Quest #47 April 2001

CONSENSUS UPDATE

By: Marj van de Sande, B. Ed., Grad. Dip. Ed,

Consensus Coordinator & Director of Education

The ME/CFS consensus clinical definition, diagnostic and treatment document has had its minor revisions as suggested at the consensus meeting. The revised document has been sent back out to the ME/CFS consensus panel for their approval. We should have all responses in shortly. We are presently working on the FMS consensus document.

There are really two aspects of the consensus document. First there is the working clinical definition which is important as the American definitions were designed for research purposes. Second, the entire document is designed to be a "doctor's manual" and is therefore quite lengthy and could be extremely expensive to publish. We are looking into the various options for publishing the consensus documents and we will keep you updated.

POLIOVIRUS / ME/CFS - FM Survey

In our **Communication #44** we announced the up-coming survey being done by **Dr. Richard Bruno** to test the hypothesis that a childhood illness may predispose to developing CFS/ME, and FM later in life. Dr. Bruno has discussed evidence that a childhood poliovirus infection may cause chronic fatigue in baby-boomers. In a paper entitled "Paralytic Versus ‘Non-Paralytic’ Polio: A distinction without a Difference", Dr. Bruno reviewed extensive documentation of a 1947 outbreak of the "Summer Grippe" by Dr. Albert Sabin, developer of the oral polio vaccine.

For references and Dr. Bruno’s Biography, please see Newsletter #44 or our website. For those who do not have that issue but would like a copy of the mentioned article, please send stamped (47 cents), self-addressed envelope to our Network for a copy of that article.

[NOTE--Survey missing in Electronic Newsletter--Go to website under Active Projects to download]

Please complete the enclosed survey and return it to Dr. Richard L. Bruno 151 Prospect Avenue Box 17A

Hackensack, NJ 07601 USA or e-mail harvestctr@AOL.COM

[Ed. note: This survey can also be found on our website]

CHILDREN WITH ME - **By: Kate Andersen, M.Ed., Youth Consultant**

"When I attended a Board meeting of a group of adults with M.E. some years ago, I told everyone that my daughter might also have the illness. I was moved, but not surprised, to see tears come to the eyes of the adults at the table. Only an adult who has suffered this illness can fully appreciate how devastating it must be for the young. I was deeply touched."

This story was reported to me some time ago. I am the Youth Consultant of the **National ME/FM Action Network** and along with **Mary Ellen,** Project Manager of the Network, I have been working on the Child and Youth Initiative for the past two years. We have been compiling information regarding the illness in children and youth, setting up a web page (**http://www.geocities.com/youthcanada**), corresponding with researchers and parent advocates, and reaching out to Canadian youth with ME and FM and their families. Under the guidance of Mary Ellen, a former teacher now homebound with M.E., a group of other Canadian teachers with M.E. or F.M. have been working on a Sourcebook for Teachers to be distributed by the **National ME/FM Action Network** some time early in 2001.

The Medical Editor of the Sourcebook is **Dr. David S. Bell**, the world's leading paediatric researcher on the illness. Assisting Dr. Bell and the Network team is **Mary Z. Robinson**, U.S. parent advocate.

Kate would like to hear from young people with M.E. and their families. She can be reached at **(604) 855-9615** (between 10 a.m. and 3 p.m. weekdays) or by e-mail at **katejandersen@home.com**.

