

InforME Magazine

An informal publication for people concerned with ME, CFS, and CFIDS.

ME — Myalgic Encephalomyelitis

CFS — Chronic Fatigue Syndrome

CFIDS — Chronic Fatigue Immune Dysfunction Syndrome

M.E. Victoria Association

Spring 2017

mevictoria.ca

Inside this Issue...

Millions Missing Letter to Minister Philpott	1
Editorial	2
ME/FM BC GoFundMe Campaign	4
ME Patients and Advocates Meet with Health Canada, 23 March (excerpt)	6
Grocery Delivery in Greater Victoria and Beyond	7

Millions Missing Letter to Minister Philpott *Anonymous*

Dear Minister Philpott,

Finding myself in the unenviable position of representing more than one very distinct group of sufferers from the ME community, the weight of which does not escape me, I will be as direct as possible. There is little time to waste on words, thoughts, or actions that are gratuitous in nature but lead nowhere. We've had much too much of that already.

The perspective from which I write will be as a long-term severe sufferer, as well as a parent and long-term primary caregiver of a severely ill child with ME. This letter, then, will be representing the interests of my child, myself, as well as extending to include my fellow long term, extremely ill sufferers – 'lifers' subsisting – those who have exceeded the twenty-five year mark with this illness, who are also seriously affected, and who many, tragically, are barely capable of speaking, let alone speaking up for themselves.

There's something very significant about reaching the twenty-five year mark with ME. Many things change forever with this 'sickversary'. Realizations become reality ingrained into one's very being.

Continued on page 3...

New look!

InforME Magazine has been redesigned and streamlined to make it easier and less expensive to produce.

We hope you enjoy the new format!

Editorial

With ME, CFS, FM and Lyme disease Awareness Day/Month approaching quickly, I'm happy to announce that the ME Victoria Association has been busy making a difference! One of them being, we, along with the ME/FM Society of BC and the National ME/FM Action Network, have a voice at the Complex Chronic Diseases Program (CCDP) on the Community Advisory Committee (CAC).

In November the CCDP invited the patient representatives to a Community Engagement Session. We teamed up with doctors, one of them being Stephanie Rhone (a present Director of the CCDP), and department heads at BC Women's Hospital, to focus on the vision for the program and to action them. It was a full day and much was accomplished. We thank them for inclusion and for hearing us.

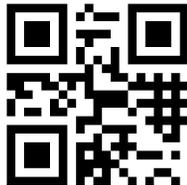
The patient representatives on the Community Advisory Committee have been listening to the voices of those suffering with ME for many years and one of the goals is to express the needs and opinions of the patient groups. If you would like to share your thoughts about the CCDP please email us at me.victoria@shaw.ca.

The CAC patient reps were also asked if we would like to participate in finding a new Medical Director. We were contacted by a team specializing in Talent Acquisitions, who asked us for best places to search. We were thrilled that our suggestions were taken seriously. We were even more thrilled when we heard they were going to set up a recruitment table at the IACFSME Conference in the most obvious spot, looking for candidates. We were later included in the interview process. We feel encouraged about future possibilities for the CCDP at the Woman's Hospital. We have a very unique program that is recognized by the international ME Community.

The CCDP together with the ME/FM Society of BC will be hosting the **"World Cafe!"** On Saturday, May 27, 2017 at 1:00 – 3:15 pm. It will be held at the Chan Education Centre and Auditorium, at the Child and Family Institute BC on the Woman's Hospital campus in Vancouver, BC, 4480 Oak Street (Oak St. at 29th Ave.).

Continued on page 4...

InforME Magazine



M.E. Victoria Association
PO Box 50032
Victoria BC V8S 5L8
CANADA

E-mail: me.victoria@shaw.ca
Web: mevictoria.ca (new!)

