

Quest #5 April 1994

Dear Friends:

This newsletter is a little longer than usual due to the fact that it is the last edition before May 12th - International ME/CFS Awareness Day.

I am also happy to announce that we have been approved for charitable status and will therefore be able to issue tax receipts for any donation we receive. This status applies to all of Canada, except for the Province of Quebec for which we have had to apply separately.

It has been a very tough winter and everyone deserves to be congratulated for having the courage to go on, despite the many obstacles that needed to be overcome.

Please take comfort in the fact that we are making progress and although the road ahead is still a difficult one, it is uphill due to the efforts of all of us towards a common goal.

Sincerely,

Lydia E. Neilson.

DIAGNOSTIC RESULTS - INFORMATION WANTED

HISTORY: E.G., a patient diagnosed with ME/FM, in addition to the usual brain scans, was referred to a neurosurgeon who performed a stereotactic temporal lobe biopsy. The following are the results:

"Microscopic examination of serial sections of the frozen and paraffin embedded material reveals small fragments of cortex and subcortical white matter. There is a very mild degree of hypercellularity of the subcortical white matter. There is no evidence of obvious malignancy displayed by the cells in the subcortical part of the specimen. Small fragments of gray matter show occasional cells (three identified in the entire specimen) showing nuclear hyperchromasia, multilobulation and sharp angulated outlines of nuclear membranes. There is focally increased perineuronal satellitosis. However, it is difficult to diagnose any of the satellite cells as malignant. Two fragments show groups of slightly larger cell nuclei with nucleoli, and no visible cytoplasm. These cells may represent abnormal neoplastic or dysplastic neurons."

WANTED: Information on whether other individuals have had a stereotactic temporebe biopsy performed and what the outcome was. To preserve the confidentiality of the individual, only researchers and doctors will be released more pertinent information about this person for their research and studies.

[Editor's note: Please reply directly to me. Confidentiality assured.]

CDC ATLANTA UPDATE: In response to our enquiry, we received the following reply: "I am writing in response to your request for a draft copy of The Facts About CFS. The Facts About CFS is a CDC information brochure intended primarily for CFS patients and secondarily for health care providers. It was written because of the large volume of requests CDC receives concerning CFS. The brochure was written by the CDC CFS Research Group after a complete review of the peer reviewed CFS medical literature, and in consultation with academically affiliated physicians who treat CFS patients and conduct clinical research.

A draft of the brochure was circulated for comment at an opening meeting held at CDC in September, 1993. CDC received many excellent comments, discussed them in detail, and made many changes to the

brochure. In order to assure adequate opportunity for further public comment, we are sending this draft to individuals like you who request it. We also distributed this draft at the March PHS CFS Interagency Coordinating Committee Meeting.

This draft has been submitted for Public Health Service and CDC clearance. We are eager to receive additional constructive criticism prior to publication. Please send any comments directly to me by 1 April, 1994." Sincerely yours, (Signed) William C. Reeves, MD - VEHB MS A-15, Centers for Disease Control, Atlanta, GA 30333 U.S.A.

Editor's note: 1) One sentence on Page 1 of draft reads "Patients with CFS may become exhausted with only light physical exertion." We requested Dr. Reeves to amend this to read "Patients become exhausted with only light physical or mental exertion or stress." Will keep you posted on developments.

2) A copy of the CDC draft brochure can be obtained from the CDC or from our Network by sending me a stamped (86 cents) self-addressed envelope.

CDC LETTERS: Frank Fowler of The Manitoba Chapter of ME Canada sent an excellent letter to the Centers for Disease Control in Atlanta that would be great to be used by other groups and people in the attempt to get a better criteria list and a change of the name CFS. If you would like a copy, just send a stamped self-addressed envelope to us (\$1.00 cheque or international coupon for international). This might also be great for May 12th CFIDS/ME Awareness Day or for doctors who want to participate.

EYE SYMPTOM SURVEY - Dr. Walter Potaznick, O.D., FAAO, of THE NEW ENGLAND COLLEGE OF OPTOMETRY, in Boston, MA, has started the second phase of his research into CFIDS Ocular Symptomatology. Dr. Potaznick has asked us for his help as he is in need of a sample of over 10,000 total responses not only from ME/FM patients but also from health patients and patients with other chronic diseases. To date he has eleven sites in North America.

Our organization has been assigned Site #55 for identifying the source of the responses.

We have made copies of the questionnaire with Site number which will be sent to anyone who requests it. Please enclose stamped self-addressed envelope for this purpose.

Chronic Fatigue Syndrome written by Anne Rotondo Perlow, O.D. and Walter Potaznick, O.D., F.A.A.O. on the Ocular Manifestations of CFS which appeared in The New England Jour of Optometry in Spring 1991 was kindly sent by Dr. Potaznick and a copy will be sent to you along with the questionnaire, upon request.

