# Quest #29 April 1998

## TEEN WINS AWARD FOR RESEARCH ON

## CHRONIC FATIGUE SYNDROME

Toronto teenager, Dilnaz Panjwani, has won a national science award for ground-breaking research into Chronic Fatigue Syndrome. She has been awarded a top prize at this year's week-long Canada-Wide Science Fair in Timmins, Ontario for her work identifying a possible diagnostic test for CFS.

According to the selection committee for the Manning Young Canadian Innovator Award, Ms Panjwani may have discovered a possible physiological basis for CFS as she has identified a "statistically highly significant" relationship between low levels of a blood enzyme called 2,3, diphosoglycerate (2,3-DPG) and patients with CFS.

The significance of Ms Panjwani's research stems from the fact that researchers have not even found the cellular basis for the disease, let alone a cure. If the tests are further borne out with more research, there is the possibility of having a blood test for the disease.

Ms Panjwani got her inspiration from a 1971 report by a U.S. researcher, William Osko, who speculated that low levels of the 2,3-DPG enzyme in one of his patients might be linked to Chronic Fatigue Syndrome. Ms Panjwani used Oski's thought as a hypothesis and with the help of her psychiatrist father, Dr. Dilkush Panjwani, assembled a group of patients to test the theory.

When her first group of 13 patients correlated her hypothesis, she got another set of 18 patients to replicate the

results. The study's parameters were guided by physicians from the Homewood Health Centre in Guelph.

Ms Panjwani hopes that a pharmaceutical company will back her in finding the cause of the low levels of the enzyme.

[Ed. Note: Our research is continuing on 2,3-DPG and hope to have more answers in the next 'QUEST'.]

## Another Part of the Puzzle: Circulation Disturbances

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

There have been three significant pieces of research in different aspects of blood components and cardiac structure that have surfaced in connection with ME/CFS:

- misshapen red blood cells - Dr. Leslie O. Simpson, New Zealand
- cardiac myopathy - Dr. A. Martin Lerner, United States
- enzyme deficiency - Ms Dinaz Panjwani (teenager), Canada

The research, the individuals who conducted them, their ages and their locations in the world are all very different. However, their results blend beautifully and support one another.

During his tour of Canada in the fall of 1996, Dr. Simpson lectured on his theory that misshapen blood cells caused impairment in blood flow. From analyzing over 2,000 samples from around the world through the use of electron microscopy, he found that more than 80% of ME sufferers had more deformed red blood cells than blood from healthy individuals. Red blood cells normally have 6 distinct shapes - two are flexible and four are rigid to differing degrees. The red blood cells are larger in diameter than the capillaries they must pass through in body tissues. This is where the life-giving oxygen and nutrients are released for cellular metabolism, and carbon dioxide and metabolic wastes picked up and taken away by the blood for disposal. The flexible red blood cells can squeeze through because of their flexibility. However, the more rigid red blood cells cannot change shape resulting in a pile up of cells at the entry to the capillaries in the tissues. This jam slows the flow of blood, and reduces the rate of oxygen below that required to support normal metabolism and energy production. As a result, the person would have reduced energy production and thus be fatigued. This theory also supports explanations for many of the symptoms of ME/CFS.

In the beginning of 1998, the research of Dr. Lerner was brought to our attention. This research has been well documented, reproduced by another researcher, published and peer reviewed. In his study, 100% of the ME/CFS participants showed abnormal oscillating T-waves at 24 hr. holter monitoring, which indicates that the left ventricle is pumping blood out of the heart and to the body with lower efficiency than normal. In addition, biopsies of cardiac tissue exhibited evidence of cardiomyopathy or disease of muscle in the heart. The researcher found 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. Thus, persistent viral infection of heart muscle could account for the chronic fatigue condition and its many symptoms.

Then this month, a Toronto teen, Dilnaz Panjwani, won a nation science award, the Manning Young Canadian Innovator Award, for her ground-breaking research into ME/CFS. While she examined a statistical printout of results of a blood test conducted by Med Cam, a Toronto laboratory, she noticed low levels of an enzyme for 100% of the ME/CFS participants. The enzyme that she thinks may be linked to ME/CFS is 2,3-DPG. This enzyme is called 2,3, diphosphoglycerate, which is present in the red blood cells to decrease the affinity of hemoglobin for oxygen and thus helps to release oxygen from the hemoglobin molecule when it arrives at the capillaries in the tissues. When the 2,3-DPG combines with hemoglobin, the molecule binds with oxygen less tightly. The greater the level of 2,3-DPG the more oxygen released from hemoglobin, and therefore, the less 2,3-DPG present the less oxygen released to the cells of tissue. This in turn means less oxygen is available for energy production leading to a decrease in energy and the resulting increase in fatigue.

