NATIONAL ME/FM ACTION NETWORK

Quest Newsletter

www.mefmaction.com Quest 115, Summer 2018 mefminfo@mefmaction.com

Montreal Conference

Four of us officially represented the National ME/FM Action Network at the ME/CFS conference in Montreal May 3-5 – Lydia Neilson (founder and CEO), Sherri Todd (director), Anne Marie MacIsaac (director) and me. There were 250 researchers, clinicians and patients and caregivers attending in person. There were people from Canada, the US, the UK, Sweden, Germany, Australia and Finland. Another 70+ people signed up to listen to day 2 on line.

On the morning of May 3, the four of us met with Dr Karim Khan, Scientific Director of the Institute of Musculoskeletal Health and Arthritis of the Canadian Institute of Health Research, along with Tanya Gallant his acting assistant director and Marilyn Desrosiers a manager in CIHR's external affairs group. People from Millions Missing Canada and MEFM BC were in the room already. We talked about unmet needs and the consequences of the poor science that has plagued ME/CFS. We stated the position of the National ME/FM Action Network – that CIHR should be funding ME/CFS research at the level of at least $10M/year not counting retroactive entitlement. (We think that FM research should receive that much also!) We noted that seed funding for networks, followed by project funding, appears to be a workable method to launch research. We asked ourselves if there were enough topics for networks, and had no trouble suggesting a substantial number of topics. Dr Khan showed keen interest in our ideas and talked about meeting with us again soon.

On the afternoon of May 3, the National ME/FM Action Network organized a workshop on meeting unmet needs. We were fortunate to have patient representatives from six provinces in the room. We were also fortunate that health professionals from three provinces joined us since they have important perspectives on the issues. A big thank you to Margaret Soden who helped organize and run the workshop, all on a volunteer basis.

Contents

Unrest Screening in Montreal

A screening of the documentary film Unrest was held in Montreal on May 3rd coinciding with the ME/CFS research conference.

After the film was a discussion session with guest panelists Nancy Klimas, M.D. (Institute for Neuro Immune Medicine), Vicky Whittemore (United States National Institutes of Health), Scott Simpson (Millions Missing Canada) and Cort Johnson (Health Rising).

A video recording of the panel discussion is available at the following link:

https://www.youtube.com/watch?v=fBO7dtXhnvE

Our launching point for the workshop was the interim report of the Ontario Task Force on Environmental Health. We were fortunate that Dr Ray Copes, the Ontario Task Force chair, was able to attend. Prior to the workshop, we had offered people the opportunity to comment on the interim report. Over 20 written comments were received and a document compiling them was passed to Dr Copes at the workshop. Generally, people found that the report did a very good job of listing the steps needed to improve services and then the people added suggestions and observations. The workshop discussion followed the same positive lines.

The interim report talked about the importance of agreeing on diagnostic and treatment protocols and of having a model of care for Ontario. These are indeed needed for all provinces and territories. There was general discussion of diagnostic and treatment protocols and then the workshop split into three groups to discuss care pathways. The groups were each given a flipchart to record their thoughts. At the end of the workshop, people were quickly asked to identify next steps which were recorded on another flipchart. These are complex topics that deserve careful discussion, but hopefully the complexity will not be used as an excuse for inaction.

Dr Copes had planned to leave at 4 pm, but he was so interested he delayed his flight home so he could stay to the end.

In the evening, Lisa Schneiderman organized a screening of Unrest with the double goal of raising awareness and raising money. She raised over $13,000, with some going to Millions Missing Canada, some to Dr Moreau's research, and some to the National ME/FM Action Network. We would really like to thank Lisa for her initiative.

Friday May 4th started with welcoming statements. The lead speaker was Jennifer Brea (via video). Nobody from the Canadian federal government provided opening remarks, indicating that the federal government is still not comfortable with ME/CFS. Special awards were given to two leading Montreal doctors, Dr Denis Phaneuf and Dr Richard Morisset who have worked in the ME/CFS area for years. This was followed by presentations by Dr Byron Hyde and Dr Ron Davis.

The groups then split into professional and patient/caregiver sessions. The latter session had a range of presentations. I gave one making many of the same

In Attendance

Left to right:

Dr Louise Neuendorff-El Helou (MacMac-Master University)

Marilyn Desrosiers (CIHR),

Scott Simpson (Millions Missing Canada)

Adam Ladak

Dr Ron Davis (Open Medicine Foundation)

Dr Alain Moreau (Université de Montréal, conference Organizer)

Jane Seary

Sabrina Poirier

Dr Nancy Klimas (Nova Southeastern University)

Unrest Screening Discussion Panel

Cort Johnson, Dr Nancy Klimas, Dr Vicky Whittemore, Scott Simpson

At the Unrest Screening

David Schneiderman

Linda Titleman

Lisa Schneiderman

Carol Head (President Solve ME/CFS Initiative)

Margaret Parlor (President National ME/FM Action Network)

From the National ME/FM Action Network

Sherri Todd (Direstor)
Lydia Neilson (CEO)
Margaret Parlor (President)
Anne Marie MacIsaac (director)

