NATIONAL
ME / FM
ACTION NETWORK

Quest

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CONTENTS

Canadian Blood Services First to Ban ME/CFS Blood Donations

Canadian Blood Services announced on April 7, 2010 that although no definitive link has been established between the virus [XMRV] found in some people with ME/CFS, it will err on the side of caution by banning blood donations from anyone with ME/CFS. Dr. Dana Devine, Vice-President, Medical, Scientific & Research Affairs of CBS stated that Canada is the first country to do so.

Dr. Devine states that "…I think we're stepping out of the gate [first] for two reasons, one is that we have a concern about this virus because we don't have enough information, and because we also don't understand what actually does cause chronic fatigue syndrome". She further states that "It's not known how prevalent the virus is or whether it causes disease. But Canada's cautionary approach comes from its history of pathogens in the blood supply years ago, which continues to affect the agency's decision making."

Ed. notes: *The Canadian Diagnostic and Treatment Protocols, 2003, recommended that ME/CFS patients not donate blood because it could exacerbate symptoms and also it was possible that some patients were carrying infectious agents in their blood.*

The National ME/FM ACTION NETWORK supports the Canadian Blood Services' decision to ban blood donations from people with

ME/CFS. This ban does not mean that it has been established that ME/CFS is caused by XMRV. Until independent researchers have replicated the XMRV virus and have done more studies to establish what role, if any, it plays in ME/CFS, it would have been irresponsible for the CBS not to take this precaution. We all know what errors have been made in the past because this precaution was not taken.

MAY 12 - Awareness Day

> *"If a cause and cure are to be found for ME/CFS, FM, MCS and related illnesses in the near future, government and medicine must be made fully aware of their scope and impact. Despite the efforts of a number of dedicated groups and individuals, there are still vast pockets of ignorance and misunderstanding. To this day, many patients run directly into a medical establishment that, in general, knows very little about these serious threats to human health. It is therefore crucial that all those affected by the illnesses make their voices heard, especially on May 12th of each year."*

This year, 2010, marks the 18th year for an International May 12th Awareness Day. The idea originated with **Tom Hennessy**, the founder of **RESCIND, Inc.** (Repeal Existing Stereotypes about Chronic Immunological and Neurological Diseases). Mr. Hennessy is based in the U.S. but understood that it needed to be an International event. He designated May 12 as the International Awareness Day for the spectrum of illnesses he called Chronic Immunological and Neurological Diseases (CIND).

May 12 was chosen as it coincided with the birth date of **Florence Nightingale**, the English army nurse who inspired the founding of the International Red Cross. Nightingale became chronically ill in her mid-thirties with a Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)-like illness. She was often bedridden for the last 50 years of her life. Despite suffering from a debilitating illness, she managed to found the world's first School of Nursing.

Mr. Hennessy included ME/CFS (also known as Chronic Fatigue and Immune Dysfunction Syndrome -- CFIDS), Fibromyalgia, Multiple Chemical Sensitivity and Gulf War Syndrome under the CIND umbrella. These illnesses, characterized by cognitive problems, chronic muscle and joint pain, extremely poor stamina, and numerous other symptoms, afflict people around the world in alarming numbers.

From the beginning in 1993, various ME/CFS organizations were behind the idea. Early support came from a UK group called BRAME (Blue Ribbon Awareness for the awareness of Myalgic Encephalomyelitis). They highlighted the May 12th International Awareness Day at a World Medical Conference on ME/CFS in 1995. This was instrumental in the campaign being adopted internationally for ME/CFS.

Efforts by Fibromyalgia organizations took a little longer and efforts by MCS groups have been limited. National FM efforts in the United States started in 1997 with the National Fibromyalgia Association (NFA). Multiple Chemical Sensitivity and Environmental Sensitivity groups have, for the most part, not taken up the day, although there have been some in the US who have used the month of May to raise awareness for Multiple Chemical Sensitivity and Toxic Injury Awareness.

The **National ME/FM Action Network** was founded in 1993 by **Lydia Neilson** and became a Canadian registered charitable organization on June 16, 1993. Through the efforts of this newly founded organization, May 12th has been Awareness Day in Canada since 1994. For the first year, it was only for ME/CFS but from 1995 and onward it has been for both ME/CFS and for FM. On May 12, 1996, Parliament declared a National Awareness Day for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia. In 2006, the Senate proclaimed May 12 to be a National Awareness Day for Fibromyalgia and ME/CFS. In Canada, May 12 is included in Health Canada's Calendar of Health Promotion Days as "Fibromyalgia and Chronic Fatigue Syndrome National Awareness Day".

Many provinces and cities across Canada have proclaimed May 12 ME/CFS and Fibromyalgia Awareness Days and many individual support groups have organized May 12 Awareness activities. Please see **http://www.mefmaction.net** for support group information.