INFORMATION ABOUT M.E. IN YOUNG PEOPLE

There have been no epidemiological studies of Canadian youth with M.E. We can only guess as to their numbers from looking at U.S. figures on Chronic Fatigue Syndrome. After the CFIDS Association of America challenged them on the reported low incidence of CFS in young people, the US Centers for Disease Control re-examined their data and did find a higher prevalence than they previously reported, the new figure being 116 per 100,000. In a new study that looks not only for classic CFS but also fatigue-like syndromes, researcher **Dr. Karen Jordan** reported at the April 10 CFS ICC meeting that four of the first 370 children contacted by her telephone surveyors have "CFS-like" problems. (Source: **Frank Albrecht**, Ph.D. from **http://www.cfids.org/youth**) One of the problems in both diagnosing and studying M.E. in the young is the fact that the pattern of symptoms may be a bit different when compared with adults. **Dr. David S. Bell**, a leading paediatric M.E. researcher and clinician, has commented that young people commonly report episodes of severe episodes of pain (often headaches and/or stomachaches) but actually cope better with the illness than adults. An insidious-onset appears to be more common than acute onset in younger children, whereas adolescents often have an apparent acute onset. Generally, though, the illness in young people seems to be the same illness that adults experience. What a horrible thought that is!

Obtaining a diagnosis of a child or adolescent may be even harder than with adults. Youngsters may not use the word fatigue to describe their symptoms. Some are acutely aware of their cognitive changes. They commonly report light-headedness other symptoms which may be mistaken for school phobia or emotional problems (in spite of the fact that the youngsters may have sore glands and sore throats). Older children and adolescents may realize that "something is wrong" but they just don't know what it could be, However, younger children in whom the cognitive problems came on slowly may never realize they are ill and not meeting their full potential because they are so used to feeling and performing the way they do. It is likely that many cases of emotional problems, 'difficult temperament', food allergies, learning disabilities, attention deficits and perhaps even some types of autism and other developmental disorders are actually misdiagnosed cases of paediatric M.E.

Needless to say, undiagnosed and unaddressed M.E. in young people can lead to terribly tragic situations, among them depression and suicide. School problems are the most frequent complaint of parents, who become desperate when teachers and school administrators refuse to develop flexible accommodations for these ill youngsters. The good news is that young people can be helped a great deal by a physician who really understands the illness, as well as by supportive teachers and parents.

Recovery seems to be a very real possibility in the young, although some patients think this recovery is really either adaptation or remission.

For citations supporting the comments above, please feel free to contact me.

E-Mail: **kate_andersen_uvic@yahoo.com or Tel. (604) 732-6030**

Kate Andersen, M.Ed., Youth Consultant, National ME/FM Action Network

[Ed Note: Kate Andersen is an adult who has recovered considerably from M.E. She works as an educational consultant in Early Intervention, is a parent counselor and works part-time as an instructor for the School of Child and Youth Care at the University of Victoria]

ENVIRONMENTAL HEALTH CLINIC - YEAR-LONG STUDY

By: Nancy Bradshaw, **Education Coordinator** - **Environmental Health Clinic**

As reported in the **National ME/FM Action Network's** newsletter, **QUEST #42** - June/July 2000 issue, the **Environmental Health Clinic** at **Sunnybrook** and **Women's College Health Sciences Centre** conducted a study over the past year to help the clinic in prioritizing our clinical, educational, resource/referral and research services. The study involved a survey, focus groups and telephone interviews to determine the needs of our patients and others across Ontario with environmental sensitivity disorder (ESD), chronic fatigue syndrome/M.E. and Fibromyalgia (FM). This article will cover the highlights of our findings.

The results reflect the responses from **487** survey participants, 3 focus groups and 14 telephone interviews. **79%** of the survey respondents had **ES**, and **47%** each had **CFS and/or FM**. This is reflective of other studies that show an overlap of symptoms from the 3 conditions (see Environmental Health Clinic's January 2000 newsletter).

Demographics

Eighty-six percent of the survey respondents were female, the mean age was **49** and **31%** had completed university. Most significant, **30%** had a total household income of less than **$20,000.00** per year and **22%** received under **$12,000.00** yearly.

Employment

In our focus groups one of the key areas of concern was a decreased ability to work with resulting financial problems. In our survey, only **22%** of the respondents listed employment as their main source of personal income, **42%** had reduced their hours of work, **57%** were off work due to disability and **89%** noted that their ability to work had changed as a result of their ESD, M.E. and/or FM. Many participants in the focus groups and interviews talked about the difficulty in dealing with financial problems and insurance companies when their health was already compromised.

