

Quest #8 October 1994

CENTERS FOR DISEASE CONTROL UPDATE

Re: 'THE FACTS ABOUT CHRONIC FATIGUE SYNDROME'

The long awaited booklet from CDC can now be ordered. Dr William C. Reeves, MD Chief - Viral Exanthems & Herpesvirus Branch - Atlanta. Dr. Reeves letter of June advises **'Scientists and clinicians from CDC, other Federal agencies, several universities and private practise are collaborating to revise the case definition. This revised version will be submitted for publication in a peer reviewed medical journal. Once published, the revised case definition replaces the older version in the brochure's appendix'**

To get your copy, either write or phone: **Ms Dottie Knight, Mail Stop A-15,Center**

1600 Clifton Road NE, Atlanta, GA 30333 U.S.A. Tel. (404) 639-1338

INSURANCE MATTERS

Private Investigators In a letter dated Aug 24 1994 Mr. David Christopherson, MPP Hamilton Centre, Solicitor General & Minister of Correctional Services wrote as follows:

"Private Investigators in Ontario are licensed under the Private Investigators and Security Guards Act, R.S.O. administered by the Private Investigators and Security Guards Section of Records and Registration Branch, Ontario Provincial Police (OPP). The RCMP are not involved in this process.

Applicants for licences are required to meet the following standards established by the Registrar:

1. 3-5 years investigative experience;
2. proven knowledge of related legislation and of the field;
3. police investigation conducted into applicants' suitability;
4. applicant required to post a \$5,000.00 bond and insurance totalling \$1,000.

Private Investigators' licences are renewed on an annual basis and no legislation empowers Private Investigators with greater rights or powers than those of private citizens.

Complaints against Private Investigators may be reported to the Investigative Unit, Private Investigators and Security Guards Section, Records and Registration Branch, Ontario Provincial Police, 125 Lakeshore Boulevard East, Toronto, ON M5E 1P6, Telephone No. (416) 326-0033, Fax No. (416) 326-0034.

I trust the information provided is satisfactory.

Sincerely, [Signed] David Christopherson, MPP - Hamilton Centre, Solicitor General and Minister of Correctional Services."

INSURERS' MISCONDUCT:"If the Superintendent considers that the conduct of a financial institution is misleading, deceptive or unconscionable, he may institute proceedings with a view to protecting the rights of an insured. However, in this situation it is difficult to conclude that the actions of the insurance companies are misleading, deceptive or unconscionable, given the divergence of medical opinions on

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and/or Fibromyalgia and given that the doctors who express such opinions have their own professional standards of independence to which they must adhere." [Signed] Robert J. Hobart, Superintendent and Chief Executive Officer, Financial Institutions Commission, Province of BC, 1900, 1050 West Pender Street, Vancouver, BC V6E 3S7 - Tel. (604) 660-2947 - Fax (604) 660-3170.

Insurers' 'independent medical report'?

ONTARIO - Blair Tully states in his letter of Oct 12/94 "To the extent there may be doctors who are not prepared to accept ME as a genuine medical condition, I would suggest this is a matter more appropriately considered by the Ontario College of Physicians and Surgeons. Similarly, if there is evidence to suggest that a physician is deliberately alter his or her findings and opinions, that might be a matter that warrants reporting to the Ontario College of Physicians and Surgeons." Signed Blair Tully, Commissioner, Ontario Insurance Commission, 5160 Yonge St., Box 85-15th Flr, North York, ON M2N 6L9 - Tel. (416) 590-7000 - Fax (416) 590-7078.

NEW BRUNSWICK - "There is no definition on this matter in the New Brunswick Insurance Act, nor have provided any guidelines to the industry. In my experience, these situations are usually resolved through a mutual understanding of all parties as to who is acceptable in providing an independent medical report. It is usually the interpretation of the medical reports that creates disharmony, the matter may need to be resolved in a court of law.....New Brunswick does not maintain records on specific losses or claims...."Signed R.W. Richard, Superintendent of Insurance, P.O. Box 6000, Fredericton, NB E3B 5H1 - Tel. (506) 453-2512 - Fax (506) 453-2613

[Editors note: As disability insurance is a provincial issue, the provincial equivalent of the Ontario College of Physicians and Surgeons is the appropriate body to deal with these matters in other provinces.]

TIP: 1) Whenever you need to make an important phone call or write an important letter, be sure to call or write the same contact person who would be familiar with your file.

2) When you get a call from an important contact but it is made by phone, follow it up in writing, outlining the particulars of that call. This information can become important if there is a disagreement as to what was decided on the phone and what actually happened. This way, if the contact does not agree with what you wrote or what they thought transpired, they will be forced to write you a rebuttal.

3) Whenever possible, keep notes of important events in your life, on either a daily or weekly basis so that you can keep track of developments.

