www.mefmaction.com Quest 101, Winter 2014 mefminfo@mefmaction.com

Research and Researchers

CIHR Research Fellowship for ME/FM

The Institute of Musculoskeletal Health and Arthritis (IMHA) of the Canadian Institutes of Health Research (CIHR) has announced designated funding for a research fellowship in the priority area of ME/CFS or FM. Fellowships provide support for highly qualified candidates at the post-PhD degree or post-health professional degree stages to add to their experience by engaging in health research. The announcement stated that

$275,000 is available to fund an application relevant to Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, and/or Fibromyalgia...The maximum amount awarded for a single award is $55,000 per annum for up to five (5) years.

Priorities that will be considered for funding are:

- *Developing a better understanding of the complex causes and clinical manifestations;*
- *Defining optimal strategies of care and management through improved models of care;*
- *Improving our understanding of the impact and consequences.*

Applications closed on November 14 and the recipient will be announced early in the new year.

We would like to thank IMHA and CIHR for recognizing the importance of ME/FM research and making this funding available.

Primers Now Available in French

The 2014 IACFS/ME Primer for Clinical Practitioners is now available on the Network's home page mefmaction.com. Thanks to our translator Hélène Dion, to our reviewer Dr PhilippeTournesac of Paris France, to Rosemary Underhill who answered our questions and to the ME/FM community for your financial support.

AQEM, the Quebec Association for ME, would like to announce that the International Consensus Primer for Medical Practitioners is also available in French. Thanks to Hélène Dion, Dr Tournesac, and AQEM for this translation.

It is very important to have material available in French as well as English because health services in Canada are provided in both languages.

Aviva Contest – Fundraising for Research

The Aviva contest gives the Network the opportunity to raise money for research. Aviva (an insurance company) has set aside $1M for community projects. We are one of sixty projects in the large category of the "semi-finals". The twenty projects that receive the most on-line votes between Dec 1 and Dec 12 will automatically receive $5k. Judges will then review those twenty projects using the criteria of impact, likelihood of success, longevity and sustainability, originality, submission quality and votes received. They will give out prizes of up to $100k to the ones that are judged the best.

Please vote every day between December 1 and December 12, at www.avivacommunityfund.org and encourage your friends to do so as well. You can sign up for daily reminders by emailing us or contacting our Facebook page.

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CIHR Workshop and Symposium

The National ME/FM Action Network was invited to a Workshop in September and a Symposium in October, both sponsored by the Institute of Musculoskeletal Health and Arthritis (IMHA) of the Canadian Institutes of Health Reseach (CIHR). CIHR is the government agency responsible for distributing the federal dollars allocated to health research, currently around $800M a year.

There are essentially two ways CIHR could hand out the money, 1) reactively - picking the best submissions from the research community and 2) proactively - choosing what research should be done. CIHR distributes most money reactively in open competition, with researchers in all areas competing against each other. Researchers apply for funding, applications are given scores by peer-review committees, and the applications with the highest scores receive funding. Proactive strategies include designated funding and the institute system. There are 13 institutes focused on different areas of health research.

The table on page 3 shows CIHR funding over the past 3 years. The table was compiled from CIHR's funded research database which gives a brief textual description of each study receiving funding. I compiled the table using keyword searches, looking for words like "fibromyalgia" in the brief descriptions. You can see that very few funded studies mentioned "fibromyalgia" or "chronic fatigue syndrome", and no funded study mentioned the phrase "multiple chemical sensitivities". I then converted the funding to annual per capita spending using prevalence figures from the Canadian Community Health Survey. Note that the CCHS does not include all Canadians. People in care institutions are not included, meaning that the number of people with conditions like Parkinson's and Alzheimer's are underestimated, meaning that the spending per capita for these conditions is overestimated. Even taking methodological issues into account, it is obvious that research on ME/CFS, FM and MCS is seriously underfunded. There is a need for proactive measures.

This summer, the National ME/FM Action Network received invitations to two events sponsored by the Institute of Musculoskeletal Health. IMHA is just launching a 5 year strategic plan with three priorities: 1) chronic pain and fatigue, 2) inflammation and tissue repair and 3) mobility, disability and health. The first event was a workshop to discuss the Chronic Pain and Fatigue theme. The second was a larger symposium to launch the strategic plan.

To prepare for the workshop, I looked at

- work that has been done on Arthritis in Canada - page 4.
- statistics on chronic pain – page 8-9
- the kinds of biomedical studies that ME/FM patients would like to see – page 14-15

There were about 20 people at IMHA's September workshop on Chronic Pain and Fatigue including several ME/FM clinicians, researchers and patient advocates. At that meeting, IMHA announced that it would be funding a research network in Chronic Pain and Fatigue – about $1M per year for five years. It also announced funding of two research fellowships, with one designated for ME/FM (see page 1) and the other for chronic pain.

The Network has mixed feelings about these developments. On the positive side, we know that chronic pain and chronic fatigue deserve more attention. We see that FM patients want more chronic pain studies. On the worrisome side, we know that chronic pain and chronic fatigue are broad topics and the specific issues relating to ME/CFS and FM could get lost. Looking at pain tables 1 and 2, you can see that many people with a diagnosis of CFS or FM have severe or moderate pain. Looking at pain tables 3 and 4, you can see that most people with severe or moderate pain have other chronic conditions.

In October, IMHA held a symposium launching its strategic plan. This was piggy-backed on the a meeting organized by the Arthritis Alliance of Canada, meaning that the symposium was arthritis-heavy. Again there were mixed feelings. On the positive side, a bit of attention was paid to ME/FM. On the worrisome side, it wasn't much attention.

We will be continuing our dialogue with CIHR and will keep you posted on developments.