Patient Advocates

Back: Kevin Mejo (AQEM), Valérie Miller (AQEM) Elizabeth Sanchez (ME/FM BC), Nicole Choptain (ME Manitoba), Gloria Gray (ME Victoria), Sherri Todd (National ME/FM Action Network), Neill Shewan (Action CIND),

Front: Bev Friesen (ME Manitoba), Alison Rae (Action CIND), Diane Ching (ME Edmonton), Anne Marie MacIsaac (National ME/FM Action Network)

points as for the CIHR meeting the day before. Dr Stein and a patient-based team gave another talking about patient education. At the end of the day, we heard patient/caregiver representatives from the Victoria, BC, Edmonton, Manitoba and Quebec ME groups along with Millions Mission Canada, Action CIND, the Open Medicine Foundation (US) and Solve CFS/ME (US).

On the morning of Saturday May 5th, there was a session bringing together patients/caregivers, clinicians and researchers to discuss how to move research forward together. I gave a presentation describing how Lydia was able to bring people together to create the consensus criteria for ME/CFS and FM and then describing how the network is trying to open up conversations around health services, around CIHR funding and around supporting researchers.

As could be expected with a topic as broad as moving research forward, the discussion was stimulating but scattered so there will be a need to draw it together. There seemed to be great interest in the European model Euromene, the European ME research network http://www.euromene.eu/ I suspect it will be a model for a Canada/US collaboration. Time will tell.

I asked several attendees coming away from the conference what had surprised them. One said that she was surprised by the breadth of the issues, another said that he was surprised by how much cause there is for hope, and a third said that she was surprised by how much is already known about ME/CFS. My own reaction was how exciting it is to be moving forward, but also how much work will be needed to overcome the inertia and misdirection of the last several decades.

All in all, the conference was high quality and exciting. Many thanks to Dr Moreau and his organizing committee for their fantastic work.

Margaret

A Fair Research Program

In discussions with CIHR on Day 1 and at the conference itself, I talked about building a fair research program.

What is fair funding for a disease area? This is not a simple question but generally it should be based on the national impact of the illness. Other that factors might be considered including how much benefit is expected from the investment, the international impact and historical factors. Unfortunately in the past, funding appears to be supply driven – going to where research is most organized. Researchers and private funders do not generally gravitate to stigmatized areas. Related to this, funding also appears to be gender driven with male dominated diseases receiving more funding than female dominated diseases.

Back in 2012, looking at per capita spending for diseases with comparable impact, I suggested that CIHR should be allocating $10M/ year to ME research, and the same to FM research. This does not include retroactive entitlement for years of underspending or other special considerations. Funding has been running at around $100k per year for ME and for FM in recent years. The US National Institutes of Health calculated the illness burden for a number of illnesses. An ME team calculated the equivalent illness burden for ME, plotted the illness burdens against NIH funding, and calculated the appropriate funding for each illness. ME should be receiving $188M/year, which compares unfavourably to the $13M/year it is currently receiving. The NIH funds more research than CIHR, leaving the $10M estimate for Canada looking extremely reasonable.

How can CIHR get ME funding from $100k per year to $10M/year?

The answer seems to be to offer small grants for meetings to build research ideas or for small studies, followed quickly by larger grants for follow-up work. The Montreal conference was funded primarily by a small ($70k) CIHR research grant and there was a recent announcement of a $355k/year for 5 year funding competition.

$355k/year is progress, but we would need 28 of these grants to get to $10M.

Interestingly, CIHR recently announced a funding opportunity for a Lyme disease network at $1M/year for 4 years. We would need only 10 of those grants to get to $10M.

The question becomes - are there multiple research opportunities in the ME area?

The answer is yes. A colleague with CIHR experience and I had no problem coming up with multiple themes or “mandates”. Several of these (notably the first an second) could be broken down into multiple grants. And the different areas would appeal to different kinds of researchers so we would minimize having the same people on all the projects.

- Cause biomarkers and subgroups
- Treatment
- Assessing prevelance
- Clinical diagnosis
- Pediatrics and youth
- Longitudinal studies/Evolution of disease
- Co-morbidities
- Exertion Intolerance/Post Exertional Malaise
- Functional capacity, employment and income security
- Care pathways
- Social isolation
- Education/Awareness

Interestingly, we learned later that CIHR talks about 4 pillars of research which tie into the ideas we put forward - biomedical; clinical; health services; and social, cultural, environmental and population health research. We also learned that the European ME research network of 20 countries has five working groups (plus one on researcher development) that cover a similar range of topics: epidemiology; biomarkers; socio-economics; clinical research enablers and diagnostic criteria; and dissemination and exploitation. This tells us that we are on the right track.

The key message is that we want fair funding, and there is a path to fair funding for ME within years rather than decades, and that strategy is based on building a holistic research program.

And the same type of strategy is needed for FM.

Co-Morbidities

One of the theme areas we identified for further research is the issue of co-morbidities – when people have ME or FM, what other medical conditions could they have? And what are the consequences?

