

REACHING OUT

SUMMER 2010

A Publication of the Myalgic Encephalomyelitis
Association of Ontario

meao

MAY 12 AT QUEEN'S PARK A SUCCESS!

After months of planning, May 12 International Awareness Day took place at Queen's Park, Toronto and was a very successful awareness event. Thank you to everyone who participated. This is just the beginning!

This event began with the initial efforts of just seven individuals, all who share the same illnesses as you. Then the group of volunteers grew to over 15. Those numbers grew to over 100 volunteers for our photo shoot on April 3rd (pictured to the right) and then to over 170 who attended our May 12 International Awareness Day at Queen's Park on a very chilly day. A special thank you to everyone who participated.

It's daunting when you are so ill that just getting out of bed is exhausting. To think of being able to do anything to help your cause feels overwhelming, but it is up to all of us to raise awareness.

The task this year was huge, but the effort was worth it. If you couldn't physically take part, you bought the May 12 T-shirt, or wore our new ribbon. You offered the names of other people who could provide us with the expertise that we needed to move this event forward. You wrote your MPPs and asked them to support us.

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REACHING OUT

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MAY 12 AT QUEEN'S PARK A SUCCESS! (Cont'd)

We visited most of the support groups in southern Ontario as part of our outreach, where we met with many of you and made connections that will serve us well in all future efforts. Personally I found this part of our journey extremely rewarding. We all have so much to share and so much support to offer one another.

A new MEAO brochure was developed and wonderful promotional photos and videos were shot by volunteers. These are now on the MEAO website. Special ribbons were handcrafted in recognition of all three illnesses. These are available through your support group facilitators.

Once again this year we were honoured that the Mayor of Toronto issued a Proclamation for May 12th, as did the City of Vaughan, and both posted these proclamations on their website. Women's College Hospital had an information booth in the lobby the entire day, educating staff and patients.

We developed Media Kits and contacted more than 50 reporters and news editors. We saw substantial articles for the next two weeks in the *Toronto Star healthzone.ca* section. *Global CanWest* had print and online news stories in their publications across Canada. *CBC* filmed a short piece that aired after the event. The

Queen's Park Media Room staff were especially helpful to us in promoting our event and allowing us to use the Media Room to make a DVD of our speeches, for future government outreach. We would have liked more coverage, so we will continue our media efforts throughout the year.

The May 12 Awareness Committee crafted a letter to send to MEAO members and supporters that could be personalized by each of us and then sent to our MPPs. Dozens of you sent personal letters to your MPPs urging them to educate themselves about our three illnesses and to back our funding requests. The Committee also sent packages to all Ontario MPPs.

Finally, we hosted May 12th International Awareness Day at Queen's Park. Inspiring speeches were given by Dr. Alison Bested, Dr. Darryl Appleton, lawyer Hugh Scher, Lin Grist of the Environmental Health Association of Ontario and MEAO President Jeanne Samonas. Inside Parliament, the Honourable Kathleen Wynne, MPP, announced our event in the morning session, along with MPPs John O'Toole and Linda Jeffrey, and MPP Joe Dickson spoke to our cause in the afternoon. Other MPPs joined us on the front lawn or wore our ribbons in support inside Queen's Park. We are grateful for their efforts and we will continue to reach out to the Ministry of Health for funding and all our MPPs for support throughout the summer and fall.

Our efforts did take their toll, on all of us and our families, but we are all so thankful that we could begin this effort. **WE ARE REAL PEOPLE, WITH A REAL ILLNESS, WHO NEED REAL SUPPORT!**

The template is in place for May 2011, but we need your help to make this event even bigger. Please contact the MEAO and volunteer in any capacity you can. With over 440,000 people in Ontario with ME/CFS, FM and MCS, think of what we could do if everyone got involved!

