Agreement #40665071

REACHING OUT

Spring 2008

INCOME TAX TIME!

Free Income Tax Preparation
Revenue Canada will be offering free Clinics to assist individuals who have low income in completing their Income Tax Return.
To obtain the locations of the Clinics, please call Revenue Canada at the end of January: **1-800-959-8281, TTY: 1-800-665-0354** , or visit their web site at **www.cra.gov.ca**
Click on "Taxes" then "Individuals" then "Ask about your Tax Return" then, "Community Volunteer Income Tax Program**".**

Federal tax credits, deductions and exemptions:
We have compiled some information for those of you about to prepare your income tax return. Understanding that some of you may not have access to a computer or the internet, we have listed telephone numbers where possible.
The following information is from the booklet entitled *Services for People with Disabilities* published by the Government of Canada. Only a few of the available services are listed in this article. For the complete guide, to view or download, go to:
http://servicecanada.gc.ca
Click on "I am A Person with a Disability", or to order one **Call 1-800-622-6232**
TTY: 1-800-926-9105.

The **Disability Tax Credit** (usually called the disability amount) reduces the income tax that persons with a disability have to pay. To be eligible for the disability amount you must have a *severe and prolonged impairment in physical or mental functions*. If you don't need to use some or all of the tax credit because you have little or no income, you may be able to transfer all or part of it to your spouse, common-law partner or other supporting person.
To get the credit, you must complete a **Disability Tax Credit Certificate (Form T2201),** have it signed by a qualified medical doctor, optometrist, audiologist, occupational therapist, psychologist or speech language pathologist, and return it to the Canada

ALSO IN THIS ISSUE:

Revenue Agency.

If you have been previously refused the Disability Tax Credit, continue to apply for it. Send the completed form to your CRA tax centre. To find your tax centre, refer to **www.cra-arc.gc.ca/wheretofile.**

If you have been on CPP Disability payments, request Canada Revenue Agency to back date your Disability Tax Credit to 1996, the year it was established.

You can submit Form T2201 any time of year or attach it to your income tax return.

You are responsible for any fees that a qualified practitioner may charge to certify Form T2201. These fees are not covered by the CRA or by provincial medicare plans, but you may be able to claim them as an eligible medical expense on line 330 of your tax return.

If you receive a disability pension, do you qualify for the disability amount? The fact that a person receives other types of disability pensions or insurance benefits does not necessarily mean that the person qualifies for the disability amount. Other types of disability pensions or insurance benefits have other purposed and different criteria, such as an individual's inability to work.

For more information about the disability amount, go to:

www.cra.gc.ca/disability or

Call 1 800 959-2221.

If you are under 18 and qualify for the Disability Tax Credit, you may be eligible for the **Child Disability Benefit**. The benefit, of up to $166.66 a month, is tax-free. The Child Disability Benefit is a supplement to the Canada Child Tax Benefit and Children's Special Allowance payments. It helps low-income and modest income families who care for a child with a severe and prolonged mental or physical impairment. To apply, families must obtain a signed Disability Tax Credit Certificate and the Canada Child Tax Benefit application form (RC66) for the child.

Canada Child Tax Benefit enquiries:

1-800-387-1193 TTY: 1-800-665-0354

To order Forms T2201 and RC66 call

1-800-959-2221 TTY: 1-800-665-0354

http://www.cra.gc.ca/disability/

To get the forms you need, click on

http://www.cra.gc.ca/forms/

Use the **Benefits Online Calculator** to get an estimate of the amount of **GST/HST credit** you may be entitled to receive:

http://www.cra.gc.ca/benefits-calculator

Use the Benefits Finder to learn about the full range of federal and provincial/territorial programs for people with disabilities, such as hearing devices, visual devices, special services at home, rehabilitation services and more. **http://www.canadabenefits.gc.ca**

If you have **medical expenses** associated with a disability, you may be able to claim them to reduce your taxes. Or, a supporting person such as your spouse, common-law partner or other family member may be able to claim them. Some examples, of allowable medical expenses are:

- payments for certain assistive devices
- costs of an attendant who cares for you.

In addition, you may be eligible for the **Refundable Medical Expense Supplement** if you have low income and high medical expenses.

Many goods and services used by people with disabilities are exempt from the goods and services tax /harmonized sales taxes (GST/HST). Some examples are health and personal care services, programs like 'Meals on Wheels", guide and hearing-ear dogs, some recreational programs and camps, and medical devices and supplies including wheelchairs, walkers, hearing aids, patient lifters and specially designed clothing.