CIHR Funding for Research Into Chronic Conditions

Keyword	Average Annual per patient funding 2012-2015	Canadians affected CCHS 2010	CIHR funding (3 years) 2012-2105	Number of studies funded 2012-2015
Parkinson	$428.16	39,000	$50,094,279	234
Alzheimer	$287.05	111,500	$96,016,737	433
Muscular dystrophy	$178.34	26,000	$13,910,775	83
Epilepsy	$76.33	134,500	$30,800,227	133
Multiple Sclerosis	$66.46	108,500	$21,631,220	106
Cerebral palsy	$60.38	36,000	$6,521,061	30
Diabetes	$37.11	1,841,500	$205,010,686	1,024
Crohn	$36.23	102,500	$11,141,448	70
Tourette	$34.74	18,000	$1,875,895	7
Dystonia	$26.10	15,500	$1,213,861	14
Heart Disease	$24.21	1,431,500	$103,971,956	475
Spina Bifida	$10.10	35,000	$1,060,941	8
Bronchitis, Emphysema, COPD	$8.39	805,000	$20,272,121	75
Asthma	$6.59	2,246,500	$44,425,625	212
Arthritis	$4.63	4,454,000	$61,807,451	352
Fibromyalgia	$0.89	439,000	$1,166,409	11
Chronic Fatigue Syndrome	$0.52	411,500	$645,925	2
Multiple Chemical Sensitivities	$0.00	800,500	$0	0

Using keyword searches; Updated to Oct 23, 2014; Funding provided by CIHR – April 2012-March 2015

Learning from the Arthritis community

What can we learn from the Canadian arthritis community that would help advance the situation for ME and FM? ME, FM and Arthritis are chronic conditions that affect Canadians, often during their working years, and are not easy to "sell". Arthritis, however, is more prevalent than ME or FM, is better recognized, and has more services in place.

In exploring the question, I discovered the Arthritis Alliance of Canada and the Canadian Arthritis Network.

The Arthritis Alliance of Canada, now 12 years old, brings together 36 organizations with an interest in arthritis. The list of members (available on the ArthritisAlliance.ca website) includes organizations for health care professionals, research groups, funding agencies, government agencies, voluntary sector agencies, industry groups and arthritis consumer organizations. The professional organizations include rheumatologists, orthopaedists, chiropractors, physiotherapists and occupational therapists. Among the barriers that the ME and FM communities face are the lack of an official physician specialty focusing on ME and FM and the lack of appreciation of the seriousness and complexity of the conditions among other health disciplines. The Alliance includes two key federal government agencies, the Canadian Institutes of Health Research and the Public Health Agency of Canada. We have long insisted that CIHR and PHAC have important roles to play in ME and FM.

Before going further, I explored whether the Arthritis Alliance considers Fibromyalgia to be within its scope. I looked at seven important documents, six prepared by the Alliance and one prepared by the PHAC. The PHAC document (128 pages) mentioned Fibromyalgia only three times. Each time it was to explain that the Canadian Community Health Survey asked respondents if they had "Arthritis excluding Fibromyalgia". This implies that Fibromyalgia is not part of arthritis. However, several sections of the report used databases based on ICD (International Classification of Diseases) codes and the code for Fibromyalgia was in scope. Thus, Fibromyalgia was sometimes included and sometimes excluded. As for the six Alliance reports (262 pages total), Fibromyalgia was mentioned only twice and both times in insignificant ways (once in the title of an article in the list of references and the other in a short biography of a person with rheumatoid arthritis and fibromyalgia.) One has to conclude that Fibromyalgia is not an issue on the Alliance's radar screen.

Now let us go through the Alliance's reports. The reports are presented in chronological order, showing the evolution of the Alliance's work.

Report from the Summit on Standards for Arthritis Prevention and Care, 2005: This report arose out of a three day meeting held in Ottawa in 2005.

You can see that their key selling points are already in place - four million Canadians, no age limits, leading cause of long-term disability, burden of illness is increasing, costly to society, strategies must be developed to reduce the burden....

The meeting of Alliance members came up with 12 "standards" such as:

1. Every Canadian must be aware of arthritis
2. Every Canadian with arthritis must have access to accurate information and education on arthritis that meet a defined set of criteria and are appropriate for their age and stage of disease
5. All relevant health professional must be able to perform a valid, standardized, age appropriate musculoskeletal screening assessment.
6. Inflammatory arthritis must be identified and treated appropriately within four weeks of seeing a health care professional.
9. Every Canadian with arthritis must have timely and equal access to appropriate medications.

Standards 1, 5 and 9 were identified as priorities for immediate action.

Canadian Arthritis Funding Landscape Review, 2011: Looking at the period 2005-2010, this study identified 843 grants toward arthritis research worth over $206 million from 21 different funders/organizations. The study found the following leading sources of research money:

Leading funders of arthritis research - 2005-2010

CIHR	$117 M
Canada Research Chairs	$ 24 M
The Arthritis Society	$ 17 M
Arthritis and Autoimmune Research Centre Foundation	$ 13 M
Canadian Arthritis Network	$ 12 M
Alberta Innovates	$ 5.6M
Natural Sciences and Engineering Research Council	$ 3.6M

The study found that CIHR spent $19M on arthritis-related research in 2005-2006 "representing just $4.30 for every person with arthritis." The study concludes that Arthritis research is underfunded considering its growing prevalence and its economic and social burden compared to other disease areas. The report made comparisons to diabetes ($12.83/person) and cancer ($138.60/person).

The report notes that most of the arthritis funding was focused on understanding mechanisms of disease, treatment and disease management. It found that few projects related to prevention and diagnosis/screening, hinting at the need for rebalancing.

Several messages stand out for the ME and FM communities. Firstly, CIHR is a major source of funding for health research, and most of the other funders are federal agencies or receive financial support from the federal government. Secondly, the arthritis community argued that it was underfunded by CIHR at $4.30 per patient, but in 2005-2006 Fibromyalgia was funded at less than $1 per patient and ME was awarded no research funding at all. Thirdly, there are issues about how funding is allocated. The optimal allocation between disease mechanism, prevention, diagnosis etc could be very different for ME and FM than for arthritis. Fourthly, the federal government founded and funded a research network for arthritis, so it can do it again for ME and FM.

The Impact of Arthritis in Canada: Today and over the next 30 years, 2011: This report finds that Arthritis affects 4.6 M Canadians. (It is not clear where this number comes from since the 2010 Canadian Community Health Survey shows 4.4M Canadians reporting "arthritis excluding fibromyalgia". The additional 200k might be people reporting fibromyalgia who were not already included). The study estimates that there are 4.4 M Canadians with Osteoarthritis (a progressive joint disease that occurs when damaged joint tissues are unable to normally repair themselves resulting in a breakdown of cartilage and bone) and 272,000 Canadians with Rheumatoid Arthritis (an inflammatory joint disease). Note that some people might have both OA and RA. The study predicts that the rate of Osteoarthritis and Rheumatoid Arthritis will increase quite dramatically over the next 30 years due to the aging population and people being overweight or obese.

The report identifies four strategies "thought to offer the greatest return on public investment", namely:

For Osteoarthritis

- Total joint replacement intervention
- Reduction of obesity rates in Canada
- Adequate pain management strategies

For Rheumatoid Arthritis

- Early diagnosis and treatment with cost-effective Disease Modifying Anti-Rheumatic Drugs (DMARDs) and for those who do not respond to traditional DMARDs, access to Biologic Response Modifiers (Biologics).