Some organizations have an International ME/CFS Awareness Day (May 12), others have a week (this year, May 9-15), still others, such as the newly formed European ME Alliance which includes 9 European countries, use the whole month of May. Awareness activities also occur in Australia and New Zealand.

Purpose of Day and Need for Action

ME/CFS & Fibromyalgia Awareness Day activities are designed to increase public awareness of ME/CFS and Fibromyalgia and chronic pain illnesses, as well as to assist patients, patient support groups and organizations in educating the general public, healthcare and legal professionals, government officials, and legislative bodies.

Spreading awareness of ME/CFS, Fibromyalgia and MCS and related conditions is important. You only need to have a look at the Statistics published in the Special Edition of our Spring-Summer 2009 *Quest* newsletter. This data was compiled by **Margaret Parlor**, President of the National ME/FM Action Network and former statistician with the Federal government for 25 years. It highlights the profile and impact of 23 chronic illnesses and indicates high levels of impairment, socio-economic disadvantage, and unmet health delivery needs for ME/CFS, FMS and MCS. To view these statistics, see our website at **http://www.mefmaction.net/Portals/0/docs//Quest%2080.pdf**

Tom Hennessy

In 2008, Cort Johnson of Phoenix Rising (about mecfs.org), did an interview with Tom Hennessy Jr. about his role in the founding of May 12 and RESCIND, Inc. As Cort notes, Tom was a former advertising executive and is a very articulate advocate. He developed RESCIND (http://www.rescindinc.org/) as a virtual lobbying group. Unfortunately Tom has been disabled for many years with a horrendous case of ME/CFS and, to add insult to injury, he was critically injured in a car accident in Florida in 2009 and is still recovering in a nursing home.

Social Media Groups

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The development of social media provides new opportunities to share information about these illnesses and new groups have been formed to take advantage of these opportunities. Here are some social media groups:

- WAMCARE (Worldwide Association for ME/CFS Awareness and Research **http://www.wamcare.org/index.html**) was formed in 2009 and they use social media to spread awareness for ME/CFS. They are active on Facebook, Twitter and Live Journal
- The Blue Ribbon Campaign established by Andrea Martell (from Ottawa) **http://www.blueribboncampaignforme.org/What_You_Can_Do.html** was also formed in 2009 and is a campaign to raise awareness for ME/CFS. One of their activities this year is a Facebook event to display a blue ribbon as your avatar on May 12th 2010 **http://www.facebook.com/event.php?eid=83125971055**
- An innovative Facebook group focused on May 12th is working to improve the sharing of May 12th ideas -- May 12th is International Awareness day for ME/CFS and FM. Share your plans for May 12th and get involved to help spread awareness on May 12th. **http://www.facebook.com/pages/May-12th-International-MECFS-FM-Awareness-Day/220534562160**
- **http://meaware.wordpress.com/2010/02/15/blogging-for-mecfs-awareness-2010/** -- is asking participants to blog for ME/CFS awareness and is posting a list and links to their blogs on this site.

Ribbons

Ribbons are used by many groups as symbols of support or awareness. The ribbon colour used for ME/CFS is blue, for Fibromyalgia it is purple and for MCS it is green. In all cases, the ribbon color is not unique to the cause but is used for other causes as well.

Green ribbons have been adopted by those with Multiple Chemical Sensitivity and those with Environmental sensitivity. As well as for other causes, this color ribbon is also used for Environmental protection and for Lyme disease awareness.

One MCS campaign, originating in Hawaii, in February 2010 with website aptly called the canary report, is using yellow to represent the canary.

Ed. note: *We gratefully acknowledge the background research and input by* ***Maureen MacQuarrie*** *and* ***Rachel Groves of RachelCreative***

One Person Can Make a Difference How?

- BECOME a member of the National ME/FM Action Network and be part of a united voice;
- ASSIST when the National ME/FM Action Network needs your voice;
- JOIN your local support group and help when you are needed;
- ASK others what they know about ME/CFS or FMS when the opportunity arises;
- REFUSE to react to unfairness but help to change the attitude;
- WRITE when something is in the media which is not accurate or demeans ME/CFS and FMS;
- CALL and let your voice be heard when programs talk about ME/CFS or FMS;
- REFUSE to be treated with disrespect by anyone who doesn't believe in your illness;
- ASK for help when you need it and explain why;
- PASSION, PATIENCE & PERSEVERANCE of a lot of one persons make a powerful team; and
- REMEMBER you are still you regardless of being ill.

XMRV Research Planned at Hunter-Hopkins Center

The Hunter-Hopkins Center in Charlotte, North Carolina, has been asked by the US Department of Health and Human Services to participate with the Centers for Disease Control and the National Institutes of Health in a prospective study of XMRV in ME/CFS people. This working group has three goals: 1) validate and standardize XMRV testing; 2) confirm the prevalence of XMRV in the general population; and 3) identify modes of transmission. They hope to soon be able to start enrolling patients and controls for this study.

