

REACHING OUT

FALL 2009

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SPOTLIGHT ON EDUCATION: STUDENTS WITH ME/CFS IN THE ONTARIO PUBLIC SCHOOL SYSTEM

by Maureen MacQuarrie

September, for many, means back to school. But what about children and youth with ME/CFS? Access to education for every young person is a fundamental value of Ontario's education system but it has not been the reality for many students with ME/CFS. The MEAO recently called upon Ontario's Minister of Education, the Honourable Kathleen Wynne, to convene a panel to develop *Guidelines on Access to Education for Students with Chronic Disabling Illnesses* to ensure that these students, many of whom are homebound or unable to attend school full-time, are not forgotten. We believe students can be helped in the following ways:

- by training all educators on the needs of students with ME/CFS;
- through improved absenteeism policies;
- by working with special education provisions to adapt them to the needs of children with chronic physical illnesses; and
- by continuing to work with the Ministry on mandatory physical activity requirements.

In an August package from the MEAO, and endorsed by the National ME/FM Action Network, we provided the Minister with a number of specific recommendations. We have asked the Minister's Advisory Panel on Special Education (MASCE) to support this work.

The MEAO has been hard at work over the years to assist youth with ME/CFS. This has included contacting 215 schools and school boards and providing them with copies of the excellent resource *Teach-ME* written by the National ME/FM Action Network, along with MEAO's own materials for parents and youth. MEAO has been fortunate to have the skills of some very active volunteers to work with parents and young people. In particular we would like to thank Cathy Prescott and Margaret Parlor (now President of the National ME/FM Action Network).

One of the results of our combined efforts is a presentation for school boards across the province entitled "*Understanding and Accommodating Students with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS)*".

(continued on page 2)

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is published four times a year by
The Myalgic Encephalomyelitis
Association of Ontario (MEAO),
a registered charitable organization
#892267568RR0001

Our mailing address is:

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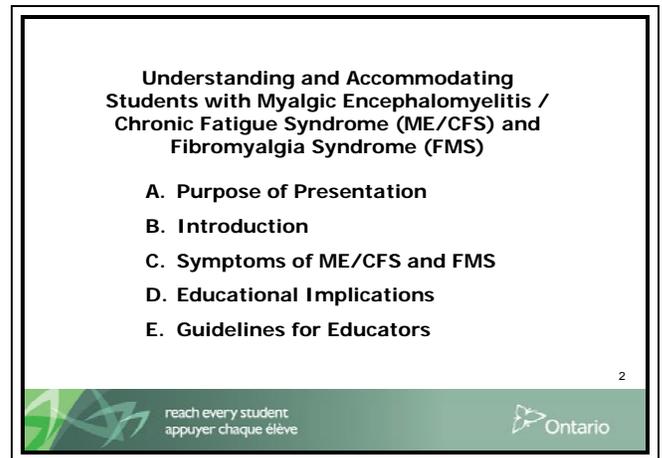
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We are grateful for our funding from:



your children and teens. The Introductory slide from the presentation is reproduced below and the entire presentation has been posted on the MEAO website in English and French. Please see: www.meao-cfs.on.ca/school.html



We all know that physical activities, particularly cardiovascular activities, pose serious challenges to children and adults with ME/CFS. On the mandatory physical activity issue in schools, keep in mind the December 8, 2006 letter from Elizabeth Harding, Director, Policy and Program Branch of the Ministry of Education (posted in full on the MEAO website). “It is important to remember that no child should be required to participate in inappropriate levels of exercise nor should they need to be removed from school to avoid participation. Communication with parents and with school staff is important in determining any accommodations and adaptations to daily physical activities.”

We will continue to try and clarify how students with ME/CFS fit into the education system so that the guarantee of access to education is actually met. In the meantime, parents of ME/CFS students should be aware of the presentation and its contents in your discussions with individual schools. In particular, be aware that part-time and homebound instruction are both possible in the appropriate situation. Please continue to contact the MEAO Info Line with your concerns related to children and youth or if you would like further information about this initiative.

