Agreement #40665071

REACHING OUT

FALL 2008

THE HOLIDAYS ARE COMING! THE HOLIDAYS ARE COMING!

(SHORT CUTS TO A MORE ENJOYABLE HOLIDAY CELEBRATION)

Those of us who have M.E./ CFS often have a difficult time getting through the Holiday / Christmas Season. This is a time when expectations of ourselves and from others are high. It's so hard to just say 'NO', and to face the disappointment it may cause. We asked our members for ideas of how they manage their health and energy during the festive season, and we thank them for the following :

Jenna:

1) Put together your standard holiday recipes into one document, with a suggested timetable. Also, make note of what people actually eat and stop making whatever doesn't get eaten.
2) Go for a simplified decorating scheme, putting up one or two things a day, and get someone else to help take it all down.

Jody:

1) Have multiple cooks and alternate whose house to gather at.
2) Soups and baked goods can be made a few days or a couple of weeks ahead of time and frozen.
3) Start looking for gifts now and consider donations to charity in lieu of gift giving.
4) The book 'One Hundred Dollar Christmas' by Bill McKibben, emphasizes the social and spiritual aspects of the holiday rather than the spending of money and could help readers get the most out of the holidays without putting unreasonable pressures on themselves.

Lucia:

Have a Potluck with everyone bringing dishes of food to share. Last year I ordered Lasagna and we also prepared Salmon, which took about 20 minutes to cook, so presto a simple meal put together.

Continued on page 2.

ALSO IN THIS ISSUE:

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO (MEAO)

REACHING OUT

is published 4 times a year by
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 INFO 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

THE ONTARIO TRILLIUM FOUNDATION

Continued from page 1

Lydia:
Have an open house where everyone comes to you for a couple of hours whenever you have your best energy, instead of running from party to party. This way you get to see everyone in one chunk of time. Have some simple snacks or make it pot luck, and make sure you have an end time so you know when you get to go lie down afterwards!

Ana:
I am the full-time caregiver for my 23 year old daughter with M.E./CFS. These are some of the things I did to save my own strength:
- only gifts for the children's generation
- no Christmas tree due to mould allergy; balls in large glass bowl on table instead
- no baking due to allergies and her not wanting temptation of empty sugar calories.
- combined my own menu items with some ordered from a store
- asked dinner guests to bring something.

We don't live in a poor society where holidays are associated with excess and feasting. With this restrained approach, I also hope to send the message of health and moderation. You can see friends and family and have fun without being overstuffed, overspent and overtired.

Thanks to our members for sharing their ideas. Here are **some other useful TIPS:**
- Use disposable plates, glasses, etc.
- Don't be afraid to ask for help
- Order gifts online; Buy Gift Cards
- Order groceries, cooked turkeys, baked goods, etc.
- Use gift bags instead of wrapping
- Give a year's MEAO membership
- Plan ahead
- **Learn to say NO.**

TIP

SHOWERS take up a lot of my energy. So when I have somewhere to go tomorrow or a lot to do, I take my shower the night before. It really makes a difference!

FROM THE PRESIDENT

Greetings everyone!

I am very pleased to be writing to the membership in this issue of ***Reaching Out.***

In our last issue, our Provincial Coordinator **Kim Dowds** reported on our two meetings with federal officials (the Health Minister's senior policy advisor, PHAC and CIHR) as well as a meeting with provincial officials (the Health Minister's senior policy advisor). Follow-up discussions to these meetings are on-going as MEAO continues to advocate for people living with M.E/CFS, some of whom also have FM and/or MCS.

Thanks to Kim Dowds, MEAO now has a new and very informative website, www.meao-cfs.on.ca. I invite all of you to visit our website and to register on the site so that you can enjoy all of the benefits that our new site can offer you. Also, with the assistance and leadership, of our new Provincial Coordinator, the Board has been very busy and active these past several months. Together, we continue to work on and plan for further advocacy work, upgrade our director's liability insurance, "clean up" our constitution and bylaws, implement a risk management review, establish and finalize an Awards Recognition Program and, most recently, we embarked on a Strategic Planning Process. Thus far, the Board met for two half-day Strategic Planning sessions; but the process is an on-going one as we try to incorporate input from stakeholders. Through this process we will develop a better sense of who we are as an Association, where we have been and where we want to go and how to best get there given our strengths and available resources. Our intent is to share some of this information with the membership at our up-coming AGM (September 20th) and thereafter provide an opportunity to individual members to offer their input in the process.