We have a starting point for discussion. The Canadian Community Health Survey (CCHS) asks people if they had been diagnosed with certain chronic conditions – Chronic Fatigue Syndrome, Fibromyalgia, Multiple Chemical Sensitivities, anxiety, arthritis, asthma, etc. Respondents can answer yes or no to each of these conditions.

The Network has compiled the following table based on the CCHS Public Use Microdata Files for 2010 and 2014. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network. Information about the CCHS can be found on page 12 of the insert to Quest 108.

The table has been subdivided into four sections for ease of reading. The figures show what percent of people with a diagnosis of the chronic condition in the first column have the additional diagnoses shown across the top. For example, 29.2% of people reporting a diagnosis of CFS also reported a diagnosis of FM in the 2014 survey and 22.9% of people reporting a diagnosis of FM also reported a diagnosis of CFS.

On average, people reporting a diagnosis of CFS or FM reported an additional five diagnoses from the list. The most common additional diagnoses were back problems and arthritis, but CFS and FM showed some overlap with every chronic condition on the list.

Let's look at arthritis to illustrate how the data can be used. The statistics show that 50.9% of people with a diagnosis of CFS and 64.6% of people with a diagnosis of FM also had a diagnosis of arthritis in 2014. This means that health care providers treating people with CFS and FM need to be knowledgeable about arthritis. Coming from a different direction, among people diagnosed with arthritis, 4.3% had an additional diagnosis of CFS and 6.8% had an additional diagnosis of FM. This means that health care providers treating people with arthritis need to be knowledgeable about CFS and FM.

The data show that people with a diagnosis of CFS are three times more likely than the total population to have a diagnosis of arthritis (50.9%/16.5%). People with FM are four time more likely than the total population to have a diagnosis of arthritis (64.6%/16.5%). Why this is the case needs to be explained. Is it because the conditions genuinely occur together? Is it because the definitions of CFS, FM and arthritis overlap? Is it because health providers are more likely to diagnose arthritis when somebody already has a CFS or FM diagnosis or when the symptom of pain is raised?

Having two years of data helps interpret the data. Because the CCHS is based on a sample, some variability is to be expected. Data changes may also reflect actual events. In interpreting this data, please refer to the time series analysis done in Quest 112 where we discussed changes in

The proportion (%) of Canadians with chronic conditions having additional diagnoses, CCHS, 2010, 2014

Chronic Condition	Chronic Fatigue Syndrome		Fibromyalgia		Multiple Chemical Sensitivities		Anxiety Disorder		Arthritis	
	2010	2014	2010	2014	2010	2014	2010	2014	2010	2014
Chronic Fatigue Syndrome			23.1	29.2	23.4	15.1	32.6	36.8	50.8	50.9
Fibromyalgia	21.6	22.9			16.4	14.0	19.3	26.6	56.2	64.6
Multiple Chemical Sensitivities	11.9	8.5	9.0	10.0			17.4	18.6	39.5	40.1
Anxiety Disorder	9.0	7.1	5.7	6.5	9.4	6.4			28.3	26.6
Arthritis	4.7	4.3	5.6	6.8	6.9	5.9	9.1	11.4		
Asthma	3.3	3.3	4.2	4.8	7.5	8.2	10.6	14.5	24.7	24.8
Back Problems	3.7	4.3	4.4	5.8	6.3	4.9	10.4	12.5	37.3	37.0
Bowel Disorder	8.2	7.2	7.2	9.8	8.8	8.5	15.6	17.9	37.1	34.2
Cancer	5.5[E]	4.8[E]	3.0[E]	3.5[E]	5.4[E]	4.8[E]	6.7[E]	8.5[E]	40.6	36.5
COPD	7.8	8.9	6.1[E]	10.7	10.5	8.8	15.3	16.4	47.8	50.2
Diabetes	2.9[E]	3.7	2.6[E]	3.7	4.1	3.7	6.0	7.3	35.5	35.3
Effects of a Stroke	7.7[E]	15.3[E]	6.4[E]	7.7[E]	8.7[E]	7.0[E]	13.8[E]	14.8[E]	48.1	40.5
Heart Disease	4.6	4.8	3.4[E]	4.3	5.6	4.4	8.2	10.8	45.0	42.4
High Blood Pressure	2.7	2.7	2.5	3.0	4.5	3.9	6.5	8.9	35.7	36.4
Migraine Headaches	4.8	4.7	4.1	5.5	6.8	6.5	13.2	17.1	22.2	22.7
Mood Disorder	8.7	7.4	5.8	7.3	7.6	6.4	35.2	42.7	30.5	29.4
Scoliosis		4.8[E]		5.5[E]		5.5[E]		12.6		27.5
Stomach or Intestinal Ulcers	8.6	8.1	5.2[E]	10.4	10.0	7.0[E]	16.6	20.6	37.0	39.8
Urinary Incontinence	9.0	7.8	5.3[E]	8.3	8.4	7.4	13.3	16.2	51.2	52.0
Total Population	1.4	1.4	1.5	1.7	2.8	2.4	5.2	7.0	16.1	16.5