Ed. note: ***http://www.drlapp.net*** *for future developments* ***& http://www.mefmaction.net****]*

Japanese Red Cross Investigates XMRV on Blood Service

To estimate the impacts of infection with XMRV on the blood service, the Japanese Red Cross Osaka Blood Center, Department of Research investigated the prevalence of XMRV in both prostate cancer patients and healthy blood donors in Japan.

Two of 32 serum samples collected from the prostate cancer patients and 5 of 300 serum samples collected from healthy blood donors tested positive for antibodies against XMRV Gag protein.

The researchers then inoculated blood cells from three healthy volunteers with a culture taken from the blood cells of one of the prostate cancer patients who had tested positive for XMRV. They then detected the XMRV-specific nucleic acid sequence in the genomic DNA of the blood cells obtained from 2 of the 3 healthy volunteers.

The results indicate that XMRV is sustained in a few fractions of blood cells and can spread through blood even though the virus replication rate appears to be very low.

Source: 1. Department of Research, Japanese Red Cross Osaka Blood Center, 2. Laboratory for Viral Pathogenesis, Institute for Virus

Research, Kyoto University, 3. Department of Urology, Nishiwaki Municipal Hospital.

Whittemore Peterson Institute (WPI) and UK Study

By: Dr. Derek Enlander, member of the Scientific Panel of the European Society for ME.

February 18, 2010: WPI is aware of the recent UK study that was unable to detect the presence of **XMRV in** any CFS patient samples. Although researchers at the WPI were not involved in this project, our work in XMRV continues with researchers around the world. We look forward to the results of studies which replicate the methods used in the original research described in the journal *Science* in October, 2009.

Information Regarding XMRV Studies

1. The authors of the Science paper established the existence of XMRV as an infectious human blood borne retrovirus for the first time in blood of patients diagnosed with Chronic Fatigue Syndrome (CFS). Previous studies had established the presence of XMRV sequences and protein in human prostate tissue.

2. In the Science paper, the presence of XMRV in well-characterized patients with CFS was established using multiple technologies:
a) PCR on nucleic acids from un-stimulated and stimulated white blood cells;
b) XMRV protein expression from stimulated white blood cells;
c) Virus isolation on the LNCaP cell line; and
d) A specific antibody response to XMRV.

3. The authors of the two UK studies did not attempt to “replicate” the WPI study. Replication requires that the same technologies be employed. The WPI sent reagents and information to several groups of researchers in an effort to support their replication studies. Neither UK study requested positive control blood, plasma or nucleic acids from the WPI.

4. The collection, preparation and storage of DNA were completely different between the Science and UK papers. The latter studies do not show data on blood harvesting or storage. Nor do the studies disclose the quantity of isolated cells. Insufficient number of cells analyzed may result in failure to detect a low copy virus like XMRV, regardless of the sensitivity of the assay. Neither UK study provides detail to allow interpretation of how many white blood cells were analyzed.

5. Patient population selection may differ between studies.

6. The UK authors were unable to detect XMRV, even though 4% of healthy individuals were found to be infected in the US. Japanese scientists detected XMRV in 1.7% in healthy blood donors in Japan. The two previously identified human retroviruses have distinct geographical distributions.

7. Perhaps the most important issue to focus on is the low level of XMRV in the blood. XMRV is present in such a small percentage of white blood cells that it is highly unlikely that either UK study’s PCR method could detect it using the methods described. Careful reading of the Science paper shows that increasing the amount of the virus by growing the white blood cells is usually required rather than using white blood cells directly purified from the body. When using PCR alone, the Science authors found that four samples needed to be taken at different times from the same patient in order for XMRV to be detected by PCR in freshly isolated white blood cells. More importantly, detection methods other than PCR showed that patients whose blood lacks sufficient amount of XMRV detectable by PCR are actually infected. This was proven by the isolation of viral proteins and the finding of infectious XMRV isolated from the indicator cell line LNCaP.

The authors of the Retrovirology paper admit that their neutralization assay did not detect bacterially expressed XMRV gag and that positive control sera was needed to validate their assay. The WPI’s monoclonal antibodies specifically and sensitively completed the immune response demonstrating the assays sensitivity and specificity for XMRV envelope. Simply stated the only validated reliable methods for detecting XMRV in CFS patients, to date, are the methods described in Science. Failure to use these methods and validated reagents has resulted in the failure to detect

XMRV. A failure to detect XMRV is not the same as absence of this virus in patients with CFS.
In October the Whittemore Peterson Institute in Nevada published a report on the presence of XMRV virus in the ME/ CFS patients. This report, published in Science, created much excitement in the medical world and in the media. The report suggested the aetiology of ME/CFS was indeed a physical disease, tending to change public opinion. However, we must temper this excitement with careful research that replicates or denies the thesis. This new research must be careful to replicate or deny the original research with a large cohort of patients and controls.

