

REACHING OUT

SPRING 2009

Largest-Ever Chronic Fatigue Syndrome Research Initiative Announced by CFIDS Assoc. of America

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CHARLOTTE, North Carolina - December 3, 2008. The four million Americans who suffer from chronic fatigue syndrome (CFS) have new reason for hope today with the announcement of an unprecedented research program to help identify biomarkers to improve diagnosis and treatment of CFS. The announcement was made by the CFIDS Association of America, which is funding the program, called the Accelerate CFS Research Initiative.

The initiative was made possible by the successful completion of a yearlong, million-dollar fundraising campaign, the largest research campaign for CFS to date in the United States. The CFIDS Association has funded more than \$5.4 million in research since 1987, making it second only to the federal government in CFS research spending.

"The campaign is enabling us to develop a revitalized research program for CFS," said Kimberly McCleary, president and CEO of the CFIDS Association. "Today, the Accelerate CFS Research Initiative has already resulted in research grants totaling \$647,940 to six research teams in the U.S. and Canada. This

will lead to an international network of scientists who routinely collaborate and communicate to accelerate the pace of CFS research."

The grants were awarded following a rigorous process that included a review of proposals by 44 independent experts for scientific merit and by CFIDS Association board members for strategic merit. "We were very impressed with

the number and caliber of grant proposals we received this year, which signals a heightened level of interest in CFS research," said Suzanne Vernon, PhD, the CFIDS Association's scientific director. "And most of the grant recipients, while experts in their respective fields, are new to CFS research. It's critical to attract new investigators to CFS research in

order to propel the field forward."

Continued on page 2



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REACHING OUT

is published 4 times a year by
The Myalgic Encephalomyelitis
Association of Ontario (MEAO),
a registered charitable organization.

Our Mission Statement

- *To provide M.E./CFS sufferers with support, current information and direction to the best possible professional services*
- *To educate the public on the illness, its debilitating effects, and concomitant social and economic consequences, and*
- *To promote, facilitate and raise funds for research on the causes and cure for Myalgic Encephalomyelitis.*

Our mailing address is:

The Myalgic Encephalomyelitis Association
of Ontario, P.O. Box 84522, 2336 Bloor St. W.,
Toronto, Ont. M6S 4Z7

Our INFO LINE is:

416 222-8820, or 1 877 632-6682.

Charitable Registration No:
89226 7568 RR0001



Continued from page 1

The grant recipients are:

- Gordon Broderick, PhD, associate professor in the Department of Medicine at the University of Alberta in Canada
- Kathleen Light, PhD, a research professor at the University of Utah Health Sciences Center
- Marvin Medow, PhD, associate director

of the Research Division of the Department of Pediatrics at New York Medical College

- Bhubaneswar Mishra, PhD, a computational biology expert and professor at the Courant Institute of Mathematical Sciences at NYU.
- Sanjay Shukla, PhD, a microbiologist and research scientist at Marshfield Clinic Research Foundation
- Dikoma Shungu, PhD, a physics professor and research scientist at Weill Medical College of Cornell University.

“Not only will several of the investigators collaborate directly, all of them will be sharing their data with each other and with other scientists,” Vernon said. “This is essential if we are to make rapid progress in unraveling the complexities of a multisystem illness like CFS and in providing medical professionals with better diagnostic and treatment tools to improve patients’ lives.”

For more details on each of the six new studies, go to www.cfids.org/about-cfids/research-release12-08.pdf.

TIP

Trading skills: I am a fairly good typist. In exchange for typing his essays, the teenage boy next door shovels my snow and brings in my groceries from my car. My other neighbour and I trade too: I take care of her cat when she is working late or on vacations, and she cuts my grass.

FROM the PRESIDENT



Meteorologists tell us that compared to recent years, 2008 was a year of much colder than normal temperatures, with much more precipitation and substantially fewer days of sun. The combination of these factors have made it difficult for everyone to get around this past winter, particularly for people with M.E./CFS.

However, with winter now almost gone, we all anxiously look forward to the upcoming season of spring - a time of growth, renewal and finally the arrival of much warmer, enjoyable and relaxing spring days.

With the coming spring, the MEAO Board of Directors is looking forward to making progress on a number of important issues. We've written before that we are trying to raise funds to open an office for our Association – a place for the community to reach us for information and assistance. The Ontario Trillium Foundation is providing us with a three-year, grant for staffing (currently, we are in year two of that grant) so the MEAO can raise additional funds to open a “staffed provincial office” by the end of 2009. So expect to hear news from us in the future about our fundraising initiatives. We hope that all of our supporters will donate to our new office and to our services. And we are approaching foundations, corporations and other donors to ensure the long-term growth and sustainability of the MEAO.

On behalf of the MEAO, I would like to acknowledge the generous bequest of the late Helyn Ruth Mcauley. Helen left more than \$12,000 to our Association to support our research efforts. We appreciate all donations, but we are particularly touched when donors give us gifts to honour a special

occasion, or as a memorial to a loved one. Planned gifts, such as bequests or gifts of life insurance, stocks or other property, mean everything to groups like the MEAO. We are grateful for Helyn's bequest and we would welcome a call from any of our supporters who would like to consider such a gift.

