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REACHING OUT

WINTER 2009

meao

XMRV: What Does it Mean?

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

The ME/CFS world was excited by a paper published in early October 2009 in the prestigious journal “Science”. This paper reported that a virus, a human gamma-retrovirus called XMRV (xenotropic murine leukemia virus-related virus) had been identified in peripheral blood cells of 67% of 101 patients with ME/CFS compared to only 3.7% of 218 healthy control patients. A publication in this important journal helps move ME/CFS into mainstream science legitimacy.

The quality of the science is impeccable, as one would expect of this journal. US-based scientists from several institutions identified the virus in blood by a technique known as “nested PCR” (which can however cause problematic false reactions) but they also showed that the virus was actually present in these cells by specific antibody-based tests (further evidence).

In addition, they were able to isolate the virus and to pass it to other cells, showing that the virus can likely be passed to other people, at least in blood. Immunological tests were used to show that patients develop an immune response when exposed to XMRV, though this immune response was clearly inadequate to clear the infection.

In summary, there is a high association between the XMRV retrovirus and ME/CFS.

XMRV is an unusual virus, a retrovirus (as is HIV, the cause of AIDS). This retrovirus has only recently been identified and it is estimated that it is ¼ the size of the HIV virus and so difficult to find. XMRV was also isolated from human patients with a subset of prostate cancer. These cancer patients had changes in an antiviral enzyme in their body known as RNaseL. This may be a crucial feature, as RNaseL was thought to be affected by ME/CFS, although XMRV infection in these CFS patients did not correlate with their RNaseL type.

Is this the breakthrough we’ve been waiting for?

It’s hard to say, and caution is advised.

(cont’d on Page 2)

IN THIS ISSUE OF *REACHING OUT*:

REACHING OUT

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XMRV: What Does it Mean?

(cont'd from Page 1)

This discovery raises many questions, not least whether the findings can be replicated elsewhere. Replication will involve other independent scientists studying new groups of patients to see if they can find the same results. Several groups are now starting to do this around the world.

Is XMRV a causal factor in ME/CFS or is it simply a marker for immuno-suppression? ME/CFS patients can be infected with other viruses including Epstein-Barr Virus (EBV), Human Herpes Virus 6 (HHV-6), which are thought to be dormant viruses that have become re-activated, so that XMRV may be simply another virus that has escaped the impaired antiviral pathways of ME/CFS patients and not the cause of the illness.

How does this discovery link to the evidence that ME/CFS is the result of a post-viral persistent immune dysregulation that increases mitochondrial ribonuclease, and causes “cellular hypoxia” (lack of oxygen in the blood)? How does it link to the other viral infections associated with ME/CFS, such as EBV, HHV-6 or Parvovirus 19, recently found in the gastrointestinal biopsies of 40% of patients in one study (*In Vivo.* 2009 Mar-Apr;23(2):209-13)? Or is XMRV the virus that starts ME/CFS off, with the others as passengers?

What does this mean for testing and treatment? However it relates to ME/CFS, the presence of XMRV DNA might become a simple diagnostic test for ME/CFS since we still need a rapid and inexpensive laboratory test. Doctors are better at diagnosing complex diseases if there is laboratory confirmation. If, however, the findings can be replicated by other studies, there may also be a reason to try anti-retroviral treatment in ME/CFS patients, since this has been so spectacularly successful in the treatment of HIV/AIDS.

It is, however, premature to overreact. For example, among the emails flying around as a result of this paper, there was the unjustified suggestion that people with ME/CFS must be at increased risk of cancer and that women with ME/CFS should warn their past sexual partners that they might be at risk for prostate cancer!

For me, the best part of this paper was where it was published and the conclusion that “mainstream” science has moved beyond questioning whether ME/CFS is a true disease, and has started to do some of the hard work that will lead to the breakthroughs that we so desperately need.

