

# REACHING OUT

Fall 2007

## OHIP CODES

By: Anthony Rovito

When doctors diagnose patients with CFS/ Myalgic Encephalomyelitis, they can now report the **diagnostic code (795)** to OHIP. This code for CFS was first approved in 2003. Use of this code can mean that the provincial stats for CFS/M.E. can become more representative of the actual number of people who suffer from this illness across the province of Ontario. Improved provincial statistics for CFS/M.E. will, in the end, also assist all of us in advancing the cause of CFS/M.E. locally, provincially and nationally, especially when raising funds and promoting more research.



you for CFS/M.E. It is important for doctors to use these approved codes so that all individuals being diagnosed with, or treated for CFS/M.E. can be counted in the CFS/M.E.

statistics for Ontario, and so that the treating doctors can be fairly compensated.

### Thought for the Day

*We are all inventors, each sailing out on a voyage of discovery, guided each by a private chart, of which there is no duplicate. The world is all gates, all opportunities.*  
Ralph Waldo Emerson

A “time-based” Fibromyalgia/ CFS **treatment billing code (K037)** was approved in 2005. Some physicians, in the past, refused to treat patients with these illnesses given that they consistently required more time at visits for which the physicians were not being paid. Now physicians whose practices include CSF/M.E. and FM patients can spend more time with those patients and be paid for that additional time. Also, more physicians may be willing to accept M.E./CFS/FM patients if they will not be penalized financially for doing so.

Please take the information about these two codes with you when seeing a doctor treating

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## FROM THE PRESIDENT



As I sit down to write this greeting to the membership for our Fall issue of **Reaching Out**, I notice that the days are already getting shorter and Fall has arrived. Thinking back however, I also realize that much has happened over the past few months that will, in future, significantly affect our Association.

The sudden passing of Audrey MacKenzie was significant not only, for many of us, in terms of losing a dear friend and confidant but also in no longer having a valuable resource that we can call upon when we need direction, advice or some background history on CFS/M.E. Audrey will be dearly missed but she will not be forgotten!

Early in 2007, we established a "Newsletter Advisory Committee" with Maries St. Paul as chair. The purpose of this committee was to implement as many of the suggestions as possible that were recommended by the membership in the 2006 Membership Survey. As Newsletter Editor, Audrey was quite excited about incorporating most of those recommendations. Our last issue, which was devoted almost entirely to Audrey, did in fact, incorporate a few of the proposed changes - two column letter format, and reduced length.

Continuing with the proposed changes, this issue is in a 4-colour format with more graphics to keep the interest of the reader. We are also introducing a section "Ask a Lawyer" whereby a lawyer provides answers to questions that our readers may ask. This section is in response to the many inquiries that we receive on our Help-Line with regards to legal matters. For our next issue we hope to introduce a section called "Ask a Doctor / Naturopath". As we implement these changes, we would very much appreciate your input. In preparing each issue of **Reaching Out**, we try to keep in mind the fact that most of our readers have to deal with CFS/M.E. related limitations, that some may be quite isolated and on their own, and that

all of our reader are always looking for new and useful research information and some strategies for coping with this syndrome.

A few issues ago, I shared with you the fact that our Association had submitted a grant application to the Ontario Trillium Foundation (OTF). I am delighted to report to you that on June 28, 2007, The Ontario Trillium Foundation Board of Directors did, on our second submission, officially approve a partial grant for The Myalgic Encephalomyelitis Association of Ontario. These designated funds (\$154,500 over three years - 2007 - 2009) will now enable us to hire a part-time "Provincial Coordinator" to help conduct the business of the organization, and also to 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 expectations of OTF is that the Association will open a small provincial office by 2008. To facilitate the opening of such an office, the Association will soon embark on a fundraising campaign (focusing on corporate sponsors) to raise the required funds for "rent and utilities" for the provincial office. If you can help in raising such funds, please call our Help-Line at 1-877-632-6682 or 416-222-8820.

Our success in finally obtaining a grant from the Ontario Trillium Foundation is the result of a very capable grant writer graciously agreeing to volunteer her time and expertise to write the OTF grant submissions for us. Her name is **Teresa Dobko**. On behalf of the Association, I would like to extend to Theresa my heartfelt appreciation for doing this for our Association and for continuing to provide advice to us in the areas of general fundraising and grant writing.

