Agreement #40665071

REACHING OUT

SUMMER 2009

Government Data Shows Ontarians with CFS Are Disadvantaged

by Margaret Parlor

The following information was extracted by the National ME/FM Action Network from the Statistics Canada datafile for the 2005 Canadian Community Health Survey.
An estimated **138,000 Ontarians have been diagnosed with CFS.** Roughly one third were less than 45 years old, another third were between 45 and 59 years old, and one third were 60 or over. Two thirds were female, and one third were male.

Ontarians with CFS showed a high degree of activity limitation.

% of group reporting	Ontarians with CFS	Ontarians in General
Need help - preparing meals	17%	3%
Need help - getting to appointments & running errands	33%	5%
Need help – doing housework	37%	6%
Need help – spring cleaning / gardening	58%	12%
Need help – personal care	10%	2%
Need help – moving about inside the house	11%	1%

Ontarians with CFS also experienced socio-economic disadvantage.

% of group reporting	Ontarians with CFS	Ontarians in General
Permanently unable to work (ages 15 – 74)	21%	2%
Annual personal income less than $15,000 (15 +)	39%	28%
Food insecure	18%	5%
Weak sense of belonging to local community	23%	10%

There are gaps in service to Ontarians with CFS.

% of group reporting	Ontarians with CFS	Ontarians in General
Unmet health care needs over the previous 12 months	30%	11%
Unmet home care needs over the previous 12 months	13%	2%

Continued on page 2

ALSO IN THIS ISSUE:

REACHING OUT

is published 4 times a year by
The Myalgic Encephalomyelitis Association
of Ontario (MEAO),
Charitable #892267568RR0001.

Our Mission Statement

- ***To provide M.E./CFS sufferers with support, current information and direction to the best possible professional services***
- ***To educate the public on the illness, its debilitating effects, and concomitant social and economic consequences***

Our MAILING ADDRESS is:
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Our INFO LINE is: 416.222.8820, or 1.877.632.6682

We are grateful for our funding from:

The Ontario Trillium Foundation
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TORONTO

Continued from page 1

The Myalgic Encephalomyelitis Association of Ontario and the National ME/FM Action Network have being saying for years that:

- **ME/CFS is a very disabling illness,**
- **the illness has substantial impact on people's lives**
- **there are significant gaps in health delivery.**

Now Canadian government data shows that this is true.

Please share this important information with others. Help to make this information as widely known as possible.

About the Cdn. Community Health Survey:
The Canadian Community Health Survey is a major survey designed by Canadian health authorities to identify and monitor health issues affecting Canadians aged 12 and up. There were 10,600,000 Ontarians in scope for the survey.

Report on 2009 IACFS/ME Conference in Reno Nevada

by Maureen MacQuarrie

The International Association for CFS/ME (IACFS/ME) held its 9th research and clinical conference (held every 2 years) in Reno, Nevada from March 12 to 15, 2009. The IACFS/ME estimates total attendance at the conference at over 400 with representation from 17 different countries. There was a small presence from Canada including our own Dr. Alison Bested.

The conference was a veritable Who's Who of the ME/CFS world and a most exciting event. The conference kicked off with a one day patient-oriented conference and with 4 professional workshops (Treating Pain, Sleep and Fatigue; Behavioural assessment and Treatment of ME/CFS; How to apply for grants; and Research 101). The patient conference provided an overview of current research and management.

The conference itself featured the latest advances in biomedical research in CFS/ME and fatiguing illness more generally. It featured sessions on a whole range of topics including the brain, triggering agents, subgroups, metabolic/mitochondrial dysfunction, therapy/treatments, genetics/genomics and pediatric/childhood

CFS. Many of the studies are in their infancy but results are promising.

Dr. Anthony Komaroff, MD closed the conference with a summary of the presentations, including those delivered from the podium and by poster (115 in total). It is available as video at http://progressive.uvault.com/pd1005/CFS091/75/player.HTM.

One of the first cluster outbreaks of CFS occurred in Nevada at Incline Village (Lake Tahoe) 25 years ago. Dr. Daniel Peterson and his then-partner, Dr. Paul Cheney, recognized a cluster of CFS among their sick patients. Both doctors have been at the forefront of CFS care since that time.

