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ACTION NETWORK
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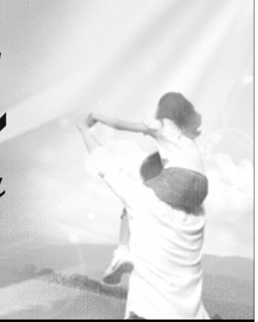
Quest
Newsletter



www.mefmaction.com Quest # 91, Summer 2012 mefminfo@mefmaction.com

This is Quest #91. It is the first issue where Lydia Neilson is not the editor. Lydia founded the National ME/FM Action Network in June 1993 and published the first Quest two months later. Quest #1 was short but still very relevant. We have reproduced it in this newsletter.

After almost 20 years at the center of the Network, Lydia has decided to take a reduced role and to develop new interests. She will be missed. We wish her happiness and success in her new activities.

In this issue, we look at Canadian based resources on ME/CFS and FM, including three important documents released in Spring 2012. We also look at CPP-Disability from the perspective of adjudicators and policy makers and at Celiac disease in an article written for us by a Canadian expert, Dr. Mohsin Rashid of Halifax.

We invite your feedback on this issue and suggestions of topics for future issues. If you would like to submit an article, we would be interested!

Margaret Parlor
President
National ME/FM Action Network

Where is Quest #89?

We received a call recently. “I have Quest #88 (Statistics 2010),” the caller said. “I have Quest #90 (the IACFS/ME conference),” she added. “I must have lost Quest #89. Could you send it to me?” That is when we realized that we had skipped #89. Quest #89 does not exist. Don't look for it. We goofed and we apologize.

Meeting With Federal Officials

On June 6, 2012, Maureen MacQuarrie and Margaret Parlor had a short meeting with a senior staff member in the office of the federal Minister of Health. Also in attendance were a senior manager from the Public Health Agency of Canada and a senior manager from the Canadian Institutes of Health Research. There was acknowledgment from these officials that a number of issues need to be addressed, in particular support for research, information on health websites, and disease surveillance. Follow-up activities are now being organized.

MEAO Looking for Ontarians to Participate in Study

MEAO recently received an Ontario Trillium Foundation grant to examine the needs of patient with ME/CFS, FM and/or Multiple Chemical Sensitivities. The purpose of the study is to identify opportunities to improve the quality of care and support for patients in Ontario. Details of the study haven't been finalized, but the study could ask for volunteers:

- to be interviewed about their experiences and insights (late summer, 2012)
- to participate in groups discussions (likely in Sarnia and Toronto and possibly in Kingston, mid September 2012)
- help with the project itself

If you are interested in contributing to this study, please send an email to qocproject@meao.ca or leave a message on the MEAO help line at 416-222-8820 or 1-877-632-6682

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Canadian-Based Literature on ME/CFS and FM

Canada and Canadians have made an enormous contribution to the literature around ME/CFS and FM. Here are some highlights.

- A very early reference book was The Clinical and Scientific Basis of ME/CFS by Dr. Byron Hyde which was published by the Nightingale Research Foundation in 1992. Lydia Neilson worked with the Nightingale Research Foundation before founding the National ME/FM Action Network and participated in the publication of this book.
- The Canadian consensus panel for ME/CFS published diagnostic and treatment protocols in the Journal of Chronic Fatigue Syndrome in 2003. This panel was spearheaded by the National ME/FM Action Network and the panel included a number of Canadians, including Dr. Bruce Carruthers, the lead author. This document can be viewed on our website or purchased from amazon.ca or chapters.ca.
- The Overview of the Canadian consensus document on ME/CFS was published in 2005 by Dr. Bruce Carruthers and Marjorie van de Sande of Calgary. It is now available in English, French, Spanish, Italian, German and Dutch. The Overview can be viewed on our website www.mefmaction.com.
- The Canadian consensus panel for Fibromyalgia published diagnostic and treatment protocols in 2003 in the Journal of Musculoskeletal Pain and in The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners. This panel was spearheaded by the National ME/FM Action Network and the panel included a number of Canadians, including Dr. Anil Jain, the lead author. This document can be viewed on our website or purchased from amazon.ca or chapters.ca.
- The Overview of the Canadian consensus document on FM was published in 2005 by Dr. Bruce Carruthers and Marjorie van de Sande of Calgary. It is now available in English, French and Spanish. The Overview can be viewed on our website, www.mefmaction.com.
- The Teach-ME Sourcebook for Teachers of Students with ME/CFS and/or FM was originally published by the National ME/FM Action Network in 2002 and

was then updated in 2005 to reflect the Canadian diagnostic and treatment protocols. This document is available in English and French from our website.