Hope you all had a safe, relaxing and very enjoyable summer!

*Anthony Rovito, President,  
M. E. Assoc. of Ontario*

## MEMORIAL FOR AUDREY MACKENZIE

By: *Maries St. Paul*

On Sunday June 24<sup>th</sup>, 2007, a perfect summer's day, a memorial for Audrey MacKenzie, past president of the Myalgic Encephalomyelitis Association of Ontario, was held at Women's College Hospital. Many of those who came to know, admire and love Audrey attended. Several people spoke about their special moments with her. Many of us felt comforted by each others' presence. All of us appreciated the beautiful ceremony, the songs and music, the slides of Audrey growing up, the eulogies and tributes - a fitting tribute to an exceptional woman. For those of you who were not able to attend the Memorial and would like to see additional photos of the various activities and speakers and hopefully, the slide presentation – A Celebration of Audrey's Life as well, we ask you to keep checking our website. We are currently working on putting all of this information in the "events" section of the website. Also, if you would like a copy of the Memorial Booklet with all of the tributes, songs, poems and quotes, we ask you to request one through our Help-Line at 416 222-8820 or 1-877-632-6682. A \$5.00 donation for the printing and shipment costs of the booklet would be appreciated. Thanks are extended to Tony Rovito and his team for a job very well done.



Dr. Bested speaking at Audrey' memorial

## UPCOMING EVENTS:

The Myalgic Encephalomyelitis Assoc. of Ont. will be hosting its **ANNUAL GENERAL MEETING, Saturday, November 24, 2007**, at **Women's College Hospital, Main Auditorium, at 1:00 – 4:00 p.m.** The hospital is located at 76 Grenville Street , Toronto. **Guest Speaker: Nancy Bradshaw, Outreach Education Coordinator, Environmental Health Clinic.** Ms Bradshaw will speak on the **Services provided by the Environmental Health Clinic.** A Question and Answer period will follow.

FREE ADMISSION  
DONATIONS APPRECIATED  
EVERYONE WELCOME!

Wheelchair accessible  
Scent Free Policy

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**DR. ALISON BESTED** will be speaking at the **Ontario College of Family Physicians' 45<sup>th</sup> Annual Conference in November 2007.** She will be speaking on Fibromyalgia (and CFS): how to diagnose and treat it.

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**WOMEN'S HEALTH MATTERS FORUM AND EXPO, January 18 – 19, 2008, Metro Toronto Convention Centre, South Building.**

**Topic: Environmental Health.**

One of the doctors from the Environmental Health Clinic will be speaking at the forum.

## YOUR HEALTH

### PREVENTING AND REDUCING MOLD

This is a follow-up to the article on mold and health in the last issue, which outlined the health problems related to mold. For those who are affected by mold, it is important to ensure not only that any mold is removed, but also that it is prevented. This article is taken from Canada Mortgage and Housing

from Canada Mortgage and Housing Corporation's publications, "Fighting Mold: The Homeowners' Guide" and "The Tenant's Guide to Mold". Both can be downloaded from the CMHC web site at [www.cmhc-schl.gc.ca](http://www.cmhc-schl.gc.ca).

### Basic steps

Mold needs moisture to grow. Controlling moisture and keeping the home dry prevents the growth of mold. Keep your home or apartment dry. Think of the different ways activities such as cooking or bathing produce moisture inside the home.

- Exhaust fans remove moisture as it is produced. If there are no fans, open windows for a short time, but remember that moist outdoor conditions will not dry the inside air.
- Find and fix water leaks in the bathroom, kitchen and basement, or ask your landlord to do so.
- Discard clutter and excess stored materials. Molds grow on fabrics, paper, wood and practically anything that collects dust and holds moisture. Only washable items should be stored.
- Clean and maintain the home regularly. Vacuum often. If you are buying a vacuum cleaner, get one with a HEPA filter. Clean hard floors with a damp mop.
- Separate footwear worn outside from footwear worn inside.
- Allow good air circulation by reducing the amount of furnishings.
- Heat areas of the apartment or home adequately. Condensation occurs on cold walls in unheated rooms or in apartments that are kept too cool.
- Cut down the number of potted plants in the apartment—soil is a good place for mold. Frequent watering of plants adds moisture to the air.
- Recognize conditions that lead to excess moisture and mold—overcrowding or too many pets. Increase ventilation (open windows

and or use exhaust fans) when there are more occupants than the unit was designed for.