GST/HST Information

1-800-959-5525, TTY: 1-800-665-0354

To order forms:

1-800-959-2221, TTY: 1-800-665-0354

http://www.cra.gc.ca/disability/

To get forms you need, click on

http://www.cra.gc.ca/forms/

FROM THE PRESIDENT

With winter almost gone, we now look forward to the arrival of spring and the kaleidoscope of colours that it brings as new plants and flowers magically grow and bloom. We, at The Myalgic Encephalomyelitis Association of Ontario feel very similar about our Association as we bring on board additional staff (a part-time fundraiser) and as we, along with our Provincial Coordinator, Kim Dowds, begin to streamline, strengthen and expand our current programs and initiatives and embark on new ones so as to better advocate for and service all of those who suffer with M.E./CFS.

The Board of Directors is very excited about the talents and expertise that Kim Dowds has brought to MEAO and we are most impressed with the quality of work that she has been doing on a number of our files/initiatives. One such file is the re-vamping of our website. The new website is being built off-line and should be ready for launch within the next month. When the new website is, in fact, ready we will ask Kim to write the "introduction/launch" article. As Kim becomes more familiar and actively involved with other Association files, she will be reporting to you on specific initiatives through our newsletter.

Beginning with the 2008 Summer issue, Kim will also be writing the letter "From the Provincial Coordinator". This new column will thereafter appear alternatively with the letter "From the President".

In reading the current issue of ***Reaching Out***, you will notice that MEAO has now begun to make advertising space available in our quarterly newsletter. The revenue generated from this advertising will be used to offset the costs of printing and distributing our newsletter. Although our Association appreciates the financial support that advertising generates, MEAO does not, in any way, endorse the products and services advertised within our newsletter. If you are aware of specific products and services that may be of interest to our readers, we suggest that you make the providers of such products and services aware of the opportunity of advertising in our quarterly newsletter.

As I write this letter to the membership, more snow accumulates outside my window. However, I know that spring is "just around the corner" and, as that new season does arrive, I wish for all of you an increased level of energy so that you may truly enjoy all of spring's wonders!

Anthony Rovito, President
The Myalgic Encephalomyelitis Association of Ontario

NEWS and UPCOMING EVENTS

Durham Health Matters Expo, Sunday March 2, 2008: The M.E. Association will be featured at the upcoming Durham Health Matters Expo. The expo is a health and wellness show featuring Durham Region health products and services. The M.E. Association has been selected as one of the benefiting charities and will receive a share of the proceeds from tickets sales. Visit us at our booth! The show will run from 10:00 a.m. to 5:00 p.m. at the Ajax Convention Centre, located right by the new Hilton Hotel at Salem Rd. just north of the 401. More details at: **http://www.showsdurhamregion.com/event_view.php?id=181**

CFS Documentary: The Downtown Toronto Fibromyalgia Group will be showing the acclaimed documentary about ME/CFS/CFIDS called "I Remember Me" on **Wed. March 12, 2008**, at St. Andrew's United Church, 117 Bloor St. E., Toronto, from 7 – 9 p.m. Members of the CFS community are welcome. Admission is free, but voluntary donations are appreciated.

May 12th is M.E./CFS Awareness Day - Help Us Get the Word Out!

The M.E. Association of Ontario will be launching an awareness campaign throughout the month of May to highlight M.E./CFS Awareness Day on May 12th. The campaign will include outreach to all media outlets in Ontario - dailies, weekly newspapers, community papers, radio, television, magazines, as well as ethnic and cultural media outlets. In addition, this year our campaign called ***"Do You Know M.E.?"*** will highlight personal stories of people living with M.E./CFS.

We need your help: Are you willing to share your M.E./CFS story with the media? We are creating a list of those willing to tell their own personal story of living with M.E./CFS. Please call the Help Line, **416 222-8820 or 1 877 632-6682** to be added to the list. We are looking especially for people who speak other languages. If a media outlet in your area is looking for a personal story during May, we will contact you to see if you are available and able to speak with the journalist. Your information will not be shared with the journalist until you give us permission.

We will also be launching our new website in time for the campaign and we will have a ***"Do You Know M.E.?"*** section of the website where many personal stories will be shared. To submit your personal story for consideration for the website please email it to: **info@meao-cfs.on.ca .**

The Catholic Women's League of St. Joseph's Parish hosted a free lecture on **Jan.14th**, given by Dr. Alison Bested. She spoke on raising awareness about CFS and Fibromyalgia. Afterwards, Dr. Bested signed copies of her book 'Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia'. The Catholic Women's League of Canada presented and passed Resolution 98.06 Myalgic Encephalomyelitis (Chronic Fatigue Syndrome) to urge the federal government to provide funding for research to find the cause and a cure for ME/CFS.

