

MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

meao



believe in me

understand me **treat me** diagnose me believe in me

diagnose me **understand me** support me **treat me**

BELIEVE IN ME BELIEVE IN ME

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ANNUAL REPORT
2008 | 2009



A Letter from Our Board President

LOOKING BACK AND MOVING FORWARD



BELIEVE IN M.E. Whether you know the illness as Myalgic Encephalomyelitis or “Chronic Fatigue Syndrome”, believe that it is one of the most debilitating illnesses known and believe the person who has M.E. when they tell you how sick they are. M.E. is a medical syndrome with more than 5,000 articles now verifying the symptoms and anguish that accompany this illness. We must begin to diagnose, and treat, and support everyone with M.E.

More than 140,000 Ontarians have been diagnosed with M.E. This may represent as little as 10-25% of those actually ill. Fewer than 30% will achieve any significant recovery

The MEAO has served the Ontario community from our base in Toronto for 18 years, until recently on less than \$25,000 a year. Yet with those funds we've handled 850-1,000 calls a year to our free Info Line Service, along with hundreds of online requests for support. We've delivered free workshops, ran a website, published our quarterly Reaching Out newsletter, and delivered thousands of packages to doctors, lawyers, school officials, and government and community agencies.

SUPPORT M.E. / SUPPORT MEAO. Most provincial organizations are networks of local groups, and the local groups deliver most of the services. The MEAO was created before most local initiatives began – though the ones that exist now are wonderful. So in effect, our “Association” is both a front-line service organization, especially in Toronto, and a provincial association, working to build community capacity in cities across the province.

In 2008, we began our three-year grant from the Ontario Trillium Foundation, as well as continuing our relationship with the City of Toronto Community Service Partnership Program. With these funds we have been able to secure a Provincial Coordinator and dramatically increase our work. Soon we will be opening Ontario's first community-based ME/CFS centre and we are advocating for diagnostic/treatment centres, education to family physicians, help for children and youth with M.E. – at home and in school – and much more. We have

opened the doors with the Public Health Agency of Canada, Ontario Ministry of Health and the Ministry of Education. Now we need to bring back through those doors significant policy changes, funding and support and deliver the services that people living with M.E. deserve.

Are we satisfied? Absolutely not. As you will read throughout this Annual Report, M.E. is one of the most common chronic or permanent disabilities and yet we receive a fraction of the funding and services of other disabling illnesses. Working almost weekly with the National ME/FM Action Network, and many other provincial and local partners, we will advocate for more funding for research, medical care, home care services, disability services and community support agencies – like the MEAO.

Reflecting on my volunteer work with MEAO, I realize that I have now been a board member for seven years and, upon the unfortunate passing of Audrey MacKenzie, I've been President of the MEAO since 2005. As we head into our Annual General Meeting in October 2009, I will be stepping down from the board, and I feel comfortable doing so because this comes at a time where there are now a number of very capable and talented volunteers on the Board. These volunteers are, in fact, very excited in helping MEAO to open up a staffed provincial office which, in turn, will enable our organization to finally catch up with current ME/CFS community needs. It is always difficult to leave but I believe we have turned a corner. With new volunteers and growing community and government support, I feel excited about our future.

Going forward, it may be appropriate for me to now share with you a “front page” slogan that the late 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

DIAGNOSE M.E.

COUNT M.E. IN!

In 2008 and 2009, the MEAO met with the Public Health Agency of Canada and the Ontario Ministry of Health and shared our concerns with them on issues pertaining to the ME/CFS community, particularly emphasizing the need to count our numbers.

All patient recovery begins with an accurate diagnosis A healthy community response begins with recognizing the need

Until recently, no government agency was tracking statistics of people suffering from Myalgic Encephalomyelitis or Fibromyalgia. The MEAO, and other national and provincial organizations, knew the numbers were large. We knew that only a fraction of patients were being accurately diagnosed. So how do we convince doctors to learn about the illness and accurately diagnose and treat it in their patients? And how should we convince politicians, government staff and health care agencies to care enough about us to count us in when it is time for funding and research?