The University of Nevada Reno is also the home of the Whittemore Pearson Institute for Neuro-immune Diseases. Although they are not the only ones involved, Annette and Harvey Whittemore have been credited with getting this initiative off the ground. They have a now adult daughter (Andrea) who suffers from CFS. This institute, with Dr. Peterson as its medical director, is within the University of Nevada School of Medicine's Center for Molecular Medicine. It is the first institute in the world dedicated to neuro-immune disease integrating patient treatment, basic and clinical research, and medical education. It is already beginning to produce results. A state-of-the-art building in which the institute will be housed is scheduled to be completed in 2010.

The IACFS/ME hopes that their quarterly newsletter, the Bulletin of IACFS/ME, can be evolved into a Medline peer review journal. If they are successful in this undertaking it will be a great benefit in getting research more broadly known and accepted.

There are excellent summaries of the Conference on the CFIDS website at www.cfids.org/cfidslink/2009/040103.asp -- (includes a lot of other great information too) and on the IACFS/ME website http://www.iacfsme.org/IACFSMEConference More Info/tabid/221/Default.aspx – go to Conference Summary).

Remembering Audrey

Audrey MacKenzie
Past President of MEAO

by Diane Meitz, friend and colleague

It's been two years since Audrey's passing, but the celebration of her life is ongoing as we remember Audrey and honour all her valuable contributions to our ME/CFS community.

I was reading the lovely comments from Audrey's Memorial Service and I would like to share with you some of the words mentioned to describe Audrey....***kind, caring, inspirational, determined, compassionate, honourable, dedicated, funny, wise*****.....Her smile and eager nod gave so many the reassurance and hope they needed in that moment.

This past winter Audrey's beloved cat Fang passed away in her 26th year. Fang was Audrey's ray of sunshine and support just as Audrey was to so many of us with ME/CFS.

I leave you with her reassuring words: **"Never give up. It will get better."**

FROM the PRESIDENT

While I write this column, I glance frequently through my window to enjoy the beautiful sunny day and the lush greenery that the spring weather has facilitated. I hope that all of you have also had opportunities, this spring, to truly appreciate nature.

In our last issue, I reported that with the arrival of spring, the Board of Directors was looking to making progress in a number of important areas. One of those areas involved hiring a new Provincial Coordinator to guide us through our plans for our second and third years of our Ontario Trillium Foundation grant, and to help us raise the funds to open Ontario's first Centre for people living with M.E.

At this time, we are pleased to report that after posting the position and then conducting a thorough interview process, MEAO has now hired **Theresa Dobko** as our new Provincial Coordinator. Theresa has over 25 years of experience within the non-profit sector and has the experience and skills to help us succeed with all of our services going forward. Theresa is also someone who has lived with M.E. and Multiple Chemical Sensitivities for 23 years and has experienced what she calls "the waves of Relentlessness, then Remission, then Relapse and even some Recovery" that comes with M.E. The Board is very pleased to have Theresa on board!

Theresa will be writing the next "FROM the Provincial Coordinator" column in our fall issue, but in the meantime she'd like to say a few words about our **May 12th Fundraising Campaign** this year:

"I'm so honoured to be working as the PC for the Association and one of my first goals is to help the Board raise the funds to open a Centre for the MEAO and for all people living with M.E. Diabetes is the number one chronic illness in North America, but M.E. and Fibromyalgia combine to be the second largest illness group! Yet there are no M.E. Centres, research chairs or hospital departments that are dedicated to our care.

On May 12th, our Association mailed out a letter to all of our members and donors asking each of you to donate what you can – or find us other donors if you wish – so we can raise the $39,000 we need to open our Centre for the first year.

If you haven't already, please donate what you can. Once we open a Centre, we can answer our Info Line in real time and take all of your calls. We can start a small library of materials for people with M.E. to read and copy. We can hold support groups, workshops and many other services. Our volunteers can work collaboratively in one setting. We will have an office to bring physicians, lawyers and government officials to educate them about our needs. We will have a home. With that home, we can make greater strides and work to create the support systems people with M.E. deserve. Please mail in your donation or check out our improved website and donate online at www.meao-cfs.on.ca.

Best wishes for an enjoyable summer!

Anthony Rovito

P.S. You will notice a slight change to the newsletter's format: 'FROM OUR KITCHEN TO YOURS' and 'ON THE FUNNY SIDE' will be inserted in your newsletter as a separate, removable page.

NEWS and UPCOMING EVENTS

THE COGNITIVE BEHAVIOURAL THERAPY GROUP, run by Dr. Alison Bested, begins on **Friday June the 5th: 1 to 3 p.m.**, every Friday for 12 weeks, and is covered by OHIP, If you wish to join, please phone the office at **416 283-0007**.

