Presentation to MPs and Senators on May 8, 2013

Real Person. Real Illness. Real Solutions.

Today I would like to tell you a little bit about my personal experience with ME/CFS and fibromyalgia, and suggest some of the ways in which the Federal Government can improve the situation for patients with these illnesses. I've structured my presentation around a slogan often used by ME/CFS advocates: "Real people. Real illness. Real solutions."

In 2006, I graduated from McGill University Law School and began a clerkship at the Special Court for Sierra Leone, an international war crimes tribunal. It was an amazing time in my life. There was so much to learn that every day was an adventure, full of new experiences. After my clerkship I intended to remain in Sierra Leone for a few years working in international development before returning home to Canada to continue pursuing my career, as well as start a family.

However, a few months into my clerkship, I got malaria and my life has never been the same. Although the malaria was properly treated and is no longer present, it triggered ME/CFS and fibromyalgia. For a while, I continued to work, but all of my non-working hours were spent sleeping. I scaled back to part-time, but I continued to get worse and eventually my health forced me to stop working all together.

Although people have different triggers, including ones more familiar to us Canadians, such as the flu, I've learned that my symptom pattern is fairly typical. For the first few years, I had a migraine, all day, every day. My entire body hurt. I had sore throats, runny noses and stomach issues. I developed food and chemical sensitivities.

I was so tired that I couldn't stand for more than a few minutes without having to lie down afterward. Preparing a simple meal became an all day event because I had to break it up into small parts with lots of rest of periods in between. For example, to prepare soup, I'd cut a few vegetables, lie down for a while, and then I'd cut a few more, and so the day passed until my meal was prepared and the dishes were cleaned. As a result, I learned to organize my life differently. Making a big pot of soup and freezing the extras because I didn't have the energy to cook everyday. Some days I had to take a bath. Or do laundry.

Personally, the most frustrating symptoms may be the cognitive impairments, often lumped together under the term 'brain fog' because you have so much trouble concentrating that you feel as though you're living in a fog. Most of the time, I function on autopilot. It's horrible because I never feel like my best self, fully present with all of my thoughts at my disposal. There are forgotten words and ideas, and difficulties expressing them.

At my worst, there was a year where I had also lost my ability to do basic math. I could not believe it. Growing up, math had been my best subject. And now, I couldn't add 2+3 because I couldn't remember the numbers long enough to add them together. I still have trouble reading. And when it comes to typing, the timing and processing of information from my brain to my hands is impaired.

It's hard for people to understand that I am ill because I look fine and have a sunny disposition. Nor do people see that after a short activity, such as a meeting a friend for a cup of tea, that I spend the next few days lying on my couch, alternating between resting and sleeping. It's a fatigue, mental and physical, with flu and pain symptoms that worsen for days after a small activity, and is unlike anything that I have ever experienced.

I want to give myself the best chance at recovery so I've made lots of lifestyle changes. I am careful about what I eat – no gluten, no dairy, no sugar, no additives. I eat a lot of vegetables, healthy fats, and good quality proteins. I have taken up meditation and restorative yoga. I go to bed early and at the same time every day. These changes have helped, as they would for most health conditions, but they aren't a cure.

As Margaret, explained there's little treatment offered in Canada. In Ontario, which is my home province and slightly ahead of most areas in Canada, there's an Assessment Center, called the Environmental Health Clinic. After a 13-month wait, where patients don't know what's wrong, what to do and continue to get worse, they get two possibly three appointments where they are finally given a diagnosis and some general tips on managing their illness. That's it. And the general tips are lifestyle adjustments like the ones I've told you about. Helpful, but not curative.

I know people who were diagnosed in the 90s. And since then, they haven't seen a specialist or received any medical care for their condition. Imagine having one appointment where you're told that you have diabetes, a follow-up appointment where you're given a few suggestions for managing the illness and then no on-going care. Ever. That's the situation facing my community.

