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REACHING OUT

SPRING 2010

A Publication of the Myalgic Encephalomyelitis Association of Ontario

MEAO Brings Dr. David Bell to Toronto: "Current Findings and Research into ME/CFS: XMRV Virus and What it Means"

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

On March 5th in Toronto, guest speaker Dr. David Bell talked to a packed audience of 150 about the recent discovery of the XMRV virus and what it might mean to ME/CFS. Dr. Bell, a leading ME/CFS physician, author and researcher, and a delightful speaker, told the audience that the discovery of XMRV has "changed everything".

XMRV, which stands for "Xenotropic Murine Leukemia-related Virus", is a retrovirus that at some stage in evolution became inserted into the human genome. Curiously, given its name, it can't actually infect mice.

XMRV was first recognized in 2005 in human prostate cancer cells where it was associated with a decrease in the enzyme RNAaseL. Because of a suspected link between abnormalities in the RNAaseL enzyme and ME/CFS, researchers decided to look for the virus in ME/CFS patients. Of 101 ME/CFS patients tested, 68 had the virus compared to only 8 of 218 healthy controls, a highly significant difference. Dr. Bell emphasized that a consortium of blue-ribbon researchers in different laboratories spent two years using four unrelated methods (PCR, virus isolation, immuno-blotting, serological tests) to confirm this remarkable finding. They did not just use the PCR technique which some are using in later studies, and is liable to contamination and sometimes has other problems.

The *Science* paper that broke the news in 2009 created tremendous excitement for both ME/CFS patients and researchers. *(continued on Page 2)*

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TORONTO

MEAO Brings Dr. David Bell to Toronto, cont'd

Disappointingly however, three subsequent studies using just the PCR test have failed to confirm the basic findings of the *Science* paper. Dr. Bell spent considerable time discussing the nature of retroviral infections and therefore why the PCR tests used by these other researchers might have failed to detect XMRV. He concluded that the failure to replicate the PCR findings of the famous and carefully performed *Science* study is currently a mystery, but it is now the focus of intense research activity around the world.

Dr. Bell also discussed whether XMRV was actually the inciting cause of ME/CFS or whether it was just associated with ME/CFS, in the way that Epstein Barr Virus (EBV) is often activated in ME/CFS patients and is therefore "associated with" ME/CFS rather than being the actual cause. He suggested that it might take researchers a year to come up with a conclusion. He acknowledged that his "personal bias" is that XMRV is the cause of ME/CFS, but only good science will ultimately sort this out. If correct, it opens the way for effective antiviral treatments. The model for a human retroviral infection is the Human Immunodeficiency Virus (HIV), which is now a treatable infection.

Dr. Bell and Dr. Alison Bested then shared the podium in a long, broad-ranging and outstanding Question and Answer session.

Among the many interesting points:

1. The conclusion, supported in part by the new findings around XMRV, that ME/CFS patients should not be blood or organ donors (for more on blood and organ donations see page 3);

2. That, despite the association of some retroviruses with cancer (and contrary to what the *Science* paper implied), neither Dr. Bell nor Dr. Bested reported any increased incidence of cancer in ME/CFS patients over the rest of the population;

3. That Ontario needs a full-time diagnostic and treatment center for ME/CFS more than ever, now that we have this exciting new research.

The MEAO and the Environmental Health Clinic, Women's College Hospital, deserve congratulations on hosting Dr. Bell, and for organizing such an excellent Q and A session and successful event.

FROM THE PROVINCIAL COORDINATOR

TWENTY-FIVE YEARS AGO, I became profoundly ill after what seemed like a routine flu. Walked to the charity I was working for at the time, maybe 10 blocks away, collapsed onto the couch and had to be driven home. What followed is what every person living with ME/CFS understands – months of being bedridden, followed by years of short remissions and then long relapses, until your body just never recovers again. I was diagnosed with Post-Infectious Neuromyasthenia. We didn't know of Myalgic Encephalomyelitis or Chronic Fatigue Syndrome in 1986.