In our last newsletter, **Izzat Jiwani**, the Chair of our Awards Committee, provided information on the two newly established MEAO annual awards - the **Audrey MacKenzie Memorial Award** and the **Volunteer of the Year Award** to be presented at the AGM. If you would like to nominate someone for either of these two awards, I encourage you to do so now by calling our Help-Line (1 877 632 6682) or emailing MEAO/the Awards Chair at info@meao-cfs.on.ca.

Over the past few months, our various initiatives in trying to attract and hire a part-time Fund Development Consultant, given the limited designated Trillium funds, have all been unsuccessful. Given this situation, MEAO, in consultation with the Ontario Trillium Foundation, has offered a portion of that position to Kim Dowds. Kim is currently working part-time for the MEAO and has experience in the area of fundraising. She has now accepted this position and fundraising initiatives are now underway. If you would like to assist the Association with its fundraising projects, I encourage you to volunteer now by calling our Help-line or contacting us at info@meao-cfs.on.ca.

Lastly, I would like to acknowledge and extend my sincere appreciation to Kim Dowds and all of the members of the Board for all of the hard work, the dedication and the commitment that they have shown in working collaboratively to advance the cause of M.E./CFS as well as FM and MCS in Ontario and beyond. Their individual expertise, talents and perseverance are collectively contributing to the overall success of our Association. As well, on behalf of MEAO, I would like to extend a heartfelt thank you to all of our volunteers who continue to give of their time, energy and talents to this organization. People with M.E./CFS, their families and caregivers are truly appreciative of your involvement and contributions.

Anthony Rovito, President
The Myalgic Encephalomyelitis Association of Ontario

NEWS and UPCOMING EVENTS

MEAO ANNUAL GENERAL MEETING

Saturday, September 20, 2008,
Women's College Hospital, Main Auditorium, 1:30 – 4:00 p.m.
76 Grenville Street , Toronto

We are holding the AGM earlier than usual, in warmer weather, so as to accommodate more of our members.

PANEL OF EXPERTS to Address your Questions Regarding M.E./CFS, FM and MCS Treatment Options, and

1st Annual MEAO Awards Ceremony
AGM Meeting to Follow

FREE ADMISSION, EVERYONE WELCOME!
DONATIONS APPRECIATED
Wheelchair accessible
Scent Free Policy

NOTE: If you have questions for the panel regarding possible treatment options for M.E./CFS, FM or MCS, you are encouraged to email them to info@meao-cfs.on.ca.

EDUCATION & SUPPORT GROUP

Lead by Dr. Bested & T. Beaulne, ND
8 Sessions, 1 – 3 p.m., in Toronto
Beginning in Sept. 2008
416 283-0007

The 1st Alberta Interdisciplinary Research Symposium & Discussions

Saturday, November 8th, 2008
9:00 am - 4:30 pm
University of Calgary

For registration form and Call for Abstracts - see **www.cme.ucalgary.ca**

Public Lecture, Research Update and Clinical tips from the experts

Of interest to patients with M.E/CFS and other fatiguing illnesses, their families and the general public.

Sunday, Nov. 9th, 2008
1:30 - 4:30 pm

Speakers: Dr. Nancy Klimas, Pres. of the International Assoc. for CFS/ Myalgic Encephalomyelitis (IACFS/ME), and **Dr. Alison Bested**, MD FRCPC, a Hematological Pathologist and Acting Medical Director of the Environmental Health Clinic at Women's College Hospital, Toronto,
For registration form, please go to **www.cme.ucalgary.ca**

Women's Health Matters Forum & Expo, Jan. 16 & 17th, 2009, Metro Toronto Convention Ctre., South Building.

ADVOCACY / DISABILITY ISSUES

Encouraging Support Vs Put-Downs

As a person with M.E., I have encountered various professionals and advocates who doubted me and thereafter treated me in a demeaning manner. Such reactions from professionals and advocates often delay our acceptance of the illness and usually interfere with our adherence to therapeutic protocols. Have you personally experienced such behaviors from people in your environment? Would you, be willing to share your experiences?

The Association would like to know if this is a significant problem for our population and how prevalent it may be. Your information would serve as the basis for a possible research proposal and perhaps a more in-depth survey in the future.

If this is an area of concern to you, you are strongly encouraged to now share your personal experience/frustrations with MEAO staff by forwarding an email to: Staff at MEAO at www.meao-cfs.on.ca.

