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Contents

Understanding XMRV and MLVs

By Anthony L. Komaroff, MD

To understand the murine (mouse) leukemia retroviruses (MLVs), let's start by reviewing a few "basics". Many viruses are able to infect just one kind of animal. For example, certain retroviruses infect only cats, others infect only mice. Sometimes, however, viruses develop gene mutations that allow them to infect more than one type of animal. This is particularly true of retroviruses, which have a high rate of mutations in their genes.

The MLVs were discovered first in mice. They fall into three general groupings:

Ecotropic MLVs are still able to infect only mice. *Xenotropic* MLV-related virus (XMRV) was so named because it is able to infect humans, but no longer is able to infect mice. *Polytropic* MLVs are able to infect mice and some other species, possibly including humans.

As you would expect, no study has reported finding ecotropic MLVs in humans.

Most experts agree that XMRV can infect the human prostate gland. It is not clear, however, that XMRV can cause human disease. One study suggests that XMRV also can infect human white blood cells, but this remains controversial. One study has reported finding XMRV in the blood of patients with chronic

fatigue syndrome (CFS). The authors of that study have reported that, with further experience, they also find polytropic MLVs in the blood of patients with CFS.

One other study, on which I am a coauthor, has reported finding polytropic MLVs in the blood (inside white blood cells and in the liquid part of the blood). This study did not find XMRV, but the number of patients was relatively small.

Still other studies, however, have not been able to find XMRV or polytropic MLVs in patients with CFS. These studies have basically used only one type of technique for finding a virus, something called polymerase chain reaction (PCR). PCR tests are tricky. They can be falsely negative (the test comes up negative, but the virus is really there). And they can be falsely positive (the test comes up positive but the virus is not there: something else turned the test positive). An intensive effort is underway, involving laboratories with different results, to try to understand why the laboratories have come to different results. Even if it is proven that these viruses are found in CFS, that does not mean that they would be proven as a cause of CFS. Much more work needs to be done to clarify these questions.

Ed. *Note*: *Dr. Anthony L. Komaroff is a Professor of Medicine at the Harvard Medical School*

President of the IACFS/ME Speaks Out on CDC XMRV Study

July 30, 2010

Science and the Hold on XMRV Studies

A positive XMRV study in CFS conducted by a NIH/FDA research team was accepted for publication in the *Proceedings of the National Academy of Sciences* (PNAS) but was then put on hold apparently in June, 2010. As reported in an online editorial in *Nature* (July 2; *http://www.nature.com/news/2010/100702/full/news.2010.332.html*), one scientist familiar with the issue said that the journal's editor-in-chief sent the paper out for further review after government agencies requested the publication delay. That review came back with requests for additional studies.

Stephen Monroe, director of the CDC's Division of High-Consequence Pathogens and Pathology, called the delay a "strategic pause" given the conflicting findings between the CDC's own XMRV negative study in CFS -- also put on hold but recently published in *Retrovirology* -- and the positive XMRV findings of the NIH/FDA group (unpublished) Of course, we're concerned about a full airing of the scientific data on XMRV. But it appears that the transparency and timely reporting that is so essential to science was not in evidence in this unusual government action.
Ed.note – The NIH/FDA findings were published at the end of August in *Proceedings of the National Academy of Sciences*.

Examining the Rationale of the Hold

Although the specific purpose of the hold was the subject of speculation among scientists and others, it was not clearly explained by any government official or journal editor. If the purpose of the hold was to re-examine conflicting data with an effort toward reconciling disparate findings, the approach taken here did not achieve this goal (as of this writing). In my view, if the extraordinary step is taken to delay conflicting peer-reviewed studies accepted for publication, then both studies should be held until all further analyses are done.

Once all additional work is completed, the research groups should review each other's manuscripts. This should be followed, in one of the journals, with a thoughtful discussion among the investigators that examines the discrepancies between the studies with the goal of providing informed recommendations for subsequent research. Finally, both articles should be published simultaneously or as close to it as possible. This process has the potential to advance the science.

By contrast, the CDC article alone was published weeks ago without considering or even citing the findings of the PNAS paper. I argue that the CDC paper should have been held until its authors could respond to the NIH/FDA study when its additional work is completed. If there's still time, I would like to see the CDC and NIH/FDA research groups have a discussion of their conflicting findings with the

aim of publishing their talks in the issue of PNAS that contains the NIH/FDA study.

Implications of a Second Positive XMRV Study

Once we get past the hold period, the publishing of the second XMRV positive paper is likely to change the nature of the debate. Prior to this second positive report, the original *Science* paper was becoming an outlier study that could be dismissed in light of several published failures to replicate. With the new replication, the XMRV link to CFS, whatever it may be, will become an ongoing controversy that demands resolution of key issues such as the differences in testing protocols for XMRV as well as the characteristics of patient groups that are tested.