GETTING A DIAGNOSIS: Doors began to open in 2003 and then in 2005 when the Journal of Chronic Fatigue Syndrome and the “Overview of the Canadian Consensus Document” became two of the best guidelines for diagnosing ME/CFS in the world. The MEAO has distributed more than 1,250 copies of these guidelines to doctors and hospitals.

In Ontario, the MEAO worked with M.E. specialists to create a new OHIP diagnostic code so doctors could finally diagnose patients with “chronic fatigue syndrome” and our numbers could be counted. At the national level, we advocated so the Canadian Community Health Survey would add questions on ME/CFS, Fibromyalgia or Multiple Chemical Sensitivities. They finally did in 2005, and when the numbers were recently released the result was astounding:

COMPARISONS WITH OTHER CHRONIC DISABLING ILLNESSES

Number of Canadians with the Illness in 2005

Diabetes	1,324,874	(Canadian Community Health Survey, 2005)
Heart Disease	1,288,009	(CCHS, 2005)
M.E. /Fibromyalgia*	723,598	(CCHS, 2005)
Multiple Chemical Sensitivities (MCS)*	598,535	(CCHS, 2005)
Cancer	370,763	(CCHS, 2005)
Effects of Stroke	297,547	(CCHS, 2005)
Alzheimer’s and other Dementias	280,000	(Canadian Institutes of Health Research, 2005)
Physically Disabled Children/Youth	155,000	(CCHS, 2005)
Parkinson’s Disease	100,000	(Health Canada / Parkinson’s Society, 2005)
HIV/AIDS	58,000	(Public Health Agency of Canada, 2005)
Multiple Sclerosis	55,000	(MS Society of Canada, 2006)

* As some patients may be diagnosed with more than one of these conditions, the CCHS reports 1,135,225 Canadians have at least one of these conditions, almost as many patients as have heart disease or diabetes

Going forward, the MEAO will continue to push for better diagnostic care and for the funding and services needed to meet the demand.



MEAO SUPPORT ACTIVITIES FOR 2008-2009

Since 1991, the M.E. Association of Ontario has been a front-line service charity as well as a provincial association of support groups and individual members. We are dedicated to meeting the needs of those living with M.E. and related illnesses, their family members and their health care professionals. We are funded for these services by the Ontario Trillium Foundation and the City of Toronto, as well as by community donations. In 2008, we helped 1,275 clients.

“ There is a true bravery for any individual fighting and managing a chronic physical illness ... This is evidenced by our strength and commitment to meet our illness head-on. ”

Suzanne
MEAO Info Line Volunteer

Provincial Info Line and Email Service

The MEAO has the only Info Line in Ontario to answer the needs of people with M.E. Trained personnel respond to requests five days a week. In 2008, we received almost 850 calls and more than 200 email requests. 65% of contacts came from first-time callers and 60% required detailed or ongoing follow-up. A large percentage of calls came from small towns and rural areas. Our Info Line is the heartbeat of the M.E. community for hundreds of patients, most too ill to leave their homes or isolated from any other support services. We support callers as they struggle to find medical care and obtain disability benefits, and we provide referrals to more than 150 doctors, lawyers, counsellors and support groups.

Educating People Living with M.E. | Our financial resources are tiny, but what we do with them! This past year, we distributed almost 10,000 brochures, fact sheets and articles to individuals, support groups and community agencies. Our basic brochure is available in English, Portuguese, Mandarin Chinese and French. In the fall of 2009, we will be producing a new brochure for the public and we are working on a series of booklets for patients, whether newly diagnosed, or living with M.E. for many years.

Reaching Out Newsletter | Four times a year we publish our Reaching Out newsletter, complete with the latest medical updates, research information, first person stories on survival and coping, as well as lists of support services and websites. The newsletter is free to all MEAO members and back issues are available on our website. More than 1,550 copies were distributed last year.

Visit our Improved Website | Our address is: www.meao-cfs.on.ca and thanks to the help of community members and volunteers who write or submit articles, as well as our volunteer designer who updates our website each month, we are getting better than ever.

