

Quest #28 February 1998

RESEARCH BREAKTHROUGH: ME/CFS AN INFECTIOUS CARDIOMYOPATHY?

By: Philipa D. Corning, Ph.D., B.Sc.

(Reviewed and approved by Dr. A. Martin Lerner)

Dr. A. Martin Lerner, M.D. at the University of Newcastle's Chronic Fatigue Syndrome/Myalgic Encephalomyelitis Research Conference in Sydney, Australia has offered "hard data" that shatters the myth that ME/CFS is a psychiatric disorder, depression, hysteria or deconditioning due to patient refusal to exercise. In the United States, Dr. Lerner, an infectious specialist at William Beaumont Hospital and at Wayne State University, and his colleagues, have found evidence that ME/CFS may be caused by a persistent herpesvirus infection of the heart.

Research Replicated and Peer-Reviewed

This research is significant and well documented. Dr. Lerner's results have recently been reviewed by Maryann Spurgin, Ph.D. of Medical Professionals with CF(ID)S. Dr. Spurgin writes: "The most acutely perceptive and pioneering work on CFS these days is happening in a quiet corner of the country, out of the CFS limelight."

Cardiomyopathy - 100% in ME/CFS Patients

In this study, 100% of the ME/CFS participants showed abnormal oscillating T-waves at 24 hr. holter monitoring and 24% showed weakened function on the left side of the heart (abnormal cardiac dynamics). This is the side of the heart that pumps oxygenated blood to all of the body, except the lungs. Data, gathered from biopsies and a 24-hour electrocardiogram (EKG) Holter monitor, showed that patients exhibited evidence of cardiomyopathy or disease of muscle in the heart.

These researchers tracked EKGs over a 24-hour period with a Holter monitor device and documented abnormal T-waves. This wave measures electrical recovery after contraction of the left ventricle. A normal T-wave should be shaped like the rolling crest of a wave in water. In 100% of ME/CFS patients, Lerner and his associates documented T-wave Inversions and/or T-wave flattenings. This finding is so consistent, they suggest that the Holter results should be included as part of the CDC case definition; it distinguishes ME/CFS patients from those with fatigue or unexplained origin. This research holds the potential to distinguish ME/CFS patients from FM patients, from those with other pain syndromes who do not relapse with exertion, and from those with fatigue associated with depression, which is a group that also does not suffer relapse with exertion. This work offers hard evidence to back up ME/CFS patients' much disbelieved claim that exercise is harmful and causes disease progression in ME/CFS.

Cause - Viral Infection of Cardiac Tissue

No single virus has been found to cause ME/CFS. Dr. Lerner's work accounts for this, since a 2 viruses, singly or in combination account for the majority of CFS cases. The implicated viruses are Epstein-Barr virus and Cytomegalovirus. The basic thesis of this research is that ME/CFS is a persisting infectious disease of the heart resulting from single or dual viral cause. In many cases, the resulting disease process is progressive. According to the theory, ME/CFS follows an initial infection with a virus, or a reactivation of a latent virus.

For example, Epstein Barr Virus (EBV) or Cytomegalovirus (CMV) attacks the heart tissue producing exercise intolerance, the hallmark of ME/CFS. The human heart muscle fibers become the site of

persistent virus infection. The infected person worsens his condition when he or she exerts him or herself physically. In addition, this theory explains what has baffled researchers for years - why some EBV-infected people who do NOT develop ME/CFS the heart was never involved even though these people tested serum positive for EBV. This same scenario holds well for CMV. Therefore, in this hypothesis, EBV or CMV serum positive non-ME/CFS subjects will not show EBV or CMV nucleic acids (viral genetic material) in heart muscle fibers, whereas ME/CFS patients will present viral nucleic acids in cardiac tissue.

Cardiac tissue Biopsy Results

These researchers have backed up their work with biopsies on the cardiac tissue of ME/CFS patients. They have found for heart muscle disorganization, muscle fiber disarray, abnormal formation of fibrous tissue in the place of heart muscle cells, fat infiltration and increases in the intracellular structures that produce energy (mitochondria) within heart muscle cells. All these results are indicative of cardiomyopathy.

In addition, Dr. Lerner and his associates have observed that patients with acute EBV mononucleosis who recover promptly, have normal 24-hour EKG Holter monitoring throughout their illness. Conversely, patients with prolonged illnesses of EBV mononucleosis consistently have abnormal 24-hour EKG Holter monitor results.

Post-exertion Deterioration

In Dr. Lerner's model, the weakened heart is aggravated by physical activity, accounting for the post-exertional sickness and accounting for the post-exertional sickness so common in this disease - including flu symptoms, chills, fevers and increasing weakness. Indeed, the cardiac connection is what is so ground-breaking about this research.