Dr. Bested signing her books at St. Joseph's Parish Hall.

Women's Health Matters Forum & Expo, January 18, 19 2008, Metro Convention Ctre: MEAO was invited to exhibit with the Environmental Health Clinc. This year's theme: linking environmental impacts and women's health issues. It provided invaluable insights with the goal of optimizing health for ourselves, our families, friends, community and the environment. Dr. Deva Davis, head of the first Centre for Environmental Oncology in the U.S., was one of the main speakers. Nancy Bradshaw, from the EHC, gave an excellent talk on how your work and home environment can impact you. Many thanks to Diane and her volunteers for their hard work at the show.

ADVOCACY / DISABILITY ISSUES

By Margaret Parlor

Supreme Court of Canada to hear ME/CFS Case: Honda vs. Keays

On February 20, 2008, the Supreme Court of Canada will hear the case of Keays vs. Honda. This is a case of an employee with Chronic Fatigue Syndrome who was fired by his employer. Mr. Keays sued Honda for wrongful dismissal and for breaches of his human rights. The trial judge decided in his favour, as did the Court of Appeal. Honda then appealed to the Supreme Court of Canada.

The Supreme Court will consider the relationship between employees and employers. It will look at the best way to compensate victims and punish perpetrators of bad faith conduct, discrimination and harassment. This case will give the Court the opportunity to reconsider one of its decisions from thirty years ago that has prevented lower courts from providing compensation for discrimination and harassment.

The Supreme Court has granted “intervener” status to a number of organizations including the National ME/FM Action Network. In granting intervener status, the Supreme Court is recognizing the importance of the case to the M.E./FM community.

Huge credit goes to Hugh Scher, the lawyer representing Mr. Keay. Mr. Scher's practice focuses on employment, insurance and human rights law, especially in the area of disability rights. He is legal advisor to the Myalgic Encephalomyelitis Association of Ontario. He has taken on this case at considerable personal financial risk and has achieved remarkable results to date.

Special thanks go Chris Paliare, Andrew Lokan, and the law firm Paliare Roland of Toronto who are representing the National ME/FM Action Network at the Supreme Court of Canada.

While the hearing is scheduled for February 20 in Ottawa, the decision is not expected for some months afterwards. We will keep you posted.

Life is not measured by the breaths we take, but by the moments that take our breath away.

ASK A LAWYER

I’ve made an application for CPP Disability Benefits. What do I do if my application is denied?

By Greg Neinstein, B.A., LL.B.

Your CPP disability applications may be denied for a number of reasons, but it does not mean that the CPP will not reconsider your application.

If you disagree with the denial of benefits, you can ask for the decision to be reviewed or reconsidered by Social Development Canada (SDC). It is crucial to be aware of the time limits associated with a reconsideration request. A reconsideration request must be in writing and the letter must be received by SDC within 90 days of receiving the denial letter. It is not necessary to include additional medical information with your reconsideration request. Nonetheless, it remains your responsibility to provide all information required to support your case, including any new medical information when it becomes available.

The SDC usually gives reasons why CPP disability benefits are denied. One reason that a CPP application can be denied is that you may not have contributed to the CPP for enough years. There are certain provisions which may help you to qualify for a CPP disability benefit identified by SDC as exceptions. These exceptions include the child rearing dropout provision for parents who take time off work to care for their children. There are other exceptions.

It is more common that the denial is based on the lack or type of medical information provided to the SDC. To qualify for CPP disability benefits, you must show that your condition satisfies the definition of disability and that your condition is both 'severe and prolonged.' In practical terms, your medical records must show that you are not able to return to any gainful employment. Many times the CPP application and your medical records don't spell out the full extent of your injury and limitations and how that impacts on your life and ability to work.

Therefore, if the denial is based on the lack of medical evidence supporting a severe and prolonged disability, it is very important to speak with your family physician or specialist, show them the CPP disability definition and ask if they could specifically write a report to address whether your injury falls within the CPP disability definition.

If, after a reconsideration request, the SDC denies your application for CPP disability, you can appeal the decision to deny benefits to the Office of the Commissioner of Review Tribunals (OCRT). Again it is crucial to be aware of the time limits of this appeal. An appeal request must be made in writing and the appeal letter must be received by the OCRT within 90 days of receiving the reconsideration denial letter of SDC. It is important not to send your appeal request letter to SDC; it must be sent to the Office of the Commissioner of Review Tribunals. You can also use the Notice of Appeal form available on the OCRT website to prepare your letter (www.ocrt-bctr.gc.ca/).