Use of the Health Care system

Seventy-five percent of respondents had been to their family physician in the past year with an average of **six visits** per year. The total number of visits to all health care practitioners including specialists, psychologists, dietitians, massage therapists, occupational therapists, physiotherapists, chiropractors, homeopaths, naturopaths and acupuncturists was **30 visits** per year. This shows a high use of the health care system, which, in our experience, often results from patients going to several doctors to get a diagnosis, use of different health care practitioners for ongoing care and the chronic, relapsing natures of these conditions.

Satisfaction with Family Doctor

Seventy percent of the respondents were somewhat satisfied to very satisfied with their family doctor. The other **30%** were not satisfied, with the major complaint being "the doctor doesn't know (about ESD, M.E. or FM)."

Educational Needs

We heard that doctors, both GP's and specialists, need more education on all of these conditions; several individuals noted that this is the most pressing need. Other health professionals that need education are home care workers, psychologists, dentists, occupational therapists and physiotherapists. Schools need more information, as well as workplaces and insurance companies. All of the participants noted that family and friends need more education on these illnesses to be truly supportive. Not surprisingly, those with ESD mentioned the need for more public policy regarding scent-free spaces.

The overwhelming message that the participants wanted to convey to others was that "this is a real illness." There was much discussion about the chronic nature of the illnesses, the cognitive impairment, the debilitating effect on all areas of one’s life and the changing symptoms. Indeed, the **Rand-36 Health Status Inventory** tool that we used, which measures quality of life from a health perspective, showed that these conditions affect people in many aspects, particularly in physical functioning, role limitations due to physical functioning and social functioning. Participants said that these issues need to be understood by health professionals and need to be explained to patients when they first become ill. Participants wanted more information on coping skills to deal with these issues, particularly when they were first diagnosed. A number mentioned that a support group is useful, particularly in knowing that they are not alone and having a place to share with others.

Most of the participants use newsletters, books and the Internet to obtain information about ESD, M.E. and FM. Some individuals liked interactive web-sites however some were concerned about the quality of information provided and noted that an interactive website or list serve needs to be monitored by knowledgeable people. Participants wanted a variety of information, such as the latest research and treatment; practical tips for daily living, particularly around preparing easy and healthy meals and avoiding environmental exposures, as well as inspirational messages. In addition, there was a concern about the quality of information in the public media and it was suggested that the clinic refute inaccurate articles and enlist journalists who will "take the information seriously."

Clinic Plans

The Clinic has reviewed the information from the survey, focus groups and interviews to develop a comprehensive educational program for patients and their families, health professionals and the general public. As a result of this study, the Clinic will be offering group sessions on nutrition, and reducing environmental exposures, to patients and their families in the new year. The waiting room has been stocked with a number of books and newsletters from your recommendations in the survey; fact sheets on ESD, M.E. and FM are being developed and we are investigating the use of an interactive web-site. We also have plans to provide further education for doctors and occupational health nurses and are members of the newly revised hospital "green team" to work on environmental issues in our hospital. We are on committees working to educate workplaces and schools and are planning a communications/media strategy with the help of one of our patients, a specialist in communications and media relations.

We have worked closely with provincial and national associations representing these conditions to develop our study and provide input for our plans. We wish to thank all of these associations for their input, in particular the **Myalgic Encephalomyelitis Association of Ontario**, the **Environmental Hypersensitivity Association of**

Ontario, the **Ontario Fibromyalgia Association** and the **National ME/FM Action Network**.. We will be working more closely with provincial and national organizations in the future to link with services across Ontario. If you have any questions about the survey or our educational plan, you may contact **Nancy Bradshaw**, Education Coordinator at the **Environmental Health Clinic** at **(416) 323-6400 ext. 4993** or at **HYPERLINK** mailto:**nancy.bradshaw@swchsc.on.ca**

