

REACHING OUT

Summer 2008

Report on 2008 MEAO meetings with Federal Ministry of Health and Provincial Meeting

The old adage when it rains it pours has never been more true than in the last three months as our Association has had the opportunity to meet with Senior Policy advisors from the federal and provincial ministers of Health.

On **February 27th**, after many months of hard work by volunteer and advocate Maureen MacQuarrie, a meeting was secured with the **Senior Policy Advisor to the federal minister of Health**, Tony Clement.



The meeting, attended by **Tony Rovito, President, Maureen MacQuarrie and Kimberley Dowds**, our new Provincial Coordinator, was greatly successful. Representatives from the Minister's office, Health Canada and the Public Health Agency of Canada were receptive to our issues and wanting to assist us. Almost immediately following the meeting, The M.E. Association of Ontario was contacted by the Public Health Agency of Canada (PHAC) to further discuss our needs and issues as they relate to research.

A subsequent meeting with **PHAC** and representatives from **CIHR (Canadian Institutes of Health Research)** was held on

May 7th in Ottawa. Eight representatives from PHAC and CIHR as well as researchers and clinicians, representatives from The M.E. Association of Ontario and the wonderful Lydia Neilson, President of the M.E./FM Action Network. While PHAC and CIHR were not able to provide immediate funds for research, there were a number of funding opportunities suggested that our association, in collaboration with the National M.E./FM

Action Network, will discuss further. Future meetings and discussions are still planned and our Provincial Coordinator, Kimberley Dowds, will be working closely with PHAC on those next steps.

While preparing for the

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REACHING OUT

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The Myalgic Encephalomyelitis
Association of Ontario (MEAO),
a registered charitable organization.

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, and*
- *To promote, facilitate and raise funds for research on the causes and cure for Myalgic Encephalomyelitis.*

Our mailing address is:

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

Our HELP-LINE is:

416 222-8820, or 1 877 632-6682.

Visit us on our new web site at:

www.meao-cfs.on.ca.

Charitable Registration No:

89226 7568 RR0001

Report on MEAO Meetings, continued

May 7th meeting in Ottawa, the determined and diligent work of Maureen MacQuarrie and the persistence of our President Tony Rovito paid off when Tony received a request from the **Ontario Minister of Health's** office to meet on **May 9th**.

This meeting was held in the Minister's board room with the **Minister's Senior Policy Advisor**. While no immediate commitments could be made, we were given a better understanding of the new strategic plan for the Chronic Disease Management Strategy

and given suggestions as to the best avenues to pursue our issues and concerns.

There is much to do to advocate for change in the health system. **You can help us today by writing a letter to your M.P.P. and M.P. or by donating to The M.E. Association of Ontario's advocacy campaign. Together we will make great things happen!**

Photo on the cover page was taken at the Ottawa Airport following the May 7th, 2008 meeting with PHAC and CIHR. Front row from left: Lydia Neilson, Dr. Eleanor Stein, Maries St.Paul; Back row: Margaret Parlor, Tony Rovito, Dr. Alison Bested, Izzat Jiwani and Kim Dowds.

HELPING MEAO RAISE CORPORATE FUNDING

By: *Anthony Rovito*

In 2007, MEAO (The Myalgic Encephalomyelitis Association of Ontario) received a grant from the Ontario Trillium Foundation. The Foundation provided this grant for the purpose of hiring a new part time Provincial Coordinator; and to also access the services of a "fundraiser" to assist with our long-term sustainability. (Some minor funds were also provided for the expansion of our province-wide programs.) One of the Trillium Foundation's expectations is that the Association will now **open a small provincial office by 2008**. To facilitate the opening of such an office, we need to embark on a fundraising campaign to help us raise the required funds to cover the "rent and utilities", etc.

We need your help on this fundraising campaign!

Did you know that most of you may have, within your circle of family / friends / neighbours, an employee of a corporation who we could approach for corporate sponsorship? This employee could connect us to the person responsible for sponsoring a charitable organization like ours. Perhaps

they work for a service oriented organization such as a bank or insurance company, or, retailers such as Canadian Tire, Home Hardware, Wall Mart, or Loblaws – just to name a few.

An example of such corporate sponsorship is the “The CIBC World Markets Children’s Miracle Foundation”. An employee of CIBC can request that a charitable organization (such as MEAO) be placed on its list of approved charities that CIBC employees can then direct their charitable contributions to. CIBC employees are encouraged to donate a minimum of one day’s pay per year to a charity on the approved list.

These corporate contacts may lead to opportunities for us to distribute our M.E./CFS pamphlets within that organization, thereby raising awareness of M.E./CFS.

Another example of corporate sponsorship was the “Mark’s Work Wearhouse” flyer for April 23 to May 4, 2008. The flyer announced that the store would donate \$5 to Breast Cancer for every \$65 spent during that period of time. The goal for this initiative was to raise a minimum of \$250,000.

If you have such a contact with whom we can discuss corporate sponsorship, please email us all of the relevant information and together we can explore the possibility of corporate sponsorship. Please email us for further information on this at info@www.meao-cfs.on.ca.

LETTER FROM THE PROVINCIAL COORDINATOR



I am so honoured to write to you today for the first time as your new Provincial Coordinator. The past few months have been a whirlwind of activity as a number of new initiatives have been undertaken. As well, the hard work of many over many years has created new interest in M.E./CFS within the Federal and Provincial Ministries of Health.

I am so grateful for the fabulous volunteer team that The M.E. Association of Ontario has. I had the opportunity to meet our great Help Line volunteers in the new year. They are truly the heart of the organization, providing one to one support to people struggling to cope with M.E./CFS.

Tony Rovito, our President and Maries St. Paul, our Vice President have sacrificed so much over the last few years to ensure that the association continues to flourish and that Audrey MacKenzie’s dream for the association becomes a reality.