Again, you are required to provide the OCRT with any new information with your appeal. However, if you have new information in support of your appeal, you should always mail your new information to the OCRT **as soon as possible** and far in advance of your hearing date.
Once your appeal is received, staff from the OCRT will contact you about what you have to do to prepare for the appeal hearing and where and when it will take place. They will also send you documents related to your case, and answer any questions you have.

At least one month before your scheduled hearing, the OCRT will send you SDC's document called the *"Explanation of the Decision"*. Although your lawyer's decision letter and reconsideration letter will give the reasons why your application was denied, the *"Explanation of the Decision"* document contains much more detailed information related to your individual case. This document will help you prepare your case.

At the appeal hearing, you will present your case before a three-member Review Tribunal panel. After your hearing, the OCRT will send a registered letter to you and SDC explaining the Review Tribunal's decision and the reasons for it.

If your application for CPP disability Benefits is not granted by the OCRT Review Tribunal panel, you may have an appeal to the Pension Appeals Board (PAB). You must seek leave (permission) to appeal to the PAB in writing within 90 days of receiving the OCRT decision letter. This appeal is more complicated and rare than the previous appeals. If you are interested in pursuing this level of appeal, you should consult a lawyer for more details.

If you do not qualify for CPP, there are other government funded disability benefits you may consider applying for. If you are a resident of Ontario who is in financial need and disabled, you maybe eligible for the Ontario Disability Support Program (ODSP) http://www.mcss.gov.on.ca/mcss/english/pillars/social/programs/odsp.htm. When you first discover you are disabled, you may choose to apply for both CPP benefits and ODSP benefits in the event that your CPP application is denied.

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YOUR HEALTH

CFIDS and ANAESTHESIA: what are the risks?

By Elisabeth A. Crean

Printed with the permission of the CFIDS Association of America.

***Editor's note: PWC means Person With CFS or CFIDS. CFIDS stands for* Chronic fatigue and immune dysfunction syndrome.**

Anecdotes have piled up over the years about the especially difficult time persons with CFIDS (PWCs) have recovering from anesthesia. PWCs are hypersensitive to many medications, including anesthetics, often tolerating just a fraction of the standard dosage levels. The reactions some patients experience may be a sign that their immune and endocrine systems don't respond normally to pharmaceutical challenges and stimuli. Unfortunately, no rigorous scientific studies have been published on any of these issues. Meanwhile, every day PWCs are facing the imminent possibility of surgery, and need to educate their doctors now.

What the doctors say

When a question about anesthesia and PWCs was posted on the Internet, most responses quoted two doctors, Dr. Patrick. L. Class of Nevada and Dr. Paul R. Cheney of North Carolina. Here is what Dr. Class recommends for CFIDS patients who must undergo surgery: "I prepare long before the surgery takes place by performing skin tests for all the agents I am considering using, to see if the patient is allergic to any of them. With CFIDS patients, I recommend Diprivan as the induction agent; Versed, fentanyl (a short-acting narcotic) and droperidol (an anti-nausea agent) during anesthesia; and a combination of nitrous oxide, oxygen and Forane as the maintenance agent."

In contrast, Dr. Class notes, "There is a commonly used group of anesthetics, known as histamine-releasers, which are probably best avoided by CFIDS patients." This group includes the thiobarbituates, such as sodium pentathol, probably the most common induction agent and a known histamine-releaser. "In addition, there is a broad group of muscle relaxants in the Curare family, namely Curare, Tracrium, and Mevacurium, which are also potent histamine-releasers and should be avoided by CFIDS patients."

Because many histamine-releasing agents are commonly used during emergency surgery, Dr. Class advises PWCs: "Wear a medical alert bracelet in the event you are unconscious. I would mention on the bracelet that you cannot receive any histamine-releasing drugs." Other options for communicating this information include carrying instructions in your wallet, educating your family and insisting that it be included in your medical chart.

CFIDS can be an indication that certain organs, like the liver, may already be overtaxed, and processes like cell metabolism disturbed. An anesthesia plan must take this into account. Dr. Cheney advises against using anesthetic gases like Halothane that can potentially be toxic to the liver. "Patients with CFIDS are known to have reactivated herpes group viruses, which can produce mild and usually subclinical hepatitis. Hepatotoxic anesthetic gases may provoke fulminate (sudden, severe onset) of hepatitis."