Finally, the report estimates the cumulative savings of implementing these strategies, both direct savings and indirect savings (disability-associated wage-based productivity loss). Thus, for instance, the report concludes that "[i]f all new cases of RA and all people living with RA who require DMARDs and Biologics had access to early and appropriate treatment:

- 12,200 cases of severe RA could be avoided over 10 years....
- 6,700 workers could avoid severe RA over 10 years...
- $1.7 billion could be saved in cumulative direct health care costs over 10 years...
- $11.6 billion could be saved in cumulative productivity losses over 10 years..."

Joint Action on Arthritis: A Framework to improve arthritis prevention and care in Canada, 2012.: Underlying this document seems to be frustration that important messages about arthritis are not getting through. The bullets on the front cover summarizes the situation – note particularly the third bullet:

- A growing and costly burden.
- Solutions are available.
- A response is required.

The document review the arthritis community objectives and set priorities for the future. The three primary goals are

- Communicate the arthritis community's vision of the actions and interventions required to improve the lives of people living with arthritis
- Galvanize action around long-term strategies to improve arthritis prevention, and quality and efficiency of care
- Facilitate and focus collaboration among governments and arthritis stakeholders in awareness, models of care and research.

Tool for Developing and Evaluating Models of Care, 2012: The context for this document is the desire to articulate how health services are delivered to a patient group or how health services should be delivered. What questions should be answered in the document describing the existing or proposed system?

If I were describing an existing or proposed system, I would address questions like – why is the service needed, what is the service trying to achieve, who would have a role in providing services, and what would they have to do? If I were funding the service, I would want to know how much it will cost and what the advantages and disadvantages are. If I were evaluating the service, I would want to know if there is evidence of benefits and how happy people are with it. This document supposedly covers all these perspectives and comes up with a checklist of topics the description should cover. I found the checklist hard to understand and seeming incomplete.

Let me observe that developing models of care in a well established and settled area is much easier than developing models of care in a poorly established and unsettled area. I am unclear how "model of care" relates to "clinical practice guideline" as described by the US National Guideline Clearinghouse, though I suspect that they are closely related. I am intrigued by a statement in the Preface of the new IACFS/ME Primer: "Since the extant literature does not adequately describe the nature and treatment of this illness, this document is written as a primer and is not 'clinical practice guidelines' as recently redefined" [by the National Guideline Clearinghouse]. There was concern that, if the primer had official guideline status, doctors could be disciplined for not following it exactly. This recognizes that our understanding of ME is incomplete and evolving.

A pan-Canadian Approach to Inflammatory Arthritis Models of Care, 2014: This report puts forward an elegant treatment model for rheumatoid arthritis and other inflammatory forms of arthritis affecting about 1 million Canadians. Under the model,

- Patients recognize symptoms and seek care;
- There is early identification and referral to a rheumatologist. Patients with non-inflammatory arthritis would be sent to a different type of specialist or treated by the primary care provider;
- There is constant monitoring by the specialist to ensure effectiveness;
- Treatment decisions are made through agreement between the patient and the health care team;
- The patient is fully educated about their medical conditions and the importance of adherence to the treatment regime; and
- The performance of the health system is monitored to inform quality improvements.

A similar model of care could be implemented to serve the one million plus Canadians with ME, FM or MCS. That would require a system of specialists. How many would be required? There are about 400 rheumatologists in Canada for about a million patients with inflammatory arthritis. Assuming similar levels of medical complexity and similar needs for ongoing care, this suggests that the ME/FM/MCS community should be aiming for over 400 neuro-immune specialists, a far cry from what we have today.

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Having reviewed the Alliance documents, I turned my attention to the Canadian Arthritis Network (CAN) which was mentioned in the research funding table. The Canadian Arthritis Network was a research network founded in 1998 with federal financing. Its aim was to create, translate and transfer arthritis research to produce benefits to people with arthritis, their families and Canadian society.

Its priorities were

1. Identify strategic research investments
2. Develop highly qualified research personnel and consumers to engage in the research process
3. Create tools and platforms to improve research efficiency and magnify impact
4. Engage in knowledge transfer and exchange activities to improve the uptake of research.

In fact, the Canadian Arthritis Network preceded the Arthritis Alliance of Canada – CAN claims at least some of the credit for starting the Alliance. CAN itself was disbanded in 2014.

CAN was involved in may valuable research projects. Here are some examples:

- identifying mechanisms that cause OA pain
- new therapies for OA
- identifying factors that predict OA
- new biomarkers to detect and treat OA and RA
- molecular biomarkers that precede development of OA
- new measure to assess the impact of arthritis on people living with arthritis
- new clinical tools to measure children's pain
- internet education and support program for teens with arthritis
- measuring work disability
- understanding the impact of arthritis on work

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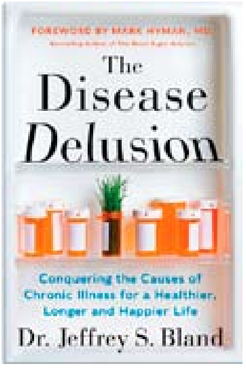
Just as I was putting the finishing touches on this article, our director from BC forwarded me an article published in the Vancouver Sun. It was titled "BC gives $3 Million to arthritis research." The money is going to one of the research groups that belongs to the Alliance. The newspaper article repeats the messages developed by the Alliance. This shows that the careful, fundamental work that the Alliance has been doing over the past decade is bearing fruit.

As the National ME/FM Action Network moves forward, we will keep the arthritis experience in mind.

Functional Medicine



When exploring the library recently, I found a book called "The Disease Delusion" which describes functional medicine. A few weeks later, I was in the doctor's office and the same book was sitting on his desk.

We have learned about the body organs – heart, lungs, etc. We have learned about the body systems – gastrointestinal system, nervous system, etc. Functional medicine looks at seven core processes of the body:

1. assimilation and elimination (digesting, absorbing and using nutrients and then excreting the wast products)
2. detoxification (converting toxic substances into nontoxic by-products and eliminating them)
3. defense (standing guard to protect the body from infection and cellular injury)
4. cellular communications (sensing and responding to the environment and sending messages from one region of the body to another)
5. cellular transport (moving substances from one part of the body to another)
6. energy (converting food to energy and managing the use of energy)
7. structure (ensuring that structure of the body supports the functions)

Statistics on Chronic Pain

From the Canadian Community Health Survey 2010 questionaire:

The next set of questions asks about the level of pain or discomfort you usually experience. They are not about illnesses like colds that affect people for short periods of time.