LUNCH and LEARN

Sponsored by the Environmental Health Institute of Canada, featuring Dr. Alison Bested as speaker.
June 7, 2009, 12 noon. Tickets available through Dr. Bested's office, **416 283-0007.**

MEAO'S ANNUAL GENERAL MEETING
Saturday, October 3, 2009, Women's College Hospital, Main Auditorium,
1:00 – 4:00 p.m.
76 Grenville Street, , Toronto.
FREE ADMISSION, EVERYONE WELCOME!
DONATIONS APPRECIATED
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May 12 M.E. Awareness Day Events:

MEAO: On May 12th the MEAO launched its campaign to open a Centre for the Assoc. so people living with M.E./CFS will finally have a place to go to get help and to help others. The MEAO is committed to raising the $38,000 it needs to open its first Centre.

M.E./FM Association of Peterborough and District celebrate M.E. Day, May 12th:
The Association asked Peterborough's Mayor to declare May 12th International Awareness Day. An information display was set up at the LETS Market on May 9th; May 12th they held an open house at their Library, followed by a presentation on Laughter Yoga. News releases were sent to two local papers.

£ 730,000 for Research into CFS in Children

University of Bristol Press Release, 2009

A new area of ground-breaking research to provide a better understanding of the cause, treatment and prevention of Chronic Fatigue Syndrome/ME in children has secured a prestigious fellowship and funding of £730,000. The National Institute of Health Research has awarded the Clinician Scientist Fellowship to Dr Esther Crawley, Senior Clinical Lecturer at the Centre for Child and Adolescent Health at the University of Bristol. This will be the first study to look at CFS/ME in children in such detail.
CFS/ME is a common childhood condition with potentially serious consequences for those affected, and is the most common reason for long-term absence from school. Despite this, very little is known about it.
"I want to answer the many unresolved questions about the best ways to treat and manage the patients for whom I am responsible," said Dr Crawley who is also Consultant Paediatrician at the Royal National Hospital for Rheumatic Diseases NHS Foundation Trust.
Dr Crawley's research has three parts: 1) Investigate the causes of CFS/ME in children. Dr Crawley will use data from the University of Bristol's Children of the 90s study to see how many children in the study had CFS/ME age 13yrs, and what factors predict CFS/ME. 2) Identify effective treatments for CFS/ME. She will examine the outcomes of care in children diagnosed with CFS/ME in different types of services across England to understand which are most effective in providing treatment. 3) Develop a school-based early intervention tool to prevent the development of CFS/ME in children. Dr Crawley will develop and test an education package for children who are missing school because of fatigue, to see if development of CFS/ME can be prevented. The economic impact of school absences due to fatigue will

also be measured.
"This research is crucial to help us to understand the risk factors and prevalence of CFS/ME in children, and to give us an improved understanding of the most effective ways to treat and prevent the development of this condition," she continued.

Dr Crawley's research has been prompted by her involvement in the development of the National Institute for Health and Clinical Excellence (NICE) guidance for CFS/ME

She said: "My experience as a member of the NICE guideline development group for CFS/ME brought into sharp relief the deficits in the current evidence base. We do not know how common CFS/ME is in children, what the risk factors are for developing CFS/ME, whether CFS/ME can be prevented in children at high risk or what the best model for treatment is. Current models of care for children are based on adult evidence and there is no information on outcome, treatment or prognosis for children who are severely affected, or the very young. These gaps in knowledge were listed as research priority areas by the guideline development group, and this research plans to begin to address them. Throughout my clinical career I have aimed to base my practice on robust research evidence. This award provides an ideal opportunity for me to achieve my long-term goal of transforming the care of children with CFS/ME."

The project will begin in March 2009 and will be carried out over a 5 year period.

The paediatric CFS/ME service at the Royal National Hospital for Rheumatic Diseases is the largest regional paediatric CFS/ME clinical service in the UK, and has a national reputation. The paediatric CFS/ME team treats around 200 new children and young patients from across the UK and Western Europe each year.

http://www.bris.ac.uk/news/2009/6217.html

ASK A DOCTOR

Is there a relationship between Obesity and Environmental Illness?

By John Molot, Environmental Health Physician

Obesity is a major health problem in the industrialized world, but is there a relationship between obesity and environmental illness?

At the Environmental Health Clinic, we assess patients who may have Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM), Environmental Sensitivities and/or Chemical Neurotoxicity from a significant chemical exposure.

