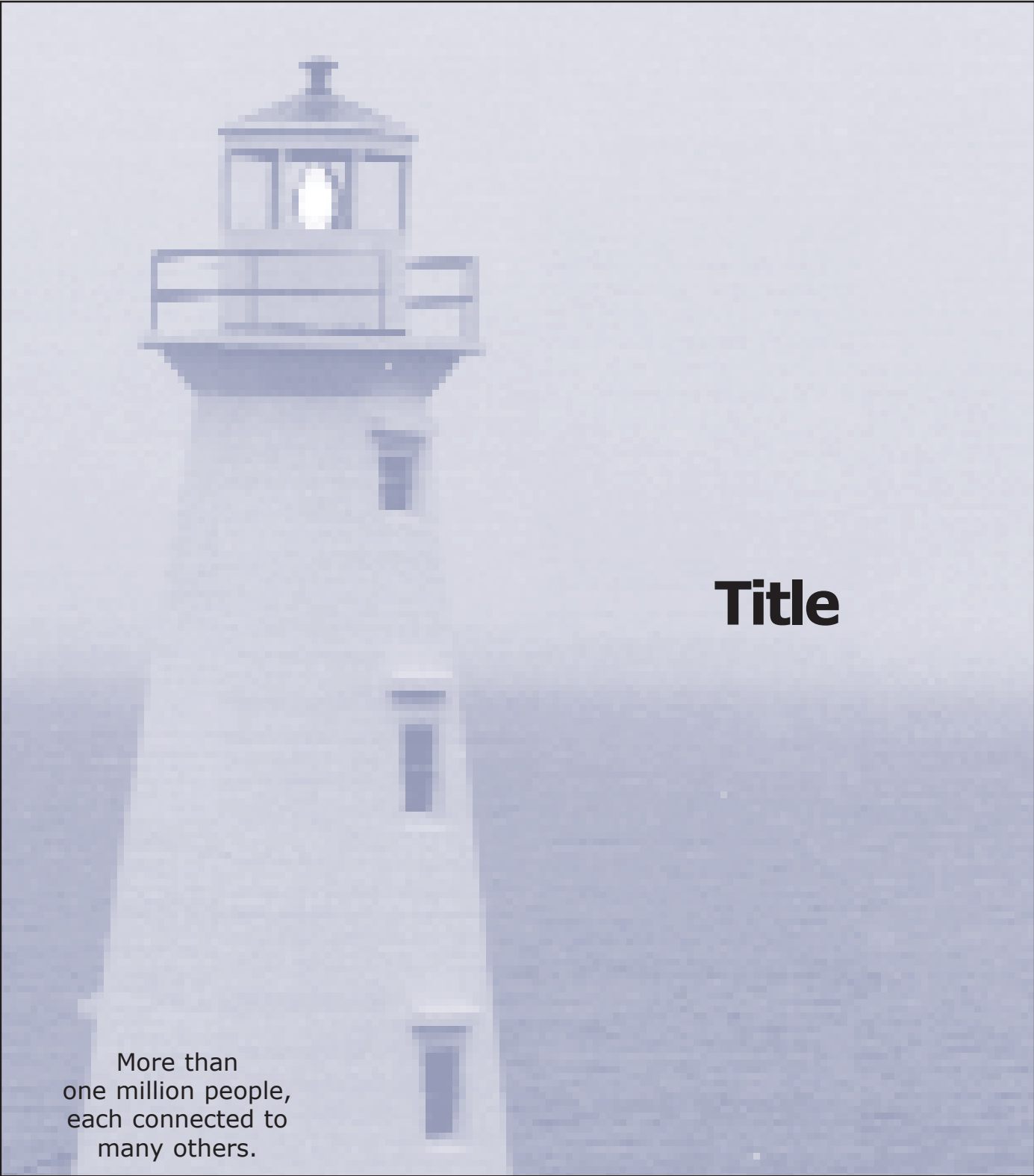


Your Logo

Date



Title

More than
one million people,
each connected to
many others.