NINETEEN YEARS AGO, the Myalgic Encephalomyelitis Association of Ontario was formed and they have been fighting for funding and public awareness ever since. Recently, I was helping the board put together our third request for funding from the Ontario Ministry of Health in the past 18 months. It is painful for us that the Ontario government has yet to fund our organization, though it provides funding to most chronic disease charities, for services or research or both. Their funding to the only diagnostic clinic in Ontario, at Women's College Hospital, remains very low after many years, limiting the clinic to seeing 400 people suspected of having ME/CFS or Fibromyalgia or Environmental Sensitivities.

FOUR HUNDRED PATIENTS OUT OF HALF A MILLION AFFECTED. From the Canadian Community Health Survey of Statistics Canada, we know that more than 500,000 people living in Ontario have one or more of our illnesses and we have only one specialty clinic, virtually no specialists who are accepting new patients, and most family physicians have little information how to diagnose and treat these syndromes.

EIGHTEEN YEARS AGO the MEAO began advocating for provincial help. Each year, for eighteen years, the MEAO has asked the Government of Ontario to fund ME/CFS care.

Each year we ask a supportive MPP to stand up in the house and declare May 12th as International ME/CFS and FM Awareness Day, and many have asked the government to give us funding. A member of the ME/CFS community actually pulled up every reference to the MEAO in Ontario's government publication Hansard, and we sent a copy of all of those references to the Ministry of Health with our last request for a provincial plan and MEAO funding. The MEAO is trying, but we need more vocal support.

MAY 12, 2010, 10 A.M. QUEEN'S PARK, TORONTO. We know that you are ill. We know that you are suffering, but they need to know too. Our disability keeps us isolated and invisible and government agencies, researchers and doctors respond to numbers. We've given them our numbers but it is not enough. We believe that they literally need to see our numbers. So please come to Queen's Park in Toronto on May 12th. Bring a cane or a folding chair if you need or a wheelchair if that is what it takes. Help us help you get the recognition, funding and services we all need.

For more information, read about our plans on the next page and visit our website for updates.

Hope to see you there, Theresa Dobko

Donating Blood or Organs when you have ME/CFS:

I was a regular blood donor, and I had signed a card to donate my organs until I became ill with ME/CFS. Canadian Blood Services has always asked those who are ill not to donate and recently they sent a letter to the National ME/FM Action Network saying that until we know more about XMRV, or other possible viral causes, that patients with a history of ME/CFS should refrain from being a blood or organ donor. It's a sensible precaution. You can read more in Quest 82, the Winter 2010 issue, available at ***www.mefmaction.net***

ME/CFS & FM
INTERNATIONAL
AWARENESS DAY
MAY 12
meao

Join us on May 12th, 2010 for International ME/CFS and FM Awareness Day!

At the Queen's Park Front Lawn, Toronto
Listen to Speakers, Promote Awareness,
Let Your Voices Be Heard at All Levels of Government

How to get involved!!

BUY an **Awareness T-Shirt** for yourself, family members and friends!

Available at Support Group Meetings in Toronto and surrounding areas for $20 each (cash), and at:

- Dr. A. Bested's office - 3600 Ellesmere, Unit 4, Toronto ON
- The Group Photo Shoot on April 3rd as of 12 noon

BE PART of the **Awareness Campaign Photo Shoot**

Help us to create a buzz in the media with our campaign that will use this photo to promote Awareness in the Community and May 12th event at Queen's Park

Come to the Group Photo Shoot, on **April 3rd, 2010** at the Scarborough Civic Centre, 150 Borough Drive, Toronto, from 1-2 pm. For the group photo, meet at the entrance to Albert Campbell Square, rain or shine.

Please bring family and friends!

JOIN US for **May 12th International Awareness Day at Queen's Park, Toronto**

More Details to come about this amazing event!
Keep checking our website for updated information!!! www.meao-cfs.on.ca

If you plan to attend the photo shoot, the Queen's Park event, or both, please email us at: info@meao-cfs.on.ca
Please direct any questions to the same address.

It's Time!! IT IS UP TO US TO PROMOTE AWARENESS!!

IACFS/ME
International Association for CFS/ME

The National ME/FM Action Network Will be Hosting the 10th International IACFS/ME Research and Clinical Conference in Ottawa, in September 2011.