In experiments with mice, Dr. Lerner has shown that raised myocardial coxsackie viral titers accompany physical exertion in the mice. When the heart muscle tissue is infected, overactivity causes death of cardiac tissue and disease progression. This is in direct conflict with the U.S. government research conclusions that ME/CFS disease symptoms are caused by underactivity due to a sedentary lifestyle. Dr. Lerner advises resting the heart in order to "do no harm" and to prevent death of cardiac tissue.

Abnormal Ejection of Blood from Heart

Dr. Lerner and associates also have documented abnormal ejection fractions in ME/CFS. Normally, over half of the blood in the left ventricle is ejected when the left ventricle contracts (part of the heart that pumps oxygenated blood out to the body). In Dr. Lerner's ME/CFS subjects, the ejection fraction is sometimes decreased, an indication that not all the normally-expelled blood leaves the ventricle. Some patients had reduced ejection fractions at rest while others had an ejection fraction that decreased during exercise from 51% to 36%. In a normal subject, the ejection fraction will rise over 5% during exercise. Stationary or falling ejection fraction is abnormal in coronary artery disease or cardiac muscle disease. Declining ejection fractions are not seen in normal persons leading sedentary lives.

Anti-Viral Therapy

These cardiac abnormalities are hypothesized to be virally induced. In some CMV patients, ejection fractions reverted to normal after anti-viral therapy with ganciclovir.

Lerner Model Explains Results of Others

This model explains the John Hopkins' finding of Rowe et al in which ME/CFS patients exhibited abnormal response to upright tilt. Lerner argues that it is abnormal cardiac response of cardiomyopathy instead of abnormal neural response. Indeed, Dr. Lerner's thesis explains a myriad of phenomenon that other research has not. For example, it explains why patients relapse with exertion and why only physically active young persons may acquire the disease. It also explains why stress is a major aggravator in this disorder. Stress may aggravate both herpes viruses and heart conditions. It also explains the anti-viral lymphocyte enzyme system, the 2-5 A pathway, suggesting the presence of a chronic infection.

Summary

In short, Dr. Lerner's work explains why previously healthy, vigorous young adults fall ill with chronic cardiomyopathy due to viral infection and cannot exercise for fear of causing further heart damage. This is directly opposite to the work of Dr. Stephen Straus at National Institute of Health (NIH) whose theory states that ME/CFS is a psychiatric disorder. This new research of Dr. Lerner et al is both refreshing and insightful. Needless to say, it has also been long awaited.

Please note that Dr. Lerner is not equipped to handle phone calls from patients or physicians caring for individual patients. More details can be obtained by reviewing these published records.

NUTRITIONAL BASIS FOR ME and FM - By: Philipa Corning, B.Sc., Ph.D - PART V - FINAL

Part V of Dr. Corning's article "Nutritional Basis for ME and FM" will appear in our April/May '98 issue.

'TOTAL DISABILITY' INSURANCE CLAIMS

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1. The purpose of this article is to discuss how the Courts have interpreted the definition of "total disability" for the purpose of determining whether a person is entitled to disability insurance benefits (LTD).
2. People who are rendered disabled from working due to a medical condition, (such as M.E./chronic fatigue, fibromyalgia, or some other chronic pain condition), often have coverage for wage loss replacement through a disability insurance plan. This coverage is often available through their group benefit plan at work, or from statutory schemes such as CPP, WCB, or social assistance disability benefits.
3. In order to be entitled to disability benefits, the claimant must be considered "totally disabled" as

that term is defined in the insurance policy. Many legal disputes arise when the insurance company decides that the claimant is not disabled within the meaning of the policy definition and, accordingly, refuses to pay disability benefits.

4. Often, the disabled person may be surprised to learn that the long-term disability (LTD) insurer is not prepared to recognize their condition or their disability. Insurance companies routinely deny applications for LTD benefits on the basis that there is no "objective" evidence of disability. They will often deny that the claimant has M.E./chronic fatigue or fibromyalgia at all.

A. MEDICAL-LEGAL ISSUE

5. The question of whether a claimant is "totally disabled" and therefore entitled to disability benefits is not **solely** a medical issue. It is a medical-legal issue. Ultimately, the court determines whether the claimant's medical condition meets the legal definition of "total disability" set out in the insurance policy.

6. The primary medical-legal issue in these cases is whether the patient has been disabled from working according to the definition of "total disability" in the insurance policy.