THE CPP AND THE DEFINITION OF CHRONIC FATIGUE SYNDROME

By: George Cameron-Caluori, Consultant

The workplace reality for many people is that they are being asked to work harder with less resources. Recent workplace research suggests that the very ways in which we have organized our work environment are causing new emerging illnesses. We are required to work hard and fast to complete too much work in too short a time. As well, our decision making ability and our competence in learning new skills are being replaced by repetitive work. The combination of these two factors results in stressful employment and may be one causal factor in the rise of Chronic Fatigue Syndrome and consequent claims for disability benefits. Indeed, Chronic Fatigue Syndrome (CFS) is becoming a more common medical condition cited as a basis for disability pension claims.

With the claim process in mind, it might be worthwhile therefore to compare the definition for Chronic Fatigue Syndrome as given by the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC) in Atlanta, GA, with the definition currently being used by the Canada Pension Plan (CPP). The question is whether CPP is using the most current definition and what difference that makes when it comes to deciding cases.

The CPP policy directive on CFS, Adjudication Working Tool, Bulletin Number 16/97-CPP-09, page 5, dated September, 1997 refers to major and minor criteria. The major criteria are incapacitating exhaustion lasting at least six months and which impairs activities of daily living by more than 50%; and the exclusion of any medical or psychiatric causes of the fatigue. Minor criteria include mild fever, sore throat, painful lymph nodes, generalized muscle weakness, muscle discomfort, fatigue lasting more than 24 hours after exertion easily tolerated prior to the illness, new onset headaches, migratory arthralgia without joint swelling, at least one neurological complaint of photophobia, transient visual scotoma, forgetfulness, irritability, confusion, difficulty thinking, inability to concentrate, or depression, sleep disturbance, and acute onset of symptoms. Physical signs include low grade fever, sore throat, and palpable or tender lymph nodes.

The policy directive then concludes the following:

"A diagnosis of chronic fatigue syndrome requires that

- both major criteria be met and;

- either 8 of 11 minor criteria

- or 6 of 11 minor criteria and 2 or 3 physical signs be met."

The original CDC article, "Chronic Fatigue Syndrome: A Working Case Definition," Annals of Internal Medicine, 1988;108:387-389, Holmes et al, describes the same major, minor, and physical criteria and gave the following case definition:

"A case of the chronic fatigue syndrome must fulfill major criteria 1 and 2, and the following minor criteria; 6 or more of the 11 symptom criteria and 2 or more of the 3 physical criteria; or 8 or more of the 11 symptom criteria."

CPP appears to match the CDC definition exactly. However, in 1994, in a subsequent article entitled "The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study," Annals of Internal Medicine, 1994;121:953-959, Fukada et al, the CDC updated its definition, and evaluative methods based on research during the intervening five years.

"A case of the chronic fatigue syndrome is defined by the presence of the following: 1) clinically evaluated, unexplained, persistent or relapsing chronic fatigue of new or definite onset,...; and 2) the concurrent occurrence of four or more of the following symptoms all of which must have persisted or recurred during 6 or more consecutive months of illness..."

The new definition restates the major criteria of persisting fatigue, and introduces the notion of "clinical evaluation" in part as an exclusionary diagnosis. The symptoms listed are substantially those minor criteria previously listed with the exception of mild fever and depression but including headaches of a new type. The physical signs are not mentioned. A critical difference, however, is the fact that the 1994 definition is broader in scope than the 1988 definition, relying on a smaller actual symptom complex of four symptoms instead of eight and consequently capturing more cases.

In its most recent publication, "Chronic Fatigue Syndrome," dated May, 1999, the CDC reaffirmed its 1994 version of a minimum of four symptom criteria.