The Conference Theme is: Translating Evidence into Practice: Chronic Fatigue Syndrome, Fibromyalgia, and Related Illnesses

Dates and Location:

Crowne Plaza Hotel in Ottawa, Canada from September 22nd to 25th, 2011.

This Conference will consist of a 4-day professional meeting and a one day (September 22nd, 2011) patient meeting which will coincide with the professional meeting. It is anticipated that this event will be accredited for continuing medical education.

The professional conference themes focus on fatigue, pain, sleep, pediatrics, cognition and brain function in ME/CFS/FM and related illnesses. There will be scientific sessions on assessment and treatment, and original research in the fields of immunology, virology and neuroendocrinology. There will be workshops for clinicians and researchers. The patient meeting will focus on matters that are of concern to you i.e. diagnosis, treatment, disability and legal issues, etc.

To find out more about the IACFS/ME and its activities, please visit its site at **www.iacfsme.org**

The National ME/FM Action Network needs your help for this major project. Why? Because it is an opportunity to have the best researchers in the world here in Ottawa, Canada, to meet with our government officials, the Public Health Agency of Canada, Canadian Institutes of Health Research, and more. Together, we will all advocate for more research and service funding for ME/CFS and FM.

The estimated funds needed to host this event are **$150,000**. Donations for the conference should be made to “The National ME/FM Action Network”. All donations will receive a tax receipt. And remember that no amount you contribute is too small. You can send a cheque, pay by VISA or MasterCard, or through CanadaHelps on our website. You can make a difference by participating and making this conference a success, which will lead to more research and treatment for all those affected for many years to come.

Lydia E. Neilson, M.S.M., Founder and Chief Executive Officer
National ME/FM Action Network
512 – 33 Banner Road, Nepean, ON K2H 8V7
Tel. **613.829.6667** Fax: **613.829.8518** Email: **ag922@ncf.ca**

PAGING DR. YOU

***Gloria Troyer** is an award winning freelance writer, broadcaster and author.*

She is a member of the Professional Writers Association of Canada www.pwac.ca. *You can read more about her at* www.writers.ca.

This article originally appeared in the Fall 2008 issue of Abilities Magazine

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After a few years of living with a chronic illness, I realized that I could not provide a new doctor with my critical health information – not from memory, anyway. I became very frustrated with filling out new "medical history" forms at each doctor's office. I could not keep track of everything related to my illness, such as medication, tests and rehabilitation therapies.

At that time, it also became apparent to me that I could not rely on my doctors to retrieve my history on their computers. It seems that most doctors keep very little electronic patient info – and that's if they use a computerized system at all. The majority of hospital emergency rooms do not have a copy of patient records.

According to a program on CBC Radio One, "the scale and impact of medical errors are staggering." Dr. Brian Goldman, the program's host, cited a 1999 report from the U.S.-based Institute of Medicine that estimated as many as 98,000 people die in hospital each year in the States due to preventable human errors. In 2007, a report on patient safety by the Canadian Institute for Health Information (CIHI) revealed that one in 10 patients receives the wrong medication or dose, and another one in 10 acquires an infection while in hospital.

The statistics are daunting. I knew that I had to have some sort of system in place, since my case is so complicated and I am at high risk for errors like adverse drug reactions. On two separate occasions, fellow encephalitis survivors mentioned that I needed to write a "medical resumé." At first, I thought they were joking, but then I realized there might be something to the idea, and that having all my medical information in one concise document could prevent errors and help health-care professionals do their job. I visualized it like a job resumé, starting like this:

Job Applied For: Chronically Ill Patient
Employment History: 1996–present: chronically ill person, part-time freelance writer
Education: 12 years of on-the-job training as a chronically ill person

I encourage you to write out information about your illness using a traditional resumé or CV format. Elaborate on your experiences in each of the sections. Have some fun with it. After all, on some days, living with a chronic illness is like having a full-time job! It's not a job I signed up for, but what the heck – I might as well make the most of it and try to find the humorous side to the situation.

What works for one person will not necessarily work for another. Since my working career was as an archivist, I have created my own techniques that work for me when it comes to the organizing, sorting and saving of paper.