Community Workshops and Forums | From one Medical Update a year, to our new series of seminars and community forums, the MEAO is growing. This past year we provided free community speakers on medical updates, allergy information for patients, and legal updates for patients with M.E. and Fibromyalgia. We've also held the first of a series of ongoing meetings for community activists, to help direct our efforts and build community capacity.

Services for Parents of Children and Youth with ME

Did you know that children and teenagers get M.E.? The MEAO helped more than 60 families last year with support, information and advocacy with their doctors, schools and the Ministry of Education.

“ THIS IS REAL.
It's more than being tired.
It comes in and it completely
destroys your life. ”

Sarah
diagnosed at age 12

RAISING PUBLIC AWARENESS AND UNDERSTANDING

“The level of impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure, chronic obstructive pulmonary disease ... [and other] well-known, very severe medical conditions.”

Dr. William Reeves
(Centres for Disease Control, U.S.)

Our Association is deeply committed to public education and awareness campaigns. The greatest concern of our members, after their own medical care, is the lack of awareness of ME/CFS and the myths and stigma that frequently lead to discrimination and refusal of service. Last year, we worked collaboratively with dozens of community groups and health care professionals to address this crisis.

Here are some of our campaigns for 2008-2009

Medical Outreach | We provided 250 articles to health care professionals to help them diagnose and treat their patients. We've built our physician referral list to more than 100 strong but we need hundreds of family physicians to help everyone in the province.

Advocating for more Diagnostic and Treatment Care | MEAO board members consulted on a project with the College of Family Physicians to expand clinic services for patients and create a centre for excellence in Ontario. In 2009, we began working with the Environmental Health Clinic of Women's College Hospital and patient advocates on recommendations to the Ontario Ministry of Health to improve inpatient and outpatient care.

Education Advocacy for Children and Youth | Since many children and teenagers contract ME/CFS, we collaborated with the National ME/FM Action Network on a proposal to the Ontario Ministry of Education for educational slideshows to teachers. We also submitted a 12-page proposal to create "Guidelines on Access to Education for Students with Chronic Disabling Illnesses" and the Minister and her Special Education Committee are working hard to address the needs of our students.

"International M.E. Awareness Day", May 12, 2009 | Each year, the MEAO runs public awareness activities on May 12th. This year, the Mayor's Office of the City of Toronto again declared May 12th as International M.E. Awareness Day and the MEAO launched a campaign to raise funds for our first public office. The new MEAO Centre will house information and counselling services, a research collection, support groups and other services. Look for news of our opening in 2010.

Community Displays and Conferences | Our board and volunteers participated in eight community events and conferences in 2008-2009, including the first National Conference in Calgary. Provincial volunteers distributed 5,000 handouts at Community Health Centres, physicians' offices, clinics, libraries and other community settings across Ontario.

Public Transit Awareness Campaigns | With help from transit authorities in Toronto, Windsor, London and Sarnia, the MEAO continued its awareness posters and bus cards throughout the year, with an estimated readership in all cities of 1.25 million.



TREAT M.E.

MEAO'S RESPONSE TO COMMUNITY NEEDS

I lived through the era where HIV/AIDS was written off and people languished. Where heart disease in women was undertreated with devastating consequences. 140,000 Ontarians with M.E. are suffering with a tremendous disability that robs them of their health, their jobs and often their relationships.

We need the research, the doctors, and the community programs to end this crisis. People can now live healthy lives after HIV and heart disease. We can too. We just need the same resources and we needed them yesterday.

Person living with ME/CFS for 25 years

RESEARCH AND MEDICAL TREATMENTS

The past year was a busy one for the MEAO with local, provincial and federal meetings all designed to address government funding for research, diagnostic and treatment care. Here are some of our recommendations to government advisors:

- That the Canadian Community Health Survey update its statistics on ME/FM/MCS in 2010.
- That Health Canada establish a National ME/FM Strategy.
- That Health Canada and Ontario's Ministry of Health provide funding to train doctors and other health care professionals on diagnostic and treatment guidelines.
- That the federal and provincial governments provide significant funding for M.E. research.
- That the Province of Ontario establish a diagnostic and treatment centre that is fully funded to meet the needs of all Ontarians, and support all the needs of the Environmental Health Clinic of Women's College Hospital.
- That the Ontario Ministry of Health increase home care services to patients with our illnesses, increase OHIP support to doctors seeing M.E. patients, and provide ongoing funding to the Myalgic Encephalomyelitis Association of Ontario to support community-based services across Ontario.