It would appear therefore, that Canada Pension Plan is using a version of the CDC definition published in 1988 and not a more recent CDC definition as published in 1994 and restated in 1999. Since the definitions are distinct, the CPP policy directive may be excluding applicants with a sound medical condition by relying on the more narrow definition. We can easily imagine a patient with four minor criteria, including short-term memory loss, multi-joint pain, headaches, and unrefreshing sleep who would not qualify under the existing CPP policy directive but would qualify under the more recent CDC definition.

An important counter-argument proposes that the legislation governing the application of a disability pension does not refer to a diagnosis but simply a medical condition. Therefore, the impact that those symptoms have on an applicant's ability to work would decide the issue and not the number of symptoms. However, while this position has some merit, a diagnosis does provide some validation for the impairment is required in any medical report and does have an effect on the perception of the complaint.

Recently, two Canadian physicians experienced in diagnosing Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia, **Dr. Anil Jain** in Ontario and **Dr. Bruce Carruthers** in British Columbia, working under the auspices of the **National ME/FM Action Network**, have drafted the first Canadian clinical definitions and treatment protocols for ME/CFS and FM. Using the "Terms of Reference of the Experts Consensus Panels" established by the Medical Expert Subcommittee of Health Canada, the Network hosted and organized a peer review conference, consisting of ME/CFS and FM medical experts and doctors, from March 30 to April 1 of this year in Toronto. The clinical definitions were received with great interest by a panel of international experts and physicians. Following the conference, the final draft will be submitted to a medical journal for publication.

We can only hope that by means of this peer review process of a CFS definition, the above discrepancies in the relevant symptom complex will be resolved. Applicants with CFS and case adjudicators alike will then share a common set of principles in applying for and awarding benefits.

George Cameron-Caluori represents people with chronic illnesses nationally before administrative Tribunals and Appeals Boards. For further information, he can be reached at (**613) 237-2296** or **gcamcal@istar.ca**.

[Ed Note: This article is reprinted, with permission, from the ***Disability Reporter***, which deals with medical and legal issues related to people with chronic disabilities. For subscription information, please contact **Cameron & Associates Ltd**., **101-294 Main Street, Ottawa, ON K1S 1E1**. - Tel: **(613) 237-2296** - Toll Free: **1-877-251-4608** -

Internet: **http://home.istar.ca/~gcamcal/cmaweb.htm.**

NATIONAL DOCTORS' ROSTER - ADDITION

DR. JUDY ROSENBERG BEN-ISRAEL - Chiropractor

Chiropractic Clinic on the Park - Treats ME/CFS and FM

300 St. Clair Ave. W., Suite 104

Toronto, ON M4V 1S4

Tel. (416) 964-2056 -

E-mail: benisrael@globalserve.net

CANADA PENSION DISABILITY CONSULTANT - ADDITION

*Randy Valois, 215 Piccadilly Ave, Thunder Bay, ON P7B 5L3, Tel. **(807) 767-3965 - E-mail: jrvalois@home.com**

*A **Guide** (47 pages) that is a complete and informative guide for anyone applying for Canada Pension disability is available. The booklet explains matters from the filling out forms correctly to handling appeals. The cost of the brochure is **$10.00 + shipping costs $2.50 = $12.50** . **(Orders will be shipped C.O.D.)**. **Mr. Valois is also available for speaking engagements**.

INTER-GROUP/CONTACT:

3rd Annual Common Cause Medical Research Foundation Conference

Winnipeg--August 17-19th, 2001

At this conference, **Don Scott**, International President of the **Common Cause Medical Research Foundation** (CCMRF) and author of the book **Brucellosis Triangle**, will undertake to show you the full picture of neurodegenerative diseases such as CFS/ME and Fibromyalgia etc....; chemically, medically, molecularly, politically and historically. You will learn where they come from, why they are increasing, how they are spread, and the best hope for a cure. Yes a cure, since he will demonstrate with the research he and other researchers, doctors and scientists have marshaled in the last four years, that these tragic diseases spring from one startling source. They present as different diseases in certain people depending on the individual's immune status and varied genetic differences. For more information and to resister for conference please contact **Rose Stevens** , Director of Vaccine Safety Concerns for the CCMRF and co-chair of conference. Tel. **(204) 254-3996**. **Conference cost is $80 Canadian**, which includes the 3 day seminar, 2 banquet dinners, and a Sunday brunch. Space is limited, so please register early.