There are numerous groups with their own agenda who wish to confirm or deny the original research. Large government grants and insurance disability interests are at stake. These groups have rushed to publish unsatisfactory comparative research with anecdotal results, based on small number of ill-defined patients, stale specimens and differing research methods.

It would be helpful if there was a collaborative effort to test a significant number of the same specimens in different research centers. Perhaps 200 Fukuda criteria and Canadian criteria patients and controls could be divided and tested in multiple centers in a double-blind trial to replicate or deny the original research. It is time for the psychological and physical researchers to collaborate rather than cast aspersions on each other's work. The European Society for ME (ESME) would support such collaboration.

The European Society for ME is a non-profit group, operated entirely by volunteers. You can support ESME with a donation by visiting: **http://esme-eu.com/donate/category114.html.**

Your donation will go directly to our goals of educating doctors and helping scientists to solve the puzzle of ME/CFS: www.esme-eu.com.

XMRV Gets Attention from Health Officials

On April 4, 2010 Amy Dockser Marcus, reporter for the Wall Street Journal, reported that it isn’t clear if the virus, known as XMRV, poses a danger, and public-health officials state there is no evidence of it spreading infection. However, as preliminary evidence that XMRV is transmitted similarly to HIV, officials are quickly determining if action is needed to protect the blood supply. Dr. Epstein, director of the Office of Blood Research and Review at the Food and Drug Administration said that it is too early to understand the public health significance of XMRV and Dr. Michael P. Busch of the Blood Systems Research Institute in San Francisco notes that even if XMRV is found in large numbers of blood donors, it is still necessary to determine if XMRV causes diseases.

Ed. note: *See our newsletter No. 82 winter 2009/10 on Canadian Blood Services’ position or our website*]

Ontario Special Diet Allowance to Be Reviewed

By: Margaret Parlor, President

A letter captioned "Diet allowance is vital" appeared in the Ottawa Citizen on March 29th, 2010.
http://www.ottawacitizen.com/opinion/letters/Diet+allowance+vital/2738211/story.html
This is the first I had heard that the special diet allowance for people covered by the Ontario Disability Support Program (ODSP) was affected by the March 25th, 2010 Ontario budget..

I found the following quote from page 43 of the budget under the heading "Transforming Social Assistance":
http://www.fin.gov.on.ca/en/budget/ontariobudgets/2010/papers_all.html

What is the Special Diet Allowance

The Special Diet Allowance (SDA) is a social assistance benefit that helps people pay for extra food costs related to specific medical conditions. Last fall, the Auditor General of Ontario reported that many applications for the SDA were associated with questionable circumstances and recommended that the government review the allowance so as to limit its possible abuse.

New Program Planned

The program is not sustainable and is not achieving the intended results. With the help of its partners, the government plans to create a new nutritional supplement program that would be administered by the Ministry of Health and Long-Term Care on behalf of the Ministry of Community and Social Services. It would be medically based and would help individuals with severe medical needs who are on social assistance. The transition to the nutritional supplement program would occur over the next several months. This would give recipients the opportunity to adjust to the new program.

The government will announce details regarding these changes in the near future and we will keep you up to date on developments.

2005 Canadian Community Health Survey Findings

I went back to the Canadian Community Health Survey 2005 and found the following:

% of Ontarians who are food secure: 95%
% of Ontarians whose main source of household income is employment income who are food secure: 96%
% of Ontarians whose main source of household income is seniors' benefits who are food secure: 97%
% of Ontarians whose main source of household income is EI, Worker's Compensation or Welfare who are food secure: **58%**
% of Ontarians reporting a diagnosis of CFS, FM and/of MCS who are food secure: **87%**
% of Ontarians reporting a diagnosis of CFS, FM and/or MCS and whose main source of household income is EI, Worker's Comp or Welfare who are food secure: **44%**
As the Ontario government is reviewing nutrition for people covered by the Ontario Disability Support Program, it should keep in mind the United Nations Convention on the Rights of Persons with Disabilities in which Canada recognizes the right of persons with disabilities to an adequate food, clothing and housing. The goal of the new program should be 100% food security for Ontarians with disabilities.

We will be following developments closely and will keep you informed.

How Understanding Is your Doctor? - Survey

By: Ceara Hayden, MSc., University of St. Andrews, Scotland

Do you suffer from ME/CFS and want your views heard?

If YES, please read below:

I am an MSc student at the University of St Andrews currently researching the experiences of those with CFS/ME, with particular emphasis on the role of patient-provider communication. This brief online questionnaire aims to look at whether there is any direct impact from the experiences you may receive from within your primary health care contact on you, as someone with CFS/ME.

It is hoped that this study will illustrate the impact of understanding CFS/ME within the healthcare profession in order to tailor training for future physicians.

