Reaching Out

Spring, 2007
Agreement #40665071

It is with great sadness that we announce the death of our dear friend, colleague and family member Audrey May Mackenzie. Audrey, originally from Springfield, Ontario, was a registered nurse who became an accomplished ICU nurse, and later a head nurse. Nursing was her life and love.

For over 15 years, Audrey was a driving force and Board Member of the Myalgic Encephalomyelitis Association of Ontario (MEAO), and served as its President from 2000-2006. As President of the MEAO and a sufferer of Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (M.E./CFS) herself, Audrey tenaciously advocated for recognition and services for the illness. She tirelessly devoted all of her waking time in assisting friends, colleagues, and all who contacted the association to seek direction and advice on how to best deal with the many impacts of ME/CFS on them and their loved ones. Audrey became quite an authority on ME/CFS and was regularly called on to impart her knowledge and expertise, for example as a valued Consumer Advisor to the Environmental Health Clinic at Women's College Hospital.

While living in Toronto and working in the Health Services Field, and while persistently leading The Myalgic Encephalomyelitis Association of Ontario for so many years, Audrey nurtured many close friendships. She will be sadly missed by her many friends, colleagues and co-advocates within the M.E./CFS community.

A family funeral for Audrey was held on Saturday, June 9th in Ingersoll, Ontario.

A "Toronto" Memorial for Audrey (for all of those friends, colleagues and fellow-advocates who were not able to attend the family's funeral service in Ingersoll), was held on Sunday, June 24, 2007 at the Women's College Hospital, Toronto.

We are dedicating most of this newsletter to the words and thoughts we received from some of Audrey's friends and colleagues in order to share them with you.

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PRESIDENT'S EULOGY FOR AUDREY MACKENZIE

I initially met Audrey May MacKenzie when I was first arm-twisted to join the Board of Directors for the Association, in 2004, by my wife Rita, who has had the illness for the past 20 years. For the two years that followed, Audrey, as president, would often call on me to pick her up to drive her to our monthly Association. As we drove, Audrey would, on occasion, share with me some personal anecdotes. On one such occasion I learned that Audrey once owned a very sporty Italian sports car- a convertible Fiat Spider. She "loved" the look and feel of that car but it gave her nothing but trouble. One time, while traveling on the Don Valley parkway (in the passing lane), with the top down, feeling the wind on her face and enjoying maneuvering the curves of the road, she suddenly lost a front wheel. Her challenge, at this point, was to carefully steer and try and maintain the car on the road, without applying the breaks so as not to crash it into the guard rail or go over the embankment. That whole ordeal, Audrey said, lasted only a few minutes but it seemed a lifetime. "I don't know who was more scared, she said, me or the man driving beside me, in the inside lane, given the petrified look on his face and one of complete amazement, at the same time."

For me, this anecdote conjures up the image of a woman, full of adventure, energy and tenacity. It is this image of Audrey that will remain with me. I believe that it was these and similar traits that Audrey applied to her extensive work with the M.E. Association of Ontario, first as a Director and then as President. As president of the Association, Audrey found herself in a very complex world of a medical condition which was not very well accepted and which, in fact, was frowned upon by many within the medical establishment. Her tenacity and her inner convictions however, allowed her to successfully maneuver the various hurdles that stood in her way, as she worked to educate both the general public and the medical community about the devastating condition of M.E./CFS.

Audrey was not one to shy away from challenges. There were times when she may have been rebuffed and perhaps not taken very seriously. However, some of the negative tactics used to undermine her efforts were no match for Audrey. Like the Bunny from the Ever-Ready battery, Audrey just kept on going, going, going and going, until she found a way to work around those obstacles.

In the end, Audrey's overall commitment, in this area, helped to bring much more credibility to the condition of M.E./CFS within both the Medical and Legal communities and the general public as a whole. During this process, Audrey also became a beacon for the many sufferers of this condition who, with little support, found themselves alienated. She personally helped to reassure them that their symptoms were, in fact, real and she assisted them as well, to maneuver both the medical and legal labyrinths that they were personally encountering. Because of these steadfast efforts on everyone's behalf, there are many out there today, who have come to call Audrey MacKenzie a true friend.

Audrey may no longer, be with us, but her spirit, her tenacity and her determination will continue to motivate all of us to work harder until the condition of M.E./CFS is fully understood and accepted.

Audrey, as my mind's eye sees you driving away in your red Fiat spider convertible, I wish you a very smooth and peaceful ride.
I, along with all of those individuals, whose lives you have touched, also extend to you our heartfelt thanks.

You will be missed! You will not be forgotten!