Publication Disclaimer

The purpose of InforME is to offer a wide variety of information about coping strategies, research issues and possible treatments for ME, CFS and CFIDS. There is yet no agreement in the scientific and medical communities with regard to the causes and optimum treatment for these conditions. We make every effort to use only responsible sources but some information may be speculative. We recommend that readers consult with a health professional with regard to their own treatment plan.

A self-help registered charity: 14105 2662 RR001

...Continued from page 1

Be forewarned; we are, generally speaking, an angry lot – and with good reason. **There aren't many of us left surviving.** The politics of this disease has led us through the confusion of the '80s, the lies of the '90s, the apathy towards us during the first decade of this new century, and, in spite of the burgeoning scientific evidence, the inaction of this one.

We have lost more than half of our lives due to the **indifference and inertia of authorities** towards Myalgic Encephalomyelitis. We have survived being gravely misunderstood, suspiciously viewed, our words painfully twisted, falsely accused, outright lied about, unfairly judged, scapegoats for jokes, and a source of income for the biopsychosocial lobby.

As if being extremely ill isn't enough and being robbed of our livelihoods, quality of life, and futures by ME, as a direct result of **our government's failure to intervene, serve and protect us**, we have been ridiculed, disbelieved, bullied, ignored, neglected, abandoned, alienated, stigmatized, victimized and continually traumatized.

Because the misinformation about ME has been allowed to run rampant causing **wide spread stigma and bias**, our motives are constantly being questioned and our very integrity is consistently under attack. Through it all, persons with ME have been left, unbelievably, to deteriorate with **no intervention from the government on our behalf.** A handful of committed doctors and researchers is all we've had to cling to for future hope.

Suicide rates are five times higher in ME and it is little wonder that so many take their own life, as this kind of brutality on top of

Make no mistake. This is not just about a serious illness that there is, as yet, no complete cure for. As unfair as it might seem, we could live with that. This is not just about a nasty disease that has been misunderstood, is complicated to unravel or slow to research. This is certainly not the case either.

The kind of fallout that I've described and that we are forced to live within, happens in no other disease. Few other diseases have been **so maligned by false information** as Myalgic Encephalomyelitis.

This is about politics, cover ups, career building, professional misconduct, dereliction of duty, neglect and this has become a monumental ethical issue that must not be allowed to continue. This is about the illness ME being deliberately left behind.

Health authorities, much to their advantage, **perpetuate the myth that ME is a mysterious illness.** To the contrary, there are thousands and thousands of research papers that have been accruing for decades. So much is known about ME in fact, that it could, in all probability, legitimately fall under every single one of the thirteen institutes at CIHR for further exploration.

Why oh why, then, has such a complex illness as ME fallen into the hands of the IMHA? Not only is the Institute of Musculoskeletal Health and Arthritis an **ill-suited placement** for this ME but, judging by past performance, they appear to be **very ill equipped** to tackle the challenges of ME.

Entombed in this institution only ensures our continued malfeasance.

Continued on page 5...

Editorial, continued

The CCDP is looking to engage patients! There will be 4 tables, each with an open ended question. Three of the tables will have questions relating to the CCDP, and will be facilitated by their staff. The goal is to create an action in 2017-2018 from this conversation. The fourth table will present a question related to the ME/FM Society of BC and facilitated by one of their members. The idea is to rotate from one table to the next, 15 minutes per table, and then everyone will gather for a Q & A and discussion.

There will be an online component, so that people all over BC can participate! This means that people don't have to be at the actual event to be heard. Please RSVP at info@mefm.bc.ca to be included.

All the best,

Editor

ME/FM BC GoFundMe Campaign

The ME/FM Society of BC has launched an ambitious GoFundMe campaign to raise \$10,000 by April 26th to raise awareness about ME and FM. Their goals are to sponsor May 12 awareness events and to reach out to ME and FM patients across the province and supply them with information to help them get diagnosed and treated.

Contributions can be made at:
www.gofundme.com/mefmsocietygoals2017

Pass it on!