- Do not humidify unless necessary.

### Bathrooms

- Check the bathroom fan to make sure it exhausts to the outside. Check that it is able to exhaust air. The fan should be able to pull a piece of tissue paper held over the grille towards itself.
- Turn the bathroom fan on when you shower. Keep it running for a few minutes after you finish your shower.
- Keep the exhaust grille free of debris.
- If there is no bathroom fan but there is a window, open the window after a shower when possible.
- Take short showers.
- Keep surfaces that get wet, such as the walls around the bathtub and shower, clean and dry.
- If there is a carpet in your bathroom, remove it or ask landlord to remove it.
- Keep drains in good shape by removing debris from them.
- Hang wet laundry to dry in the bathroom as infrequently as possible.
- Condensation or dampness in the bathroom may be due to temperature being kept too low. Make sure there is heat.

### Kitchen

- If the fan over your stove exhausts outside, use it when you cook. (Tenants can ask the landlord if it exhausts outside). Regularly wash the exhaust fan's grease filter.
- Minimize open and prolonged boiling.
- Keep your drains clean and free of debris.
- Clean the refrigerator drip pan at the back of the refrigerator. At the same time, vacuum dust from the coils at the back of the refrigerator.

- Take out the garbage daily to prevent odours and spoiling.

### **Closets and bedrooms**

- Get rid of clothes and other stored items that you don't use. Keeping your closets and bedrooms tidy makes it easier for air to circulate —and harder for mold to grow.

### **Basement or crawl space**

- Dehumidify the basement during the warm months.
- Avoid carpets on slab-on-grade or below grade floors.
- Periodically clean the drain in your basement floor. Use half a cup of bleach; let it stand for a few minutes, then flush with plenty of water. Keep the drain trap filled with water.
- Regularly clean and replace furnace filters. Use a pleated one-inch filter, not a coarse filter.
- If you have a heat recovery ventilator (HRV), clean the filter inside the HRV often.
- If you notice molds or signs of dampness, such as water on your windows or wet spots elsewhere, do not humidify.
- If you have electric baseboards, vacuum the units, or have a professional clean them for you.

### **Laundry areas**

- Check that your clothes dryer exhausts to the outside.
- Remove lint every time you use the dryer.
- Don't hang-dry laundry indoors.
- Dry your laundry tub and washing machine after you use them.

### **Tips in selecting an apartment**

If mold is a major concern for you, avoid apartments with one or more of these features:

- Located in a basement
- Located on an upper floor of a building with a wet, moldy basement
- No bathroom fan, or fan doesn't work
- No kitchen exhaust fan or fan is a recirculating fan
- An old carpet
- Known history of roof or plumbing leaks
- Difficult to heat because it is leaky or inadequately insulated.

## **YOUTH/PARENT REPORT**

Margaret Parlor, Coordinator of Youth & Education Issues

As the school year begins, we would like to remind everyone that all young people in Ontario have a right to education services. This includes young people who have health conditions that affect their ability to attend school. This includes young people who are homebound through illness. The Minister of Education has assured us that these students can qualify for education services under the physical disabilities category.

Unfortunately, not all school boards are aware of their responsibilities around serving these students. It should not be a struggle to access educational services. If you encounter problems, please contact us immediately.

Meanwhile, we have asked the Ministry of Education to ensure that school boards have part-time and homebound services in place and accessible. The Ministry has not done so. We have asked the Ombudsman's Office to investigate.

## ADVOCACY / DISABILITY ISSUES

### Spotlights on Rights

Dr. Lynn Marshall, Physician, Environmental Health Clinic

(Printed with the permission of the Environmental Health Clinic.)

In May 2007, the Canadian Human Rights Commission published two reports on Environmental Sensitivities (ES): Medical Perspective by researcher Margaret Sears PhD ([http://www.chrc-ccdp.ca/pdf/envsensitivity\\_en.pdf](http://www.chrc-ccdp.ca/pdf/envsensitivity_en.pdf)), and Legal Perspective by lawyers Cara Wilkie and David Baker ([http://www.chrc-ccdp.ca/pdf/legal\\_sensitivity\\_en.pdf](http://www.chrc-ccdp.ca/pdf/legal_sensitivity_en.pdf)). On their website, the CHRC welcomes e-mail comments on these reports.