ASK A LAWYER

What can I do if my claim for Long Term Disability Benefits (LTD) is declined by an insurance company?

By Allan M. Kaufman

This article provides the pertinent details of my client's claim against an insurance company for Long Term Disability ("LTD") Benefits. The purpose of this article is to assist you to learn what to do if your claim for these benefits is declined by an insurance company. Although my client has Fibromyalgia, the following information would also apply to those who have CFS.

My client worked for an employer who provided its employees with a policy of LTD insurance. My client paid part of the premium for that insurance coverage, and the employer paid the balance of the premium. My client never gave much thought to the existence of the policy, since she had hardly ever been off work sick during a long period of continuous employment. Rather, she relied on the fact that the policy would be there for her if she ever became so disabled that she could not continue to work at her job. In other words, this policy was what Canadian courts have referred to as a psychological "peace of mind" policy.

After many years of loyal employment for the same company she became unable to perform her job, due to an undiagnosed medical impairment. Her doctors would soon diagnosis it as fibromyalgia. She was off work on short term disability for 6 months. Her LTD policy stipulated that if after that period of time she was still unable to perform *her own occupation* for her employer, she would be entitled to collect monthly LTD benefits at about 60% of her regular salary for up to 24 months. In order to continue collecting disability payments after the end of that 24 months period, she would have to demonstrate that as the result of her disability she was unable to perform "*any occupation*" for which she was reasonably qualified. This is standard wording under most disability insurance policies in Ontario today.

My client submitted her application for LTD benefits to the insurance company, together with medical information from her doctors, which all confirmed that she was unable to return to her own occupation at the company. Thirty days later she was stunned to learn that her application had been rejected for failing to submit sufficient medical verification of her disability. The policy that she had counted on as a safety net - to be there when she needed it – had just been pulled out from under her.

The insurance company employee who had made that decision to reject her application was a disabilities claims analyst – the lowest ranking person on the hierarchy of disability claims personnel at the insurance company. Two years later we would learn that he had made his decision to reject her initial application without the benefit of any medical advice from the insurance company's in-house medical staff, or the advice of the various managers/superiors to whom he reported.

Beware that the insurer's internal appeal process may be a sham

My client, who did not have a lawyer at this time, exercised her right to appeal within 90 days to the insurance company for reconsideration of her claim. She submitted additional medical information to them to substantiate her fibromyalgia disability. The insurance company declined her appeal.

It was only when I commenced a lawsuit for her against the insurance company (almost two years later) that we were able to discover, to her surprise, that their 90 day appeal process was not much of a process at all. My client had expected that the appeal that she filed with them, and the new medical documentation that she submitted with it, would be carefully examined by a committee of the insurance company's own medical experts. Instead, it turned out that the same low ranking disabilities claims analyst who had first rejected her application, was the person who made the decision to reject her appeal as well. He did so largely without the benefit of any of the more senior medical personnel. In other words, her appeal was being decided by the same person who had made the decision against her in the first place. *This is hardly in conformity with Canadian appeal standards.*

On one of her many subsequent appeals to the insurance company for reconsideration of her claim, she provided lab results that showed the level of mercury toxicity in her blood was extremely high. The disability claims analyst was unsure what to deduce from these lab results. So, for the first and only time he sought out the opinion of the in-house doctor. We would later ascertain, however, *that even before that doctor had provided his reply*, the disabilities claims analyst - in his haste to reject my client's claim – had proceeded to advise my client in writing that her appeal had been rejected.

Beware of insurer's who "move the goalposts"

My client persisted by continuing to submit a total of seven separate appeals (long after the 90 day appeal deadline had past). Each time that my client submitted more reports from her doctors, the insurance company would state that they were "insufficient" - that she had failed to provide sufficient medical documentation of her disabling condition. This is a very disconcerting ploy that insurers can use. I refer to it as "moving the goalposts." In other words, my client would never know how much medical information would be "sufficient", since this was a highly subjective decision that only the insurance company would make. This company played this "game", notwithstanding that all of the medical reports submitting by my client's doctors substantiated that she was unable to return to her job at the company. Her fibromyalgia condition, which does not show up on an X-ray and cannot be readily established to the satisfaction of insurance companies, was apparently not deemed "sufficient" to qualify her for disability coverage – notwithstanding that her medical condition was so debilitating that she could not work.