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Dr. Bested Receiving the Audrey MacKenzie Memorial Award at the MEAO AGM, presented by Diane Meitz

Questions and Answers about XMRV, by John Prescott and the MEAO

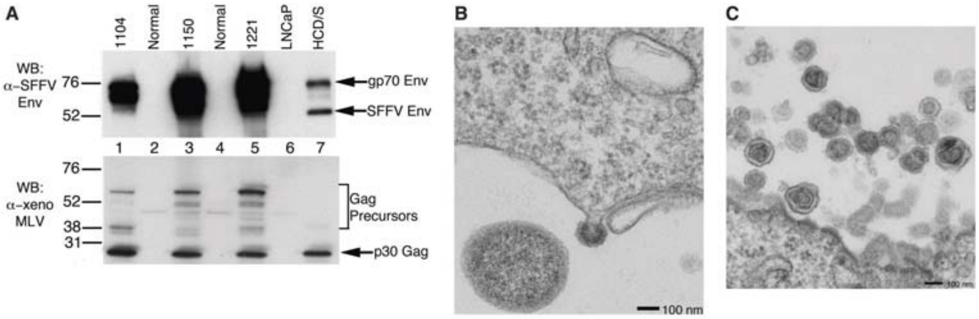
1. Does this mean that everyone with ME/CFS has XMRV?

No. In the initial study, about two-thirds of ME/CFS patients had XMRV. The researchers later reported changes to their technique and that they found XMRV in 95 of 101 patients. There are however questions about the selection of the patient population, so the studies need to be replicated by others before we know for sure.

2. Does XMRV cause ME/CFS?

Not known at this time. Many ME/CFS patients also show re-activation of other viral infections, such as Epstein-Barr virus, so XMRV may be a similar situation. Our view is caution until we know much more.

The US CFIDS organization quotes a statement from the US National Cancer Institute, that “We do not know whether XMRV is a causative agent for ME/CFS, prostate cancer, or any other disease.” This can be accessed at: www.cfids.org/temp/xmrv-guidelines-nci.asp



From Science*xpress,* Detection of an Infectious Retrovirus, XMRV, in Blood Cells of Patients with Chronic Fatigue Syndrome, Figure 3

3. Some people report chronic fatigue symptoms after damage to their brain or spinal chord or exposure to chemicals, does that mean these people don't have ME/CFS?

And some also develop ME/CFS after other viral infections, including enteroviruses, and bacterial infections such as Q fever, or after surgery (blood transfusion?). One of the really big problems of diagnosing ME/CFS is that there is no established laboratory test, so that it’s still largely a clinical diagnosis.

ME/CFS may be a syndrome with multiple causes. Or it is possible that there are other diseases that are very similar to ME/CFS – for example, fibromyalgia – with clinical overlap with ME/CFS symptoms. We need a lot more research to confirm the cause or causes.

In the meantime, if we can find a test that identifies the damage common to these illnesses that will be helpful too. That’s why Dr. Prescott was so excited by the simple, objective, tests for “cellular hypoxia” discussed in the Spring 2009 issue of the MEAO newsletter.

4. Where and when can I get a test?

This virus is not easy to detect and the tests are complex.

You can suddenly find many places in the US where you can send for a test for $400-$500 US. Someone is making a LOT of money at this level, capitalizing on the XMRV story. We don't recommend that anyone send their money for these unproven tests. We need better information about XMRV and its role in ME/CFS before we test everyone and we need one approved test for everyone. We need Canadian studies and we need a reliable test that can be done here and covered by Canadian health plans.

Consider also the possible damage to your health and even your insurance and disability claims if you take one of these unproven tests. Even the best tests can have false positive and false negative results and we do not have a "best test" yet. If you test "false positive" and then start trying antiviral drugs, you could be making your condition worse. If you test "false negative", you could have this used against you by insurance companies and disability programs. Be patient.