- A document that a number of patients have found helpful is the guide for psychiatrists on treating patients with ME/CFS by Dr. Eleanor Stein of Calgary. The guide recognizes that ME/CFS is not a psychiatric illness, but notes that it can co-exist with anxiety or depression. This guide disentangles the conditions. It can be obtained in English either from our website or from www.eleanorsteinmd.ca. It is also available in Italian, German and Norwegian on Dr. Stein's website.
- Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia is book written for patients by Dr. Alison Bested, a very experienced clinician from Toronto. The second edition was released in 2008. The book is comprehensive and authoritative yet concise and easy to read. It can be purchased from amazon.ca or chapters.ca.

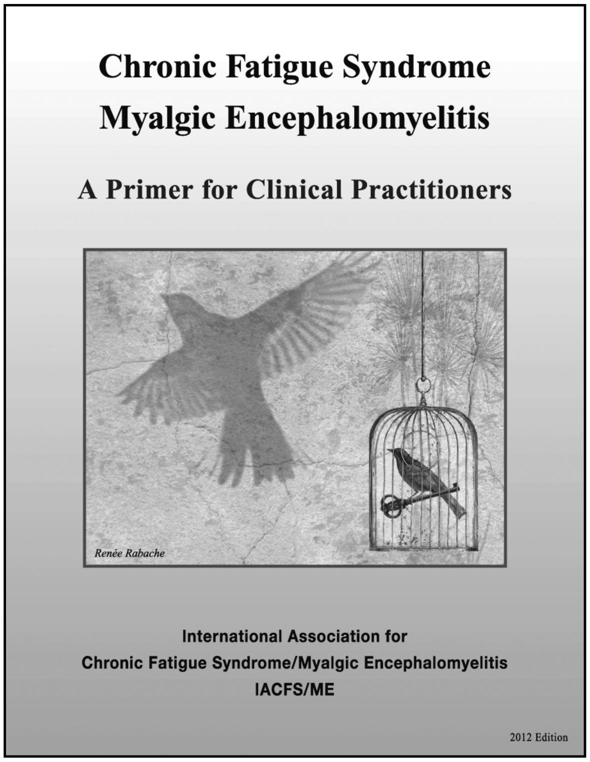
Then there are the three new resources featured on the following pages:

- The ME/CFS Primer for Clinical Practitioners was compiled by an international team that included Dr. Alison Bested. The Primer provides the latest advice for practicing doctors and builds on the Canadian ME/CFS consensus document and Overview. It can be found at www.iacfsme.org.
- Let Your Light Shine Through is a manual published by Dr. Eleanor Stein of Calgary that outlines strategies for living with ME/CFS, FM and/or Multiple Chemical Sensitivities. Dr. Stein has led workshops for patients over the past decade. This manual brings together a vast array of material and ideas that patients have found helpful. This document can be purchased in various formats from www.eleanorsteinmd.ca.
- The CPP-Disability Guide was updated and published by the National ME/FM Action Network. It guides people through the CPP-D application process. This document can be downloaded from www.mefmaction.com.

Other Canadian resources available from our website include videos of the presentations at the IACFS/ME's patient conference in Ottawa in 2011 and back issues of the newsletter Quest.

We recognize that many members of our community do not have internet access. If you would like one of our resources but don't have internet, please contact us and we will let you know what is available.

Scientific Organization Releases Chronic Fatigue Syndrome Guidelines to Educate Health Care Providers



Chronic Fatigue Syndrome
Myalgic Encephalomyelitis

A Primer for Clinical Practitioners

International Association for
Chronic Fatigue Syndrome/Myalgic Encephalomyelitis
IACFS/ME

2012 Edition

(News release from the IACFS/ME)

The International Association for Chronic Fatigue Syndrome and Myalgic Encephalomyelitis (IACFS/ME), the largest group of physicians and researchers dedicated to chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME), has released updated care guidelines directed at primary care physicians and other health care providers. The document, "Chronic Fatigue Syndrome Myalgic Encephalomyelitis: A Primer for Clinical Practitioners," can be accessed at:

http://www.iacfsme.org/Home/Primer/tabid/509/Default.aspx

"CFS/ME affects at least one million people in the US yet up to 80% of them have not yet been diagnosed. Medical providers are often uncomfortable diagnosing and treating these patients and patients tell us that they frequently have difficulty finding a knowledgeable physician. We hope that the Primer will help solve these problems," states Dr. Fred Friedberg, IACFS/ME President.

