Quest #20 October 1996

LCDC - CANADA SUPPORTS U.S. 1994 ME/CFS CASE DEFINITION

We have just received a letter by courier from the Laboratory Centre for Disease Control (LCDC) Canada, from D.T. Wigle, MD - A/Director General of the Health Protection Branch of Health Canada advising that **"As regarding the definition of Chronic Fatigue Syndrome, I [D.T.Wigle] would like to let you know that LCDC supports the use of the revised Chronic Fatigue Syndrome case definition (1994) proposed by the U.S. Centres for Disease Control for research purpose."**

We thank all of you for taking part in the Petition and especially, Mrs. Beryl Gaffney, MP who opened many doors for us that were closed to us before. This is just the beginning of what we can accomplish together. We must now focus our attention to the medical professionals as it is they who will influence the LCDC and the Governments. We will be writing about our next move in the New Year.

SNEAK-PEAK AT THE 1996 DISABILITY TAX CREDIT

Ms Jane Stewart, P.C., M.P. just forwarded us a copy of the disability tax credit information booklet as it will be for 1996. She also stated that all our concerns, in addition to the report we had sent her, she advised that as publications must reflect the current legislation governing the disability tax credit, our comments regarding changes to the *Income Tax Act* have been forwarded to the Department of Finance, which is responsible for tax policy and suggestions have now been forwarded to the Department would be forwarded to the Department of Finance which is responsible for tax policy.

The new brochure will be published under the title *Disability Tax Credit and you.* Some of the highlights are as follows:

Should you apply for the credit?

It states that you are eligible to apply for the credit if you are blind, or have a mental or physical impairment such that you are either unable, **or it takes you an excessive amount of time,** to perform

at least one of your basic activities of daily living, even when you are using appropriate aids, medications, or therapy.

You are unable to perform a basic activity of daily living if you can answer *yes* to at least one of the following questions:

- Are you unable to walk?
- Are you unable to speak?
- Are you unable to think, perceive, and remember?
- Are you deaf or severely hard of hearing?
- Are you unable to feed and dress yourself?
- Are you unable to personally manage your bowel and bladder functions?

If you answered *yes* to at least one of the preceding questions you should then ask yourself:

- Is the impairment severe enough to restrict the basic activity(ies) of daily living identified above **all or almost all the time,** even if you were using appropriate aids, medications, or therapy?

- Has the impairment lasted, or is it expected to last, for a **continuous** period of at least 12 months?

If you answered *yes* to these last two questions, you could be eligible for the credit.

It also states that the federal government recognizes that Canadians with severe disabilities face a higher cost of living. The disability tax credit reduces the income tax payable of those who qualify.

It also reminds us that the effect of a disability on your ability to perform the **basic activities of daily living** that qualifies you for the credit, not the ailment or condition itself and that starting in 1996, new claims are viewed when assessing the tax return. That means at the time of filing your return, not years later. This is a step in the right direction.

We also received a copy of a letter from one of our members which was dated October 24, 1996 from the Deputy Minister of Revenue Canada, Mr. Pierre Gravelle, QC, who stated that the intent of the legislation was to give disabled persons a tax break, something which everyone in the Revenue offices had forgotten about. As a matter of fact, we had checked with Revenue Canada personnel to see if they knew the intention of the tax disability credit and no one knew. However, through the Access of Information Act application filed by us with Revenue Canada, this has now all come to light and gives both doctors and private individuals a better understanding why this tax credit was established. (send us a stamped self-addressed envelope if you want a copy of this letter - 2 pages).

PETITION TO THE HOUSE OF COMMONS - UPDATE:

In our Communication #19 we reported on the meeting that took place on September 3rd, 1996 at Mrs. Beryl Gaffney, MP's office which was attended by representatives of the Minister of Health and the Laboratories Center for Disease Control, our Network and ME Canada. We have now received a copy of Mrs. Gaffney's Summary Report on this meeting. If you would like a copy of it, please send us a stamped self-addressed envelope (5 pages).