Anthony Rovito, President

Family and close friends request that, if desired, Memorial Donations may be made to The Myalgic Encephalomyelitis Association of Ontario and mailed to P.O. Box 84522, 2336 Bloor Street West, Toronto, Ontario, M6S 4Z7

THOUGHTS ON AUDREY FROM FRIENDS

Eulogy by Diane Meitz

My Dear, Dear Audrey...

I feel very blessed to have had this very special lady (Audrey) in my life.

Although we became friends and colleagues late in life it was as if we had known each other all of our lives:

We were both from small towns in Ontario.

We both graduated from the old school of nursing. We had the same values and ethics. We were proud of our nursing caps and black bands.

We both came to the big city to further advance our nursing careers and to develop more skills. We were fiercely independent women and fully dedicated to our profession.

We are both cat ladies having a great love and passion for our feline companions – we were always sharing our cat stories. I am glad that Audrey got to stay at home with her beloved Fang for as long as she did...

Sadly, we both suffered from severe cases of Chronic Fatigue Syndrome.

As sick as Audrey was, she was always so kind, compassionate and caring - never complaining. This past winter I was very ill and had to have surgery. In the midst of a winter storm, Audrey phones me at the hospital and tells me that she is coming to the hospital to see me so that she, and I quote, “can be with me and to hold my hand.” I thanked her for her kind offer and told her that I would be happier if she was safe at home with her cat Fang. This lady who was so ill, with so little strength and energy was still thinking of others and reaching out to them!

This past spring it was Audrey's mission to get to the Canada Blooms Show at the Metro Convention Center. She sat among the greenery and the flowers and was so happy to be there.

How she loved her flowers and herbs.
How she loved scrabble and bridge.

How she loved High Park. Her joy was in taking the little train ride around the park.

How she loved to cook. After Audrey's retirement as president of ME Association of Ontario she became obsessed with cooking. We got her a new set of pots and pans and she was so thrilled. Audrey loved watching the Cooking channel.

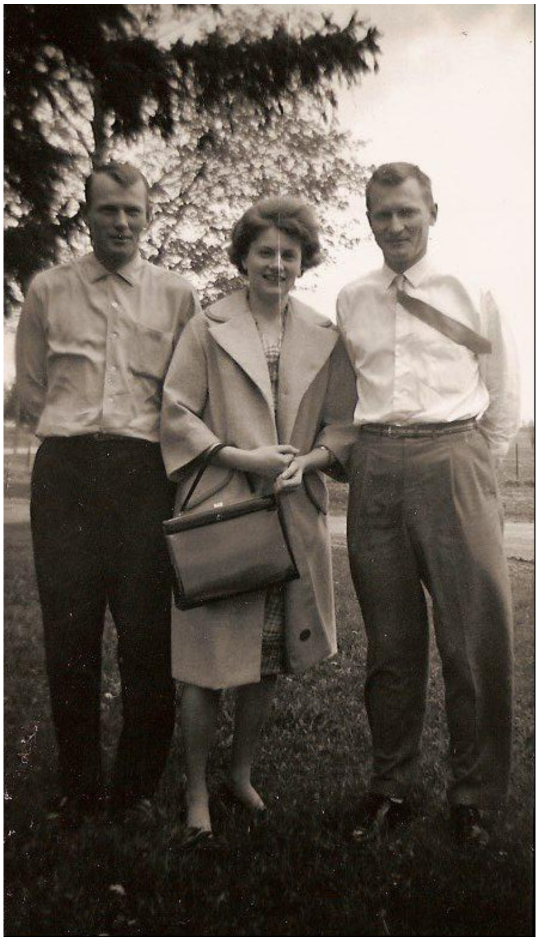
In her ME/CFS newsletter, appropriately called "Reaching OUT", Audrey always had recipes and so much valuable and helpful information. Yes, I can see her now- her arms reaching out and embracing the moment for the goodness. Telling us that now she is at peace.

AUDREY,

Lena sends her blessings.

We love you. Your spirit and kindness will always be remembered. We will miss you so much.

And of course, here is a send off, as well, from your furry friend Fang: MEOW, MEOW, MEOW, MEOW.



PHOTOS OF AUDREY'S YOUTH

Alison C. Bested M.D. F.R.C.P.(C)

When I think of Audrey I think of laughter and light.

Audrey as you know was the Past President of the M.E. Association of Ontario for many years. She was also a very special patient of mine. We had many lengthy discussions about the Association throughout the years. She was always out there educating everyone from the public, M.E. sufferers and health professionals such as me about M.E. She was a superb arm twister and would always end her request with “ah go on, you can do it, just this once”, a smile and a throaty chuckle. Once she got an idea in her head, it was full steam ahead.

She was a consummate reader, answering emails until the cows came home and reading Co-cure for the latest and greatest. She was extremely intelligent and before she became ill she was an I.C.U. Head Nurse who was in on the beginnings of transplant surgery while it was in its infancy. This was when the I.C.U. consisted of a row of beds in a big room that was divided by curtains. Talk about a harry place to work. She loved it.

