery
3 green onions, finely chopped
2 tablespoons oil
2 medium zucchini, halved lengthwise
1 cup water
1 tablespoon instant chicken bouillon granules
1 1/2 cups milk
1 tablespoon cornstarch

In a food processor bowl slice celery with slicing blade [illegible] In a 3 quart saucepan cook celery and onion covered in oil over medium-low heat for 5 to 10 minutes or till vegetables are tender but not brown, stirring occasionally.

Slice zucchini [illegible] processor [illegible] zucchini, water, and bouillon granules to saucepan. [illegible]

[illegible]

Easy Fancy Chicken

1/2 cup honey
1 1/2 cups dry white wine
1 package dry onion soup mix
Chicken pieces to fill baking pan

Mix first three ingredients and pour over chicken arranged in a baking pan. Bake in 175 degree oven for one hour, (or until chicken appears done). Baste chicken with sauce twice during baking.

Serve over any style rice. Add a favorite vegetable on the side.