meao

About MEAO

Mandate

1. To ensure that people living with ME/CFS have the information, support and referrals they need, wherever they might live in Ontario, to obtain the best possible care, and to ensure that all those affected are educated about new guidelines to protect their health.
2. To encourage a strong provincial network of services for ME/CFS, including a Provincial Info Line, support groups and other services.
3. To provide education, support and assistance to partners, family members, teachers, co-workers and friends of people living with ME/CFS.
4. To educate, and work with, health care providers and institutions, the educational system, government agencies, disability and insurance providers, employers, the media and the general public about the facts of Myalgic Encephalomyelitis and the needs of those living with the illness.

Service Activities:

The following are the activities we organize on behalf of people living with ME/CFS, Fibromyalgia and Multiple-Chemical Sensitivities.

1. **Toll-free Provincial Info-Line and Email Service** (established 1998): Trained staff and volunteers respond to requests five days a week from the Info Line and from emails. 50% of our calls come from outside Toronto and 65% are from first-time callers.
2. **Brochures, Fact Sheets and Information Kits:** The MEAO distributes a brochure on Myalgic Encephalomyelitis, Fibromyalgia and Multiple Chemical Sensitivities for distribution across Ontario. We also have a brochure in Portuguese, Mandarin Chinese and French.
3. **Quarterly Newsletter, *Reaching Out*:** We produce a 12-page quarterly newsletter with medical and research updates, articles on coping with the illness and news about provincial resources and upcoming events. The newsletter is supported by membership fees, donations and community advertising. No one is refused because of an inability to pay.
4. **Website:** To reach people across the province, we have a website where we place our print, audio and video materials. The address is: www.meao-cfs.on.ca
5. **Provincial Coordination:** We represent all ME/CFS and Fibromyalgia support groups across Ontario. Currently 25 local support groups and organizations are members of the MEAO. We advocate on their behalf.
6. **Community Referrals:** The MEAO maintains a confidential Referral Database of family physicians, specialists, complementary therapists, support groups, lawyers, disability experts and others. Over 100 health care providers are in the database, with 12 Ontario lawyers. Referrals are provided on request.
7. **Medical, Legal and Counselling Seminars on ME/CFS:** The MEAO organizes 3-4 free public seminars annually, in collaboration with Women's College Hospital, as well as offering smaller workshops in our new office and in the community.
8. **Services for Parents of Children and Youth with ME:** Key volunteers, many of them parents of children with ME/CFS themselves, provide telephone information and support, information packages, advocacy and advice to families dealing with ME in children and youth.

Public Awareness Activities:

MEAO is equally committed to public education and awareness campaigns. The greatest concern of our members, after their own medical care, is the lack of awareness about our illnesses and the myths and stigma that frequently lead to discrimination and refusal of service. We work collaboratively with national and local ME/CFS groups, as well as agencies dealing with related health conditions and disability related issues. The following are the specific education activities we organize or support:

1. **May 12th is "International M.E. Awareness Day".** We collaborate with the City of Toronto and the Ontario government to publicize the day annually. In 2010, we held a large event on the grounds of Queen's Park Ontario, held a media session in the Media Room of Queen's Park, supported other events across the province and contributed to television and newspaper stories.
2. **Public Transit Awareness Campaigns:** Since 2004, we have run posters or cards in buses, subways and stations in Toronto, Ottawa, London, Sarnia and Windsor. Estimated viewership is 1.5 million.
3. **Community Displays and Conferences:** We provide Display Boards, posters and brochures on ME/CFS and our services to Community Health Centres, physicians' offices, clinics, libraries and other community settings across Ontario. We have tables and/or speakers at conferences. More than 10,000 brochures are distributed annually.
4. **Medical Education:** Since 2005, we have distributed detailed diagnostic kits to more than 1,000 physicians, libraries in teaching hospitals, and to directors of Medicine, Nursing, Physio and Occupational Therapy and Social Work in 26 cities/regions. We also organize training workshops for staff in Community Health Centres and through Boards of Education.
5. **Medical Advocacy:** In 2006, we one of the key players to finally have ME/CFS recognized by OHIP so doctors could accurately record ME/CFS and Fibromyalgia diagnoses and be funded for extra time to provide ongoing care to patients. We are currently talking with individual specialists, the Environmental Health Clinic of Women's College Hospital, the College of Family Physicians and the Ontario Ministry of Health and Long-Term Care about the need for more diagnostic and treatment centres.
6. **Education Advocacy for Children and Youth:** Since many children and teenagers contract ME/CFS, we work province-wide with the Ontario Ministry of Education on policies related to the needs of disabled students. We have distributed more than 300 packages to educators across Ontario and we have spoken with hundreds of educators at seminars or individually. We are currently advocating with the Ministry of Education for a panel to develop guidelines for all students dealing with chronic disabling illnesses in Ontario.
7. **Media Relations and Joint Public Events:** We work collaboratively with reporters, writers, television and radio hosts to launch stories or call-in shows each year. So far in 2010, we have worked with CBC Television, CP24, CTS Television, The Toronto Star, The Globe and Mail and Global CanWest publications, distributed nationwide.
8. **Toronto Services**: We receive partial funding from the City of Toronto for awareness and education campaigns in the City. We are the only organization currently providing education in Toronto and we opened an office in Toronto in June 2010 to provide direct services in Toronto.
9. **Government Liaison and Advocacy:** In concert with the National ME/FM Action Network, and other provincial organizations, we have organized meetings with our organization, and with community members, across Ontario. This May, we held a special campaign to reach all Ministers of Provincial Parliament for May 12th, leading to more than two dozen individual meetings and the declaration of International ME/CFS and Fibromyalgia Day at Queen's Park. We are currently waiting on an answer from the Minister of Health for our request for $189,000 in ongoing funding for our Association; this represent almost from 1/5th to 1/10th of what is given to most other chronic illness groups, such as Multiple Sclerosis, HIV/AIDS, autism, physical disability organizations and more.