As a new addition to the association, I was amazed and in awe of the wealth of talent that the board of directors brings to the association. I am continually grateful to each one of them for the advice and expertise that they provide to me every week.

In addition to launching a risk management review for the association, implementing a sponsorship and advertising policy, much of my time and focus has been on two important areas: our web presence and assisting with our provincial and federal advocacy. Great inroads have been made both federally and provincially and I hope to be able to advise you of further developments in my next letter. I am confident that this association has a very exciting and successful future ahead of it and I encourage each of you reading this today to consider assisting us. Whether it be making a donation to help us with our education outreach and government advocacy; volunteering on the Help Line or with the website or contacting your local media to encourage them to run a story on M.E./CFS, all assistance, no matter how small it may seem will make a great impact on the lives of people living with M.E./CFS.

Hope you all have a restful and enjoyable summer!

Kimberley Dowds, Provincial Coordinator
The Myalgic Encephalomyelitis Association of Ontario

REMEMBERING AUDREY



By: Anthony Rovito

June 4, 2007 is a day that I will never forget. My good friend and past president of The Myalgic Encephalomyelitis Association of Ontario, Audrey MacKenzie, sadly passed away on that day.

I remember specifically that Audrey had not been well that week but she kept refusing to go to the hospital, as Audrey normally tended to do. Finally, however, after a lot coaxing and insistence from her close friends, Audrey did agree to be taken to the Emergency Department at Mount Sinai Hospital. There, she was admitted and shortly thereafter was placed in the ICU where she began to undergo a series of tests.

Audrey's friends were very aware that she loved flowers. Being in the ICU however prevented her from having flowers in her room. Nevertheless, we all agreed that she would appreciate receiving flowers. Thus we decided to bring her some flowers even if I might only be able to show her the flowers from the hallway and then hopefully place them at the nurses' station for her.

When I arrived at ICU, I walked up to the nurses' station with my flowers in hand and began to articulate my request. As the nearby staff heard me mention the name Audrey MacKenzie, they all turned and looked at me. The head nurse then walked over to me and asked me if I was family. When I identified myself as a close friend and the president of the M.E. Association of Ontario, she delivered the sad news that Audrey had just "passed away a few minutes earlier". Surprised and saddened by the news, I first asked as to when she actually died and was there someone with her. I then asked if I could still visit with her in the room. The nurse agreed and together we walked into Audrey's room where everything was still as it was when she passed on about 15 minutes earlier.

Once in the room, I remember looking at Audrey still lying there in her hospital bed. She looked, I thought, definitely very tired and quite sick but she also now looked very much at **"peace"**- a lasting peace, well earned after her many struggles with her own health and the health, security and well-being of many, many, other individuals whose lives she touched as a friend and as the president of the M.E. Association of Ontario.

In memory of Audrey MacKenzie who contributed so much to our Association, the Awards Committee of the M.E. Association of Ontario, beginning in 2008, will regularly invite nominations from the membership for the **Audrey MacKenzie Memorial Award** which will be presented regularly at the Annual General Meeting of the Association. More information on our new awards program is on page 5 of this issue. I would encourage all of the members of MEAO and all of Audrey's friends and colleagues to participate actively in this important awards program.

Through this annual award and other possible future initiatives, Audrey MacKenzie will continue to be remembered fondly for the person that she was as well as the significant contributions that she made to the M.E. Association of Ontario!

NEWS and UPCOMING EVENTS

Report on May 12th, M.E./CFS

& FM Awareness Day: A rally was held at Queen's Park to mark National M.E./CFS & FM Awareness Day thanks to the hard work and dogged determination of Gisela Imbrogno of the York Region FM and CFS Support group.

Over 50 people with M.E./CFS and/or FM and their friends and family gathered to listen as Mr. Frank Klees, an opposition M.P.P., read a short proclamation in the legislature.

Afterwards, Mr. Klees, Dr. Alison Bested and Gisela Imbrogno held a press conference which was broadcast by video to the Queen's Park press gallery.

Our congratulations and thanks to Gisela, her team of volunteers, Dr. Bested and everyone who was able to attend!

M.E./FM Association of Peterborough and District celebrate M.E. Day, May 12th:

Joan Foster reported on her support group's very successful events. A fund raiser for their group's resource library was held through Chapters book store > 15% of each sale made that day was contributed to this project. Members of the group distributed M.E./ FM information at a display table set up in the store. A large display, using some of MEAO's bus and subway advertising, was on view for a week in a large office window in downtown Peterborough. Joan emailed the local papers a copy of 'BACKGROUND INFORMATION ON MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME, as well as an invitation to Chapters.

A 2nd fund raiser is planned for later in June at a local restaurant.

Well done Joan and friends!

The Myalgic Encephalomyelitis Association of Ontario will be hosting its

ANNUAL GENERAL MEETING on

Saturday, September 27, 2008, at Women's College Hospital, Main Auditorium, 1:00 – 4:00 p.m.

The hospital is located at 76 Grenville Street, Toronto.

We are holding the AGM a few months earlier than usual, in warmer weather, in the hope that more of our members will come.

FREE ADMISSION, EVERYONE WELCOME!

DONATIONS APPRECIATED

Wheelchair accessible

Scent Free Policy

MEAO Volunteer Awards

By Izzat Jiwani, Chair, Awards Committee

The M.E. Association of Ontario is excited to announce a new awards program for 2008.

These new awards recognize the valuable contributions of our many volunteers.

Two special annual awards will be presented at the Annual General Meeting of the Association in **September, 2008.**

The first award is in honour of the late Audrey MacKenzie, Past-President of the Association. **The Audrey MacKenzie Memorial Award** will be given to a person who has shown significant dedication to our Association as well as to raising awareness of M.E. in Ontario.

The second award is the **Volunteer of the Year** award which will pay tribute to a dedicated volunteer who has gone above and beyond the call of duty to assist our association in achieving our mission. Full details and nomination forms are available on our website at www.meao-cfs.on.ca. The deadline for nominations is July 25th, 2008. If you have any questions please call our Help Line or email us at: info@meao-cfs.on.ca.