BARRIE ME SUPPORT GROUP PRESIDENT HONOURED BY PROVINCE

The **National ME/FM Action Network** congratulates **Albert Blom**, President and Founder of the **Barrie & District ME Support Group Inc.**, who was one of 11 Ontario recipients honoured by **Ontario Lt.-Gov. Hilary Weston**. She presented Albert with this year’s **Community Action Award**. The award recognizes volunteering efforts which have benefited people with disabilities achieve better access and equal opportunity.

Albert has helped everyone he has been in contact with from across Canada and can always be counted on. If you would like to send a congratulatory wish to Albert, please send it to 33 Doris Drive, Barrie, ON L4N 5W2.

[Ed. note: The Barrie & District ME Support Group celebrated its 10th anniversary on June 5th, 2001]

NEW BRUNSWICK ME/CFS ASSOCIATION

The **New Brunswick ME/CFS Association** held its Sixth Annual Elephant Walk which took place in Oromocto, N.B. on May 27th. The funds they raise each year gives them operating funds so that they can continue to help and support people who suffer from ME/CFS for another year. The Association had spent the previous two months in the malls doing awareness on ME/CFS and FM and had managed to sign up walkers and sponsors.

The **New Brunswick ME/CFS Group** again honoured **Lydia E. Neilson**, President CEO of the **National ME/FM Action Network,** with its **National Award** for her outstanding commitment to those with ME/CFS and FM.

GUIDELINES FOR INDEPENDENT MEDICAL EXAMINATIONS

Ms Margaret Birrell, Executive Director of the **BC Coalition of People with Disabilities** wrote President, **Glen McIver** of the **British Columbia College of Physicians & Surgeons** supporting our view, in principle, that the College should adopt guidelines similar to those published by the **College of Physicians & Surgeons of Alberta** which will help ensure that patients are treated respectfully and evaluated fairly when they are required to undergo medical examinations for insurance companies and Canada Pension Plan Disability.

REPLY FROM BC COLLEGE OF PHYSICIANS & SURGEONS:

The BC College replied to the BC Coalition of People with Disabilities on May 18, 2001 wherein they stated that the guidelines in effect are the **June 1995** guidelines for Independent Medical Examinations. "........ The College is currently in the process of up-dating this guideline as part of a continuing process to keep the College Policy Manual current and reflective of present day realities. The guidelines published by the Alberta College of Physicians & Surgeons are part of that review process, along with relevant documents from other licensing authorities. If and when new guidelines are created and approved by the College Council, they are distributed to members of the College for their use and guidance...." Signed M. VanAndel, M.D. Registrar.

[Ed. note: 1) Please support our position by writing Dr. VanAndel, Registrar of the College of Physicians & Surgeons of British Columbia, 1807 West 10th Avenue, Vancouver, BC V5J 2A9 outlining how important it is that the 1995 guidelines be up-dated.]

2) The National ME/FM Action Network would like to thank the BC Coalition of People with Disabilities for supporting our efforts regarding this important issue. Members,

please continue to send letters to the College of Physicians & Surgeons in your particular province indicating the urgent need for new guidelines].

