

# REACHING OUT

Winter 2007

## Flu Vaccination and Chronic Fatigue Syndrome

*Printed with permission from Dr. A. Bested*

Greetings! As we enter the flu season, I am writing to you about the flu vaccine as my patients with Chronic Fatigue Syndrome (CFS) 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

### ALSO IN THIS ISSUE

- 2 LETTER FROM THE PRESIDENT
- 3 Report on 2006 AGM
- 4 UPCOMING EVENTS
- 4 M.E. Assoc. COOKBOOK FUNDRAISER
- 4 New PROVINCIAL COORDINATOR
- 5 ADVOCACY / DISABILITY ISSUES
- 5 YOUR HEALTH – Cleaning Products  
for the Chemically Sensitive
- 7 ASK A DOCTOR
- 8 ON THE FUNNY SIDE
- 9 FROM OUR KITCHEN TO YOURS
- 11 RESEARCH
- 12 GENERAL INFORMATION

(continued from page one)

after the full dose of flu vaccine has been given.

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

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.

***Editor's note: The timing of this article is a bit late. We plan on including it next year in our Fall issue.***

## TIP

If you have a busy day planned for tomorrow, take your shower the night before. It's a great way of saving additional energy for the next day.

## FROM THE PRESIDENT



As the traditional Holiday Season fast approaches, everyone looks forward to renewing their respective rituals and traditions that make this time of year a very special and memorable period for all of us.

As president of The Myalgic Encephalomyelitis Association of Ontario I would like to extend to you all a most enjoyable Holiday Season and wish you the best of health, happiness and peace throughout 2008.

This season, we feel the loss of our dear friend and advocate Audrey MacKenzie who gave so much to this Association. Audrey will never be forgotten. She will always be in our thoughts and prayers.

This past year we were successful in securing a grant from the Ontario Trillium Foundation. Through that grant, we were able to hire our first part-time staff - a Provincial Coordinator. The successful applicant for this position is Ms Kimberley Dowds. I officially introduced and welcomed Kimberley to our Association at our recent Annual General Meeting. Kimberley comes to us with substantial administrative and field experience after working with March of Dimes Canada/Ontario for the past 9 years. We are most pleased and excited to have Kimberly Dowds join the MEAO team.

In cooperation with our new Provincial Coordinator, the Board of Directors of MEAO will now begin the process of also hiring a part-time "Fundraiser" for the Association, using designated funds from our Trillium Foundation grant. Together with our newly hired staff and our team of active volunteers, the Board of Directors plans to focus on "growing" and expanding the Association so as to make it more viable, more sustainable and more capable of successfully conducting advocacy work and providing services to the membership and others. Our goal, in fact, is to successfully provide all CFS / M.E.

sufferers across the province the best possible support, the most current information and direction to the best possible professional services for CFS / M.E.

It is now time, I believe, for the “CFS / M. E. train” to leave the station, as it were, and embark on the historic journey of having CFS / M. E. properly recognized, accepted and deemed worthy of receiving provincial, federal and corporate funding for research so that a cure for this serious and underestimated chronic illness can be found. As President of The Myalgic Encephalomyelitis Association of Ontario, I invite all of you to come on board “the CFS / M.E. train” and in so doing, become a part of what I believe will become a very historic and memorable ride for us all!

Sincerely,  
Anthony Rovito, President  
The Myalgic Encephalomyelitis Association of Ontario

## Report on 2006 AGM

*by Maries St.Paul*

On Saturday Nov. 24<sup>th</sup>, 2007, the M.E. Association of Ontario held its 2006 AGM at Women’s College Hospital, Toronto. Dan Watts, our Treasurer, chaired the meeting with his usual wit and style. The Annual Report and Financial Statements for 2006 were tabled, discussed and unanimously accepted by the membership.



Kimberley Dowds speaking at the AGM.

Once official business was completed, Tony Rovito, the President of MEAO, announced that the Association had recently hired a Provincial Coordinator for MEAO facilitated by funds made available to us by an Ontario Trillium Foundation Grant. The new Provincial Coordinator, Kimberley Dowds, was then officially introduced and given an opportunity to say a few words to the members present.