She was the master of describing situations with humour. I remember one situation in particular that particularly hit home with me. She described the first month the new interns arrived at her teaching hospital with their ‘I know it all, save the world’ attitude. She delighted in reducing the new doctors over inflated egos “just a touch” so that they would fit through the doorway when they entered a room.

Audrey may not have had the best of health but she believed in making the best of her situation. She lived alone with her long time buddy, Fang, her long-haired Persian cat. Fang talked to her constantly and his antics delighted her and kept her entertained especially in the last few months.

She had many health related food restrictions so she decided to get around this obstacle by learning to cook. She became an avid watcher of the Food Network Channel. She would constantly experiment with new recipes that would end up in the M.E. Association of Ontario’s newsletter, Reaching Out, if they were tasty. I was often the recipient of samples of these food experiments and was always delighted to give my opinion of her latest culinary endeavour. She was a great cook.

She was an avid bridge player and played with her neighbour on an ongoing basis. She used to laugh at the fact that until this year she always lost. She thought winning this year for the first time was a good sign that her “brain was coming back”.

After retiring as President of the M.E. Association of Ontario, she continued to write the newsletter Reaching Out. It was always the latest and the greatest information from around the world combined with humour and wonderfully supportive information that was a combination of Audrey’s wit and dry sense of humour. She also was involved with updating the M.E. Association’s Website to make it more accessible and user friendly. She was involved in fundraising and personally fought for the City of Toronto’s grant for the M.E. Association and other private donations. The Association under her term started mailing out the 2003 Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinical Working Case Definition, Diagnostic and Treatment Protocols to all of the Hospital Chiefs in Ontario hospitals. I can attest to the power of this mailing as more and more physicians are becoming knowledgeable about M.E./C.F.S. here in Toronto and Ontario and the attitude towards the illness is slowly changing.

As her physician it was a losing uphill battle trying to get Audrey to pace herself or to stop smoking. When I went into my ‘spiel’ about these topics, she would politely listen and say, “Okay, now can we talk about the

Association business?" with a sparkle in her eye.

Audrey gave of herself selflessly and courageously for many years. She helped not only the M.E. Association but also the national association ME/FM Action Network in any way she could. She promoted on behalf of the women, men and children that suffer with Myalgic Encephalomyelitis.

My grandmother, Bibi, used to say to us as kids, the secret of life is to give yourself away. Audrey embodied this secret.
She delighted in life. She went for daily walks for coffee at the nearby café. I was concerned about her mobility and encouraged her to use a cane for support. She happily refused saying that there were benches all along the walk and that she enjoyed walking from bench to bench and not to worry "I always make it home", she said.

After I gave a CFS talk this past November, Audrey told me that she was going to see the Cavalcade of Lights. This is the festival at Nathan Phillips Square where they have music, light up the huge Christmas tree and have fireworks to celebrate the beginning of the holidays in downtown Toronto. We had a ball watching the fireworks display. Audrey was like a big kid delighted by the spectacular light show that night - a memorable night.

To quote from Michael Landon's Little House on the Prairie's *Remember Me* episode, November 1975:

"Remember me with smiles and laughter,
for that is how I will remember you all.
If you can only remember me with tears,
then don't remember me at all."

Audrey gave me a copy of her favourite cartoon. It's hanging in my office. It is a picture of a frog that has his head in the mouth of a crane and the frog's arms are strangling the neck of the crane. The caption reads, "Never give up!" Every time I look at it I will smile and remember Audrey.

Dr. Lynn Marshall

When I was first told about Audrey's passing, and was still in shock, the first word that came to my mind in thinking about her was courageous.

Even though her health was "not good" (which was honest, but understated), Audrey had the courage to apply the energy, experience, and expertise she had for the benefit of others on a continuing basis.

I knew Audrey mainly in her capacity as a Consumer Advisor to the Environmental Health Clinic (EHC). I believe that her in-depth knowledge of the health care system, her compassion for the needs of those with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, and other commonly overlapping chronic conditions, and her clever ideas, advanced the 'consumer cause' enormously.

Audrey was connected. Because of her tremendous good will, she seemed to have contacts everywhere. She would set up meetings with politicians and media people and enlist support from us at the EHC. Whenever we at the EHC needed consumer feedback on a particular issue, she and her partner in caring, Eleanor Johnston, would communicate with key people and report back, which was extremely helpful and time-conserving.

Audrey also committed to attending meetings where the EHC might need consumer input. I can remember her warning me on several occasions that, while she would attend a particular meeting, she knew she was "not in the best shape", and so would not be able to contribute much. "It's better to have a blob in the chair than an empty chair", she would say. She would sit, being a presence, quietly listening, until things got a bit confused or off track, and then- zing! She would shoot this arrow of an insightful comment out of her mouth, and inevitably hit the bullseye at the heart of the matter!