7. In all disability claims, the claimant must provide the insurance company with medical evidence, usually from the family doctor and other treating medical specialists, that the medical condition is serious enough to prevent the person from working.

8. It is essential that physicians fully understand and address the disability issue when they fill out standard insurance medical report forms and prepare medical reports for their patient's disability claim.

9. Unfortunately, decisions to deny benefits by insurance companies are often based on very general statements in medical reports to the effect that the patient is capable of some form of work. Insurance companies are quick to deny claims if full particulars of the patient's functional limitations and resulting work disability are not clearly set out in insurance forms and medical reports.

10. It is not enough for the doctor just to describe the medical diagnosis, (i.e. that the patient has fibromyalgia or M.E./chronic fatigue). In the medical-legal report or standard insurance form the physician must address three inter-related issues:

(a) the medical history and the diagnosis;

(b) the functional limitations or restrictions arising from the cumulative effects of the patient's medical condition (both physical and mental); and

(c) provide a medical/legal opinion as to whether the functional limitations render the patient disabled from working in accordance with the definition of "totally disabled".

11. I have detected a difference between the medical profession's concept of "total disability" literally, in the sense that they would consider a patient totally disabled only if the patient is **absolutely** unable to work, even part-time, due to a medical condition.

13. However, the courts have interpreted the term "total disability" differently in the medical-legal context.

14. Moreover, an organic cause of illness need not be objectively or definitively proven for an insured to be entitled to disability benefits. The courts recognize that there are medical conditions, (i.e.,

fibromyalgia, chronic fatigue syndrome and psychological or psychiatric conditions), which cannot be shown by objective medical tests. Nonetheless, these conditions can be clinically diagnosed based on the patient's subjective report or symptoms.

B. "TOTAL DISABILITY - DEFINITION

15. The definition of "total disability" in most insurance policies is usually along the following lines:

'disability' and 'disabled' mean that because of injury or illness:

(a) **"own occupation" phase** - the insured cannot perform each of the material duties of his regular occupation; and

(b) **"any occupation" phase** - after benefits have been paid for twenty-four months, the insured cannot perform each of the material duties of a suitable alternate occupation (or any gainful occupation) for which he is reasonably fitted by training, education, or experience.

16. The courts have expressed some guidelines for interpreting the meaning of these policy definitions.

17. In law, the policy term "total disability" does not mean absolute disability, in the sense that the claimant must be absolutely and unequivocally helpless and unable to do any work tasks. Total disability in the legal sense does not require that the insured be incapable of all work activity, only that the disabled person's medical condition is such that ordinary care and reasonable prudence would not dictate that the person is not fit enough to carry out the main duties of a job or occupation.

18. The Supreme Court of Canada has held that a person is considered "totally disabled" if the person is either:

(a) unable to manage full-time employment due to the physical and/or mental condition; **or**

(b) if the claimant could only continue working at the cost or significant ongoing pain and suffering, with the possibility of aggravating the medical condition suffered. Accordingly, in order to effect a cure, common care and prudence require that the claimant not return to work.

Accordingly, the fact that the claimant may attempt to return to work or try to carry on working despite a disabling condition does not mean that the person is automatically ineligible for disability benefits.

The courts have also held that it is not sufficient that a claimant could work on a periodic, part time, or sporadic basis if the person was able to work full time prior to the onset of disability.

The issue is whether the claimant is **competitively employable**, that is, able to competently perform a **particular job** to the satisfaction of a reasonable employer on a consistent and regular basis.

C. "OWN OCCUPATION"

19. The determination of whether the claimant is disabled under the "own occupation" definition is usually quite straight-forward. The question is whether the person is able to perform the substantial duties of his/her occupation on a regular and consistent basis.

D. "ANY OCCUPATION"

20. The question of whether the claimant is disabled under the broader "any occupation" definition is often more problematic.

21. In deciding whether a claimant is disabled from engaging in "any occupation", the courts consider a number of variables: the education, training or experience of the insured; the state of health and physical capabilities of the insured; and the general suitability of alternative occupations in terms of status and reward, compared to the claimant's regular occupation.

22. The courts have stated that the test of total disability under the "any occupation" provision is a subjective one which is related to the background and medical condition of the claimant.

23. This does not require the claimant to disprove every possible alternative, that is, an inability to perform any and every conceivable job or a menial one.

24. One also cannot rely upon mere speculation of an alternative job that might be suitable to the claimant.

25. The insurance company must produce evidence of specific jobs, suited to the claimant, that are within the claimant's capability of performing competitively to the satisfaction of a potential employer.