XMRV and the Ottawa 2011 Conference

Our Sept. 2011 biennial conference in Ottawa will devote a full session to XMRV. And we will put together an expert discussion panel representing different points of view about XMRV. This is the kind of scientific forum that we need to constructively address this ongoing research issue.

Fred Friedberg, PhD, President
IACFS/ME
Web: http://www.iacfsme.org

Doctor Martin Lerner - A Passionate CFS Advocate

By Ann M. Cavanagh, CFS patient and volunteer Communications Director, Dr. A. Martin Lerner CFS Foundation

Dr. A. Martin Lerner of the Treatment Center for Chronic Fatigue Syndrome (CFS) in Beverly Hills, MI, is a seasoned CFS physician and newest addition to the National ME/FM Action Network's medical advisory board. He has had an extremely productive summer advocating on behalf of CFS patients everywhere. His medium of choice: published research.

"I believe the best way to help my patients, and CFS patients around the world, is to create, prove, and then share successful treatment options through published, peer reviewed research," says Lerner. "I had CFS approximately 20 years ago. Luckily, I had 30+ years of infectious diseases experience behind me to create a treatment plan for myself. After my full recovery, it was time for me to help others recover. The widest reach is through publishing research… for infectious disease doctors to use as a resource, and for patients to bring into their doctors and show insurance companies for treatment coverage."

Lerner's first paper published this summer in *Virus Adaptation and Treatment* was titled "Subset-directed antiviral treatment of 142 herpesvirus patients with chronic fatigue syndrome." This paper proves what many in the CFS community have believed for years – that there is a causal connection between herpesviruses and CFS. The research followed 142 CFS patients in one clinic, and identified human herpesviruses as a clear causal factor in CFS. It focused on the diagnosis of CFS, the role of Epstein Barr Virus, Human Herpes Virus-6 and Cytomegalovirus infections and Lyme co-infections, the affect these viruses have on the heart, and the successful use of long-term oral antiviral treatments for patients.

Data was collected at physician visits every 4-6 weeks, from 2001-2007, for a minimum of 6 months with the average treatment 2.6 years. The data captured included over 7,000 patient visits and 35,000 fields of information. Fatigue severity was monitored by the validated Energy Index Point Score® (EIPS®), a key measurement tool for CFS diagnosis and recovery. Baseline and follow-up serum antibody titers to EBV, HCMV, HHV6 and Lyme co-infections, twenty-four hour ECG (Holter monitors), echocardiogram, symptoms and toxicity were captured and monitored.

"I remember all too well the war room which we used to collect the data," remarked Ken Gill, one of the study investigators. "The room took on a presence of its own. The walls were filled with charts, system specifications, relational data tables, and our timeline. The only thing missing was a map to the battle field."

During the systematic data review, and extensive data mining, Lerner and his research team identified the need to keep patients with

co-infections such as Lyme disease separate from the herpesvirus-only CFS pool. Until now CFS data pools have not rigorously tested for co-infections. Through Lerner's review it was realized these patients respond differently to antiviral treatment for CFS, require additional antibiotic treatments and, therefore, skew results. Any antiviral treatment tested to date has not been proven successful due to these complex cases muddying the data pool, in addition to short time limitations of 6 months or less in previous studies. Therefore, prior studies have failed to find evidence-based etiology or proven treatment for CFS, until now.

"The systematic approach of patient treatment and data collection by Dr. Lerner was unlike anything I'd ever seen in my 30+ years of data management and IT systems," says Jim Edington, co-executive director of the A. Martin Lerner CFS Foundation. "This allowed us to create an unbelievably rich data pool that provided striking findings."

Most CFS patients have been ill for many, many years and need more than 6 months to recover. Lerner found separating the data pool and increasing the timeline improved the quality of the research and allowed for the findings to present, findings the medical community has been suspecting for years. There is a causal link between herpesviruses and CFS, and the treatment of herpesviruses by long-term antiviral pharmaceuticals can improve CFS in patients. Lifestyle changes included activities such as returning to work or raising a family, as well as improvement and/or eradication of heart, cognitive and immune symptoms occur.

The second article published this summer by *Virus Adaptation and Treatment* took a different angle. This article, titled "An update on the management of glandular fever (infectious mononucleosis) and its sequelae caused by Epstein-Barr virus (HHV-4): new and emerging treatment strategies," performed a review of the Epstein-Barr virus. The review is a culmination of over 20 years of EBV research. Lerner looked broadly at the virus make-up, and then narrowed to EBV patient demographics, EBV diagnostics, and EBV therapeutics and their efficacy.

Over the past 20 years, diagnostics for CFS have evolved. Lerner identifies the most important as serum testing, 24-hour Holter monitor testing, and clinical diagnostic assessment. It is universally accepted that the presence of serum IgM antibody to EBV viral capsid antigen indicates active EBV infection. It appears approximately 1 month after primary infection, and disappears within 6 months to a year. However, a more recent finding is that diffuse component of EBV early antigen indicate abortive non-permissive incomplete virus replication. A defining characteristic of CFS patients is their inability to prevent non-permissive EBV replication that leads to dysregulation of cellular metabolism.