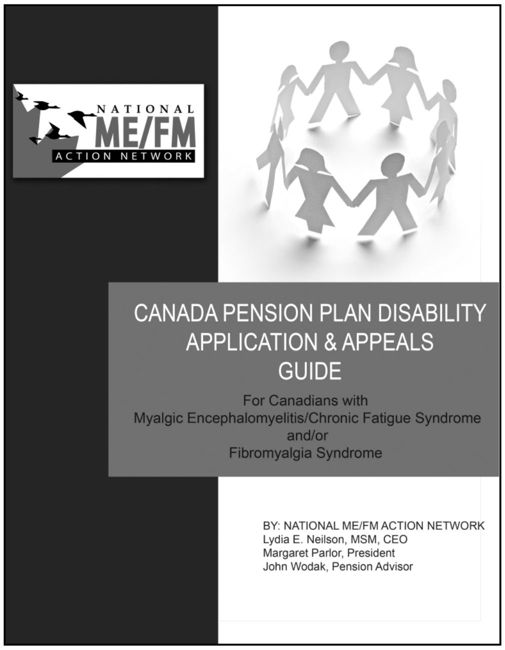
The Primer highlights areas that have not been emphasized in the past including:

- A summary of pathophysiological effects
- A user-friendly diagnostic worksheet utilizing the Canadian Consensus Criteria for CFS/ME
- Treatment suggestions covering an array of symptoms
- Post-exertional malaise, a symptom unique to CFS/ME, and activity management
- Sections on special populations/situations (e.g. severely affected patients, pediatric CFS/ME, pregnancy, pre-operative care, etc.)

CFS/ME commonly strikes healthy people following a flu-like illness, leaving them with severe exhaustion, muscle pain, joint pain and memory and concentration problems among many other symptoms. The term "CFS" is most commonly used in the United States while other countries may use "ME" instead. People of both sexes and all ethnicities, ages, and backgrounds can become ill. Sufferers are often more functionally impaired than people with heart failure, multiple sclerosis or HIV. Because the cause of CFS/ME has not yet been discovered, no one knows how to prevent or effectively treat the illness, meaning many patients are disabled for decades. According to a 2008 DePaul University study, CFS/ME drains $18-24 billion annually from the U.S. economy due to decreased work productivity, lost tax revenue, increased health care expenditures, and disability payments.

Founded in 1990, IACFS/ME is an international scientific organization comprised of researchers, clinicians, advocates, patients, and other stakeholders. The mission of IACFS/ME is to promote, stimulate, and coordinate the exchange of ideas related to CFS, ME, and fibromyalgia research, patient care, and treatment. For more information, visit www.iacfsme.org

Announcing the Canada Pension Plan Disability Application & Appeals Guide



NATIONAL ME/FM ACTION NETWORK

CANADA PENSION PLAN DISABILITY
APPLICATION & APPEALS
GUIDE
For Canadians with
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
and/or
Fibromyalgia Syndrome

BY: NATIONAL ME/FM ACTION NETWORK
Lydia E. Neilson, MSM, CEO
Margaret Parlor, President
John Wodak, Pension Advisor

ME/CFS and FM often occur among people of working age. These illnesses can seriously affect one's ability to work and to earn income. The Canada Pension Plan Disability program was introduced for exactly this situation. CPP-D applies across Canada except in Quebec which has the separate Quebec Pension Plan.

The National ME/FM Action Network has just released a new edition of its Guide for people with ME/CFS and/or FM who are applying for CPP-D benefits. It focuses on what you need to know about CPP-D and leads you through the process of putting together an application. It describes how to appeal if your application is turned down and what you need to keep in mind if you application is approved.

The new Guide can be downloaded from our website. You can also obtain a print version by contacting the National ME/FM Action Network by email, phone, fax or mail. We ask $10 for the print version to cover the costs of printing and postage. We would, of course, welcome donations from people who find the electronic version helpful!

While the guide applies specifically to people with ME/CFS and/or FM applying for CPP-D benefits, it is generally about how a person with a disabling medical condition goes about applying for a benefit. Thus, it could help people with other illnesses when applying for CPP-D, or it could help people with these illnesses when applying for other benefits. Please feel free to share this document with anyone who might benefit from it.

Canada Pension Plan–Disability Perspectives

The new guide to CPP-D is aimed at patients and guides them through the application process. CPP-D can be viewed from two other perspectives – the perspective of the adjudicators reviewing the files and the perspective of social policy.

How CPP-D Program Reviews Applications

The criteria for qualifying for CPP-D benefits are found in the Canada Pension Plan Act.

There are two conditions that applicants must meet. They must have sufficient participation in the workforce when they become disabled and they must meet the definition of disabled. The question of sufficient participation is administrative; staff look at the person's record of contributions. Decision-making generally focuses on whether the applicant meets the definition of disabled, though in some cases, the question is whether the person became disabled while coverage was in effect.

There are several stages of review. The first is by office staff who look at the documents and telephone the applicant. If the application is rejected, the applicant can request a reconsideration which is a second opinion by a different adjudicator. If the application is refused at reconsideration, the applicant can request a hearing before a 3-person review tribunal. If the tribunal rejects the application, the applicant can apply for a more formal hearing in front of the Pension Appeal Board.