26. The main criteria under the "any occupation" definition are:

(a) the alternative job must be one that is suitable for the particular claimant, in the sense that the claimant is:

i) physically and mentally able to perform the job; and

ii) qualified by education, training or experience to access the job; **and**

(b) the alternative job must be reasonably commensurate to the claimant's regular occupation in status and in reward, (i.e., range of compensation).

27. The courts have also stated that it is not sufficient that a claimant could perform an alternative occupation only on a periodic, part-time, or sporadic basis.

28. Accordingly, the claimant does not have to show that he or she is incapable of **any** form of labour in order to be entitled to disability benefits under the "any occupation" definition. The "any occupation" definition does not literally mean **any** occupation.

29. The issue is whether the claimant is **competitively employable**, that is, able to competently perform a **suitable alternative job** on a regular and consistent basis.

E. CONCLUSION

30. It is essential that claimants and medical practitioners who prepare medical reports for disability claims understand the medical-legal issue of "total disability".

31. This understanding is the first step in submitting a claim which is more likely to be accepted by the insurance company, rather than denied for lack of medical evidence of disability.

32. In my next article, I will discuss some of the issues which often cause difficulties for claimants in successfully applying for and maintaining their claim for disability insurance benefits.

CAUTION

33. The material set out in this article is general information only. It is not intended to be relied upon for legal advice in particular cases. The facts and applicable laws in each case, and in each legal jurisdiction, province, or state, are unique and must be treated as such. If you have a legal claim of any kind, you should promptly seek legal advice from a lawyer who is knowledgeable about the law in your jurisdiction.

BRIEF PRESENTED TO THE STANDING COMMITTEE ON HEALTH

On Tuesday, February 17th, 1998 at 9:00 A.M, the Fibromyalgia Society of Ontario (FSO) and our Network jointly presented a brief to the Standing Committee of Health regarding food supplements, and non-drug medication. We thank the FSO for being the one to instigate this effort and for making all the arrangements for us to attend this important panel discussion. We pointed out to the Committee that it was essential that the following recommendations are addressed:

- establish methods of licensing and regulating for all complementary medical health care professionals;
- establish a board of professionals with extensive knowledge of herbs and other natural substances to ensure quality control of natural nutrient supplements and herbs;
- ensure that all products sold in health food stores or through other modes of marketing as nutrient supplements and herbs should be properly tested and their packages labeled, including warnings of possible side effects;
- establish a body that can regulate network marketing and address any grievances from consumers against network marketers; and
- insist that any claims regarding cures, made by health care professionals or companies selling herbs or nutrient supplements, are backed up with scientific fact.

By having regulatory bodies to which unsatisfied consumers can lodge complaints, it will go a long way to rectifying the present confusion and uncertainty in the field of complementary medicine, and the market of natural nutrient supplements and herbs.

(ed.note: To receive a copy of the whole brief, please send us a stamped (45¢) self-addressed envelope).

RE:GENERIC DRUGS

The Canadian Drug Manufacturers Association has promised to go the full distance to ensure the NOC Regulations (Notice of Compliance) Regulations are repealed once and for all. To achieve their goal, they need our support. Please write or call the Prime Minister's office and request that we need lower drug costs; get generic drugs out of the courts and on to pharmacy shelves; and support the Canadian pharmaceutical industry.

PLEASE CALL/WRITE/FAX/EMAIL:

Rt. Hon. Jean Chrétien

Prime Minister's Office(no postage required)

House of Commons

Ottawa, Ontario K1A 0A6

Tel.: (613) 992-4211 Fax: (613) 941-6900 Email: pm@pm.gc.ca

To contact The Canadian Drug Manufacturers Association: 4120 Yonge Street, Suite 409, North York, ONM2P 2B8 - Tel. (416) 223-2333 - Fax (416) 223-2425 - Email: info@cdma-acfpp.org - Brenda Drinkwalter, President.

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***Treats ME/FM patients - new patients welcome.**

COMPUTER GEEK REPORT - By: AI Neilson

Today (March 27/98) marks an important milestone since the inception of the website. We have now clicked over the magic 10,000 hits (visits) to the site, and all this in less than a year, well actually eight months. I have to say that I am well-pleased in the interest in the site, and it certainly makes all the work and effort to maintain a friendly, easy to use site, a thing to look forward to. Considering that I had to teach myself how to use the HTML scripting program and then learn how to design a webpage, I can honestly say, although it was like trying to herd cats at the initial stages, I now am very comfortable in this milieu, and am happy to serve.

We have had a lot of added news and links lately, and to make things easier, I have scrounged up a little graphics file (actually stole it from a friends site) that lets you know the item or link is a new one. You will see this [new] graphic in red all over your screens from now on, and I will try to keep these

up to date by removing old ones as their time comes due.