The hypothesis of Lerner's own research, as well as many of his peers, has always been that CFS is the result of abortive, non-permissive herpesvirus (EBV, HCMV and/or HHV6) infection. CFS patients continue EBV, HCMV, and/or HHV6 herpesvirus abortive multiplication, but fail to achieve viral latency which is necessary for recovery. This hypothesis has now been tested through numerous cohorts, administering valacyclovir for suspected EBV CFS subset and valganciclovir for suspected HCMV or HHV6 CFS subsets. Through a pharmacologic, pharmacokinetic, metabolic, distribution and excretion review of antivirals, as well as published cohorts, this EBV review again substantiates their success. The use of long term antiviral treatments provides drastic improvements to quality of life for CFS herpesvirus patients with abortive non-permissive incomplete virus replication.

The cornerstone to all the research Lerner has performed since recovering from CFS himself has been the diagnostic tool he created, as he felt, out of necessity. The peer reviewed and substantiated Energy Index Point Score® (EIPS®) is a universal CFS gauge that assists physicians, and patients alike, in the diagnosis and monitoring of CFS over time. The EIPS is used internationally and translated into numerous languages. (EIPS® gauge follows this article)

"The CFS community urgently requires a common measurement to evaluate and treat patients. Just as oncologists are able to determine treatment and prognosis based on the stage of cancer, an infectious disease physician can do the same for CFS. With these

measurement tools comes a common language for research, a universal standard for evaluation and treatment, and ultimately the legitimacy this disease deserves," says Lerner. "Using the EIPS as a benchmark for my practice and research has improved my ability to gauge illness as well as capture individuals' improvements. It is also an extremely helpful teaching tool for discussing parameters with a patient…what they can and can't do as they heal."

The EIPS is a simple but critical metric. It is extremely important to set aside the terrible debilitating symptoms for a moment and simply focus on the amount of time a patient can be out of bed. There is no doubt that there is a very strong correlation to patients having the ability to be out of bed and their recovery. As Dr. Lerner and his research team worked and talked with other organizations and foundations, they found the EIPS also helped as they discussed assignments. It provided a common understanding of the resources they were working with as many organizations including their own have ME/CFS volunteers.

The EIPS has also been validated as a measurement for disability in patients with CFS through a research effort published by *In Vivo: The International Journal of Experimental and Clinical Pathophysiology and Drug Research*, titled "**Validation of the Energy Index Point Score to Serially Measure the Degree of Disability in Patients with Chronic Fatigue Syndrome."**

In the past 50 years Lerner has written over 200 original articles spanning many areas of virology, narrowing his focus in more recent years to the study of CFS. He attended Washington University Medical School in St. Louis, MI, was awarded fellowships at the National Institute of Allergy and Infectious Diseases, Harvard Medical School and Massachusetts Institute of Technology, and has held positions including Chief - Infectious Diseases, Chief - Department of Medicine, Professor of Internal Medicine, and currently acts as Clinical Professor of Internal Medicine for Wayne State University School of Medicine. He also served as Governor for Michigan, American College of Physicians, 1991-1994. In 2001 Dr. Lerner was bestowed the highest honor of the American College of Physicians, Master.

So what is next for this CFS practitioner, researcher, patient advocate, activist? First priority is always his patients. Lerner meets with patients 5 days a week at his practice, as well as continues hospital rounds for his most ill patients. Then, he must take a little time out this month to celebrate his upcoming 81st birthday with family and friends. And then, it's onto more research. He will also be found presenting his findings at the CFS Advisory Committee's "Science Day" on October 12th in Washington, DC, hosted by the U.S. Health and Human Services. This event is open for public attendance, and will be webcast live for those unable to attend in person.

"My wish for the CFS community is simple," says Lerner, "I wish to do what is necessary so that all CFS patients can benefit from antiviral therapy… so they can return to healthy, normal lives."

Ed. note. *To view copies of Dr. Lerner's most recent research, you are able to download them from his website at www.treatmentcenterforcfs.com*

Energy Index Point Score® (EIPS®)

A Functional Capacity Measurement Tool for Chronic Fatigue Syndrome (CFS) Patients

To Physicians Caring for Patients with CFS
The Energy Index Point Score® (EIPS®) chart provides the severity of patient fatigue. A change in EIPS® level of one is a significant change. The EIPS® level is determined by agreement of physician and patient with the EIPS® chart easily available for viewing at out-patient visits. As the EIPS® level increases, CFS symptoms lessen and disappear.

How to use the EIPS® system in four easy steps: 1) Post the EIPS® chart in examining room; 2) Ask patient to evaluate his/her level of activity based upon the prior two weeks; 3) Question the patient's EIPS® evaluation; 4) Record and track the EIPS® level. Report every 6-12 weeks.