Chronic Condition	Diabetes		Effects of a Stroke		Heart Disease		High Blood Pressure		Migraine Headaches	
	2010	2014	2010	2014	2010	2014	2010	2014	2010	2014
Chronic Fatigue Syndrome	13.1	18.2	5.9[E]	12.2[E]	16.2	17.3	32.8	35.8	33.8	33.5
Fibromyalgia	11.1[E]	14.5	4.5[E]	4.9[E]	11.2[E]	12.4	28.7	30.8	26.9	30.8
Multiple Chemical Sensitivities	9.3	10.3	3.4[E]	3.2[E]	10.0	9.1	28.0	29.1	24.5	26.2
Anxiety Disorder	7.4	6.9	2.9[E]	2.3[E]	7.9	7.5	21.7	22.5	25.6	23.5
Arthritis	14.6	14.7	3.3	2.7	14.4	13.0	39.5	40.3	13.8	13.4
Asthma	7.1	9.1	1.7[E]	1.8[E]	5.8	6.6	20.2	20.6	18.0	16.7
Back Problems	9.5	10.6	1.9	2.1	9.0	8.7	26.5	27.2	18.7	17.9
Bowel Disorder	7.9	9.8	3.2[E]	2.7[E]	10.8	7.6	23.5	22.8	21.0	21.3
Cancer	17.0	13.3	4.6[E]	4.2[E]	18.6	16.0	37.6	36.4	12.3	9.3[E]
COPD	15.5	19.0	5.6[E]	5.7[E]	18.6	21.9	38.3	42.0	17.8	18.5
Diabetes			4.3	4.0	19.0	17.5	56.5	57.9	8.2	8.0
Effects of a Stroke	25.6	24.9			36.6	35.8	62.2	62.2	15.2[E]	14.4[E]
Heart Disease	24.4	23.6	7.9	7.8			57.9	57.1	10.1	9.0
High Blood Pressure	21.1	21.9	3.9	3.8	16.8	16.0			9.7	8.9
Migraine Headaches	5.3	5.5	1.6[E]	1.6[E]	5.0	4.6	16.7	16.3		
Mood Disorder	9.5	9.7	2.7[E]	2.3[E]	8.3	7.1	22.4	23.7	26.0	22.9
Scoliosis		5.6[E]		2.1[E]		6.6[E]		17.8		19.1
Stomach or Intestinal Ulcers	10.9	11.1	4.2[E]	4.3[E]	14.4	14.2	32.3	29.8	25.2	25.0
Urinary Incontinence	18.9	17.4	6.6	6.1	20.3	19.7	46.5	46.1	13.2	13.2
Total Population	6.4	6.7	1.1	1.1	5.0	4.9	17.1	17.7	10.0	9.7

Source: Statistics Canada, Candian Community Health Survey, 2010, 2014, Public Use Microdata Files

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

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

Chronic Condition	Asthma		Back Problems		Bowel Disorder		Cancer		COPD	
	2010	2014	2010	2014	2010	2014	2010	2014	2010	2014
Chronic Fatigue Syndrome	19.6	19.9	49.5	57.6	24.6	23.8	7.4[E]	6.5[E]	18.1	19.8
Fibromyalgia	23.2	22.8	54.7	60.3	20.3	25.4	3.8[E]	3.7[E]	12.1[E]	17.7
Multiple Chemical Sensitivities	22.7	27.6	42.8	36.5	13.6	15.8	3.7[E]	3.7[E]	12.9	11.6
Anxiety Disorder	17.3	16.8	38.0	31.9	13.0	11.6	2.5[E]	2.2[E]	12.6	10.0
Arthritis	12.8	12.2	45.4	41.3	10.2	9.5	5.0	4.2	9.0	8.8
Asthma			29.8	28.0	7.5	8.4	2.5	2.0[E]	19.5	19.6
Back Problems	13.3	12.7			8.6	9.4	3.4	3.0	8.6	7.6
Bowel Disorder	14.9	15.3	37.9	37.7			4.7	3.2[E]	10.2	10.9
Cancer	11.0	8.9[E]	33.7	29.4	10.6	7.8[E]			10.0	12.2
COPD	34.8	36.7	48.0	41.5	12.3	14.0	6.7[E]	8.0		
Diabetes	9.4	11.1	28.3	28.5	5.3	6.6	5.1	3.7	7.1	7.9
Effects of a Stroke	13.4[E]	13.4[E]	33.8	34.3	12.7[E]	10.9[E]	8.2[E]	7.0[E]	14.7[E]	14.6[E]
Heart Disease	9.9	11.0	34.5	31.6	9.4	7.0	7.2	5.9	10.8	12.3
High Blood Pressure	9.9	9.4	29.2	27.5	5.9	5.8	4.2	3.8	6.5	6.5
Migraine Headaches	15.3	14.0	35.5	33.2	9.0	9.9	2.4	1.8[E]	7.8	7.8
Mood Disorder	17.2	16.0	37.2	35.5	13.5	12.7	2.9[E]	2.6	11.6	11.3
Scoliosis		13.4		51.6		12.1		2.2[E]		8.4[E]
Stomach or Intestinal Ulcers	14.3	14.0	43.6	43.7	20.5	23.4	4.1[E]	3.5[E]	13.1	12.4
Urinary Incontinence	12.4	13.2	45.6	38.5	18.1	16.1	7.9	6.2	13.0	11.2
Total Population	8.5	8.1	18.9	17.9	4.3	4.5	1.9	1.8	4.3	4.0