MEAO's New WEB SITE: In December 2007, the board of directors agreed that a review and update of the current website needed to be undertaken immediately. The newly updated website was launched

May 1st and includes many exciting new features.

A new website address was created that was easier for people to remember: meao-cfs.on.ca. The old website address will now point you to the new location.

The theme of the new design was to make it **interactive and user friendly**. The new site has a robust search engine and a categorized menu.

New interactive features include **a live chat area and an online discussion forum**.

In addition, an M.E./CFS Directory was created so that over time we can list all programs and services available to help those living with M.E./CFS. Anyone can make a submission to the directory and I encourage you to do so.

We have also added an events calendar.

Here too, anyone can suggest new events to be added to the calendar from support group meetings to conferences and social events.

Please take a moment if you have internet access to look at our new site. **If you know of an event, a resource or an article that you think should be on the site, please use the links provided on the new site to submit your suggestion. Our newly re-designed web site will be for people with M.E./CFS, built by people with M.E./CFS!**

ADVOCACY / DISABILITY ISSUES

By Margaret Parlor, Coordinator of Youth & Education Issues

Honda v Keays / Update

The case of Honda v Keays was heard by the Supreme Court of Canada in February 2008.

Mr. Keays, an employee of Honda, came down with Chronic Fatigue Syndrome. He missed days of work. Tensions escalated and he was eventually fired.

The Supreme Court has to decide what rules apply in the workplace. Do contractual rules apply? (Honda hired Mr. Keays to be at work. Because he wasn't there all the time, did he

breach the terms of their contract?) Or do human rights rules apply? (Mr. Keays had a disability that meant he couldn't be at work every day. Did Honda have a duty to work out accommodations? Did Honda respect Mr. Keays rights and if not what should be the consequences?)

The nine Supreme Court judges listened to lawyers for Honda, for Mr. Keays, and for nine other organizations interested in the case, including the National ME/FM Action Network. The decision is expected this summer or fall. This is considered one of the most important workplace law cases in the past decade and will receive a lot of media attention.

Education Advocacy

I had the opportunity to attend a conference of Ontario education advocates in late April 2008 on behalf of the MEAO. Much of the discussion at that meeting was around the application of human rights for students.

The Honda v Keays case is questioning if and how human rights law applies in the workplace. A very similar question is if and how human rights law applies in schools. We would like to think it does, but some school boards are human rights friendly, others stick to procedures and rules under the Education Act. As a result, some young people with M.E./CFS find supportive situations and others do not. We would like to hear about the experiences of young people with M.E./CFS in Ontario schools, both positive and negative.

The Ministry of Education has informed us that it intends to discuss issues around M.E./CFS and FM with school boards at their regional special education meetings this spring. We are delighted by this news. The discussions will help make boards aware of these conditions and will draw attention to ways that boards can support these students. Please note also that a French version of the Teach-ME Sourcebook for Teachers of students with M.E./CFS and FM is now available through the National ME/FM Action Network.

ASK A DOCTOR



For those of us with CFS, the question of how to improve our health, and thereby reduce the symptoms of our illness is always before us. In this issue, we present 3 articles that talk about the effect of what we ingest on our bodies, and our symptoms: **Food, Food Allergies and Supplements.**

These articles are not meant to be the final word on any of these 3 topics, and we encourage you to continue informing yourself, using the web or reading material, for the most up-to-date facts.

Read all food package ingredients.

See our section **HELPFUL WEBSITES**, **page 17**, for more websites.

1) Can the FOOD I eat affect my M.E./CFS symptoms?

By Tracey Beaulne ND

The past few weeks have been non-stop for me with our new baby boy, "Nate", born April 13. A good non-stop, but still exhausting. Never before has it been so important for me to eat well however, thinking about what I want to eat, finding the energy to prepare it, and then eat it - uses more energy than I have at some moments. It would be so easy to eat ready prepared processed foods; however, I don't because I know what these foods do to a body - many patients have heard me say food can be medicine or it can be poison!!! I have a few tricks for getting those healthy, whole foods into your diet that I am happy to share!

Whether you have M.E. or Fibromyalgia, there are some very important things to keep in mind when you are making food choices. Please **stay away from all food additives, preservatives, colourants** - if it is on a label and you can't pronounce it - don't eat it. Chemicals in our food have the ability to cross the very important blood brain barrier in our

brains and wreck havoc with our central nervous symptoms causing symptoms such as migraines, increased heart rate, mental fog, irritability and anxiety to name just a few. People with M.E. are even more susceptible, as research has shown there is an increased permeability of the brain blood barrier. More of these chemicals in our food have the capacity to cross over and cause increased symptoms in susceptible people. For you this could mean the difference of having a good M.E. day and a bad M.E. day. The same could be said for the **pesticides** in our foods. Thankfully the Environmental Working Group keeps tabs on the food industry and has a very convenient list citing the dirty dozen - **the top 12 foods that you need to buy organic.** The list is continually updated - have a look at www.ewg.org. They also have a very convenient tuna calculator that tells you how much tuna you can eat per week without too much worry about mercury overload from this tasty fish.

People with Fibromyalgia should be aware of those **foods that promote inflammation** in the body. Generally, processed grains - especially wheat, refined sugar, foods high in vegetable oils - found in all prepared baked goods, and the nightshade family of foods - including tomatoes, potatoes, peppers and eggplant. As many with FM have noted: if they remove the inflammatory foods for a good 6 weeks, they start to notice a decrease in their pain levels. In the clinic I have found that patients that have been able to identify their food intolerances or potential allergies and remove these foods as well can have a significant reduction in their pain levels. Leaving both of us in shock as to how profound an effect a change of diet can have on their level of health.