To participate go to
www.surveymonkey.com/cfsonlinesurvey

Neuroendocrine Immune (NEI) Center ™ Awaits Passage

A resolution encouraging the establishment of the NEI Center™ awaits passage from the New Jersey State Senate. This Center to be based in Newark, New Jersey is a community patient-driven project of **P.A.N.D.O.R.A**. (Patient Alliance for Neuroendocrine Immune Disorders) in partnership with the **Lanford Foundation-Lifelyme™**

This would be the first research center in the state of New Jersey dedicated to understanding and treating chronic neuroendocrine immune illnesses which will include Chronic Fatigue Syndrome and Fibromyalgia. Chronic illness represents 75% of all the health care costs in the U.S. Senator Weinberg stated that "It makes sense to locate the NEI Center in New Jersey as the nation's medicine chest is home to research institutions and private businesses that can cooperate to find a cure for these debilitating diseases."

For more information, please visit **http://www.pandoranet.info,** **http://neicenter.com** or visit its Case page on Facebook.

Adverse Reaction of CFIDS Patients to Anesthesia

By: Gail Kansky, President, The National CFIDS Foundation

Information about anesthesia

Anesthesia has adversely affected patients with CFIDS (also known as chronic fatigue syndrome and myalgic encephalomyelitis). The reason for this has been found. Recent research* funded by the National CFIDS Foundation, Inc. found that a substance, much like ciguatera toxin, is being produced in the body by a disease process in those with CFIDS/ME/CFS. Dubbed the ciguatera epitome, this research explains the danger of using any anesthesia that uses the sodium channel at the cellular level. Some anesthesiologists have had success blocking the sodium channel during anesthesia for CFIDS/ME/CFS patients.

*_J Clin Lab Anal, 6/2003, Hokama_
(http://www.ncf-net.org/library/Hokama-JClinLabAnal.htm) et al
*_J Toxicology, 12/2003, Hokama_
(http://www.ncf-net.org/library/JoTox-CPhaseLipids.htm) et al

A 2008 publication in the Journal of Clinical Laboratory Analysis, a medical journal for researchers that only publishes replicated work, found that the assay for ciguatera is a biomarker for autoimmune diseases and one published in 2009 pointed out, specifically, that what we call CFIDS, when we are referring to myalgic encephalomyelitis (ME), is in that category. These medical articles can also be seen on our website at **http://www.ncf-net.org_ (http://www.ncf-net.org) .**
For better health,
Gail Kansky , President, National CFIDS Foundation, Inc., 103 Aletha Rd. , Needham, MA 02492-3431 U.S.A.

Ciguatera Testing Protocol for Blood Sample Submission

University of Hawaii Department of Anatomy, Biochemistry, and Physiology

Blood sample requirements and protocol for sample submission:

Fee: Please include a laboratory testing fee of $100 USD for each CFS test sample mailed for testing. Checks can be made out to "RCUH 1977" (Research Corporation of the University of Hawaii, acct# 1977).

Blood Sample:

1. Draw 5 ml in a Tiger Top or Plain Red tube.
2. Spin blood, remove serum from tubes and place in a new and clean tube (at least 2 ml of serum is required for testing purposes).
3. Fully seal tube and label with the patient's name, contact information and date. Keep serum cold (do not freeze). See shipping requirements below.

Shipping

1. Tube should be placed in a sturdy container and packaged to PREVENT BREAKAGE. Pack with some form of coolant (i.e. ice pack, gel pack) and reinforce with packing material. Seal package, place in shipping box.
2. Label package including complete physician's name, address, phone/fax numbers, email address (if available), along with the patient's name, age, sex, and mailing address. Please check the 'No Signature Required' box in Section 8 of the FedEx airbill.
3. Ship overnight priority via FedEx to:
   Dr. Yoshitsugi Hokama/Dr. Harry Davis
   University of Hawaii at Manoa, JABSOM
   Department of Anatomy, Biochemistry and Physiology, 1960 East-West Rd., Biomedical Bldg. T-606, Honolulu, HI, 96822 Office (808) 956-7178
   e-mail: yoshitsu@hawaii.edu

4. Shipping and packing charges to be paid for by patient.

Results

The patient's physician will be contacted regarding the test results. Only the physician is authorized to call the laboratory for further information regarding the test result. Thank you for your understanding.

Multi-Institutional Study Under Way For Biochemical Marker in ME/CFS Blood

The **University of Southern Queensland** and **Bond University**, with **Queensland Health** in Australia is investigating whether a biochemical marker found in blood can be used as a diagnostic for ME/CFS. The research will involve completion of a questionnaire and blood collection from healthy individuals and from people with ME/CFS or fatigue related syndrome (FRS). The researchers will determine if similarities exist in ME/CFS and FRS in the markers and how this differs from normal healthy individuals.

This study is not to identify a cure or treatment for ME/CFS or FRS but is designed to determine if improved diagnosis is possible. The duration of this study is two years, with blood collections every six months from participants.