The insurer's lack of medical documentation to the contrary

When my client finally sued the insurance company as a last resort, we discovered for the first time that it had no medical documentation whatsoever on its file to undermine any of her own medical reports; nor had it exercised its right to obtain its own independent medical examination ("IME") of my client's medical condition.

It was only after she finally sued the insurance company that it finally saw fit to obtain its own IME's on her. Ironically, this company's IME's - from specific doctors hand-picked by the company - expressly supported my client's claim to be disabled! Yet even when faced with such daunting evidence, this insurance company continued to allow the litigation to continue.

Beware of mediation meetings with the insurer

Having received IME's that supported my client's case, the insurance company must surely have realized that it had a problem case on its hands. This may explain why it was very eager to proceed to a mediation meeting with my client and me as quickly as possible, while the lawsuit continued. My client mistook the company's eagerness to mediate as an indication that they would finally pay her a fair settlement of her claim, or reinstate her onto disability coverage. Throughout the entire three years that had expired from the date of her application to the insurance company, to the date of that mediation meeting, she had not received one cent from the company. However, after putting my client through a protracted and highly stressful full day mediation meeting at which the company continued to deny that she had been unable to return to her job, it finally made her a “low ball offer” at the very end of the all-day mediation meeting. The insurer’s strategy was no doubt to take advantage of my client’s heightened fatigue and impoverished financial condition, in order to entice her to accept a lesser sum that she was entitled to by law. My client and I rejected that offer, even though it meant walking away from a larger lump sum cheque than she had ever seen in her lifetime.

Final resolution

More than three months after that unsuccessful mediation meeting, the insurance company finally agreed to increase its offer substantially to my client – but only after I had prepared the court documentation to set the case down for Trial in Ontario Superior Court. My client and I accepted that offer, and her lawsuit was withdrawn.

Lessons learned

I am writing this article so that other fibromyalgia claimants for LTD insurance will be able to learn the following lessons:

- If your claim for LTD insurance benefits is declined by the insurance company, do not walk away from the claim.
- Understand that the insurer will often inform you that the medical documentation of your claim is “insufficient.” This is all part of a process, so as to justify their rejection of your claim – in the hope that you will walk away.
- However, do not expect the insurer to change its mind on the status of your claim just because you have invoked the insurer’s own internal appeal process.
- If you have an “invisible disability” such as fibromyalgia, you will most likely have to sue the insurer before they change their mind about your claim, and in order to ensure that their senior personnel pay proper attention to your claim.
- If you undertake a lawsuit, do not jump at the first offer of settlement that the insurer makes to you. Rather, in order to prevail you and your lawyer must have the necessary perseverance for a protracted fight with the insurer. This is no doubt very difficult to do when you are medically incapacitated at the same time.

Allan M. Kaufman is an employment law lawyer. He can be contacted at: 416-364-1068, or at: a.kaufman@bellnet.ca

TIP

Being involved in a lawsuit is very stressful at the best of times. For those of us with M.E./CFS, it can be a serious threat to our health. One way of reducing the stress is to have someone you trust (e.g. a friend or family member) go through the whole process with you, such as reviewing the documents from your lawyer, attending each meeting and helping to make the decisions along the way. A person with business experience would be ideal.

YOUR HEALTH

Flu Vaccination and Chronic Fatigue Syndrome

Printed with permission from ***Dr. Alison Bested***

Greetings! As we enter the flu season, I am writing to you about the flu vaccine as my patients with Chronic Fatigue Syndrome (M.E.) often ask me whether or not they should have it. This depends on a number of factors:

- If you are allergic to eggs, you should not get a flu shot as the vaccine contains egg protein.
- If you had the vaccine in the past and did not have any problems with it, then probably you would tolerate it this time.
- If you have never had it before, then the first question is whether you need it. If you are totally isolated in your own home and your caregivers and family are very aware that they should not come to visit you or care for you if they are ill, then your risk of exposure is minimal.
- If you go outside your home, then you could take the following precautions: Take a disposable paper mask with you if you have to visit public places, e.g. doctors' offices, churches, stores, etc. If anyone is coughing then put your mask on immediately so that you do not breathe in viral particles. Try to keep your hands off your face, especially after coming into contact with another person (e.g. shaking hands) or an object just used by another person (e.g. a pen), so that you do not transfer viruses from your fingers to your eyes and nose. These are easy entry routes for viruses into your body.