What do these entities have in common? First of all, they are frequently comorbid, which means that they are more likely to occur together. Secondly, they are all related to oxidative stress. Oxidative stress is a harmful condition in which there is an excess of highly reactive molecules called ‘oxidants’, or ‘free radicals’. This is why antioxidants are so important. Oxidative stress can cause damage to cells, including changes to DNA, the cell wall, protein and/or mitochondria. Mitochondria are the parts of the cell responsible for the storage and utilization of energy. Reduction in the number and function of mitochondria occurs in CFS and FM as well as in aging and after significant chemical exposures.

Evidence of oxidative stress has been demonstrated not only in CFS and FM, but also in sick building syndrome associated with indoor moulds, cancer, cardiovascular disease, chronic respiratory disease, diabetes, hypertension, low sperm counts and reduced life span.

There is also a relationship with many of the above diseases and obesity. Oxidative stress influences fat metabolism and contributes to obesity, as well. In fact, weight reduction leads to a reduction of oxidative stress and lengthens life span.

So, what's the connection between obesity, oxidative stress and chemical pollutants? First of all, we all know that obesity is also associated with cardiovascular disease, hypertension and diabetes. These same diseases are also related to pollution, specifically the particulate matter in polluted air (the ultrafine particles) are small particles that are absorbed and enter cells. Luckily, every cell has a system to clear toxins, which are normally produced by cell metabolism. Those toxins that can't be broken down are released into the blood stream to be detoxified by the liver and secreted by the kidneys. Note that these systems have been present for millions of years and were not developed with the 21st century pollutants in mind. When these systems are overburdened, we have oxidative stress, because we can't keep up the pace of detoxification.

Chemical pollutants stimulate more production of oxidants or free radicals; they drive the oxidative stress system. It is not just the air borne pollutants that drive oxidative stress. Other environmentally persistent pollutants, such as pesticides, plastics and fire retardants, also drive it.

Many persistent organic pollutants are stored in the fat of all animals, and dozens are present in all humans tested in the industrialized world. We (humans) sit at the top of the food chain, accumulating toxins. Our natural detoxification enzyme systems can become over-taxed. Extra body fat just provides more cupboard space to accumulate these toxins and contributes to the oxidative stress load.

Furthermore, several studies, including the first one published by the University of Toronto, have shown that patients who have chemical sensitivities have a different genotype (genetic makeup) for these detoxification systems. Also, patients with CFS, FMS, sick building syndrome and chemical neurotoxicity are also more likely to be chemically sensitive.

What should we do? Lose weight (to achieve suggested weight on body mass index), reduce our pollutant exposure, and increase our antioxidant intake. Practicing environmental control and avoidance is more than cleaning the indoor environment or avoiding air pollution. It should also include reducing or eliminating high-fat meat and dairy products (supplement with calcium and Vitamin B12 if necessary). Fill yourself up on foods lower down the chain. Fruits and vegetables are not only very rich in antioxidants, they contain much less calories per gram, plus more fibre to fill your digestive system and reduce your appetite. Eat organically if you can afford it.

Suggested reading: "Eat to Live" by Joel Fuhrman.

Dr. John Molot, MD
Staff Physician at the Environmental Health Clinic, Toronto

HELPFUL WEBSITES

Health Canada, Insect Repellents, It's Your Health fact sheet:
http://www.hc- sc.gc.ca/hl-vs/alt_formats/pacrb-dgapcr/pdf/iyh-vsv/lifevie/insect-eng.pdf.

Organic clothes made of natural fibers for everyday wear, hiking, biking, etc.:
www.underthecanopy.com
www.patagonia.com
www.mamasearth.com
http://www.mec.ca (Mountain Co-op)

- http://www.mayoclinic.com/health/chronic-fatigue-syndrome/DS00395 From Mayo Clinic – their definitions and take on CFS.

YOUR HEALTH

A Good Night's Sleep, Without Medication

by Maries St.Paul

Many of those living with M.E./CFS find it very difficult to fall asleep and / or to stay asleep for at least 8 hours. **Insufficient sleep interferes with your recovery.** There are things you can do to improve your quality of sleep.

DIET – stay away from food and drinks that contain **caffeine**; not just coffee and regular tea, but carbonated drinks too. There are also special teas that help you relax.

ENTERTAINMENT – Since television can contribute to your inability to fall asleep, try setting aside the last hour of the day for something **soothing and relaxing**. For many, reading books is a great way to relax (your library has thousands). Many others have found meditation or relaxing music extremely helpful just before bedtime.