Dan Watts receiving his gift from Tony Rovito and Maries St.Paul

Beginning this year, the Board of Directors for MEAO decided that it would be most appropriate for the Association to formally and regularly honour its volunteers at the Annual General Meeting. This year, Tony Rovito (President), Maries St.Paul (Vice President), and Diane Meitz (Director), formally acknowledged and presented a token gift to retiring **Dan Watts**, Director for 6 years and Treasurer intermittently, **Carlos Rajkumar** who printed, assembled, emailed and posted our newsletters for the past 5 years and **Yvonne White** who is retiring from the Board, but has generously agreed to continue her excellent work as Provincial Membership Coordinator.

At our 2006 AGM, we said good-bye to three Directors: Lisa McGill, Dan Watts and Yvonne White, and welcomed four new Directors to the Board of MEAO: Christiane Garcia, Izzat

Jiwani, Chris Pike and Debbie Starkman (Treasurer).



Carlos Rajkumar with Diane Meitz

Our guest speaker was **Nancy Bradshaw, from the Environmental Clinic**. Nancy spoke on the services of the EHC, as well as living and coping with CFS. Following her very informative talk, Nancy and Dr. Bested answered questions from the audience.



Nancy Bradshaw and Dr. Bested taking questions from the audience at the AGM.

The M.E. Association, it seems, has turned a corner this year in so many ways: the passing of our dear Audrey MacKenzie, the receipt of the Ontario Trillium Foundation Grant and the subsequent hiring of Kimberley Dowds, our Provincial Coordinator. Perhaps some of our long-held dreams for the Association will now come true!

## NEWS and UPCOMING EVENTS

We recently hired our **New PROVINCIAL COORDINATOR** for the MEAO. Her name is Kimberley Dowds. (See LETTER FROM THE PRESIDENT on page 2 for details.)

### COOKBOOK FUNDRAISER

Diane Meitz, (Director on the Board of the M.E. Assoc.), along with a group of volunteers, is creating a cookbook to be sold in 2008. They are gathering their favourite recipes, and invite you and your friends to submit yours too. Along with your recipes, you can send a story or antidote as to why the recipes are special. Her group is also looking for recipes that have been helpful to you in dealing with ME/CFS, FM and MCS. The best ones will be selected. Proceeds from the sale of the cookbook will be donated to the M. E. Assoc. of Ont. to support its education and awareness activities. Please print or type your recipes and mail them to: M.E. Assoc. of Ont., P.O. Box 84522, 2336 Bloor St. W., Toronto, Ont. M6S 4Z7

### 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.

## CFS Documentary

The Downtown Toronto Fibromyalgia Group will be showing the acclaimed documentary about ME/CFS/CFIDS called "I Remember Me" on Wednesday 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.

## ADVOCACY / DISABILITY ISSUES

### UK Advocacy Group Takes Fight for ME/CFS to the High Court

While the World Health Organization has recognized ME/CFS as a physiological not psychological condition, in the UK, ME/CFS organizations are still fighting for understanding and recognition. The United Kingdom's National Institute for Health and Clinical Excellence issued new guidelines for ME/CFS this past August recommending Cognitive Behavioural Therapy/Graded Exercise Therapy (CBT/GET) as the primary management strategy for ME/CFS patients. Concerned that the guidelines will result in wasted time and more suffering for those with ME/CFS, the health advocacy group One Click has gone directly to the High Court for judicial review to have the guidelines changed.

One Click in their submission to the High Court referred to the Canadian Consensus guidelines as the most comprehensive and requests "Full consideration and application of the Canadian ME/CFS Case Definition and Treatment Protocols".

For more information on One Click visit:

[www.theoneclickgroup.co.uk](http://www.theoneclickgroup.co.uk)

The NICE guidelines can be found at:

[www.nice.org.uk/guidance/](http://www.nice.org.uk/guidance/)

The Canadian Consensus guidelines can be found at:

[www.mefmaction.net/documents/journal.pdf](http://www.mefmaction.net/documents/journal.pdf)

## YOUR HEALTH

### Cleaning Products for the Chemically Sensitive

Those who are chemically sensitive already know it's important to watch every thing you use. Chemicals used in cleaning products can be particularly harmful. Following are some tips on non-toxic, safe products to use for cleaning.