5. Should I be signing up for antiviral drugs right now?

No, this is premature given the current state of knowledge. In the past, the value of antiviral drugs in treatment of ME/CFS has not been clearly established. The drugs used to treat HIV are also very strong and usually taken in complex "cocktails" of antiviral drugs and immune-boosting drugs. Given that most people with ME/CFS report adverse reactions to many medications, treatment will have to be very cautious. Wait for the current studies to prove or disprove the *Science Magazine* results and wait for the appropriately designed clinical studies to assess the value of antiretroviral drugs.

6. If XMRV is a virus that can be transmitted by blood in the lab, does that mean it can be sexually-transmitted or transmitted through pregnancy?

These facts are unknown at this time. Viruses that are found in blood sometimes are found in sexual fluids, however this is not always the case. Some viruses that are carried in the blood transmit easily from person to person whereas others can be very difficult to transmit. Some infections can pass from mother to fetus, or through breast milk, others cannot. If XMRV is sexually-transmitted, we'd expect to see illness show up in the partners of those who are ill over time – which we haven't seen yet. If it could be passed from mother to child, we might expect to see infants with ME/CFS symptoms. If XMRV were the only cause of ME/CFS, and can only be spread by blood and sexual fluids, it would also be difficult to explain the findings of Dr. Bell and others who have studied ME/CFS in pre-pubescent children, with no known risk for blood or sexual transmission. Many adults with ME/CFS report a serious "chronic fatigue illness" as children or young teens. There may be an onset pre-puberty for some, a long dormant period, and then significant relapses in mid-life. This can happen with other illnesses, one of the most familiar being Post Polio Syndrome.

7. If I have ME/CFS, should I be donating blood?

In Canada, the Canadian Blood Services removes white blood cells from blood donations and this is believed to have a protective role against many viral transmissions, including XMRV. They believe this removal of the white blood cells likely protects others, but they are investigating. This is more of an issue in the US, where the Department of Health and Human Services Safety removes the white blood cells in approximately 70% of their blood, or other countries that leave all white blood cells in donated blood.

Regardless of the role of XMRV, it has long been the view of blood donation groups that if you are ill (acutely or chronically) you should not donate blood. Blood clinics will always ask this question. Unless we learn otherwise, it is safest if people with ME/CFS do not donate blood or donate organs at this time. Don’t forget that the mere fact of donating blood may also aggravate your symptoms as well.

8. If XMRV might be linked to one or more cancers, does this mean I am at risk for cancer?

There is no evidence that ME/CFS patients are more likely to develop cancer at this time. This was an unsubstantiated suggestion in the *Science Magazine* article that was very unfortunate. A second study into XMRV in prostate cancer did not find the same relationship as the first study and much more work must be done to see if XMRV causes any illness let alone leading to cancer.

9. Where can I find out more about what others think of the XMRV study? (click on websites)

Dr. Nancy Klimas video available at:
http://cfsknowledgecenter.ning.com/video/video/show?id=2477197:Video:24944

The original Science News article:
www.sciencenews.org/view/generic/id/48157/title/Retrovirus_might_be_culprit_in_chronic_fatigue_sy

A BBC article, written right after the announcement, http://news.bbc.co.uk/2hi/health/8298529.stm

And you can track some excellent discussions on what XMRV means on these websites:
www.meassociation.org.uk
www.cfids.org
www.mefmaction.net Canada’s National ME/FM Action Network

FROM THE PRESIDENT

As I sit down to type, I see the first snow of the season falling. As a boy, I was told to make a wish during the first snow…

My wish today is for Ontario to become a friendlier place for people living with ME/CFS. I wish for adequate – no ABUNDANT medical care and social service support for those living with M.E. I wish for more awareness, more understanding, and more compassion for those with this illness. I long for a unified and focused M.E. community that mobilizes for change. I wish for healing and health to return to those living with ME/CFS, and for those who remain ill, I wish all the acceptance and support necessary to live with ME in as good a way as possible. Sadly my wish list alone could fill this entire newsletter.