Chronic Condition	Mood Disorder		Scoliosis		Stomach or Intestinal Ulcers		Urinary Incontinence	
	2010	2014	2010	2014	2010	2014	2010	2014
Chronic Fatigue Syndrome	39.8	42.3		10.8[E]	16.9	14.9	21.5	21.0
Fibromyalgia	24.6	33.0		9.7[E]	9.7[E]	15.1	11.3[E]	17.2
Multiple Chemical Sensitivities	17.8	20.7		7.0[E]	10.2	7.3[E]	10.4	11.5
Anxiety Disorder	44.5	47.2		5.4	9.1	7.3	9.8	10.2
Arthritis	12.8	14.1		5.1	6.7	6.2	10.8	11.4
Asthma	13.2	15.4		5.0	4.7	4.3	6.3	7.3
Back Problems	12.8	15.4		8.8	6.5	6.1	8.4	8.1
Bowel Disorder	20.5	22.2		8.2	13.5	12.6	14.6	13.2
Cancer	9.8	11.2		3.6[E]	6.0[E]	4.7[E]	13.2	12.0
COPD	19.6	23.3		6.6[E]	11.0	9.2	14.5	14.3
Diabetes	9.7	11.3		2.5[E]	4.8	4.1	9.6	9.2
Effects of a Stroke	16.3	16.7[E]		5.8[E]	11.1[E]	9.9[E]	19.5	20.1
Heart Disease	10.9	11.2		4.0[E]	8.2	7.2	13.3	14.2
High Blood Pressure	8.6	10.4		3.0	5.3	4.2	8.8	9.1
Migraine Headaches	16.9	18.4		6.0	7.1	6.5	5.2	5.7
Mood Disorder				5.5	7.8	6.3	10.7	10.1
Scoliosis		14.1				5.3[E]		8.0
Stomach or Intestinal Ulcers	18.1	19.6		6.4[E]			13.2	14.8
Urinary Incontinence	19.4	19.4		5.9	10.8	10.0		
Total Population	6.5	7.8		3.0	2.8	2.5	4.0	4.3

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

Row totals are greater than 100% due to people having more than one additional diagnosis

Missing responses were excluded from the calculations

the diagnostic criteria for FM and we expressed concern about the 2014 sample for MCS. Also note that there was a lot of emphasis on mental health between 2010 and 2014 which would likely explain their higher overall rate of diagnosis for anxiety and mood disorders.

Some of the figures for 2010 are slightly higher than those published in a co-morbidity table found in Quest 98. This is simply due to the fact that we included non-responses as no in the Quest 98 table but did not include non-responses in this table. This brings our methodology in line with that used by Statistics Canada.

Where do we go from here?

The quality of the data need to be investigated. What we want to know is real-life overlap of conditions. What the survey shows is co-diagnoses. Co-diagnoses would be the same as co-morbidities if every condition was diagnosed correctly.

This is basic analysis, which is a good place to start. The likelihood ratios would be expected to change if the table were adjusted for age and gender. Arthritis is generally found in seniors while CFS and FM predominate in people of working age. Therefore, the risk of arthritis among working age people with FM may be somewhat higher than four times.

This table focuses on pairs of conditions. Additional analysis could be done to look at clusters of diagnoses. One study has been done adjusting for the number of co-diagnoses and it showed that the CFS and FM diagnoses were influential. See "Chronic fatigue syndrome and fibromyalgia in Canada: prevalence and associations with six health status indicators" C Rusu, ME Gee, C Lagacé and M Parlor, 2015.

Health providers need to understand how to disentangle the various conditions to give the patient the best diagnosis for moving forward. The Psychiatrist Guide to ME/CFS by Dr Stein is a guide on disentangling ME/CFS, mood disorders and anxiety disorders. This guide makes an excellent model of the types of information needed for all the overlapping co-diagnoses.

The bottom line for patients is that ME and FM bring with them multiple symptoms and that people can have other medical diagnoses as well. It is important to understand the full medical picture and to understand how the various symptoms interact.

Feedback on Ontario Task Force Report

For our workshop in Montreal, we invited people to comment on the Ontario Task Force Report. We received two dozen replies. These were packaged and presented to the Task Force Chair. You can read the full comments online. This is a quick overview.

There was general consensus that the current health care system is dysfunctional and that the report identified very important actions for change.

The importance of dealing with stigma was raised over and over. People emphasized that this is a real illness, that acceptance is needed, and that stigma is a burden to individuals.

The importance of professional training was raised over and over. Also raised was the need for information to patients, caregivers and the public.

It was questioned whether "environmental illnesses" is an appropriate umbrella term. It was also questioned whether the three illnesses, ME/CFS, FM and ES/MCS could indeed be lumped together.

When it came to diagnostic protocols, there was strong reaction. The task force was advised not to repeat work already done or to take undue time seeking the prefect product. There was also emphasis that this is a national issue and Ontario should not go it alone.