Dr. Cheney also notes that electron beam x-ray spectroscopy techniques have shown that PWCs do not have enough magnesium and potassium in their cells, which can be problematic. The mag-nesium and potassium depletion can result in cardiac arrhythmias during anesthesia. "For this reason, I would recommend the patient be given Micro-K using 10mEq tablets, 1 tablet BID and magnesium sulfate 50% solution, 2cc IM 24 hours to surgery."

As technological advances like laproscopy make surgery less invasive, surgeons can perform more procedures where they combine a local anesthetic with a sedative instead of using general anesthesia. But even local anesthetics used outside of surgery should be approached with caution when being administered to PWCs. "Lidocaine should be used sparingly and without epinephrine," Dr. Cheney says.

In an article for the February CFIDS Support Network update, Dr. Charles Lapp of North Carolina also emphasizes checking serum magnesium and potassium before surgery and replenishing these minerals if the levels are borderline or low. Seriously ill patients, or those frequently on steroid therapy, might need pre-operative cortisol testing and supplementation as well. According to Dr. Lapp, doctors may also have to modify pre- and post-operative sedation. "Most CFIDS patients are also extremely sensitive to sedative medications--including benzodiazepines, antihistamines and psychotropics--which should be used sparingly and in small doses until the patient’s response can be assessed."

The consequences of neurally mediated hypotension (NMH)--frequently seen in CFIDS patients--concern Lapp as well. These include low plasma volume, low red blood cell mass, venous pooling and vasovagal syncope (fainting). "Syncope may be precipitated by catecholamines (epinephrine), sympathomimetics (isoproterenol) and vasodilators (nitric oxide, nitroglycerin, beta-blockers and hypotensive agents)," Dr. Lapp says. "Care should be taken to hydrate patients prior to surgery and to avoid drugs that stimulate neurogenic syncope or lower blood pressure." The need for extra hydration might mean checking into the hospital the day before surgery--as was customary in pre-managed care times--instead of just a few hours before.

Almost everyone feels weak and tired after an operation. But people with CFIDS should prepare to experience increased fatigue and problems with memory and concentration for a much longer period than normal, says Dr. Charles Shepherd of Gloucestershire, England, in his book Living with ME. He speculates that reduced blood flow to the brain during surgery and the immediate post-operative recovery period may partially explain this. Other possible culprits may be specific anesthesias, particularly those used to correct a low heart rate or reverse muscle paralysis, which can further disturb brain chemistry already altered by CFIDS.

Dr. Shepherd suggests referring surgeons and anesthesiologists to a research paper about acetylcholine levels in PWCs (such as Chadhuri, A., et al, Chronic fatigue syndrome: a disorder of central cholinergic transmission, *Journal of Chronic Fatigue Syndrome*, 1997; 3: 3-16). This may be a good way to alert them to possible complications with your recovery.

How you can prepare

These steps should help you get ready in the event that you need anesthesia. Remember that the following applies to dental procedures requiring anesthesia as well, so don’t forget to inform your dentist or oral surgeon.

1. Avoid unnecessary surgery, since the risks of anesthesia for PWCs are still not well-defined.
2. Ask that the specific information about the use of anesthesia in PWCs mentioned in the "What the doctors say," section of this article be placed in your medical chart in case you need emergency surgery.
3. Always seek a second opinion--and a third or fourth, if necessary--when a doctor recommends you have surgery. This applies even in emergency situations. Let your family know your wishes.
4. If non-surgical treatment options exist, explore these first. For instance, there are new, non-surgical techniques to remove kidney and gallstones.
5. If you have to have surgery, choose the least invasive surgical technique. There are new "keyhole" procedures available that involve less anesthesia, less trauma to the body and a quicker recovery time. This may mean traveling to a big city hospital where

the higher tech equipment is more prevalent and surgeons have more experience using it. Be careful to investigate all options carefully first, so you can avoid being a guinea pig for an inexperienced doctor trying equipment for the first time.

6. Insist on meeting with the anesthesiologist and surgeon as far ahead of the surgery as possible, so you can discuss CFIDS-specific issues and he can have time to do additional research on what will work best for you. Ask him or her to explain exactly what will happen during the procedure.
7. Make sure your surgeon and anesthesiologist know the dosage and frequency of every medi-cation you are taking, including herbs, supplements and vitamins. Don't forget to mention any drugs you have recently stopped taking, as some substances take weeks to clear from your system. There may be contraindications to or interactions with the medicines they plan to use.
8. Make sure your doctors know all allergies and hypersensitivities you have to medications, foods and chemicals. A latex allergy is an obvious example, but did you know that a shellfish allergy might mean you will react badly to certain x-ray dyes?No allergy information is too insignificant to mention.
9. Ask if you can leave information on CFIDS for the nurses who will be caring for you after the surgery. They may not read it, but it is worth the attempt to educate them about possible complications.