If you decide you would like to be vaccinated, then I recommend starting with an injection of one third the usual adult dose. If there are no side effects, then the same dose can be repeated in a month's time, and the same again after one further month. The reason for this is that physicians specializing in CFS, including myself, have reported cases of flu symptoms in some patients with CFS for 4 or more weeks after the full dose of flu vaccine has been given.

It is unknown whether patients with Fibromyalgia or Environmental Sensitivities / intolerances are more prone to such a response. However, overlap of these conditions with CFS has been reported in the medical literature, and so caution is probably wise.

Having symptoms for this length of time is not normal after a flu shot. It is called an adverse vaccine event and needs to be reported to the Department of Health. There is an Adverse Vaccine Event Form that must be filled out by the doctor. Each region has its own Department of Public Health (in Toronto, 416 392-1250).

All the best to you and yours,

Dr. Alison Bested,
EHC Staff Physician and Hematopathologist

Editor's note: Some additional tips for the winter season:

- ***Wash your hands with warm, soapy water immediately upon returning home after being out among the general public***
- ***Wash your hands before eating finger foods in a restaurant***
- ***Magazines in a doctor's office and door knobs in places outside of your home are just some of the places that are covered in germs; so carry a package of 'Wet Ones' or an antibacterial wash***
- ***Because some of us have shallow breathing, if you do get a cold, remember to do deep breathing exercises (3 deep breathes at a time) and cough up the sputum.***

Sharing our Experiences:
DENIAL and M.E.

By Maries St. Paul

Denial is the refusal to acknowledge the existence or severity of unpleasant external realities or internal thoughts and feelings. Chronic or terminal illnesses may encourage denial. People with such illnesses may think, "It's not so bad; I'll get over it," and refuse to make any lifestyle changes. Others may be in denial when they say, "I'm fighting this illness as a way of getting over it", and they too refuse to take the steps necessary to improve their health.

Denial comes in many forms. As human beings, it is likely we have been in denial about something – our relationships, our behaviour, our health, our family, etc. We all want everything to 'be fine'. We have Denial in order to keep us from pain. For those of us with M.E./CFS, Denial can often worsen our condition: we ignore our body's need for rest; we do not monitor our daily activities and do not schedule our day to include rest periods throughout. We are in Denial when we try to keep up with our friends and family who do not have the illness. Living with an illness that others, especially doctors, do not accept makes it all that much harder to accept for ourselves.

How do we know we are in denial? If you have M.E./CFS, these following examples may help you to determine this for yourself:

Simple Denial: Denial is one of the biggest challenges to someone who has just come down with this illness. Simply denying you have M.E./CFS, especially after receiving the diagnosis that you have the illness. Many of us find it very hard to accept having an illness for which there is no cure. 'I know that if I try hard enough, exercise enough, medicate enough, I will get over this!'

Minimizing: is admitting the illness to some degree, but in such a way that it appears to be much less serious or significant than it actually is.

Examples of this: ignoring your body's need to rest by telling yourself that you've already had one rest today and that is all you require; eating foods that worsen your symptoms; paying little or no attention to your needs for a living space / bedroom that is quiet and calming.

Blaming: is maintaining that the responsibility for taking better care of yourself lies somewhere else.

Examples: 'my doctor doesn't understand so why should I try?'; using your husband / family as an excuse for overextending yourself in household chores; disregarding your need to rest because you want to keep up with your friends.

Bargaining: is cutting deals or setting conditions for when things will be suitable to deal with the problem.

Examples: 'I will take better care of myself / eat healthy foods / get more rest once this happens….'

Passivity: is ignoring the situation, or being its victim.

Example: 'I'm too sick to take care of myself.'

Denial is automatic; and not usually a matter of deliberate lying or willful deception. The denial system distorts our perception and impairs our willingness to accept we are ill. **Acceptance of the illness does not mean giving in or giving up**. **But as long as we fight this illness, we cannot accept it, and until we accept it, we are not able to take the steps needed to get better.**

M.E./CFS is a journey we take. **It doesn't have to be a bad place, just a different one from where we thought we were headed.**

Some recommended web sites:

http://www.arthritis/ca/tips - click on 'Dealing with Emotions' in purple box on right side of web page > discusses the emotional difficulties of dealing with a chronic illness.

http://www.cfidsselfhelp.org/archive_emotions.htm – CFIDS Self Help section which talks about the emotional challenges of a long-term illness.

http://www.ptsdhealing.net/ptsd%20book/ptsdDenial.htm - general inform. on Denial

http://www.sportsmansarticleresource.com/Article/The-Role-of-Denial-in-Chronic-Pain-Managament/195 - Discusses the role of Denial in chronic pain management.