The purpose of the Medical Perspective paper was to examine issues related to ES, including awareness, diagnosis, prevalence, recognition by international, federal, and municipal bodies and medical communities, initiating factors, triggers, symptoms, treatment, building codes and workplace accommodations. The scientific literature on ES was extensively reviewed and summarized in an annotated bibliography that is available on request from the author at [environmentalhealthmed@gmail.com](mailto:environmentalhealthmed@gmail.com).

The objective of the Legal Perspective paper was, via review of legislation and case law in Canada, the United States, Australia, New Zealand, and the United Kingdom, "to examine past legal assessments of accommodation for environmental sensitivities, including how third parties may be involved, and the relevance of building codes and standards" (Wilkie and Baker, p.6).

For both reports, the authors consulted widely with professionals, government departments, and non-governmental organizations, including patient support associations. Representing the Environmental Health Committee of the Ontario College of Family

Physicians, Dr. John Molot and I were active collaborators in developing the Medical Perspective report. Dr. Kathleen Kerr served as a reviewer of that report, and the authors of both papers consulted Nancy Bradshaw.

The conclusions of both reports noted the necessity for those with ES to avoid exposure to toxins and triggering agents and acknowledged their need for accommodation in the workplace. It was also noted that their conditions and unique needs are increasingly being recognized nationally and internationally, and in medical education. Furthermore, new policies and laws such as "no smoking, scent-free, pesticide-free, no idling, and least-toxic cleaning policies in health care and other public institutions are increasingly common" (Sears, p. 48).

The Allergy and Environmental Health Association of Quebec issued a Media Release that had considerable uptake. President Rohini Peris noted that the large number of Canadians with ES represents "a large, unnecessary and avoidable tragedy, as well as a drain on society and the economy".

With these two reports, I believe that the CHRC has shone two important spotlights on the rights of those with ES, and, furthermore, on July 19, 2007, the Commission issued a Policy on Environmental Sensitivities which should inspire renewed hope among ES sufferers. ([http://www.chrc-ccdp.ca/legislation\\_policies/policy\\_enviro\\_n\\_politique-en.asp](http://www.chrc-ccdp.ca/legislation_policies/policy_enviro_n_politique-en.asp)) The final paragraph reads: *"Successful accommodation for persons with environmental sensitivities requires innovative strategies to minimize or eliminate exposure to triggers in the environment. These may include: developing and enforcing fragrance-free and chemical avoidance policies, undertaking educational programs to increase voluntary compliance with such policies, minimizing chemical use and purchasing less toxic products, and notifying employees and clients in advance of construction, re-modeling*

and cleaning activities. Such measures can prevent injuries and illnesses, and reduce costs and health and safety risks”.

## ASK A LAWYER



### When should people who have been denied long-term disability benefits hire a lawyer?

Lawyers should be retained at the earliest opportunity once benefits have been denied or terminated. Without a lawyer, there is a terrible imbalance, a great inequality of bargaining power between the insurance company, which has denied benefits, and the chronic fatigue / fibromyalgia / chronic pain survivors who are seeking to have the contract honoured. Knowledge is power and the insurance company with its team of experts, lawyers and claims adjudicators has a powerful advantage which can only be equalized if the chronic fatigue / fibromyalgia / chronic pain survivors have their own counsel. Those who suffer from chronic fatigue / fibromyalgia / chronic pain and other chronic conditions or illnesses are not in a position to act on their own behalf. The terrible pain, distress and lack of concentration that afflict them on a daily basis make them ill-suited to advocate for themselves. Accordingly, lawyers should be retained at the earliest opportunity once benefits have been denied or terminated.

There are also important time limits to adhere to regarding starting a lawsuit and appealing from a denial of a claim. Failure to adhere to the time limits may very well mean that the entitlement to benefits is taken away.

Many people are worried about the costs and expenses of hiring a lawyer. Lawyers provide access to justice to people who need help. Chronic fatigue / fibromyalgia / chronic pain survivors should never hesitate about retaining counsel. Some firms (like Bogoroch & Associates) do not require any upfront money and are happy to wait to get paid at the end of the case and only if the case is successfully concluded. Many people do not retain a lawyer to advocate on their behalf and far too often, justice is denied. Inaction is not the answer. Action, advocacy and access to

justice are what lawyers provide and what all chronic fatigue / fibromyalgia / chronic pain survivors are entitled to receive.