After the surgery, try not to overdo and give your body appropriate time to heal. Keep in mind that your healing may be slower than is normal, and make sure your health care providers and caregivers are aware and prepared for that possibility beforehand, so that a longer hospital stay or special care can be arranged.

***This article appeared in the* Winter 2000 issue of the *CFIDS Chronicle* .**

Editor's Notes:

1) very useful information on Anaesthesia can also be found at: http://www.ahummingbirdsguide.com/topicanaesthesia.htm

2) also check out: the guidelines developed by the Canadian Society for Environmental Medicine, 'Part II, Environment-sensitive Care: Anaesthesia and Respiratory Care' www.mcscanadian.org/hospital.html.

Do you have a health issue that affects people with CFS that you would like to read more about? Call us at 416 222-8820 or 1 877 632-6682 or write us with your suggestions (see CONTACT US on the back page).

TIP

**I take out several library books
at one time. When the books
are due, I call the Library Renewal
Answer Line, 416 393-7130 (Toronto)
to renew the books.
(I've written my library card no.
next to the tel. no, so that
I don't have to go looking for my
library card each time I renew.)
I can renew the books every 3 weeks,
for a total borrowing time of 9 weeks.
This reduces the total no. of times
I visit the library each year,
and yet have plenty of books to enjoy.
Other library systems
throughout Ontario may have
the same policy.**

Sharing our Experiences:
Guilt and M.E.

Thanks to our contributors: Donna Engelhardt, Suzanne Mossman, and Cathy Prescott. Compiled and written by Izzat Jiwani.

This is the first in a series of articles where we will share some of the emotions, feelings and experiences - the inner struggles - as we deal with the new reality of our limited abilities and the impact it has on the lives of our family members and friends. This article is not intended to provide solutions. Sharing our experiences reminds us that we are part of a group of thousands of other people with M.E./CFS who have experienced similar emotions, and hopefully we will find strength in moving forward with the challenges in our lives.

The word **guilt** is a weighty and ominous word. It is the monkey on the back of probably every person who has M.E./CFS. Guilt is just one of many emotions we feel as we realize we simply cannot do many of the things we once used to. As sufferers of this illness we have done nothing wrong, but our limitations and restrictions make us extremely conscious of our shortcomings. We are forced to witness the people you love working overtime to do extra household chores and take over many roles in the home that were once our responsibility.

> I've had it (guilt) in spades for 20 years. Guilt that I have held my spouse back from so much in life.
>
> I lived with the guilt that my husband had so much more to do with the kids, and that there was so little we could do together. I wasn't the wife I had set out to be either.

The feeling of guilt can be overwhelming when those of us with M.E./CFS have children, and while our mind and heart wants us to be an active part of their life, our bodies do not allow that.

> My worst guilt came from not being the mother I had envisioned. When I 'came down with CFS" my twins were exactly four years old. I was the mother who sewed their clothes, knitted their sweaters, and cooked everything from scratch. When my kids started school that fall, I often couldn't even get up to see them on the bus. How many times did I stay at home on the couch sobbing because they were at their Christmas concert and I was at home missing it? I became the 'absent Mom'.
>
> I have had guilt that I brought children into the world who came down with CFS probably because of my genes – even though I didn't have it at the time.

Prior to having M.E./CFS, all of us were active contributing members of our family and community. Not being able to contribute financially to family income can also be a major source of guilt**. It's easy to feel that we are letting our family and co-workers down. To compensate, we often <u>ignore</u> our need for <u>rest and pacing</u>.** Many in our society, including those in the health care profession do not understand the nature of the illness and disability that CFS brings and often criticize our limitations. In the process they hurt us and make us feel guilty.
Most of us have found ways to deal with this guilt over time. Some helpful suggestions include: be educated about your illness and become empowered; communicate to your

loved ones in an open way about your illness and feelings; freely say “no” without feeling blameworthy; and try counselling. Look at the silver lining in our illness.

> Even though my kids didn't have the Mom I thought they should have had, they have grown up to be much more patient and empathetic than I think they otherwise would have without their experience with CFS.

M.E./CFS is not a journey you go on alone. You take everyone else with you. **Remember - it doesn't have to be to a bad place, just a different one from where we thought we were headed.**

The next article in this series will be on “grief” e.g. grief at the loss of who you were. We encourage you to write about your losses, and to share them with our readers. See CONTACT US on the back page for our address. Thank you.