There were many suggestions of areas that need more thought, including the availability of testing, the availability of aggressive treatments, poverty, housing, isolation, home care, the consequences of post-exertional malaise ("exercise can kill you"), use of the media, quiet areas in hospitals, telemedicine to avoid having to travel and the role of support groups.

It was suggested that a human rights specialist be added to the task force.

It was suggested that a processes are needed to ensure patients are not treated poorly or refused diagnosis, testing or treatment, and that a process is needed to correct incorrect medical records.

Very importantly, the issue of money came up. How should doctors be paid? But also it was also pointed out that a business case can be made for implementing changes since money is currently being wasted on ineffective appointments and testing with the societal cost of the illnesses are staggering.

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WORKWELL FOUNDATION

Opposition to Graded Exercise Therapy (GET) for ME/CFS

Dear Health Care Provider, May 1, 2018

We are greatly concerned by the promotion of graded exercise therapy (GET) as an intervention for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) [1]. Our experiences working with ME/CFS patients are that graded exercise aimed at training the aerobic energy system, not only fails to improve function, but is detrimental to the health of patients and should not be recommended.

Graded exercise therapy mistakenly assumes that ME/CFS fatigue and disability result from inactivity and deconditioning [2]. However, exercise as treatment seems counterintuitive when the hallmark of ME/CFS is a distinctive post-exertional malaise or PEM, whereby even minimal mental or physical exertion leads to symptom exacerbation and reduced function [3]. ME/CFS is not deconditioning nor are its symptoms explained by inactivity. It is a complex, multi-system disease involving neurological, immunological, autonomic, and energy metabolism impairments [4]. The debility in ME/CFS is much greater than is seen with deconditioning [5].

Scientific studies have demonstrated that even mild exercise can provoke ME/CFS symptoms [6]. This low tolerance for physical activity is typified by an abnormally early transition to anaerobic metabolism [7]. In ME/CFS the aerobic energy system does not function normally. Physical exertion elicits a reaction so distinctive that many researchers, including the National Institute of Health's ME/CFS Intramural Study [8] and Cornell's Collaborative ME/CFS Research Center [9], use exercise, not as a therapy, but as a way to aggravate the illness so that it can be studied.

Indications of metabolic dysfunction in ME/CFS suggest that limiting sustained activity whenever possible is a more reasonable therapeutic approach. This minimizes risk of relapse. We contend that listening to patients provides evidence-based support for interventions that help rather than harm. Management programs for ME/CFS patients should first aim to reduce and stabilize symptoms before increasing activity levels. We believe this is best achieved through pacing that utilizes energy conservation techniques mindful of heart rate limits. Only then can careful training of the anaerobic energy system, (i.e., improving the body's tolerance for and ability to clear lactate while increasing ATP in resting muscle) be initiated [10].

This letter is motivated by concern about the potential harm to ME/CFS patients from GET. The views expressed here reflect the experiences of many ME/CFS patients, which we feel are well supported by the scientific literature.

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Findings from the Quest 114 Questionnaire

In the last Quest newsletter, we included a questionnaire. We wanted to learn more about individual experiences with ME/CFS and FM.

We would like to thank the 10 people who have responded so far. The replies were thoughtful and helpful. It was exciting was to receive some of the responses by regular mail and phone. This means that we heard from people who often are not heard.

Illness Onset

The Institute of Medicine's 2015 report from a panel of experts noted that many cases of ME/CFS go undiagnosed for long periods of time. The panel therefore thought about tools to help health care providers recognize possible cases of ME/CFS much earlier. The IOM panel suggested that health care providers look for reduction in pre-illness activities, fatigue that is not lifelong, etc.

The questionnaire asked people how they described their condition during the pre-diagnosis stage.

Some people talked about the onset being a flu or a cold or an injury or mono. Some people talked about simply having difficult at school or work. Everyone talked about additional symptoms. The symptoms mentioned included pain, chronic flu or colds, poor sleep, low energy, headaches, stiffness, tremors, bowel issues, slurred speech, cognitive impairment, stress, fevers, nausea, vomiting, weakness, exhaustion, need to lie down, chest pain, shortness of breath, rashes and anxiety. One person described the pre-diagnosis stage as exhaustion and a collection of disabling symptoms that did not make much sense but were very much real. Another person described the pre-diagnosis stage as confusing and a living hell. Two others talked about new symptoms appearing and the difficulty explaining the problems.

Diagnosis/IOM

The questionnaire explored whether people would have been diagnosed sooner if the IOM criteria were used.

Some of the respondents said that, with the IOM criteria, they would have been diagnosed earlier which would have helped them to avoid many problems down the road. But overall people who responded pointed out that it was not so simple.

Concerns were raised around the wording in the IOM criteria. One person pointed out the wording overlaps with descriptions of depression. Someone was told she did not qualify because she had symptoms in childhood so the fatigue was not new. Someone suggested that pain and muscle fatigue be included in the criteria. Someone would put more emphasis on pain, fatigue and concentration difficulties on exertion. People seemed to use the terms exhaustion, tiredness and low energy rather than fatigue.