The initial consultation is usually free. At this meeting, the facts of the case are discussed and the merits of the case are weighed, considered and analyzed.

All relevant documents should be brought to this initial meeting, including:

1. Copies of any and all correspondence from the insurance company or Canada Pension Plan, as the case may be;
  2. Copies of any medical reports in your possession. The insurance company should provide you with copies of reports that they are relying upon to terminate your benefits or to justify a denial of a claim; and
  3. A list of all the treating physicians.
- You should obtain the following shortly after the meeting:
4. A timetable as to how long the proceedings will take;
  5. Information as to what is involved in suing the insurance company or appealing a decision of Canada Pension Plan benefits;
  6. An indication as to the medical legal assessments that will be arranged in order to bolster or strengthen your case.

You should attend the meeting with a family member or friend. It is helpful to you and to the lawyer if you attend with a family member or friend to provide support and guidance. In conclusion, contact a lawyer as soon as possible after losing benefits. A lawyer's assistance is indispensable to obtain a just and fair result. Without a lawyer's assistance, justice may very well be denied and benefits to which you are entitled not obtained.

By: Mr. Richard M. Bogoroch  
 Bogoroch & Associates  
 150 King Street West, Suite 1707,  
 Toronto, Ontario M5H 1J9  
 Tel: (416) 599-1700, Fax No: (416) 599-1800  
 E-Mail: [rbogoroch@bogoroch.com](mailto:rbogoroch@bogoroch.com)  
 Website: [www.bogoroch.com](http://www.bogoroch.com)

*Editor's Note: If you have legal questions, please forward them to us. See **CONTACT US** on the back page of the newsletter.*



## Initiative for raising awareness of CFS in your Community / Neighbourhood is now ready to launch!

With the help of a donation from a long-time member, the Myalgic Encephalomyelitis Association of Ontario has created colourful paper placemats. These placemats come in 2 versions (see samples above) and contain information about Chronic Fatigue Syndrome (CFS), how to contact our Association and Web Site address. One version includes easy-to-read details on the Symptoms of CFS.

We invite you to talk to your local restaurants about using these placemats for their diner, as a way of increasing awareness of the illness. Another idea is to post one or both of these placemats on the bulletin board of your local health clinic, health food store or pharmacy.

We provide these to you free of charge. Once you have made arrangements, call our Help-Line number, 1 877 632-6682, or 416 222-8820, and tell us how many you need, your name and mailing address. We will send them to you.

This is an excellent way of getting the word out about CFS, as well as reaching out to someone in your community who has the illness and is in need of the support and information our Association can provide.

## HOLIDAY / CHRISTMAS GIFT IDEAS

There are many ways of sharing our blessings at this time of the year.

In our Winter 2007 issue, one of our members wrote a personal story of how her family makes Christmas more meaningful. They pick names, set a limit on the cost of a gift, and ask that whatever else might have been spent is given instead to a charity.

Another member informed us that their family picks names from a hat as well. Each person's name has written beside it the name of their favourite charity. And, instead of receiving a gift, they receive a card from their 'Kris Kringle' stating that their favourite charity has received a cash donation in their name.

Please be reminded that the federal government is about to launch its annual United Way/Health Partner's campaign. Under this campaign, you have the opportunity to donate to any United Way Agency, any Health Partner agency, or any

Canadian registered charity of your choice. Different employers may have similar programs. Please consider asking that your donation be directed to **The Myalgic Encephalomyelitis Association of Ontario, Charitable Registration Number 89226 7568 RR0001.**

## ON THE FUNNY SIDE

### Wisdom of an elderly woman / THE BOTTLE OF WINE

For all of us who are married, were married, wish you were married or wish you weren't married, this is something to smile about the next time you see a bottle of wine.

Sally was driving home from one of her business trips in Northern Arizona when she saw an elderly Navajo woman walking on the side of the road. As the trip was a long and quiet one, she stopped the car and asked the Navajo woman if she would like a ride.

With a silent nod of thanks, the woman got into the car. Resuming the journey, Sally tried in vain to make a bit of small talk with the Navajo woman. The old woman just sat silently, looking intently at everything she saw, studying every little detail, until she noticed a brown bag on the seat next to Sally. 'What in bag?' asked the old woman. Sally looked down at the brown bag and said, 'It's a bottle of wine. I got it for my husband.'