Earlier in the year, the directors of MEAO embarked on a very important initiative – the process of developing a comprehensive **Strategic Plan** for the Association. Board members attended a number of lengthy planning sessions where the **Vision**, the **Mission**, the **Values** and the **Goals** of the MEAO were discussed, debated and finally resolved. This process resulted in some important seminal work being done within this area and a commitment has been made to continue this process later this year.

I would also like to draw your attention to the interesting article in the Research section, page 8, of this issue, in which Dr. John Prescott writes about a major finding in M.E./CFS research.

Finally, as we talk about transitions, I would like to wholeheartedly thank Christiane Garcia and Brenda Van Ginkel for their past efforts and significant contributions as Directors of the Board of the MEAO. Both have recently stepped down from the board and they will be sorely missed.

At this point, I would like to wish all of you a very pleasant spring and summer for 2009, and good health to enjoy these wonderful seasons.

Best wishes,
Anthony Rovito

NEWS and UPCOMING EVENTS

A Christmas 'Afternoon Social'

On December 17, members and Board Directors of the MEAO gathered at the Granite Brewery Restaurant to celebrate the holidays. In spite of the stormy weather, a genial group of people braved the snowy roads, some coming from as far as Ajax. The photos below were taken at the gathering:



Government of Canada issues a Call for Proposals for projects that remove barriers for people with disabilities

OTTAWA, ONTARIO, Feb. 23, 2009—The Honourable Diane Finley, Minister of Human Resources and Skills Development, today announced a multi-year Call for Proposals (2009–2012) focusing on projects that will improve services or accessibility for people with disabilities to fully participate in society. “Our government is committed to providing all Canadians with opportunities to participate in every aspect of life,” said Minister Finley. Proposals will be accepted from February 23, 2009 to April 6, 2009. For more details go to <http://news.gc.ca/web/article-eng.do?nid=434789>

ASK LAWYER



What is the ARCH Disability Law Centre?

ARCH Disability Law Centre is a specialty legal aid clinic with a provincial mandate dedicated to defending and advancing the equality rights of persons with disabilities.

ARCH was founded in 1979 under its previous name, Advocacy Resource Centre for the Handicapped (ARCH). ARCH is primarily funded by Legal Aid Ontario. ARCH is a not-for-profit charitable organization with a provincial mandate. Its membership consists of over sixty disability consumer and service organizations. Its staff report to a consumer-controlled volunteer board of directors.

ARCH fulfills its mandate in many ways, through law reform initiatives, community development, a telephone summary advice and referral service, public legal education, and test case litigation. ARCH does not provide legal representation except for selected test-case litigation.

ARCH proceeds on the following premises: Persons with disabilities are confronted with unique legal challenges.

- Persons with disabilities must have control over their own lives.
- A cross-disability approach to advocacy issues is essential, but it is equally important to recognize and respect difference.
- Persons with disabilities may also face disadvantage due to other reasons such as their gender, race, age economic status and sexual orientation, compounding their experience of discrimination or exclusion.

Getting advice from ARCH Direct service to persons with disabilities from around the province

ARCH provides basic legal information as it relates to various disabilities. This service is free and confidential and includes the following areas: abuse, attendant services, capacity, disability supports, disability-specific funding, education, employment, guardianship, home care, human rights, powers of attorney, privacy, transportation.

ARCH can refer you to your local community legal aid clinic, specialized legal aid offices, lawyers in private practice or other services where appropriate for assistance with:

- civil litigation
- CPP-Disability
- criminal law
- employment insurance
- family law
- housing
- immigration
- LTD/STD Insurance
- medical malpractice - professional negligence
- ODSP
- personal injury
- tax
- wills & trusts
- workers' compensation.

ARCH does not provide legal representation except for selected [test-case litigation](#). If you are seeking representation, please contact your local clinic first to see if they are able to assist or represent you. ARCH provides this service over the telephone to persons with disabilities. If, because of your disability, you cannot speak with them over the telephone, ARCH will try to communicate with you in a way that meets your needs.

CONTACT INFORMATION: To access this service call ARCH at (416) 482-8255 or toll-free at (866) 482-2724. Its local TTY number is (416) 482-1254 and the toll-free number is (866) 482-2728. Office hours are 9:00 AM to 5:00 PM, Monday to Friday. The phones are

closed daily from 1:00 PM to 2:00 PM. Messages can always be left on its answering service.

WEB SITE: www.archdisabilitylaw.ca

If your matter is urgent you may contact the **Lawyer Referral Service** at 1-900-565-4577. There will be a \$6 charge added to your phone bill for using this service. You will, however, be entitled to a free half-hour consultation with a lawyer.