My medical resumé is a summary of all of my important health information that I would need to share with a new doctor or take with me to an ER. It is important to keep your resumé updated.

To get ready for an appointment, I update a section where I describe my current symptoms and medications. (Don't forget to list your supplements.) I also include a list of all of the doctors who are presently seeing me as their patient, and I write down any questions that I plan to ask at that specific appointment. Then I print a copy and take it with me (and I leave it with the doctor if requested).

In order for me to keep my medical resumé accurate, I had to first organize my medical papers. The initial gathering of the information and the set-up is labour-intensive but well worth it once your system is in place.

I am a great fan of dollar stores, and was able to find folders that have plastic sleeves where I can insert and remove papers quickly and easily. Duo-tang folders don't work as well since you must mechanically remove and insert any paper, which gets very frustrating. Separate binders with transparent protectors also work well. I use five folders, each one labelled and organized chronologically.

Medication – Both past and present. Get a list from your pharmacy and highlight any that caused problems.

Medical Tests – Ask your GP for paper copies. Most hospitals and imaging centres will provide CD copies of any tests (there may be a charge).

Doctors' Reports – Ask for these, or apply to Medical Records at hospitals to obtain copies. Arrange them chronologically in your folder for easy reference.

Rehabilitation and Therapies – Get reports on-site if possible.

Miscellaneous – Use this folder to file away receipts for medical parking fees and other expenses.

It is advisable to make a copy of your folders (electronically or by photocopying) and store them somewhere other than your home in case of a disaster.

I recently met with a new cardiologist, since my other one had to cut back on patients. The new doctor asked me to bring my medical information to my next appointment. I intend on taking all of my folders plus CDs of my various scans.

As an unexpected benefit to writing my medical resumé and organizing my folders, I feel like I have let go of some of the negativity, grief and trauma related to my medical condition. Seeing all the organized information has validated my experience, and I no longer feel the need to prove my medical history to anyone. My medical resumé was also instrumental both to me and my attorney with regards to getting a small disability pension.

As you can see, organizing your medical info is a low-cost and rewarding project that helps you take charge of your medical experience. It is a very positive thing to do.

The MEAO thanks Gloria Troyer for her article

WHAT IS OSTEOPATHY?

Heather Dart BKin, BScPT, DOMTP, CSCS

Heather Dart graduated with a Diploma in Osteopathic Manupulative Therapy from The Canadian Academy of Osteoapathy and Holistic Health Sciences and is Vice President of the Ontario Osteopathic Association. She is also a registered Physiotherapist and operates a private practice in Port Perry, ON. The MEAO thanks Heather for this article.

Osteopathy was founded in the late 1800's by Dr. A. T. Still. An American medical doctor, Dr. Still suffered great personal crisis by losing 5 children to diseases such as spinal meningitis and pneumonia and his first wife due to complications from childbirth. Feeling helpless to be able to help them with his current knowledge in medicine, he rejected most of what he had learned and searched for new and better methods. His explorations were grounded in the study of anatomy. He became convinced that most disease could be alleviated or cured without drugs. The key was to find and correct anatomical deviations that interfered with the free flow of blood and "nerve force" in the body. From the beginning, Still met with considerable opposition to his new theories and techniques but eventually word spread about the doctor whose system of drugless, manual medicine was able to cure apparently many hopeless cases.

Dr. Still officially coined his treatment method as Osteopathy in 1889. "Osteo" referred to structure or form and "pathy" referred to suffering and therefore, its literal interpretation was treating the suffering of the structures of the body. He founded The American School of Osteopathy in Kirksville, Missouri in 1892.   Osteopathy has since spread throughout the world, taking on a strong drugless manual treatment presence.

In its ideal form, it is both an art and a science.

The art of Osteopathy is founded on the safe and effective application of the following principles:

- A human being acts as a complete dynamic unit of function including the concept and relationship of the body, mind, and spirit.
- The body possesses self-regulatory mechanisms, which are protective and self-healing in nature.
- Structure and function are reciprocally inter-related.
- Rational treatment is based on understanding and utilizing these principles.

