Quest #1 August 1993

ANNOUNCEMENT

I have resigned as Communications Director of The Nightingale research Foundation as of March 1, 1993 in order to concentrate solely on support and be independent of any association or group. Therefore, a non-profit organisation was incorporated as of June 18, 1993 under the name of NATIONAL ME/FM ACTION NETWORK. We have applied for charitable status which will take some time to obtain.

This is an ACTION support group and will reflect actions and communications of all groups and associations across Canada regardless of their affiliations and will also have an international input. It will be actively involved in issues that are of great concern to all of us, as voiced by individuals and support groups leaders i.e. insurance problems, government involvement, children and young adults and the school system, media misinformation, lack of proper medical testing and doctor and lawyer referrals etc.

CHANGE OF ADDRESS NOTICE:

Dr. Anil Jain has moved to 1025 Grenon Ave., Suite 118, Ottawa, Ontario K2B 8S5 - Tel. (613) 596-3211. Dr. Jain will still be seeing ME patients (both adults and children) for diagnosis and treatments as well as other patients.

FIBROMYALGIA:

You will note from the proposed name of the organisation that Fibromyalgia has been added to the name. Very few people escape the pain of Fibromyalgia when they are ill with ME nor do many FM people escape the central nervous system (CNS) problems experienced by ME individuals. It is possible that both conditions have the same origin and may actually be variations of the same illness.

TIP: BEFORE you call long-distance to a government agency, insurance company or other big organisation, DIAL 1-800-555-1212 to check if they have an 800 number.

IMPORTANT WORLD NEWS:

INTERNATIONAL STATISTICAL CLASSIFICATION OF DISEASE AND RELATED HEALTH PROBLEMS (ICD-10) - 10TH Revision, Volume 1

WORLD HEALTH ORGANIZATION (W.H.O.), GENEVA 1992.

CHAPTER 6 DISEASES OF THE NERVOUS SYSTEM

Page 414 - 93.3 Postviral Fatigue Syndrome -

Benign Myalgic Encephalomyelitis

This is the first W.H.O. edition that ME appears in. Canada is one of forty-three member countries who will be collecting statistics under the recognised names of Portviral FatigueSyndrome or Benign Myalgic Encephalomyelitis. Ms. E. Taylor of Health and Welfare Canada is one of eight officers who took part in preparing the 1992 edition which took three years to complete.

NEWSLETTERS:

Please include me on your mailing list to receive copies of your group's newsletters. If your group does not have a newsletter, please appoint someone to keep me informed about your group so that you will not be left out.

FUNDING:

Many of these projects have already been started. However, I now desperately need financial help to see me through this next period. As always, I am not looking for any financial gain but I am unable to bear the financial burden alone. If everyone could give something, I will be able to obtain the basic necessities to function effectively and quickly. Stamps and stationery are my major concern right now. However, a Fax and a filing cabinet are also a must. No matter how small your gift, it is very much appreciated.

ESTABLISHMENT OF TASK FORCES:

Anyone interested in becoming involved in these important and necessary projects, please get in touch with me and let me know where your interests lie. Everyone is welcome regardless of affiliations.

DENTAL ALERT:

A few months ago, I had to see my dentist whom I had not seen for awhile. I had to fill in a new form for my records which specifically asked about illness etc. I put down ME and when I saw the dentist, he refused to treat me. He explained to me that the mouth is full of bacteria etc. and when an individual has immune problems, they should take precautions before visiting a dentist. He gave me a prescription for: 9 NOVAMOXIN at 500 mgs, 6 capsules to be taken one hour before the appointment and 3 capsules to be taken six hours after the appointment.

The dentist also advised that since we have problems due to lack of adequate saliva in the mouth, it causes more rapid tooth decay as saliva is necessary to combat the toxins in our mouth. He therefore suggested that teeth be brushed after every meal. If that is not possible, chew sugarless gum to promote saliva or suck on a sugarless candy.

It must be remembered that before you follow any kind of treatment, you must discuss it with your doctor or dentist first as he/she is familiar with your illness and its problems.

WARNING: NEVER presume that a new symptom you experience is related to your ME/FM. See your doctor to have the new symptom checked out, and once other factors have been ruled out, you can then be comfortable in knowing it is related to ME/FM. There are many conditions that can be treated and some can become very serious if not taken care of immediately. Too often we have become resigned to our symptoms that we fail to remember that some may not be related at all and therefore suffer needlessly.

DOCTORS' COMMENT:

I asked some medical professionals if there is any suggestion they could make regarding ME/FM patients that would help in their diagnosis and treatment. They unanimously stated that rather than give just a symptom, the patients get into the habit of also relating what they were doing at the time it happened. For instance, whenever I stand up from a sitting position, I become dizzy - I get a headache each time I go into the sunlight.

CLOSING REMARKS:

LET'S NOT REACT TO UNFAIRNESS BUT ACT FOR CHANGE.

Lydia E. Neilson