#### New products:

##### Dryer Balls

Instead of fabric softeners or dryer sheets, you can now use "dryer balls" in your dryer. These are still hard to find in Canada, but are beginning to be seen in some drug stores. They are rubberized balls that last for years, are non-toxic and do the same job as fabric softeners. Throw two of them in your dryer and forget about them. Not only are they safe, but they also save you money.

##### Microfiber Cleaning Clothes

Microfiber cleaning cloths allow you to clean almost everything with just the cloth and hot water. They can also be used dry to dust. These durable, reusable cloths are made from synthetic fibers and are not treated with chemicals.

In the kitchen, the tiny fibers pick up dirt and food residue when cleaning counters and stovetops. □ In the bathroom, they can clean tub, sink and shower stall surfaces. Chrome faucets, taps, and showerheads can all be polished with microfiber alone. Windows can be cleaned with just microfiber cloths and water. Use one cloth to wash, and another to dry. No dirt, no streaks.

Dusting is easy with microfiber. The little fibers trap dust so that it stays in one place instead of flying around. When the job is

finished, shake the cloth outside, or rinse in lukewarm water and hang to dry.

Floors can be dusted and washed with microfiber mops. The microfiber head can usually be removed from the mop handle, rinsed in a small amount of warm water, and replaced on the handle to continue the job. Microfiber clothes should be cleaned after use by washing in warm water with a little dish detergent. They can be washed in the washing machine but must be kept away from fabric softener. Fabric softener clogs the fibers and will ruin the cloth. For tough cleaning, use microfiber cloths with vinegar solution.

Prices range from cheap (\$1.00) to pricey (\$20.00). There are differences in quality and durability. Higher priced cloths usually have smaller fibers and pick up more dirt and dust, but even the cheap ones get good results. They can be purchased at Canadian Tire and Home Hardware.

### **Tried and True products**

#### Vinegar

Vinegar naturally cleans like an all-purpose cleaner. Mix a solution of 1 part water to 1 part vinegar in a new spray bottle and you have a solution that will clean most areas of your home. Vinegar is a great natural cleaning product as well as a disinfectant and deodorizer. Always test on an inconspicuous area.

It is safe to use on most surfaces and has the added bonus of being cheap. Don't worry about your home smelling like vinegar. The smell disappears when it dries. You can clean the stovetop, appliances, bathtub, toilet, sink, and countertops. Mop the floor in the bathroom with the vinegar/water solution. It will also remove the soap scum and hard water stains on your fixtures and tile. However, make sure it is safe to use with your tile by testing a small area first. Improperly diluted vinegar is acidic and can eat away at tile grout. Never use vinegar on marble surfaces. Use vinegar as a natural fabric

softener. Add ½ cup of vinegar to the rinse cycle in place of fabric softener.

#### Lemon Juice

Lemon juice is another natural substance that can be used to clean your home. Lemon juice can be used to dissolve soap scum and hard water deposits. Lemon is a great substance to clean and shine brass and copper. Lemon juice can be mixed with vinegar and or baking soda to make cleaning pastes. Cut a lemon in half and sprinkle baking soda on the cut section. Use the lemon to scrub dishes, surfaces, and stains.

#### Other Products

Baking soda can be used to scrub surfaces in much the same way as commercial abrasive cleansers.

Borax disinfects, deodorizes, kills mold and mildew in toilets, tubs and on floors.

#### HANDY HINT

To clean silverware:  
line a casserole dish with silver foil. Add 2 tablespoons of salt and boiling water. Add your silver ware and watch your silver clean itself!

### COPING TIPS and IDEAS FROM YOU

You will see in this issue **TIPS** (in the orange boxes) on how to save your energy and make life a little easier. Have you any tips or Handy Hints you could share with our readers? We are looking especially for those ideas that help you cope at the best and the worst of times. We'd love to hear from you! Please mail them to: The M.E. Association of Ont., Newsletter Tips, P.O. Box 84522, 2336 Bloor St. W., Toronto, Ont. M6S 4Z7.

## ASK A DOCTOR



By Dr. Alison Bested,  
MD FRCPC

**1) How much exercise should someone with CFS do in a day?**

**2) How much rest should someone with CFS get in one day?**

Balanced Exercise and Rest = Pacing

### Question #1:

Start where you are. If you are in bed do range of motion exercises which means you move your arms and legs fully in the directions they can move naturally. If you think you can walk for 20 minutes then start and walk 5 minutes then reassess. If you are tired at 5 minutes, then turn around and walk back. A total of 10 minutes daily is better than 20 minutes and crashing the next day.