Showing: Vancouver May 12 & 13
doxafestival.ca

Sponsored by ME/FM Society of BC

UNREST



...Continued from page 3

We 'lifers', have **lost all confidence in the medical system** and all hope from our government. We are no longer naive, no longer moved by false promises and are no longer swayed by lip service. We have accumulated many horror stories over the years and we have become a sceptical lot.

We have become the 'Living Dead', hidden away in silence and solitude where no one can see us, imprisoned in our bodies, buried in our bedrooms and locked in our homes. Others, such as yourselves, are holding the keys for ME; however, are not willing to insert those keys into the locks that will open these doors.

Our collective cry is, "Open the Doors for ME!"

...

We need the Health Minister of Canada, Jane Philpott, to urgently engage with other health officials and all stakeholders, ***commit to developing an inclusive and comprehensive National Strategy in conjunction with those stakeholders, and tackle how each disturbing aspect of this devastating disease will be effectively addressed.***

...

Orphaned by the indifference of the health care system, deprived of any effective treatment that is available in other countries, hope disintegrated by our country's lack of interest in collaborating on international research, constantly misdirected by the lack of any accurate science-based counsel or guidance from the medical establishment, even the most basic concern for our welfare and myriad of distressing and scary symptoms is often times, completely absent.

...

There is something so painfully twisted about having those authorities that are responsible for

your health care, overlook your personal suffering day after day, year after year, decade after decade, ignoring your pleas and invalidating your anguish.

...

Excuses for the negligence of our government towards ME can be tolerated no longer. Science has left Canada in the dark ages with regards to this illness and her citizens with ME need immediate intervention. Health officials must be held accountable to provide that intervention!

...

Act with urgency on behalf of us all and

'Open the Doors for ME!'

Signed,

Severe Sufferer/Caregiver/Advocate Turned Activist

23.02.17

Author Name Removed for Privacy

Excerpt, with original emphasis, from "The ME Crisis: 'Lifers'" published on the *Millions Missing Canada* Facebook page:

www.facebook.com/MillionsMissingCanada

Direct link: bit.ly/2nUMi5c

Contact Minister Philpott:

Hon. Jane Philpott
Minister of Health
House of Commons
Ottawa, ON K1A 0A6
(no postage required)

Phone: 1 613 992-3640

Email: jane.philpott@parl.gc.ca

ME Patients and Advocates Meet with Health Canada, 23 March (*excerpt*)

Elizabeth Sanchez

Scott Simpson, Jeffery Smith, Barbara Fifield and I had spent a lot of time planning, plotting and preparing for this meeting. We sought advice from experts; researched, wrote and re-wrote and re-wrote our Briefing Notes. We did all this while trying to put ourselves in the shoes of the civil servants in whose hands the future for our community rests. The same civil servants who are bombarded with requests from Canadians, from people like us who feel underserved, who feel their needs are critical yet unmet. We debated how to distinguish ourselves. (Well, that's obvious, we are TOTALLY neglected!)

But the main question for us was about expectations: what is a realistic expectation for a half hour meeting with these folks? How do we set things up for success, push as hard as we can without pushing them off-side? How do we get what our community desperately needs?

Caroline Pitfield, Policy Director for Jane Philpott, and Ashleigh White, Special Assistant, gave us a very warm welcome. Any doubts we had about their taking the meeting seriously were put to bed when we were introduced to Marilyn Desrosiers, Manager Business Development and Analysis at Canadian Institutes of Health Research (CIHR). As Caroline made clear, the CIHR are the ones with the big money for research, and Caroline had arranged it so all of us could meet.

[Nathaniel Erskine-Smith] managed to pitch the idea of partnering with researchers around the world who are way ahead of us, in order to speed up the development of

treatments and biomarkers, then quickly ran back to participate in a vote in the House. Nate's effort was truly appreciated. Caroline had also planned for the Minister of Health herself to come join us, but, as it turned out, she too had to rush off for the vote.