Concerns were also raised around the awareness and sensitivity of health professionals. One person noted that she has found only one doctor (now retired) who believes in ME/CFS. Another noted that the criteria are useful only if physicians are aware of it. Someone else noted that definitions and protocols are only as good as they are understood and utilized. One person pointed out that diagnosis would not be made if the health care provider did not take the time to listen to the patient recounting the symptoms and another said a diagnosis would not be made if a doctor denies the illness.

On the question whether similar criteria could be used to identify FM cases, there was relatively little feedback. However, considering that several people identified pain as an early symptom, let me hypothesize that if the IOM criteria were modified to include pain, additional cases would be captured, though that would require sorting out ME and FM cases at the next stage.

The conclusion I came to reading the replies is that the concept of screening criteria has merit but this is an area that needs professional study – social scientists and clinicians looking at how patients start their journey, how they communicate their symptoms and what health providers hear. One of the respondents came to a similar conclusion stating that more patient stories might help train doctors about how different patients explain their illness and the different ways the illness presents in the spectrum and over time.

Post-exertional malaise with FM?

The questionnaire asked people with a diagnosis of FM (and not ME) if they experience post-exertional malaise. Generally respondents had both ME and FM. One respondent stated that she had both and added "I think the post-exertion malaise from FM is signified by my legs feeling "vibrating" with pain at the end of every day even from just ordinary around the house activity ... I think the post-exertion malaise from CFS is more signified by the "buzzing" I get in my head after exposure to phone

calls, visitors, or when I have to go out. Also the inability to "turn off" the brain from thinking." Another person wrote "I don't know why they separate them because pain is exhausting." One person with FM only said that exertion resulted in fibrofog - extreme pain and not being able to get out of bed for days.

Family doctors or specialists?

The questionnaire asked – 1) Do you think that family doctors can meet the needs for ME/CFS and FM patients? And 2) Rheumatologists question whether they provide value to patients In your experience, do specialists provide value to patients, How?

In answering this section, some people looked at how things currently are. Two people talked about a being disbelieved by family doctors and one of them added "I eventually fired his ass". Another pointed out that family doctors are too rushed and are confused by the issues. Two people noted that family doctors are limited in the procedures they can implement or the tests they can order. Another person observed that specialist don't look at patients as a whole, just a part. Another talked about getting a diagnosis from a specialist, and no further help. Yet another talked about how family doctors refer patient to specialists who don't do anything, so time is spent and the patient is no further ahead.

Some people talked about how things could be. Several people thought that family doctors could help if they had training and interest. One person noted that family doctors need to be able to at least screen for the disease.

The strongest statement was as follows – Can family doctors meet the needs of patients? Hell no. Would you like your family physician to manage your chemotherapy should you get diagnosed with cancer? ME and FM deserve a medical specialty for many reasons. The perks of belonging to a medical specialty is to actually interact with experts in the field, physicians who are focusing in these diseases, attending conferences and hopefully participating in research and clinical trials. Family practice will never ever move us forward. Each family doctor may have one or 2 patients with ME – not enough for them to get education and feel comfortable in deciding treatments. We will never move forward if there is not medical specialty assigned to our diseases. How do specialists provide value? 1) expertise, 2) time 3) advocacy 4) expertise and assistance with disability papers 5) validation 6) rule out other diseases.

Thanks to everyone for their very insightful comments.

May 12th Awareness

Into the Light - An ME/FM Awareness Event with the P.E.I Lieutenant Governor

P.E.I. Lieutenant Governor, Madame Antoinette Perry, hosted an information and awareness session on May 16, 2018 at Government House. Entitled Into the Light, the event shone light onto ME and FM , two of the most prevalent illnesses in the world yet largely unknown.

Dolores Griffin, Her Honour Antoinette Perry, Dr. Jonathan Fox

Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS) is a debilitating illnesses characterized by persistent post exertional malaise and numerous other symptoms related to cognitive, immune and autonomous dysfunction which cannot be explained by any other medical condition. Fibromayalgia (FM) is characterized by chronic widespread pain of the muscles, ligaments and tendons and accompanied by other symptoms affecting various systems within the body.

There are nearly a million Canadians and approximately 4500 Islanders diagnosed with ME/CFS and FM for which there is no treatment or cure. These illnesses are more common than breast cancer, Parkinsons and MS combined.

It was special event with Dr. Jonathan Fox, MD from the Integrated Chronic Care Service in Fall River, NS as key note speaker. He is a specialist in the treatment and care of patients with ME/CFS and FM and multiple chemical sensitivities. The Center at which he works is the only one of its kind in the Maritime region and accepts referrals from other provinces.

The Center adopts a holistic approach to treatment and care and has a wide range of health care professionals on staff to meet the varied needs of its patients.

The event was also special in another way, in that the Kay Larkin, Janice Coady and Dolores Griffin followed Dr. Fox's presentation by providing a personal perspective

on the impact ME/CFS and FM has had on their lives. This was followed by a poem entitled Do You See Who I Am written and read by Rita Stanley who lives with the daily struggles of FM and the many other health issues that come with it.