YOUR BEDROOM - In the **TIP** following this article, there is a great idea on how to prevent your phone from disturbing your sleep. Here are some additional tips for creating a calm, restful, sleeping environment in your bedroom:

- Choose the room in your house that is the **quietest**; therefore farthest away from the noisy areas (like the living room and kitchen), and should also be away from the noisiest area of your street / neighbourhood.
- Your bed should have a **good mattress.**
- Remove all electronics like your computer and television. It's important to **remove all distractions**.
- If you live with a partner who disturbs your sleep, consider sleeping alone.
- Use window coverings / shades that **block out the sun**. If this is not possible, wear a blindfold (available in drug stores) to cover your eyes – you'll be amazed how easily the sun shining into your eyes will wake you up in the early hours of the morning!
- Furnish the room with **lots of storage** (closets / cupboards, chests of drawers) so that there is plenty of room to put things away. A **calm bedroom**, tidy and serene, conveys a strong message to the brain that this place is simply for sleeping.
- If you hate making the bed (as I do), invest in a set of fitted sheets and a duvet – you can **make your bed** in less than a minute. Another way of creating a calm environment.
- Finally, every couple of days prepare your bedroom as if a special guest is coming to sleep there tonight, like adding candles, etc. Of course that special someone is YOU!

It's important to go to bed at the same time every night. Do not change your bedtime just because it's the weekend.

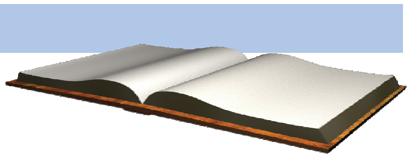
Lastly, for those who still cannot sleep, it may be necessary to take medication; please consult with your Family Physician on this.

TIP

Most of us have more than one phone in our homes. I set the main phone on a low ring and my bedroom phone on silent. This prevents my sleep from being disturbed by the telephone ringing. My bedroom is for resting and sleeping. There is nothing worse for people with M.E./CFS than to be suddenly woken by a ringing phone as it is so difficult for us to get back to sleep.

Thanks to Diane, a Nurse, for this tip.

RESEARCH



Research Findings on CFS/ME

By John Prescott,
DVM, PhD, Professor,
University of Guelph

The 9th International Conference of the International Association for CFS/ME, held in Reno, Nevada, March 12th-15th 2009, attracted an encouraging array of scientists from around the world, with 220 participants. Such conferences are hugely important in scientific progress, by providing opportunities not only for collaboration between scientists but also the intellectual stimulation that allows new ideas to emerge, as well as old ideas to die. Most scientific conferences represent a fast-moving marketplace of facts, ideas and, indeed, very different expertises, which can be confusing to outsiders but on which scientists thrive.

Several presentations reported on treatment of CFS patients with “Cognitive Behavioural Therapy”, with the general conclusion of its lack of efficacy. Antiviral treatments were more promising, particularly the use of isoprinosine (which is very expensive). There were interesting studies on the more frequent presence of a variety of viruses (EBV, HHV6, HHV7, CMV, Parvovirus B19) in patients with CFS than in healthy controls, supporting studies that suggest that one of the problems of CFS is defective antiviral pathways. Not all the studies presented however support active persistent viral infection as important in CFS. One study found that the ratio of the antiviral enzymes RNaseL could not be used as a blood “biomarker” of CFS, in contrast to several previous studies. Immunological findings that analyzed blood cytokines directly or through DNA microarrays seemed to show a shift in CFS patients in their immune systems from effective (Th1) to ineffective (Th2) antiviral immunity.

One of the issues in CFS is whether it is “one disease” or several, which may depend on the factors that trigger it (for example, a viral infection or trauma). DNA microarray analysis of blood of CFS patients was reported to differentiate up to eight subgroups, two of which were reported associated with antibodies to EBV and enterovirus viruses, which may be helpful in targeting treatments. Work relating CFS symptoms to genetic differences in genes (“polymorphisms”) encoding immune-mediators (cytokines) support the belief that genetic factors influence the development of CFS. One day “genomic medicine”, which could involve low-cost sequencing of the entire DNA of CFS patients, may hold the key to diagnosis and treatment of CFS.

One interesting simple diagnostic test reported from the USA was graded exercise on two different days. CFS patients don’t recover well from exercise, and thus show reduced oxygen consumption on the second day compared to healthy controls. The UK group reported on their tests of mitochondrial function in the diagnosis of CFS. Another presenter reported that electroencephalography (EEG) could be used to diagnose CFS.