Energy Index Point Score® (EIPS®)

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0
Bed-ridden, up to bathroom only
1
Out of bed 30 - 60 minutes a day (sitting in chair is out of bed)
2
Out of bed sitting, standing, walking 1 - 2 hours per day
3
Out of bed sitting, standing, walking 2 - 4 hours per day
4
Out of bed sitting, standing, walking 4 - 6 hours per day
5
Perform with difficulty sedentary job 40 hours a week, daily naps

RECOVERY

6
Daily naps in bed, may maintain a 40 hour sedentary work week plus light, limited housekeeping and/or social activities
7
No naps in bed. Up 7:00 a.m. to 9:00p.m. Able to work a sedentary job plus light housekeeping
8
Full sedentary workweek, no naps, some social activities plus light exercise
9
Same as 8 above plus exercise approximately 1/2 to 2/3 normal without excessive fatigue, awakens next morning refreshed
10
Normal

Ed. note - *Dr. Martin Lerner is on our Medical Advisors Panel*

New Diagnostic Criteria for Fibromyalgia

By: Ellen N. Thompson MB BS, FRCP

New diagnostic criteria for fibromyalgia (FM) have recently been published by The American College of Rheumatology Wolfe et al, (1),They were based on research that “aimed to develop practical criteria for clinical diagnosis of fibromyalgia "---suitable for use in primary and specialty care---that do not require a tender point examination.” The goal was to make the diagnosis of FM "easier”. This follows a similar initiative by European clinicians.

The resulting diagnostic criteria form a hold-all accommodating both fibromyalgia (FM) and myofascial pain (MPS), when the latter affects several body regions. This seems scientifically and clinically unsatisfactory. Myofascial pain is a distinct entity with important differences from FM; the most important being response to treatment. Inactivation of a myofascial trigger point by injection or by other physical means can abolish pain and prevent chronicity. Such treatments would aggravate pain in individuals with pure FM.

MPS most commonly affects a body region such as face and jaws in temporo-mandibular disorders, or head/neck/shoulders in “whip-lash” related pain. It is the most common cause for low back pain according to John Bonica (2). When MPS affects several body regions it can be difficult to distinguish from FM. This difficulty is exacerbated by the fact FM tender points and MPS trigger points tend to occur in the same locations. Palpation of the point will cause marked increase in local pain in FM patients, while the palpation of a MPS trigger point will cause referred pain into areas that can be quite distant. MPS trigger points in the interscapular muscles in the upper back can often refer pain down the arm for instance. Thus, making the distinction is not difficult, but it does require the clinician to palpate the sore points.

It is also well known that some individuals have a mixed picture of FM and MPS. For these individuals a flare-up of MPS trigger points can be associated with a flare-up of the FM. In some patients inactivation of the trigger points, usually with injection of local anaesthetic and a

very small quantity of depot steroid can abolish the FM flare. (Personal observations.)

While few randomized clinical trials (RCTs) regarding MPS and the treatment thereof have been published, a large amount has been written by good clinicians: Janet Travell and David Simons (2), John J Bonica and Anders Sola (3), Devin Starlanyl and ME Copeland (4) have all written books or book chapters. More recently Shah et al (5) published important data on the biochemical abnormalities found in trigger points.

Adopting diagnostic criteria that further blur the lines between FM and MPS will hinder good clinical care and further confuse research.

References

1. Wolfe F, Clauw DJ, Fitzcharles MA, Goldenberg DL, Katz RS, Mease P et al.,The American College of Rheumatology Preliminary Diagnostic Criteria for Fibromyalgia and Measurement of Symptom Severity. Arthritis Care & Research 2010, 62: 600-619.
2. Bonica's Management of Pain, Second Edition Chapters 21 and 72.
3. Myofascial Pain and Dysfunction. The trigger point Manual. Williams and Wilkins, Baltimore, 1983.
4. Fibromyalgia and Chronic Myofascial Pain Syndrome. A Survival Manual. New Harbinger Publications, Oakland CA.
5. Shah JP, Phillips TM, Danoff JV, Gerber LH, An in vivo microanalytical technique for measuring the local biochemical milieu of human skeletal muscle. J of Applied Physiol 2005, 99:1977-1984.

Ed. Note: *Dr. Ellen Thompson is on our Medical Advisors Panel*

Resting Brain Activity Associated with Spontaneous Fibromyalgia Pain

Published Thursday, July 29, 2010 in Psychology & Sociology

Researchers at Massachusetts General Hospital and University of Michigan discovered evidence of a linkage between elevated intrinsic (resting-state) brain connectivity and spontaneous pain intensity in FM patients. Details of the study appear online and in the August issue of *Arthritis & Rheumatism*.

