NATIONAL ME/FM ACTION NETWORK
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Quest Newsletter

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Celebrating 20 years of Service

June 18, 2013 marks the 20th anniversary of the founding of the National ME/FM Action Network. We are very proud of what has been accomplished over the years. We have highlighted some of our accomplishments throughout this newsletter. Overall, our most important contribution has been to bring a sense of community and hope to individual Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM).

Our community has let us know that they appreciate our work. We were enrolled in a contest where the three charities with the most on-line votes receive money from Nature's Bounty, a vitamin and supplements company. After about 25 days (with still a week left to go), we had over 20,000 votes, which means that nearly a thousand people voted for us every day. We really appreciate the support and loyalty!

For this newsletter, we reached out to organizations across the country and asked them to say a few words about their activities. You will see that some very creative and valuable work is being done. Thanks to our new volunteer Maralyne Narayan for pulling the material together and thanks to everyone who submitted. We plan to highlight more groups in upcoming newsletters. Thanks also to John Wodak for bringing us up to date on the CPP-Disability appeal changes, Michelle Skop-Dror for her analysis of the 2012 Canadian Fibromyalgia Guidelines, and Susanna Figuer for her insightful poems.

Margaret Parlor
President

June 18, 1993: The National ME/FM Action Network is officially founded by Lydia Neilson to support Canadians with ME/CFS and/or FM.

Dates to watch:

April 1, 2013: The CPP-Disability appeal process changes with the introduction of the Social Security Tribunal. See page 13.

May 7, 2013: MEAO holds an awareness event at Queen's Park in Toronto. See page 3

May 8, 2013: The National ME/FM Action Network, in collaboration with Members of Parliament Dr. Carolyn Bennett and Dr Hedy Fry, hosts a breakfast to raise awareness of ME/FM. Please contact your Member of Parliament and encourage him/her to attend. See page 18 for details.

May 12, 2013: Awareness Day for ME/CFS and FM. Many individuals and groups will organize events across the country and around the world. If you are planning an event and would like material to hand out or display, please contact us as soon as possible so that we can get it to you in time.

June 18, 2013: The 20th birthday of the National ME/FM Action Network. We invite you to send us a birthday greeting saying what the Network means for you.

Contents

MEFM Society of BC

The MEFM Society of BC has been involved in several activities in the past year which we would like to share with you.

Last fall, we welcomed Dr. Alison Bested to BC as the inaugural Medical Director of the new Complex Chronic Diseases Program at BC Women's Hospital for people with ME, FM and tick-borne illness like Lyme Disease. The clinic was originally announced in 2011 by the BC Government. The MEFM Society of BC, along with the National ME/FM Action Network and the ME Victoria Association are all participating on the Community Advisory Committee for the Program. While the wait has seemed excruciating, we are encouraged by Dr. Bested's appointment and the progress she has made in a short time towards opening the program for patients as quickly as possible. In early March, the Program started accepting referrals! Meanwhile, the clinic space is undergoing renovation, staff and clinicians are being hired and we are hopeful that the first patients will be seen in just a few weeks. We are all very grateful that Dr. Bested accepted the challenge to run the program and we wish her great success!

The MEFM Society of BC is also involved again this year with the UBC Medical School's Doctor, Patient and Society Course and their At-Home Interview program. In this program, first and second year medical students interview patients with chronic illness in their own home and learn about the impacts of living with their disease. The student must research the patient's illness, interview the patient, write a report on their findings and then present to fellow students in their study group (about 10 students). We have three members who have done this for the past few years and found the experience to be very fulfilling as they educate tomorrow's doctors about ME, FM and the devastating effect these illnesses can have on someone's life. We provide the students with enough information and educational materials for their colleagues, including patient brochures and the Canadian Consensus Documents, with the hope that they will learn about the illnesses and become empathetic and understanding towards chronically ill patients. It's a very grass roots approach, but if we can influence the thinking of tomorrow's doctors through sharing our experiences then we feel it's very worthwhile and valuable. We were also very excited to learn that through the Complex Chronic Diseases Program and Dr. Bested, ME and FM will both for the first time be included in the UBC Medical School curriculum in 2013. It might be worthwhile for other groups to contact their local medical schools to see if a similar program might exist for patients to participate in.

As a result of our participation with the At-Home Interview Program we have also been invited for the past two years to participate in the Medical School's Community Health Fair, where about 40 – 50 community and health based groups set up an all day 'trade fair' for health science students to visit. This helps all the health science students (medical school, nursing, physiotherapy, pharmacology, etc) learn about various health conditions and learn what community supports are available for their future patients. This past year we were able to educate over 80 students who visited our booth about ME and FM, and also inform them about the Complex Chronic Diseases Study and the Complex Chronic Diseases Program. We were so pleased to learn that students have since approached the Study to become involved in the research.

We feel very fortunate to be in a province where ME and FM are seemingly for the first time being taken seriously. There remains so much more work to be done, but we are hopeful and optimistic that the coming years will mean better, more thorough and more respectful care for people living with ME and FM.

Susan MacLean, President

The Myalgic Encephalomyelitis Association of Ontario (MEAO)

WHAT'S NEW AT MEAO

Quality of Care Project: As many of you know, MEAO was awarded a grant from the Ontario Trillium Foundation to conduct a study examining health care delivery in Ontario for people with ME/CFS, FM and MCS. It is called the Quality of Care Project. The project is seeking to improve the quality of life for people with these illnesses by proposing a new model of community care that engages providers of health and social support systems.

The objectives of the project are:

1. to identify the major needs of those with ME/CFS, FM and MCS and the major 'gaps in service' in terms of those needs, and

2. to propose solutions for filling those gaps. Our findings and recommendations are meant to be of use to key decision makers in the Ministry of Health and Long Term Care and in the service delivery part of our health care system.

Thanks to everyone who participated in our Quality of Care research project. Your generosity in sharing your stories has given us a wealth of information that we are putting together to prepare a report that we feel will lead to greater understanding and awareness.

MEAO's Awareness Day: MEAO is planning our annual International Awareness Day for Tuesday May 7th at Queen's Park. We will have several speakers plus messages from many MPPs along with some light refreshments. Complete information will be sent out by MEAO in due course.

Keith Deviney President MEAO - and –
Denise Magi Vice-President MEAO

1995: The National ME/FM Action Network asks to speak at an appeal after the trial Judge states that "Fibromyalgia doesn't exist." The Alberta Court of Appeal expresses regret for the hurt caused by the statement.

Update on the British Columbia Clinic

Dear Friends,

I just wanted to give you a quick update on the new Chronic Complex Disease Clinic.

After our monthly board meeting on March 6, we toured the almost completed clinic, and I am genuinely pleased with all I see. The very final details are almost finished, and patients will soon arrive. This has been a long, drawn out process for everyone, but the wait will be worth it. A tremendous amount of time, effort, meetings and negotiations has gone in to every aspect of the Clinics set up. Every thing from physical location, ethical standards, patient surveys, floor plans, staffing, the web site, and the creation of a team coming together, will benefit each and every person coming to the clinic.