ME/CFS Topic of Radio Interview on May 27, 2001

ETC Communications, a professional media firm, was hired by Crystaal, the sponsor of the National ME/FM Action Network, to help raise public awareness about the debilitating illnesses of ME/FM, to let the public know that help and support is available through the National ME/FM Action Network and to publicize the clinical definitions/protocols documents once they are published. As a start, on Sunday May 27/01, from 2:00p.m. - 3:00 p.m., CFRB Radio 1010 AM hosted a one-hour live show on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) on the program The Health Show. Host, Karen Horsman, interviewed a patient, Doreen Van Gijn, and a doctor, Dr. Alison C. Bested, M.D., F.R.C.P. (C). Haematological Pathologist, one of the expert doctors chosen by the committee of Health Canada to take part in the peer-review of the Canadian Clinical Definitions, Diagnostic and Treatment Protocols Document for ME.

Some important topics covered in the interview included:

- the organic nature of the illness;

- the difference between the fatigue of healthy individuals and that suffered by ME patients;

- ME as an invisible disability;

- the debilitating nature of the illness and how it affects all aspects of one's life;

- how ME affects women, men and children;

- the need for energy conservation;

- the issue of independent medical examinations requested by insurance companies and CPP;

- the difficulty of severely disabled patients receiving disability benefits;

- some research into potential markers and treatments;

- the new Canadian Clinical Definitions, Diagnostic and Treatment Protocols Document;

- the advocacy work and support offered to patients by the **National ME/FM Action Network**.

Please send a short note to:

Pat Holiday, Vice-President and General Manager of CFRB and Karen Horsman, host of the Health Show

Address: 2 St. Clair Avenue West, 2nd Floor, Toronto, Ontario, M4V 1L6

Please thank them for airing this show on Sunday May 27 from 2:00 p.m. - 3:00 p.m. and ask that they please have these guests back in the near future because raising public awareness about the debilitating illness of Chronic Fatigue Syndrome is so important.

POTENTIAL OF MILLIONS OF DOLLARS FOR KING'S HEALTH CENTRE THROUGH IME'S AND REHABILITATION

By: Mary Ellen, Special Projects Manager

In Quest 44, October/November 2000, in the article CREDIBILITY OF IME REPORTS FROM KING'S HEALTH CENTRE MAY BE IN QUESTION, our members were alerted to the public scandal of the private Toronto clinic, King's Health, which had been closed down following the disappearance of both millions of dollars and its founder Ron Koval and his wife on October 12. From Ontario, Saskatchewan, Alberta and British Columbia, our National Registry of people who have been asked to attend an Independent Medical Examination by an insurance company has received an overwhelming number of strong complaints of unfair treatment from the former MRS Health Services of Hamilton, Ontario, who became King's Health Services in July 1998, the insurance arm of the clinic. Numerous insurance companies across the country were using the services of King's Health for independent medical evaluations (IME's).

The cover story of the July issue of TORONTO LIFE magazine called "PARTNERS IN CRIME" reveals the "UNTOLD STORY" of the Kovals and their clinic. Of particular interest are the following two paragraphs which explain the relationship between the clinic and the private insurance companies:

".Insurance companies have enormous reserves dedicated to long-term disability claims. King's could get claimants suffering from fibromyalgia or chronic fatigue - the types of illnesses that can be treated with a behaviour modification program- back to work. For every claim successfully resolved, King's would be paid as much as 50 per cent of the reserve amount. It was a potential multimillion-dollar saving for the insurer: Win-win.

" The good news for the Kovals was that insurance companies liked the idea. Sun Life, Great-West Life,Clarica- all agreed to pilot the program. Fortis Benefits Insurance Co. in Missouri authorized King's to work on 24 files valued at $4 million (U.S.). The fee for that work could have been as much as $2 million. King's assessed its average treatment cost at just $20,000 per patient. Of 14 files that Clarica sent over in its pilot, eight claimants entered the King's medical rehabilitation program, and five of those were resolved."

It is particularly alarming to learn that not only was King's Health doing the IME but also the rehabilitation program. The new Guidelines for doctors who perform an IME at the request of an insurance company written by the Alberta College of Physicians and Surgeons clearly state that the person performing the IME cannot take over the rehabilitation. Therefore, facilities like King's Health, who perform the IME, must be seen to be objective and not have millions of dollars to gain by taking over the treatment of patients. Can a facility be viewed as objective when it stands to gain a possible 400 per cent profit on its initial investment?