ABOUT FM, CFS, & YOUR GROUP NAME

Fibromyalgia, and Chronic Fatigue Syndrome, aka, Myalgic Encephalomyelitis. More than 1 million Canadians have these life-changing, unforgettable illnesses. Possibly as many as 1.5 million Canadians. Many children have it.

With respect to symptoms, FM is at the extreme of the chronic pain spectrum, with lesser degrees of fatigue and cognitive disturbance. ME/CFS is at the extreme end of the chronic fatigue spectrum but often involves significant cognitive dysfunction and widespread pain as well.

Respected research shows that if cared for, patient health improves, generally. Unfortunately, it hasn't received much attention.

Your Message

Thank you for your e-mail concerning Fibromyalgia and Chronic Fatigue Syndrome. It is my pleasure to have this opportunity to extend my moral support and encouragement to your organization and to the millions of people afflicted with these diseases.
Hon. Stephen Harper, P.C., M.P., Leader of the Opposition

YOUR MESSAGE

Your Logo

The cost to the Federal and Provincial government is already in the billions of dollars per year; in addition to all the other related costs incurred by the sufferers of these conditions.

Senator Marjorie LaBreton, May 12th, 2005

Charitable Registration #

Huge Federal Costs:

The costs to Federal and Provincial Governments amount to billions per year, and will continue for decades unless society changes course.

Numerous prevalence studies suggest at least one million FM patients in Canada.

Federal statistics: 393,000 FM patients, 341,000 CFS patients, diagnosed by doctors, as of 2003.

To consider the costs, Federal losses for only 20% of one million and 20% of 393,000 patients are:

Disability Insurance and Welfare

200,000 patients (20% of 1 million) x \$10,000 per year disability insurance = **\$2 billion**

98,250 patients (20% of 393,000) x \$10,000 per year disability insurance = **\$.9825 billion**

Lost Income Taxes 280,000,000

200,000 x \$6,000 (20% tax x \$30,000 (Canada's average income)) = **\$1.2 billion lost taxes**

98,250 x \$6,000 (20% tax x \$30,000 (Canada's average income)) = **\$.5895 billion lost taxes**

Lost Sales Taxes

200,000 x \$1400 (7% of \$20,000 = \$30,000 - \$10,000 income drop) = **\$.28 billion lost GST**

98,250 x \$1400 (7% of \$20,000 = \$30,000 - \$10,000 income drop) = **\$.13755 billion lost GST**

Totals based on the 20% estimate:

200,000 of 1,000,000 patients:

\$3.48 billion annual cost for the Federal Government, nearly \$10 million 365 days a year

98,250 of 393,000 patients:

\$1.70955 billion annual cost for the Federal Government, \$4.68 million 365 days a year

FM-CFS Canada seeks \$10 million from the Federal Government to take action on this long-standing opportunity for better results. Long term savings will be created that can never be lost.

Lost Volunteer Contributions

Based on national averages: **\$.6 billion**

Average: 25% of Canadians contribute

162 hours at an average of \$15 per hour.



**More than you
thought?**

How much is spent on Medication?

1,000,000 x \$100 month = \$1.2 billion

Our research suggests it is much higher.

How much is spent on Physicians?

1,000,000 patients x \$25 month = \$.3 billion

Based on brief 5-7 minute meetings.

Most patients use more time.

Specialist's fees are higher.

+ Other costs:

Billions in non-reimbursed medications and therapies.

Hospital visits and extended stays.

Legal fees incurred seeking coverage.

Bankruptcies. Lost savings, RSPs.

Employer losses: employees, training.

New demands on local social services.

Societal investment losses. Lost genius.

Family costs. Break-ups. Human costs.

Suicide.

YOUR BACKGROUND...



EDUCATION

PHYSICIAN EDUCATION

FM-CFS Canada is working with Canada's leading medical associations to educate their members about FM & CFS/M.E.. Experts are developing educational Guides for each profession. Physician education will increase early intervention, reduce misdiagnosis, and improve treatment. It has been a long standing problem, and will require funding.