Jeff, Scott and I told our stories, what led us to be at that meeting. Everyone listened. Our brief, titled "The ME Crisis", was on the table, and we reminded them that the need was tremendous in the ME community, the suffering is overwhelming, and the science is tantalizingly close to finding a biomarker, and possibly a treatment. We told them of the treatments that are currently being used in other parts of the world, with some definite success, but which are not available here. Caroline was particularly interested in learning more about ME, the issues and the research. She mentioned the Special Access Program, a Health Canada program for considering requests to access for drugs not available in Canada, and that this may be a possibility for getting access to treatments for ME. Marilyn agreed to a digital conference with stakeholders, to develop an effective plan for research funding and disseminating the Canadian Consensus Criteria. And invited us to join in discussions about the Catalyst Grant results in April.

Our meeting was booked for half an hour, and they gave us almost twice that. We didn't walk away with a promise of millions, but we walked away feeling there is much hope; that these people believe us and want to help; that, if we push and guide and lead, we will find partners in the Ministry and the CIHR to help us with this ME Crisis.

Full story: bit.ly/2nKvWND

Grocery Delivery in Greater Victoria and Beyond

Lifestyle Markets

Online health food and supplements shopping: lifestylemarkets.com

Delivery: Local delivery in a few days. Shipping by Canada Post outside Greater Victoria.

Fee: Free local delivery. Shipping charges apply outside Greater Victoria.

Info: 1-800-937-5433 info@lifestylemarkets.com

Pepper's

Order by phone, fax, or online form: peppers-foods.com/delivery

Delivery: Same day delivery if ordered before 1pm, Monday to Friday.

Fee: \$5 within 5km (Cadboro Bay), extra \$5 beyond 5km; \$50 minimum order

Info: 250-477-6513 Fax: 250-477-6432

Save On Foods

Online shopping: freshdelivery.saveonfoods.com

Delivery: You choose delivery time.

Fee: \$7.95

Info: Saanich: 250-475-3300 Tillicum: 250-384-7714

Small Potatoes Urban Delivery (SPUD)

Online local organic grocery shopping, Victoria to Nanaimo: spud.ca

Delivery: On the regular delivery day for your area.

Fee: Free for orders over \$30

Info: 250-383-7969 vanisland@spud.ca



The Market Stores

Phone-in shopping: Downtown: 250-381-6000

Millstream: 250-391-1110

Delivery: Same day between 4pm and 8pm if ordered before 2pm.

Fee: Free delivery

Thrifty Foods

Online shopping, available from most stores: thriftyfoods.com

Delivery: You choose delivery time. Same day delivery if ordered before 11am (\$2 surcharge).

Fee: \$7.95

Info: 250-544-1234 Outside Victoria: 1-800-667-8280

Sendial volunteer shopping service for the elderly and disabled. Order by phone at a regular time once a week. Register by phone (250-544-1234 or 1-800-667-8280) or online: www.thriftyfoods.com/community/sendial

Delivery: Next day.

Fee: \$5.00

MEVA Membership

Please use this form to apply for, renew, or update your MEVA membership. Let us know if you or someone you know would like to volunteer with MEVA in any way, large or small.

Name: _____
Address: _____
City: _____ Province: _____
Postal Code: _____ Phone: () _____
Email: _____

I consent to be contacted by email
 Please send me InforME by email
 I am updating my information
 I am interested in volunteering

<input type="checkbox"/> 2016 Catch-up	\$ 20
<input type="checkbox"/> 2017 Membership	\$ 20
<input type="checkbox"/> Donation	\$ _____
Total enclosed	\$ _____



Send your cheque to:

ME Victoria Association
PO Box 50032
RPO Fairfield Plaza
Victoria, BC V8S 5L8



Thank You!

M.E. Victoria Association
P.O. Box 50032
Victoria BC V8S 5L8
CANADA