Best regards in health and healing,

Sherri Todd
BC Director – The National ME/FM Action Network

Note: Only BC residents are eligible to use the BC Clinic.

1996: The National ME/FM Action Network collects 15,000 names on a petition to Parliament.

Une Note positive Pour le Québec

Comme c'est le cas probablement dans chaque province du Canada, le Québec fait face à un problème de reconnaissance du EM/SFC. L'EM/SFC demeure une entité médicale très peu connue du milieu de la santé et la majorité des personnes atteintes rencontrent énormément de difficulté à obtenir un diagnostic et un suivi médical adéquat.

En 2010, l'AETMIS (Agence d'Évaluation des Technologies et des Modes d'Intervention en Santé), maintenant connu sous le nom de INESSS (Institut national d'excellence en santé et en services sociaux), a émis un rapport pour le Ministère de la Santé et des Services sociaux (MSSS) expliquant le manque de ressources et de soutien pour les personnes atteintes d'encéphalomyélite myalgique (PAEM) ainsi que le manque de connaissances médicales des médecins face à ce problème de santé. L'AETMIS recommandait une meilleure prise en charge des patients, l'implantation de centres de référence, de la formation universitaire et de la formation continue et de stimuler également la recherche dans le domaine.

C'est ainsi que l'INESSS a produit un dépliant explicatif sur le EM/SFC destiné au grand public et que le MSSS a commencé à travailler sur la mise sur pied d'un programme d'expertises en soins et services de santé pour les patients atteints du syndrome de fatigue chronique. Nous sommes présentement très loin du but, mais de petits pas se font tranquillement. Ce mandat a été confié au Centre de réadaptation Constance-Lethbridge (CRCL), affilié au RUIS (Réseau Universitaire Intégré de Santé) McGill . [Il y a quatre RUIS au Québec basé sur les quatre grands centres de médecine universitaire. Chacun de ces réseaux est responsable des soins de santé dans leur territoire respectif.] Ce projet consiste à implanter, au Québec, les structures nécessaires pour pouvoir desservir la clientèle atteinte du SFC, d'offrir de la formation générale et continue sur le SFC et de promouvoir la recherche sur le SFC.

Comme vous pouvez le constater, ce programme est immense, surtout lorsque vous devez partir de la base, étant donné qu'il n'y aucune structure existante actuelle pour la prise en charge des PAEM. Les représentants de l'AQEM (Association Québécoise de l'Encéphalomyélite Myalgique) ont rencontré, à la fin de l'été, Madame Lefebvre, directrice des programmes de réadaptation à cette époque ainsi que Madame Bouvrette-LeBlanc, chargée du projet au CRCL, pour discuter de ce mandat. Dans un premier temps, ce programme sera développé sur

Positive News from Quebec

As is probably the case in every Canadian province, Quebec has a problem with the recognition of ME/CFS. ME/CFS is a medical condition that is not well known in medical circles and the majority of people with it encounter serious difficulties in getting diagnosed and treated.

In 2010, AETMIS (the Quebec agency responsible for evaluating health technologies and interventions) now known as INESSS (the Quebec institute for excellence in health and social services), issued a report to the Minister of Health and Social Services describing the lack of resources and support for people with ME/CFS as well as the lack of knowledge among doctors about this health issue. AETMIS recommended better support for patients, the establishment of centers of expertise, strengthened initial and continuing medical education, and the encouragement of research around ME/CFS.

With this background, INESSS produced a brochure about ME/CFS aimed at the general public and the Quebec Ministry has started to set up a center of expertise in care and health services for people with ME/CFS. We are currently a long way from completion, but important stepping stones are being put in place. Responsibility has been given to the Constance Lethbridge Rehabilitation Centre which is affiliated with the "RUIS McGill", the health care network coordinated by McGill University. [There are four health care networks in Quebec based on the four faculties of medicine. Each network is responsible for health services to a section of the province.] The project involves developing the infrastructure to serve people with ME/CFS, to provide initial and on-going medical training about ME/CFS and to promote research into ME/CFS.

As you can tell, the challenge is immense, especially when you take into account that there is no infrastructure in place at the moment. Representatives of AQEM (the Quebec Association for ME) met late last summer with Mme Lefebvre who was, at the time, the director of rehabilitation programs and Mme Bouvrette-LeBlanc, the project manager at Constance Lethbridge Rehabilitation Center, to discuss the scope of the work. Initially, this program will be developped for the area of Quebec served by the McGill health network. When the McGill program is up and found to be working, it could then be incorporated into the other university networks for Quebec to serve the whole province.

le territoire du RUIS McGill. Lorsque les structures seront implantées et évaluées comme étant efficaces, elles pourront alors être mises de l'avant dans les autres réseaux universitaires du Québec.

Cette rencontre a été très positive d'autant plus qu'un ou des représentants de l'AQEM pourront probablement siéger au niveau du comité de développement du programme de prise en charge du SFC. Tout cela ne veut pas dire que nous aurons tous demain matin notre médecin traitant, mais une chose est certaine, il y a présentement de l'avancement pour notre cause et nous ne pouvons qu'entrevoir l'avenir sur une note positive.

Claudine Prud`homme, Vice-présidente , Association Québécoise de l'Encéphalomyélite Myalgique

The meeting was very positive and, as a bonus, one or more representatives of AQEM will likely be invited to sit on the program development committee for ME/CFS services. That doesn't mean that we will have treating doctors tomorrow morning, but one thing is certain – our cause is moving forward and we can look to the future with optimism.

Claudine Prud'homme, Vice-president, Quebec Association for Myalgic Encephalomyelitis

1997: The National ME/FM Action Network launches a website and gets 3,000 hits in the first two months.

Fibromyalgia Support Group of Winnipeg

Since October of 1992 our group has done our utmost to provide our members and their families as well as medical professionals with up-to-date information, education and treatment options for Fibromyalgia. We continue to produce a newsletter three times per year, offer an Education Course two times per year, and maintain an extensive library of FM resources for our members. In addition, we hold monthly meetings with invited speakers who cover a wide variety of topics relevant to those with Fibromyalgia. We also have two Neighbourhood Groups which meet monthly at local restaurants for informal social gatherings and we sponsor a Tai Chi program.

In June of 2008 we did a mail out to all Family Physicians/Surgeons in Manitoba. This mail out consisted of a copy of the informational booklet entitled "Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners: An Overview". We also included some of our pamphlets for distribution to their patients.

Over the past few years we have evolved greatly. We now have our own website (www.fmswinnipeg.com), a Facebook page and can also we found on Twitter. These changes have enabled us to reach out to more people than we ever have in the past. Our membership has doubled.

We continue to advertise and create awareness through running a bus ad for 1 month each year, taking part in a coin collection fundraiser through the Manitoba Liquor Commission and placing ads in Community Newspapers.

This past October (2012) we celebrated our 20th Anniversary with a sit down dinner with guest speaker, Dr. Kevin White. The evening was a huge success enjoyed by 134 members and guests.