So what to eat when your energy is low and those processed foods seem like such a good idea? Have some **nuts and seeds** on hand - no salt or oil added. **Walnuts** are especially good for their omega 3 fatty acids - a known inflammatory reducer. Keep some **hummus** in the fridge as well as some **cut up carrots**

and celery. Try some alternative grain crackers like rice, rye or spelt - but read the label first! **Make extra food at the meals you are able to prepare** - a whole cooked chicken can go a long way - put it on some mixed greens, in a sandwich, in some pasta. The same goes for a turkey (or turkey breast) - you don't have to just cook a turkey at Christmas! Have plenty of extra virgin olive oil, some apple cider vinegar or lemon juice for an easy dressing over some canned beans. Buy **frozen vegetables** - steam them or stir fry them and add them to whatever you are preparing - a nice soup, a pasta dish or on top of your mixed greens. Finally, **use your blender** - even if you are just throwing in some rice cream, unsweetened almond milk, plain yogurt or keifer with a banana, frozen berries, a couple tablespoons of ground flax powder and some greens+ - you are powering up your nutrition and giving your body some medicine to heal.

Tracey Beaulne ND
Doctor of Naturopathic Medicine
Integrative Care Centre of Toronto
www.thedoctors.ca
416 283-0007

2) Can allergies aggravate M.E./CFS or Fibromyalgia?

By B. Zylberberg, M.D.

During the early years in my practice of allergic diseases, I was essentially following the paradigm that I had been trained to follow, one where it would seem that if you did not have sneezing, wheezing or hives, you did not really have allergies. But times have changed over the years and any complex of symptoms can come into play in making the diagnosis.

As a practicing allergist, I have encountered many more people who have developed auto-immune conditions. In some instances a

person may present with 2 – 3 of these conditions including **Chronic Fatigue Syndrome, Fibromyalgia**, Rheumatoid Arthritis, Ulcerative Colitis, Crohn's Disease, Lupus Erythematosus, just to name a few. This situation caused me to try and assess patient's histories, developing a possible evolutionary history of the illness / illnesses. These histories provided a timeline of development of the patient's conditions in relation to the developing clinical picture. This created an interesting paradigm for me, which could quite easily be applied to the eventual management of the condition / allergy. Patients with clinical problems such as eczema or asthma, fatigue, and pain, or all the above originally began with a basic allergy such as hay fever, which had become modified over the years to leading to the more serious conditions.

An allergy is basically an inflammatory response to a stimulus which can either be environmental, inhaled, ingested or contacted. If not controlled, the outcome is what we could easily imagine as a bush fire which could burn continuously. The result of these flaring events which cause the symptoms is damage to the tissues, i.e. muscles, fibers, nerve endings and blood vessels. This will then involve the response of the immune system which does not view this development as normal and will then proceed to further the inflammation in an inappropriate way. We could then find ourselves in the downside of auto-immune disease, i.e. **Chronic Fatigue Syndrome, Fibromyalgia**, Rheumatoid Arthritis, Ulcerative Colitis, Crohn's Disease, Lupus Erythematosus, etc.

The management of the presenting problem (allergy) has become a complex matter that I feel should start with the identification of provocative factors. By providing nutritional counseling and having the patient remove allergic foods, the patient can then concentrate on trying to address the condition as a whole.

It is my belief that most conditions I see evolve from atopic allergy (hay fever, eczema, asthma, and some CFS / Fibromyalgia symptoms) and the most common denominator is **mold allergy**. I find that the immune system can often be enhanced by offering allergy injections for **MOLDS**. These have been fairly successful in strengthening the immune system so that it does not continue to respond inappropriately and aggravate any auto-immune condition. **Many CFS patients with fatigue, brain fog and fibro pain who start receiving weekly allergy shots for mold, report more energy, reduced brain fog and less fibro pain.**

I have also concluded that about 60% of people I see also have a sensitivity / allergy to **CORN**. Antihistamines have a cornstarch base so anyone with a corn allergy would have difficulty using them. Therefore to handle allergic problems I have suggested Quercetin which is an anti-inflammatory flavanoid along with a good antioxidant complex like Network Synergy to address the question of damage to the tissues. Of course many people have allergies to other foods, not just Mold and Corn; while others are allergic to chemicals and environmental stimuli.

I firmly believe in using superior type supplements which I consider a little further advanced than simple vitamins. These supplements have been devised so that the physiological mechanisms are addressed in an appropriate way and may even strengthen the immune system. Also successful thus far has been the use of certain homeopathic remedies.

If you suspect that you have a Mold or Corn allergy, these are the foods to avoid:

Mold - yeast, all fermented foods like wine and alcohol; vinegar and foods that contain vinegar; strawberries, cantaloupe, grapes and all dried fruits; cheeses: parmesan, brie, cheddar, camembert, gorgonzola, Roquefort and blue cheese.

Corn - corn, cornstarch, MSG, all sugared and diet soft drinks; and many prepared foods. Did you know that some yoghurts contain corn starch?

**Dr. B. Zylberberg, M.D., 416 787-1894
2797 Bathurst St., Suite 204
Toronto, Ont. M6B 4B9**

Editor's note: read all food package ingredients.

YOUR HEALTH

Supplements

By Dr. Gabriella Chow, B.Sc., N.D.

I am sure that many of you have come across numerous supplements marketed on websites, magazine articles, and in health food stores claiming that they will take away your symptoms of chronic fatigue and/or fibromyalgia. As tempting as these ads may sound, unfortunately, there is no 'magic bullet'. It pains me to see individuals with Myalgic Encephalomyelitis or Fibromyalgia (ME/FM) bring in several bags full of supplements to show me what they are taking and also tell me that none of them seem to be helping. Fortunately, there are some supplements that both science and clinical experience show are very important in the management of the symptoms of M.E./FM.