The Navajo woman was silent for another moment or two. Then speaking with the quiet wisdom of an elder, she said:

'Good trade.....',

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### DID YOU KNOW?

When trying to open a jar, put on the rubber gloves that you use when washing dishes and turn.

This is a Martha Stewart hint.. Works like a charm.

## FROM OUR KITCHEN TO YOURS

### POTATO LATKES

Simple and so delicious!

4 large Yukon Gold potatoes, peeled  
2 medium onions, peeled  
1 egg  
Salt and pepper  
2 tbsp. (25 ml) flour  
¼ cup (50 ml) vegetable oil

Grate potatoes and onions (by hand on a grater, or, on grater blade of food processor).

Wrap potatoes and onion in tea towel and squeeze out any excess liquid.

In a bowl, mix together the potatoes, onions, 1 egg, salt, pepper and flour.

Heat some of the oil in a large, heavy skillet on medium heat. Drop 2 tbsp. (25 ml) of potato mixture and flatten with a fork.

Fry on both sides until golden brown and crisp, about 3 minutes per side. Continue frying in batches, adding oil as needed.

Drain on paper towels.

Makes about 24 latkes.

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Don't walk in front of me,  
I may not follow.  
Don't walk behind me,  
I may not lead.  
Just walk beside me and be my friend.

## RESEARCH



### Research Findings on Chronic Fatigue Syndrome (M.E.)

John and Cathy Prescott

Research continues around the world into many aspects of CFS/ME. Progress is slow but steady as CFS/ME becomes more accepted by the medical establishment and more researchers enter the field.

The main needs in CFS are still to understand its cause (or causes), to develop a definitive laboratory test, and to develop specific treatments.

A study of **brain activity**<sup>1</sup> by examining blood flow and brain oxygenation using functional magnetic resonance imaging (fMRI) showed that CFS patients had greater activity than healthy control subjects in several parts of their brain when challenged with a tiring cognitive test, essentially validating objectively just how exhausting mental activity is for CFS patients.

The neurologic effects of CFS may cause some of the sleep problems associated with CFS. Analysis of a large number of **sleep studies** of CFS patients in Belgium<sup>2</sup> showed that CFS patients had trouble getting to sleep and had poor sleep efficiency, with less slow wave sleep as well as experiencing 'wake-up' alpha-wave intrusion during slow wave sleep. There was however no association between RNAase L elevation and alpha-wave intrusion. RNAase L is an anti-viral protein that often becomes abnormal in CFS patients. The lack of correlation with alpha-wave intrusion in this study argues against the hypothesis of the Belgian researchers that RNAase L dysfunction causes immune function disturbance through a "channelopathy" that disturbs the movement of potassium into cells.

Another **sleep study**<sup>3</sup> compared the early sleep cycle (non-REM sleep) of 13 pairs of identical twins, of which one of each pair had CFS. The study also found reduced deep sleep in the CFS patients. The use of identical twins in this study was a neat trick to rule out any effects of genetic differences between individuals.

Most cases of **CFS seem to follow an infection of some kind**. An interesting series of studies in Australia is looking **prospectively** at patients who develop CFS following exposure to Epstein Barr virus (EBV), Ross River virus, and the bacterial agent of Q fever. *Prospective studies* mean trying to identify cases as they occur, rather than after they have occurred. Most patients infected with these agents do not develop CFS, but about 10% have done so in the Australian study, and met the criteria of CFS six months after initial infection. EBV causes mononucleosis ('mono') in adolescents. Patients developing CFS after 'mono' were sicker with 'mono' than those who didn't but, perhaps surprisingly, were quicker to develop an antibody response.<sup>4</sup>

Research is often painfully slow, but modern technologies potentially allow more rapid progress to be made than in the past. In a stunning application of microarray technology<sup>5</sup>, this Australian group **examined the early response of 30,000 genes** in mononuclear cells obtained from the blood of 7 patients who developed CFS in comparison with 8 patients who didn't. 30,000 genes represent virtually all the genetic make-up of humans! Over 700 genes were more expressed in patients who developed CFS, and the expression of over 200 were significantly correlated to the severity of the fatigue. Over half of the genes that had increased expression in the CFS patients were involved in ion channel activity, metal ion binding, immune responses and intracellular signalling. Increased expression of genes controlling ion channel activity may support the 'channelopathy' theory of the



Belgian workers mentioned earlier in the sleep study.