The people reviewing the applications are balancing competing objectives. On one hand, their job is to provide benefits to deserving applicants. On the other hand, there is pressure to deny benefits because of costs and because receiving benefits supposedly takes away the incentive to work. Adjudicators are asked to judge whether, based on the information in front of them, they are comfortable in deciding that the applicant qualifies for benefits. If the adjudicator is cautious and turns down a deserving application, the applicant is put to additional time, effort and stress in appealing, or the applicant may forgo benefits completely. If the adjudicator approves an application that isn't deserving, this is costing the program money and sending the “wrong” message.

What is meant by 'deserving'? Let me suggest a simple, somewhat over-simplistic, model for ME/CFS and FM patients. The functional capacity scale, found in the Primer runs from 0 (no energy, bedridden...) to 10 (no symptoms, excellent concentration...) Level 7 reads:

Mild or no symptoms at rest with good concentration for up to ½ day; can do more intense activities of daily living (e.g. grocery shopping, vacuuming), but may get post extertion fatigue if 'overdo'; can walk 30 minutes per day; can work limited hours, less than 25 hours per week; no or minimal social life.

Someone at Level 7 is a borderline case. The person may or may not meet the CPP-D definition of disability. Someone at Level 6 (*...can do volunteer work – maximum total time 4 hours per week, with flexible hours...*) would prima facie meet the definition of disability, while someone at Level 8 (*...can work 40 hours per week...*) would not. The ME/FM community should be concerned if ME/FM patients at Level 6 or lower are regularly denied benefits or forced to go several rounds to obtain benefits. For people around Level 7, the decision could go either way. Our experience is that people with ME/CFS or FM do not want to be on CPP-D. People do not apply unless they are having great difficulty functioning. We don't think that people above Level 7 even apply.

The CPP-D program has put together an “adjudication tool” to guide adjudicators when reviewing ME/CFS and FM files (as well as MCS and Chronic Pain files). This document was given to us by CPP-D staff and is posted on our website. The adjudication tool does not use standard definitions for ME/CFS and FM. It puts emphasis on the dynamic between the patients and health professionals (Is there a contrary view on file? Has the patient complied with recommended treatment?) We know that the dynamic between the ME/FM patient community and health professionals is complex and that issues around diagnosis and treatment are common.

We would rather see the adjudication tool focus on the degree of disability the patient is experiencing. We have recommended that this document be revised to incorporate standard definitions and the concept of functional capacity. We believe that changes to to the adjudication tool would help applicants and their health providers frame submissions. We believe that the office process needs to be reviewed so that deserving applications are approved at the early stages.

The government published an evaluation of the CPP-D program in August 2011. Findings included:

- It is hard to qualify for CPP-D, with the approval rate at the initial stage of adjudication averaging only 45%.
- The application process was found to be long, complex and stressful for applicants.
- 60% of a sample of applicants that were denied CPP-D had not returned to gainful employment during a three to four year period following denial, suggesting that many were genuinely disabled despite the adjudication decision
- The idea that CPP-D is a disincentive to work was found to be overrated.

On a final note, the government has announced changes to the appeal process to be implemented in 2013. In particular, the 3-person review tribunal will be replaced by a single-person hearing. The question is: what impact will this change have on the sensitivity of hearings and on the fairness and timeliness of decisions.

CPP-D as part of Social Policy

The social safety net is the concept that government should step in when things go wrong to ensure that Canadians are not left in financial dire straits.

There are essentially three social safety nets depending on age. For seniors there is Old Age Security and the Guaranteed Income Supplement. For working age Canadians, there is Employment Insurance, CPP-D, welfare, disability benefits and veterans benefits. The social safety net for children is implemented through their families.

The evaluation of the CPP-D program found that:

- Only about two-thirds of working-age Canadians had CPP-D coverage. (The others do not have sufficient attachment to the workplace.)
- For 12% of CPP-D recipients, those payment was their sole source of family income. The maximum CPP-D payment in 2005 was $12,123 and the average payment was $10,390. The LICO (low-income cut-off) in 2005 was $14,303 for a single person living in a rural area and $20,778 for a single person living in a large city.
- Doctors perceived an unnecessary duplication in providing documentation for CPP-D and other disability programs.

These findings suggest that the social safety net for working age Canadians would benefit from review. In fact, the Ontario government set up a commission to look at social assistance from the province's viewpoint. That report is due to be released to the public in September 2012.

