

Fibromyalgia and Chronic Fatigue Syndrome Wellness Support Group  
Richmond Hill and Area  
c/o St. Mary's Catholic Church  
10295 Yonge Street  
Richmond Hill, ON L4C 3B9

October 6, 2004

Technical Advisory Committee on Tax Measures  
for Persons with Disabilities  
140 O'Connor Street  
Ottawa, ON K1A 0G5

Dear Technical Advisory Committee:

### Who We Are

The Richmond Hill Fibromyalgia and Chronic Fatigue Syndrome Wellness Support Group is a grassroots, community-oriented group that meets monthly to empower persons who have been diagnosed with:

- 1) Fibromyalgia,
- 2) Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalomyelitis,
- 3) Multiple Chemical Sensitivity/Environmental Illness.

We are a wholly volunteer based group. We pay our own membership in order to carry out our activities and do not obtain any grants from governments or other agencies. In short, we "listen" to each other, to ensure that no one is left out when dealing with these devastating and disabling illnesses. Another important mandate of our group is to educate the public and to raise the awareness and support of especially employers, insurance companies, medical and legal professionals, and all levels of government.

### Background

The above three syndromes are debilitating and complex disorders characterized, depending on the condition, by widespread pain, profound fatigue, and/or severe allergic reactions. People who suffer from these syndromes most often function at a substantially lower level of activity than they were capable of before the onset of illness. In some cases, these conditions persist for years and are severely disabling to the individual to the extent that he or she is unable to report for work, attend to family, or complete basic functions of everyday living. In addition to these key defining characteristics, patients report various additional symptoms including: headaches, recurrent sore throats, hypersensitivity to environmental factors, and non-restorative sleep.

The co-occurrence amongst these three disabling illnesses is quite high. For example, approximately 75% of those suffering from Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS)/Myalgic Encephalomyelitis (ME) also meet the criteria for

Fibromyalgia. Although CFIDS/ME and FM share many similar symptoms, both can be differentiated by clinical determination.

All three illnesses affect all segments of the population regardless of ethnic origin or economic status. For CFIDS/ME, prevalence is estimated at between 0.75% to 2.6%. Fibromyalgia is estimated to afflict up to 10% of the general population. Multiple Chemical Sensitivity (MCS)/Environmental Illness (EI), in turn, has been diagnosed in up to 6% of the population. Surveys by Statistics Canada have yet to be initiated for these specific illnesses. Thus, it should be noted that the above statistics tend to represent specific areas of Canada and the United States and that completely random surveys of the general population still need to be conducted. Nevertheless, these statistics show that the occurrence of these afflictions is significantly higher in women than in men.

The lack of knowledge concerning these three syndromes and the emphasis on pharmaceutical drugs leave people suffering from FM, CFIDS/ME, and MCS/EI in the position of being marginalized in society and their health requirements inadequately addressed. The almost exclusive reliance upon the use of pharmaceutical drugs that attract the research and development funding as well as the exclusive regulatory and competitive monopolies, often actually exacerbate these illnesses. Additionally, incorrect diagnoses and inappropriate pharmaceutical treatments are common. As a result of this general lack of understanding, those attempting to overcome the debilitating effects of their conditions frequently have to advocate on their own behalf against doctors, insurance companies, employers, and government disability tax benefit programs. These daily struggles to make themselves equal in society only delay their recovery, prolong their suffering, and severely adversely affect their financial status.

### Proposals for Reform

#### 1) Disability Tax Credit

Persons suffering from Fibromyalgia, Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalomyelitis, and Multiple Chemical Sensitivity/Environmental Illness must be allowed to claim the disability tax credit should they qualify as being unable to perform any one of the basic activities of everyday living.

“Brain Fog” and severe migraine headaches are common for persons suffering from these diseases and thus the ability to “perceive, think and remember” may be significantly impaired.

As well, besides affecting mental capacity, any of these disabling illnesses may affect physical abilities such as feeding, dressing, or walking, which are also categorized as basic activities of daily living for the purpose of the disability tax credit. Persons in a severe stage of Fibromyalgia, for example, are often bedridden and unable to take care of themselves.

In order to properly address the needs of people struggling with these conditions, the Canada Revenue Agency must recognize that Fibromyalgia, Chronic Fatigue and

Immune Dysfunction Syndrome/Myalgic Encephalomyelitis, and Multiple Chemical Sensitivity/Environmental Illness are disabling illnesses and, as such, qualify a diagnosed person for the Disability Tax Credit. As well, due to the nature of these disabling illnesses, we are unable to predict when we will have "good days" or "bad days", and if or when a prolonged relapse will occur. Thus, the words "all or substantially all the time" should be replaced with a phrase such as "at significant risk".

## 2) Medical Expense Tax Credit

Many of our members have claimed medical expenses such as vitamins, herbs, homeopathic remedies, organic and natural foods, and bottled water, only to be denied such medical expenses for the purpose of the medical expense tax credit. A Federal Court of Appeal decision, called *Rhonda Ray v. H.M.Q.* 2004 D.T.C 6028, was devastating upon our community in that it not only disallowed such medical expenses, which are incurred in purchasing substances which are so essential to our health, but also severely narrowed the medical expenses to be only those that are pharmaceutical in nature.

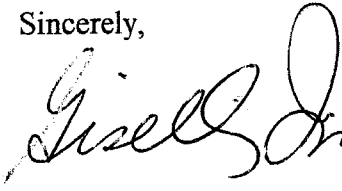
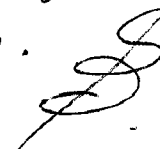
The key provision in the Income Tax Act under scrutiny in the above case consisted of the words, "as recorded by a pharmacist", which is a very significant obstacle for us as many of these substances cannot be purchased at a pharmacy. Thus, we would recommend that Parliament strike out the words, "as recorded by a pharmacist" completely as such would not impact other patients suffering from other diseases or ailments. The words "as prescribed by a medical practitioner" already exist, thus ensuring a safeguard that the medical expense tax credit will not be abused.

We strongly advocate such a legislative change. However, if Parliament refuses to change the provision as above, then we would recommend adding an additional provision to the interpretation bulletin dealing with the medical expense tax credit, as follows:

"Medical expenses, as prescribed by a medical practitioner, for the purpose of alleviating the symptoms associated with Fibromyalgia, Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalomyelitis, and Multiple Chemical Sensitivity/Environmental Illness, such as: vitamins, herbs, homeopathic remedies, organic and natural foods, bottled water, and pharmaceuticals."

You may contact me if you have any questions. My phone number is 905-884-6169.

Sincerely,

  
Gisella Imbrogno, on behalf of the  
Richmond Hill Fibromyalgia  
Wellness Support Group. 

Gisella Imbrogno