Spotlight on Education, cont'd from page 1

This presentation was developed by the Ontario Ministry of Education (June 2008) after a request initiated by Margaret Parlor. We have been advised by the Minister that this presentation has been distributed to ministry regional offices across the Province, to in turn be provided to school boards. We will work to ensure this slideshow is posted on the Ministry website and distributed to school boards and schools across the province.

This presentation makes suggestions as to how students with ME/CFS and FM can be served. It raises awareness about ME/CFS and could be very helpful for parents when you are working with your schools to get accommodations for



FROM THE PRESIDENT



President's Column,

As I write this column, I am finally enjoying a clear, sunny day, away from work and household chores. I hope that during the coming fall, we will have many more of these warm sunny days.



Reflecting on my volunteer work with MEAO, I realize that I have now been a Director for seven years and, upon the unfortunate passing of Audrey MacKenzie, I've been President of MEAO since 2005. Last fall, when I became involved in a small business venture, I expressed the desire to step down as president but agreed to stay for one last year to help the board find my successor and to support our new Provincial Coordinator. Now that that has occurred, I will be resigning from the MEAO Board, at our upcoming AGM.

My decision to resign from the Board has not come easy but it has fortunately come at a time where there are now a number of very capable and talented volunteers on the Board. These volunteers appear to be ready and willing to take the MEAO to the next level – a level involving an expanded governance structure which incorporates a variety of standing and ad hoc committees which, in the end, will result in more opportunities for volunteers to become actively involved in the various MEAO initiatives.

If you would like to become more active in MEAO, I encourage you to explore the various opportunities that are available to you. Some volunteer areas involving working on occasional tasks, some involve ongoing committees. If you are able, volunteer on a committee of your choice. Committees generally do not require a substantial commitment of time. They give one an opportunity to contribute his/her talents and expertise and, at the same time, one can learn

more about the operations of MEAO and be a part of our community of volunteers.

As for myself, I will continue to be available to the Board as the Past President; I hope to see many of you at our future seminars, community meetings and the Annual General Meetings.

Going forward, it may be appropriate for me to now share with you a "front page" slogan that Audrey MacKenzie used in one of our past newsletters:

**The MEAO train is now leaving the station,
Plan to be on board!**

Respectfully,
Anthony Rovito, President



**Come to our AGM and Medical Update
Saturday, October 3, 2009, 1 - 4 p.m.
Women's College Hospital Auditorium
76 Grenville Street, Toronto**

Order of Events:

- Greetings from the Board
- 2nd Annual MEAO Awards Ceremony
- Presentation of the Audrey MacKenzie Award to Dr. Alison Bested for her dedication to ME/CFS
- Featured Speaker: Dr. Riina Bray, Medical Director, Environmental Health Clinic
- Q & A with our Experts: Dr. Bray and Dr. Bested will field your questions about ME/CFS and Environmental Sensitivities
- Final Event is the MEAO Business Portion of the AGM: our Year in Review, Audited Statements and the Election of the Board of Directors (voting open to members as of Sept. 3, 2009)

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ASK THE LAWYER – HUGH SCHER

*This month, we bring you Part I of a two-part series on legal issues that affect many people with ME. In Part I, MEAO board member **Chris Pike** interviews **Hugh Scher** about **workplace insurance issues**. Hugh Scher is the founder of Scher Law Professional Corporation, a specialty law firm with a focus on employment, human rights and disability insurance litigation and CPP disability claims, particularly on behalf of people with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia.*

Q: As we are currently in the midst of an alarming doctor shortage for those living with Myalgic Encephalomyelitis and as there is no diagnostic test (yet) for ME, what evidence do you commonly gather to support these claims and win Long Term Disability cases?