Japanese scientists lead the world in “fatigue science” (however, not just focused on CFS), and were well represented. They described among other things their study of “fatigue foods”, including natural sources of anti-oxidants and polyphenols.

This summary, based on that provided by Rosamund Vallings on the IACFS/ME website, can only give a flavour of a stimulating and wide-ranging conference. This will both inspire and energize CFS scientists for the hard slog in their laboratories as they work over the next year to understand this complex and important illness.

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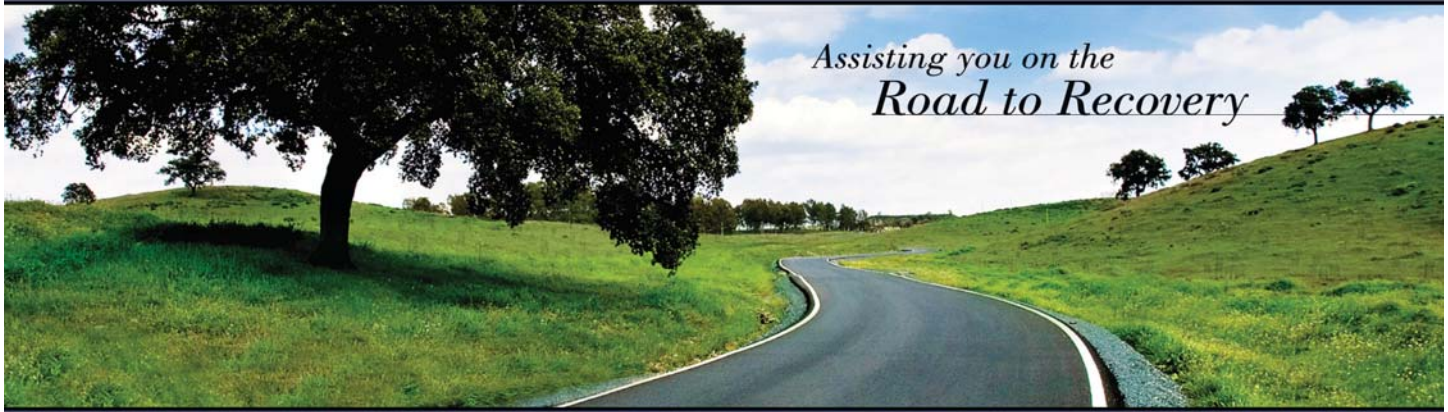

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Kelli-Ann Woulfe

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"After my surgery, I tried to go back to work - against my doctor's advice. But I just couldn't do my job any more."
"So I applied for disability benefits. I couldn't believe it when they turned me down! I was very sick, as well as depressed and broke.
"My case was deemed to be without merit by several law firms. Then I found David Share Associates. They were a Godsend. The settlement allowed us to pay off our mortgage and has enabled me to live at home with dignity."

If your disability benefits have been wrongly denied, call 416-488-9000 or Toll free 1-888-777-1109. You will receive a Free Booklet 'Benefits Denied - What To Do When Your Insurance Company Denies Your Claim' by David Share.

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GENERAL INFORMATION

If you know of an event that may be of interest to our members, please call us on our INFO LINE number below. THANKS!

CONTACT US

Our mailing address:
The Myalgic Encephalomyelitis Association of Ontario, P.O. Box 84522, 2336 Bloor St. W., Toronto, Ont. M6S 4Z7.

Our INFO LINE is:
416 222- 8820, or 1 877 632-6682.
Call to receive information on M.E./CFS, Support Group and doctors.

Our email address:
info@meao-cfs.on.ca.

MEMBERSHIP AND DONATIONS

Our annual membership is $20.00. Donations are greatly appreciated, as they help us increase education and awareness of M.E./CFS throughout Ontario. Donations of $10.00 and over are issued a charitable tax receipt. We also welcome those who request a Complimentary Membership!
Members receive our quarterly newsletter ***'Reaching Out'*** with news on M.E./CFS, Research, Coping Tips, Recipes, Upcoming Events, and much more! Members with emails are also notified regarding updates on: Conferences, Television Programmes on M.E./CFS and special M.E./CFS events.
See our Membership / Donation Form below.

As a resource group, the function of our organization is to provide you with current information on M.E./CFS. As we are not medical professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your health with your attending physician.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
P.O. Box 84522, 2336 Bloor St. W.
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