However, I am grateful to report that along with my wish list comes a gratitude list that reflects the good footwork of our members and allies.

This November, representatives from the MEAO, along with longtime MEAO ally and ME/CFS physician Dr. Alison Bested, met with the Ministry of Health to pursue our longstanding list of recommendations for Ontario. There was great interest in the needs of people with ME/CFS, particularly their medical and homecare needs. This is good and encouraging news and we are eagerly pursuing a follow-up meeting.

The recent XMRV retrovirus media explosion has garnered much attention to ME/CFS. This increased focus creates a great opportunity for all ME/CFS organizations to capitalize upon…finally we are being taken seriously. You will find two extensive articles in this newsletter on XMRV which we hope will address all your questions.

Our Board of Directors is taking strides to secure an office space that best meets the needs of our membership while giving members a home away from home and a more solid base for our organization. We continue to fundraise for this new space and welcome all donations towards this important next step in our organizational evolution.

The National ME/FM Action Network has just announced that they will be hosting the next International Scientific and Clinical Conference of the **International Association for Chronic Fatigue Syndrome**, www.iacfsme.org, to be held here in Ontario, in Ottawa, and is tentatively scheduled for fall 2011.

Finally, I am grateful for your participation. Change requires action. Once again, I put out a call for your volunteer time. We have many opportunities for you – from stuffing and mailing envelopes to staffing our toll free info line, to serving on a key committee – **we need you!** There are many with talent, skill, and time in this community, every member counts, and as I have heard many times, “many hands make light work”. So please contact us through our email or Info Line and we’ll put you right to work.

Warmly,

Chris Pike

Disability Issues to Consider Before Tax Time:
Registered Disability Savings Plans, check out the articles from:
Canada Revenue Agency
www.cra-arc.gc.ca/tx/ndvdls/tpcs/rdsp-reei/menu-eng.html
www.abilities.ca and search for RDSP
www.rdsp.com

Recent Television Shows Available Online:
A great W5 Show on Lyme Disease, go to www.ctv.ca/w5 and search for “Out of the Wild”

From www.swo.ctv.ca, search for, “Pained by Lack of Public Resources”, on pain management

Read About New Research and Surveys:
FM Wellness Project Online Survey, www.fmwellness.org/index.htm

What Everybody with ME/FM Needs to Know about their Legal Rights – A Community Forum by Hugh Scher

In the last issue of *Reaching Out*, Board President Chris Pike interviewed lawyer Hugh Scher on basic legal issues for people with ME/FM. In the final part of our two-part series, Leslie Pearl provides us with notes from Hugh Scher's November 7th talk to the MEAO community.

When do you need a lawyer?

At some point during the process of applying for disability benefits, or after having been refused benefits by your workplace or by government agencies, you may need to retain a lawyer. Although it's not necessary to have a lawyer at the early application stages, the forms you have to fill out can be vague and you may be uncertain how to present your health issues and your inability to work in the way the insurance company needs. From Mr. Scher's point of view, getting legal advice early on can make a huge difference in whether your claim is granted.

Choosing a Lawyer

In choosing a lawyer, contact your provincial or national ME/FM organization to find a lawyer who is already experienced with your health issues. If they don't know one in your area, The Law Society of Upper Canada has listings of lawyers with different types of practices. All lawyers now have websites. You can also check out any papers they've written or talks they've given at conferences run by the Bar Association to see if they are experts in your area.

Fee Structures

Keep in mind that each moment you are asking a lawyer to meet with you, read your material or talk with you over the phone will cost you money. Be respectful of their time and your pocketbook. Understand how much you are being charged and use your lawyer wisely. It's an important relationship but not a counselling one so keep to the legal issues and get your emotional support from a counsellor or social worker.

There are two typical kinds of relationships between lawyer and client:

1) The retainer relationship: The lawyer charges the client on an hourly basis. A retainer (a certain sum of money) is usually required up front for the lawyer to proceed with the case. Lawyers will have different hourly rates depending on their years of experience and expertise. Getting the cheapest lawyer doesn't necessarily mean getting the best lawyer for you.