EYE PROBLEMS: "Many, many people say that they can't read very well because things go blurry and they can't really focus on the sentences let alone retain what they did see. ...Actually that part of CFS is not looked at very well and it might be a very interesting area to look at because there are devices. . . that will actually measure your eye movements as to how you're tracking, for example. It could be that you don't track properly...It could be the ciliary muscles which don't allow you to focus, or your extraocular muscle which moves your eye that is actually affected." Dr. Grant Stiver, UBC, BC, Canada.

LEGAL PRECEDENTS Mr. James Vigmond, Lawyer, has photocopied a brief synopsis of several dozen cases which have been decided on Fibromyalgia /Fibrositis, chronic pain syndrome, myofascial pain syndrome and chronic pain. He has these available to copy should anyone require their use. Please contact him at: Oatley, Purser, Barristers & Solicitors, 151 Ferris Lane, Suite 200, P.O. Box 760, Barrie, ON L4M 4Y5 - Tel. (705) 726-9021 - Fax (705) 726-2132

INSURANCE QUESTIONNAIRE/SURVEY is being sent to support group leaders for distribution to its members. For those who did not receive a copy and would like to participate, please let us know and we

will send you one. This is a confidential survey and names will be replaced by numbers. The statistics derived from this insurance survey will give us the status of insurance claims which will be extremely useful for negotiations.

TREATMENT INFORMATION

KUTAPRESSIN In response to many of you asking about how to obtain Kutapressin in Canada, we received the following reply:

".....KUTAPRESSIN, as you are aware, does not have an indication for the treatment of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome. The Bureau of Human Prescription Drugs does not have any data that support the use of KUTAPRESSIN in Chronic Fatigue Syndrome. The U.S. distributor for KUTAPRESSIN is: SCHWARZ PHARMA KREMERS URBAN CO., 5600 West County Line Road, P.O. Box 2038, Mequon, Wisconsin 53092 U.S.A. Contact: S.S. Wagle, Science Director - Tel. (414) 354-4300.

Permission to import KUTAPRESSIN from the United States may be obtained by a physician for the treatment of individual patients under his/her care from the Emergency Drug Release Programme of the Bureau of Human Prescription Drugs: Holland Cross, Tower 'B', 3rd Floor, 1600 Scott Street, Ottawa, Ontario K1A 1B8 - Tel. (613) 941-2108. Enclosed please find a copy of the Product Monograph for KUTAPRESSIN for additional information." Signed A. Liakopoulou, Ph.D., A/Chief, Aids and Viral Diseases Division, Bureau of Human Prescription Drugs, Health & Welfare Canada.

[Editor's note: to obtain a copy of the Product Monograph for KUTAPRESSIN, please send stamped (43 cents) self-addressed envelope to me.]

MAY 12TH INTERNATIONAL CFIDS/ME AWARENESS DAY - UPDATE:

The Hon. Diane Marleau, Minister of National Health & Welfare responded as follows-

"As Minister of Health, I would like to express my support for National ME/CFS Awareness Day.

Myalgic encephalomyelitis (ME), or chronic fatigue syndrome, can have considerable debilitating consequences. Many Canadians are affected by this disease for which there is not yet an effective treatment. I hope that ongoing research will continue to unravel this difficult and perplexing problem.

I commend the National ME/FM Action Network, and the many volunteers in self-help and mutual aid groups across the country, for the information, advice and reassurance they provide to those afflicted by this syndrome.

Please accept my best wishes for a very successful ME/CFS Awareness Day." Signed: Diane Marleau, Minister of Health.

MINISTERS OF HEALTH - BY PROVINCE/TERRITORY

In preparation for May 12th, we have listed the Ministers of Health and their Deputy Ministers together with addresses, phone and fax numbers in order to make it easier for you to contact them.