Answer: In the context of long-term disability insurance claims, there are a number of strategies that can be employed to marshal evidence and to bolster the strength of a claim. These include meeting with leading doctors and other clinicians to obtain independent assessments, and obtaining relevant diagnostic assessments which include sleep studies, neuropsychological testing, psychiatric opinions and opinions from pain specialists, occupational therapists and vocational assessors.

Q: Do you have any 'legal tips' for people that are scared they'll be bumped off LTD by their insurance company?

Another challenge in today's economy is the concern that many who are on LTD insurance benefits may be cut off at any time. Insurers have the right and the duty to adjudicate (assess and determine) your claim. However, there are things that you can do to keep yourself ready for that adjudication. This includes regular assessments by your treating physicians and healthcare practitioners. It may include keeping a daily activity journal, and attending appropriate medical and alternative interventions.

Q: What are the most common mistakes people make in dealing with their insurance providers?

The biggest mistake made by clients and doctors, and some lawyers in these cases, is their failure to recognize the functional assessment that is required by the doctor or lawyer in order to meet the terms of an insurance policy.

An assessment of limitations and restrictions and functional impairment is what the insurer is looking to understand. Exactly what activities can the patient not do and how does this specifically impact on their ability to work in their job, or any other job for which they may be qualified for? It is not enough simply to indicate that you are sick or that you are suffering from ME or FM. What matters is the impact of these conditions upon the individual. Often doctors are not very good at providing that sort of information as they tend to limit their opinions to diagnosis, symptoms and prognosis. The challenge is to make sure that they are asked the proper questions to illicit their opinions as to functional impairment and its impact on ability to work.

Alternatively, some form of vocational or functional assessment by an independent expert knowledgeable about ME or FM may assist. Unfortunately, the number of true experts with this knowledge is limited, although many who work for insurers hold themselves out as such an expert. A functional assessment by somebody who is in a position to provide that assessment is critical to ensure that the insurer has all the relevant and appropriate information to make a proper adjudication.

For all patients, in order to gather all the relevant evidence and to determine what assessments are needed and best in your case, it is useful to obtain professional advice from both your treating healthcare practitioner as well as from a lawyer.

I have worked for the past 15 years on behalf of people with ME/FM and have learned what information is required and understand the kind

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of questions that need to be asked of physicians and healthcare practitioners in order to obtain that relevant information.

Q: What information does a sick employee need to give their employer about the nature of their illness? How much information is too much?

When dealing with an employer, it is always difficult to assess how much information one should provide related to one's illness. Where one is seeking accommodation, there is an obligation to cooperate with the employer and to provide information as to the limitations and restrictions, and the functional impairments experienced by the disabled employee. This does not mean that it is necessary to divulge the diagnosis or other relevant medical information. In some instances, however, it may be useful to do so. This is something that must be assessed on a case-by-case basis.

Q: Are employers obligated to continue to provide extended benefits such as medication and dental coverage to employees that have been on long-term disability for months or years?

A common difficulty experienced by employees who are either on LTD benefits or who are cut off LTD benefits or denied them, is the employer's decision to terminate other health, dental, life and welfare benefits. These health and welfare benefits are benefits of your employment and not benefits of your insurance unless the policy provides specifically for them.

As such, it is entirely a matter of employer policy as to whether or not they decide to continue such benefits during a period of an unpaid leave of absence or after one is denied disability benefits. At the same time, the denial of health and welfare benefits may itself give rise to a legal case for wrongful or constructive termination of employment, which may entitle the employee to some kind of notice or termination pay. This is a matter on which employees should receive legal advice before making any final decisions. For

this reason, employees on disability should be careful not to resign their employment without proper legal advice.

Q: Any advice to people who suspect they are under surveillance by their insurance company?

A common tool used by insurers to assess their insured is surveillance. In 15 years, I have yet to see surveillance significantly impact any case that I have been involved with.