Multi-vitamin:

All individuals living with M.E./FM should supplement with a high quality multi-vitamin. As many of you are well aware, eating 3 meals a day may not be possible at times due to the severity of the fatigue or pain that you may be experiencing. Furthermore, those meals may not be well-balanced and nutritious, but rather quick-and-easy, which often involves less nutrient-dense foods. Research also shows that people living with M.E./CFS have decreased levels of many

nutrients, thought to be because of the physiological changes brought on by the illness and the decreased ability to absorb nutrients from food. Therefore, the importance of nutrition in managing your condition becomes even more clear. A multi-vitamin will never substitute the health benefits you receive from eating high-quality, nutritious meals. But it will provide you with the nutrients you need to cover the days that you aren't eating as well as you would like to – kind of like a health insurance policy. **Beware of multi-vitamin supplements that contain additives, such as FD&C dyes, fillers, and coatings, as they will aggravate your symptoms. Also avoid multi-vitamin supplements that are “one-a-day” as the levels of nutrients provided are generally too low.** Professional brands are generally free of additives and contain adequate levels of nutrients, so you may want to discuss this with your health-care provider.

Omega-3 Fatty Acids:

Researchers have found that people with M.E./FM have abnormal levels of various fatty acids in their bodies, especially the omega-3 and 6 fatty acids. Omega-3 and 6 fatty acids are the essential fatty acids, meaning that our body does not make them so we must get it from our diet. Getting sufficient levels of omega-6 is not a problem since it is predominant in most diets, as it is derived from commonly used oils such as corn, sunflower, and safflower which are used in almost all prepared foods (whether it be cereal, bread, salad dressing, etc.). The problem lies in getting sufficient amounts of omega-3 fatty acids, which is only found in sufficient amounts in only several foods, such as walnuts and certain types of fish, especially salmon. But not everyone enjoys eating walnuts or fish, and you generally cannot get enough omega-3 fatty acids from the diet in the amounts that are needed to control the symptoms of M.E./FM. Therefore, supplementation is necessary. Research studies have found that fish oil supplementation can improve pain, fatigue,

mobility, and depression in people living with M.E./FM. Also, in people taking anti-depressants, fish oil has been shown to enhance its effectiveness. Most fish oils are a mixture of EPA and DHA, but it is the EPA that provides these therapeutic effects.

Therefore, **choose pure EPA fish oils or those that have much higher amounts of EPA versus DHA. Talk to your health-care provider before supplementing with fish oils** – too high a dose can have blood-thinning properties and dosages depend on what is being treated – for example, the dose of fish oil for depression versus pain is very different.

Probiotics:

Many people with M.E./FM have gastrointestinal complaints, such as bloating, constipation or diarrhea, or alternating constipation and diarrhea, acid reflux, gas, food allergies, and abdominal pain. In fact, research has shown that the gut of those with M.E./FM often has an overgrowth of bacteria in the small intestine and less of the “good” bacteria that is normally supposed to be naturally present in the colon. The overgrowth of bacteria in the small intestine and the excess of “bad” gut bacteria produce toxins that can cause the symptoms listed above, interfere with the absorption of many nutrients, and cause cognitive difficulties such as “brain fog”, difficulty concentrating, and poor memory. In addition, stress can reduce the levels of “good” bacteria in the gut – and I am sure anyone living with M.E./FM can attest to the stress of living with their condition. Research studies have shown that when the overgrowth of “bad” bacteria is controlled by probiotic supplements, there is improvement in memory, concentration, pain, and depression in people with M.E./FM. Other benefits of probiotic supplements include: the synthesis of vitamins, balancing the immune system, reducing allergies, and maintaining the health of the bowels. A common question is “can't I just eat yoghurt?”. The answer is both yes and no. Some yoghurts do have active cultures. However, many yoghurts do

not have active cultures and in most cases, you cannot obtain sufficient levels of the “good” bacteria that you need from yoghurt alone, and depending on the condition being treated, the strain of probiotic bacteria chosen will vary. For instance, the strain of bacteria used to treat food allergies will be different from the strains used to regulate the bowels. Specific strains can only be supplied by probiotic supplements. Once again, **it is best to discuss the use of probiotics with your health-care provider to find the probiotic that is best for you.**

Summary:

The supplements discussed above are the basic supplements that all people living with M.E./FM should consider to help manage their symptoms. They are the ones that research and clinical experience have shown to be helpful. There are other supplements that may be helpful as well, but the choice of supplement depends on what the presenting symptoms are and the length restrictions of this article preclude me from discussing them all. In addition, **supplements should never take the place of a well-balanced, nutrient-dense diet.** When in doubt, talk to your health-care provider about what supplements to take, especially if you are taking other pharmaceutical medication.

Gabriella Chow, N.D.

www.gchownd.com

Dr. Chow practises at 3 locations in Toronto and can be reached at: 416-400-5598, 416 283-0007 and 905-597-1331.

Think big:

The most realistic way for you to tackle greater goals is to enlarge your notion of ‘you’.— Josh Mitteldorf

Sharing our Experiences: GRIEF and M.E.



Thank you to our contributors, Chris Pike and a parent who wishes to remain anonymous. Written and compiled by Suzanne Mossman.

This article, in our series of articles, talks about the emotion of **grief**. Our writers’ stories are poignant in their candor. They discuss how ill health has impacted their lives, as well as the lives of their children. Feelings such as shock, denial, anger, bargaining and depression are all reactions that a grieving individual might experience. As the reader will see, the duration and intensity of grief are unique and different for everyone. There is no charted course for grief.

Chris Pike’s Story

In my lifetime, both of my parents and both sets of my grandparents have passed away, and my dog Oona died just this March 8. I have felt and continue to feel sorrow in the passing of all these loved ones, and am freshly feeling the sadness, pain, and loss of my dear Oona. I have taken great comfort in the words of my friend who wrote that “grieving is the purest evidence that we have loved”. Every time I cry or feel sad that my mother is no longer living, 11 years after her death, I look to my pain as proof of my strong connection with her.