2) The contingency fee relationship: The lawyer takes your case without fee up front and is only paid if there is a successful resolution to your claim, either through a settlement process or a court judgment. A fee of 20 to 30% of the final settlement is usual.

Both types of lawyers will ask you to pay for any filing fees, phone or copying charges, etc. along the way. Most clients start off thinking they will like the contingency arrangement because it doesn't cost them anything until they win. Mr. Scher has some cautions about contingency arrangements: 1) Lawyers may give faster service to clients who pay on an hourly basis since their reimbursement is immediate. 2) If your case is one that can be speedily resolved, it might end up costing you less on an hourly rate than a 20-30% contingency fee.

If you cannot afford the retainer and hourly fees, and your case may be long-term and best solved by a contingency fee arrangement, you still need to be mindful to respect the lawyer's time; if the relationship breaks down before the successful conclusion of your case, you may get a bill for the time the lawyer has put in before you parted ways. Whichever type of relationship you're in with your lawyer, communication is key. You need to enter into a contract that clearly spells out the fee arrangements and the role of both parties from the very beginning.

Proving You Are Entitled to Benefits

Disability claims are most often denied because the medical evidence you've produced doesn't address what the insurance company needs to know to make their assessment. You have to know what tests are needed for your insurance policy or the Canada Pension Plan (CPP). It isn't sufficient for a doctor to say that you have ME/CFS and that you can't work. The assessors need to know EXACTLY how your medical impairment impacts your ability to do your job. Your insurer may require you to attend one or more "Independent Medical Assessments" (IMEs). You have an obligation to attend these assessments, but the IME assessors have a duty of neutrality. If they breach this duty, you may have a claim against them as well as the insurance company. Sometimes you can negotiate whom you will see. If you are asked to do a rehabilitation assessment or a functional capacity assessment, consult with your lawyer first. (See Part 1 in *Reaching Out*, Fall 2009)

Typically, for the first two years of your disability, you have to demonstrate that you are disabled from being able to perform the duties of <u>your own occupation</u>. After that time, you need to demonstrate that you are too ill to perform <u>the duties of any job for which you are reasonably qualified</u>, referred to as the "any occupation" definition. After two years, you are usually expected to find some kind of work – if you are able to hold any job – even if it isn't your old job. This can be the really tricky period since your employer/insurer may suddenly say you are "qualified" for all kinds of occupations you've never done. Since it can be very unclear what jobs your employer may reasonably ask you to consider, Mr. Scher believes a lawyer can be important at this time. There has to be at least some relationship between your skills and background and whatever job is being proposed, but this can be hard to navigate without a lawyer.

Just prior to this change in definition – from two years onward – insurers tend to get far more aggressive. They ask for independent medical examinations, activity logs to show what you do each day, and they may want to send you to rehabilitation assessments. As we mentioned in Part 1, they may even conduct surveillance or take other steps to show you no longer meet the definition of disability. If you find yourself in that situation, you can request a different medical examiner or assessor, but this is very delicate and requires legal assistance.

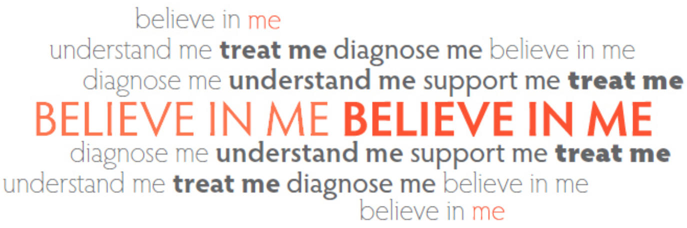
Arranging Settlement and Appealing Denials

If you have been denied workplace or CPP claims, now is definitely the time to get legal assistance so you take the right action, within your legal deadlines. We've talked about CPP in other newsletters (see below). For workplace denials:

- NEVER resign your employment without talking to a lawyer first.
- After denying your claim, the insurer will typically give you 30 days to appeal. Always write something back to them within 30 days but know that you can fight their denial for a longer period than 30 days.
- If you are denied a second time, you are definitely into a litigation situation.
- At this point, your lawyer may advise that your best option is to fight to keep your ongoing disability benefits or he/she may advise a final lump sum settlement. This will depend on factors such as: your age; current health; potential for future disability; amount of your claim; the strength of your medical and other evidence. It's complex which is why legal advice can be so important.

We thank Hugh Scher for his interview and November 7th Community Forum.

For information on handling CPP denials see Greg Neinstein's article in our Spring 2008 issue. For more on LTD Denials see Allan Kaufman's article, Fall 2008, both available from our website.



BELIEVE ME WHEN I SAY I AM DISABLED! Part I

by Theresa Dobko, MEAO Provincial Coordinator

This year, for the MEAO Annual Report, we created the "Believe in M.E." or "Believe in Me" graphic – intentionally created to reflect both meanings (http://meao-cfs.on.ca/files/MEAO-08_09-Annual_Report.pdf). Every effort our organization has made for the past 18 years has hinged on whether those we approached *believed* in the existence of ME/CFS or accepted that it could be, for most, a real life-long disability. This has been an exhausting battle, trying to convince so many people of the existence of ME/CFS disability:

- If our doctors do not believe in M.E. we cannot be accurately diagnosed. They label us mentally ill.
- If our governments do not believe in M.E. there will be no funding for research or treatment.
- If our workplaces, insurance companies and government services do not believe in M.E., we are fired, denied disability payments, refused homecare and reduced to poverty and isolation.
- If our loved ones, affected by the climate of disbelief around them, do not believe in M.E., we lose friends, family members, marriages and even, sometimes, our own will to live.

We are not the only community to face medical misunderstanding and disbelief: Multiple Sclerosis patients went through decades of disbelief, with sufferers believed to be drunk or malingering. We would hope by now that our medical associations would have learned that: **failure to find the cause of a medical illness does not mean the illness is unreal or psychological in nature.**

As a society, we often fear an illness without explanation, or a minority group we do not understand. But it is also true that **members of a stigmatized group can begin to feel an *internalized* shame for their own condition**. As an adult, I have had ME/CFS for 24 years. I had a sudden onset of illness with months of unrelenting disability. Eventually I recovered, but I had bouts of repeated illness afterward and the healthy periods became smaller and smaller. By year 15, I was again too weak/dizzy to walk outside of the home. I could work on the computer or phone for a few hours a day but I could do little else. I had a partner, loving siblings and friends, but I was housebound and suffering. An old friend visited who had met me during a healthier time. She listened and observed and then asked why I wasn't using a wheelchair to get around. Since my dizziness was minimized when I was sitting down, perhaps I could enjoy the nearby park or a trip to the corner store, with just a little mechanical help. Before I could even respond, my partner replied "oh, she's not that sick". I realized, in that moment, that my friend was right, and that I had known all along that to use a wheelchair or a cane would be to admit I was disabled … to my unprepared partner and to my unwilling self. I felt a profound shift that day.

Over many years, and with painstaking effort, my health slowly improved. I could now work four days a week, walk short distances, bird watch, even navigate the subway a few stops. Then a series of viruses hit me this fall and my dizziness, joint pain and unstable walking began again. This time, I got a cane immediately. The decision was emotionally painful, but the cane helps me manage my disability until I can walk independently. And, if ever warranted, I will use that wheelchair – anything my disability requires to keep me connected to the outside world. As a community, I think we need to demonstrate to all those around us our true reality. We should not allow ourselves to suffer by internalizing any of the myths about our illness. If we do not accept our limits and, worse yet, if we conceal our level of disability by hiding in the home when a cane or wheelchair might help us, then we are feeding the misunderstanding of the outside world and change will never happen.