At the EHC, for several years, Dr. Annette Lorenz and I facilitated a 10-week coping strategies program for EHC patients. Annette, a former pilot, liked to use the aviation alphabet, “alpha, bravo, charlie”. She talked about “the three charlies” that were key to discovery and maintenance of purpose and meaning in life, even with the adversity of chronic illness. Audrey had found purpose and meaning in her life and epitomized Annette’s “three charlies”: compassion, communication, and companionship.

Interestingly, just like the EHC patients kept spontaneously adding “charlies” to these three that they found helpful as mantras for themselves, I also have naturally added several “charlies” to cement my memories, and help articulate my appreciation of Audrey: courage, continuing, cleverness, connected, contact, caring, commitment, contribution.
I can think of more, and I am sure many of you will associate other great “charlies” with Audrey, which it would be lovely to hear. However, I will add only one more, which I think was especially key for Audrey: chortling.

Audrey’s chortle not only served her well, but cheered us all. May it remain forever in our memory banks!

Lydia Neilson, President/CEO
National ME/FM Action Network

I cannot remember when I first met Audrey. It seems like I knew her forever. She was my friend and my confidante. She was always there to lend a helping hand. Anyone who met Audrey would never forget her.

Whenever someone called our organization and special intervention had to be done, Audrey would go out of her way to assist. She represented unselfishness and caring of the highest form. She is the role model for us to follow. I will miss her terribly.

A Friend to Everyone /
Things Audrey Would Never Say
Maries St Paul

As we gain in wisdom, one of the things we learn is how to recognize what makes a person a good friend. In all the articles people have sent us, they wrote about all the wonderful things that Audrey did.
I have another view of Audrey I would like to share: it’s all the things you never heard Audrey say:

- No thanks, I’m cutting back on my coffee intake.
- Can I call you tomorrow? I’m watching my favourite TV Show.
- There’s no way I can get that done in time unless I pull an ‘all nighter’!
- Sorry, I can’t talk (or help, or listen) to you right now; I’m too tired.
- Haven’t I heard you say the same thing a dozen times before?
- No, I can’t make it to your party.
- Can I call you back, I’m just sitting down to have my dinner.
- I have no patience with people.
- No thank you, I’m cutting back on my smoking.
- I won’t take ‘no’ for an answer!
- I would rather sit and do nothing.
- Do you realize you’re calling me at 2 a.m.?

Robert Service
Treasurer,Waterloo/Wellington M. E. Assn.

Despite having the severe health challenges that she faced, Audrey managed to consult with members of the provincial government and other agencies on behalf of all people that suffer from M. E. and kept us up to date with any progress that she was able to make. With her newsletter, she kept people in our support group informed as to upcoming events and plans of the M. E. Association of Ontario and also of her interaction with other like-minded associations and groups. That helped our members see a bigger view of the status of our disease in the province of Ontario and also nationally. Her efforts and progress helped to keep hope alive, especially in our region which has been chronically under serviced by the medical profession.

Her most recent support activity for our group was to coordinate the loan of one of the 3' x 3' display boards created by the M.E.O. This display is currently in a prominent location at the central library of Wellington County.

In reviewing the seven years of correspondence that I have enjoyed with Audrey, a few things stand out. She never lost her sense of humour and was always prepared to help in any way she could. This meant that talking with her was a pleasure and that dealing with her was straightforward and productive.

Over the years, she has been a unifying advocate for all support groups in Ontario, successfully putting forth the plight of people with and M. E. to the responsible institutions in the province. In addition, she has been a supporter of the Waterloo Wellington M. E. Association as a donor and as a member for many years.

Tiina Leivo-Watts
Friend and Colleague

To Audrey, reaching out to other people came naturally. I was gently reminded of this one warm winter day when I visited her High Park neighborhood. She suggested we walk to her local café/deli that she visited almost daily. Both looking forward to having coffee and a chat, we casually propped ourselves on two bar stools that were tucked in the corner of the tiny store. There were numerous Polish foods for sale and I noticed an elderly Polish man in a worn but tidy dark grey suit leafing through an ethnic newspaper in the opposite corner. As we made ready to leave, he began a lively conversation with Audrey. Assuming he knew her, I eyed some of the store shelves to let them banter on a while. Not really listening, I was aware that he had a thick accent. Audrey smiled and nodded as the fellow spoke passionately about what I took to be a political situation in Poland. Finally she bid him farewell and we headed toward her apartment. For a few moments Audrey was quiet and then I commented on her enthusiastic friend. I knew that she easily met local people and had friends throughout High Park. Smiling, she told me she sees the same man, every time she visits the café. That was an indication to me that Audrey was again using her power of connection with others, finding common ground with diverse individuals and sharing their concerns. As we turned the corner onto High Park Ave. she glanced at me sideways and said “ and I never understand a single word he says!”. Apparently the man spoke Polish to her every time they met. Every conversation brought out her broad smile, eager nods and intermittent “right!”, “sure!”, and “OK” without her comprehending the least bit about his message.