NEWSLETTER/BOOKS/VIDEOS ETC.

HEADLINE, quarterly newsletter of the B.C. HEAD INJURY ASSOCIATION, 218 SIXTH STREET, New Westminster, B.C. V3L 3A2 Canada - Tel. (604) 520-3221 - Fax (604) 520-3206. It has excellent information on head injuries which are very helpful but also has information on professionals who may be able to help you.

The essential guide to understanding migraine and its treatments by: Valerie South, RN [Director, Communications of The Migraine Foundation] Endorsed by The Migraine Foundation and The Canadian Medical Association - Advance order, send \$14.95 (plus \$2.00 shipping (total \$16.95) along with your name and complete mailing address to: The Migraine Foundation, 120 Carlton St., Suite 210, Toronto, ON M5A 4K2 CANADA.

TIP: INFORMATION ON INTERSTITIAL CYSTITIS (I.C.) can be obtained from **I.C.A. CANADA, Station "A", P.O. Box 5814, Toronto, ON M5W 1P2 - Tel. (416) 920-8986**

ARCH TYPE - "the magazine that defends the rights of people with disabilities" - 6 issues per year - Cost: \$15.00 individual; \$25.00 Organization and add \$5.00 for International. Write to: Advocacy Resource Centre for the Handicapped (ARCH), 40 Orchard View Blvd., Suite 255, Toronto, ON M4R 1B9 - (416) 482-8255 (voice); 416-482-1254 (TTY); 416-482-2981 Fax.

"Reborn or how I cured myself of ME. by Dr. Philipa Corning (2 pages) - please Stamped self-addressed envelope to: **69 Roblyn Way, Nepean, ON K2G 5Z5**

Re: Canadian Investigational and Emergency Drug list

The Drugs Directorate does not maintain a public registry of all the clinical trials conducted within Canada.

However, the Canadian Society of Hospital Pharmacists publishes the **Canadian Investigational and Emergency Drug List** which provides limited information on trials conducted within Canada. Further enquiries regarding this list can be directed to: THE CANADIAN SOCIETY OF HOSPITAL PHARMACISTS, 1145 Hunt Club Road, Suite 350, Ottawa, Ontario K1V 0Y3 - Tel. (613) 736-9733 - Fax (613) 736-5660 [Signed] Sheila Hills, Head, ATI Section, Drug Regulatory Affairs Division.

GOVERNMENT GRANTS:

Q: Who is responsible for handing out grants?

A: Dr. Campione-Piccardo replies in his letter of June 9, 1994 as follows: "The main agencies granting support to researchers who may wish to contribute to a better understanding of ME/FM are the Medical Research Council and the National Health Research Development Program (NHRDP). These agencies assign grants through a peer-reviewed competitive process on the basis of perceived merit. Every Canadian with the required qualifications can apply for different types of grants to carry out research in ME/FM in different universities or other institutions." Signed: José Campione-Piccardo, M.D., Ph.D. Chief, National Laboratory for Viral Oncology, Laboratory Centre for Disease Control, Ottawa.

HEALTH QUESTIONS

Introduction: We are very pleased to announce that Dr. Jain has agreed to contribute his valuable expertise to our Newsletter. As you probably know, in addition to his general practice, Dr. Jain has seen thousands of M.E./CFS patients. He will discuss matters which appear to be of particular concern to these patients.

Dear Dr. Jain: Q: What is your opinion on Flu Shots?

A: The Flu shot generally gives immunization against the most prevalent virus strains of that year. However, it does not prevent common colds or bacterial infections.

The flu shot is presently recommended for any person over the age of 65 and those who have a serious illness, such as cardiovascular or lung disease. These individuals are most vulnerable to death by the influenza virus.

The flu shot is generally not required for ME/CFS patients. At our clinic, we generally recommend it to patients who are having repeated significant respiratory infections which may resemble influenza. These include symptoms of fever, frontal headaches, muscle pain, and a non-productive cough. However, in the above-mentioned vulnerable group, these individuals can become severely sick with even pneumonia with possible death.

These symptoms, however, do not include the non-specific flu-like symptoms often seen in ME/CFS.

Also, as an already compromised immune system is further taxed with the flu shot, we do not recommend it for severely ill ME/CFS patients or patients who have not plateaued in their health. **Anil Jain, M.D.**, 118 - 1025 Grenon Ave., Ottawa, ON K2B 8S5 - Tel. (613) 596-3211.

Dr. M J Holmes cautions "not to raise false hopes in CFS sufferers [quotes made on his behalf without his knowledge]. This has been done far too often in the past, particularly by sensationalist media-rodents and has caused a lot of additional, quite unnecessary and quite inexcusable suffering to patients when they learn the truth." Meanwhile, we would prefer that you asked us directly about our activities. M J Holmes MD, Senior Lecturer in Microbiology, University of Otago, P.O. Box 56, Dunedin, New Zealand - Phone (03) 479-7728 - Fax (03) 479-8540

[Editor's Note: Thanks to Carol Carpenter for sharing her letter of August 25/94 from Dr. Holmes, with his permission and also Roger Burns CFS Wire].