Interestingly, and **very disconcertingly**, none of these genes had been identified in previous studies of gene expression in CFS patients. This study illustrates some of the problems of comparing different patient groups with different control patients using complex large scale molecular technologies on peripheral blood white cells. These cells are not an obvious target for the disease process in CFS patients but are the easiest nucleated cell in the body to collect. It is going to be hard to tease out the basis of CFS from such studies, but they have to be done to leave no stone unturned in understanding such a complex illness.

#### Studies cited

<sup>1</sup>Cook *et al*, *NeuroImage* 2007.

<sup>2</sup>Van Hoof *et al*, *American Journal of Medicine* 2007.

<sup>3</sup>Armitage, *SLEEP* 2007.

<sup>4</sup>Vernon *et al*, *BMC Infectious Diseases* 2006.

<sup>5</sup>Cameron *et al*, *Journal of Infectious Diseases* 2006.

## HELPFUL WEBSITES

**Canada Mortgage and Housing Corporation:** [www.cmhc-schl.gc.ca](http://www.cmhc-schl.gc.ca). This site has information and research on mold in housing, healthy housing and fighting asthma in your home.

**ME-NET Home Page:** <http://www.me-net.dds.nl> > at the bottom of the ME-NET home page, you will find a CFS newswire in tickerformat with the latest 250 CFS newspaper stores 24 hours/day.

**CFS Blogs** that were published in the CFIDS Chronicle:

Learning to Live with CFS > [www.livewithcfs.blogspot.com](http://www.livewithcfs.blogspot.com)

Fighting Fatigue > [www.fightingfatigue.typepad.com/my\\_web\\_log/](http://www.fightingfatigue.typepad.com/my_web_log/)

### 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.

**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.**

## GENERAL INFORMATION

### Global Fibromyalgia Awareness Quilt

**announced:** If you are interested in joining this Global event, please go to:

<http://fmsglobalnews.wordpress.com/>

**WEB SITES:** If you are aware of interesting CFS/M.E. 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.

## CFS / M.E. EDUCATIONAL MATERIALS

**Video #1:** Sept. 12, 2001 CFS/M.E. Medical and legal Information Session with **Dr. Alison Bested F.R.C.P. (C), Dr. Alan Logan ND, and lawyer, Russell Howe, as speakers.**

**Video #2:** June 21, 2003, CFS/M.E. Medical Information Session with **Dr. Alison Bested F.R.C.P. (C), Dr. Alan Logan ND and Dr. Peter Powles**, Past chief of Medicine, St. Joseph's Health Care, Toronto and Sleep Disorder Specialist. Dr. Powles speaks on the possibility of mitochondria dysfunction in CFS/M.E.

**Video #3 & DVD:** A Medical Information Session with Dr. David Bell, internationally known expert on children/youth and adults with CFS./M.E.. Question and Answer session provided by Dr. Bell and Dr. Alison Bested.

Video #1 and #2 are \$20.00 each for members and \$25.00 for non-members. S&H and tax are included.

Video #3 and DVD are \$15.00 each for Members; \$25.00 for non-members. S&H and tax are included.

**CFS/M.E. Brochures:** our brochures contain the Canadian M.E./CFS Definition, and are

now available in English, French, Chinese and Portuguese, and on our web site. Please contact our **HELP-LINE** to order brochures to place in your neighbourhood. See CONTACT US below. THANK YOU FOR YOUR HELP.

## MEMBERSHIP AND DONATIONS

Our annual membership is \$20.00 and donations are greatly appreciated, as they are crucial in increasing the education and awareness of M.E./CFS throughout Ontario. Charity Receipts are issued for income tax purposes. We also welcome those who request a Complimentary Membership. Members receive our quarterly newsletter 'Reaching Out' with news on CFS/M.E., Research, Coping Tips, Recipes, Upcoming Events, and much more! We also contact our members with updates on Conferences, Television Programmes on the illness and our Annual General Meeting. Charitable Registration Number: 89226 7568 RR0001.

## CONTACT US

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

To receive information on CFS / M.E. or Support Groups, please call our **HELP-LINE**, 416 222-8820, or 1 877 632-6682. **Check out our Web Site: [www.meao-cfs.on.ca](http://www.meao-cfs.on.ca).**

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.