If you want to increase your activities, increase by 10%. This means if you can walk for 10 minutes already you add 10%, which means another 1 minute of total walking time.

According to the CFS/ME Clinical Definition the exercise program should be individualised. "Exercise programs must be adapted to accommodate the patient's circumstances and needs. Those patients who are more impaired and not able to tolerate an exercise program should be encouraged to increase physical activity within their limits." Exercise programs that are designed for Chronic Fatigue Syndrome patients "must be entered cautiously, as clinical studies have indicated that symptoms worsen in approximately half of the ME/CFS patients." This was published in the Journal of Physiotherapy, August, 87, 2001.

The Clinical Working Case Definition states that "the goal of a management/treatment program is to empower the patient by encouraging them to **trust their own experiences**, to enhance the patient's

awareness of the activities in which they can cope without exacerbating symptoms and to pace themselves accordingly. The program should aim optimizing the patient's ability to maintain function in everyday activities, being as active as possible, within their boundaries, and then gently extending those boundaries." The Journal of Chronic Fatigue Syndrome with the clinical working case definition also states that the patient should be educated "teaching patients to recognize early warning signs and prevent crashes; mindfulness exercises encourage patients to be mindful of the impact of activities and environments on their physical, cognitive and emotional states within the ongoing flux of experience. This encourages recognition of the early warning signs of excessive fatigue and/or sensory stimulation, information overload, pressure from excessive speed, excessive stress or inability to organize tasks, etc. This provides patients with the opportunity to respect warning signs and prevent crashes, or for early treatment."

### Question #2:

The reason to pace is to prevent crashing and days in bed after going over your personal physical limits. By pacing and not crashing you stay on a more even keel, get more things done in the long run and also don't get so frustrated, anxious and depressed.

How do you pace? You listen to your body. Some of you are mind and body disconnected. You are so used to pushing your bodies that you are writing cheques with your mind that your body can no longer cash.

How do you listen to your body? You close your eyes and ask yourself every half hour to begin with, "Body in this moment what do I need?" If your answer is rest, ask yourself, "Body, how much time do I need?" Then count by 5s e.g. 5, 10, 15 etc. until a number comes up for you. This number is how much time you need to rest at this time.

**Then go and rest, which means lying down flat, eyes shut, either meditating or**

**sleeping: not watching TV or reading or talking on the phone.** Have a nap after lunch if you need it but not past approximately 3 p.m. because it will interfere with sleeping at night.

Some of you will need to rest every half hour if you are severely fatigued. Others may need to rest 10 minutes out of every hour. Your body will tell you – if you listen.

Denial is a great coping mechanism until it no longer works and you're in a crash. When you are lying in bed during a crash, I challenge you to ask yourself in that moment if you are lazy – of course not, you're just too tired to move. I challenge you to keep a daily diary (activity log) every hour and track your activities, rest periods and crashes. Learn what pattern of activities and rest works best for you. Then ask your family to support you to keep you on track. Seeing your diaries helps to get you through your denial and your family's denial. It may open up other feelings that are a result of being chronically ill. Grieving your losses including your job, social activities and income, is part of dealing with your illness. You may need help from your doctor or other health professional to deal with these feelings during this time.

I find most patients learn to cope better with their CFS/ME once they learn to pace so they can stop crashing and look forward to better days ahead.

All the best,  
Alison C. Bested MD FRCPC

### **References:**

A. Bested, A. Logan and R. Howe, *Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia*, Cumberland House, 2006.

*Editor's note: ' Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia' provides much needed and valuable information for those with CFS and Fibromyalgia.*

J. Carruthers et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols; Journal of Chronic Fatigue Syndrome, Volume 11, Number 1, 2003.

<http://www.mefmaction.net/documents/J094v11n04.pdf>

[www.ocfp.ca](http://www.ocfp.ca) -->Communications -->Publications, scroll to Environment & Health

## **TIP**

I keep a quarter in each of my jacket and coat pockets so that when I am grocery shopping and need a cart, I never have to go digging into my purse and wallet.