In my five years of living with CFS/ME after an abrupt onset in June 2003, I continue to live with, mourn, weather and even grow from the many related losses. As a result of living with CFS/ME I have lost my full-time job as I cannot work for pay. I have therefore also lost the financial abundance, security,

flexibility, choices, and status that money brings. Obviously, I have lost the vast options and opportunities afforded by good physical health including hiking or even good long strolls. And perhaps most troubling to me, I have lost the instant respect, respectability, and cultural currency of having a 'good job' and 'good health'. When I meet new people, I am no longer protected by the security these cultural icons confer. Saying I am sick with Chronic Fatigue Syndrome (try saying "Myalgic Encephalomyelitis" at a dinner party) and live off a disability pension is much less glamorous or well-received by strangers, or even acquaintances and friends, and I always avoid these conversations now. I have certainly lost a couple of fair-weather friends, but still more troubling for me has been my loss of social acceptability and the 'social security' that my former life gave me.

I have learned a few things about grieving;

1. I have learned that the foundation of community and spirituality I had built before I got sick have sustained me greatly in being ill;
2. I have learned that having understanding people in my life who hold no stopwatch on grief is invaluable. I have people in my life who listen, know me, care for me, and are willing to hear me cry and hand me Kleenex. Having people like this who do not try to fix my feelings, but let me have my feelings has been priceless;
3. I have learned to trust the trustworthy and not the untrustworthy. I take the time to learn about people before I share intimately with them, and I will not share vulnerabilities with people who do not or may not possess the tact and care to support me;
4. I have learned to strike a balance between feeling what is there for me to feel, learning what is there for me to learn in my grief, and keeping some constructive productive focus in my life. While I give myself time to cry and feel sad, I also make time to volunteer, to

take responsibility for trying to improve my health, and I do have some fun. I am even taking a university correspondence course now!

5. I have also learned that grief is taxing and I need to take extra care when I am grieving.

As a result of my losses, I have learned a great deal as well. I have learned so much that delineating the rest now would take up more space, time, and mental stamina that I can afford to spend.

Some highlights: I now see how strong, creative, and adaptable I can be. I see better who my real friends are. I have learned that on some level there is always truth in "this too shall pass". I have relearned the gift of being of service to others. I have learned to be more compassionate to those who are sick physically, emotionally and mentally, even those who have rebuffed me for my illness. I have also gained time and space from the relentless and frenetic pace of my 'former life', time and space which offer me gifts. I have thus re-evaluated who I am and what it is I really want to do in this life, and I have gotten clearer. I have further learned that acceptance and adaptability are assets that can be cultivated with time, work and support, and that there is indeed wisdom in having the "serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference". So while indeed I have lost much, I have also gained. To the best of my ability I have tried to take the metaphorical lemon of CFS/ME and squeeze every last ounce of juice out of it to make something that is much less sour.

Grief Experienced by a Parent

It has been difficult to write about my grief as I know that I should be grateful that my daughter doesn't have a life threatening illness. I am grateful - most of the time. In the 10 years that my daughter has had M.E/CFS, it has been heart breaking to see a young girl, once known as "the life of the

party”, turn into a listless teenager; an avid computer enthusiast turn into someone barely able to focus on a television programme; an all star basketball player unable to even go on a walk with me.

It hurt her even more than me to watch her many friends drift away as they had no patience with someone who couldn't be depended on to hang out after school, couldn't commit to go on a sleepover or to carry out plans made a few days earlier. It was a great disappointment to see a very bright girl, who was once the head of her class receive no awards at graduation. My daughter couldn't drag herself to a full day of school; she was of course falling behind her peers and feeling the social repercussions. It made me angry that the school board would not provide her with a tutor and that I had to fight to get her into an alternative education programme. It terrified me that her depression got so severe that she attempted suicide. It made me so sad that she tried to have a normal teen life but just couldn't pull it off – missed parties, little dating, and extra curricular opportunities. She always wanted to go to university and finally made it. As much as she loves university, it's taken a toll on her health. She can't take a full course load, participates in only a few social activities; but thanks to 'brain fog', she has to work twice as hard as most students. Sadly she gave up her dream of becoming a lawyer.

It is a terrible thing to say, but I am glad my daughter lives on campus. Seeing her pain every day when she lived at home, knowing how exhausted she was, watching her make bad decisions because she was just so sick of being sick, just ripped me apart some days.

Anger, sadness, helplessness

- this is my grief;

Not being able to make her healthy

– this is my grief;

Watching my child in such emotional and physical pain

– this is my grief;

Knowing that she will probably never reach her potential

– this is my grief;

Afraid for her future

– this is my grief.

M.E./CFS is not a journey one ventures on alone. You take everyone else with you.

Remember, it doesn't have to be a bad place, just a different one from where we thought we were headed.

The next article in this series will be on **DENIAL**. We encourage you to write about your experiences and email them to us at meacfsnews@gmail.com. The limitation of space requires us to select only some of the submissions, but we appreciate each and everyone!

How it Feels to be Sidelined by ME/CFS

By Maureen MacQuarrie (Sidelined by ME/CFS in 2001)

S – sick

I – invisible

D – despair & desolation

E – empty (no energy, a shell)

L – loss

I – isolated

N – numerous symptoms, nightmare

E – endure

D – disbelief (by me & by others)

FROM OUR KITCHEN TO YOURS



Oatmeal Cranberry Flaxseed Cookies

This recipe originally comes to us courtesy of Sick Kids Hospital.

From our new **Food Editor, Mary Lou:**

Recipe makes 2 dozen cookies.

Ingredients:

1/2 cup canola oil
1/4 cup brown sugar
*1/4 – 1/2 cup white granulated sugar (I found 1/2 cup of sugar made the cookies too sweet; however each person can be their own sweetness monitor.)