Do you have a story you want to share with us about living with M.E.? Stay tuned for our next issue where we will have articles for those coping with a new diagnosis and more help for those living with long-term disability.

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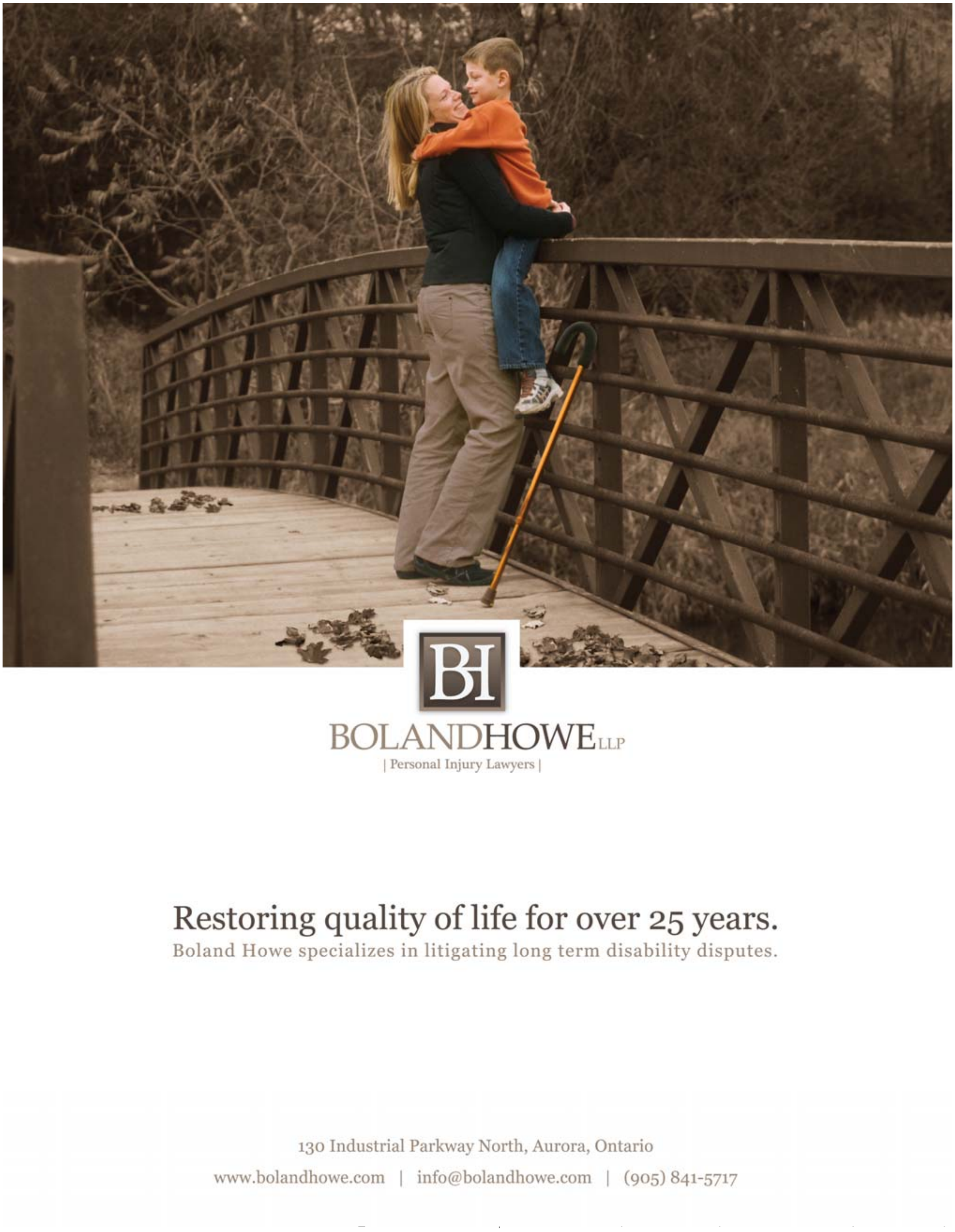