That study, conducted by Vitaly Napadow, Ph.D. and colleagues, indicate that individuals with FM have a greater connectivity between multiple brain networks and the insular cortex, a brain region previously linked with evoked pain processing and hyperexcitability.

The current findings provide a better understanding of the underlying brain mechanisms of clinical pain in FM and may potentially lead to markers of disease progression. Dr. Napadow pointed out, however, that their results were derived strictly from FM patients and may not be generalized to other pain states.

Links: http://www.healthnews@wiley.com
http://www.rheumatology.org

Preparing for 2011 Research and Clinical Conference – Your Input Needed

In anticipation of the Network hosting the 10th International IACFS/ME research and clinical conference in September 2011, we are now preparing a roster of medical professionals to alert them to that conference.

Please send us the names of medical professionals or organizations you are aware of, together with their addresses so that we may be sure to add them to our list. You can send us the information by email, fax or land mail.

News Snippets

Canada

- An article dated August 25, 2010 by Jenna McMurray in the Calgary Sun reported that Alberta researchers were hoping to prove once and for all through an ambitious study in Calgary and Edmonton, Alberta that ME/CFS is viral in original.

- Dr. Eleanor Stein, a Calgary ME/CFS specialist and researcher stated that this study will look to confirm if ME/CFS is in fact linked with the retrovirus XMRV. Dr. Stein will be joined by Dr. Lorne Tyrrell, founding director of the Li Ka Shing Institute of Virology in Edmonton and Dr. Michael Houghton of the University of Alberta who holds the Canada Excellence Research Chair in Virology for a preliminary study.

  Approximately 100 participants, 50 diagnosed with ME/CFS and 50 healthy controls are needed for this study. Subjects who are severely affected by ME/CFS are invited. They will answer questionnaires as well as have their blood drawn. The research team intends to apply for a grant early next year to fund a larger study. Calgary participants are asked to call **403.287.9941** and in Edmonton at **780.492.8415**.

United Kingdom

- Professor Jill Belch, an expert in vascular research medicine at Ninewells Hospital in Dundee found blood changes that suggest chronic inflammation in children. She stated that this was important as …."it's showing an abnormality that we might be able to devise a treatment for, but it's also important because some people do suggest that ME is a disease of the mind and here we are showing that it is a disease of the body."

- A meeting of Subgroup on XMRV of the National Expert Panel on New and Emerging Infections concluded that:

1. XMRV can infect humans but there is currently no evidence that it causes human diseases;
2. Development of a robust diagnostic tool to accurately detect infection is a priority for further investigation of this infection;
3. Further work is required to investigate tissue tropism and pathogenicity, epidemiology of infection and whether this infection is of any public health significant; and
4. On the evidence before the Group, no public health action is required at this time.

China

- Sixty-five (65) CFS patients and 85 blood donor controls were enrolled in a study to analyze the XMRV infection status of the participants. The study reported that XMRV was not detected in the 65 CFS patients and 65 normal individuals out of 85 controls. *Virology Journal 2010, 7:224 www.virologyj.com/content/7/1/224*

United States

- Mindy Kitei for CFS Central reported that Dr. Paul Cheney, a long-time ME/CFS physician and researcher presented his poster at the XMRV conference at the National Institutes of Health in September 2010 "*Detection of XMRV in a National Practice Specializing Exclusively in Chronic Fatigue Syndrome*". Dr. Cheney had selected 47 patients (38 female and 9 males) from 24 States in the U.S. plus Canada and Australia who met the 1994 CDC Fakuda definition with an average length of illness of 19 years.

  The results indicated that of the 47 patients, 35 were positive for XMRV, 8 of 16 healthy family members and non-family "exposure controls" were XMRV positive as well.

- Over 200 researchers from around the world met September 7th and 8th at an international workshop on the campus of the National Institute of Health (NIH) to discuss XMRV. The workshop included

presentations by researchers who had found the retrovirus as well as by those who had not. Dr. John Coffin of Tufts University stated that ".....it was a big step toward helping to get all these discrepancies resolved." He stated that he was optimistic that standardization of methods for detecting the virus in patient samples should be available within a year. For complete article visit http://www.cancer.gov/ncicancerbulletin/092110/page5

Canadian Blood Services

Q. Do you know when CFS patients were put on the blood questionnaire to be screened out and by what process they could prove they were well in order to donate? Not a single newspaper article I've read has answered these questions, and I would really like an answer to them. I know when the CCC were published in 2003 they carried a blood donation warning for health reasons and because of "unknown pathogens" ME/CFS patients might be carrying. I'm curious to know if this original exclusion happened before 2003 or after, and if so, how long after?