Of course, when I'm finished with the cart, the quarter will go back into my pocket for the next time.

## **ON THE FUNNY SIDE**

### **Why We Love Children**

1. A nursery school pupil told his teacher he'd found a cat, but it was dead. 'How do you know that the cat was dead?' she asked her pupil. 'Because I pissed in its ear and it didn't move,' answered the child innocently. 'You did WHAT?' the teacher exclaimed in surprise. 'You know,' explained the boy, 'I leaned over and went 'Pssst' and it didn't move'.

2. An exasperated mother, whose son was always getting into mischief, finally asked him 'How do you expect to get into Heaven?'



The boy thought it over and said, 'Well, I'll run in and out and in and out and keep slamming the door until St. Peter says, 'For Heaven's sake, Dylan, come in or stay out!''

3. One summer evening during a violent thunderstorm a mother was tucking her son into bed. She was about to turn off the light when he asked with a tremor in his voice, 'Mummy, will you sleep with me tonight?' The mother smiled and gave him a reassuring hug. 'I can't dear,' she said. 'I have to sleep in Daddy's room.' A long silence was broken at last by his shaky little voice: 'The big sissy.'

4. When I was six months pregnant with my third child, my three year old came into the room when I was just getting ready to get into the shower. She said, 'Mummy, you are getting fat!' I replied, 'Yes, honey, remember Mummy has a baby growing in her tummy.' 'I know,' she replied, but what's growing in your bum?'

5. A certain little girl, when asked her name, would reply, 'I'm Mr. Sugarbrown's daughter.' Her mother told her this was wrong, she must say, 'I'm Jane Sugarbrown.' The Vicar spoke to her in Sunday School, and said, 'Aren't you Mr. Sugarbrown's daughter?' She replied, 'I thought I was, but mother says I'm not.'

6. A little girl asked her mother, 'Can I go outside and play with the boys?' Her mother replied, 'No, you can't play with the boys, they're too rough.' The little girl thought about it for a few moments and asked, 'If I can find a smooth one, can I play with him?'

## FROM OUR KITCHEN TO YOURS

### "Santa's Whisker's" Cookies

#### Ingredients

3/4 cup Margarine  
2 cups Flour  
3/4 cup Sugar  
1 tablespoon Milk

1 teaspoon Vanilla  
3/4 cup finely chopped candied red or green cherries  
1/3 cup finely chopped pecans  
3/4 cup coconut

#### Directions:

Beat margarine with an electric mixer on medium to high speed for 30 seconds. Add about half the flour, the sugar, milk, and vanilla. Beat till thoroughly combined. Stir in remaining flour. Stir in cherries and pecans. Shape into 8-inch rolls. Roll in coconut.

Wrap in wax paper; chill 2- 24 hours.

Cut into 1/4-inch slices. Place on an ungreased cookie sheet.

Bake in a 375 degree oven 10-12 minutes or until the edges are golden.

Cool cookies on a wire rack.

Makes about 60.

### Candy Cane Cookies

#### Ingredients

1 cup butter or margarine  
1 cup powdered sugar  
1 egg  
2 teaspoons vanilla  
2 1/2 cups flour  
1 teaspoon salt  
1/2 cup finely crushed candy cane mixed with  
1/2 cup sugar  
1/2 teaspoon red food coloring

#### Directions:

Mix all ingredients. Split dough into equal portions. Color one portion of the dough red. Refrigerate the dough long enough to be able to easily work with it. Break off one piece (approx. one teaspoon of each color) and roll by hand into four to five inch tubes. Twist the two pieces together and bend forming a candy cane. Sprinkle the top with the candy cane/sugar mixture. Be careful when removing from the cookie sheet, they will break easily. Bake at 350 degrees for 6 – 9 minutes.