We had never done anything of this magnitude before and are very proud of ourselves for being able to accomplish our goal. Although our Board is comprised solely of people who have Fibromyalgia, we have managed to maintain these activities and strive to do more as our time and energy permits.

Fibromyalgia Association of Regina

Fibromyalgia Association of Regina has been around since the early 1990's.

We have a one page FM Flash that is mailed (or e-mailed) to our supporter list (in total about 110 folks) and we drop copies off at the Arthritis Society office.

We meet of the first Thursday of nine months (no meetings in January, July or August). Luckily, one of our members has a business with a big front open space and she lets us meet there and store our rolling library and file cabinet. SO no renting a meeting place.

The only fund-raiser we have each year is a raffle for which we get all the prizes donated, and. We generally make around $1,000.00 and that is enough to pay the expenses for the year.

For five or six of the meetings, we bring in a speaker that is from a profession we have to deal with due to the FM; pharmacist, massage therapist, chiropractor, pain specialist, yogi laughter, reiki master, tai chi instructor, and such. We try to have two Care-and Share meetings to just talk among ourselves and share how we cope with different things. At the Christmas meeting, we bring a treat and a small present and have a social. Our June meeting is when we elect our executive and hold the draw for the raffle (usually over 35 prizes).

Our fiscal year runs from June 1st to May 31st and we are a Non-Profit Corporation. Membership fee is $12.00 for the year but it is not required to attend our meetings.

We have a library with books, tapes and CDs for members to borrow.

Mississauga Fibro Group

I was diagnosed with Fibro after a car accident in 1990. I have attended the group since I was diagnosed. I was trying to educate myself on how to get a handle on this illness – learning from other member and trying to find how I would have a better quality of Life without medication.

The leader of the group left the country in 2000 and I took over to teach and guide others on how to feel better. I also handle all the incoming phone calls and answer questions and concerns. I have backup from the other Greater Toronto Area(GTA) facilitators and also a lawyer and a holistic chiropractor to help me move forward. Having these people to support me I could eventually help others.

One of my goals was to bring in informative guest speakers that would provide support and guidance on how we could have a pain free body and find what could help at least one person to feel better. We try to educate ourselves and the doctors so that members could be helped. We have also produced a pamphlet that we can hand out to doctors, walk in clinics and libraries, in order to produce awareness, letting the public know that this is a real illness.

Another goal was to bring awareness of the illness within our community of Mississauga by getting involved in the community centres and attending health fairs that are conducted on a yearly basis.

On May 7th we will be going to Queens Park and there our MPP's will bring awareness in Legislation.

For May 12th there will be events conducted in our GTA community once again trying to obtain awareness for the illness by handing out literature and pamphlets.

My other goal is to help someone calling me so that they are not alone and that there is hope for this illness – knowing when you are diagnosed there is a solution to your problem. I was there and know how overwhelming this illness can be.

Susan Monaco
Mississauga Fibro Group
Meetings Held at Loblaws Mavis and Dundas
Last Monday of the Month
No Meetings in Dec/June/July/Aug.

2002: The National ME/FM Action Network holds a symposium on the parallels between post-polio sequelae and ME/FM. Over 400 people attend.

1997-2004: The National ME/FM Action Network identifies the need for clinical guidelines for ME/CFS and FM, supports Dr. Bruce Carruthers and Dr. Anil Jain who prepare first drafts, convinces Health Canada to establish expert panels to review the drafts, and supports the work of the panels. The results are the Canadian Consensus Guidelines for ME/CFS (2003) and Fibromyalgia (2004). These guidelines have had international impact.

Brockville ME Association

Photo by Virginia Bulanda-Ostler

For the past 20 years, the Brockville M.E. Association has provided support for those suffering from Myalgic Encephalomyelitis, Fibromyalgia and Multiple Chemical Sensitivities. We have also welcomed those suffering from other chronic illnesses who share similar symptoms.

We are a determined corps of volunteers who have managed to hang in despite our illness. We have been privileged to have the support of the United Way of Leeds and Grenville, the Volunteer Centre of St. Lawrence Rideau and the continued and loving assistance from our families and friends who have stepped in to help out with our ongoing activities.

We have nine monthly support group meetings during the year. Group sharing often focuses on coping strategies, medications and laughter. We frequently invite speakers whose topics may include various therapies, exercises and diet or how to deal with CPP, ODSP or insurance companies. We celebrate eating with potluck fare at our November and June (AGM) meetings. Our Kemptville branch opened one year ago – they have enjoyed chatting over paintbrushes and canvas.

We stay in touch with those unable to attend meetings through the newsletter which is published nine times per year. We also send the newsletter to other agencies as well as doctors and medical centres in our area. We maintain our website to provide information about our upcoming meetings and special events.

While it can be exhausting for us to maintain our group, positive feedback from those whom we have helped through a rough patch encourages us to continue to spread awareness and education about ME/FM and related illnesses.

Like our mascot, the tortoise, with a slow and steady pace, we can still be winners!

Carol Nix and Betty Cirne

PARC (Promoting Awareness of RSD/CRPS)

PARC (Promoting Awareness of RSD/CRPS) is holding a spring event on Chronic Pain and Complex Regional Pain Syndrome (CRPS) in St. Catharines in April.

In conjunction with the Niagara Chronic Pain Support Group, we present:

Dr David Shulman, CCFP, FCFP,DAAPM Wilderman Clinic, Toronto and

Dr. Flavio Iammarino PhD (drflavio.ca) Niagara Falls, Ontario.

The event is being held at Russell Ave. Community Centre, 108 Russell Ave., St. Catharines on Saturday April 13 @ 1 PM. For more information please visit: www.rsdcanada.org . To register: parc21026@yahoo.ca

In 1995, the name Reflex Sympathetic Dystrophy (RSD) was changed by the medical community to Complex Regional Pain Syndrome (CRPS).The aim was to better reflect the nature of the disease and to unify the 30 or so confusing terms into one appropriate label for worldwide research purposes. Most doctors use the term CRPS but patients and families still use the familiar term RSD; we will use both terms.

Helen Small-PARC

The Gift of Hope

Each day brings the gift of new hope
Teaches us we have strength and can cope

Hope is there even if we think it is not
And helps us deal with life's challenges we feared a lot

Hope will always let us see the light
And give us comfort that everything will be alright

By: S.A. Figuer

My FibroMoves Journey

I believe that my journey started with a bout of pneumonia in 1995 that took months to resolve including a doctor ordered trip to Florida to be nursed by my 70-something mother. During the next five years I had a series of symptoms. One time it was severe headaches for a month. Then it was chest pains. Next it was tremors like Parkinsons. My dear, patient doctor sent me for the tests and the results were always negative.

Finally in 2000, I believed that I was dying and I wanted to go to Ireland. So I booked the trip and started doing some extra walking in preparations for the touring. Within weeks my knees, hips and ankles were sore so back to the doctor I went. He prescribed an anti-inflammatory which settled down the pain and off I went to Ireland. Halfway through the trip the pains were back so I dragged myself through the rest of the trip on Advil and Tylenol.