DENIAL AND VALIDATION

Poem by Christiane Garcia, November 2007

No stranger to fatigue and to pain,
I learned long ago to grin and to bear.
People I cared for were sick and in pain.
My insignificant complaints could never compare?

I denied what I felt and I learned not to need;
to hide my true feelings; to want what I'm given. And in silence,
I screamed 'Is my mind unstable'?
I learned to be invisible;
Not to count on anyone.
I believed my own mantra.
I was not to be cared for.

I believed do for others and you will heal; so I took on the world.
I excelled as a doer but I felt an imposter.
I fooled everyone, even me, for a while!
I denied my problems until I could bear it no longer.

I worked on my childhood, my life and my family.
I got to know Freud, Maslow and Rogers.
Yet, the problems persisted.

I tried to make sense of my myriad of symptoms so vague and so common!
Scanning books and the net,
Dragging and haggard;
I researched diseases.
I sought out solutions.
I saw specialists.
I took medication and learned meditation; but still,
I was told just to grin and to bear it.

A doctor once told me
I'm a high maintenance patient.
57 symptoms apparent but no positive lab tests!
Infections, accidents and infertility too,
responsibilities and losses took their toll.
So, in bed for 4 months unable to move;
I remained with my head on the pillow not as planned.
I ignored all the signals.
I pushed even harder.
Several jobs I did lose;
I was unable to deliver!
With memory loss and unable to walk
I was told once again nothing's wrong.
I believed I was crazy; but,
I fought back again and
I tried to push harder.

My adrenaline jolts I never regained.
Yet, I did what I knew how to do:
Push harder till I crashed once again!
I longed for validation, comfort and care; and I searched for someone to listen; but ask - I didn't dare!
Until finally too much was too much,
My body said stop.
My brain said not much.
My emotions were raw.
In desperation, I gave in.
I wrapped my arms around my aching body and I cried myself to sleep.

I was diagnosed and undiagnosed and re-diagnosed.
I was labeled "difficult" and "one of those patients'; and then, I found help.
I am validated.
I know I'm not crazy.
I can face my challenges.
I have hope.
I have tools.
As I learn to pace and what foods my body tolerates;
I ease my pain and improve my sleep.
And lo and behold!
When it no longer matters,
I now test positive to help validate.
I believe life challenges us with what we can handle.
So now I am given the opportunity to be what I always wanted to be.
Art is my comfort, my hope and my answer.
Who knows what will spurt forth?
I can only ponder and wonder!

The MEAO's INFO LINE – Our Volunteers are Listening

By Suzanne Mossman

The MEAO's Help-Line was officially established in 1999. Its early development in 1994 was made possible through the generosity of an anonymous individual who paid for its costs. On August 12, 2008 the MEAO's Board of Directors changed the name of the Help-Line to the **INFO LINE**, in order to better define the purpose of this service.

The INFO LINE was created to provide information and assistance to those who have M.E./CFS. Individuals would call the Association's toll free or local phone number, leave a message with their name and information and an INFO LINE Volunteer would call them back within a short time frame to discuss what oftentimes could be a confusing and bewildering medical condition.

It is important to note that the INFO LINE Volunteers, past and present, share a commonality with the callers they speak with – they too have M.E./CFS and are struggling right alongside them. A big **THANK YOU** goes out to all past and present volunteers for their generosity and compassion!

There has been substantial growth of the INFO LINE and the number of calls has increased. We presently have 5 INFO LINE Volunteers who are allocated specific days of the week to pick up messages and to respond to callers within a 24 hour time frame. On occasion it may take a little longer to gather information given the complexity of the request. Individuals call the INFO LINE for various reasons, e.g. the name of a doctor, specialist or lawyer in their area, or a local support group they can attend. They also call to request an Adult or Youth information package which the MEAO will mail out. Others call to talk; looking to find an empathetic ear of a Volunteer; the INFO LINE Volunteers however cannot provide Crisis Intervention. The INFO LINE Volunteers are available and responsive to answer all calls seven days a week.