All three of these theories support the reduced delivery of oxygen to tissue for the production of energy:

- reduced oxygen delivery due to impaired blood flow brought on by rigid shaped red blood cells clogging the entrance to capillaries;
- reduced oxygen delivery due to inefficient ejection of blood from the left ventricle of the heart; and
- reduced oxygen delivery due to low levels of 2,3-DPG which enhances the release of oxygen from the hemoglobin molecule.

In fact, a combination of the three theories can account for the wide variation in the degree of chronic fatigue experienced by those afflicted, i.e. some can do part-time work while others may be bedridden.

Finally, some of the research projects are not only providing answers, but they are also unraveling some of the mysteries surrounding this debilitating chronic condition. And, IT IS NOT At ALL IN OUR HEADS: the results are hard data!

[Ed. note: Nutrional Basis for ME and FM, Part V Final - By: Philipa D. Corning, B.Sc., Ph.D. to be published in Quest #30]

***BAILLIE v. Crown Life Limited, 1988 A.J. No. 235***

## Alberta Court Accepts CFS as an Organic Illness

**Report by: Peter N. Downs**

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A recent court decision from Alberta provides Chronic Fatigue Syndrome sufferers with a strong cure for insurers who refuse to accept CFS as a real and debilitating disease.

### Background:

Sharon Baillie was employed by the Crown Life Insurance Company from 1986 to 1990. One of the benefits provided by Crown Life was long term disability coverage. In 1989 Ms Baillie contracted CFS. Crown Life refused to pay long term disability benefits, claiming that CFS did not exist and could not be defined as a disease pursuant to the terms of the insurance policy.

### Employment History:

Ms Baillie held a variety of jobs in the area of entertainment and public relations and in the area of technical support in the computer field prior to her employment with Crown Life. She started out with Crown Life as a systems analyst and progressed to being a lead technical analyst and finally a manager of computer operations. She was in charge of supervising 35 employees. She had good evaluations each year and her salary increased commensurately. In her 1989 evaluation, Crown Life found Ms Baillie to be extremely hard-working and dedicated, and credited her for clearing up years of neglect and poor maintenance with respect to the computer system she oversaw. She was described as a self-motivated worker and a valuable asset.

During this time, the plaintiff's health was basically good. She played squash three times a week and enjoyed sailing, canoeing, and hiking. She did volunteer work in the community and she worked within in her church in an outreach program. In addition to these activities she worked between 40-60 hours per week. All in all, Ms Baillie was an energetic and hard-working person.

### Illness:

In 1989 Ms Baillie went on a two week Caribbean cruise. While on the cruise she contracted what she suspected at first to be seafood poisoning. Initially she suffered from diarrhea and fever. Later she developed fatigue and aching limbs. Soon she found herself constantly exhausted and nauseated.

Ultimately it was determined by her family doctor that she had contracted giardiasis. Yet despite treatment for giardiasis, Ms. Baillie continued to suffer from headaches, muscle weakness, night sweats, and exhaustion. In addition, she began to have difficulties with her memory. Prior to the onset of giardiasis, she was an avid reader. After the onset, she found herself unable to remember what she had read just a few pages before.

Of even greater significance was Ms Baillie's inability to perform at work. She continued at her normal job with Crown Life, but eventually found herself totally exhausted at the end of the day. At trial Ms Baillie recounted one incident where she came home from work so exhausted that she simply fell asleep on the couch without even taking off her coat.

During her initial disability, Crown Life put Ms Baillie on short term disability. Ms Baillie tried to return to work, but found she was unable to concentrate and recall information. The most distressing thing for her was not knowing what was happening and how to stop it. Her family doctor was equally perplexed. Eventually he came to the conclusion that she was suffering from CFS and referred her to a specialist, Dr. Jorundson. Dr. Jorundson concluded that Ms Baillie was indeed suffering from CFS triggered by the giardiasis infection.