If you are interested in participating, please contact **CRRAH** at **07-4631-5444** or email **crrah@usq.edu.au** Further information is also available on the web site at **http://www.usq.edu.au/crrah**

Submission on the Use of Audiotapes during Independent Examinations - Part 1

By: Faith E. Hayman, Lawyer

The Trial Lawyers Association of British Columbia recommends that a provision be introduced in the Rules of Court for independent medical examinations (IME's) to be audio recorded. Rule 1(5) states that the objective of the rules is to "secure the just, speedy and inexpensive determination of every proceeding on its merits." The TLABC considers that audio taping will, at relatively little cost, provide increased quality and transparency in expert opinion evidence which in turn will increase the likelihood of securing a just result.

While videotaping occurs in many medical settings and its benefits are that much greater than audiotaping because it provides a visual record as well an oral record, there may be a corresponding increase in costs. Consistent with the practice of proceeding with small, incremental changes to the rules, it is recommended that the initial step be limited to introducing audio recording.

Background

A. Independent expert evidence in an adversarial system

The common law is based on an adversarial system, in which each party is responsible for obtaining evidence in support of their position and against that of the opposing party. In this setting, there is potential for tensions to arise between the interests of parties and the independence of experts retained to provide an opinion supporting one party and/or attacking the other.

Experts are the only category of witness allowed to give opinion evidence. While there are specified limits to the use of expert evidence, in the last several decades, the expansion of knowledge has led our judicial system to increasingly accept the evidence of experts to shed light on issues in dispute.

At the present time, the B.C. Rules of Court provide limited tools to test the independence and accuracy of independent expert evidence. These generally consist of cross-examination and the use of opposing expert opinion evidence. Unfortunately much can transpire in a medical examination which pits the expert's version of what was said and done against a party's version. Without any objective record of what was actually said and done, courts and parties are left to piece together the foundations of an expert's opinion based on circumstantial evidence. The dynamics of a system, in which experts are assumed to be highly knowledgeable and independent on one hand, while a party's credibility is routinely subject to attack on the other hand, create a degree of imbalance that can undermine the public's confidence in fairness of the system. This is particularly applicable to medical examinations where the subject matter of the expert's opinion is the party him or herself.

Given the potentially vital role that experts can play in the litigation process, it is worthwhile to examine whether technology can introduce greater accountability without excessively increasing costs or delaying proceedings. It is anticipated that such measures will in turn increase the likelihood that litigation will produce a fair and just result and may also enhance the potential for settlement.

B. Use of audio recording in BC

At the present time, the *Rules of Court* do not provide for the recording of medical examinations. In *Wong v. Wong* 2006 BCCA 540 [*Wong*], the Chief Justice held that it was "well within the discretion of a chambers judge to make an order concerning the use or non-use of an audiotape recorder on a medical examination under Rule 30." (par. 25). Considerations behind refusing to order an audiotape of the IME are found in the following passage:

> "A medical examination under Rule 30, although part of the discovery process, is quite different in nature. The examination is often referred to as an "independent medical examination" (IME), and with good reason. The examination may only be conducted by "a medical practitioner or other qualified person". The examiner must have qualifications as an expert in some aspect of medicine or other relevant discipline. The examination may only be compelled on court order. This provides the means of assuring that the proposed examiner is truly qualified, that his qualifications are in a relevant field of medicine, and that he is independent and therefore likely to be impartial and objective." (par. 28).
>
> … "I do not think what a plaintiff says to an independent medical examiner can in any way be equated with statements taken under oath on an examination for discovery under Rule 27." (par. 29)

The court then reviewed previously decided cases in BC as well as Alberta and Ontario, and in particular, the Ontario Court of Appeal decision in *Bellamy v. Johnson* (1992) 8 O.R. (3d) 591. In that case, a master who had ordered the use of an audio tape recording because of a "defence orientation" on the part of a doctor was set aside on the basis that there was no evidence to support such a finding.

The essence of the court's analysis in *Wong* is that "expert opinion evidence … is *prima facie* objective and impartial." (par. 41)

While agreeing with the majority decision on the basis of the facts in the case before her, Madam Justice Saunders pointed to the general legal right of individuals to audiotape conversations as well as advances in technology and its widespread use to promote transparency to conclude that "a robust attitude to the use of recording devices should be the norm, such that any reasonable explanation for their presence may justify their use, absent clear and convincing reason for their curtailment." (par. 56)

C. Considerations supporting the use of audio recording

The primary reason for allowing the recording of IME's is substantive – it enhances the court's access to the truth. The more that is known about the IME process, the better able the trier of fact is to assess the expert's opinion.