We have added sound to our Goose Story page! If you have sound on your computer and are willing to wait for the download, (usually about a minute) you will hear our geese in flight! Some older computers will not be able to hear due to configuration problems, but you will be told this at the end of the download.

Lastly, the newsletter Archive site is working out very well, and is now completely up to date (two newsletter lag). Once again, my thanks to Sandy Shaw for the organization at this remote access facility.

If you can think of any other material to be inserted into the Archives, please let us know and we will comply.

BOOKS/NEWSLETTERS/REPORTS/VIDEOS ETC.

FIBROMYALGIA CHEF - By: Mark J. Pellegrino, M.D. How to feel better by scheduling meals and snacks and by achieving nutritional balance. **ANADEM PUBLISHING**, 3620 N. High Street, Columbia, OH 43214 U.S.A. Tel. **1-800-633-0055 \$19.00 U.S.**

Zeneca Pharma, the Migraine Association of Canada has developed a cookbook for the country's 3.2 million migraine sufferers. Fabulous Cooking Ideas offers gourmet, **migraine-friendly recipes**.

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Call (416) 663-1500 or 1-800-663-3557

LEGAL/RESEARCH PACKAGE - There has been **extensive updating** to this package by Ms Marj van de Sande, Director of Alberta. To receive a copy, please send a cheque in the amount of **\$15.00** payable to Ms Marj van de Sande, 151 Arbour Ridge Circle NW, Calgary, AB to cover photocopying and postage charges.

QUESTIONS & ANSWERS ABOUT FIBROMYALGIA - By: Dr. S.C. Man, MD, et al

Dr. Man is the Director of the Pain Management Clinic in Winnipeg, Manitoba. \$14.99 plus 7% GST - Toll Free No. 1-800-465-6564 Fax (204) 661-8530

HELP YOURSELF VIDEO - By: Shirley Arsenault - A new Help Your Self Video - it is 84 minutes long and addresses the issues facing those caring for people (young and old) with Chronic Fatigue syndrome, Environmental Sensitivities and Fibromyalgia. Price: \$23.50 (includes postage) - To order, mail cheque or money order to Shirley Arsenault, 1191 J. Jordan Rd., R.R. #5, Canning, NS B0P 1H0

REPORT ON PERSONAL EXPERIENCE OF SIX-WEEK REHAB COURSE - By: Glenda Bowen. (3 pages) Please send us a stamped (45¢) envelope to receive a copy.

FIBROMYALGIA & CHRONIC MYOFASCIAL PAIN SYNDROME - A Survival Manual - By: Devin Starlanyl M.D. and Mary Ellen Copeland M.S. M.A. Available in book stores. Approximate price: \$25.00.

OUR WORLD

STIFFNESS: Like my body were a pair of jeans left on the line to dry in sub-zero weather!

TIRED: Like a stop sign set in cement!

EXHAUSTED: Like lifting a toothpick that feels like a 2" X 4"!

Author: Lorraine Legendre, Ottawa.

'HASTI NOTES' - A QUICK WAY TO SEND A MESSAGE

A package of four different cards was designed for us by Mary Harris of Peterborough, a ME person. The front of the card shows a picture of a turtle and the back of this card contains information on who we are and how to obtain information on ME/FM. **Cost: \$4.00 per package.** Contact us for ordering these 'Hasti Notes' and have the satisfaction of helping our organization at the same time .

MEMBERSHIP: \$20.00 per year which includes newsletters every two months. Please show your support by becoming a member or by making a donation.

ELECTRONIC MAIL: our e-mail address: ag922@freenet.carleton.ca

WEB: <http://www3.sympatico.ca/me-fm.action/>

A free Guide to the many information resources available via Computer for chronic Fatigue syndrome/Myalgic Encephalomyelitis and Fibromyalgia. For an individual the guide shows where to get information and have discussions with others interested in ME/CFS and FM. For a Support Group, the guide is a resource for obtaining newsletter articles for your newsletters, and to communicate with other support groups. You can obtain a free copy by mailing a self-addressed stamped envelope to:

In Canada: CFS/ME Computer Networking Project, 3332 McCarthy Road, P.O. Box 37045, Ottawa, Ontario K1V 0W0, Canada.

In the United States: CFS/ME Computer Networking Project, P.O. Box 11347, Washington, DC 20008-0547 U.S.A. Please note that for mailing outside of Canada please include an International Reply Coupon.

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product and assumes no responsibility for any treatment or action undertaken by its readers.