### Experts:

Dr. Jorundson proved to be an effective witness for Ms Baillie at trial. Relying on the definition of CFS set out by the United States Centre for Disease Control, Dr. Jorundson testified in a convincing manner that CFS is an organic disease and not a psychiatric disorder. Dr. Jorundson concluded that Ms Baillie was disabled as a result of CFS and that the disability was likely permanent. The trial judge was impressed by and accepted the evidence of Dr.Jorundson.

In contrast, the trial judge was highly critical of the evidence presented by Crown Life. At trial, Crown Life relied on the evidence of Dr. Pearce, a psychiatrist, who diagnosed the plaintiff as suffering from conversion disorder, a type of psychoneurotic complaint. The trial judge was troubled by the evidence of Dr. Pearce, noting that Dr. Pearce described himself as one of those physicians who believe that CFS had no basis in reality, but rather is a convenient label for certain psychosomatic symptoms which individuals under stress develop. He was also concerned that Dr. Pearce's diagnosis of Ms Baillie was done on the basis of a pre-conceived notion of what that diagnosis should be. He further noted that Dr. Pearce was in the process of building a career based on the idea that there is no such thing as CFS and that people who have that condition have psychiatric problems. In the end, the trial judge was of the opinion that Dr. Pearce was a highly biased witness.

### A Ground-Breaking Decision:

*Baillie v. Crown Life* is a very important case because it acknowledges for the first time in a Canadian court of law that CFS is a real disease. It also illustrates the important role expert evidence plays at trial. Plaintiffs with CFS are well-advised to retain credible experts in this area in order to effectively counter suggestions that CFS is a psychiatric disorder only. This case also illustrates the importance of plaintiff credibility. Ms Baillie was successful in no small part because the trial judge believed her testimony about her disability.

## CUGLIARI v. WHITE: COURT DECIDES CPP BENEFITS ARE NOT DEDUCTIBLE IN ONTARIO MOTOR VEHICLE DAMAGE CASE

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## A. INTRODUCTION

1. I have been asked to prepare an article regarding a recent decision of the Ontario Court of Appeal pronounced on April 23, 1998, in the case of Cugliari v. White.

2. The Ontario Court of Appeal decided that disability benefits payable under the Canada Pension Plan are not deductible from an award of damages for income loss arising from an automobile accident claim in Ontario.

3. I understand that many people, particularly recipients of long term disability (LTD) benefits under private disability policies, have been wondering whether the Cugliari case also means that CPP disability benefits are not deductible from LTD benefits received under a private disability insurance policy.

4. Unfortunately for LTD claimants, the Cugliari case does not involve a private LTD benefit policy. Therefore, it does not deal with the relationship between CPP disability benefits and LTD policies.

## B. DISCUSSION

5. In Cugliari, the claimant/Plaintiff's lawsuit involved a claim for personal injury damages arising from injuries suffered in a motor vehicle accident. Accordingly, Cugliari involved a tort or negligence action, and not a claim for breach of contract to enforce an LTD benefit policy.

6. The Court held that CPP disability benefits are not deductible from a damages award in the motor vehicle tort action, pursuant to the common-law rules regarding the deductibility of benefits in the context of personal injury tort actions. The Court also decided that CPP disability benefits are not deductible from the Plaintiff's income loss award pursuant to the provisions of a specific statutory rule in the Ontario Insurance Act, (Section 267 (1) (c) of the Insurance Act, R.S.O. 1990, c. I.8).

7. The Court's decision, therefore, involved a review of the common-law rules respecting the deductibility of benefits in a tort action, and also the Court's interpretation of Section 267 (1) (c) of the Act.

8. From a national perspective, the legal issues and the scope of the Cugliari decision are limited in a number of other aspects.

9. This statutory provision in the Ontario Insurance Act applies specifically to damage awards in automobile accident claims; therefore, the section does not apply to other legal claims, including lawsuits for breach of contract to enforce payment of LTD benefits. Furthermore, Section 267 applies only to Ontario automobile accident claims. In addition, the Ontario Court's decision does not constitute binding legal authority on other courts outside the Province of Ontario.

10. Section 267 (1) (c) provides, *inter alia,* that damage awards arising from automobile accidents must be reduced by the amount of all payments that the claimant received or was entitled to receive for loss of income "under the laws of any jurisdiction or under an income continuation benefit plan . . . "

11. The Court held that CPP disability benefits are not included within the meaning of that statutory wording. Accordingly, the Court held that Section 267 (1) does not require that CPP disability benefits received by the claimant must be deducted from the damages awarded for income loss arising from an automobile accident.