Margaret Parlor

Audrey was special.

I first talked to Audrey about how the education system treats young people with ME. "Let's get it fixed" was her attitude and she gave the project her full support.

Audrey had her fingers in a number of pies. She coordinated the provincial association, raised funds, raised awareness, defended the Environmental Health Clinic, and supported individuals. Most of this was done from her bedroom.

One of her special pleasures was preparing the newsletter. One time I teased her about its size. "Don't forget", she told me, "that there are people outside the big cities who are isolated and I want to give them information and hope".

I happened to call Audrey five days before she died. She did not sound well at all. I asked if she wanted me to call an ambulance. "No", she replied. "I am too tired to go to hospital tonight. I plan to call an ambulance tomorrow". That was typical Audrey. She knew what she wanted and she did things on her own terms.

Marilyn McCurdy
Childhood Friend

Audrey was undecided if she could be a teacher or a nurse. Thank goodness she chose nursing for all of us here to-day. Audrey graduated from Victoria School of Nursing London and we ended up working at Victoria Hospital in London.

We used to pick up Audrey and her accordion when we were in training and go to parties. Audrey would play her accordion in the car; we called her our radio.

Audrey had a back injury and surgery and then diagnosed with M.E. Through all the surgery and pain and discomfort she did enjoy her research on M.E. Traveling was a burden and painful many times for her but she maintained that caring, soft spoken friend. On our visits we would catch up on family news and her bridge parties as we both enjoyed our bridge. Audrey would elect to stay in Hyde Park around her friends who had become her family also and shared her ups and downs with her and understood what she was doing for M.E. and saw the drive and determination and dedication she had.

Your sense of humor in maintaining your independence and living for each day and what you could do to help others is not forgotten by cherished friends. Audrey you have shown us that it is not always what life has given you but what you accomplish in this life that counts no matter how short of time we have.

We love and honor you to-day and thank you for being my life long friend: my guardian angel.

Irene Turrin
Former President, MEAO

I was so shocked and saddened to hear the news about Audrey. She was an extraordinary woman who worked so hard and so faithfully for the ME/CFS community and for the MEAO. I first met her when serving on the board together some time ago. After sometime I became completely burned out, had to leave the board, and eventually moved out of Toronto; Audrey however continued on and took up an even greater load of work and responsibility, working selflessly and seemingly tirelessly.
Her passing leaves an extraordinary loss and sadness in the hearts of all those who knew her or were lucky enough to have crossed life paths with her. Please extend my condolences, thoughts and prayers to her family members and all of her dear friends and colleagues in the MEAO community. If there is anything I can do to help with the memorial service, please do not hesitate to call/contact me.

Tributes to Audrey

I was shocked and saddened when I opened up your message last Thursday and learned that my beloved friend Audrey had died. We have been friends since 1990 and I always treasured her loving nature, her quick wit and her keen mind. We had a very close bond.
I certainly plan to attend the Memorial - provided I am feeling okay.
Audrey was a blessing in my life and I will miss her but I would like to help celebrate *her life* with all others who were touched by this extraordinary woman.
Helena Caesar

I so saddened by the news of Audrey's death. I doubt if I will feel well enough to come to Toronto for a funeral or visitation.
But could you let me know the details. Francis has offered to drive me if I think I could manage it. We all feel badly and admire Audrey so much for all the work she did on behalf of ME.
Cathy Prescott

I never met Audrey personally, but knew her for over a decade by way of phone and email. I 'discovered' her and the M.E. Association after having the illness for a few years, and couldn't believe how helpful she was. She was my ray of hope sometimes, and the M.E. Association was a Godsend. I always thought the two were inseparable, and later realized that they were - she WAS the M. E. Association for so long. Not to take away from all the people who have worked so hard for years, but I know she worked on the newsletter from her bed, even when she should have been following her own advice and resting. There were times of total despair that I went through and Audrey's voice and calm advice would get me through. No matter what she was going through, she always laughed. Even though we had talked on the phone a month before she passed away, I had no idea that she was feeling that ill. I know things weren't well, because she was stepping down from some of her duties, and she promised on the phone that she was going to start taking it easier, but she would end out laughing about something and you hung up feeling good about life again. It's a testament to her that I never met her in person, and yet feel a hole in my life and that I've lost a friend. I don't think she ever knew how important she was to the Association and to the people out there who knew her through it. She got me through the worst of my M.E. and I'll always be grateful to her Audrey.
Donna Englehardt