Are you usually free of pain or discomfort?

[If not,] how many activities does your pain or discomfort prevent?
1. None 2. A few 3. Some 4. Most

Table 1: Canadian population aged 12 and older with chronic conditions having pain preventing most activities, 2010 CCHS

Chronic condition	% with Severe Pain
CFS	26.2
FM	21.4
Effects of a stroke	18.1
COPD	16.8
Urinary incontinence	14.7
Mood disorder	12.7
Arthritis	12.2
Heart disease	11.8
Anxiety disorder	11.5
Ulcers	11.5
Bowel disorder	11.3
Back problems	10.4
MCS	10.1
Cancer	9.7^E
Diabetes	9.1
Migraines	7.3
High blood pressure	6.7
Asthma	6.7
Total population	3.1

Table 2: Canadian population aged 12 and older with chronic conditions having pain preventing some activities, 2010 CCHS

Chronic condition	% with Moderate Pain
FM	23.0
CFS	18.2
MCS	14.9
Arthritis	14.4
Ulcers	13.7
Urinary incontinence	13.4
Back problems	13.0
Bowel disorder	13.0
COPD	12.9
Effects of a stroke	11.8^E
Mood disorder	11.6
Heart disease	11.2
Cancer	10.6
Anxiety disorder	9.7
Migraines	9.3
Diabetes	9.2
High blood presure	8.2
Asthma	6.9
Total population	4.3

Source: Statistics Canada, Candian Community Health Survey, 2010, Public Use Microdata File

^E Use with caution (Coefficient of Variation between 16.6 and 33.3)

Arthritis = ages 15+; COPD = ages 35+; Urinary incontinence = ages 25+

Tables prepared by The National ME/FM Action Network. This analysis is based on the Statistics Canada Canadian Community Health Survey Public Use Microdata File, 2010. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network.

- 895,000 people reported pain preventing most activities. See tables 1 and 3.
- 1,226,000 people reported pain preventing some activities. See tables 2 and 4.

We see from table 1 that 26.2% of people with a diagnosis of CFS and 21.4% of people with a diagnosis of FM report severe pain. This shows that chronic pain is a serious issue for the ME/FM community. We see from table 3 that 63.1% of people with severe pain have back problems and 18.1% have CFS or FM. This shows that ME/FM may not be a central issue for the chronic pain community.

Table 3: Canadian population aged 12 and older with pain preventing most activities having chronic conditions, 2010 CCHS

Chronic condition	% with Chronic Condition
Back problems	63.1
Arthritis	60.9
High blood pressure	37.2
Mood disorder	26.7
Migraines	23.5
Anxiety disorder	19.2
Heart Disease	18.8
Diabetes	18.7
Asthma	18.4
CFS and/or FM	18.1
COPD	16.7
Urinary incontinence	15.7
Bowel disorder	15.6
CFS	12.1
FM	10.5
Ulcers	10.3
MCS	9.1
Effects of a stroke	6.3
Cancer	6.0^E

Table 4: Canadian population aged 12 and older with pain preventing some activities having chronic conditions, 2010 CCHS

Chronic condition	% with Chronic Condition
Back problems	58.0
Arthritis	52.3
High blood pressure	33.1
Migraines	21.8
Mood disorder	17.8
Asthma	13.8
Diabetes	13.7
Bowel disorder	13.0
Heart Disease	13.0
CFS and/or FM	12.6
Anxiety disorder	11.8
Urinary incontinence	10.7
COPD	9.8
MCS	9.7
Ulcers	9.0
FM	8.2
CFS	6.1
Cancer	4.8
Effects of a stroke	3.0^E

Source: Statistics Canada, Candian Community Health Survey, 2010, Public Use Microdata File

^{E} Use with caution (Coefficient of Variation between 16.6 and 33.3)

Arthritis = ages 15+; COPD = ages 35+; Urinary incontinence = ages 25+

Tables prepared by The National ME/FM Action Network. This analysis is based on the Statistics Canada Canadian Community Health Survey Public Use Microdata File, 2010. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network.

Margaret Oldfield

PhD Candidate
Rehabilitation Science,
University of Toronto

Tell me a little about your background.

After completing a master's degree in social policy planning, I worked on many social-research projects in the areas of education, community health, women's issues and other topics for over two decades. I'm currently in the last year of a PhD in Rehabilitation Science at University of Toronto.

How did you become interested in ME/CFS or FM?

I had FM myself.

What is your particular research focus?

My PhD research examines how women with fibromyalgia and other chronic illnesses remain employed despite numerous challenges. Three surprises in the research were how ill the women I interviewed were, that they had other stigmatized chronic illnesses, and that fatigue was as much of a problem for many as pain.

The thesis begins my long-term research plan: finding out what influences enable women with invisible chronic illnesses to stay at work. These influences could include individual characteristics and strategies, qualities of workplace and home environments, policies, societal factors, even ways of thinking about fibromyalgia, ME/CFS and other illnesses. I hope to use the research to promote social changes that can help women with fibromyalgia, ME/CFS and other invisible chronic illnesses to remain employed.

Many of the issues that make it difficult for women with chronic illnesses, including fibromyalgia and ME/CFS, to remain employed are social problems that cut across diseases. This is why I take a social approach to research as well as a qualitative approach, looking at how and why things happen by listening to people.

What have you learned from your research?

For women with FM, workplace relationships, the culture of workplaces (how they operate and how people interact), and their home lives are as important as functional capacity to remaining employed.

Telling people at work that you have fibromyalgia and how it affects you can be risky unless you're sure they'll understand. Otherwise, they may not react the way you would like. Co-workers may unfavorably compare you to others they know with FM, blame you for aggravating your illness, and give you advice you haven't asked for. Supervisors may not want to know about your illness if they're aware that human rights legislation prohibits them from asking about it. Or they may jump to conclusions about your abilities based on stereotypes that don't apply to you. Be careful who you tell and how much you tell.

What was your source of funding?

University of Toronto Faculty of Medicine, Women's College Research Institute, and Centre for Research on Work Disability Policy

What follows from here?