We are still awaiting a reply from the Hon. Roger Simmons, P.C., MP, Chair of the Standing Committee on Health requesting that a subcommittee be established to particularly deal with ME/FM issues. At the present time there is no particular source in the government where a physician or a private individual will get proper information on ME/FM. A follow-up to our request for a sub-committee to be established has been sent to Mr. Simmons.

NEWSLETTERS, BOOKS, VIDEOS ETC.

REPORTS by Dr. Philipa D. Corning, Ph.D., B.Sc.

1) NUTRITION: (3 Pages) Did you know, that you can follow Canada's Food Rules and still suffer from malnutrition?; and

2) NUTRITION & FATIGUE: (3 pages) How Nutrition fights fatigue.

To receive a copy of these reports, please send us a stamped self-addressed envelope.

THE FIBROMYALGIA HELP BOOK by **JENNY FRANSEN, RN and I. Jon Russell, MD, PhD -** A practical guide to living better with Fibromyalgia. $22.95 U.S., payable to Fibromyalgia Information Resources, P.O. Box 690402, San Antonio, TX 78269 U.S.A.

DIRECTORY OF DISABILITY ORGANIZATIONS IN CANADA $35.00. To receive this Directory, consisting of 4,000 organizations nation-wide, please send a cheque to: Canadian Abilities Foundation, 489 College St., Suite 501, Toronto, ON M6G 1A5 Canada - Tel. (416) 923-1885 - Fax (416) 923-9829 - E-mail: able@interlog.com. (This Directory includes 1 year subscription of ABILITIES magazine).

CFS - WHERE IT CAME FROM...THE CHANCES OF IT BEING CURED, By: Donald W. Scott, M.A., M.Sc. (19 pages). Please send stamped self-addressed envelope to the Northern Ontario Fibromyalgia Association, 800 LaSalle Blvd., Suite 300, Sudbury, ON P3E 4V4 - Tel. 1-800-560-4936.

THE EXTREMELY UNFORTUNATE SKULL VALLEY INCIDENT, By: Donald W. Scott and **William L.C. Scott** - A report on Chronic Fatigue Syndrome/Acquired Immune Deficiency Syndrome/Gulf War Illnesses Syndrome and U.S. Biological WarfareTesting. Published by: The Chelmsford Publishers (320 pages). Price: $15.00 Canadian or $12.75 U.S PLUS $2.00 shipping and handling. To purchase a copy, send cheque payable to The Chelmsford Publishers, 405 - 190 Mountain St., Sudbury, ON P3B 4G2 Canada.

ANNOUNCEMENT: NEW WEB PAGE

KEN COLEMAN, Director of M.E.S.S. (Myalgic Encephalomyelitis Support Services), is a former member of the Board of Directors of the M.E. Association of Ontario. He also actively led the Scarborough Support Group between 1989 and 1994 when he had to curtail his activities due to ill health and surgery.

We are happy to announce his return and location on the internet! His web page was Designed, Implemented, and sponsored as a public service by SECURIBYTE CONSULTING INC of Toronto. This web page features the NEW CDC (Atlanta) case criteria and definition (Published in the Annals of Internal Medicine, Dec.15,1994; Vol.121, No. 12: Pgs 953-9) - AS WELL AS a guide for physicians to assist them in the accurate diagnosis of CFS by ruling out all other organic diseases as the cause of the patients' fatigue.

www.legalmind.com/mess

....will enable both the casual and the dedicated researcher to access information from around the world. This web site has been implemented as a public service. Ken can be reached at any of the following: Telephone: **(416) 245-4001**; (e-mail) **kcoleman@visionol.net**; and (internet) **http://www.legalmind.com/mess**

INTER-GROUP/CONTACT COMMUNICATION

The NORTHERN ONTARIO FIBROMYALGIA ASSOCIATION has just informed us that twice-yearly they will be forwarding our Network $2.00 for each member they have on their books. They advised us that they wanted us to concentrate on the work we are doing, without having to worry about raising funds.