**Pamphlet: Overcoming Systemic Barriers to Effective Management of Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS / M.E.) in Canada**

The pamphlet which is included in this newsletter was originally produced by the participants involved in the Chronic Management Conference that was held in Calgary, Alberta from October 28 to November 1, 2007 organized by Dr. Eleanor Stein. The pamphlet was produced to highlight the barriers that CFS / M.E. patients have with the medical system when trying to get a diagnosis or treatment for their illness. The pamphlet also highlights the fact that: 1) Doctors have not been taught about CFS / M.E.; 2) Doctors are not financially compensated when dealing with patients who have complex medical conditions; 3) CFS / M.E. is a newly recognized physical syndrome and 4) There are currently no research funds available for CFS / M.E., often referred to as an "invisible illness". The MEAO encourages all of its members to actively distribute this pamphlet within the medical profession, the various levels of government and the general public. The Association fully endorses this pamphlet because it accurately represents the status of CFS / M.E. currently in Canada - a status that needs to change now! If you require additional copies of this pamphlet, please call our Help-Line. The MEAO is currently exploring the possibility of reproducing this pamphlet in a "brochure" format. We will keep you posted on this initiative.

**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.**

## HELPFUL WEBSITES



### Abilityonline.org

Phoenix Rising, web site plus newsletter:  
[www.phoenix-cfs.org](http://www.phoenix-cfs.org)

For more information on the Environmental Health Clinic and the Women's Health Matters Forum, in Jan. 2008 go to:  
[www.womenshealthmatters.ca/centres/environmental](http://www.womenshealthmatters.ca/centres/environmental)

Website of Dr. Byron Hyde, author of "The Clinical and Scientific Basis of Myalgic Encephalomyelitis":  
[www.ahummingbirdsguide.com](http://www.ahummingbirdsguide.com)

For an excellent source of information on healthy oils and their benefits:  
[www.udoerasmus.com/FAQ/FAQ4\\_en.htm#4\\_1](http://www.udoerasmus.com/FAQ/FAQ4_en.htm#4_1)

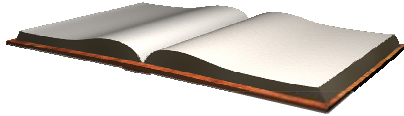
But You Don't Look Sick website with the Spoons story:  
<http://www.butyoudontlooksick.com/>

An excellent "research site" is: [MDLinx.com](http://MDLinx.com)

## ARE YOU MOVING?

Each year several newsletters are returned to us by the Post Office because these members have moved and forgotten 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 progress from the EHC  
by Kathleen Kerr, MD

A number of research projects are at various stages currently at the Environmental Health Clinic. A paper entitled "Functional Impairment in Patients with Chronic Fatigue Syndrome, Fibromyalgia, and Multiple Chemical Sensitivity Referred to the Environmental Health Clinic, Toronto, Canada" has been completed and is being submitted to a peer-reviewed journal for publication. In this study we found that patients coming to the clinic had very low functional status as measured by a commonly used questionnaire called the SF-36 which rates functions in 8 areas including physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to emotional health problems, emotional well-being, social functioning, energy and fatigue, and general health perceptions. We looked at people diagnosed with chronic fatigue syndrome (CFS), fibromyalgia (FM) or multiple chemical sensitivity (MCS), or with 2 or more of these illnesses. Those with all three had the lowest scores. Our findings were very similar to a recent study from the US (Brown & Jason 2007), and earlier studies, including an international study from the UK, Germany and the US in 2001 (Hardt et al 2001). [Another similar study by Komaroff et al (1996) was the first to point out that the SF-36 scores were lowest for physical problems, but not as low for mental problems. This pattern is clearly different than the SF-36 scores from people with depression. It was interesting to see that this same pattern emerged in our study, just as in the other similar studies.]

Another interesting study is just starting, in which a second year medical student is

assessing difficulties people with MCS have had finding safe housing or shelter. He would be interested in anyone's personal experiences of lack of availability of suitable housing and what they ended up doing. We occasionally hear of someone living in their car or a tent, etc. We want to see if there is a way to keep track of these situations and, additionally, to find referral resources for people with MCS who are unable to live in their current homes. Anyone with information or personal experiences they would be willing to share could contact Nancy Bradshaw at the EHC.

There are more plans, but these are the most current projects.

Kathleen Kerr MD, Dip Env Health  
Staff Physician and Medical Research  
Liaison,  
Environmental Health Clinic, Women's  
College Hospital  
Lecturer, Department of Family & Community  
Medicine  
Faculty of Medicine  
University of Toronto

## GENERAL INFORMATION

**ASK A DR. / ASK A LAWYER:** We invite you to submit your questions to either or both. The most popular questions will be used in future issues. Mail your question(s) to us; see CONTACT US below.

**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 included.

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