When I returned home, I immediately went to the doctor saying, "I don't know what's wrong with me. I hurt from the tips of my toes to the ends of my hair! Everything hurts." His response was to send me to a rheumatologist. After the examination he asked me if my husband would like to join us. The alarm bells went off in my head...am I dying? So I asked George if he would like to join us. His response was, "Would I?" In the end the diagnosis was fibromyalgia.

Now it's not a death sentence, it's a life sentence, with which you have to find a way to live. So I had heard about a warm water therapy class and although being in warm water was something akin to being part of a stew, I decided to try it. The warmth felt so good on my aching body but the actions tended to irritate. So being a teacher, I decided to do what felt best for me. First, I didn't do the 12-16 repetitions that are typical of aquacize programs. I found that 8 was my max. Then when we were doing stretches, I couldn't hold them as long as suggested without lasting cramps. So I only held a stretch for 3 deep breaths. As well I found that I would get fatigued and was yawning all the time during the class. I became aware that I was holding my breath which is typical of anyone starting a new exercise program but is standard for fibro people if not reminded to "Breathe!"

It was interesting how I discovered that I wasn't breathing. Our instructor had great 50s and 60s music and I love to sing. I found that when I sang I didn't get tired as quickly and didn't yawn. Why is that? Well, try singing without breathing and you'll know right away.

Unfortunately the program was cancelled because it was a loss leader. However I knew that I needed it for my fibromyalgia body. So I inquired at facilities that had warm water pools whether they would let outside groups use it and found one. So I led the others and honed my program which the others found suited their bodies better too. Then a nearby city facility was opening a new warm water pool so I contacted the manager asking whether she would consider running FibroMoves (the name which I gave to my program) for an hour once a week on speculation.

After the first term the numbers of participants were growing so I contacted a city facility across town asking whether they would be willing to run it once per week too. I made sure that the classes were separated by at least one day so participants' bodies had time to adjust. After two terms we were up to two classes per week at each of the facilities. Then the manager of the first facility suggested that we needed to give validity to the program by me becoming a certified aqua instructor. So I became a Canadian Aquafitness Leaders Alliance (CALA) instructor. The CALA president invited me to present FibroMoves to a group of instructors in Cuba in 2004. What a thrill that was!

Since that time the program has grown to four facilities: Kitchener-Forest Hts., Kitchener-Breithaupt, Elmira-Woolwich, Guelph-West End. Also the facilities in Kitchener have the program running continuously. It only pauses for statutory holidays and maintenance which the two facilities co-ordinate so that we are never totally without a pool. I have presented regularly at the CALA conferences in Kitchener and once in Mississauga.

The best part of the program is the number of fibromyalgia people who are enjoying and benefitting from this experience. They say things such as: "I hate it when I can't get there." "It feels so good." And the look on their faces as they enter the water and the "AHHHH" says it ALL!

I love leading the FibroMoves classes voluntarily, presenting at CALA conferences and teaching new instructors how to implement the program because it feels so good to help others. It's my hope that everyone with chronic pain can find a warm pool in which to relax and learn how to move to improve their quality of life.

Kathy Zador, CALA Specialized Trainer
zadors@golden.net

Local Support for Those with MCS and Homelessness

In 2011 I had been involved with the Environmental Health Association for about 2 years. In, 2009 we had started a London satellite and I sat on the board of the Ontario group, attending meetings by conference call. I decided that the nature of the satellite wasn’t directly benefitting this area, so we started Scent Free London to get the word out about scent free policies and how serious the need for safe housing is here. We now have myself and two volunteers.

Currently there are a few dozen or more people in housing crises in London unique to our specific health needs. I myself have been in a housing crisis this past year due to neighbors who smoke. What it looks like is this: one rents a place and upon move-in discovers products used in cleaning the floors or scents escaping from other units have polluted the new (sensitive) tenant’s space. He or she can’t live there, becomes homeless and broke, and must search for another place to live. Homelessness, discrimination and poverty pervade this experience, yet it has been very difficult for others to understand and even listen to the needs of their tenants. There are some smoke-free buildings in London but most people who are Chemically Sensitive need more than that in order to feel well at home. The barriers in helping these people to be housed are appalling.

2013 marks a new era of poverty in London Ontario, as the Community start up and maintenance benefit for recipients of Ontario Works and Ontario Disability Support Program was discontinued on January 1. Now OW and ODSP recipients do not have funds to pay for a move.

In short, housing is not accessible in London. This has become my focus. Housing must be in place before anything else can be tackled. How can one even try to get well while homeless?

As director of Scent Free London I attended several meetings with the city of London staff to address the unique needs of our group. We also participated in the attempt to ban smoking in city parks, which was voted down by City Hall.

This year, 2013, I have attempted to start a support group for Scent Free London, although this is very difficult. Many of those with health issues can’t leave their own homes or use computers, so the group may be a long time in coming.

For now we have a wonderful website with resources such as advice on housing, workplace accommodation and links to my talk at last year’s event, titled “A Matter of Accessibility”. We also held a Nature Clean products giveaway contest with results to be published soon. Please visit our website and send feedback. *www.scentfreelondon.weebly.com*

Amelia Does, B.A.
Scent Free London Executive Director

Ehlers-Danlos Syndrome

Ehlers-Danlos Syndrome is a group of genetic conditions where connective tissue is affected. The symptoms of EDS are very similar to the symptoms of ME/CFS and FM. In 1999, Dr. Peter Rowe, a pediatrician at Johns Hopkins University published a study finding that 12 out of 100 adolescents who had been diagnosed with Chronic Fatigue Syndrome met the criteria for Ehlers-Danlos Syndrome.

People with ME/CFS or FM might suspect EDS if they have lax muscles, are double jointed, have hypermobility, or experience frequent dislocations of their joints. Another clue is having a number of blood relatives with ME/FM symptoms.

I have talked to several people with a diagnosis of EDS. The benefits of getting a diagnosis include validation of the symptoms one is experiencing and a better understanding of why the symptoms exist. The treatment for EDS is along the same lines as for ME/CFS and FM.

If you suspect EDS, discuss it with your family doctor. You may be referred to a geneticist or a rheumatologist for further investigation.

Margaret Parlor, President, National ME/FM Action Network

Minister of Health (Canada) and Secretary of State for Health and Human Services (United States) Respond to Questions about ME/CFS

In the last issue of Quest, we presented a list of question that were addressed to the Minister of Health by Member of Parliament Dr. Carolyn Bennett. Dr. Bennett's questions focused around ME/CFS but also touched on FM and MCS. The topics included four area where the federal government can play an important role: supporting research, sharing information, improving service delivery and statistical monitoring.

In the United States, the Senate Majority Leader, Senator Harry Reid, had a conversation with the US Secretary of Health and Human Services, Kathleen Sibelius about ME/CFS. Ms Sibelius provided Senator Reid with a written reply touching on the same four issues.