ALBERTA: HON. SHIRLEY McCLELAN, Minister of Health

Donald J. Philippon, Deputy Minister of Health

P.O. Box 222, Edmonton, AB T5J 2P4

Tel. (403) 427-7164 - Fax (403) 427-1577

BRITISH HON. PAUL RAMSEY, Minister of Health

COLUMBIA: Lawrie McFarlane, Deputy Minister of Health

1515 Blanchard St., Victoria, BC V8W 3C8

Tel. (604) 387-4840 - Fax (604) 356-8203

MANITOBA: HON. DONALD W. ORCHARD, Minister of Health

F.A. Maynard, Deputy Minister of Health

599 Empress Street, P.O. Box 925

Winnipeg, MB R3C 2T6

Tel. (204) 945-3777 - Fax (204) 945-0441

NEW HON. DR. RUSSELL H.D. KING, MD, Minister of Health

BRUNSWICK: Jean-Guy Finn, Deputy Minister of Health

P.O. Box 5100

Fredericton, NB E3B 5G8

Tel. (506) 453-2542 - Fax (506) 453-5243

NEWFOUND- HON. DR. HUBERT W. KITCHEN, Minister of Health

LAND & Dr. R.J. Williams, Deputy Minister of Health

LABRADOR West Block, Confederation Bldg, 8th Fl, P.O. Box 8700

St. John's, NF A1B 4J6 Tel. (709) 729-3125 - Fax (709) 729-5824

NORTHWEST HON. JOHN POLLARD, Minister of Health

TERRITORIES: Dr. David Kinloch, Deputy Minister of Health

Building SC-8, P.O. Box 1320

Yellowknife, NT X1A 2L9

Tel. (403) 873-7113 - Fax (403) 873-0266

NOVA SCOTIA: HON. RONALD D. STEWART, MD, Minister of Health

Cathy MacNutt, Deputy Minister of Health

Joseph Howe Bldg., 1690 Hollis St., 12th Fl, P.O. Box 488

Halifax, NS B3J 2R8

Tel. (902) 424-7570 - Fax (902) 424-0559

ONTARIO: HON. RUTH GRIER, Minister of Health

Margaret Mottershead, Deputy Minister of Health

Hepburn Block, 8th Fl, Queens Park

Toronto, ON M7A 1S2

Tel. (416) 327-4296 - Fax (416) 326-1576

PRINCE HON. ALAN BUCHANAN, Minister of Health

EDWARD Barry MacMillan, Deputy Minister of Health

ISLAND: Sullivan Bldg., Fitzroy St., P.O. Box 2000

Charlottetown, PE C1A 7N8

Tel. (902) 366-4935 - Fax (902) 368-4969

QUEBEC: HON. LUCIENNE ROBILLARD, Minister of Health

Christos Sirros, Deputy Minister of Health

1075, ch. Ste-Foy

Quebec, PQ G1S 2M1

Tel. (418) 644-5848 - Fax (418) 643-3177

SASKATCHEWAN: HON. LOUISE SIMARD, Minister of Health

Diane Adams, Deputy Minister of Health

3475 Albert Street

Regina, SK S4S 6X6

Tel. (306) 787-3041 - Fax (306) 787-9000

YUKON HON. WILLARD PHELPS, Minister of Health

TERRITORY: Gaye Harrison, Deputy Minister of Health

P.O. Box 2703

Whitehorse, YTY1A 2C6

Tel. (403) 667-5770 - Fax (403) 667-3096

[Editor's Note: The National ME/FM Action Network has undertaken to write all Provincial Health Ministers as well as our National Health Minister to support you.]

We are happy to also report that all of Canada is participating in May 12th. Some groups, in addition to contacting the Provincial Ministers of Health, are setting up information booths in local shopping centers. This is the time to make final arrangements with your newspapers and other media so that everything will be in place for that important Day. This unified effort can make an important statement so please take advantage of it. Actions, no matter how small, will make an impact when done en masse.

WALK ON PARLIAMENT HILL - AIDAN WALSH, Coordinator

Aidan will be taking calls, in preparation for the Walk on Parliament Hill in Ottawa, commencing May 1st. Please contact him at (514) 487-6620 so that final arrangements with you and your groups can be organized. Encourage family members and friends to join you there. Doctors and other health care professionals welcome.

[Editor's Note: I will be on Parliament Hill on that day and look forward to seeing you there]

BOOKS/NEWSLETTERS/LETTERS

Take Charge of Your Body by: Dr. Carolyn DeMarco (Dr. DeMarco is a general practitioner, Author & Journalist, specializing in women's health,). To Order: Fax, phone or send your order to: R & R Book Bar, 14,800 Yonge Street, Unit 106, Aurora, ON L4G 1N3 Canada - Tel. (905) 727-3300 - Fax (905) 727-2620 or 1-800-387-4761. 1 to 4 books at 20% off - \$15.95/ 5 or more books at 40% off \$11.95 Plus 7% Shipping & GST.

EMEERGE newsletter by the M.E./Chronic Fatigue Syndrome Society Victoria Incorporated, Editor: Jim Oakley, President: Yvette Creighton. Address: 24 Livingston Close, Burwood, Victoria 3125 Australia.

"M.E. Update" published four times per year (next issue April '94) by THE M.E. SOCIETY OF CALGARY, Box 800, 330-5th Ave. S.W. Calgary, AB T2P 2J7 CANADA - Tel. (403) 248-7773. Membership fee \$12.00 per year and includes the "M.E. Update" newsletter. President: Cynthia Lane

"YOU M.E. & US" published four times per year (next issue April '94) by The M.E. SOCIETY OF EDMONTON (CFS), Box 465, Suite 21, 1045 Jasper Avenue, Edmonton, AB T5J 3S2 - New published Tel. #(403) 944-0809 - Co-Presidents: Dolores Wiart and Gerry Michael. Tax receipts issued on donations of \$5.00 and over.