That said, it can be very disconcerting to insured persons who feel that they are being followed, stalked and put at risk. If you feel you are under surveillance, many individuals will approach the surveillance team and demand to know whether or not they are conducting surveillance on behalf of somebody. We don't recommend this but if you feel that you are under surveillance, you can contact your local police as well as your disability insurer to confirm that they are in fact the ones that are conducting the surveillance.

My best advice to individuals under surveillance is to maintain their daily activities and continue to function as best they can. In my experience, surveillance has typically been an ineffective tool of an insurer in disability insurance cases. This is particularly so where individuals are legitimately suffering and experiencing difficulties on a consistent basis.

Mr. Scher has worked for the past 15 years on leading cases before the Supreme Court of Canada, the Ontario Court of Appeal and other courts and tribunals to create precedents that advance the rights of people with disabilities across Canada. He has benefited dozens of individuals with ME and FM across the country. He lectures broadly on these issues before the Law Society of Upper Canada, the Ontario Bar Association, and educational organizations across the country. He also serves as voluntary counsel to the Myalgic Encephalomyelitis Association of Ontario (MEAO) and to the National ME/FM Action Network. We thank Hugh for his interview with us this month.

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YOU AND THE SWINE FLU – H1N1

Written by Theresa Dobko, MEAO Provincial Coordinator, from government and medical sources

What is H1N1 flu virus?

The H1N1 flu virus is a serious respiratory disease that can spread from person-to-person. This fall, it is expected to increase as we return to work and school.

How does H1N1 flu virus spread?

Flu viruses are spread mainly from person to person through the droplets released from coughing or sneezing. Sometimes people become infected by touching objects contaminated with H1N1 and then touching their mouth or nose.

- H1N1 can stay on your hands for 5 minutes if not washed correctly
- On fabric for 10 minutes
- On surfaces for 2 days if not disinfected

What are the symptoms of H1N1?

The symptoms of H1N1 flu virus are similar to the symptoms of other seasonal flus: chills, cough, sore throat, fatigue body aches or headaches. Most, but not all, people will get a fever. Some children and adults have diarrhea and vomiting. H1N1 can lead to pneumonia and other serious illnesses, including death.

How does my having ME/CFS affect getting H1N1?

Like other flus, H1N1 can be worse for those with another underlying medical condition. People with ME may have compromised immune systems which could make the virus harder to fight.

What should I do if I get sick?

If you become ill with the symptoms listed above, contact your doctor immediately, or call TeleHealth 1.866.797.0000, if your doctor is not available. They will help you determine if you need to be seen for treatment. Make sure you tell any health care provider you see that you have ME/CFS and that you may be at more risk for complications.

How long is someone infectious?

Someone with H1N1 may be infectious for 24 hours before the first symptom appears and for 7 days after becoming sick. Young children may be contagious for longer. That is why it is recommended that anyone with H1N1, or anyone exposed to H1N1, should stay home until medically cleared.

Can I protect myself from H1N1?

For people with ME/CFS, avoid anyone who is ill, if you can, and consider avoiding busy public places during an outbreak. The following advice is for all Canadians:

- Wash your hands often with soap and warm water, for at least 20 seconds. Wash after each time you cough/sneeze and when coming home.
- 60% -90% alcohol-based hand rub is effective when soap/water are not available. Use unscented product without other additives if you have ME. *Microsan Encore* is one brand.
- Sneeze and cough into a tissue or your sleeve so the virus droplets can't spread. Throw tissues into the trash right after use.
- Most people should not wear a surgical mask in public because most do not wear them right and may actually contaminate the mask taking them off and on. People with ME that wish to wear a mask in public should be trained by a health care provider. You may wish to buy a N95 mask from a supply store.
- Vaccines: This is very complicated for people with ME. Dr. Bested wrote a piece for us in our Fall 2008 issue you should reread. Don't have a copy? Send an email to: info@meao-cfs.on.ca and we'll send you one.