Real Illness

While much remains unknown about ME/CFS and fibromyalgia, there are a lot of medical interventions that could be helping Canadians.

With my family's financial help, over the past year, I have been seeing an immunologist in the United States who specializes in ME/CFS and fibromyalgia. She takes a multifaceted approach, treating different aspects of these complex illnesses. And thanks to her help, the quality of my life has improved dramatically. A year ago, I would not have been well enough to stand here today speaking with you.

So how have I improved? I'd like to share with you a few of the treatments, which have helped me. Firstly, my doctor has been restoring my immune function. My natural killer cells, which are a group of white blood cells that kill viruses, are severely impaired. When you put the NK cells of a healthy control subject into a petri dish, they kill 28% of the virus-infected cells. My NK cells only killed 2% of the virus-infected cells. Not only were my NK cells ineffective, but I had far fewer than I should have allowing a number of latent viruses, such as Epstein-Barr, to reactivate. As a result, my doctor prescribed a medication also used by HIV patients among others, to improve my NK cell function, and an antiviral drug to deal with the reactivated viruses.

Secondly, a sleep study showed that I was only getting a few minutes of stage 4 sleep at night. Stage 4 is deep sleep where the body heals itself, repairing and regenerating tissues, building bone and muscle, and strengthening the immune system. With medication, I am now getting a healthy 90 minutes of stage 4 sleep every night.

Thirdly, my doctor is treating symptoms of autonomic system dysfunction. Normally, when a person stands up, 60% of their blood is below their belly button. When I stand up, 80% of my blood is below my belly button. So my upper body and brain are functioning on 50% less blood than a healthy person's upper body. I've starting taking a medication which vasoconstricts my veins and sends blood to my upper body. During the 4-hour period that the medication works, I can see clearly.

I think it's important to mention that all of the medications that I am taking are available in Canada, and being used to treat other illnesses.

Real solutions

According to the Canadian Community Health Survey (CCHS), 756 000 Canadians have ME/CFS and/or fibromyalgia. It is a shockingly high statistic, and yet few people have heard about them and little is being done to remedy the situation. Aside from the physical, emotional and financial strain that it places on individuals and their families, it makes financial sense for the government to invest in research and treatment. (74% ME/CFS patients and 77% of fibromyalgia patients are of working age (18-64). 44% of ME/CFS patients and 46% of fibromyalgia patients are between the ages of 30 and 55). Almost half of the people with fibromyalgia are between the ages of 30 and 55 when they should be at their greatest earning potential. And yet most are unable to work, and with no treatment, they're usually out of the market for the rest of their lives.

A 2004, US study (based on 1997 data collection) estimated that the annual loss of productivity was approximately $20 000 per person with ME/CFS.[1] If that same figure holds true for all 756 000 Canadians diagnosed with ME/CFS and fibromyalgia, then the Canadian economy is losing out on $15.12 billion a year. And the amount is probably a lot higher given inflation over the past 9 years and the fact that the number of people with these illnesses has probably continued to increase since they were last included on the CCHS in 2010.

Moving forward, there are four areas of focus where the Federal Government can take action to improve the situation for Canadian patients and families dealing with ME/CFS and fibromyalgia: Research, knowledge transfer, surveillance, and service delivery. Due to time

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[1] Reynolds KJ, Veron DS, Bouchery E Reeves WC. The economic impact of chronic fatigue syndrome. Cost Effectiveness and Resource Allocation 2004, 2:4.

constraints, I've limited my discussion to ME/CFS even though most of the solutions apply equally to fibromyalgia.

Research

Although we've learned a lot about ME/CFS in recent years, there is still a lot that we don't know. I watch online videos from ME/CFS conferences in the United States where researchers and clinicians present their work and it gives me so much hope to know that people are working on my behalf to understand the illness and find a cure.

And then it saddens me to learn that there is no similarly active ME/CFS research community in Canada, and that my government, has no plans to develop one and stop this area of research from being neglected.