12. This serves to underscore the fundamental difference between tort or negligence actions for personal injury damages, (i.e., claims for injury compensation arising from automobile accidents, falls on another person's property, and other types of negligence actions), and lawsuits for breach of contract, (i.e., a lawsuit against a private disability insurer to enforce payment of LTD benefits under an insurance policy).

13. The Cugliari case does not, therefore, directly apply to claims for LTD benefits under a private insurance policy.

14. The rights and obligations as between the recipient of LTD benefits and the insurance company under an LTD policy are defined in the contract or policy of insurance.

15. Many such LTD policies including specific provisions which require that the amount of monthly LTD benefits payable by the insurance company must be reduced by any benefits the claimant receives from the Canada/Quebec Pension Plan, any amount payable under a Workers' Compensation Act and any other amount of income received by the claimant.

16. Indeed, many private LTD policies specifically require the claimant to apply for CPP disability benefits or similar other disability benefits to which the claimant may be entitled.

17. In each individual case, the specific disability policy must be examined to see if it contains provisions or terms providing for the deductibility of CPP disability benefits or any other form of income/benefits to which the claimant may be entitled. The specific policy wording in each case must be carefully examined to see what, if any, other income or disability benefits the disability insurer is entitled to deduct from the claimant's monthly LTD benefits.

18. LTD recipients would be well advised to consult with a lawyer who is knowledgeable about insurance matters to ensure that only those benefits which the insurance company is entitled to deduct pursuant to the terms of the policy are, in fact, taken into account.

19. Cugliari is one of three recent landmark decisions by the Ontario Court of Appeal involving insurance benefits issues and section 267 (1) (c) of the Ontario Insurance Act. The other cases are Chrappa v. Ohm and Bannon v. McNeely.

20. Some commentators have suggested that the Court's reasoning in these cases may eventually, in future court cases, affect other types of insurance benefits including LTD benefits.

21. One could imagine a situation where the Ontario Court of Appeal's decisions could be of assistance to LTD claimants if the LTD policy contains a general provision for the off-setting or deductibility of other disability or income benefits, and if the policy wording is similar to the statutory provision affecting automobile claims in Section 267 (1) (c) of the Ontario Insurance Act. Moreover, if the LTD policy does not include a term specifically requiring that CPP disability benefits must be deducted from the claimant's LTD benefits under the policy, then it might be argued that the Cugliari decision, by analogy, should be extended to provide for the non-deductibility of CPP disability benefits in an LTD claim.

22. Private disability insurers would strongly oppose any such efforts to extend the Cugliari decision to the area of LTD benefits.

23. For the time being, the Cugliari case does not constitute legal authority for the proposition that CPP disability benefits, (or similar other disability benefits), are not generally deductible from a claimant's LTD benefits under a private disability policy.

24. It is, of course, to the insurance companies' financial benefit if CPP disability benefits and other income received by their insureds must be deducted from LTD claims if the terms of the policy so require.

25. Insurance companies will not give up that benefit without a fight!

## CAUTION

26. 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.

## NETWORK TO CHALLENGE DISABILITY TAX CREDIT IN COURT

We have applied and approved by the court Challenges Program for case development funding for our challenge to the Disability Tax Credit (Form T2201). As you know, applying for this tax credit has been causing our ME/FM people many difficulties. This development funding will assist our Lawyer, Hugh Scher of Scher & De Angelis in Toronto, to develop arguments for a proposed challenge to Section 118.4(1)(c) of the *Income Tax Act* on the basis that this section discriminates against persons suffering from ME/FM.

We are now in the midst of looking for suitable plaintiffs that might be able to carry forward a court challenge of this kind and who have been denied the disability tax credit for reason either they do not comply with the definition contained in the Act of disability or that they have been denied the tax credit because they have ME/FM, regardless of the functional effects of this condition on their abilities to carry out the activities of daily living.

Suitable plaintiffs would be persons who have minimal income and whose ability to carry out the activities of daily living is greatly impacted by the functional effects of ME and/or FM. It will also be important to determine what added costs can be associated with the plaintiff's disability by way of physiotherapy, massage therapy or other drug and therapeutic costs associated with managing the disability. This information is important in view of the original intent of the disability tax credit to lessen the burden for the added cost of disability experienced by people with disability.

It will also be important to consider people who are unable to carry out the activities of daily living on a regular basis but who may be capable of carrying out these duties for a short period of time on an intermittent basis. In this respect, we will be looking at individuals who are disabled pursuant to the terms of the *Income Tax Act* but are not so disabled continuously, depending on the effects of their disability.