Hon. Leona Aglukkaq (Minister of Health, Minister of the Canadian Northern Economic Development Agency and Minister for the Arctic Council, CPC):

Mr. Speaker, the government supports provincial and territorial health care delivery through fiscal transfers and targeted programs. Unlike previous governments that balanced their books on the backs of the provincial and territorial governments, we have committed to a long-term stable funding arrangement that will see health care transfers reach historic levels of $40 billion by the end of the decade. Health transfers from the federal government to provinces grew by 40 percent between 2005-2006 and 2012-2013. Our investments in health care will help preserve Canada’s health care system so it will be there when Canadians need it.

With respect to research and awareness, in May 2008, the Public Health Agency of Canada, PHAC, and the Canadian Institutes of Health Research, CIHR, coordinated a meeting with the Myalgic Encephalomyelitis Association of Ontario and other stakeholders to explore ways to increase knowledge and awareness of myalgic encephalomyelitis/chronic fatigue syndrome, ME/CFS, and to address research needs. This meeting led to the first Canadian national scientific seminar on ME/CFS in Calgary in November 2008. This seminar was held to raise awareness, increase medical practitioners’ knowledge, and improve medical treatment for patients with ME/CFS. An article on this seminar was published by PHAC and can be found at:
http://www.phac-aspc.gc.ca/publicat/cdic-mcbc/29-3/pdf/cdic29-3-6-eng.pdf

CIHR has invested $28,000 since 2009-2010 in research related to ME/CFS. In addition, CIHR’s Institute of Musculoskeletal Health and Arthritis,

L'hon. Leona Aglukkaq (ministre de la Santé, ministre de l'Agence canadienne de développement économique du Nord et ministre du Conseil de l'Arctique, PCC):

Monsieur le Président, le gouvernement du Canada appuie la prestation des soins de santé par les provinces et territoires grâce aux transferts fiscaux et aux programmes ciblés. Contrairement aux gouvernements précédents qui ont équilibré leur budget sur le dos des provinces, nous nous sommes engagés à donner un financement stable à long terme qui verra les transferts fédéraux en santé atteindre des niveaux historiques de 40 $ milliards à la fin de cette décennie. Les transferts en santé du gouvernement fédéral aux provinces ont augmenté de 40 % entre 2005-2006 et 2012-2013. Notre investissement dans les soins de santé aidera à préserver le système des soins de santé du Canada afin qu'il soit là lorsque les Canadiens en ont besoin.

En ce qui a trait à la recherche et à la sensibilisation, en mai 2008, l’Agence de la santé publique du Canada, l’ASPC, et les Instituts de recherche en santé du Canada, les IRSC, ont coordonné une réunion avec l’Association de l’encéphalomyélite myalgique de l’Ontario et d’autres intervenants afin d’explorer des façons de mieux faire connaître et d’accroître la sensibilisation à l’encéphalomyélite myalgique-syndrome de fatigue chronique, l’EM-SFC, et de répondre aux besoins en recherche. Cette réunion a abouti au premier symposium scientifique national canadien sur l’EM-SFC, qui a eu lieu à Calgary en novembre 2008. Le symposium visait à faire mieux connaître l’EM-SFC, à accroître les connaissances des médecins et à améliorer le traitement médical des patients atteints d’EM-SFC. Un article sur le symposium a été publié par l’ASPC et se trouve à l’adresse suivante:
http://www.phac-aspc.gc.ca/publicat/cdic-mcbc/29-3/pdf/cdic29-3-6-fra.pdf

IMHA, has set aside a separate pool of funds in its undergraduate studentship program for myalgic encephalomyelitis and fybromyagalia. Details are available at:
http://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtls.do?prog=1699

Surveillance of ME/CFS and fibromyalgia is undertaken by PHAC in looking at trends in disease prevalence in order to inform program and policy decisions. Data from the 2010 Canadian Community Health Survey, CCHS, allow PHAC to produce scientific surveillance information on ME/CFS, raise awareness and support efforts to increase understanding of the impact of these conditions.

The questions on ME/CFS, fibromyalgia, and multiple chemical sensitivities were asked of all CCHS respondents in 2010. Analysis of the 2005 and 2010 data demonstrated that there were no changes in the prevalence of these conditions in this five-year period; therefore, maintaining the data collection on these conditions every four years is appropriate.

The Public Health Agency of Canada's website is aimed at delivering information and services to users that are relevant and applicable to its mandate and that of the Government of Canada. While PHAC facilitates the sharing of clinical information via its website, it is the responsibility of health care professional associations and medical bodies to ensure that relevant clinical information is available to their members. The following documents are available at the links indicated below: Canadian Consensus Document for ME/CFS: A Clinical Case Definition and Guidelines for Medical Practitioners at:
http://www.phac-aspc.gc.ca/cd-mc/az-index-eng.php#C
and Canadian Consensus Document for Fibromyalgia: A Clinical Case Definition and Guidelines for Medical Practitioners at:
http://www.phac-aspc.gc.ca/cd-mc/az-index-eng.php#F

2005: The Teach-ME task force publishes the second edition of the Sourceboook for Teachers of Students with ME/CFS and/or FM incorporating the Canadian definitions. The document is translated into French. The National ME/FM Action Network, MEAO and other groups raise money to distribute the Sourcebook to schools, school boards, ministries of education, faculties of education and children's aid societies.

Les IRSC ont investi 28 000 $ depuis 2009-2010 dans la recherche sur l'encéphalomyélite myalgique ou le syndrome de fatigue chronique, l'EM-SFC. De plus, l'Institut de l'appareil locomoteur et de l'arthrite des IRSC a mis de côté des fonds distincts dans le cadre de son programme de bourse d'étudiant de premier cycle pour la recherche sur l'encéphalomyélite myalgique et la fibromyalgie. On trouve plus de renseignements à l'adresse suivante:
https://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtls.do?prog=1699&language=F

L'ASPC effectue la surveillance de l'EM-SFC et de la fibromyalgie, ce qui lui permet d'observer les tendances de la prévalence de la maladie en vue de prendre des décisions éclairées en lien avec les programmes et les politiques. Les données de l'Enquête sur la santé dans les collectivités canadiennes, l'ESCC, de 2010 permettent à l'ASPC de produire de l'information de surveillance scientifique sur l'EM-SFC, de faire accroître la sensibilisation et d'appuyer les efforts visant à mieux comprendre l'incidence de ces maladies.

Les questions portant sur l'EM-SFC, la fibromyalgie et d'autres polysensibilités chimiques ont été posées aux répondants de l'ESCC en 2010. L'analyse des données de 2005 et de 2010 a démontré qu'il n'y avait pas eu de changements dans la prévalence de ces maladies durant cette période de cinq ans. Par conséquent, il est approprié de recueillir des données à leur sujet tous les quatre ans.