To improve the situation, we need an increase in the amount money invested in ME/CFS research from basically nothing, 35¢ per ME/CFS patient per year,[2] to the equivalent to what is spent on equally disabling diseases that effect such a large population. In addition to a financial commitment, policy and structural changes will also be required to overcome several obstacles.

Firstly, as a multi-system illness, ME/CFS research falls under the scope of 11 of the 13 CIHR Institutes, such as "Infection and Immunity," "Circulatory and Respiratory Health" and "Genetics." Since it doesn't fit neatly into one Institute, it doesn't get studied at all. We call it an orphan illness because it does not have a home in any Institute.

ME/CFS research also faces difficulty getting funding in the CIHR's open competition. Right now, the CIHR has a fair process to evaluate grant applications and it works well, but only for illnesses that already have an established research community since applying for grants is an expensive and time-consuming process that shuts out new entrants.

The solution is simple. The CIHR should create a new institute. The existing institutes were developed a decade ago and should not be set in stone. If that cannot be done then the CIHR should create a ME/CFS Committee that brings together members from all of the relevant research areas to ensure that ME/CFS is being adequately studied in an efficient, effective and coordinated manner.

The committee should be given a specific amount of money for ME/CFS research over several years. Doing so would have the same effect as affirmative action policies. It would attract researchers to the field and help develop a ME/CFS research community. Applications would still have to reach the same high scientific standard as other CIHR grants, but of those, which met the standard, at least a number of them would be guaranteed funding.

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[2] http://www.mefmaction.com/index.php?option=com_content&view=article&id=448%3Anetwork-inquiry-to-cihr&catid=69%3Anetworknews&Itemid=287

Thirdly, the CIHR should reach out to Canada's scientific community by issuing policy announcements stating that it considers ME/CFS to be a serious and disabling condition, and outlining areas of research that they feel are priorities and are interested in funding. This will increase awareness, prestige and signal a shift that CIHR is ready and willing to fund ME/CFS research.

Knowledge transfer

Show of hands – who here has heard of ME/CFS before you were invited to this breakfast?

Most of the time, doctors and the general public are unfamiliar with these illnesses, and often react toward them in a hostile or dismissive way, adding an unnecessary level of stress and suffering.

It's time for PHAC to alleviate that burden by implementing a public awareness campaign aimed at educating both the general public and medical professionals. The campaign should publicize a clear, up-to-date PHAC website about ME/CFS where patients and medical professionals can access information by a trusted source. Similar PHAC websites exist for other illnesses such as cancer, diabetes, and osteoporosis. Right now ME/CFS is listed on PHAC's website under chronic diseases, and beneath the ME/CFS heading are two links. That's it.

There is a lot of information that could be made available. In the United States, the Centers for Disease Control and Prevention's ME/CFS website has information for individuals and physicians on the illness regarding the causes, signs and symptoms, making a diagnosis, and treatment and management of the illness. It also hosts online workshops and is a source for educating medical professionals.

The website has links to free online continuing education courses. In the first 10 months that the video entitled "CFS: Challenges in Primary Care" was posted online, it was viewed 31,000 times, and 5000 medical professionals had already received Continuing Education Unit Credits for it.[3] It shows that there is a huge need and I'm sure similar courses would be just as popular in Canada.

PHAC should also emulate the US by organizing regular ME/CFS conferences involving patients, patient advocates, clinicians, researchers, and policy-makers to exchange ideas and work toward solutions.

Surveillance

Since the Canadian Community Health Surveys showed a 23% increase in the number of ME/CFS patients between 2005-2010 to 411 000 Canadians, and ranks ME/CFS #1 among the top 23 chronic conditions for unmet healthcare needs, unmet homecare needs and food

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[3] Stated by Elizabeth Unger, PhD, MD, Branch Chief, Chronic Viral Diseases Branch, Centers for Disease Control and Prevention, during the CDC Chronic Fatigue Syndrome (CFS) Patient-Centered Outreach and Communication Activity (PCOCA) Conference Call was held on Monday, January 14, 2013.

insecurity, it's too important an issue to let the situation go unmonitored. ME/CFS should be included in the Canadian Community Health Survey every year, not every four years.