If the above applies to you and you did not receive our questionnaire, please write us a summary of your denial keeping in the mind the kind of case we are looking for.

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## NETWORK RECEIVES ANOTHER GRANT FROM HEALTH CANADA

The Health Promotion and Program Branch of Health Canada has awarded us another Grant in the amount of $20,000 to help us become independent and raise our own funds. This has enabled us to hire a part-time assistant to help us with our many projects. The Department stated that "...I want to assure you, on behalf of the Department, that we recognize the value of the work you undertake to support patients, family members and support research.....I would like to express my personal appreciation to the

Board, volunteers and staff of the National ME/FM Action Network for their dedication and contribution to improving the health and well-being of Canadians" Signed Ian Potter, Assistant Deputy Minister.

None of our efforts would have succeeded, if it wasn't for the cooperation of the support groups and the private individuals who have helped us whenever we contacted you for your assistance. Please accept our thanks and we hope to continue to work together towards achieving our goal for better understanding and help for all of our ME and FM people across Canada.

Once again, thank you so much. Your help makes a difference to us achieving what we set out to do.

Lydia E. Neilson,

President CEO

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## COMPUTER GEEK REPORT - By: Al Neilson

Well, seems we LUDITES (me) are forced to enter the 90's with the installation of Windows95 on one of our computers. For two years now, and after much wailing and moaning, and wringing of hands, we have our Windows for Workgroups 3.11 platform working just like a Swiss Watch, and now we must yet again plow through the Microsoft Mud Hole and try to figure out what new headaches ole Bill Gates has in store. I don't envy me at the moment, because a rough tour through the 95 jungle leaves me twirling like a demented ballerina, and if you ever saw my silhouette, you might think that last line rather amusing.

I did find that once I got the modem ISP line connected, however, that the sound file download included with the Goose Story on the website, will not play for me. Oh joy!!---another day of hair-tearing and utterances unknown by mortals!! Like trying to juggle jello sometimes.

This all leads me to this -- If ANY of you experience a problem with our website---PLEASE get in touch with me (GEEK) via the onboard E-mail and let me know will you?? I try very hard at great personal risk and peer humiliation to get it right, and I can't be everywhere at once--although Lydia keeps saying I am always underfoot--so--Let Me Know--OK??

## BOOKS/NEWSLETTERS/REPORTS/VIDEOS ETC.

**DR. A. MARTIN LERNER - Published works re: Cardiac Myopathy (See 'QUEST' No. 28).** Please make **cheque payable to the National ME/FM Action Network** in the amount of **$6.00** to cover photocopying, mailing charges etc.

**CONFRONTING MITRAL VALVE PROLAPSE SYNDROME - By: Lyn Frederickson, M.S.N.**

**Price: $17.99 plus $3.50 S & H - H.B. Fenn & Company Ltd.,** 34 Nixon Road, Bolton, ON L7E 1W2 - Tel. 800-267-3366 - Fax: 800-465-3422

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**PILLS AREN'T ENOUGH - By: Cody Wasner, MD -** Stories for Emotional Healing in Chronic Illness. Published by Anadem Publishing Inc., 3620 N. High Street, Columbia, OH 43214 U.S.A. Price: **$22.00 U.S. - 1-800-633-0055**

## PERSONAL:

**Hello to M.L.P. in Slovenia -** Hope you enjoy our newsletters.

**PEN PALS -** Hi from Britain and all of us at the 'Association of Youth with M.E.!". We are setting up a penpal network so that you can write to fellow young ME/CFS sufferers here in Great Britain. If you are aged 25 or under, we want to hear from you!

Please forward your name, address, age and hobbies, and whether you want male or female penpals to: Ms R. simpson, 1 Lewisham Drive, Goldenhill, Stoke-on-Trent, Staffordshire. ST6 5QX England. It may take a while to set up these friendship so please be patient.

## OUR WORLD

JOINT PAIN: like having your joints nailed by a construction stapler.

CONFUSION: like watching 10 different TV channels at the same time.

WEAKNESS: like lifting an ant that feels like an alligator.

Thanks to 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 .

**LEGAL/RESEARCH PACKAGE** - Please make **cheque payable to Marj van de Sande** in the amount of **$15.00** (our Director for Alberta) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V6 -**

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**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.