PATIENT EDUCATION

FM-CFS Canada is developing trustworthy educational materials for patients with advice from a wide range of medical disciplines. Available free at FM-CFS.ca, patients will learn how to deal with all aspects of their illness to achieve better outcomes. Better health leads to more who continue working.

PUBLIC EDUCATION

There has never been a national campaign for FM & CFS. We have a national network of media contacts with nearly 100 patient groups, each connected to physicians and patients. Patients have shared testimonials. More than 100 MPs have expressed support. May 12th is our international awareness day.

INVITING SUPPORT

FM-CFS Canada has presented the first plan and issues paper to Government since the 1980's, with nearly 100 groups in agreement. The patient community needs a helping start,

CLASSES FOR PATIENTS, FAMILIES

Patient education is now widely recognised as an important factor in improving patient health in long-term illnesses. Increasingly common are courses where patients and their families learn about the illness from experts, efficiently in groups settings. In some cases, patients can become certified to teach other patients and physicians.

FM-CFS Canada has been preparing plans with help from other health charities currently running patient education programs.

FM & CFS patients need a network of healthy people dedicated to arranging these classes, and to help organise community resources.

PATIENT & CAREGIVER GROUPS

FM-CFS.ca's homepage links to patient groups across Canada, helping patients connect with local support. Nearly 100 patient groups are working together and support a national strategy.

Ideally, local groups have tools to promote education and awareness, so we've developed free educational tools in print and video, with a CD to come. The early promotional tools will include TV & radio ads, bookmarks and posters. There's a lot of donated kindness here, our thanks to all.

RESEARCH

NETWORKING RESEARCHERS

To foster collaboration across Canada, and across disciplines, all can meet at FM-CFS.ca where information services are provided, alongside the Patient Registry database.

There is no known cause, no cure yet.

Canada needs more research. Only one research study has been funded for FM by the Federal Government.

PATIENT REGISTRY

A securely operated national patient contact list to help researchers freely and easily find patients. Three universities helped in 2004. We'll build the free database while encouraging research funding for pilots and studies.

Patient groups nationwide and the Canadian Pharmacists Association distributed 250,000 bookmarks in February and March, 2005.



CFS, AGE 10

DID YOU KNOW?

Health Crisis - No known cause.

With about 500 cases appearing weekly, more than 30,000 per year, and no way to stop it, these illnesses are a real and present danger.

Ripped from Prime of their Life:

Children even younger than 10 have FM & CFS, and will require lifetime support unless better treatment is provided or a cure is found.

Waiting Lists

For many patients, the waiting list to see a specialist is measured in years. Some of them have never seen one at all.

One condition leads to another

FM raises cancer risks. Stress raises coronary risks. Stress can shorten human cell life spans. Chronic pain can decrease the density of the brain's grey matter. Medications can harm internal organs. The drugs usually have side effects. The immune system usually becomes dysfunctional, raising health risks. Depression can further weaken the immune system.

Your contact info

Fallon's story

Fallon's condition is getting worse...much worse., the fatigue is aggressive, the pains more often than not, and she is losing weight due to a lack in eating.....she is missing more school, she is depressed. There is still a misconception that CFS is "all in their heads". That angers me.!!!

Fallon comes to me as her Mom, and is so tired that she is nearly grief stricken in her attempt to make me understand, she lays my hand on her wrist or leg as if I could feel what she is feeling.....and looks to me to "do something." That IS what us Mom's do isn't it? We fix the bumps, and bruises, we mend the broken toys, and are a sounding board for our children's day to day triumphs and disappointments.

For anyone who is reading this.....how would YOU feel if your child, wanted you to, NEEDED you to help them.....and there is nothing you can do, there is no magic cure, and no time frame to give your child hope that on this certain day you will be all better.

We are willing to do ANYTHING for our children.....but what if there is NOTHING you can do?

Fallon could be anyone's child....she loves Berenstain Bears, Hillary Duff, and N64.....she loves Arts and Crafts, and Ice Cream Sundaes.....

On a good day her blue eyes still sparkle, and she gives you a heart melting smile.....and then she tells you how tired she is.