It’s almost time to plant those fresh herbs in your yard or on your balcony. This will supply you all summer and into the fall with fresh herbs such as rosemary, tarragon, several varieties of basil, mint and thyme. Now is the best time to stock up on your seeds.

ON THE FUNNY SIDE

Some Irish humour:

Reilly went to trial for armed robbery. The jury foreman came out and announced, "Not guilty."
"That's grand!" shouted Reilly. "Does that mean I can keep the money?"

Irish lass customer: "Could I be trying on that dress in the window?"
Shopkeeper: "I'd prefer that you use the dressing room."

Mrs. Feeney shouted from the kitchen, "Is that you I hear spittin' in the vase on the mantle piece?"
"No," said himself, "but I'm gettin' closer all the time."

Q. What do you call an Irishman who knows how to control a wife?
A. A bachelor.

Slaney phoned the maternity ward at the hospital. "Quick!" He said. "Send an ambulance, my wife is goin' to have a baby!"
"Tell me, is this her first baby?" the intern asked.
"No, this is her husband, Kevin, speakin'."

"O'Ryan," asked the druggist, "did that mudpack I gave you improve your wife's appearance?"
"It did surely," replied O'Ryan, "but it keeps fallin' off!"

In a Podiatrist’s office:
“Time wounds all heels.”

A SWEET STORY ABOUT ITALIAN COOKIES

This is for all the Italians out there, and those who are lucky enough to be married to an Italian, and even to all the friends of Italians.

An elderly Italian man lay dying in his bed. While suffering the agonies of impending death, he suddenly smelled the aroma of his favorite Italian anisette sprinkle cookies wafting up the stairs. Gathering his remaining strength, he lifted himself from the bed.

Leaning against the wall, he slowly made his way out of the bedroom, and with even greater effort, gripping the railing with both hands he crawled downstairs. With labored breath, he leaned against the door frame, gazing into the kitchen. Were if not for death's agony, he would have thought himself already in heaven. For there, spread out upon waxed paper on the kitchen table were literally hundreds of his favorite anisette sprinkled cookies.
Was it heaven? Or was it one final act of heroic love from his devoted Italian wife of sixty years, seeing to it that he left this world a happy man?
Mustering one great final effort, he threw himself towards the table, landing on his knees in a crumpled posture. His parched lips parted, the wondrous taste of the cookie was already in his mouth, seemingly bringing him back to life.
The aged and withered hand trembled on its way to a cookie at the edge of the table, when it was suddenly smacked with a spatula by his wife............

"Get out of here!" she shouted, "They're for the funeral!"

FROM OUR KITCHEN TO YOURS

Sweet Potato Soup

(one of Audrey's favourites)

Ingredients: servings: 4

sweet potatoes 2-1/4 lb (1.125 kg)
1 tbsp (15 mL) vegetable oil
1 small onion, finely chopped
2 cloves garlic, minced
1 tbsp (15 mL) minced gingerroot (or 1 tsp/5 mL ground ginger)
2 tsp (10 mL) mild curry paste (If curry isn't a favourite accent, decrease the curry paste to 1 tsp (5 mL))
4 cups (1 L) vegetable or chicken stock

Preparation: Peel and cut sweet potatoes into 1/2-inch (1 cm) cubes; set aside.
In a large saucepan, heat oil over medium heat; cook onions, garlic, gingerroot and curry paste, stirring occasionally, for 3 minutes or until softened. Add sweet potatoes; stir for 1 minute or until coated.
Add stock and bring to a boil; reduce heat, cover and simmer for 10 minutes or until potatoes are tender. With immersion blender, or in a blender, puree soup. Reheat if necessary.

We welcome to our editing team **Mary Lou**, our new **Cooking Editor!** She will select the recipes for each newsletter. Do you have a favourite recipe you would like to share?

Send it to her at:
THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO,
P.O. Box 84522,
2336 Bloor St. W.,
Toronto, Ont. M6S 4Z7.

TIP

From one of our Readers:
When cooking turkey bones to make a broth for soup, cook the bones in a crockpot on low. This way you won't have to deal with the broth until the next day, thus conserving energy.
In the past, after cooking the bones in a pot, I would have to wait until it cooled before freezing it. By that time, I was too tired and ended up throwing it away.