Next year, I'll be doing postdoctoral research at McGill University about remaining employed with breast cancer. It is now considered a chronic illness, since 85% of women survive it. Pain and fatigue from the after-effects of treatment can make work challenging. When women have primary responsibility in their families for taking care of children and elderly parents, and doing housework, remaining employed can be even more challenging. The project, which grew out of observations in my PhD thesis research, will look at the interplay of women's unpaid family work with their chronic illness and employment. I suspect that the findings will apply to women who struggle to balance work and family with other chronic diseases, like fibromyalgia and ME/CFS.

Petra Schweinhardt

Assistant Professor
Alan Edwards Centre for
Research on Pain,
McGill University

Tell me a little about your background.

I trained as a medical doctor but after graduating, I went to the Karolinska Institute in Stockholm for a two-year research fellowship instead of starting specialist training. At the Karolinska, I got the research bug and decided that this is what I would like to do in my professional life. Subsequently, I went to Oxford University to complete a PhD in pain neuroscience. Since this time, my worked has focused on how our brain processes pain and what having pain for a long time does to the brain.

How did you become interested in ME/CFS or FM?

To be honest, this was a bit of a coincidence. I came to Canada in 2006 to pursue postdoctoral research in the laboratory of Dr. M Catherine Bushnell at McGill University. My main postdoctoral project investigated the role of the brain chemical dopamine in placebo analgesia. When I arrived, Dr Bushnell and her group had just finished a study in patients with FM that showed that patients release less dopamine in the brain in response to a pain challenge compared to control participants. This caught my interest because of the role of dopamine plays not only in pain processing but also in motivation and cognitive processing. I thought that such brain changes could be related to the symptoms patients with FM are experiencing.

What is your particular research focus?

I have been focusing on studying brain differences between patients with FM and controls and how such differences could be related to the various symptoms FM patients are suffering from. For my research, I employ various brain imaging methods and we have been looking at the structure and the function of the brain in patients with FM and other chronic pain conditions.

What have you learned from your research?

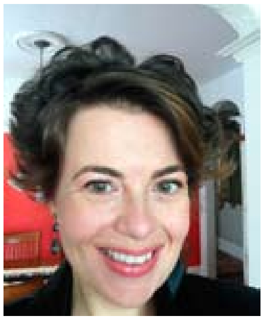
We have learned several things: first, as I mentioned above, patients with FM have disturbances in brain chemicals and release less dopamine. Second, we have seen an altered structure of the brain in FM. It appears that in younger patients with shorter disease duration there is more brain gray matter (gray matter is the part where nerve cells reside), which might be indicative that there is some inflammation. In older patients with longer disease duration, gray matter is reduced. By the way, this does not seem to be happening only in FM but also in other chronic pain conditions. Third, we have also observed that in some patients with FM, two brain structures that are really important for pain processing ‘talk’ less to each other – interestingly, those are patients who are not particularly pain sensitive. This could be some sort of coping mechanism.

What was your source of funding?

Dr Bushnell and myself held a grant from the American Fibromyalgia Syndrome Association, AFSA.

What follows from here?

I am currently trying to obtain more funding to pursue an exciting new line of research, in collaboration with my colleague Dr. Gracely at the University of North Carolina. Our fundamental supposition for this research is that the symptoms observed in fibromyalgia are not accidental but that they are mounted by the body for a purpose.



Michelle Skop

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Faculty of Social Work
Wilfrid Laurier University

Tell me a little about your background.

I have an Honors Bachelor of Arts degree in English and Women's Studies from the University of Toronto, as well as a Master of Social Work degree from Wilfrid Laurier University. As a Registered Social Worker, I worked in hospital and community-based healthcare settings before pursuing doctoral studies in the Faculty of Social Work.

How did you become interested in ME/CFS or FM?

I became interested in fibromyalgia (FM) while working as a coordinator in a home healthcare organization. I had several clients with FM who suffered from stigma within the healthcare system. I questioned whether these experiences were indicative of a healthcare trend. I subsequently reviewed some of the FM literature and was intrigued to discover that some of the themes in my clients' narratives were echoed in the qualitative research. Consequently, I pursued doctoral studies to build a program of research on the social aspects of FM.

What is your particular research focus?

In the dissertation study, I combined interviews and focus group sessions with body mapping, an arts-based research method, in order to explore the healthcare experiences of men and women with FM.

The purpose of this dissertation study was to: (a) help fill the gap in the literature by exploring the healthcare experiences of both men and women with FM; (b) examine the gendered aspects of healthcare experiences; and (c) share the findings and collaborate with stakeholders in order to potentially improve the delivery of healthcare services to Ontarians living with FM.

What have you learned from your research?

In the dissertation study, many male and female research participants reported experiencing compromised healthcare. Specifically, they encountered structural barriers, as well as a lack of empathy from healthcare providers who labelled FM as an illegitimate illness. Participants also shared innovative ideas for improving the healthcare system.

The study's preliminary findings raised interesting issues to examine in future research, including:

1. the ways in which chronic illness impact sexuality and intimacy in relationships;
2. how insurance company policies and practices impact people with FM who are on work leave;
3. healthcare providers' attitudes and practice with clients with FM;
4. how primary healthcare providers and specialists can work together to improve services for people with FM and other chronic illnesses;

Although the dissertation study is qualitative, I value the importance of conducting both quantitative and mixed methodology studies and plan to use these different approaches in future studies.

What was your source of funding?

Since 2009, I have received funding from Wilfrid Laurier University, as well as several other provincial and federal sources. For example, in 2009, 2012, and 2013, I was the recipient of Ontario Graduate Scholarships **(**Ministry of Training, Colleges and Universities). In 2011, I worked as a Strategic Training Fellow in Interdisciplinary Primary Health Care Research, Canadian Institutes of Health Research (CIHR) Strategic Training Program - Transdisciplinary Understanding and Training on Research – Primary Health Care (TUTOR-PHC). In 2010, I was awarded the Hilary M. Weston Scholarship (Ontario Ministry of Citizenship and Immigration).

What follows from here?

The dissertation study is the first in a program of applied research based on: exploring how variables of difference (e.g. gender, age class, race, and culture) intersect and shape the experience of living with chronic illnesses such as FM, ME/CFS; evaluating the availability, efficacy and cost of delivering healthcare services to populations suffering from chronic illnesses; and, building community partnerships to develop innovative, accessible, and cost-effective models for delivering healthcare services for FM and ME/CFS.

In 2015, I will organize a community art gallery to showcase the study participants' brilliant and inspiring body maps.

In January 2015, I will begin a Postdoctoral Fellowship at the University of Toronto, Department of Psychology, Laboratory of Cognitive Neuroscience and Women's Health. This opportunity will help me develop further expertise in research and teaching.