There were over 60 people in attendance which included health care professionals, and organizations, government officials, politicians and policy makers, university staff and students and patients and their family and friends. Following the presentations, guests were treated to an afternoon tea hosted by Her Honour, Madame Perry.

The event was organized by Dolores Griffin, a local volunteer member of the ME/FM Acton Network, which is a national non-profit organization dedicated to supporting ME and FM patient through advocacy, information, research and education. Support for the event was also provided by Confederation Center of the Arts, Murphy's Pharmacies and the Dundee Arms Inn.

The event was also followed up by an interview with Dr. Fox by PEI's evening TV program Compass.

Senator Speaks on ME/CFS

SENATOR DIANE F. GRIFFIN

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  Senator Diane F. Griffin
  The Senate of Canada
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On Thursday, May 24, 2018 President, Margaret Parlor, and Lydia Neilson, CEO & Founder of the National ME/FM Action Network were invited by Senator Griffin to hear her speaking in honour of May 12 International ME/FM Awareness in the Senate.

The Network encourages you to send a thank-you note to the Senator.

Diane.Griffin@sen.parl.gc.ca
https://sencanada.ca/en/senators/griffin-diane/

SENATOR STATMENT

Remarks of the Honourable Diane F. Griffin
Senator for Prince Edward Island
May 24, 2018

Honourable Senators,

May 12 was International Awareness Day for myalgic encephalomyelitis - also known as Chronic Fatigue Syndrome - and Fibromyalgia.

This date was chosen as it was the birthdate of Florence Nightingale, the British Army nurse who became chronically ill with what is thought to have been Chronic Fatigue Syndrome and was housebound and often bedridden for most of her life.

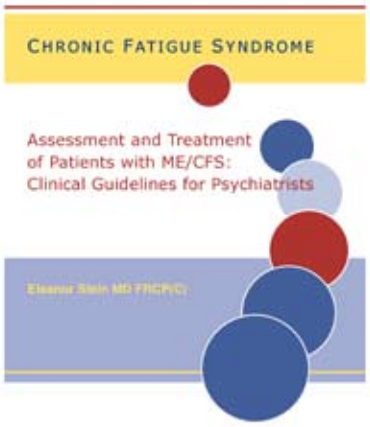
Symptoms include fatigue, inappropriate loss of physical and mental stamina after exertion, sleep dysfunction and pain. It also affects the neurological, endocrine and immune systems.

My own family has been impacted with two sisters-in-law, one with Chronic Fatigue Syndrome and the other with Fibromyalgia. These formerly very active women find it difficult to plan their lives as they don't know how they will feel when the day of an event arrives. For instance, will they have the energy and feel well enough to participate in a family reunion and enjoy it? Another instance, a cousin had to retire early as a high school art teacher even though she loved teaching art to appreciative students.

There are not yet tests to identify Chronic Fatigue Syndrome or Fibromyalgia, so all other illnesses with overlapping symptoms must be ruled out before these diagnoses are considered.

Because we don't have good diagnostic tools, it is hard for sufferers to get proper care.

There is much that can be done to help these Canadians including supporting research, raising awareness, combating stereotypes and ensuring programs are inclusive.



The Psychiatrist Guide to ME/CFS by Dr Stein is a guide on disentangling ME/CFS, mood disorders and anxiety disorders. This guide makes an excellent model of the types of information needed for all the overlapping co-diagnoses.

http://mefmaction.com http://twitter.com/mefmaction http://www.facebook.com/MEFMActionNetwork

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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 and on developments affecting the ME/FM community in Canada and internationally.

ME/CFS and FM Brochures - FREE

Coloured pamphlets on ME/CFS and FM are available in English and French. You can view them on our website

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]
- The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4]

The consensus documents are available at Amazon.ca or at Chapters.ca or view them on our website.

ME/CFS and FM Overviews - $7.00

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents.

- You can view the ME/CFS Overview in English, French, Spanish, German, Italian and Dutch on our website. English versions of the ME/CFS Overviews are available for purchase from the National ME/FM Action Network. French versions of the ME/CFS Overview are available for purchase from Quebce Association for ME, AQEM (aqem.ca)- call (514) 369-0386 or 1-855-369-0386 or email info@aqem.ca.
- You can view the FM Overview in English, French, Spanish and Italian on our website. English versions of the FM Overview are available for purchase from the National ME/FM Action Network.

TEACH-ME (Second Edition) - $25.00

Our TEACH-ME Source Book is for Parents and Teachers of children and youth with ME/CFS and/or FM. This document is available in English and French.

CANADA PENSION PLAN DISABILITY GUIDE 2015 Edition- $10.00

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

Chronic Fatigue Syndrome / Myalgic Encephalomyelitis - Primer for Clinical Practitioners
Syndrome de fatigue chronique Encéphalomyélite myalgique - Petit guide pour la médecine clinique - $25.00

The ME/CFS Primer was produced by the International Association for Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (IACFS/ME). It was translated into French by the National ME/FM Action Network. You can view both the English and the French on our website. Bilingual versions are available for purchase from the National ME/FM Action Network.

All of the above resources can be viewed on the
National ME/FM Action Network website at http://mefmaction.com

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