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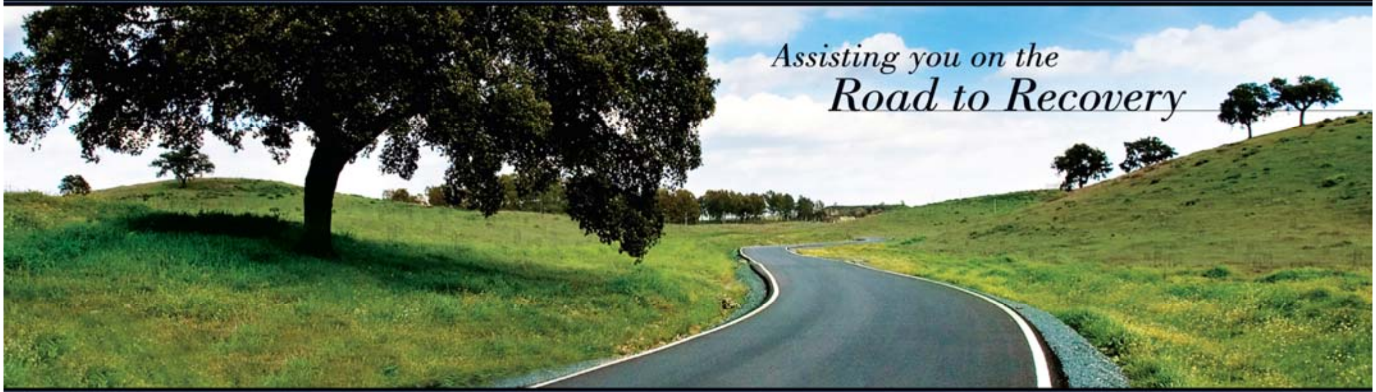

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Kelli-Ann Woulfe

DISABILITY CLAIM DENIED?

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

"After my surgery, I tried to go back to work - against my doctor's advice. But I just couldn't do my job any more."
"So I applied for disability benefits. I couldn't believe it when they turned me down! I was very sick, as well as depressed and broke.
"My case was deemed to be without merit by several law firms. Then I found David Share Associates. They were a Godsend. The settlement allowed us to pay off our mortgage and has enabled me to live at home with dignity."

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

FREE Consultation - NO FEES Until We Settle

DAVID SHARE
ASSOCIATES • LAWYERS

416 488-9000
3442 Yonge St - at 401

www.sharelawyers.com

CONTACT US:

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

Our website can be found at:

http://www.meao-cfs.on.ca

You can email us at:

info@meao-cfs.on.ca

Our INFO LINE is:

416.222.8820, for callers in the Greater Toronto Area, **or 1.877.632.6682** for toll-free calls across the Province.

Our Info Line is a message centre. Please leave your name, number and the best times to call you on our machine, and a volunteer will call you back to help with information and referrals.

MEMBERSHIP AND DONATIONS

Our annual membership is $20.00. Members receive our quarterly newsletter ***'Reaching Out'*** with articles on ME/CFS Research, Coping Tips, Legal Issues, Upcoming Events, Helpful Websites and Books and much more! Members are also eligible to direct the work of the MEAO and vote at our Annual General Meeting.

Paid memberships help support our charity and our mailings but we do have complimentary memberships for those experiencing financial hardship. See our Membership / Donation Form below.

Donations are our lifeblood. Donations of $10.00 and over are issued a charitable tax receipt. You can mail us a cheque or donate by credit card through CanadaHelps on our website.

Disclaimer: As a resource group, the function of our organization is to provide you with current information on ME/CFS. As we are not medical or legal professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your needs with your doctors, lawyers and other professionals before making any decisions.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
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