A. CBS got our approval from Health Canada to change the process for managing donors reporting a history of CFS and implemented the change in April, 2010. Prior to that time, if a donor reported that they had a history of CFS and they were currently feeling well (recovered) and able to function normally we had been allowing them to donate. We used the Consensus Conference statement on CFS as one of the pieces of information to help us decide to change the way we manage donors with a history of CFS. The process that the donor used to qualify for donation was simply their responses to questions asked by our screening staff. This is how we get additional information when any donor reports an unusual medical history on the record of donation, we ask further questions and then depending on the answers that person is either deferred or permitted to donate. There are literally dozens of medical scenarios that we might ask questions about, and we have standardized ways of dealing with the answers to these questions. Our new way to manage donors who tell us that they have a history of CFS is to defer them no matter whether they are currently feeling well or not, and no matter how remote their CFS episodes were.

Dana V. Devine, Ph.D., Vice-President,
Medical, Scientific and Research Affairs
Canadian Blood Services

Submission on the Use of Audiotapes during Independent Examinations - End

If the *raison d'être* of an IME is to enhance the search for truth, surely an independent record of what transpires in an IME is not only consistent with this objective but is an important complement to it and ought to be allowed unless there are compelling arguments and/or evidence to the contrary.

The potential costs of audio recording IMEs include the following:

a) the purchase or rental of recording equipment by the party being examined and the examiner;
b) the cost of transcribing the interview;
c) the cost of having counsel and the examining and/or opposing expert review the audio recording and/or the transcript;
d) the additional time involved in reviewing the audio recording and/or the transcript at trial.

Technological advances have made recording devices portable, affordable, and reliable. A digital voice recorder that records 9 hours of high quality recordings can be purchased at a cost of approximately $80. A quality recorder that produces stereo sound quality and near-absence of background noise with four integrated microphones can be purchased for approximately $200.

The costs for reproducing the recording depend to some degree on the nature of the medical examination. Most IMEs last between two and three hours. A forensic psychiatric examination would likely have the most lengthy interview, lasting up to 3 hours. Neuropsychological

assessments and functional or work capacity evaluations are longer and may last the better part of a day. In most other assessments, the interview portion of the assessment lasts no more than 1 hour, with the remaining time spent on a physical examination.

The cost of transcribing a 2 hour interview in British Columbia would be no more than the cost of a 2 hour examination for discovery.

Whether an audio recording would be transcribed or reviewed and whether it would be used at trial will likely depend on the perceived benefit in doing so, which will vary from case to case. It is likely that if made available, an audio recording would significantly reduce the time that would otherwise be spent cross-examining an expert concerning what transpired in the IME.

Proposed rule allowing audiotaping of IME

The following issues arise if audio recording is to be introduced:

1. what are the circumstances in which taping will be allowed?
2. what are the uses to which the recordings could be put?
3. what measures can be taken to make the recording reliable/authentic?

It is recommended that any party ordered to undergo an IME under Rule 30 be allowed to audio tape the assessment, subject to the discretion of the court to disallow taping. In other words, the parties would have a *prima facie* right to record. While there do not appear to be any cogent reasons for not allowing an examination to be audiotaped, it would be advisable to grant the court discretion to address whatever circumstances may arise.

The use to which the recordings are put should be self-evident: they are designed to shed light on the issues for which the IME assessment was ordered and the IME process itself.

In order to ensure the fair use of audiotaping, a provision would be required for parties to give notice of their intention to tape an opposing expert's IME and notice of their intention to use the tape at trial. The requirement for such notices can be added to Rules 30 and 40A. It would be incumbent on the party seeking to use the audiotape to cover the cost in the first instance of transcription and to provide a copy of the recording and the transcript to the opposing party when notice is given.

Reliability of the recording process can be most easily addressed by allowing both parties to record the interview and requiring notice to be given if there is any concern about the reliability of the recording. This is what is contemplated by the BC College of Physicians and Surgeons. If instances of tampering are found to have occurred (it should not be assumed that conduct of this nature will happen), arrangements could be made for the actual recording device to be picked up from the doctor's office from the doctor's office immediately following the IME and delivered to court reporters to prepare an "official" disc and/or transcript.

Appendix A sets out the proposed wording of Rules 30 and 40A allowing audiotaping.

Conclusion

Within the legal setting, the ultimate goal of our legal system is to achieve justice. Within the medical setting, codes of ethics are built around principles of accountability and transparency, which are designed to ensure fairness to the public. These principles operate in harmony and form a strong foundation for the introduction of simple measures to allow the audio recording of IMEs under Rule 30. It is anticipated that such a measure will reassure individuals who are compelled to undergo Rule 30 examinations of the value placed on fairness and openness in civil proceedings and will in a general sense promote public confidence in our system of justice.

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Ed. Note: *Faith Hayman is on our National Lawyers' Roster for referral purposes*.

Principles Governing the Request of Defence Psychiatric Medical Examinations

By Hugh Scher and Caroline Schulz

As many plaintiffs with ME and FM in the midst of personal injury or disability insurance litigation know, defence counsel may presume to be entitled to compel a plaintiff to attend at any medical examination of its choosing.