As the MEAO continues to grow, so do the hopes and ambitions for the future of the INFO LINE and the services it provides. Once our future office is in place, the Association hopes to implement a call centre wherein INFO LINE calls will be picked up from a central location from a live individual. To contact the INFO LINE you may call: 416-222-8820, or toll free 1-877-632-6682.

Photos: Two of our wonderful INFO LINE Volunteers.

ON THE FUNNY SIDE

A man and his wife were awakened at 3:00 a.m. by a loud pounding on the door. The man gets up and goes to the door where a drunken stranger, standing in the pouring rain, is asking for a push.

'Not a chance,' says the husband, 'it is 3:00 in the morning!' He slams the door and returns to bed.

'Who was that?' asked his wife.

'Just some drunk guy asking for a push,' he answers.

'Did you help him?' she asks.

'No, I did not, it is 3:00 in the morning and it is pouring rain out there!'

'Well, you have a short memory,' says his wife. 'Can't you remember about three months ago when we broke down, and those two guys helped us? I think you should help him, and you should be ashamed of yourself!'

The man does as he is told, gets dressed, and goes out into the pounding rain.
He calls out into the dark, 'Hello, are you still there?'

'Yes,' comes back the answer.

'Do you still need a push?' calls out the husband.

'Yes, please!' comes the reply from the dark.

'Where are you?' asks the husband.

'Over here on the swing,' replied the drunk.

SPELLING CHEQUER ???

Eye have a spelling chequer
It came with my pea sea
It plain lee marques four my revue
Miss steaks eye kin knot sea.

Eye strike a key and type a word
And weight four it two say
Weather eye am wrong oar write.
It shows me strait a weigh.

As soon as a mist ache is maid
It nose bee fore two long
and eye can put the error rite.
Its rare lea ever wrong.

Eye have run this poem threw it
I am shore your pleased two no
Its letter perfect awl the weigh
My chequer tolled me sew.

Sauce unknown.

FROM OUR KITCHEN TO YOURS

Autumn Soup

(a tasty Immune Booster; makes 8-10 servings)

Ingredients:
2 cups green beans, cut *(fibre and vitamin source)*
2 cups carrots, sliced *(rehydrating, potassium source)*, or you can substitute with any other root vegetable
1 large onion, chopped *(antibacterial, antiviral)*
1 leek, white part only, chopped *(antibacterial, antiviral)*
4 cloves garlic, minced *(antibacterial,*

antiviral)
1 cup celery, sliced *(fibre and vitamin source)*
3/4 cup red kidney beans *(potassium source)*
4 dried or fresh shiitake mushrooms, sliced *(immune stimulant)*
1/4 Tsp. each of basil, parsley, tarragon, sage, a pinch of cayenne,
1 or 2 whole bay leaves, and / or any other herbs and spices to taste that you might like to add *(antibacterial)*
1 lb. firm tofu, cut into small cubes *(protein source)*
1-2 Tbs. white miso paste *(alkaline, rehydrating)*
1 cup quinoa *(fibre source)*
2 Tbs. olive oil
8 cups chicken broth
Optional: 4 or 5 astragalus root sticks *(immune stimulant, antiviral)*
or 2 - 4 Tsp. of the pounded root form of this herb, put into a spice pouch for cooking.

Directions:
-Saute onion, leek, and garlic in oil in a large stockpot until softened.
-Add broth and bring to a boil.
-Add vegetables (excluding celery) and astragalus root.
-Simmer covered for 30 minutes.
-Add tofu and simmer covered for an additional 20 minutes.
-Add herbs, celery,and quinoa, and simmer covered 10 minutes.
-Remove from heat. - Remove astragalus root and bay leaves.
-Stir in miso paste to taste.

I selected this recipe because it's just what we need when the cold and flu season comes upon us, and because it can be made into large batches and frozen for future use.
Enjoy and be fortified!   Mary Lou

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

http://environmentalhealthandsafetyoffice.dal.ca/radiatio_7455.html - Lists scent-free products.

http://lesstoxicguide.ca/index.asp?fetch=usage – Guide to Less Toxic Products

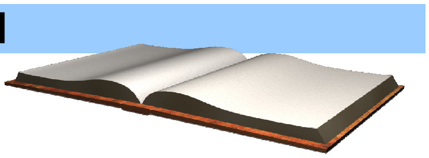
www.cosmeticsdatabase.com - An excellent database and safety guide for cosmetics and personal care products. All products are rated on a 0-10 hazard level.

www.allnaturalbeauty.us - Designed for the individual who may have multiple chemical sensitivities and is looking for healthy beauty alternatives.

http://creatinghealthybeauty.com - Discusses the dangers lurking in cosmetics and formulas to make your own all natural beauty products.

www.hennaforhair.com - Discusses replacing harsh hair colouring techniques with the natural alternative, henna.