Thanks again to you all,

Lynn Holmes and the May 12th Awareness Committee

EVIDENCE OF FUNCTIONAL IMPAIRMENT FOR ME/CFS, FIBROMYALGIA AND MCS

Too often people living with Myalgic Encephalomyelitis, Fibromyalgia or Multiple Chemical Sensitivities must defend the reality of their illness to their employers, insurance companies and even government agencies. They are looking for proof these illnesses cause “functional impairment” severe enough to warrant long-term or permanent disability support. Here are two articles that provide proof of the level of impairment for those with ME/CFS, FM and MCS.

FIRST ARTICLE

In the MEAO’s Summer 2009 *Reaching Out* Newsletter, we reported on a wonderful document from the National ME/FM Action Network, called “Profile and Impact of 23 Chronic Conditions in the 2005 Canadian Community Health Survey”, pictured below. This Survey is the gold standard for measuring the health needs of Canadians. The results clearly showed significant functional impairment, unmet medical needs and poverty. To read the full article, click on the snapshot below or go to: www.mefmaction.net/MECFM/Overviews/tabid/122/Default.aspx



Profile and Impact of 23 Chronic Conditions In the 2005 Canadian Community Health Survey

The Canadian Community Health Survey was designed by Canadian health authorities and conducted by Statistics Canada. The CCHS provides valuable information about the profile and impact of chronic health conditions. This is information that can be used to guide priority setting and resource allocation. You can learn more about the survey at the end of this document.

Attached are 8 factsheets from CCHS 2005 that show how Canadians with 23 chronic conditions fared on issues of impairment, socio-economic disadvantage and health service delivery relative to each other and to the national average. In particular, the factsheets show the percent of people with each condition who reported:

- unmet medical care needs
- unmet home care needs
- food insecurity
- very weak sense of belonging to the community
- needing help with tasks
- experiencing difficulty in social situations
- being permanently unable to work
- personal income under \$15,000

SECOND ARTICLE

Now we have a new article just published in *Canadian Family Physician*, from the medical team at the Environmental Health Clinic of Women’s College Hospital.

Functional impairment in chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivity

M. Ruth Lavergne MSc, Donald C. Cole MD MSc FRCP, Kathleen Kerr MD Dip Env Health, Lynn M. Marshall MD FAEM FRSM

ABSTRACT

OBJECTIVE To characterize patients diagnosed with multiple chemical sensitivity (MCS), chronic fatigue syndrome (CFS), or fibromyalgia (FM), to compare their level of function with Canadian population average values, and to assess factors associated with function.

DESIGN Chart review and abstraction of clinical information.

SETTING The Environmental Health Clinic (EHC) at Women’s College Hospital in Toronto, Ont, which is a provincial referral centre for patients with illnesses with suspected environmental links, especially MCS, CFS, and FM.

PARTICIPANTS A total of 128 consecutive patients diagnosed with 1 or more of MCS, CFS, or FM, seen between January 2005 and March 2006 at the EHC.

MAIN OUTCOME MEASURES Demographic and socioeconomic characteristics, comorbid diagnoses, duration of illness, health services usage, life stresses, helpful therapeutic strategies, and functional impairment measured by the Short Form-36, compared with Canadian population average values. Factors significantly associated with function in bivariate analyses were included in multiple linear and logistic regression models.

RESULTS The patient population was predominantly female (86.7%), with a mean age of 44.6 years. Seventy-eight patients had discrete diagnoses of 1 of MCS, CFS, or FM, while the remainder had 2 or 3 overlapping diagnoses. Most (68.8%) had stopped work, and on average this had occurred 3 years after symptom onset. On every Short Form-36 subscale, patients had markedly lower functional scores than population average values, more so when they had 2 or 3 of these diagnoses. Having FM, younger age at onset, and lower socioeconomic status were most consistently associated with poor function.