1 large (omega 3) egg
1 tsp. vanilla extract
1/2 cup all-purpose flour
1/2 cup ground flaxseed meal
1/2 tsp. baking soda
1/2 cup dried cranberries
1 cup rolled oats

Instructions:

Preheat oven to 350F
In a bowl, thoroughly mix canola oil and sugars together.
Add egg and vanilla, mixing well.
Add flour, ground flaxseed and baking soda and mix until well combined.
Stir in cranberries and rolled oats.
Drop 1 Tbs. of dough, 2 inches apart, on a parchment-lined baking sheet.
Bake 10-12 minutes.

Nutrients per cookie:

calories – 78 (based on 1/4 cup of sugar)
protein - 1g
fat - 4g

carbohydrates - 8g
fiber - 1g
omega-3 - 0.5g
(canola oil, flaxseed meal, eggs, especially from chickens fed flaxseed, all are very good sources of Omega 3.)



'FOOD FOR THOUGHT'

[This is not a joke, but some interesting facts about food.]

A sliced Carrot looks like the human eye. The pupil, iris and radiating lines look just like the human eye...and YES science now shows that carrots greatly enhance blood flow to and function of the eyes.

A Tomato has four chambers and is red. The heart is red and has four chambers. All of the research shows tomatoes are indeed pure heart and blood food.

Grapes hang in a cluster that has the shape of the heart. Each grape looks like a blood cell and all of the research today shows that grapes are also profound heart and blood vitalizing food.

A Walnut looks like a little brain, a left and right hemisphere, upper cerebrums and lower

cerebellums. Even the wrinkles or folds are on the nut just like the neo-cortex. We now know that walnuts help develop over 3 dozen neuron-transmitters for brain function. Kidney Beans actually heal and help maintain kidney function and yes, they look exactly like the human kidneys.

Celery, Bok Choy, Rhubarb and more look just like bones. These foods specifically target bone strength. Bones are 23% sodium and these foods are 23% sodium. If you don't have enough sodium in your diet the body pulls it from the bones, making them weak. These foods replenish the skeletal needs of the body.

Eggplant, Avocadoes and Pears target the health and function of the womb and cervix of the female - they look just like these organs. Today's research shows that when a woman eats 1 avocado a week, it balances hormones, sheds unwanted birth weight and prevents cervical cancers. And how profound is this? It takes exactly 9 ! months to grow an avocado from blossom to ripened fruit. There are over 14,000 photolytic chemical constituents of nutrition in each one of these foods (modern science has only studied and named about 141 of them).

Figs are full of seeds and hang in twos when they grow. Figs increase the motility of male sperm and increase the numbers of sperm as well as overcome male sterility.

Sweet Potatoes look like the pancreas and actually balance the glycemic index of diabetics.

Olives assist the health and function of the ovaries.

Grapefruits, Oranges, and Other Citrus fruits look just like the mammary glands of the female and actually assist the health of the breasts and the movement of lymph in and out of the breasts.

Onions look like body cells. Today's research shows that onions help clear waste materials from all of the body cells. They even produce tears which wash the Epithelial layers of the eyes.

Author unknown

ON THE FUNNY SIDE

Love Those Church Bulletins: Thank goodness for church ladies with typewriters. These sentences (with all the BLOOPERS) actually appeared in church bulletins or were announced in church services:

- > The Fasting & Prayer Conference includes meals.
- > The sermon this morning: 'Jesus Walks on the Water.' The sermon tonight: 'Searching for Jesus.'
- > Ladies, don't forget the rummage sale. It's a chance to get rid of those things not worth keeping around the house. Bring your husbands.
- > Remember in prayer the many who are sick of our community. Smile at someone who is hard to love. Say 'Hell' to someone who doesn't care much about you.
- > Don't let worry kill you off - let the Church help.
- > Miss Charlene Mason sang 'I will not pass this way again,' giving obvious pleasure to the congregation.
- > For those of you who have children and don't know it, we have a nursery downstairs.
- > Next Thursday there will be tryouts for the choir. They need all the help they can get.
- > Irving Benson and Jessie Carter were married on October 24 in the church. So ends a friendship that began in their school days.
- > At the evening service tonight, the sermon topic will be 'What Is Hell?' Come early and listen to our choir practise.
- > Eight new choir robes are currently needed due to the addition of several new members and to the deterioration of some older ones.

> Scouts are saving aluminium cans, bottles and other items to be recycled. Proceeds will be used to cripple children.

> Please place your donation in the envelope along with the deceased person you want remembered.

> The church will host an evening of fine dining, super entertainment and gracious hostility.

> Potluck supper Sunday at 5:00 PM - prayer and medication to follow.

> The ladies of the Church have cast off clothing of every kind. They may be seen in the basement on Friday afternoon.
> This evening at 7 PM there will be a hymn singing in the park across from the Church. Bring a blanket and come prepared to sin.

> Ladies Bible Study will be held Thursday morning at 10 AM. All ladies are invited to lunch in the Fellowship Hall after the B. S. is done.

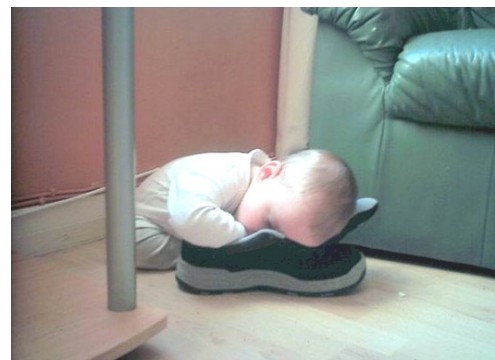
> The pastor would appreciate it if the ladies of the Congregation would lend him their electric girdles for the pancake breakfast next Sunday.

> Low Self Esteem Support Group will meet Thursday at 7 PM. Please use the back door.

> The eighth-graders will be presenting Shakespeare's Hamlet in the Church basement Friday at 7 PM. The congregation is invited to attend this tragedy.

> Weight Watchers will meet at 7 PM at the First Presbyterian Church. Please use large double door at the side entrance.