The science includes the behavioural, biological, chemical, and physical knowledge related to the establishment and maintenance of health as well as the prevention and alleviation of disease. An Osteopathic Manipulative Therapist will assess the whole body and the goal of a treatment is to restore function through gentle and controlled manipulation that corrects the imbalance of the structural elements in the body. The patient's neuromusculoskeletal system is considered to be a key element in the application of Osteopathy. Therefore, it is a means by which health-promoting changes may be facilitated through the appropriate use of manipulation. Appropriate exercises can then be given to aid in the body's restoration and maintenance of balance.

The symptoms of ME/CFS symptoms are often widespread and therefore, a whole body treatment approach such as Osteopathy may be a suitable option for people suffering with ME/CFS in order to help alleviate discomfort and promote health within the body.

To find out more about Osteopathy and to find a therapist in your area please visit **www.ontarioosteopaths.com** and **www.osteopathyontario.com**.

YOUR RIGHTS
UNDER HUMAN RIGHTS LAW

A Summary of a recent ***ARCH Disability Law Centre*** *talk*

By MEAO Board Member, Arvinder. S. Bindra

On February 11th, 2010, Laurie Letheren, a staff lawyer at the ARCH Disability Law Centre, and her colleague Amy Spady, gave a presentation at the offices of the Canadian National Institute for the Blind. Their talk reviewed how the Canadian Human Rights Act and the Ontario Human Rights Code work to protect people with disabilities from discrimination.

Under these laws, people with disabilities have the right to equal treatment, the right to be free from discrimination, and the right to be free from harassment in areas such as employment and the receipt of services.

The ARCH presenters also guided the attendees through a workshop component exploring examples of discrimination and of the "duty to accommodate" – which is the duty of an organization or workplace to make changes and take steps to stop or prevent discrimination.

They highlighted that as a result of recent changes people who feel their rights have been violated can now file an application directly with the Human Rights Tribunal of Ontario without first going to the Ontario Human Rights Commission.

If you feel your rights have been violated, you can get some help and discuss the case with several organizations, depending on your need.

To find out more about your rights and discuss any discrimination you may be experiencing, contact:

ARCH Disability Law Centre
at 416.482.8255 or 1.866.482.2724
www.archdisabilitylaw.ca; or,

Human Rights Legal Support Centre at
416.314.6266 or 1.866.625.5179

If you decide to file an application because you believe you have encountered discrimination, you can contact the **Human Rights Tribunal** at:
655 Bay St, 14th Floor, Toronto, ON M7A 2A3;
416.326.1312 or 1.866.598.0322 or go to their website at www.hrto.ca

For General Legal Assistance:

For other legal problems (not directly pertaining to human rights), for example:

- Apartment rentals and housing rights;
- Ontario Disability Support Program (ODSP) applications and appeals;
- Employment Insurance or Canada Pension issues
- Workplace Insurance or WSIB claims

Individuals can obtain assistance from a lawyer specializing in these areas or from their local legal aid clinic, for most cases. The MEAO maintains a small list of lawyer referrals for those with workplace, WSIB, ODSP or CPP appeals. To find a legal aid clinic, call 416.979.1446 or check the website www.legalaid.on.ca