This article was published in *Can Fam Physician*, February 2010;56:e57-65. You can click on the snapshot above or go to the website to read the article: www.cfp.ca/cgi/content/full/56/2/e57

The study involved a total of 128 consecutive patients diagnosed with one or more of ME/CFS, FM or MCS, seen between January 2005 and March 2006 at the EHC. The researchers collected data on all patients for their age, sex, socioeconomic status and other characteristics. They identified whether the patients had either Chronic Fatigue Syndrome, Fibromyalgia or Multiple Chemical Sensitivities, or more than one illness. They identified the duration of illness, health services usage and any life stresses. Each patient completed “The Short Form – 36” survey, to measure their level of functional impairment. The study compared the results of the 128 patients with the average values for the Canadian population from previous studies.

The authors concluded: “Patients seen at the EHC demonstrated marked functional impairment, consistent with their reported difficulties working and caring for their homes and families during what should be their peak productive years.”

Theresa Dobko, Provincial Coordinator

FROM THE PRESIDENT

It is hard to believe but when this newsletter reaches you, we will officially be in our summer season. I am a gardener. I think, like most gardeners, I understand that there are seasons and timelines for our plants, as there is for life.



I also believe we are in a season of huge growth and change in our organization. Much has been happening these last few very busy months. Three key events have occurred: first the MEAO office opening. We have indeed opened the doors to our new office. MEAO is now bricks and mortar! We on the board are thrilled to realize the dream after three years of planning and fundraising.

Many volunteers over many years were responsible for this success: from those who wrote our original Trillium Foundation application, to those who scouted for offices and those who donated cash and office equipment so we could open our doors. We are now open for meetings and special events, volunteer teams and more. We hope to increase our office hours as more volunteers are trained to help at the office. Finally we will be able to put down roots and grow here. Well done!

Second we had our successful May 12th Awareness Event at Queen's Park. May 12th is the International Awareness day for ME/CFS, FM, and MCS. My thanks to the May 12th Awareness Committee – Lynn Holmes, Committee Chairperson; Chrissy Chin; Elaine Bell; Cecilia Chung; Joanne Saraiva. It was wonderful leading them and let me just add that this Committee was supported by a larger group of the best volunteers one could wish for.

Our thanks to everyone who came to Queen's Park on May 12th, most of you sporting our MEAO blue T-shirts and our awareness ribbons. The ribbons incorporated the blue for ME/CFS, purple for Fibromyalgia and green for MCS. I am very grateful to have been able to speak at Queen's Park. This event was the opportunity to

educate and send a clear message. That message is that everyone has the right to quality health care – to an early and accurate diagnosis and the best treatment possible. We need funding for a treatment centre and for the MEAO, so we can provide services in the community.

The third event was actually held earlier, on April 3rd 2010. To prepare for May 12th, we need images for our outreach and media campaigns. The May 12th Committee organized a photo shoot at the Scarborough Civic Centre, which was a huge success. More than 100 individuals – men, women, and children – came and donned these beautiful blue T-shirts to have their pictures taken. I would like to thank everyone who took time from their busy long weekend to attend. It was wonderful.

We produced a wonderful photo slideshow that with the song "I Have a Dream" by Abba. Please check the MEAO website to see our slideshow. Thank you, Peter! On a personal note, standing in the sea of blue shirts, and knowing that all of you were there to support our cause is one feeling that I will not forget.

What can we do at this time to continue to create awareness and education? We can contact our MPPs and send them information kits. Wear our T-shirts and ribbons. I wear my ribbon everyday and encourage everyone else to do so. We can continue to advocate for change.

In closing, I would like to wish all MEAO members and their families a healthy happy summer. I look forward to seeing you all at Dr. Stein's talk on September 12th and our AGM on October 3rd, with speaker Russell Howe, LL.B.

*Thank you for your support,
Jeanne Samonas, President MEAO*



MEAO OFFICE OFFICIALLY OPENS!