On October 3rd, 2009, the MEAO will honour DR. ALISON BESTED with our Audrey MacKenzie Memorial Award for her 18 years of dedicated service as Ontario's premier medical specialist on M.E. We honour her commitment and she would be the first to say we need more specialists and family physicians to join her in caring for this wonderful community.

TREATMENT MEANS COMMUNITY SUPPORT

Imagine having cancer and there was no cancer society office you could go to for information and support. In Ontario, we need a Centre for People Living with M.E. and the MEAO, with the help of an Ontario Trillium Foundation grant, is working to raise the funds to open that centre. We are half-way to our goal and we will be calling on the Government of Ontario in 2009-2010 to help us with ongoing funds toward our staffing and program costs. We will be turning to the community to help as well. We are so close we almost have our hands on the doors. **If you would like to help with our fundraising drive, please contact us at info@meao-cfs.on.ca**

FINANCES

STATEMENT OF OPERATIONS
For the year ended December 31, 2008

REVENUES	
Grant – Ontario Trillium Foundation	\$ 56,600
Grant – City of Toronto (CSP)	7,140
Donations	20,337
Membership Fees	3,200
Sale of Materials / Advertising Revenue	2,015
	\$ 89,292
EXPENSES	
Provincial Coordinator	33,160
Program and Outreach Expenses	10,447
General Office Expenses	3,282
Professional Fees	1,538
Rental Space for MEAO Activities	1,450
Volunteer and AGM Expenses	568
Bank Charges and Interest	200
	\$ 50,645
EXCESS OF REVENUE OVER EXPENSES	\$ 38,647
INCL. RESTRICTED TRILLIUM FUNDS FOR 2009	\$ 18,728
UNRESTRICTED OPERATING SURPLUS	\$ 19,919

Condensed financial statements are prepared by the Board of Directors from our audited financial statements. Full audited statements are available on request.

BOARD OF DIRECTORS DURING 2008-2009

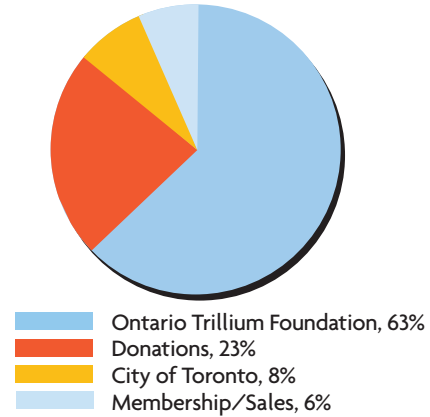
- Anthony Rovito, President
- Maries St. Paul, Vice-President
- Denise Magi, Secretary
- Deborah Starkman, Treasurer
- Arvinder S. Bindra
- Christiane Garcia
- Brenda van Ginkel
- Izzat Jiwani
- Diane Meitz
- Chris Pike

PROVINCIAL COORDINATOR FOR 2009

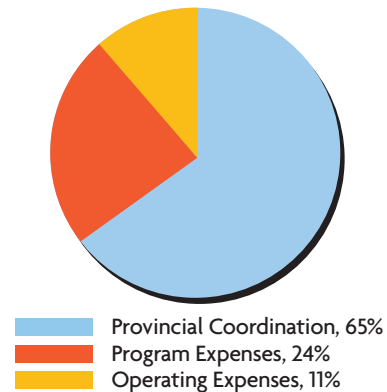
Theresa Dobko

OPERATING REVENUE AND EXPENSES
For the year ended December 31, 2008

REVENUE 2008



EXPENSES



The MEAO would like to thank the Ontario Trillium Foundation and the City of Toronto for funding our services and our volunteer programs.

To all of our donors and volunteers, we thank you. We would not exist without your help.

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