RESEARCH



Research Findings on M.E./CFS

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

Should people with M.E./CFS exercise, and if so, how much and in what way?

The Cochrane Collaboration, a collaborative evidence-based consensus process that guides medical practice, recommends that physicians implement graded exercise therapy for CFS patients, using cognitive behavioural principles.[1] "Cognitive behavioural therapy" is an approach that assists people to re-evaluate concepts related to their illness. "Graded" exercise therapy, as described by the Cochrane Collaboration, advises patients to continue exercising at the same level even when they develop symptoms in response to the exercise. There is however disagreement as to how helpful these approaches are, since almost all CFS patients know that over-exertion can make symptoms much worse. In addition, the evidence is also conflicting because trial groups in which these recommendations have been assessed have been small and the methods sometimes questionable.

More recent studies have suggested that "pacing" exercise is a far more successful approach. This involves reducing or even stopping exercise depending on symptoms, and only increasing exercise levels (intensity, duration) once a person can cope with current increased exercise.[2-4] A major well-designed study ("the PACE trial") is underway in the United Kingdom to examine these issues.[5] 600 patients who meet diagnostic criteria for CFS are being recruited into a randomized trial of 4 treatments. The treatments are: 1. Standardized specialist medical care (SMC); 2. SMC + adaptive pacing therapy; 3. SMC + cognitive behavioural therapy; 4. SMC + graded exercise therapy. The outcome will be assessed after 12, 24 and 52 weeks. The assessment of these standardized treatments in such a large number of patients should finally answer these questions in a way that is statistically valid.

Defining the basis of the fatigue experienced by CFS patients is the "Holy Grail" of CFS research, since it should lead to improved diagnosis and treatments. Increasingly, the focus is on dysfunction of *mitochondria*, which are the tiny but vital structures found in every cell that produce the energy packets that cells require to function. Ongoing work in Belgium supports the concept that post-viral persistent immune dysregulation at the level of the cell increases ribonuclease activity that in turn breaks down mitochondrial RNA, and thus leads to loss of their enzymes.[6] A recent study using microarrays also identified changes in genes involved in mitochondrial oxidative phosphorylation as being typical of patients with CFS.[7]

These findings link to the question of exercise. Can CFS patients be guided to use very carefully paced exercise to gradually increase the activity of mitochondria in their cells and thus reverse at least some of the changes of this illness? The PACE study may answer this important question.

Studies cited:
[1]Price, Cooper, Cochrane Database Systematic Reviews, 1998; [2]Coutts et al, Psychosomatic Research, 2001; [3]Walkman et al, Medical Journal of Australia, 2005; [4]Nijs et al, Journal of Rehabilitation Medicine, 2008; [5]White et al, BioMed Central Neurology, 2007; [6]Nijs, Fremont, Expert Opinion in Therapeutic Targets, 2008; [7]Saiki et al, Molecular Medicine, 2007.

Kelli-Ann Woulfe

DISABILITY CLAIM DENIED?

Kelli-Ann Woulfe's disability case settled successfully after she was turned down by several law firms and after much bullying from her insurance company.

"After my surgery, I tried to go back to work - against my doctor's advice. But I just couldn't do my job any more."

"So I applied for disability benefits. I couldn't believe it when they turned me down! I was very sick, as well as depressed and broke.

"My case was deemed to be without merit by several law firms. Then I found David Share Associates. They were a Godsend. The settlement allowed us to pay off our mortgage and has enabled me to live at home with dignity."

If your disability benefits have been wrongly denied, call 416-488-9000 or Toll free 1-888-777-1109. You will receive a Free Booklet 'Benefits Denied - What To Do When Your Insurance Company Denies Your Claim' by David Share.

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GENERAL INFORMATION

Did you know that our members receive email announcements about upcoming events that are of interest to those with M.E./CFS? We email them whenever a TV programme, Seminar, etc. is taking place. If you are not on our email list, email us at:: **meaocfsnews@gmail.com.**
If you know of an event that may be of interest to our members, please call us at our INFO LINE number below. THANKS!

CONTACT US

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

Our INFO 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** 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.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
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