Considering Celiac Disease in the Differential Diagnosis of Chronic Fatigue

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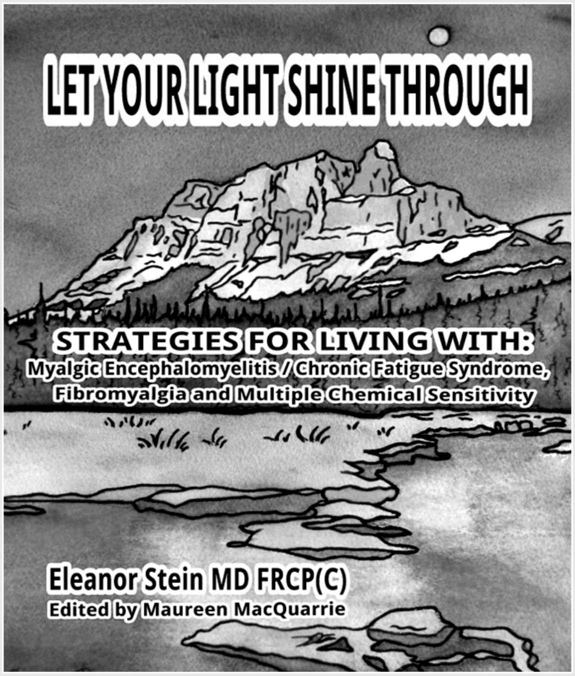
Member, Professional Advisory Board, Canadian Celiac Association
07, June 2012

Chronic fatigue is a common symptom that can occur in several disorders, both physical and psychiatric. Although the terms weakness, fatigue and tiredness may mean different things to different individuals, they are often used interchangeably. Fatigue is a subjective symptom but can be severely disabling in some patients. The assessment of a patient with chronic fatigue should include a detailed history, complete physical and mental examination and appropriate laboratory investigations. In some cases, the cause of chronic fatigue is apparent while in others it is a diagnostic dilemma. One of the causes of chronic fatigue is a disorder called celiac disease. This article provides some basic information on celiac disease that may be of use to both patients and health care professionals.

Celiac disease was thought to be a rare malabsorptive disorder of infancy and early childhood, however, it is now known to be a common, multi-system disorder that can present at any age when gluten is present in the diet. Celiac disease is one of the most common chronic,

Canadian Doctor Releases Self Help Manual for Patients With ME/CFS, FM and MCS



“**Let your light shine through**” is designed for patients and has enough referenced medical material for health care professionals.

In this manual Dr. Stein shares the ideas and strategies that she has found to be the most successful for patients in her ME/CFS, FM and MCS practice.

Readers are guided through a 260 page, 4 month program specific to these conditions. There are scores of management suggestions and tools for how to use them. Mission: better health

“**Let your light shine through**” includes both self-management strategies and those that require the assistance of a health care professional.

Note: Dr. Stein is making the manual available in various formats. Costs are $20 for an e-manual download, $22 for a manual on CD, $27 for a coil bound print version in black and white ($37 in colour) and $40 for a colour manual in 3-ring binding. Postage costs are extra. Go to www.eleanorsteinmd.ca. You can also call (403) 287-9941

inherited disorders in the world. It is estimated to occur in about 1% of the North American population, 90% of whom remain undiagnosed.

One of the major symptoms of celiac disease is chronic fatigue, The Canadian Celiac Health Survey conducted a few years ago revealed that of 2,681adults with confirmed celiac disease, 68% had extreme weakness and tiredness as one of the symptoms at diagnosis (Cranny A et al. *Dig Dis Sci* 2007; 52:1087). Similarly, of the 168 children (<16 yrs) in the survey, extreme weakness was reported by 64% of respondents (Rashid M et al. *Pediatrics* 2005;116:e754).

Celiac disease is a permanent intolerance of gluten, a protein present in wheat, barley and rye. Ingestion of gluten causes damage to the mucosa (lining) of the small intestine by an autoimmune mechanism in genetically susceptible individuals. The ensuing intestinal damage not only can cause a variety of symptoms but can also lead to malabsorption of nutrients including protein, fat, iron, calcium, folate and fat soluble vitamins (A, D, E and K).

Celiac disease is a “clinical chameleon” because it can mimic almost any other disorder. Typical symptoms of celiac disease are abdominal pain, diarrhea and weight loss. However, many patients present with non-intestinal (atypical) symptoms including anemia, extreme weakness, osteoporosis, short stature, oral ulcers, migraines, menstrual irregularities and infertility. Additional symptoms in children include delayed growth and puberty, vomiting and dental enamel defects. Dermatitis herpetiformis (DH) is “celiac disease of the skin”. It presents as a chronic, severely itchy, blistering rash that is poorly responsive to conventional therapies. A skin biopsy confirms the diagnosis of dermatitis herpetiformis.

The various causes that may lead to chronic fatigue in celiac disease are listed in the Table below. A patient with celiac disease may have one or more of these problems.

Possible Mechanisms of Fatigue in Celiac Disease

Anemia (iron, folate, vitamin B12 deficiency)

Other nutritional deficiencies

Hypothyroidism

Other autoimmune disorders

Circulating pro-inflammatory cytokines

Anemia (lack of blood) is one of the most common manifestations of celiac disease, especially in adults. Iron, folate and vitamin B12 are necessary for the formation of red blood cells. Intestinal damage leads to impaired absorption of these nutrients. A deficiency of vitamin E can also lead to anemia in some cases. Lack of blood reduces the supply of oxygen to various tissues of the body causing fatigue and weakness. Fatigue is almost universal in patients with anemia. Furthermore, diarrhea and loss of weight can also make patients feel weak and tired.