The Court of Appeal decision in M.C. v. L.A.C. [1990] B.C.J. No. 134 is instructive of how the overriding interests of justice mandated use of a new technology (paternity tests) under Rule 30 because it offered the best evidence of an issue before the court. Locke J.A. wrote:

> "I agree with the House of Lords in S. v. S. and in particular with the statement of Lord Denning in the Court of Appeal at (1970) 1 All E.R. at 1165 quoted by Lord McDermott in his speech at 117:
>
> > "... Finally, I must say that, over and above all the interests of the child, there is

> > one overriding interest which must be considered. It is the interests of justice. Should it come to the crunch, then the interests of justice must take first place ... In my opinion, when a court is asked to decide whether a child is legitimate or not, it should have before it the best evidence which is available. It should decide on all the evidence, and not on half of it. There is at hand in these days expert scientific evidence - by means of a blood test - which can in most cases resolve the issue conclusively. In the absence of strong reason to the contrary, a blood test should be made available. The interests of justice so require ...."
>
> The last argument related to opening the floodgates. I am not impressed by the argument and where the evidence can be conclusive, to deny it just because it is new or comparatively costly does not accord with the statement of Lord Denning…
>
> The pleadings show that the issue of paternity and thus support is squarely before the court. To deny the use of the best evidence to the court would be wrong unless overriding considerations show it to be to the child's detriment."

The value of recordings in enhancing the court's understanding of what transpires in a police interview was addressed in *R. v. K.G.B.* [1993] 1 S.C.R. 740 where Cory J. (dissenting, but not on the issue of videotape recordings) wrote:

> "In passing, I would observe that the videotape serves as well to monitor the conduct of the police during the interview. It goes far to ensuring that nothing untoward happened in the course of the interview. The usefulness of the videotape of an interview was aptly described by A. Heaton-Armstrong and D. Wolchover in "Recording Witness Statements", [1992] Crim. L.R. 160, at p. 169:
>
> > "The more accurate and comprehensive the record of a statement the stronger the case becomes for introducing it as evidence of the facts contained in it. There is a world of difference between a conventional witness statement signed by the maker but written by a police officer and a video-recorded interview with a witness which will include the questions and other potentially important features such as a witness's demeanor, in modern parlance non-verbal communication or, as it is popularly known "body language".
>
> The videotaped statement with its complete and comprehensive record of the questions posed, the answers given and the demeanor of the witness will often serve as a complete answer to the issues of reliability and voluntariness of the statement."

With respect to the court's reasoning in *Wong,* it is respectfully submitted that the court failed to consider the context in which a presumption of independence is made.

A presumption of independence is both necessary and appropriate when applied to a judge or jury, given their explicit role of impartiality in a trial, and their complete financial independence of the outcome.

With respect to parties or witnesses, however, whether lay or expert, the dynamics of an adversarial system introduce pressures that leave the door open to conscious or even subconscious polarization. In situations where experts are regularly retained by either plaintiffs or defendants, financial considerations add to the potential for polarization. It is naïve to assume, without more, that a medical expert who generates significant income from providing IME's for a particular "interest group" is completely immune to these pressures, whether they are acted on or not. It should also be recognized that the pressures may well increase in the presence of a large institution that regularly requires IME experts to provide opinions taking a particular view of the issues[1]. While obvious instances of unreliable expert evidence may be infrequent, any time an expert is less than honest, the potential for a just result is undermined.

The pressures facing medical experts which are inherent in an adversarial system are inevitably exacerbated in an IME setting where the party being examined (often the plaintiff) is cognitively or emotionally vulnerable, or where the person being examined has limited language skills or faces cultural inhibitions that impact on the assessment. Clearly one hopes that a medical expert will not only be qualified to conduct a competent assessment but will also be independent and unbiased in formulating his/her opinion. But what if he or she is not? Experiences in many settings involving interactions between persons in positions of authority and those in positions of vulnerability (e.g. residential schools, prisons and seniors homes) demonstrate that the greater the imbalance of power and the less accountability there is in the system, the more potential there is for abuse. How does a plaintiff with functional or memory impairments challenge the evidence of a highly trained, articulate and experienced expert? The optics of forcing a vulnerable party to be examined by an opposing expert who will be able to testify from a position of power and prestige, and depriving the party of any independent record of the event, are not good. Justice must not only be done but be seen to be done. Experts can and should be given a mandate of independence. This cannot be confused with granting them a *presumption* of independence.

Insight into these concerns can be found in Rule 6. A "person under disability" receives layers of protection, including the involvement of a litigation guardian, a lawyer, protection in the discovery and trial process, and review of a settlement (and in cases, the lawyer's fees) by either the Public Guardian and Trustee or the court. Given that disabilities occur in a spectrum, it would be preferable for rules to be structured to recognize this reality. Creating some protection and accountability within the IME process would be an important step in this direction.

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[1] Note the use by ICBC of Dr. Murray Allen, discussed in *Paris v. Scott* [1996] B.C.J. No. 2839 and *Rai v.Wilson* [1997] B.C.J. No. 2984, affirmed [1999] B.C.J. No. 611 (BCCA).

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Books/Reports/Links, Etc.