R. Nicholas Carleton

Associate Professor, Department of Psychology, University of Regina

Tell me a little about your background.

I studied the components of chronic pain for both my Masters and my Doctorate and did clinical psychology training in Alberta and Saskatchewan. I am actively involved in clinical and experimental research looking at the measurement, assessment, and treatments of pain, mood, and anxiety disorders. I believe that psychological techniques can make important contributions to a person's well-being as part of a multifaceted and holistic approach.

How did you become interested in ME/CFS or FM?

Our department here at the University of Regina has a focus on chronic pain. I am very lucky to be working with people who have made amazing contributions to pain management, such as the work that has led to better pain medication protocols following hip surgery. I have had the opportunity to meet a number of people with Fibromyalgia and, while I cannot make their Fibromyalgia go away, I hope that I can make their pain more bearable.

What is your particular research focus?

Using computer software administered in laboratories, researchers have shown that people with pain automatically (unconsciously) react to pain-related words. This makes intuitive sense because regular pain experiences will change how the brain reacts to pain. Researchers have now demonstrated that computer software can be used to change some of those automatic reactions. After using the software for only a few minutes a day, twice a week, for four weeks, people reported fewer symptoms including reduced pain. It is like teaching the brain a new way to interact with pain. The pain does not go away entirely, but it does appear the software helped to reduce the pain, which is an exciting prospect.

My study builds on this work in four ways.

- First, the protocol has been successful in only three studies, one with patients who had acute back pain, one with patients who had chronic back pain, and one with patients who had fibromyalgia. Rigorous extension and replication are required. This means more thorough initial assessments and monitoring to ensure the program is really changing the pain experience.
- Second, in all three studies the protocol was administered in laboratory settings. We want to test if it will work if we administer it via the Internet in patients' homes.
- Third, we want to know whether the protocol can also reduce physical disability.
- Fourth, we want to assess how long the changes last.

What have you learned from your research?

We are at an early stage of research, much too early to answer the specific questions in our study. That said, we have learned a great deal through our interactions with the extraordinarily patient and helpful members of the Fibromyalgia community who have participated so far. We have learned that most of our participants have become extremely adept at navigating their world in spite of the challenges they face. We have learned that there is a great diversity of approaches to managing Fibromyalgia symptoms including pharmaceutical and even surgical options as well as complementary and alternative medicine approaches.

One issue that comes up over and over is whether Fibromyalgia pain is "real". Many of our study participants have reported feeling as though people do not believe they have "real" symptoms or as though people attribute their symptoms to depression and anxiety. We believe that people with Fibromyalgia have real pain. We also believe that people with Fibromyalgia have real emotions. We aren't sure if it would possible, or even advisable, to completely separate the emotions from the pain. It is exhausting, emotionally and physically, to tolerate chronic pain. We see emotions intervening when headache patients become anxious while experiencing auras and when people with chronic lower back pain report fear just before bending over. In our study, we ask participants about pain, anxiety, and depression. Our participants are helping us understand how these factors interact.

What was your source of funding?

We were privileged to receive a grant from the Canadian Institutes of Health Research.

What follows from here?

We are looking for volunteers to participate in this study, to help us understand how helpful the protocol is for improving the lives of people with Fibromyalgia. Participants will be randomly assigned to either an active or a placebo condition. If the active condition proves helpful, we will make it freely available to all participants. For more information go to www.fibropain.ca

Biomedical Study Suggestions

In August 2014, online users of Facebook and Phoenix Rising were asked to list their suggestions for research to be done in Canada. The following is a list of their suggestions in no particular order:

Myalgic Encephalomyelitis Research Studies

1. A study of commercially available nutrients and their mechanisms assisting with ME .
2. Replicate the Japanese neuroinflamation study see www.ncbi.nlm.nih.gov/pubmed/24665088/.
3. Replicate Rituximab study done in Norway so it can be used in Canada.
4. Clinical study of the efficacy of LDN (low dose naltrexone) in ME and/or FM. It's currently used off label and many doctors are unaware of it. Objective is to have it more accessible for patients to use.
5. Clinical study of Ampligen so it can be approved for use in Canada.
6. Establish a Canadian Bio Bank for ME and FM. Some patients would like to be able to donate their bodies at death for ME/FM studies. Define and implement the criteria for autopsies and saving of tissue samples/organs and provide a mechanism for the donation of bodies at death.
7. Canadian involvement and support of Dr Lipkin's research - www.microbediscovery.org.
8. Validation and implementation of Drs Snell and Stevens 2 day exercise studies so they can be available across Canada. See www.workwellfoundation.org.
9. Fund the next steps in Dr Patrick McGowan's epigenetic research. See his recently completed study www.plosone.org/article/info:doi/10.1371/journal.pone.0104757
10. Replicate or advance the work being done by the UK Gut Microbiota projects. Professor Wileman suggested developing unbiased research using the genome sequencing facility at the Norwich Research Park, The Genome Analysis Centre (TGAC), to look at all known and unknown viruses in the faecal samples of ME patients. He introduced Professor Carding, a gut immunologist at the Institute of Food Research (IFR), to the project as the emerging science was increasingly showing that the gut microbiota played a major role in many chronic diseases." www.investinme.org/LDR UK Gut Microbiota.htm
11. A study on the number of Canadians who have ME. The Canada Community Health study numbers are based on patient reported diagnoses of Chronic Fatigue Syndrome. Test if those people have ME. Many may have fatigue that is unrelated to ME.
12. A study to see what percentage of Canadian people with ME, as defined by the Canadian Consensus Criteria (CCC), have an infectious component underlying, by funding testing for mycoplasma/Cpneumoniae/Lyme/Bartonella etc by tests that will actually pick these diseases up.......this is the first step to seeing if we can improve treatment beyond pacing and anti-inflammatory diets.
13. Research on a definitive test that would separate ME from CFS to end the confusion and ensure everyone gets appropriate treatment. There is huge debate in the patient community which gets very heated and nasty. Some think they are the same while others insist they are very different.
14. Replication of the Duffy EEG study or build on the work of Dr Flor-Henry to establish a diagnostic marker for ME. See www.biomedcentral.com/1471-2377/11/82
15. Clinical studies using existing antivirals (eg Valcyte)
16. Any project that will get us a biomarker(s).
17. Metabolome and Proteomics analysis - maybe blood gasses.
18. NK cell function studies, like the ones Dr. Nancy Klimas does. It shows how the cells are actually functioning (or not). You may have the appropriate number of NK cells but if they aren't doing much or are doing things they shouldn't, then that points to a problem.
19. Replication of the Howard, Myhill et al paper www.ncbi.nlm.nih.gov/pmc/articles/PMC3403556/
20. Studies on methylation support similar to work done by Dr Sarah Myhill (www.drmyhill.co.uk/wiki/CFS_-_The_Methylation_Cycle)