Patients with celiac disease are at risk of developing other autoimmune disorders, most commonly thyroid disease. This can lead to destruction of the thyroid gland and low thyroid activity (hypothyroidism). The thyroid hormone is vital in maintaining various metabolic functions of the body. An underactive thyroid can lead to exercise intolerance and chronic fatigue, among other symptoms. Conversely, patients with hypothyroidism are also at higher risk of developing celiac disease. Other autoimmune disorders such as type-1 diabetes and Addison’s disease (insufficiency of adrenal glands) can also occur in patients with celiac disease and lead to tiredness.

A variety of neurological and psychiatric symptoms can also occur in celiac disease. One of them is depression. Chronic fatigue often occurs in patients with depression.

In some patients with celiac disease, there is no obvious cause for fatigue. Circulating pro-inflammatory cytokines may play a role in these cases. Cytokines are chemicals released from the white blood cells when there is inflammation in the body. Cytokines help modulate the inflammatory response and can have several systemic effects on the body such as malaise and fatigue. In untreated celiac disease, there is constant intestinal inflammation and these cytokines are released in large quantities. After adequate treatment, the intestine heals, the inflammation decreases and eventually resolves. Patients with celiac often find a dramatic improvement in their fatigue after starting treatment.

Celiac disease is a hereditary disorder. Both first and second-degree relatives of a patient with celiac disease have a significant (5-15%) risk of developing the disorder. Other high-risk groups include patients with autoimmune disorders such as type 1 diabetes and thyroid disease and Down syndrome. Serological (blood) screening is recommended for all high-risk individuals.

Knowledge and awareness of celiac disease amongst health professionals remains poor and delays in diagnosis are common. The mean duration of symptoms before diagnosis of celiac disease in Canadian adults is 11.7 years (see study references above). Serological screening of minimally symptomatic patients or those with atypical/non-intestinal complaints can significantly increase the rate of diagnosis of celiac disease. Delays in diagnosis of celiac disease can lead to a variety of serious complications. These include nutritional deficiencies like anemia and osteoporosis, reproductive disorders including infertility, increased risk of developing other autoimmune disorders and intestinal cancer.

Highly sensitive and specific serological blood tests are available to screen for celiac disease. The currently recommended test is the serum immunoglobulin A (IgA)-tissue transglutaminase antibody (TTG). This test has a sensitivity and specificity of greater than 90%. This means that the test will be positive (abnormal) in the vast majority of patients with untreated celiac disease. The TTG is currently the test of choice and is widely available and covered by the health care in all provinces of Canada except Ontario. There are efforts underway to make it available in Ontario as well. IgA deficiency is common in celiac disease and hence total serum IgA level must also be measured to avoid a false-negative result. The serological tests are less reliable in children under 2-3 years of age. Furthermore, a negative test does not rule out celiac disease but makes it less likely. Patients with a positive TTG test should be referred to a gastroenterologist for endoscopic small intestinal biopsies for confirmation of the diagnosis.

Celiac disease (and dermatitis herpetiformis) is incurable at present but can be effectively treated by a strict, life-long adherence to a gluten-free diet. However, a gluten-free diet should not be started before a biopsy is done, as the diet will heal the intestinal lesion and affect the interpretation of the biopsy, making confirmation of the diagnosis difficult. Individuals who suspect that they may have celiac disease should contact their family physicians and request the TTG test for screening.

Celiac disease needs to be considered early in the differential diagnosis of any patient with chronic fatigue. This disorder is common and, once indentified, can be effectively treated with a gluten-free diet. A timely diagnosis can prevent the complications and suffering of undiagnosed celiac disease and can also reduce the health care costs involved in investigating patients with chronic fatigue.

On-line Petitions

Liisa Lugus started an on-line petition for a specialized care unit for ME/CFS patients in a Toronto Hospital. Here is an excerpt from her petition:

In memory of ME/CFS patient, activist and author, Emily Collingridge, who died March 18, 2012 just shy of her 31st birthday (in hospital), I ask that a dedicated care unit for people with ME/CFS be created in a Toronto Hospital so this group has a safe, healing place to go when they need Long Term Care, hospitalization or respite for themselves or their caregivers. Emily was not the only person with ME/CFS to relapse from standard hospital care, but I really want her to be the last.

Dedicated care units for ME/CFS inpatients are needed in every major urban center throughout the world. I call upon Ontario legislators to lead the way by creating the first one. Please mandate that an 8-bed dedicated care unit be created in one Toronto hospital to start serving those with ME/CFS who are in need of in-patient hospitalization, rehab, respite and TLC.