Thanks for sending out this announcement. It is very sad news indeed and a great loss for our community. I can't attend the funeral but I hope to be able to pay respects at a memorial service. Please extend our condolences to her family.
Jody Berland

This is really tragic news and although I live in Scotland I am thinking of you all. I wondered when one of the newsletters said that Audrey had stepped down whether she had a serious illness but there was no further information. I am a doctor with ME, who Once lived in Toronto where my family still live. On a visit there I became very ill with my ME and Audrey came to visit me in the hospital. I'll never forget her for that. Please pass on my condolences to her family, what an inspiration she was. If there is a collection for some kind of memorial to her please contact me.
(Dr) Marilyn McNeill

Thank you so much for letting us know about Audrey. We are very saddened to hear about her passing. I will miss her occasional phone calls & chatting to her. She has touched so many lives and given so many others hope. Her strength and the way that she gave of herself right until the end is an inspiration to everyone. She was a truly wonderful person.
Gillian

YOUR HEALTH

Mold and Health

Diana An, Nursing Student, University of Toronto

As a student nurse at the Environmental Health Clinic, I noticed that many of the patients coming into the clinic have had mold exposure in their homes. Molds can have a negative impact on your health. The good news is you can take action today to reduce your exposure to mold.

What is mold?

"Mold is a type of fungus that can grow on any moist surface". You may have heard of the form "toxic mold". This term is not accurate because while molds can produce toxins, the molds themselves are not toxins, the molds themselves are not toxic. A fungus is a plantlike life form that grows by releasing tiny reproductive cells (spores) into the air. Indoors, these airborne spores can expose people through breathing or through skin contact. The most common indoor molds are Cladsporium, Pencillin, Aspergillus, and Alternaria.

How does mold affect your health?

The health effects of mold vary. With mold exposure, symptoms can include allergy, infection, irritation, or toxicity. The most common response to mold response to mold exposure can be allergy. Symptoms of mold exposure include nose and throat irritation, headache), eye irritation, nausea, decreased attention and dizziness.

How do you know if you have mold in your home?

1. Discolouration. Molds can be any colour. Dab a spot of bleach onto the suspected spot. If the stain loses its colour, it may be mold, but if there is no colour change, it probably isn't mold.

2. Earthy or musty smell. Molds will grow anywhere indoors where there is moisture. Signs of moisture problems include wet spots, dampness, or water leaks. Molds can grow on cloth, carpets, leather wood, insulation, foods, etc..

When should you seek professional help?

Contact a trained Indoor Air Quality (IAQ) investigator when:

- There is a lot of mold.
- The home is very damp and moist.
- A household member who suffers from health problems associated with mold appears to be getting worse inside the home.

The IAQ investigator operates a private business and sells his/her services to you.

How can I clean up mold?

Patches smaller than three-square metres can be cleaned up yourself). For patches larger than this, contact a professional. Visit www.cmhc.ca for more information.

Tips to reduce mold exposure

- Keep humidity between 40% - 60%.
- Regularly clean all surfaces where moisture collects. Try using baking soda solution one day and vinegar the next; each can kill different types of mold
- Use exhaust fans in the bathroom

Conclusion

Molds are present in both the indoor and outdoor environment. Mold will grow if there is enough moisture and nutrients. If there is mold growing in your home, you need to clean up the mold and fix the moisture problem). If you can see or smell it, a health risk may be present. Please visit the web site, www.cmhc.ca. If you need more information.

The above article was based on information from Canada Mortgage and Housing Corporation, Center for Disease Control and Proevention and Healthy Ontario.com.

(The above two articles were published in the Environmental Health Clinic's Newsletter entitled *Environmental News,* Volume 8, Issue 3.)

Environmental Health Clinic (EHC)
10th Floor, Room 1001, East Wing, 76 Grenville St., Toronto, ON M5S 1B2
Tel: 416-351-3764 or 1-800-417-7092 to book an appt. or to request their free EHC brochure.
Visit their web page at: www.womenshealthmatters.ca

Pool exercise for individuals with fibromyalgia.

(From Curr Opin Rheumatol. 2007 Mar;19(2):168-73.
Gowans SE, Dehueck A.)

RECENT FINDINGS: Pool exercise has been evaluated against sedentary control groups, land-based exercise and immersion in a warm, mineralized pool. Pool exercise has been shown to be as effective as land-based exercise and may have greater benefits with respect to mood and sleep duration. Based on follow-up studies, exercise-induced improvements in physical function, pain and mood may persist for up to 2 years. Pool exercise may be better tolerated as an initial means of exercise by individuals with arthritis in weight-bearing joints (because of water buoyancy) or by individuals who fear exercise will exacerbate their pain.