21. Use of oxygen as a treatment. Dr Deckoff Jones uses oxygen for her patients at home. (blogspot.x-rx.net) She has had one patient become quite recovered from it and her daughter has done amazingly well herself. If you read her blogs it is filled with tons of information.
22. Use of Cannabis oil to treat symptoms. The American Academy of Neurology just endorsed it for MS.
23. Study of vitamin D receptors (VDR) polymorphisms.
24. Benefits of using Low dose IVIG (or SCIg).
25. A study of POTS (postural orthostatic tachycardia syndrome) in ME patients with a view to having this become standard testing done for every patient. It is a frequent finding in patients with ME. The tilt table test can be used to detect it. Studies are needed to determine the optimum intervention strategy to manage POTS in those with ME. To elevate the fatigue and brain fog, beta blockers are often prescribed to slow the heart rate so that the left ventricle can fill with blood more efficiently. This treatment results in low blood pressure so that an antagonistic drug might be prescribed to offset the effect of the beta blocker.
26. Research to discover what the reactive proteins were that showed as antibodies in ME patients in the Judy Mikovits and Frank Ruscetti study published in SCIENCE

Fibromyalgia Research Studies

1. Clinical study of the efficacy of LDN (low dose naltrexone) in ME and/or FM. It's currently used off label and many doctors are unaware of it. Objective is to have it more accessible for patients to use.
2. Establish a Canadian Bio Bank for ME and FM. Some patients would like to be able to donate their bodies at death for ME/FM studies. Define and implement the criteria for autopsies and saving of tissue samples/organs and provide a mechanism for the donation of bodies at death.
3. A study on the number of Canadians who have FM. The Canada Community Health study numbers are based on patient reported diagnoses of Chronic Fatigue Syndrome. Test if those people have FM. Many may have symptoms that are unrelated to FM.
4. Any project that will get us a biomarker(s) and definitive diagnostic criteria.
5. Use of Cannabis oil to treat symptoms. The American Academy of Neurology just endorsed it for MS.
6. Identify the natural ways or supplements to relieve pain and manage symptoms.
7. Determine what causes the nerve endings to flare and hurt and how it can they be controlled?
8. Research to prove fibromyalgia is a disease and not a condition.
9. Identify the cause of and a solution for unrefreshed sleep (ie minimal stage 3, 4 and REM sleep).
10. Research on foods as medicine, yoga, exercise, meditation, pacing and other treatment options rather than medications. Also any of these things to avoid to minimize FM symptoms.
11. The Guaifenesin protocol needs validation.
12. Research to determine the role of infection (e.g. herpes virus, EBV, Lyme, mycoplasma-any virus or bacteria).
13. Research to determine the impacts on the brain when one has FM.
14. Determine if GMO foods are a factor in FM.
15. Research done from the cellular and neurological perspectives. A study of the possible mitochondrial deficiency and the link to serotonin and dopamine receptor dysfunctions. Also a study of a gene or polygenetic susceptibility for FM.
16. Investigation of the theory that FM sufferers have more blood vessels that interrupt nerve signals causing excess nerves signals being fired resulting in pain.
17. Determine if FM is genetic.
18. Research to determine if there is a connection between genetic flaws in methionine/cysteine uptake/processing, and FM.
19. Determine if there are more or defective sensors in the skin/muscle tissues of FM patients.

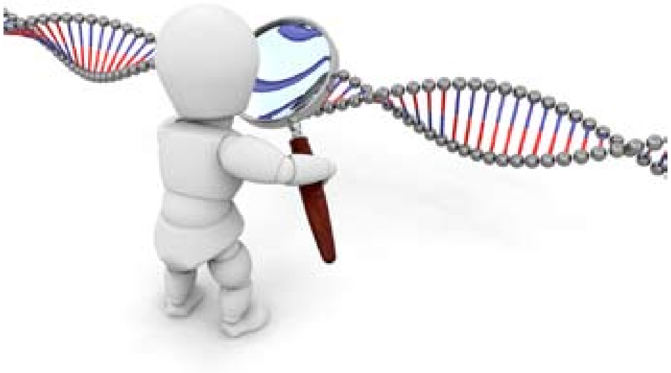
US - End ME/CFS Project

An exciting new project entitle "End ME/CFS" is getting underway at the Open Medicine Institute and they are looking for $5M per year to fund it. Here are extracts from an article by Cort Johnson found at www.cortjohnson.org/blog/2014/10/11/end-mecfs-mega-chronic-fatigue-syndrome-project-begins/:

Ron Davis PhD is the originator and leader of the project. Davis has been thinking about producing a high-level consortium to attack Chronic Fatigue Syndrome (ME/CFS) for years. His son, Whitney, has one of the worst cases of ME/CFS I've heard of.

Ron Davis PhD has directed the Stanford Genome Technology Center for twenty years. He has a long list of firsts by his name including one – using restriction fragment polymorphisms to construct genetic linkage maps – that helped launch the field of genomics in 1980 and ultimately made the Human Genome project possible. He's won numerous awards and prizes. He won the Lifetime Achievement Award from the Genetics Society of America ten years ago. PubMed lists over 500 publications for Dr. Davis. In 2013 Davis was pegged in an Atlantic Monthly article as one of eight inventors tomorrow's historians will consider the greatest inventors today.

Davis believes both the field and medicine itself are ripe for breakthroughs. He's been making the rounds telling everybody that ME/CFS is the field to be in now. This is the place to make big breakthroughs that resonate throughout the medical field. He is convinced that cracking ME/CFS will not just solve ME/CFS, but will provide key insights to the other puzzling neuro-immune disorders that dot the medical field.



Thus far Davis been able to gather a group of partners the likes of which we haven't seen before in ME/CFS. How many boards boast two Nobel Laureates?

This is a long-term effort. Don't expect answers overnight. New technologies will need to be developed. But give this Consortium the funding and time it needs and it's hard to imagine it won't succeed.

Quotes from Dr Davis:

This group should work together to design a total attack on ME/CFS and focus on understanding the disease, finding diagnostic markers, and devising treatments.

Medicine and science have neglected and misunderstood ME/CFS for so long that they really need to make up for their mistake by inspiring and supporting the most high-powered scientists available and funding a large group of experts in different fields to generate the best data and analysis possible.