Le site Web de l'Agence de la santé publique a pour but d'offrir aux utilisateurs des renseignements et des services pertinents et compatibles avec le mandat de l'ASPC et celui du gouvernement du Canada. Même si l'ASPC peut contribuer à faire connaître l'information clinique disponible par l'entremise de son site Web, il revient aux associations de professionnels de la santé et aux instances médicales de s'assurer que leurs membres ont accès à l'information clinique pertinente. On retrouvera le document canadien de consensus sur l'EM-SFC "EM-SFC: Définitions cliniques et lignes directrices à l'intention des médecins" et le document canadien de consensus sur la fibromyalgie "Syndrome de la fibromyalgie: Définitions cliniques et lignes directrices à l'intention des médecins" en suivant le lien suivant:
http://www.phac-aspc.gc.ca/cd-mc/az-index-fra.php#S

THE SECRETARY OF HEALTH AND HUMAN SERVICES
Washington, D.C. 20201

February 22, 2013

The Honorable Harry Reid
United States Senate
Washington, DC 20510

Dear Senator Reid:

Thank you for your inquiry regarding the Department of Health and Human Services's (HHS) response to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). I am aware that more than one million Americans may be suffering from this debilitating condition; a few HHS employees have come forward to share their stories with me, and I share their frustration that neither a clear cause nor a cure have been identified despite some 30 years of scientific pursuit. We have undertaken a number of activities over the past three years, and I want to share some of this information with you. I assure you that HHS is committed to fostering the development of drugs to treat the symptoms of ME/CFS and to otherwise alleviate the experience of patients with this debilitating disease.

As you likely know, the Food and Drug Administration (FDA) recently convened a formal advisory group meeting to provide recommendations on the safety and efficacy of the drug Ampligen for the treatment of CFS. This meeting was open to the public and included opportunities for public comment. On Monday, February 4, 2013, Hemispherx announced the receipt of a Complete Response (CR) letter from FDA for Ampligen. FDA issues a CR letter to convey that its review of an application is complete and if the agency cannot approve the application in its present form. A CR letter describes all of the specific deficiencies that the agency has identified in an application, allowing the company an opportunity to correct those clearly defined deficiencies in a re-submission. FDA's decision regarding Ampligen took many factors into account, including the safety and efficacy data and the advice of the advisory committee. I understand the frustration and pain of ME/CFS patients and their caregivers and how important it is that we continue to work toward development of treatments.

FDA planned a series of activities to explore the burden of disease that impacts the quality of life for ME/CFS patients, the quantitative outcome measures or endpoints that determine if disease symptoms improve with intervention, and how drug efficacy should be clinically tested based on these endpoints or measurements. During the past five months FDA hosted a teleconference and a webinar with ME/CFS patients and advocates. Additionally, the agency will hold a drug development workshop this spring to explore what is needed to facilitate development of safe and effective treatments for ME/CFS. More information on ME/CFS-related activities at FDA can be found at:
http://www.fda.gov/Drugs/NewsEvents/ucm319188.htm.

Other, ongoing cross-Departmental efforts take a comprehensive approach to addressing ME/CFS. The Chronic Fatigue Syndrome Advisory Committee (CFSAC) is an advisory committee that meets twice a year to provide science-based advice and recommendations on a broad range of issues and topics pertaining to ME/CFS. Regular updates are provided to stakeholders via the CFSAC website (http://www.hhs.gov/advcomcfs/) and a listserv. I also established an Ad Hoc Workgroup on ME/CFS in February 2012 to increase and better coordinate the efforts of individual HHS components related to ME/CFS. The Workgroup is comprised of eight HHS agencies that are investing in programs to address ME/CFS.

The National Institutes of Health (NIH) is funding research activities that may help patients with ME/CFS. NIH is taking action to stimulate all facets of ME/CFS clinical research including clinical trials at the NIH Clinical Center with the help of its Trans-NIH ME/CFS Research Working Group. The agency is seeking proposals for collaborative projects between extramural researchers and intramural researchers (http://grants.nih.gov/grants/guide/pa-files/PAR-13-029.html) and has also implemented a process to review applications (http://grants.nih.gov/grants/guide/notice-files/NOT-AI-13-005.html) proposing to use biological samples obtained from ME/CFS patients who participated in a recent NIH-funded study. These samples from well-characterized ME/CFS cases provide a valuable resource for research on ME/CFS biomarkers moving forward.

The Centers for Disease Control and Prevention (CDC) is in the final stages of a seven-site study of the clinical characteristics of ME/CFS. This study was launched in September 2011 to collect standardized data from clinical practices of clinicians with expertise in ME/CFS. The data will be used to evaluate variation in the illness among clinics, to characterize all domains of illness in ME/CFS patients, and to provide data that could be used in evaluation of a research case definition and diagnostic criteria.

In addition to prioritizing research and patient care, HHS made educating health care providers a priority. The Agency for Healthcare Research and Quality provided technical support to the International Association for CFS/ME for the development of a primer for clinical practitioners that has been added to the National Guideline Clearinghouse. This primer can be found at www.guidelines.gov. The Substance Abuse and Mental Health Services Administration and the Health Resources and Services Administration are hosting webinars to educate providers in their networks about ME/CFS. A free, web-based continuing medical education course on ME/CFS was launched by the CDC in collaboration with MedScape Live. The course has reached over 5,000 health care providers thus far.

This is only a sampling of the numerous activities addressing ME/CFS across HHS. The Department is committed to providing ME/CFS clinicians and patients with scientific, clinical, and educational resources.

I am grateful to have your support in our efforts. I share your concern about this illness and look forward to continued dialogue with you and with the scientific, patient, and pharmaceutical communities as we seek to improve the lives of millions of Americans. Please do not hesitate to contact me if you have additional questions.

Sincerely,
Kathleen Sebelius

Changes to the CPP-D Appeal Process

by John Wodak, CPP and Disability Advisor

Shortly after our Application and Appeals Guide for CPP Disability (CPP-D) went to press last year, we learned that the federal government's omnibus budget bill (C-38, the Jobs, Growth and Long-term Prosperity Act) included sweeping changes to the two upper levels of the CPP-D appeal process. Effective March 31, 2013, the Review Tribunals and the Pension Appeals Board will cease hearing appeals and will have one year to issue all outstanding decisions. The functions of these two agencies will be transferred to a new body, the Social Security Tribunal (SST). This new tribunal is to hear Employment Insurance and Old Age Security appeal as well as the CPP appeals, and is to start operations on April 1, 2013.

After April 1, 2013, an appeal of a denial of a CPP-D application at Reconsideration will need to be sent to the Income Security Section of the General Division of the SST. Applications for Leave to Appeal of Review Tribunal decisions must be submitted to the Appeal Division of the SST. More information about the Social Security Tribunal is available on the Service Canada website: *http://www.servicecanada.gc.ca/eng/sst* or by calling Service Canada's Toll-Free number: 1-800-622-6232

Much of the advice to appellants in our Guide is based on the authors' accumulated experience over a number of years and may no longer be applicable. It could take up to several years' work with the new system before we have enough experience to provide definitive advice. In the meantime:

* Although the procedures will change, we believe the advice on how to conduct yourself at an appeal hearing will still be valid;

* We hope, but there is no confirmation as yet, that Tribunal staff will provide the same level of advice and support for appellants as the Client Service Officers used to provide for Review Tribunal appellants;

* The proposed procedures for the Appeal Division indicate that no new evidence will be allowed. It is therefore of vital importance that all available evidence be submitted when appealing to the General Division. (We have already pointed out to the federal government the likelihood that new evidence will be generated continuously for CPP-D applicants, regardless of the status of an appeal);

* It is more important than ever to seek competent legal advice when appealing to the SST.