To view Liisa's petition, go to:

http://www.change.org/petitions/save-me-cfs-patients-dedicated-care-unit-in-toronto-hospital-needed

Kati Debelic started an on-line petition to increase ME/CFS research funding in Canada. Here is an excerpt from her petition:

Therefore, we patients with Myalgic Encephalomyelitis (and supporters) feel we are discriminated against, left behind, and request immediate action be taken by the Canadian government:

- *Research funding at the same level as other chronic disabling neurological diseases, such as multiple sclerosis, which afflicts half as many people as ME/CFS.*
- *Provide financial incentives for scientists to research this disease.*
- *Provide incentives for physicians to study and care for patients with ME/CFS.*
- *Encourage clinical trials with Rituximab or other drugs that are considered hopeful from the IACFS/ME, the international organization of medical professionals specializing in ME/CFS.*
- *Stop wasting precious money on the psychiatric research as it relates to ME/CFS.*
- *Provide support for all provinces to open clinics to care for patients with ME/CFS and related complex diseases, including fibromyalgia, multiple chemical sensitivities and Lyme disease*

Kati's petition can be found at

http://www.change.org/petitions/minister-of-health-of-canada-fund-research-for-patients-with-myalgic-encephalomyelitis

Private Member's Bill on Lyme Disease

A private member's bill was introduced in the House of Commons on June 21, 2012 by Elizabeth May. Here is the summary of the bill.

This bill would require the Minister of Health to convene a conference with the provincial and territorial ministers responsible for health and with representatives of the medical community and patients' groups for the purpose of developing a national strategy to address the challenges of the recognition and timely diagnosis and treatment of Lyme disease. It also would authorize the Minister of Finance to establish guidelines in respect of the allocation of funding to provincial and territorial governments that have enacted legislation to implement that strategy.

Le projet de loi exigerait du ministre de la Santé qu'il convoque une confé renceréunissant les ministres provinciaux et territoriaux responsables de la santé ainsi que des représentants de la communauté médicale et des groupes de patients dans le but d'élaborer une stratégie nationale visant à répondre aux défis queposent la sensibilisation à la maladie de Lyme ainsi que l'établissement rapide de son diagnostic et de son traitement. De plus, il autoriserait le ministre des Finances à établir des lignes directrices concernant l'attribution de fonds aux gouvernements provinciaux et territoriaux qui ont édicté des lois pour mettre en oeuvre cette stratégie.

Valerie Fee handing out information at Planet Organic, Calgary, May 12.

May 12 Awareness Day

Once again, there was considerable activity around Awareness Day. Many thanks to people who organized events or handed out information. This all contributes to increased recognition of ME/CFS, FM and related illnesses. The following statement was made in the House of Commons on May 31, 2012:

Hon. Carolyn Bennett (St. Paul's, Lib.): Mr. Speaker, May is ME/CFS Awareness Month, myalgic encephalomyelitis/chronic fatigue syndrome.

Chronic fatigue syndrome refers to a severe, continued tiredness that is not relieved by rest and is not directly caused by other medical conditions. Four hundred thousand Canadians are bed-bound or house-bound with ME/CFS.

Often misdiagnosed and misunderstood, patients experience muscle aches, headaches and extreme fatigue. Although some patients completely recover after six months to a year, others never feel like they did before they developed CFS.

There is currently no cure for CFS and so far treatment is focused on relieving the symptoms. As a physician, I know just how the strain of dealing with this disease often leads to depression and other psychological disorders which make recovery that much more difficult.

Unfortunately, this condition still does not have the recognition it deserves. Increased awareness is the best way to defeat the stigma surrounding CFS.

We must also continue the fight to find a cure and give these Canadians back their lives.

Judi Day, director for Atlantic Canada, hands out information on May 12 in Fredericton.

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.

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.

Quest #1, August 1993

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

News from the Environmental Health Association of Quebec

On March 12, 2012, the European Parliament released a written declaration requesting that Multiple Chemical Sensitivity (MCS) and Electro Hypersensitivity (EHS) be included in the International Statistical Classification of Diseases (ICD).

The declaration states that health inequalities regarding these conditions between different European countries should be eradicated and that Member States should include MCS and EHS in their own ICDs and in their Lists of Occupational Diseases. It further states that patients who suffer from these conditions that involve 'serious risks' have 'no influence over the air they breathe and exposure to electromagnetic radiation'.

The European Parliament and also urges member states 'to apply existing rules regarding EM radiation and exposure to harmful substances and to apply the precautionary principle strictly' in order to effectively protect people with this condition, 'whose number is growing exponentially'.

The World Health Organization (WHO) is the global standard-setter for assessing and classifying health problems. It is the most important reference for physicians, governments and courts alike around the world. Uniform classification of medical conditions is important because it encourages international scientific study and sharing of results. It also creates the basis for the assignment of codes in health care systems for provision of insured diagnostic and treatment services, and it can point in the direction of the primary necessary treatment approaches.