By Denise Magi, Board Secretary

The official opening of the MEAO office on June 4th was a great achievement and was the culmination of a long search for appropriate office space. Back in 2007-2008, we began our fundraising for an office, thanks to a grant from the Ontario Trillium Foundation. Then the search began, sourcing out locations and office spaces. Over the past couple of years, several board members viewed offices that were of great interest. Finally, the one of greatest interest – that matched our health needs and our budget – was at 170 The Donway West, Suite 402, now the brand new home of MEAO!

The office now provides a meeting place for MEAO directors and volunteers. It provides us a place to meet other members of the ME/CFS, FM and MCS communities to offer each other help and support. We will hold sessions here for support groups and support group leaders, for training and education. From our new base we can continue the MEAO goal of spreading awareness to the public at large and to the various levels of government. We will continue to search for more medical practitioners and treatments to support our illnesses.

On June 4th, we had a great turnout to our Open House. There were refreshments and our guests were able to mingle with each other and meet new people and old friends. Jaan Meri, Vice-President of the MEAO said a few words of welcome to everyone. We had two very special guests – The Hon. Kathleen Wynne, the MPP for our area, and Oleg Segin, our funding manager from the City of Toronto CSP program.

Ms. Wynne, who is very knowledgeable of our issues and is a great supporter of our cause, said a few words of welcome and encouragement. We so appreciated her visit and thank her for her continued support. She spoke to many members during her stay and offered the assistance of her office. It was a very good day all around and we thank everyone who attended for their continued support of the MEAO.



Board Members Denise Magi, Jaan Meri, Diane Meitz and Arvinder S. Bindra welcome The Hon. Kathleen Wynne, MPP (second from left)

We are currently looking for more volunteers to help us run our office and to answer our Info Line (training provided). As always, if any of our members and readers require help and assistance with issues relating to ME/CFS, FM or MCS, please contact us by phone or e-mail, and we will assist you. Our contact information is at the end of this newsletter. We hope to see you soon!

REMEMBERING AUDREY MAE MACKENZIE PAST PRESIDENT OF THE MEAO

It's been three years since Audrey's passing and on June 4, 2010, the MEAO remembered and honoured Audrey at the official opening of our first MEAO office. It was her dream come true and her friends/colleagues could feel her presence that day.

In honour and in fun I brought in red hearts as Audrey was always fond of her little red hearts and would often include them in her mailings. At the end of the afternoon, Dr. Alison Bested said a few words of remembrance about all of Audrey's contributions to ME/FM/MCS. Audrey was our Guardian Angel ... always reaching out in love and kindness.

♥ We dearly miss Audrey. Diane Meitz

RECENT EVENTS AT THE MEAO

MAY 12TH AWARENESS DAY AT QUEEN'S PARK, TORONTO



100 Volunteers Representing 440,000 Ontarians



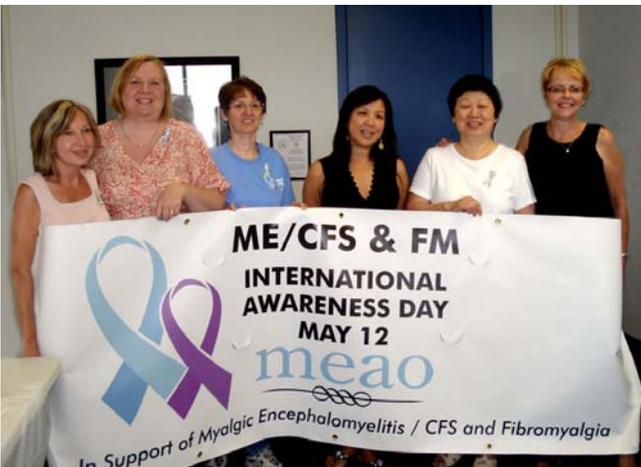
They came together as friends ...