2005: Lydia Neilson is awarded the Meritorious Service Medal by the Governor-General of Canada for her work on behalf of Canadians with ME/CFS and FM.

2008: The National ME/FM Action Network is granted intervenor status in a case before the Supreme Court of Canada looking at employment rights for people with ME/CFS. The employee is found to have been wrongfully terminated from his job because of his disability and is awarded damages.

“Out with the Old and in with the New”: An Analysis of the Revisions to Fibromyalgia Classification, Diagnosis and Management

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Fibromyalgia (FM) has become an orphan within the Canadian healthcare system. FM’s orphaned status in Canada can be traced to and through the new guidelines for the diagnosis and management of this condition, which have been adopted by the Canadian Pain Society and the Canadian Rheumatology Association (Fitzcharles et al., 2012). These Guidelines include many troubling recommendations, which were described in Issue 92 of Quest. The guidelines promote the American College of Rheumatology’s (ACR) 2010 diagnostic criteria for FM that replaced the tender point exam with scales of widespread pain and symptom severity. The guidelines also phase out rheumatologists from the diagnosis and treatment of FM without replacing them with other specialists, leaving family physicians with the job of diagnosing and treating FM.

In order to contextualize these two recommendations, I will first discuss the reasons why the ACR developed and subsequently revised its diagnostic criteria for FM. I will then argue that the revised criteria represent not only a shift in how FM is conceptualized, but also a movement that repositions FM within the healthcare system.

The ACR’s 1990 Consensus Definition and Diagnostic Criteria

In the 1970s and 1980s, biomedical researchers attempted to legitimize FM by searching for its cause. However, these researchers’ methodologies were inconsistent. For example, they used different criteria such as the number of tender points required to classify research participants (Barker, 2005). These discrepancies created confusion about what characteristics constituted FM. In 1986, in order to develop a consensus definition of FM and unified classification criteria, the ACR established the Multicenter Criteria Committee.

The Multicenter Criteria Committee conducted a multi-site study of 558 patients (193 people with FM and 265 controls) across 16 North American medical sites (Wolfe et al., 1990). They found that tender points could be used to differentiate FM from other rheumatic conditions. Based on these findings, the Committee agreed that FM could be classified via: (a) patient report of chronic widespread pain lasting longer than 3 months; and (b) patient identification of pain in 11 out of 18 tender points via physical examination[1]. The Committee expected that the classification criteria would be applied by researchers in clinical and epidemiological investigations, as well as by clinicians for patient diagnosis (Wolfe et al., 1990).

The 2010 Revisions to the ACR’s Diagnostic Criteria

Although the ACR’s 1990 criteria were widely adopted by rheumatologists for diagnostic purposes, the validity of the criteria was challenged. One critique was that the ACR’s definition of FM was tautological because “tender points both define and substantiate its existence” (Barker, 2005, p. 25). Another critique was that the criteria did not account for symptoms other than pain. In addition, the accuracy of FM diagnoses was questioned because they depended on peoples’ subjective accounts of their illness histories. A further problem was that primary healthcare physicians were not consistently or correctly conducting tender point exams and, when these exams were conducted, they did not always capture people with mild pain (Wolfe et al., 2010).

To remedy these problems, in 2010, the ACR proposed revised diagnostic criteria based on the findings of a multicentre study (Wolfe et al., 2010). The new criteria was based on scales for assessing pain and symptom severity, while deleting the tender point exam. Some modifications were proposed in 2011 (Wolfe et al., 2011).

2009: The National ME/FM Action Network publishes statistics from the Canadian Community Health Survey showing the extent and seriousness of ME/CFS in Canada. In addition, the Network publishes statistics from the Canadian Institutes of Health Research website showing how little funding is allocated for research into ME/CFS and FM in Canada.

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[1] During physical examinations, clinician-researchers were instructed to use their thumbs and fingers to apply 4 kilograms of pressure to patients’ tender points, measuring both the amount and the rate of pressure with an instrument called a dolorimeter (Wolfe et al., 1990).

The tender point exam is a visual reference for the invisibility of pain and is the only clinical evidence of FM's existence. By removing the tender point exam and not substituting another physical test, the ACR's 2010 criteria have delegitimized FM. Narrowly, removing the tender point exam is saying that FM is not rheumatological. More broadly, it might be suggesting that FM is not physical.

The looseness of the new criteria -- an "everything but the kitchen sink" definition -- may capture people suffering from symptoms that look like but are not the same as FM. Having a heterogeneous definition is problematic for research because treatments may work for some parts of the cohort and not others, confusing the findings. The broad definition also reinforces FM's reputation as a wastebasket diagnosis and reduces the condition's credibility.

Comparison of the 1990 and 2010 Criteria

The 1990 Criteria and the 2010 Criteria define overlapping but different groups. On one hand, the 2010 criteria identified 88.1% of people previously classified using the 1990 criteria (Wolfe et al., 2010). That means that 12% of people who qualified under the 1990 criteria would not qualify under the 2010 criteria. On the other hand, there are people who would qualify under the 2010 criteria but not under the 1990 criteria. The extent of this is not clear.

It is fair to question whether changing the criteria had underlying financial motivations; a diagnosis once intended for legitimation is now imposing "large economic burdens on society" (Clauw, Arnold & McCarberg, 2011, p. 907). These "burdens" have impacted both the healthcare system and insurance companies. For example, a survey of Canadian insurance company records found that a diagnosis of FM was associated with 9% of all disability payments, which annually costs $200 million (White, Speechly, Harth, & Ostbye, 1999). In this context, switching criteria could help insurance companies save money. For instance, insurance companies could ask claimants, who were diagnosed under the 1990 criteria, to re-qualify for their disability insurance. If these claimants do not fit within the 2010 diagnostic criteria or simply do not make it through the administrative process of re-qualifying, then they could lose their insurance benefits.

Alongside the insurance companies, the pharmaceutical industry may potentially benefit from the shifting diagnostic criteria. Medications are widely advertised and prescribed for people with FM. However, many people with FM do not take these medications on a long-term basis due to lack of benefits or negative side effects. For example, the Cochrane review of studies on Pregabalin (Lyrica) found that:

> Pregabalin has proven efficacy in neuropathic pain conditions and fibromyalgia. A minority of patients will have substantial benefit with pregabalin, and more will have moderate benefit. Many will have no or trivial benefit, or will discontinue because of adverse events. Individualisation of treatment is needed to maximise pain relief and minimise adverse events... (Moore, Straube, Wiffen, Derry, & McQuay, 2010).

The Cochrane review of Duloxetine (Cymbalta) came to a similar conclusion (Lunn, Hughes, & Wiffen, 2011). However, a cohort of people diagnosed with FM under the 2010 criteria may have a different response to the medications because their symptom profiles may differ from the 1990 cohort.