1) CAROLYN MARY DEMARCO, MD will be giving 2 workshops at the Seventh Annual **Conference of the B.C. College of Family Physitions** entitled: 'PRACTICAL MANAGEMENT OF CHRONIC FATIGUE SYNDROME IN VANCOUVER November, 18, 1994. This is the first time a doctor has been invited to speak because of an interest in complementary medicine. For information - Tel/Fax (604) 226-7634

2) Whole Life Expo - 1994 at METRO TORONTO CONVENTION CENTRE - November 12,13, 1994. There will be approximately 25 speakers and 200 Exhibitors - Dr. DeMarco will be speaking on "What Every Woman Should Know". For information call (416) 964-0528

[Ed note: Dr. DeMarco is author of 'Take Charge Of Your Body' which is in its fifth edition since it was originally published in March 1989. Available through R & R BOOK BAR, 14,800 Yonge Street, Unit 194, Aurora, Ontario L4G 1N3 Canada - Tel. (905) 727-3300 - Fax (905) 727-2620]

INTER-GROUP COMMUNICATIONS

Australia - A Urinary Biomarker?

Mr. Jim Oakley of the M.E./Chronic Fatigue Syndrome Society of Victoria Incorporated received the following reply from Professor Tim Roberts of the University of Newcastle who provided him with the following information:

The abstract presented at the Dublin conference is the only published work at this stage.

His team [Prof. Roberts] has seven manuscripts to send out for publication when all the legal details are worked out.

The test is not available at the moment because it requires a long and involved analytical procedure using gas chromatography combined with mass spectrometry.

A clinical trial which will assess the usefulness of the test will be conducted at the Royal North Shore Hospital in Sydney [Australia].

[Editor's note: Mr. Jim Oakley is the Editor of 'EMERGE', the newsletter of the ME/Chronic Fatigue Syndrome Society of Victoria Incorporated, 23 Livingstone Close, Burwood, Victoria 3125, Australia.

CANADA - AIDAN WALSH walk on parliament hill Re: May 12th update

We are pleased to report that Aidan's efforts regarding ME/FM have not been in vain. Due to his tireless efforts, we have learned that there have been numerous inter-departmental government activities on this matter and they are considering various ways of funding research. We will keep you informed.

LAWYERS' NETWORK - New Addition

MENZIES & ASSOCIATES Contact: Laura A. Clark, B.A. LLB.

2277 Riverside Drive, Suite 207

Ottawa, ON K1H 7X6 CANADA Tel.(613) 733-3000 - Fax (613) 523-2924

PERSONALS:

Leni J. Hang in there - you are doing a great job but take care.

Christine C. Your letter did not indicate your address - please let me know.

WELCOME TO OUR WORLD:

REMISSION - RELAPSE - RECOVERY

step forward back-up Walk on

INSOMNIA: Ideal atmosphere to meditate in absolute silence.

Thanks to Lorraine Legendre, Ottawa.

ELECTRONIC MAIL:

A free Guide to the many information resources available via Computer for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis and Fibromyalgia. For an individual the guide shows where to get information and have discussions with others interested in ME/CFS and FM. For a Support group, the guide is a resource for obtaining newsletter articles for your newsletters, and to communicate with other support groups. You can obtain a free copy by mailing a self-addressed stamped envelope to:

In Canada:CFS/ME Computer Networking Project, 3332 McCarthy Road, P.O. Box 37045, Ottawa, Ontario K1V 0W0 CANADA.

In the U.S.A.: CFS/ME Computer Networking Project, P.O. Box 2397, Washington, DC 20036 U.S.A.
Please note: for mailing outside of Canada or the U.S.A., please include an International Reply Coupon.

REMINDER - Eye survey and insurance survey still available, if you want to participate. Remember that the more people get involved, the more worthwhile information we will get. Call or write if you want the forms.

MEMBERSHIP NOTICE - WANT TO JOIN US? - Membership to the NATIONAL ME/FM ACTION NETWORK is \$20.00 per year and includes newsletters every two months.

Until next time, take care.

Lydia E. Neilson,

President C.E.O.

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DISCLAIMER: The NATIONAL ME/FM ACTION NETWORK serves as a clearing house for information on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia Syndrome. Some of the information contained herein is intended to help patients and their physicians make informed decisions about their health. However, the NATIONAL ME/FM ACTION NETWORK does not dispense medical advice or endorse any specific medical hypothesis or product and assumes no responsibility for any treatment or action undertaken by its readers.