May 12th Booth at Women's College Hospital with MEAO Volunteer Lene Desfor, EHC Staff Member Nancy Bradshaw and MEAO Board Member Diane Meitz (left to right)



To represent a friend living with illness



May 12th Awareness Committee Members: Joanne, Jeanne, Elaine, Chrissy, Cecilia and Lynn



May 12th Volunteers Jeanne, Chrissy and Lynn welcoming The Hon. John O'Toole, MPP

MAY 12TH AWARENESS DAY AT QUEEN'S PARK, TORONTO



They came though most were ill



They came though it was rainy and cold

MEAO OPEN HOUSE, JUNE 4TH, 2010



Jeanne Samonas, Hon. Kathleen Wynne, MPP, Diane Meitz and Jaan Meri



50 members and invited guests attended



(L to R) Lin Grist, EHAO, Dr. Alison Bested, Dr. Darryl Appleton, Jeanne Samonas



MEAO Members with Mr. Oleg Segin, City of Toronto, Community Service Partnerships

ANNOUNCING OUR FALL 2010 LECTURE SERIES AND ANNUAL GENERAL MEETING

**Wednesday, September 15, 2010, 2 - 4 p.m., Auditorium, Women's College Hospital
Dr. Ellie Stein, MD, FRCP(C)
"Myalgic Encephalomyelitis and Chronic Fatigue Syndrome: Coping and Hoping"**

Dr. Stein's talk will include:

- The evidence that ME and CFS differ from known psychiatric/psychological conditions
 - Having an illness with little recognition and no cure is stressful and can lead to psychological symptoms
- How to tell the difference between ME/CFS and psychological symptoms
- How to manage the psychological and neuro-cognitive symptoms of ME/CFS
 - Maintaining hope while waiting for better medical understanding



Dr. Stein is a psychiatrist and psychotherapist who for the past 8 years has been intensively learning and teaching about the management of Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivity. She runs a small, part-time private practice in Calgary, Canada. Her clinical interest is working in mind-body techniques, combining medical and psychological approaches. Dr. Stein's research includes a study of heart rate variability in ME/CFS and an upcoming study of exercise testing in ME/CFS. Dr. Stein's work is internationally recognized. She was an invited speaker at the 2007 International Association of Chronic Fatigue Syndrome (IACFS) conference in Florida, the 2007 ME Research UK conference in Scotland and the Canadian Chronic Fatigue Syndrome Conference in 2008.

**Saturday October 2, 2010, 1 - 4 p.m., Auditorium, Women's College Hospital
MEAO Annual General Meeting, with Guest Speaker Lawyer Mr. Russell Howe, LL.B**

Join Us for Our Annual General Meeting

Learn about our year in review and our new Strategic Planning Document

Elect your Board of Directors for 2011-2012

Join us for our special lecture and Q & A with Mr. Russell Howe, LL.B

"Tales from the Legal Trenches"

Mr. Howe will be covering information for those with ME/CFS, Fibromyalgia and MCS:

- The post "Keays decision" world
- The latest legal developments for disability claims
- The latest legal developments for employment claims
 - How much evidence is enough?
 - Is "Good Faith" just words?



Russ is the past President of the Ontario Trial Lawyers Association, which is a body of more than 1000 personal injury lawyers who fight at the political level to maintain the rights of the negligently injured. He is also a member of the Advocates Society, a State Delegate to the American Association for Justice, the Ontario and Canadian Bar Associations and other advocacy groups. Russ has conducted trials, appeals and tribunal hearings for his clients at every court level in Ontario. He is the co-author of *Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia*, with Dr. Alison Basted and has published multiple magazine articles and papers in legal and scholarly journals on topics related to all types of personal injury litigation. Russ is a highly sought after public speaker both in Canada and the United States.

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THE BENEFITS OF LAUGHTER

Remember the famous saying "Laughter is the best medicine"?

I love to laugh and enjoy making others laugh and smile. A laugh is fun, contagious and gives us happiness and greater intimacy. A laugh makes us live in the moment and makes us forget our problems/stresses of that moment. Laughter keeps us grounded, relaxed and can even boost our immune system.