It was decided at our Annual General Meeting of the Board and Voting members in September 1996 that our organization will not be setting up Chapters across Canada as we felt that the work we are presently doing is too important and if we got involved in Chapters/Affiliations, it would take away from what we are doing. We believe that the Provincial organizations are in a better position to handle this kind of activity.

SUMMARY REPORT ON DR. LESLIE O. SIMPSON, UNIVERSITY OF OTAGO, NZ'S BLOOD CELL ANALYSIS - By: Philipa D. Corning, Ph.D, B.Sc.:

Dr. Simpson's blood cell analysis is not a diagnostic test for ME/FM. Instead, the test shows a concrete quantitative difference between ME/FM people's blood and blood from health controls. Blood samples from ME/FM group members in six countries contain shape-changed red cells. This does not mean that the red blood cells of ME/FM people are abnormal, because they are not. Normal blood contains the same shapes of red cells as those found in blood from ME/FM peoples (six types of cell shapes). Five of the six shapes are inflexible, leaving only the one biconcave cell as the flexible one. The abnormality occurs when the percentage of one or more inflexible cell types is increased.

Dr. Simpson has found red cell shape changes in chronic disorders in which tiredness and easy exhaustibility on exertion are common features. He believes that changed red cells play a central role in the expression of tiredness, probably by reducing the delivery rate of oxygen and nutrients to levels which are inadequate to support normal tissue function. Capillaries may be only one third of the diameter of a red cell, thus red cells must be able to change shape in order to traverse a capillary bed. The average capillary diameter is the major determinant of flow in capillary systems. It has been proposed that those who suffer from ME/FM (and a number of other chronic disorders) have smaller than usual average capillary diameters. Thus, those who suffer from ME/FM-type symptoms have an anatomical basis for their inflexible cell shapes.

In 1986, Dr. Simpson demonstrated that ME/FM blood was poorly filterable due to red cell shape change. He then theorized that ME/FM can be looked upon as a blood circulation disorder. Furthermore, Dr. Simpson has found that the nature of the red cell will determine the presence or absence of symptoms. Thus events which change red blood cell shape such as stress, emotional upsets, and over-exertion must be avoided to prevent red cell changes which will lead to a worsening of symptoms.

Given Dr. Simpson's theory, treatment should be aimed at improving the flow properties of blood by means of agents such as evening primrose oil, fish oil, vitamin B12 shots and Ginko biloba. Indeed, this has proven beneficial in many cases.

[Ed note: For more details of blood cell shapes etc., please send us a stamped self-addressed envelope].

DR. SIMPSON'S TOUR IN OTTAWA: As we expand the role of the National ME/FM Action Network into research, we hosted Dr. Les Simpson who gave a presentation to the health care professionals and sponsored the collection of blood samples from interested ME/FM people. Dr. Simpson commenced his third Canada tour in Ottawa on November 5, 1996 by giving a presentation on his research findings entitled "The Role of Erythrocyte Morphology in the Pathogenesis of Degenerative Diseases" to health care professionals. There were two blood collection clinics in which 72 individuals participated. These samples were sent to New Zealand for analysis. This process consists of electron microscope examination of the blood. The participants will each receive an electron microscope picture of their blood, and concrete data on how the percentage of red cell shapes in their blood compares with blood from health males and females. This will show that there is a difference between ME/FM people and healthy people. We were glad to help Dr. Simpson start his tour on a successful and happy note.

TIP: Need information on Environmental Illness? - contact the **ENVIRONMENTAL ILLNESS SOCIETY OF CANADA (EISC) at 256 King Edward Ave., Suite 330, Ottawa, ON K1N 3M1 Canada - Tel. (613) 789-3658 - Fax (613) 789-6680.**

A NOVEL ENZYME FOUND IN ME/CFS PATIENTS - By: Philipa D. Corning, Ph.D, B.Sc.