SUMMARY: Pool exercise can be an effective intervention for individuals with fibromyalgia. Future studies should reassess subjects at multiple time points to determine the time course of exercise-induced improvements and further explore the effects of pool exercise on mood and sleep quality.

Contact info for the Durham Warm Water Aquatic Program;
Colleen at: freespiritinme@gmail.com
Tel: 905-430-1665 or 905-723-8931

PAIN MANAGEMENT

Summary of Lecture by Dr. A. Bested F.R.C.P. (C) at our 2006 AGM

By Lisa McGill

ME/CFS: Clinical Working Case Definition

1. Fatigue
2. Post-exertional malaise and fatigue
3. Pain
4. Pain (?)
5. Neurological Manifestations
6. Symptom of Categories: autonomic, neuroendo, immunological (stress makes cognitive problems worse in large crowds, shopping, etc.)

Exclusion: anemias, iron overload, diabetes, cancer, sleep apena, TB, rheumatological, AIDS, Lyme Disease, substance abuse, neurologic, primary psychiatric disorders eg. bipolar

Co-Morbid Entities:
depression, migraine, allergies, multiple chemical sensitivities, hashimoto's thyroiditis, sicca syndrome
(Once you start to feeling better, then you get depressed as see what you have been missing)

Fibromyalgia; +3 months of widespread pain
need 11 of 18 4 kg pressure points
widespread pain and fatigue sleep dysfunction, stiffness, #5 & #6 re CFS

Multiple Chemical Sensitivities: symptoms reproducible with exposure condition is chronic \ low levels of exposure provoke symptoms symptoms improve or resolve when removed\cognitive difficulties

Prevalence - Center for Disease Control / CDC says CFS is a real illness with 1 million in US - 3% of the adult population

ME/CFS 522 women/100000 and 291 men/100000
Fibromyalgia 3400/100000
AIDS 12/100000
Heart Disease 3400/100000

Theory of the Virus in CFS - abnormal production of RNaseL, doesn't turn off and chews cell membrane
Virus - Blood Mononuclear Cell - interferon - 2-5A synthetase - RNaseL band back to the virus - full circle

virus cytokines, tissue necrosis, 2-5A synthetase, increase RNaseL

Fibromylagia - theory recurrent neck injuries set if off

FM - widespread pain - mild to severe
- supersensitive to normal stimuli
- persistent/ongoing - all over
- tenderness to blanche of thumbnail
- delay of pain onset after injury
- chronic headache
- burning, aching, stabbing
- diffuse arthralgia pain
- atypical chest pain
- low back pain
- leg cramps
- generalized stiffness

Pathophysiology and Types of Pain - definition of - an unpleasant sensory and emotional experience

acute pain - purpose - protective response

chronic pain (over 3-6 months + ongoing) - cancer - constant pain changes the way the brain deals with the pain
- non-cancer pain - brain becomes more sensitzed to pain - automatic oversensitization and very diffuse

treat acute pain aggressively so doesn't turn into chronic pain. This is why one over reacts to things

Future - test blood for pain receptors and then properly put the correct Rx for pain to person

Pain centred Life adequate pain Rx and education - multidisciplinary program - increased activity and conditioning

versus

Function centred life - pain management
- mild to moderate stretch and strengthen, acupuncture, massage therapy re active muscle release (personal note osteopath very helpful) , proper diet, oils, minerals and vitamins, avoid inflammatory foods - wheat, corn, dairy, nightshades- off for 1 year - reduces inflammation in body and brings pain down,
lots of water - lots of poo, pee and sweta 3 times /day - as if material sits there release toxins so get it out
- pain - get up and move (Curves)
- pace self and then slowly move one's boundaries out - get out and walk the dog
- use art to "get time free of pain - take mind away from it
- look for aquatherapy classes-
- use cognitive behavior therapy - live in the moment
- walk 30 minutes /day or exercise
- find low impact yoga / feldenkrais = promotes parasympathetic response
- relaxation response - meditation 1) slow steady breathing 2) neutral brain - passive thoughts
- drugs to quiet parasympathetic
- muscle relaxants and anti-depressants, anti-seizure drugs , pain mends - tylenol, advil, ibuprofen, gammapentinen
- tolerance - hi vs low
- general brain overload may explain reactions to chemical sensitivities
- genetic susceptability
- a lot of your immunity occurs in your gut and so proper nutrition is key to good health - must have a healthy gut

RECIPES AND JOKES

THINKING FAST

An elderly man in Florida had owned a large farm for several years.
He had a large pond in the back. It was properly shaped for swimming,
so he fixed it up nice -- picnic tables, horseshoe courts, and some
orange, grapefruit, and banana trees.