M.E. /CFS Fact Sheet

In this issue of ***Reaching Out***, we are enclosing our revised (August 2007) ***Fact Sheet: Understanding Chronic fatigue Syndrome (CFS) / Myalgic Encephalomyelitis (M.E/).***

This is being provided to you for both your personal information as well as for possible distribution to your doctor(s), the pharmacy or clinic that you attend or to attach it to a letter that you may wish to write to your political representatives, medical authorities or a media person for the up-coming M.E. /CFS National Awareness Day – May 12th.
Please feel free to photocopy the enclosed Fact Sheet as needed or you can call our Help-Line to order multiple copies.

HELPFUL WEBSITES

Correction:
In our previous issue, Winter 2007, we printed the wrong website address for Dr. Bryon Hyde. The correct address for Dr. Hyde is: **www.nightingale.ca.**

However, another website with excellent information on M.E./CFS is: **www.ahummingbirdsguide.com**
(you can see why we got the 2 mixed up)

For less toxic items: **www.lesstoxicguide.ca**

Health Canada, Cosmetic Product Ingredient Labeling: **www.hc-sc.gc.ca/iyh-vsv/prod/cosmet_prod_e.html**

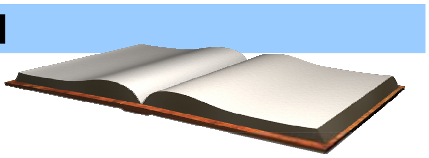
For the booklet entitled *Services for People with Disabilities,* published by the Government of Canada: **http://servicecanada.gc.ca**

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.

RESEARCH



Research Findings on CFS/M.E.

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

Two interesting research studies have recently been published – one describing persistent enteroviral infection in CFS and the other linking different genes with different clinical manifestations of CFS.

Drs John and Andrew Chia have long had an interest in enteroviruses and CFS. They examined 165 CFS patients for enteroviruses in the stomach, obtaining tissue by biopsy[1]. Most patients had mild gastritis. 135 of 165 CFS patients (82%) had cells that were positive for an enteroviral protein compared to only 7 of 34 (20%) of healthy subjects. Some patients were positive over many years. In addition, RNA from enterovirus could be detected in biopsies from more CFS patients (37%) than from healthy subjects (6%). There was more viral protein in more severe CFS. Although it was difficult to recover the virus, enteroviruses were grown from some patients but these did not destroy cells. Failure to kill cells might explain how these infections persist, since enteroviruses usually kill cells and as such would be more likely to be cleared by the immune system. One of the crucial questions about persistent viral infections in CFS is whether these are the **cause or the effect of CFS**, since others have shown that CFS patients have abnormalities in antiviral pathways.

Whichever, the presence of persistent virus offers the potential for antiviral treatment, since persistent viral infection could trigger some symptoms of CFS.

The other study that is generating interest comes from London, UK, where a group led by Dr Jonathan Kerr is using DNA microarray technology to look at the expression of genes in white blood cells of patients with CFS[2]. In a paper to be published in the *Journal of Infectious Diseases*, his group identified 88 genes that were expressed differently in 55 CFS patients compared with 75 healthy subjects. They confirmed these microarray findings using quantitative PCR. The severity of physical and mental fatigue was assessed using the Chalder Fatigue Scale, and the level of disability by the Medical Outcomes Survey Short Form-36 (SF-36). In a complex analysis just published in the *Journal of Clinical Pathology*[2] using data from the same study, Kerr's group showed that there were statistically significant correlations between the genes that were differentially expressed and the clinical manifestation of CFS, when patients were classified clinically into subtypes. Examples of subtypes were "subtype 1", patients with marked cognitive, musculoskeletal, sleep, and anxiety/depression problems, and "subtype 5", patients with marked musculoskeletal and gastrointestinal problems. These findings may open the way to using a smaller subset of genes to type individual patients with CFS, and to targeting appropriate treatment. These findings **must be confirmed by other groups**, since reproducibility and/or interpretation of microarrays and of qPCR are problematic. For example, statistically significant changes in gene expression were often slight, with a "cut-off" of only 1.5 times between CFS and healthy patients being used, and some of the 7 clinical subtypes had only 2 or 3 patients. Nevertheless, these are findings on which to develop further hypotheses and to direct future research.

Studies cited:
[1] Chia, J Clin Pathol 2007
[2] Kerr et al, J Clin Pathol 2007

DISABILITY CLAIM DENIED?

Kelli-Ann Woulfe

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

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

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

CONTACT US

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

<u>Our HELP-LINE is:</u>
416 222 - 8820, or 1 877 632-6682. Call to receive information on M.E./CFS, Support Group and doctors

Check out our **<u>Web Site</u>** 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 illness with your attending physician.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
P.O. Box 84522, 2336 Bloor St. W.
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MEMBERSHIP AND / OR DONATION

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