However, plaintiffs do not have to submit to all unsubstantiated requests by defence counsel to attend at medical examinations.

Pursuant to the applicable legislation and case law, defence counsel is only entitled to request a plaintiff to attend at its *first* independent medical examination ("IME") where the type of IME requested is relevant to a material issue raised by the plaintiff during litigation.

This is good news for plaintiffs, especially those with ME and FM whose complex, multi-faceted and frequently misunderstood conditions often compel defence counsel to request medical examinations from a number of specialists, including psychiatrists – despite there being no rational basis for such assessments in many cases.

Plaintiffs must accordingly be informed about the criteria defence counsel must establish before compelling a plaintiff to attend at a psychiatric medical assessment.

Requesting Defence Psychiatric Medical

In order to obtain a court order that compels plaintiffs to attend at defence medical examinations, defence counsel must fulfill the statutory requirements set out in section 105 of the *Courts of Justice Act* and Rule 33.02 of the *Rules of Civil Procedure*:

> 105 (2) Where the physical or mental condition of a party to a proceeding is in question, the court, on motion, may order the party to undergo a physical or mental examination by one or more health practitioners.
>
> (3) Where the question of a party's physical or mental condition is first raised by another party, an order under this section shall not be made unless the allegation is relevant to a material issue in the proceeding and there is good reason to believe that there is substance to the allegation.
>
> Further Examinations
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> (4) The court may, on motion, order further physical or mental examinations.

As such, defence counsel must first establish that the plaintiff's mental condition is relevant to a material issue in the proceeding, and that there is good reason to believe that the plaintiff's mental health is in question (s.105 (2) & (3) CJA). In establishing this criterion, courts have considered whether:

- The plaintiff suffered from a pre-existing psychological/psychiatric condition;
- The plaintiff has complained of symptoms indicative of a psychological or psychiatric disorder at the time of the accident or later;
- The plaintiff's treating physicians have raised concerns about the plaintiff's mental health in their medical reports or notes and records;
- Whether the plaintiff has received psychological or psychiatric treatment

As many ME/FM plaintiffs know, defence counsel have relied on erroneous and stereotypical views of ME/FM as psychiatric disorders, to argue that by the nature of these conditions mental health is material. However, without evidentiary basis regarding the mental health of the plaintiff at issue, such assertions are unlikely to convince a court that the plaintiff's mental condition is relevant. Defence counsel has the onus of establishing, preferably in the form of affidavit evidence from a medical specialist, that mental health is material to the proceeding. Unless defence counsel has provided such convincing evidence, plaintiffs may not be required to consent to psychiatric assessments.

That being said, plaintiffs must be wary of unwittingly placing their mental health at issue in

their Statement of Claim, during examinations for discovery, or in a medical report by their treating physician, as defence counsel will often seek to obtain further assessments based upon such information. Plaintiffs must also be careful before deciding not to consent to such an assessment as they may be deemed to be non-compliant with the rules and could be subjected to court sanctions.

As each case will turn on its particular facts, plaintiffs are best advised to seek legal advice and assistance in disputing defence counsel's unsubstantiated requests to attend at psychiatric or other examinations. Our office has extensive experience in assisting people with ME/FM in securing their just entitlement to long-term disability insurance and CPP disability benefits. We have often addressed requests for improper medical examinations, including psychiatric assessments of plaintiffs and successfully argued that such assessments are unwarranted (*The Minister of Human Resources Development Canada v. Pamela Dubowec* (2000) (P.A.B.); *Keays v. Honda Canada Inc.* 2005 CarswellOnt 1131 (S.C.J.) reversed in part by: *Keays v. Honda Canada Inc.* 2008 CarswellOnt 3747 (S.C.C.); *Lowe v. Guarantee Insurance Co. of North America* 2005 CarswellOnt 3072 (Ont.C.A.)).

In *Lowe*, we were successful in persuading the court to create a new cause of action in negligence for the improper conduct and report of an independent assessment. We acted for the National ME/FM Action Network in this case before the Ontario Court of Appeal.

Further Medical Examinations

Defence counsel is entitled to a psychiatric medical where such medical is a *first* examination pursuant to section 105 of the *Courts of Justice Act* and R. 33.02 of the *Rules of Civil Procedure* and where the plaintiff's mental health is a material issue in the proceeding. *Further* medical assessments require additional evidence or justification.

There has been some dispute under the case law whether a "first" examination during litigation is actually a *further* examination when the insurance company has recently conducted medical examinations pursuant to the insurance contract or insurance legislation.

In *Zinchuk v. Unum Provident Canada* 2005 CarswellOnt 341, the Ontario Master found that even though the insurer had yet to conduct a medical examination of the plaintiff during litigation, the three psychiatric medical examinations conducted pursuant to the insurance contract were sufficient to require defence counsel to provide justification for this *further* examination.