Our natural endorphins are increased and we feel better all over and can even have temporary relief of muscle pain and spasms.

When we laugh together the good feelings stay with us. Our focus improves as well as our communication and relationship with others.

Laughter lasts all our lives from when we are babies through to our senior years. It is free and easy to do. When having a bad ME/FM/MCS day, watch a funny movie or comedy program, read the comics or meditate remembering a situation or someone that made you laugh. Have one of those big laughs that you feel all the way down to your belly.

Best of all if I need a good laugh I call my girlfriends ... "Hey girlfriend, time to laugh and joke and share the good feelings"

I always look forward to the next laugh. I'm kept inspired and always hopeful that I will have a good day.

Take care and make someone laugh today.

Diane Meitz

HELPFUL WEBSITES ON HUMOUR AS MEDICINE

There is a great deal of medical research that supports using humour, laughter and relaxation techniques to help those living with illness or pain. Here are some websites that we found very informative and highly recommend you check them out.

http://helpguide.org/life/humor_laughter_health.htm

<http://www.umm.edu/features/laughter.htm>

<http://laughtertherapy.webs.com/researcharticles.htm>



Photography by Lisa McGill

YOUR RIGHTS UNDER THE LAW, PART 2

By Arvinder S. Bindra

In the last issue of the MEAO Newsletter, we reported on the presentation made in February at the Canadian Institute for the Blind by Laurie Letheren, a staff lawyer at the ARCH Disability Law Centre and her colleague Amy Spady. In addition to a discussion of how to file a Human Rights application, their talk also addressed a new “Customer Service Standard” that came into effect in January 2010 under the Accessibility for Ontarians with Disabilities Act.

The new standard requires companies and other organizations to:

- Establish policies, practices and procedures on providing goods or services to people with disabilities, with such policies, practices and procedures to be consistent with the core principles of independence, dignity, integration, and equality of opportunity;
- Set a policy on allowing people to use their own personal assistive devices to access goods or services;
- Communicate with a person with a disability in a manner that takes into account his or her disability;
- Train staff, volunteers, and contractors;
- Allow people with a disability to be accompanied by their guide dog or service animal;
- Permit people with disabilities who use a support person to bring that person with them while accessing goods or services;
- Where admission fees are charged, provide notice ahead of time on what admission, if any, would be charged for a support person to come with the person with a disability; and,
- Provide a process for people to provide feedback and make complaints with information about the feedback process readily available to the public.

In time, all organizations covered by the standard will be required to file a compliance report with the Accessibility Directorate – currently only public service organizations are required to file such reports.

At this time, no process has been developed to allow for complaints if you find that an organization is not following the Customer Service Standard, but watch for this process to be spelled out in the future.

FIND OUT MORE ABOUT AccessON.ca

The following information is provided by the Government of Ontario’s AccessON website, through the Ministry of Community and Social Services:

Everyone – individuals, communities, businesses and organizations — has a role to play in making Ontario accessible for people of all abilities.

On AccessON.ca, you will find information, videos and real-life stories to help you better:

- understand disabilities
- recognize and prevent barriers to accessibility
- welcome people with disabilities
- understand Ontario's accessibility laws and what they mean for you.

Visit www.AccessON.ca



MEAO Disclaimer:

As a resource group, the function of our organization is to provide you with current information on ME/CFS, FM, MCS 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:

Ste. 402, 170 The Donway West
Toronto, ON M3C2G3

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.

MEMBERSHIPS AND DONATIONS:

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 Medical 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.



THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

Ste. 402, 170 The Donway West, Toronto, ON M3C 2G3

Please go to our website for our full Membership Application or send us this form with payment
MEMBERSHIP AND / OR DONATION

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NEW MEMBERSHIP FEE: \$25.00
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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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