Helpful H1N1 Websites

Government of Ontario:

<http://www.health.gov.on.ca/en/ccom/flu/>

City of Toronto Pictorials on Handwashing and Proper Coughing Techniques:

www.toronto.ca/health/cdc/resources/index.htm

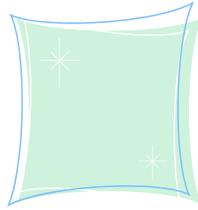
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WITH CHRONIC FATIGUE SYNDROME, MY LIFE IS A GLASS BOX

by Maureen MacQuarrie

Originally printed in the *Globe and Mail*,
Wednesday, June 24, 2009
Reprinted with permission of the author



"You have chronic fatigue syndrome."

The diagnosis brought relief after 18 months of uncertainty. I had heard of chronic fatigue syndrome. It was the yuppie flu, wasn't it? It was around in the late eighties and then disappeared. No one got it any more, or so I thought.

I was everywoman – busy with my public-service career and my family of two young children. And then in the mid-1990s, after a viral infection, something began to go wrong. I was tired all the time. "Who with children and a busy job isn't?" I told myself. We live in a society that almost requires it. So I ignored it.

Unfortunately, that didn't work. I started getting sore throats, headaches, muscle aches. I jokingly asked my husband to pick up a new body for me when he was out shopping. Too bad he couldn't.

I popped pain pills so I could go to work. But my body had other plans. In the summer of 2001, I stopped sleeping and my brain stopped working. Brain fog took over. I couldn't think straight, remember or multi-task. I was forced to stop everything.

I went to the doctor but didn't get an answer. Every test came back normal. But I knew I wasn't. And so it continued, until finally I got a diagnosis, although not a solution.

Chronic fatigue syndrome is invisible and isolating. It's almost impossible to convey with words the utter exhaustion this disease brings, not only physically but mentally and emotionally

too. Its other name, Myalgic Encephalomyelitis, means widespread inflammation in the muscles, brain and spinal column. It's also known as ME/CFS.

The fatigue is profound. It's not the welcome, sleepy tiredness most of us experience at the end of the day. It goes to the very core, a wired, jittery fatigue from which there is no relief.

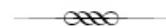
I've been told I look fine. That's good – I'd hate to think I look as bad as I feel. A sleep study confirmed I had an almost total lack of restorative sleep. Each day is an unknown. The doctor says to think of it like being in a glass box. On a bad day, the box is tiny. I can barely get out of bed, every muscle aches and my head pounds. On a good day, the box is bigger, but I need to figure out how much bigger, otherwise I will crash through and end up bedridden. The objective is to pace, to expand the size of the glass box without breaking it.

I have been virtually housebound for much of the past eight years. Even on a good day I find it hard to do the simple things most of us take for granted. I have difficulty planning a menu or deciding what groceries to buy. Going to the grocery store is a rare event and the stimulation of being out and about is overwhelming. I've learned that doing one thing a week is about my limit – so when I have a doctor's appointment, for example, that's it for the week. I need at least one nap a day to try to replenish my energy stores.

There is currently no cure. The treatment is symptom management, which is different for each person. I have had some success with pacing myself, sleep and pain medication, careful dietary choices and relaxation techniques.

Most people's eyes glaze over if I tell them I have chronic fatigue syndrome. Who isn't tired? Why don't we just suck it up like everyone else? We would if we could. This is an extremely disabling disease. It involves many different body systems and it's a trickster, affecting each person somewhat differently. Contrary to my initial

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thoughts, it's fairly common; it affects children too. People with this illness tend to drop out of sight, with the result that others do not see the devastation it brings.

Few doctors know much about it and there are no treatment centres, so people are often misdiagnosed or forced to go from doctor to doctor searching for answers. This is gradually changing. The cause remains unknown but researchers around the world are searching for answers as to how it targets the brain, the immune system and the endocrine system.