To know more:

www.aseq-ehaq.ca

Le 12 mars 2012, le parlement européen a émis une déclaration écrite demandant que la sensibilité chimique multiple (SCM) et l'hypersensibilité électromagnétique (HEM) soient incluses dans la Classification internationale des maladies (CIM).

La déclaration affirme que les inégalités de santé au sujet de ces conditions dans les différents pays européens devraient être éliminées et que les États membres devraient inclure la SCM et l'HEM dans leur propre CIM et dans leur liste de maladies professionnelles. La déclaration précise en outre que les patients qui souffrent de ces conditions qui impliquent de «sérieux risques», n'ont «aucune influence sur l'air qu'ils respirent et l'exposition aux rayonnements électromagnétiques ».

Le parlement européen exhorte aussi les États membres «d'appliquer les règles existantes en matière de rayonnement électromagnétique et d'exposition à des substances nocives et d'appliquer strictement le principe de précaution » afin de protéger efficacement la population souffrant de cette condition, « dont le nombre croît de façon exponentielle »

L'Organisation Mondiale de la Santé (OMS) est le standard mondial pour évaluer et classer les problèmes de santé. C'est la référence la plus importante pour les médecins, les gouvernements et les cours de justice à travers le monde. Une classification universelle des conditions médicales est importante parce que cela encourage la recherche scientifique au niveau international et le partage des résultats. C'est aussi la base pour l'attribution de codes pour les réseaux de la santé afin de déterminer l'éligibilité des diagnostics et des soins, ce qui indique la meilleur choix des traitements primaires requis.

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Resources

Item	Qty	Total
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QUEST $38 Collection II		
QUEST $38 Collection III		
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Disability Manual $70		
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Please transfer the above "sub total" onto the front, to tally in to the total payment being made.

Thank You

THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter – Free with annual membership of $30.00

When you become a member of the National ME/FM Action Network, you receive our quarterly newsletter QUEST. We keep you informed about medical research, disability and legal issues, as well as keeping you up-to-date about our many projects. "Quest" includes original articles by doctors, researchers, and lawyers. In addition, it has a new section entitled The Journey which covers support matters such as treatment and happenings in other groups.

ME/CFS and FM Brochures - FREE

If you would like to receive our free informative pamphlets on ME/CFS and/or FM, please contact us or you can print copies off our website at www.mefmaction.net.

Consensus Documents for ME/CFS and FM

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols [Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004 ISBN:0-7890-2207 9] and The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4}] can be viewed on our website at www.mefmaction.net and is also available at Amazon.com or at Chapters.ca
Or view the Consensus Documents on our website at www.mefmaction.net

ME/CFS and FM Overviews - $2.50 each

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents entitled Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols and The Fibromyalgic Syndrome: A Clinical Case Definition for Practitioners.

Overviews can be ordered from Marjorie Van de Sande via email at mvandesande@shaw.ca or by regular mail at 151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 Canada, or from the NATIONAL ME/FM ACTION NETWORK Or may be viewed on our website at www.mefmaction.net

ABREGE DU CONSENSUS CANADIEN SUR LE SFC: DEFINITION CLINIQUE ET LIGNES DIRECTRICES A L'INTENTION DES MEDICINES - 2.50 $ chacun

To order, please contact AQEM, 7400 Boul. Les Galeries, Box 410, Anjou, QC H1M 3M2 Canada or call 514.369.0386 or via email at aqem@spg.qc.ca

TEACH-ME (Second Edition) - $22.00 – Discount on bulk orders
TEACH-ME (TRADUCTION FRANCAISE): 22 $

Our TEACH-ME Resource Book is for Parents and Teachers of children and youth with ME/CFS and/or FM.

QUEST COLLECTION: 1993 TO 2003 - $38.00
QUEST COLLECTION: 2004 TO 2008 - $38.00

These are a collection of medical and legal articles that appeared in our newsletters for the periods indicated and combined for easy reference.

CANADA PENSION PLAN DISABILITY GUIDE - $10.00

A Guide designed for those who are disabled and wish to apply for Canada Pension Plan Disability Benefits and the various steps in the process.

LEGAL & DISABILITY MANUAL - $70.00

This manual consists of court case references and disability matters relevant to ME/CFS and FM matters.

NATIONAL LAWYERS' ROSTER

A roster of lawyers and legal advocates who are knowledgeable about ME/CFS and FM. This roster is a guide only and the National ME/FM Action Network plays no role in any decisions made by the individual or in the legal professional selected. Please contact us for more information.

NATIONAL ME/FM ACTION NETWORK WEBSITE http://www.mefmaction.com

NATIONAL ME/FM ACTION NETWORK

NEW MEMBERSHIP or RENEWAL fees

ANNUAL MEMBERSHIP FEE:
$30.00 per year including quarterly newsletter QUEST

IN ADDITION, I would like to donate *$ ______________ to help with the many projects of the National ME/FM Action Network.

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