One must also question the word "resolved". When a case is resolved, does that mean that the person is cured and back to work full time? Or does it mean that the person has had his benefits terminated and has had to hire a

lawyer to fight to have his benefits reinstated because he is still disabled and unable to work in any capacity? In either case, the insurance company is saving money. In either case, the facility has been awarded a possible

400 per cent profit.

Furthermore, research into the effectiveness of behaviour modification programs for people who have ME/FM is highly controversial. Degree of disability is not clearly stated in the research and so it is unclear if severely disabled patients are helped with these programs.

All of this begs the question: If a company is chosen by an insurance company to perform an IME and stands to gain a possible 400 per cent profit each time a patient is removed from the insurance company's books, is it

possible for that company to be viewed as objective?

Please continue to publicize our simple, confidential, 7 question Registry Submission Form to any patients who have been asked by their private insurance company or Canada Pension Plan to attend an IME or FAE with an

individual doctor or through a facility so that our National Registry will accurately reflect those doctors and facilities which are of concern.

To get a copy or copies, please contact : **Mary Ellen, Manager, Special Projects Manager,** Phone or fax: (905) 831-4744 - By Mail: P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd.,

Pickering, ON., L1V 6P7 - Email: marye@pathcom.com

or download the Form from our website at www3.sympatico.ca/me-fm.action/medexam.html

FINAL REPORT OF THE REVIEW OF THE CPSO COMPLAINTS

AND DISCIPLINE PROCESS STATUS

In Quest #39, December/January 2000, our members were urged to take part in the independent review of the complaints and discipline process of the College of Physicians and Surgeons of Ontario being conducted by KPMG Consulting LP and commissioned by the Ontario Ministry of Health and Long-Term Care. Many of our members have sent us copies of letters of complaint that they have sent to the Colleges of Physicians and Surgeons across the country regarding the unfair assessments that some doctors have performed on behalf of private insurance companies and Canada Pension Plan. We urged our members to take part in this independent review of the complaints and discipline process and hoped that the issue of a fair IME would be addressed in the report.

The review was commissioned by the Ontario Minister of Health and Long-Term Care in response to public expressions of concern about the CPSO's complaints and discipline process. The review was to examine all phases of the complaints and discipline process, from receipt of a phone call or letter of complaint against a doctor until the final resolution of the case. The reviewers were asked to make recommendations for possible modifications to the process within the constraints of existing legislation.

The Final Report of the Review of the CPSO Complaints and Discipline Process (July 2000) is now available to the public free of charge by contacting: **Teresa Cheung - Telephone: (416) 327-8890; Mailing Address: Ministry of Health, Program Policy Branch, Hepburn Block, 80 Grosvenor Block, 8th floor, Toronto, Ontario M7A 1R3; E-mail address: teresa.cheung@moh.gov.on.ca**

OUR WORLD:

SYMPTOMS: Spokeperson for the distress areas of the body.

NAUSEA: New appreciation for ‘terra firma’.

Thanks to Lorraine Legendre, Ottawa.

QUEST COLLECTION BOOK - FIVE YEARS: By popular request, **the National ME/FM Action Network** has published an easy to read book consisting of a **collection** of important articles which have appeared in our **'QUEST'** newsletters over the years. For easy reference, these articles have been grouped into sections, according to their focus i.e. medical, legal etc. We have kept the **cost** of the book to a minimum at **$20.00** each which includes shipping and printing. Please make **your cheque payable to the National ME/FM Action Network** and let us know how many copies you would like.

LEGAL/RESEARCH PACKAGE - **Medical** and **Legal** Information. Please make **cheque payable to Marj van de Sande** in the amount of **$25.00** (our Director of Education) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 -**

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