I've met many people with this illness. They, like me, have been snatched from their formerly productive lives, put in the glass box, dismissed and told it is not life threatening. Perhaps not, but it is life-diminishing. It puts extreme limits on my daily activities.

I have come to accept the disease is relapsing and remitting. It comes and goes like the tide, with crashes and then periods of moderately good health.

My glass box is getting bigger. With assistance from my family and friends and caring health practitioners, the crashes are becoming less frequent and the periods of health longer. It has been helpful to know I am not alone. I am regaining some of my former life. I have found renewed purpose in advocating for research and treatment for those suffering with this illness. I am able to get out a bit more but must constantly be vigilant not to overdo it.

I'd like to be able to say I have recovered. But I'm optimistic that with more understanding, support and research I will. Maybe I won't need that new body after all.



UPCOMING EVENTS FROM THE MEAO

Legal Issues for People with ME/CFS and Fibromyalgia An MEAO Community Seminar with lawyer Hugh Scher

Saturday, November 7, 2009, 1-3 p.m.
Women's College Hospital Auditorium
A Keynote Address
Followed by Questions & Answers

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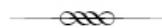
OTHER COMMUNITY EVENTS:

Super Sound Promotions presents a
"Concert to Benefit Fibromyalgia".
Friday, Sept 25, 2009. Doors open at 7:00 p.m.
Event starts at 8:00 p.m.
Gig Theatre, 137 Ontario St. N., Kitchener
Country artists **Jamie Warren and Rob Kirkham**
with Neon Rain will be playing. The purpose of this
event is to raise awareness and educate the
community about Fibromyalgia. Details available at
the Kitchener Waterloo Fibromyalgia Support
Group Website:
<http://kwfibromyalgia.webs.com/>



**The Waterloo Wellington Myalgic
Encephalomyelitis Association**
announces its new website:
<http://www.wwmea.ca/>

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SHARING OUR EXPERIENCES WITH ME/CFS – PART 4

By Suzanne Mossman

In the 2008 issues of our *Reaching Out* Newsletter, we presented a series of articles written by contributors who discussed their emotions relating to their ME/CFS. Specifically, we discussed the emotions and feelings of *Guilt*, *Grief* and *Denial* respectively. For many people, these are not easy subjects to discuss as these emotions are commonly recognized as burdensome and oppressive.



like our blood pressure, body temperature, adrenal functioning, heart rhythms and more.

While we all attempt to reconstruct and create a new version of our old life, several say it is their existing support system: family, friends, ME contacts, and even pets that have kept them strong. For others, it has been necessary to seek new forms of support for their wellbeing. Everyone's situation is unique and every situation without a doubt is a daily challenge. With an illness like ME very little is certain. What is significant however, is how we positively cope with what life has handed us. Maintaining a realistic and accurate outlook on our lives and the ever changing challenges we face is important.

A common theme that seems to resonate throughout each person's personal experience is the acute emotional pain they feel at the losses that have occurred in their lives due to their illness. An equally powerful underlying theme was the message of resilience and conviction found in these writings. Despair and pain are substantial, but as with many difficulties that occur in our lives, we may also experience acceptance, community (with others living with ME), and yes, sometimes even hope. A certain level of acceptance regarding a chronic illness can come with balance, time and understanding. Balance for a person with ME is imperative and respecting our emotions is vital.

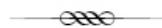
Early researchers thought that ME was actually a psychiatric disorder – a form of depression when in actual fact people with ME are very different from those with primary depression; we fight to stay active. This tenacious characteristic can unfortunately cause the opposite effect for us. Certainly there are many types of triggers which can lead to bouts of fatigue, pain, and other unpleasant symptoms. Stress, anxiety and fear are particularly debilitating, but when we overexert, and we are active beyond our physical reserves, even positive activities can lead the ME sufferer to experience distress. This reaction isn't merely emotional or psychological, it is physiological. ME alters our neurochemicals and body mechanisms

Many individuals say that contracting ME has also taught them something about themselves, through a forced recognition. Although this might sound baffling to some, particularly those in the early throes of our illness, some note that the illness that initially knocked them to their knees, has also made them re-evaluate, re-prioritize, simplify and get a better understanding on what is really important in their lives. Through their adversity they have also met extraordinary and courageous people, had some remarkable experiences, and have learned and grown significantly. Many find new areas of reward and fulfillment, within their profound physical limitations.