There should also be specialized surveys into each of those areas so we can learn more about what ME/CFS patients' need in order to improve the situation. This is standard protocol for other illnesses.

Service Delivery

With 411 000 Canadians suffering from ME/CFS and only a handful of specialists scattered throughout the country, we need a national strategy. Right now, patients are researching treatment practices online and educating their GPs. I think we'd all agree that this is not the best or most efficient method.

The federal government, in partnership with the provinces, needs to develop a program to train doctors and other medical professionals, as well as set up specialized treatment centers. This may sound like a provincial responsibility, but the Federal government is the fifth largest healthcare provider in the country. It also falls under PHAC's mandate to strengthen intergovernmental collaboration on public health and facilitate national approaches to public health policy and planning.

We also need to ensure that other services, such as unmet homecare needs and access to food and income security programs are being addressed. For example, patients with ME/CFS should not have more difficulty qualifying for long-term disability and CPP-D benefits than patients with the same degree of disability as a result of other medical conditions.

Access to CPP-D could easily be improved. Firstly, the Adjudication Tool that guides adjudicators in their review of ME/CFS cases should be posted on Human Resources and Skills Development Canada's website so they can easily be found. Secondly, there should be access to medical support and to advocates who can assist patients in navigating the application process. These support systems exist for other illnesses.

Thirdly, since there is no widely accepted diagnostic test for ME/CFS, there needs to be a clear articulation of how a patient with ME/CFS meets or continues to meet the "severe and prolonged" criteria when applying for CPP-D*.* Unfortunately, at the moment, the CPP-D Guidelines are too vague. As a result, doctors do not know how to fill out the forms and it is difficult for adjudicators to determine a case.

The overall result is that patients are questioned at every step of the application process and are often turned down, at which point they are forced to hire a lawyer and file an appeal. These difficulties place a lot of additional stress on patients, causing their condition to deteriorate significantly.

The National ME/FM Action Network, along with medical experts have some suggestions on how to clearly define the severe and prolonged criteria and would like to work with Human Resources and Skills Development Canada to improve the guidelines.

Another problem with disability programs is that many ME/CFS suffers don't qualify because of their age. Some people get sick when they are children or teenagers. In my case, I wasn't in the workforce for long enough to qualify for CPP-D. Without my family's financial help I would be living in poverty with no medical care.

Conclusion

Over the past few years there have been huge advances in research and treatment made in other countries and I am hoping that Canada will follow suit. There should be a sense of urgency to improve our national approach to ME/CFS and fibromyalgia in the areas of research, knowledge transfer, surveillance and service delivery for both compassionate and financial reasons.

I've mentioned a lot of changes that are necessary, some of which are easy to achieve like being included annually on the CCHS and others, which will require a little more effort but are vitally important such as enacting affirmative action style policies to develop a research community and a public awareness campaign to educate both the public and the medical profession.

I still have the same personal and professional goals that I did when I started my career a law clerk in Sierra Leone after graduating from McGill. Thankfully, I have been able to afford medical care in the United States and I have a good chance at being able to go back to work and, one day, start family. With your help, the ¾ of a million Canadians who are also afflicted with ME/CFS and/or fibromyalgia can also have the same opportunity.

Thank you.

The contents of this document were intended to be shared as an oral presentation on May 8, 2013 at a breakfast information session for MPs and Senators. As such, I did not include all of the references in the written copy.

Discussion of CCHS data can be found on the National ME/FM Action Network's website in their newsletter entitled Quest. For the 2005 data, see Quest # 80 (Spring-Summer 2009). For 2010 data, see Quest # 88 (Summer 2011).