One evening, the old farmer decided to go down to the pond, as he hadn't been there for a while, and look it over.

He grabbed a five gallon bucket to bring back some fruit.

As he neared the pond, he heard voices shouting and laughing.

As he came closer he saw it was a bunch of young women
skinny-dipping in his pond.

He made the women aware of his presence,
and they all went to the deep end.

One of the women shouted to him,
"We're not coming out until you leave!"

The old man frowned and shouted back,
"I didn't come down here to watch you ladies swim naked ...
or .. make you get out of the pond."

Holding the bucket up, he said, "I'm here to feed the alligator"

THE COOK'S CORNER

My Cousin's Vegetable Soup

This is a great soup for you vegetarians out there, and for those of us trying to ensure we have enough veggies in our diet. It's also great with the addition of chopped turkey or chicken.

½ large white onion
1 turnip (or Kholarbi)
3 sticks of celery
½ small cauliflower
1 large zucchini
¼ package of frozen butternut squash
1 19 oz. can of white kidney beans

Spices:
A few dashes of Mrs. Dash
2 bay leaves
Salt & pepper
1 tsp. basil
1 tsp. oregano
1 tsp. olive oil

Chop all the vegetables. Sautee all the vegetable ingredients, except for the kidney beans, in the olive oil for 10 minutes.
In a large pot, add 8 cups of water, the herbs and sautéed ingredients, and cook for 1 hour. Add the kidney beans 10 minutes before the hour is up. Delicious!

Variation to your summer Sherbert/Sorbert

Tip from foodnetwork.ca
To spark up your sherbet, add cleaned, dried and chopped genovese basil over your sherbert/sorbet. I use 'Nestles 'Over the Rainbow'. (raspberry, vanilla and orange mixture.)

ARE YOU MOVING?

Each year we receive several newsletters back from 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.

NEW FORMAT

You have obviously noticed a difference in the style of the newsletter. We are changing the format and content to respond to the feedback we received from our survey on it. This newsletter has had a few changes. The next newsletter will see even more. We hope you'll like what you see.

RESEARCH

Body Burden and Your Health

Kathleen Kerr
Physician, Environmental Health Clinic,
Women's College Hospital, Toronto, Ontario

Many studies have been done to look at cancer, neurotoxic effects and effects on the developing fetus.

Studies present conflicting evidence regarding the association of organochlorines such as PCBs and DDT with breast and uterine cancer. Certain PCBs were associated with increased risk non-Hodgkin's lymphoma. Exposure to PCBs suppresses the immune system, and PCBs are tumor promoters that enhance the effects of other carcinogenic substances. The US Environmental Protection Agency states that dioxin is best characterized as carcinogenic to humans.

PCB exposure, especially during fetal and early life, reduces IQ and alters behaviour. Children born to women who had eaten PCB-contaminated Lake Michigan fish have been followed by Jacobson & Jacobson, who have reported that in utero exposure to PCBs was associated with a lower IQ at 11 years of age and lower reading comprehension scores. Additional evidence of intellectual impairment in childhood from PCB background exposure comes from studies in the Netherlands, Germany,and Oswego,New York. Effects on IQ learning and cognition have been detected for in-uterine exposures to both environmental lead and PCB/mercury contaminated fish. Even subtle neurotoxic are of profound importance to the overall population.

PCBs alter thyroid and reproductive function in both males and females and increase the risk of developing cardiovascular and liver disease, and diabetes. Fire retardants present in fabrics, computers, foams, etc. are ubiquitous and are composed of polybrominated diphenyl ether (PBDE). Body burdens of PBDEs in North America are 20 times that of Europeans. Inadvertent ingestion of house dust is the largest contributor to exposure for toddlers through to adults, while infant consumption of human milk is the largest contributor to lifetime exposure. In spite of widespread exposure, very little is known about PBDEs, but animal studies suggest effects on the thyroid, particularly during development.

There are many other chemicals under study such as phthalates (in plastic wrap, bottles, and cosmetics) and perforated compounds (in non-stick, stain proofing or grease resistant food wraps. These chemicals form part of our body burden and may affect hormonal functions.

At the Environmental Health Clinic we see patients with chronic complex illnesses such as chronic fatigue syndrome, fibromyalgia or multiple chemical sensitivity (MCS). These conditions may be linked to exposures to environmental contaminants. A study of our patients with MCS found that these patients were more likely to have genetic variations in drug-metabolizing enzymes, which may involve altered biotransformation of environmental chemicals.

There is a great need for much more research in these areas, but in the meantime the Precautionary Principle can serve as our guide: Precautionary Principle. When an activity raises threats of harm to human health or environment, precautionary measures should be taken even if some cause-and-effect on relationships are not fully established scientifically.

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 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**.

DISCLAIMER

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.