Remember when fatigue was this easy?



Lastly, we wish you the sound sleep of these children and pets.

TIP

From Chris, 2 tips:

Do what you can and let go of the rest;
&
Putting my feet up or even just elevating them slightly allows me to stay 'up, out, and about' somewhat longer. I rarely sit upright in a chair without having one or both feet elevated on part of a chair, stool, or whatever is handy – in fact I have gotten pretty creative in finding props!

We need your TIPS on how you save your energy / health during the Christmas / Holiday Season to ensure that you enjoy the day(s). Please email your TIP to:
meaocfsnews@gmail.com

Do you know someone who would like to receive our quarterly newsletter? Please call us at 1 877 632-6682 or 416 222-8820, and leave their name, address and phone number. It's only \$20 per year. OR fill out the Membership Form on the back page.

ARE YOU MOVING?

Each year several newsletters are returned to us by the Post Office because these members have moved and forgot to tell us. If you are moving, please call us on our HELP-LINE, 416 222-8820, or 1 877 632-6682, and leave us the following information: your name, new address and new telephone number. If you have an email address, please include that too. This way we'll always get our newsletter to you!

HELPFUL WEBSITES



Environmental Working Group keeps tabs on the food industry and has a very convenient list citing the dirty dozen - **the top 12 foods that you need to buy organic**. The list is continually updated - have a look at www.ewg.org.

www.dietitians.ca, Source of information on food and nutrition for Canadians.

Computerised Electro-Dermal testing for Allergies / sensitivities (foods, molds, pollens, chemicals etc.) www.redpaw.net

Dietary Supplement Information Bureau provides science-based vitamin and supplement information, news, blogs and other resources. www.supplementinfo.org

The latest in nutrition news, plus tips for staying healthy: www.nutritiondata.com

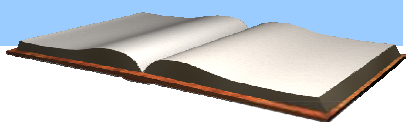
This site has both health and nutrition tips along with many other resources for healthy living. www.naturallysavvy.com

TIP

Did you know that our members receive timely email announcements about upcoming events that are of interest to those with M.E/CFS.?

We email them whenever a TV programme, Seminar / Lecture, etc. is taking place. If you are not on our email list, please email us at: meaocfsnews@gmail.com

RESEARCH



Research Findings on CFS/M.E.

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

The role in CFS of the hormone cortisol continues to attract research attention because of the link between the body's hormonal system (hypothalamic-pituitary-adrenal axis) and immune system. Cortisol, often called the "stress hormone", is involved in the body's complex response to stress, and is immunosuppressive. The suggestion is that CFS is associated with lower than normal blood cortisol levels. A recent study from the Centers of Disease Control¹ found that patients with CFS had lower cortisol concentrations in their saliva in the early morning and higher levels at bedtime, than control patients. One study found lower morning cortisol concentrations in saliva only in women.² These findings partially support earlier findings³ that urinary levels of cortisol were lower in CFS patients although, in contrast to the most recent studies, there was no difference in the normal daily rhythm. Patients with CFS behaved less well than healthy patients in producing cortisol in response to dexamethasone, but this effect was only noted when CFS patients who had a history of "early life stress" were removed.⁴ Although the consensus is that CFS patients have mildly reduced cortisol system function⁵, the problem with these studies, as can be seen from the variability of findings, is that **many different factors (including chronic illness) affect cortisol levels.**

If low cortisol is a real *problem* for CFS patients (not just an effect of CFS), **what happens when CFS patients are treated with cortisone?** In one well-designed (randomized, placebo-controlled, double-blind) study there was no beneficial effect of

low dose corticosteroid treatment of CFS patients.⁶ In a study using higher doses, some improvement in symptoms was noted, but the adrenal suppression that occurred precluded its long-term use for treatment of CFS.⁷ Recently, a California physician has used low dose cortisol in over 500 CFS patients, and claimed substantial improvement in 62% of patients.⁸ This non-peer-reviewed report was neither placebo-controlled nor double-blind, and patients had many treatments other than cortisol. Others have concluded that "cortisol replacement therapy cannot be recommended".⁵ The search continues for better diagnostic markers of CFS other than subtle changes in hormone levels, for causes rather than possible effects, and for more effective, safer and curative treatments.

Articles in the newsletter of the National CFIDS Foundation (NCF) have recently discussed research on Parainfluenza Virus-5 (PIV-5) and mentioned its links to CFS. This information has been interpreted by some as a 'breakthrough', perhaps leading soon to a vaccine or anti-viral treatment for CFS. Since we found nothing in the scientific literature on this, we contacted the NCF directly. It is a complicated and confusing story, but the bottom line is that at present there is no evidence that PIV-5 plays a role in the development of CFS.

Studies cited:

- ¹Nater et al, *Psychosomatic Medicine*, 2008;
²Nater et al, *Journal of Clinical Endocrinology and Metabolism*, 2008; ³Jerjes et al, *Journal of Psychosomatic Research*, 2006; ⁴Van Den Eede, *Psychological Medicine*, 2007; ⁵Van Den Eede, *Neuropsychobiology*, 2007;
⁶Blockmans, *American Journal of Medicine*, 2003 ⁷McKenzie, *Journal of the American Medical Association*, 1998; ⁸Holtorf, *Journal of Chronic Fatigue Syndrome*, 2008.

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GENERAL INFORMATION

WEB SITES: If you are aware of interesting M.E./CFS web sites, please let us know and we will provide a link to them.

PERSONAL STORIES: We would appreciate receiving personal stories from children/youth, adults, parents and care givers for our web site and newsletter. Your stories help others know they are not alone.

CONTACT US

Our mailing address:

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

Our HELP-LINE is:

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

Check out our [new Web Site](http://www.meao-cfs.on.ca) at:
www.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.

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