Rheumatology's Role in the Diagnosis and Treatment of FM

Historically, rheumatologists were the "diagnostic entrepreneurs" of FM; they assumed a leading role in biomedical research about FM, as well as in the clinical care of those afflicted with this disorder (Barker, 2005). However, a recent survey found that 71% of Ontario rheumatologists believed that they no longer should provide care to patients with FM. In fact, 89% of Ontario rheumatologists believed that the care of patients with FM should be transferred to family doctors (Ghazan-Shahi, Towheed, & Hopman, 2012). The argument behind this transfer of care is that FM does not fit within rheumatology's jurisdiction because it is no longer considered a musculoskeletal disorder. Instead, many researchers and clinicians conceptualize FM as a multi-symptom disorder of the nervous system (Barker, 2005). In comparison, others, including 55% of the surveyed rheumatologists, view FM as a psychosomatic illness. Interestingly, rheumatologists who considered FM a physical illness were more likely to believe that they should continue treating patients with FM, as well as to accept new referrals (Ghazan-Shahi et al., 2012).

It is possible that the underlying reason why many rheumatologists no longer want to assume responsibility for FM is because it is an illness that:

(a) has an unknown etiology, (b) does not have simple treatments, (c) has multiple symptom involvement, (d) is primarily diagnosed in women, and (e) has no cure, and therefore no sense of medical success. Regardless of the reason, rheumatologists are now able to extricate themselves from patients with FM due to the ACR's revised classification criteria. By deleting the tender point exam, the ACR has pushed FM outside of rheumatology's musculoskeletal jurisdiction.

Resituating FM within the Healthcare System

The ACR's revised classification criteria coupled with the findings of the Ontario rheumatology survey provokes questions about who could and should deliver healthcare services to the FM patient population. If rheumatologists relinquish responsibility for the provision of healthcare services, then which medical speciality would be best suited to care for patients with FM?

By default, the responsibility falls on family physicians. Certainly family physicians have a major role to play, but it is fair neither to family physicians nor patients to leave family physicians with unsupported responsibility. Family physicians need a speciality to turn to conduct research, provide knowledge transfer, and to deal with complex cases.

Until a service delivery solution is reached, FM will remain labelled as messy, controversial, time-consuming, and gendered. Patients with FM will continue to be unwanted orphans of the medical establishment. They already feel like casualties of the FM war, experiencing stigma and unmet healthcare needs. Previous studies, for example, have shown that patients with FM have faced significant healthcare barriers, including delayed diagnosis and inefficient treatments due to a lack of treatment standards (Egeli, Crooks, Matheson, Ursa, & Marchant, 2008; Lempp, Hatch, Carville, & Choy, 2009; Sim & Madden, 2008). These patients have felt delegitimized by health care providers who have asserted that their symptoms are not biomedically real and are all in their heads (Crooks, Chouinard, & Wilton, 2008; Sim & Madden, 2008)[2].

Despite the significance of these healthcare issues, patients' healthcare experiences, as well as their suggestions for the improvement of healthcare services, have not been fully examined. I found only one study that directly asked patients with FM how the quality of their healthcare could be improved (Egeli et al., 2008). The authors of this study argued that: "Identifying patients' views of what constitute positive interactions with care professionals is essential in improving health outcomes for those who may otherwise feel disempowered by the consultation and treatment process" (Egeli et al., 2008, p. 368). The study found that patients are looking for supportive care, empathetic listening and familiarity with treatments.

Concluding Remarks

In this article, I have outlined the ACR's classification criteria for FM and grappled with the ways in which the recently revised criteria will impact diagnosis, treatment and support. Although the ACR's revised classification criteria are progressive, in the sense that they offer a method of evaluating the constellation of FM symptoms, they are also regressive. The deletion of the tender point exam -- an exam which makes pain visible -- serves to further invisibilize and thereby invalidate FM. Furthermore, the deletion of the exam implicitly moves FM outside of rheumatology's musculoskeletal jurisdiction. An additional concern is that some rheumatologists are extracting themselves from care to patients with FM. They argue that biomedical evidence classifies FM as a neurobiological rather than a rheumatological disorder. Without another speciality adopting FM, it falls to family physicians to provide services when they themselves are not supported to do this. Essentially, patients with FM have become orphans within the healthcare system.

We must continue advocacy efforts to ensure that healthcare providers and policymakers engage with these issues in order to find FM an appropriate home within the array of medical specialities and to encourage research to explore the underlying causes of the illness.

2011: The National ME/FM Action Network hosts the 10th biennial conference of the International Association for ME/CFS. This brings top researchers and clinicians from around the world to Ottawa to discuss ME/CFS, FM and related illnesses. Videos of the patient conference are available on our website with English and French soundtracks.

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[2] Delegitimation refers to "the experience of having one's perceptions and definitions of illness systematically disconfirmed" (Ware, 1992, p. 347).

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2012: The National ME/FM Action Network releases the third edition of its CPP-Disability Guide for people with ME/CFS and FM. Qualifying for income support is a particular challenge for people with these under-appreciated conditions.

Finding My Strength
(With Fibromyalgia Syndrome-FMS)

Living with Fibromyalgia, I have found my strength

Although the pain others sometimes do not understand
We continue to venture on in life and stand our ground

Although we know there is not yet a cure
We find comfort with each other knowing how much
we each endure

We are grateful in life accepting how much we can do
Knowing in our hearts we have found new abilities
and strength we never knew

By: S.A.Figuer

Invitation to Members of Parliament and Senators

Please join us for a breakfast information session to raise awareness for myalgic encephalomyelitis/chronic fatigue syndrome and fibromyalgia.

Wednesday, May 8th, 2013, 7:30 AM - 8:30 AM
Parliamentary Dining Room, 6th Floor, Room 601

Speakers:

Margaret Parlor
President of the National ME/FM Action Network

Lisa Schneiderman
Patient Representative

Gordon Broderick Ph.D.
Broderick Clinical Systems Biology Group
Associate Professor, Department of Medicine
University of Alberta

Hosted by The National ME/FM Action Network, in collaboration with Dr. Carolyn Bennett and Dr. Hedy Fry. ME/CFS and fibromyalgia are neuroendocrine immune diseases that affect an estimated 756 000 Canadians. Like other illnesses at the early stages of knowledge, there is a lack of awareness, medical care, and research into the etiology and treatment of these often lifelong and disabling diseases.

Please RSVP to rsvp.mefm@gmail.com by May 1st, 2013

NATIONAL ME/FM ACTION NETWORK

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NATIONAL ME/FM ACTION NETWORK

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Resources

Item	Qty	Total
Membership Fee $30		
ME/CFS Brochure *free*		
FM Brochure *free*		
ME/CFS Overview $2.50		
FM (Eng) Overview $2.50		
FM (Fr) Overview $2.50		
TEACH-ME (Eng) $22		
TEACH-ME (Fr) $22		
QUEST $38 Collection II		
QUEST $38 Collection III		
CPP Guide $10		
Disability Manual N/A		
SUB TOTAL		

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 - Out of Print
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

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MEMBERSHIP APPLICATION or RENEWAL FORM

Please see reverse for available network resources.

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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Please see reverse.

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THANK YOU FOR YOUR SUPPORT!

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