A Novel Enzyme Found in CFS Patients May Alter Cellular Processes. Dr. Robert Suhadolnik and his research team at Temple University School of Medicine reported today that studies of patients with chronic fatigue

syndrome (CFS) have led to the identification of a new human enzyme.

We know that our bodies' line of defense is called the immune system. The defensive tactics used by this system that are most familiar to us, involve the production and action of B and T cells. However, there exists another type of defense mechanism which involves the secretion of "interferons". These substances are produced by ordinary cells within our bodies in response to viral infection. When cells are invaded by viruses, they release interferons which travel to uninfected cells to warn them of the invader by triggering the production of two enzymes which interfere with viral reproduction. Since the virus will not be able to reproduce itself upon reaching these forewarned cells, they are considered viral resistant.

Interferon induces the production of two enzymes (firstly 2,5-oligoadenosine or 2,5-A and ribonuclease L. and secondly p68 Kinase or PKR) by two separate anti-viral pathways (a pathway is a series of chemical reactions). Both enzymes interfere with the multiplication of a virus by degrading its genetic material (RNA). Recently, researchers found a pronounced dysregulation in several key components of 2-5A/RNase L and p68 Kinase (PKR) in chronic fatigue patients. Because there are malfunctioning molecules in the two anti-viral pathways mentioned above, this means that viruses (no matter which strain) can infect the chronic fatiguer without significant resistance. These two dysfunctional enzymes were found in all ME/CFS participants but not in the healthy controls taking part in this trial.

One might speculate that these researchers have finally found a marker for diagnosing ME/CFS. My concern is: "Will these same two dysfunctional enzymes be found in individuals suffering from other degenerative diseases?" If this is so, then it will not be a disease specific marker.

PERSONAL:

A FM person who has a one-year old child, living in Oakville, Ontario would like to hear from other mothers with similar circumstances. Please get in touch with our Network so that we can put you in touch with one another.

OUR WORLD

Q: WHAT IS ME LIKE?

A: Having ME can be compared to a Ferrari Engine in a Volkswagen Beetle on rims with no tires - lots of desire to move (and you can with much effort) but it takes a great toll on the car.

Doug Shore, Abbotsford, BC

[Ed. note: Written on the front cover of the ME/FM Manual which has just been published by Doug. See newsletter #19 for details on how to order]

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STATEMENT OF REVENUES, EXPENSES & ACCUMULATED SURPLUS

YEAR ENDED MARCH 31, 1996

REVENUES	
Donations	$ 3,213
Memberships	3,361
Grant	35,000
Interest	147
Miscellaneous	18
	41,739
EXPENSES	
Advertising	13
Bank charges and interest	138
Depreciation	2,142
Information packages	445
Insurance	183
Office supplies	1,134
Postage	1,620
Printing	1,125

Professional fees 3,102

Rent 1,616

Repairs & maintenance 570

Telephone 1,518

Travel 217

Utilities 20

13,843

Excess of Revenue over expenses 27,896

Accumulated surplus, beginning of year 113

Accumulated Surplus, end of year $28,009

Audited by Hughes Lebel, Chartered Accounts

Dear Friends:

We wish you the best for the Holiday Season and a Happy and Healthy New Year. Remember to take it slow. It may take a little longer but you'll get there just the same.

Take care,

Lydia E. Neilson

President CEO

MEMBERSHIP: $20.00 per year which includes newsletters every two months. Please show your support by becoming a member or by giving a donation.

ELECTRONIC MAIL: our e-mail address: ag922@freenet.carleton.ca

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 United States: CFS/ME Computer Networking Project, P.O. Box 11347, Washington, DC 20008-0547 U.S.A. Please note that for mailing outside of Canada please include an International Reply Coupon.