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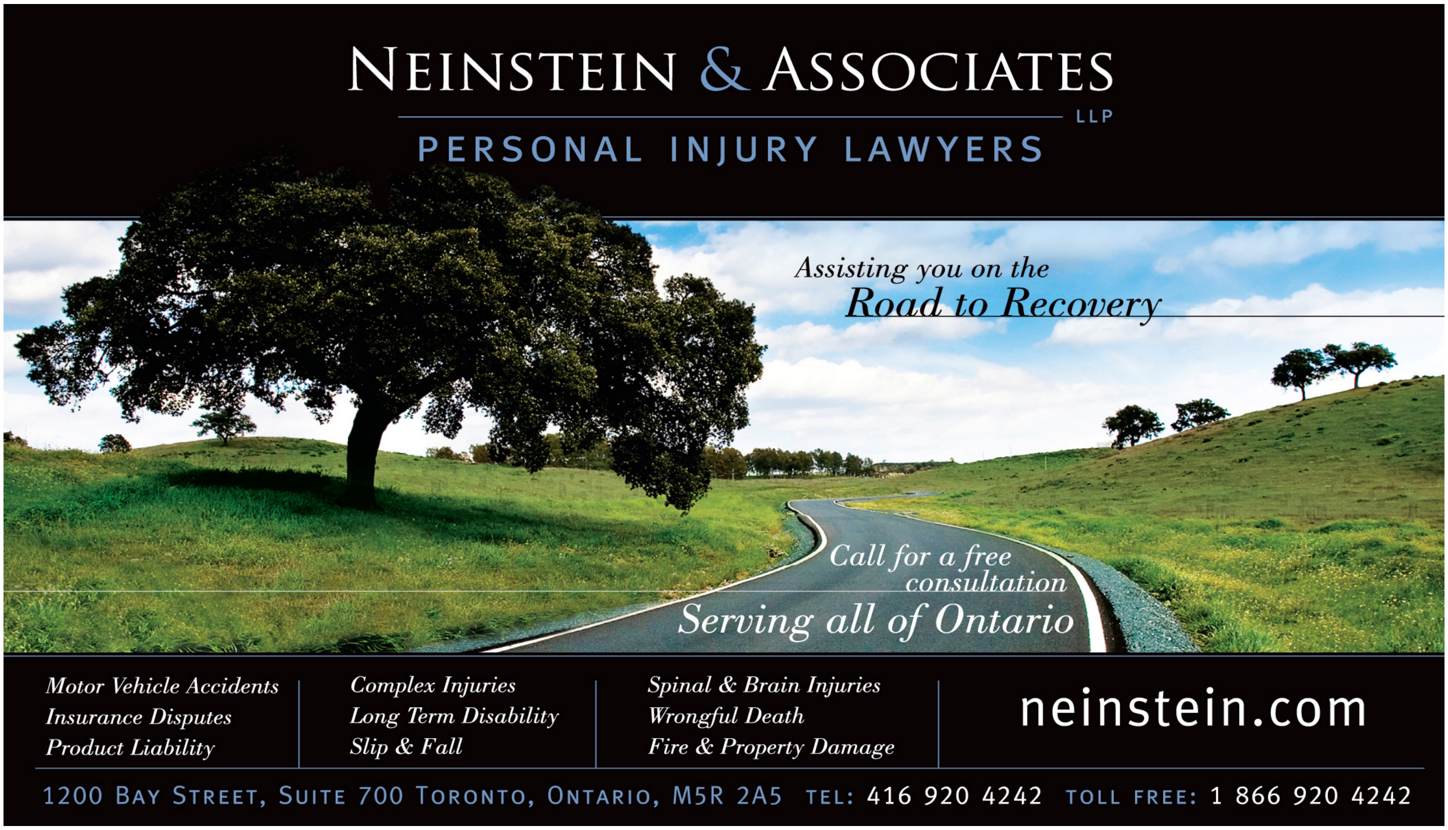
ADVERTISING



Disclaimer:

As a resource group, the function of our organization is to provide you with current information on ME/CFS and related illnesses.

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.

CONTACT US:

Our mailing address:

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Toronto, ON   M4K 3Z2

Our website can be found at:

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.

Our new annual membership is $25.00, but now we are able to give tax receipts for memberships as well as all other donations. Membership gives you our quarterly newsletter ***'Reaching Out'*** , filled with articles on ME/CFS Research, Coping Tips, Legal Issues, Upcoming Events, Helpful Websites and Books and much more! Members who provide an email address also receive special monthly email alerts, full of the latest news and events. All members are 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 on our website or use the 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.

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THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
P.O. Box 65143, 358 Danforth Avenue, Toronto, ON   M4K 3Z2
Please go to our website for our full Membership Application or send us this form with payment
MEMBERSHIP AND / OR DONATION

PLEASE PRINT
NAME____
ADDRESS_____________________________________
____
TELEPHONE NO: ______________________________
EMAIL ADDRESS: _____________________________

NEW MEMBERSHIP FEE: **$25.00**
DONATION: ______
TOTAL ENCLOSED: ______

We are now able to give Tax Receipts for Memberships and Donations!

I am requesting a free membership due to financial need ☐

I would like to get my newsletters by email, along with special email alerts for upcoming events and other news ☐

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