Further medical examinations require defence counsel to establish that:

- The plaintiff's mental condition is relevant to a material issue in the proceeding and that there is good reason to believe there is substance to the allegation;
- Further medical examinations are necessary as a diagnostic aid to assist the physician who made the initial physical examination;
- Such an examination is likely to produce relevant information. That evidence should be in the form of an affidavit sworn by a psychiatrist;
- The plaintiff has placed her psychiatric health in issue at some point during litigation in her Statement of Claim, during discovery, or by relying upon the medical opinion of a psychiatrist in the advancement of her claim for damages;

1. The defendant will be prejudiced in not having the examinations, and such prejudice exceeds the prejudice that may be caused to the plaintiff by attending the examinations;

2. The request must be made in a timely way.

Claimants who apply for Canada Pension Plan Disability Pension may also be subjected to unnecessary and prejudicial medical examinations at the request of the Minister. The Minister's entitlement to such assessments must also be considered in accordance with the principles set out in the CPP regulations and

pension appeals board case law, including the *Dubowec* case referenced above which our office successfully argued at the Pension Appeals Board.

Conclusion

Plaintiffs and claimants facing unnecessary and prejudicial requests to attend at psychiatric medical assessments ought to consider whether defence counsel and/or the Minister has properly established their entitlement to such requests and should consult an experienced and knowledgeable lawyer in ME/FM and insurance and disability benefit matters to ensure that they are not submitting to unreasonable and potentially prejudicial defence medical assessments.

Should you need assistance with your LTD or CPP claim or if you believe you are improperly being requested to attend for a medical assessment, our office would be pleased to advise you about your rights and obligations in order to ensure that your claim is properly and not prejudicially advanced.

***Note on Authors**: Hugh Scher is the founder of the law firm Scher Law Professional Corporation where he practices disability insurance and CPP litigation as well as employment and human rights law. Mr. Scher has represented dozens of individuals from across the country with Fibromyalgia and Chronic Fatigue Syndrome in disputes with long-term disability insurers, the Canada Pension Plan, employers and Revenue Canada. He served as counsel to Mr. Keays in Honda v. Keays and also represented the National ME/FM Action Network in Lowe v. Guarantee Insurance Co. of North America 2005 CarswellOnt 3072 (Ont.C.A.).*

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Ed. note: *Hugh Scher is the Legal Counsel for the National ME/FM Action Network and is also on our National Lawyers' Roster for referral purposes*

Newsletters/Reports//Links/videos, etc.

Bulletin of the IACFS/ME– Summer 2010 - This quarterly publication features the abstract "*Close Analysis of a Large Published Cohort Trial into Fatigue Syndromes and Mood Disorders that Occur after Documented Viral Infection."* The analysis calls into question the validity of broad based definitions as with such criteria primary mood disorders/psychiatric illness are included.

To view the abstract, visit

http://www.iacfsme.org/BULLETINSSUMMER2010/Summer2010SampsonAnalysisCohortTrial4481/tabid/435/Default.aspx MEshare is at: http://groups.google.co.uk/group/meshare

New Google Group which provides articles editors can use in their ME support group newsletters.

Unheard Voices: My Story Update

In our quest to put together stories of people who are ill with ME/CFS and FMS as well as their caregivers, we would also like to point out that your experiences can also be about a specific incident, such as from work, at a doctor's office, insurance issues etc.

We are accepting stories from around the world as these are world-wide illnesses. Your story can be done on your computer and emailed to us or sent via fax or through regular mail.

We hope to hear from you.

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 US$14.95

"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 on Chapters.ca, used only***.**

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 canadien sur le SFC: Définition clinique et lignes directrices à l'intention des médecins - $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; ou aqem@spg.qc.ca site web : www.aqem.org

- ***Version française : Abrégé du Consensus canadien sur le SFM: Définition clinique et lignes directrices à l'intention des médecins NEW - NOUVEAU**
Bruce M. Carruthers, MD, CM, FRCP(C)
Marjorie I. van de Sande, B Ed, Grad Dip Ed
Available on our website at www.mefmaction.net – disponible sur notre site web: www.mefmaction.net

**Hard copies will be published shortly and may be purchased through the National ME/FM Action Network*.
Le National ME/FM Action Network publiera prochainement des copies de l'abrégé sur le SFM. Il sera possible de se les procurer en s'adressant à leur bureau (voir coordonnées p.16).

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 summaries of medical and legal articles which appeared in **'QUEST'** newsletters and compiled them in an easy-to-read format in the years specified in the collections.

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 Disability Manual & Court Case References: $70.00

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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National ME/FM Action Network now on FACEBOOK and TWITTER
http://www.facebook.com/pages/National-MEFM-Action-Network/119761554710463
http://www.twitter.com/mefmaction

MEMBERSHIP: $25.00 per year, which includes quarterly newsletters
Payment can be made by CHEQUE, VISA or MASTERCARD.
Do not email credit card information

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