There is a true bravery for any individual fighting and managing a chronic physical illness. There is still a real passion for living in us; it is simply the amount of energy we are able to apply, to realize that passion. This is evidenced by our strength and commitment to meet our illness head-on.

In the ME community there is a real sense of understanding, friendship, compassion, and unity. Individuals can take comfort in the MEAO and others like it. While we still confront the prejudices and misunderstandings from others that do not comprehend our illness, we will, with the help and support of those around us, educate, assist and overcome together, hand-in-hand.

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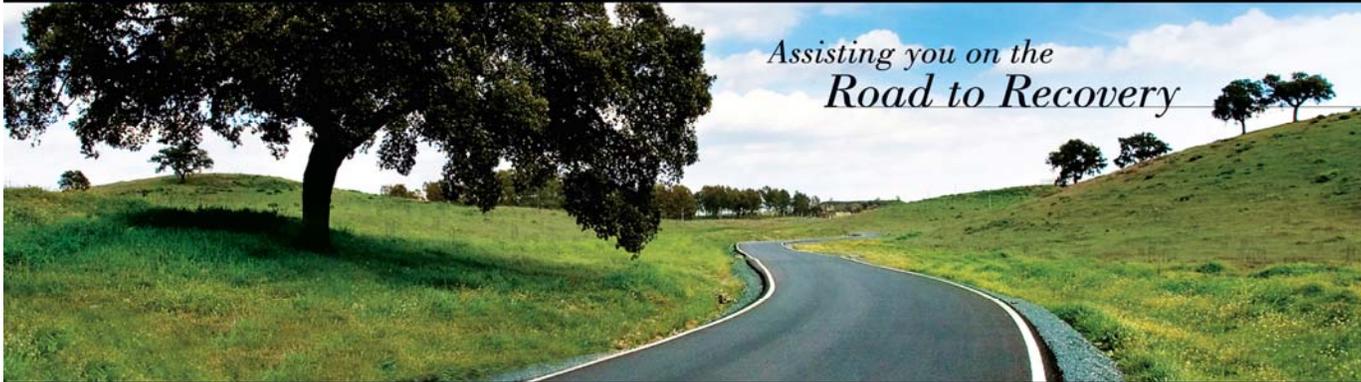
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Our website can be found at:

<http://www.meao-cfs.on.ca>

You can email us at:

info@meao-cfs.on.ca

Our INFO LINE is:

416.222.8820, for callers in the Greater Toronto Area, **or 1.877.632.6682** for toll-free calls across the Province.

Our Info Line is a message centre. Please leave your name, number and the best times to call you on our machine, and a volunteer will call you back to help with information and referrals.

MEMBERSHIP AND DONATIONS

Our annual membership is \$20.00. Members receive our quarterly newsletter **'Reaching Out'** with articles on ME/CFS Research, Coping Tips, Legal Issues, Upcoming Events, Helpful Websites and Books and much more! Members are also eligible to direct the work of the MEAO and vote at our Annual General Meeting.

Paid memberships help support our charity and our mailings but we do have complimentary memberships for those experiencing financial hardship. See our Membership / Donation Form below.

Donations are our lifeblood. Donations of \$10.00 and over are issued a charitable tax receipt. You can mail us a cheque or donate by credit card through CanadaHelps on our website.

Disclaimer: As a resource group, the function of our organization is to provide you with current information on ME/CFS. As we are not medical or legal professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your needs with your doctors, lawyers and other professionals before making any decisions.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
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MEMBERSHIP AND / OR DONATION

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