ONTARIO FIBROMYALGIA ASSOCIATION: to obtain a reading package on Fibromyalgia, please contact the Association's President, Ms. Lois Whittaker, 250 Bloor Street East, Suite 401, Toronto, ON M4W 3P2, Canada. Cost: \$5.00. Tel. (416) 631-3459.

"FIBROMYALGIA (FIBROSITIS), MYOFASCIAL PAIN SYNDROME, TMJ DYSFUNCTION, AND CHRONIC FATIGUE SYNDROME" \$5.00 contribution, if possible, to cover costs of material. Contact: NORTH AMERICAN CHRONIC PAIN ASSOCIATION OF CANADA, 6 Handel Court, Brampton, ON L6S 1Y4 - Tel. (905) 793-5230 - Dianne Kent, President.

AQEM NEWSLETTER (Quebec ME Association newsletter) included with membership fee - \$20.00 regular member or \$35.00 Corporation or professional body (medical centre, hospital, doctor, lawyer etc.) Please mail cheque to: AQEM, 6402 Maubourg, Montreal, PQ H1M 2C8 - Tel. (514) 374-2997 - President: Rodica Copilu.

CONGRATULATIONS TO KENDRA DAYGER - *Review of Mainstream CFIDS Research* has now gone into its third (and last) printing. It is a necessary, validating and readable tool for both patients and physicians. Hard Science but use-friendly. Cost: \$25.50 U.S. in Canada and \$22.00 U.S. in the U.S.A. Please make cheque payable to CFIDS-JCC and send to CFIDS Rochester Research Project, 1200 Edgewood Ave., Dept NC, Rochester, NY 14618 U.S.A.

INTER-GROUP COMMUNICATIONS -

The Durham Region Myalgic Encephalomyelitis Association has just been donated a PS/1 - Model 2155 computer and ExecJet II Printer by IBM in recognition of Mia Corey's volunteer efforts with the Durham Association. Her husband, Greg Foreman, has written an article in the Durham ME newsletter, February '94 edition entitled "How to be a More Effective Supporter" and there are other helpful articles in this issue, too numerous to mention. Congratulations to Peg Watson, Support Group Leader and her group and a special thank you to IBM CANADA LTD. for their generosity to this well-deserving group. The Durham Region M.E. Association can be reached at 305 John Street W., Whitby, ON L1N 2V2 - Tel. (905) 430-2136.

JANET BOHANON has formed an International Share and Prayer Chain, 919 Scott Ave., Kansas City, KS 66105 U.S.A. Janet felt that the spiritual needs of ME/FM patients are not being addressed and if you would like to become part of this Chain that is being formed, please contact Janet for information. Free-will donations gratefully accepted for future Chain Updates and to cover postage, printing etc. Informational packets on ME/FM also available upon request.

LONG TERM 10+ years - LAST CALL - ME/FM patients ill for 10 years plus. survey. If you want to participate, Contact Maggie McKenzie, 171 Naubuc Avenue, East Hartford, CT 06118 U.S.A. or call (203) 569-4091.

CFS YOUTH OUTREACH - This organization provides a pen-pal group for youth with ME/CFS and also puts out a bi-monthly newsletter. Please contact: Sharon Walk, Founder - CFS Youth Outreach, 14 Shetland Rd., Florham Park, NJ 07932 U.S.A. - Tel. (201) 765-0577.

BOARD MEMBERS - ADDITIONS

We are pleased to announce the following additions to our Board of Directors:

HONORARY DIRECTOR: James L. Vigmond, Esq. of Oatley, Purser, Barristers & Solicitors, 151 Ferris Lane, Suite 200, P.O. Box 760, Barrie, ON L4M 4Y5 - Tel. (705) 726-9021 - Fax (705) 726-2132;

RODICA COPILU, Director - Quebec. Rodica is also President of AQEM (Association québécoise de l'Encéphalomyélite myalgique) 6402, rue Maubourg, Montréal, Québec H1M 2C8 - Tel. (514) 899-5342. Include details of her newsletter

JEAN M. TRAINOR, RN., Director - Prince Edward Island. Jean is also leader of the Charlottetown Support Group., 57 Mariner Driver, Charlottetown, P.E.I. C1C 1M3 - Tel. (902) 892-8147.

WELCOME TO OUR WORLD!

REMEDIES: A chance to trade symptoms

NUMBNESS: Reprieve from pain

PALPITATIONS: A chance to feel like you've exercised.

SHOW YOUR SUPPORT - BECOME A MEMBER

MEMBERSHIP: \$20.00 per year, includes bi-monthly newsletters.

HELP - DONATIONS needed for our many projects.

Tax receipt issued for donations of \$10.00 and over.

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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.

Lydia E. Neilson,

President