NOISE FOR ME - U.K. Group
http://;msnforme.webs.com/
http://www.facebook.com/pages/Make-some-Noise-for-ME/

THE CLEVELAND CLINIC GUIDE TO FIBROMYALGIA
By: William S. Wilke, MD
Information about the latest scientific studies and progress in fight FM and related conditions**.** Available in book stores**.**

CFS RESEARCH ORG (Belgium):
http://www.cfsresearch.org/cfs/links.htm

"MEDSCHOOLFORYOU" PROJECT

Link to the Press Release
http://www.newswire.ca/en/releases/archive/October2009/13/c5977.html

Announcing the launch of the MedSchoolForYou project. Links to the "School" have been placed on the CPS, CPC, Painexplained and Patient Resource Centre websites and is also listed at: **http://www.medschoolforyou.com/**

"This is a valuable tool that provides, high quality accessible information to the 6 million Canadians suffering from undertreated chronic pain," said Roman Jovey, M.D., a pain practitioner and a past president of the Canadian Pain Society. *"The online Chronic Pain Self-Management Program gives patients and health care professionals a good overview*

of the principles and content of this important aspect of pain treatment".

Canadian Pain Coalition Tel. 905-404-9545
http:www.canadianpaincoalition.ca

ENDING DENIAL - The Lyme Disease Epidemic –
A Canadian Public Health Disaster
A Call for Action from Patients, Doctors, Researchers and Politicians

By: Helke Ferrie

Cost: $30.00 (50% discount for orders of 5 or more copies)
Available at: Kos Publishing Inc.
Tel. 519-927-1049 - Fax 519-927-9542
Web: http://www.kospublishing.com

In October 2008, the U.S. Center for Disease Control declared it to be an "epidemic in North America", having increased by over 100% since 1992. Yet Canadians are routinely told that Lyme does not exist in Canada and that there is no such thing as its chronic form – its most devastating form.

Mainstream clinical journals have shown that chronic Lyme may develop into Parkinson's, ALS, Chronic Fatigue Syndrome, Fibromyalgia, and numerous other diseases and that up to 50% of Multiple Sclerosis may be due to untreated Lyme infections.

Canada's Medicare system endorses only tests for Lyme known to produce false negatives and Canada's doctors are not permitted to use tests that are internationally known to be reliable.

This book not only covers the political issues and shows how to overcome them, but provides the international treatment protocols, with or without antibiotics, and exhaustive resources for patients.

RESOURCES

Complete Original Consensus Documents

- FMS Consensus Document :

"The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners".
Haworth Press, 2004, (soft cover book)
ISBN: 0-7890-2574-4

- ME/CFS Consensus Document :

"Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols".
Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003, Haworth Press 2003/2004
ISBN: 0-7890-2207 9

Available new or used on Amazon.com under Haworth Press Medical Inc. or, used only, on Chapters.ca.

Overviews of the Consensus Documents

Fibromyalgia Syndrome, 24 pp, 2006
Chronic Fatigue Syndrome, 20 pp, 2006
can be ordered from **Marjorie Van de Sande** at **mvandesande@shaw.ca** or at
151 Arbour Ridge Circle NW, Calgary AB T3G 3V9**.**
Version française : Abrégé du Consensus sur le SFC: $5.00,
payable par chèque seulement, à AQEM
Commander à AQEM, 7400 Boul. Les Galeries, bureau 410, Anjou, (Québec), H1M 3M2, Tél. Montréal : 514-369-0386; (à l'extérieur) : 1-877-369-1689 sans frais; site web : www.aqem.org

Fibromyalgia Syndrome 2006 will shortly be available in French.

Network Resources

The following resources can be ordered from the National ME/FM Action Network. Prices include shipping and handling. Cheques should be made payable to the National ME/FM Action Network or you may pay by VISA or MasterCard.

Quest Collections

By popular request, the **National ME/FM Action Network** has published two collections of important articles which have appeared in **'QUEST'** newsletters. The articles in each five-year collection have been grouped into sections according to their focus.

Quest Collection I: presently out of print

Quest Collection II (1999 – 2003): $38.00

Quest Collection III (2004-2008): $38.00

TEACH-ME: A Sourcebook for Teachers (Second Edition): $22.00 *Discount on bulk orders With Dr. D. S. Bell, Dr. B. M. Carruthers and the TEACH-ME Task Force (teachers with ME/CFS and/or FMS)***.** This educational resource book will enhance teachers' and parents' understanding of ME/CFS and FMS in young people, and assist educators in developing educational modifications and programs.

TEACH ME: (traduction française): Guide de référence pour l'enseignement aux élèves souffrant d'EM/SFC et/ou de la FM. $22.00, 120 pp.

LEGAL COURT CASE LIST (258 PAGES) $60.00 SENT VIA COURIER
The Canada Pension Plan Disability Benefits Guidelines: $7.00.

Guidelines have been designed to assist those disabled by ME/CFS and/or FMS applying for Canada Pension Plan Disability Benefits. It will help you understand the criteria, important items to include and walks you through the various steps of the process.

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