The millions of suffering ME/CFS patients are owed an apology and a concerted urgent effort to find effective treatment.

US - IOM and P2P

There are two special US government activities underway around Chronic Fatigue Syndrome.

The Institute of Medicine (IOM) was hired by the Secretary of Health and Human Services to look at the definition of Chronic Fatigue Syndrome. Many experts told the Secretary it was unnecessary – the Canadian Consensus Criteria is a good foundation. Nevertheless, the IOM is proceeding.

The Pathways to Prevention(P2P) process was put in place by the US National Institutes of Health to explore questions around diagnosis and treatment. Under this process, people with fresh perspectives (i.e. unfamiliar with CFS) look at the evidence and recommend action. A team at the University of Oregon was hired ($350k) to compile the evidence around CFS to present to the committee. Their report was released in September. The report has been criticized for using too stringent criteria, resulting in many insightful studies being screened out. The panel meets on December 9th and 10th and their recommendations will be made public a few days later.

Being Ill But Looking Well

Many a time when I'm not feeling well and when asked how I am, I am hesitant to reply because I'm not sure what to say. If I say I'm having a rough day I may get a sympathetic response or gee, you could have fooled me because you look great. It's almost as if I am not permitted to look good if I'm not well. An unwritten law that states sick people have to look sick.

One day when this happened I decided to make a list of how I could make myself look sick and actually wrote down the things I thought would help. Don't wash and comb my hair, wear absolutely no make up, no matter what, don't smile, speak in a monotone with a pathetic voice, wear unbecoming clothes and walk haltingly and hesitatingly.

I had fun making the list and then started thinking about even if I were to take such drastic steps of looking the part, what would it accomplish? First of all, I would feel absolutely terrible about myself but even if I did not, would it make me feel better if people told me how terrible I looked? I realized it would not.

I started to think that maybe I was taking the person's remark out of context and decided to think about it in another way. Rather than thinking that the person means I can't be sick as I didn't look it, perhaps the person is saying it's okay, you look better than you feel. When I looked at it that way, I felt I should give myself credit for this accomplishment in that I managed not to show how difficult it was to make myself presentable. I had succeeded.

We never give ourselves credit for what we manage to do on a daily basis. The courage it takes to face a day and make the most of it. Yes, we will have days we cannot manage and days when life seems just too much and we feel we cannot go on. It takes strength to endure and for that we need to take credit. Stop thinking you have failed because you didn't finish what you started or you couldn't start at all.

The fact you tried is the important goal.

Être Malade Mais Avoir l'Air Bien

Souvent quand je ne vais pas bien et qu'on me demande comment ça va, j'hésite à répondre parce que je ne sais pas trop quoi dire. Si je dis que je ne vais pas bien, il se peut qu'on me réponde avec sympathie, mais il se peut aussi qu'on me dise que j'ai pourtant l'air vraiment bien. C'est presque comme si je n'ai pas le droit d'avoir l'air bien quand je vais mal. C'est comme s'il était interdit d'être malade sans avoir l'air malade.

Une journée où ça m'était arrivé, j'ai décidé de faire une liste de façons d'avoir l'air malade, j'ai vraiment écrit des moyens à prendre. Ne pas me laver, ne pas me coiffer, ne pas me maquiller, ne jamais *jamais* sourire, parler d'une voix sans inflexion sur un ton pathétique, porter des vêtements laids, marcher à petits pas hésitants.

Je me suis bien amusée mais ça m'a amenée à me demander : si je prenais des moyens aussi dramatiques pour avoir l'air de ce que je suis, ça donnerait quoi ? D'abord, je me sentirais vraiment mal et, sinon, est-ce que ça m'aiderait si les gens me disaient que j'ai l'air horrible ? Je me suis rendu compte que non.

J'en suis venue à penser que je sortais peut-être la remarque de son contexte et que je devrais l'envisager d'une autre façon. Au lieu de penser qu'on me dit que je ne peux pas être mal puisque je n'ai pas l'air mal, peut-être que ce qu'on me dit vraiment, c'est que je n'ai pas l'air *si* mal. Vu de cette façon, je peux me féliciter : je suis arrivée à cacher les difficultés que j'ai à être simplement présentable. En fait, c'est une réussite.

Nous ne nous accordons jamais assez de crédit pour ce que nous arrivons à faire jour après jour. Le courage qu'il nous faut pour entreprendre notre journée et faire le maximum. Oui, il y aura des jours où nous n'y arriverons pas, et des jours où il nous semblera que la vie est tout simplement trop dure et que nous n'en pouvons plus. Il faut de la force pour résister, et nous devons nous en accorder le crédit. Cessez de penser que vous avez échoué parce que vous n'avez pas pu finir ce que vous aviez commencé ou parce que vous n'avez même pas pu commencer.

Vous avez essayé : c'est ça, l'objectif le plus important.

Lydia Neilson

Final Note

The theme of this newsletter has been Research and Researchers. We have talked about the current research situation and introduced you to four Canadian researchers. We have talked about the need for the Canadian Institutes of Health Research to get more involved. We would like to encourage you to get more involved too. There are many ways you can encourage research and knowledge translation (putting research into practice). You can volunteer for studies. You can donate to us – we are a registered charity and can issue tax receipts. You can help us raise funds by voting for us in on-line contests and encouraging others to vote. You can help raise awareness of the needs of the ME/FM community among those around you. You can support the Network by sharing your thoughts and ideas. You can provide moral support to researchers by thanking them for their interest in this topic. With everyone working together, we will move forward.

Margaret

http://twitter.com/mefmaction

http://www.facebook.com/MEFMActionNetwork

NATIONAL ME/FM ACTION NETWORK

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Resources

Item	Qty	Total
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FM Brochure *free*		
ME/CFS Overview $7.00		
FM (Eng) Overview $7.00		
FM (Fr) Overview $7.00		
TEACH-ME (Eng) $22		
TEACH-ME (Fr) $22		
QUEST $38 Collection II		
QUEST $38 Collection III		
CPP Guide $10		
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 and also covers support matters such as treatment and happenings in other groups.

ME/CFS and FM Brochures - FREE

Coloured pamphlets on ME/CFS and FM are available in English or French. Please specify if you would like copies in French.

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.com

ME/CFS and FM Overviews - $7.00 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.com

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

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.

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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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.

**Tax Receipt issued for all donations.*

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Please see reverse.

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512-33 Banner Road
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THANK YOU FOR YOUR SUPPORT!

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