You may apply for legal assistance by contacting **Legal Aid** directly at (416) 598-0200, or toll-free at 1-800-668-8258. Legal Aid can refer you to your local legal clinic. For information on community, social, health and government services in Toronto you may call Community Information Toronto. From within the 416 and 647 area codes simply dial 211; from outside of Toronto call (416) 397-4636.

www.archdisabilitylaw.ca To learn more about ARCH's programmes, check out their web site, where you may also read about 'Arch Papers, Fact Sheets, Law Reform Submissions, and more. Links on a variety of services and informative web sites are also available. See our section, HELPFUL WEB SITES, on page 13 for a few.

ARCH Alert The *ARCH Alert* is an electronic newsletter produced by ARCH that deals with various legal issues as they concern disability. It is available free of charge on its website or you can subscribe to receive *ARCH Alert* by email.

ARCH usually publishes an *ARCH Alert* every 2 months. With increased spam security via e-mail, there have been difficulties in successfully sending the *ARCH Alert* to its subscribers. If you have not received an *ARCH Alert* in the past few months, please complete the 'Subscribe to *ARCH Alert*' box on their web site. You will then be added to the *ARCH Alert* e-mail distribution list.

YOUR HEALTH

Chronic Pain Management: A Physiotherapist's Perspective

By Iris Weaverman

Editor's Note: Faced with unexplained medical symptoms and varying degrees of frustration with conventional treatments, some people with M.E./CFS and Fibromyalgia are trying alternative / complementary modalities. The following article is an example of such alternative practices.

I am a registered physiotherapist in Toronto, Canada. I have been helping people who have chronic pain, myofascial pain, chronic fatigue syndrome and fibromyalgia for over 20 years. I would like to share my personal views and protocols on the topic of how to deal with chronic pain.

Since I am a physiotherapist I will concentrate on exercise. However, I am aware that patients with M.E. and Fibromyalgia are dealing with a multifaceted condition and thus need to engage in a comprehensive wellness program. Such a program should include medical intervention, nutrition, pain inhibitors, exercise, meditation/relaxation techniques, and spiritual and emotional counseling.

Before developing an exercise program for an individual with M.E./ Fibromyalgia, I have to investigate the person's specific medical issues. For example, if someone has Irritable Bowel Syndrome their sleep may be disturbed as they may have to get up frequently to go to the bathroom. It is difficult to even think about exercising when one is dealing with disturbed sleep patterns no matter the cause. Thus the first thing I must do is find help for any underlying issues.

The second step is to motivate people to change their behaviour. I do this by having them first think about their fitness level. I then discuss the pros and cons of their situation. I set up a plan to help them start moving more

regularly and help them to activate this plan. This can take a few weeks.

The next step is to encourage self-management. You can feel better if you have an understanding of the nature of your disorder. Do as much as you can to keep fit and reduce stress. You need to review and follow your action plan and understand that only you can do this - no one else can do it for you.

How to Begin an Exercise Routine

You will often hear that exercise is very important and you may start a program given to you by a professional or one you find in a book. However, the program may actually make you feel worse and you may soon give up. If this happens, my belief is that you started too much, too soon, and too fast. Like children learning to walk, you first have to take tiny baby steps. It is possible that the exercises with which you started were the wrong kind for those with M.E./Fibromyalgia. I am very specific about the type of exercises to do, how to introduce them, and how to progress them.¹

You need to start small. Try to enjoy the challenge. If you relax and look forward to your next "move" so will your muscles - this is the mind-body connection. The key to the healing process is to get in tune with your body and listen carefully to the small messages it gives you. Try to exercise daily. You will figure out which exercises need to be done daily and which can be done three times per week e.g. strength / cross training. An exercise program should contain the following: warm up, range of motion, stretching, aerobic activity, breathing, muscle conditioning and relaxation. You should

¹ For more details regarding how to exercise, please read the document entitled "How to exercise with Fibromyalgia": <http://www.fibrophysio.ca/physio/fibro-protocol.pdf>

increase the exercises gradually and don't try to make up for lost time as you start to feel better.

Before actually starting an exercise program, I encourage people to do a little more in their activities of daily living. My concept in teaching exercise, or increasing people's energy levels, is pacing by adding a small pause into their lives. The idea is to do an activity, then sit down and rest, and then do the rest of the activity. This pause concept should be used whether doing dishes, working in the garden, shopping, or exercising. It is the way you think, act and move on a daily basis that will get you feeling better. You may not be the person you were before you got sick, but you can be better.

Try to find your balance of sleep, exercise, nutrition, and psychological / spiritual well being. Try to find a coach or a friend to help you. It may not be easy, but it will be worth it.

Iris Weverman Registered Physiotherapist can be contacted for consultations at (416) 593-7700 or (416) 482-5560

For more information visit
<http://www.fibrophysio.ca/>

TIP

Standing in line is very exhausting. To avoid line ups, it's best to go to the bank, post office, grocery store, etc. during quiet times. Avoid lunch time (12 – 2 p.m.), and after work hours (4 – 6 p.m.). When is the best time to go Christmas shopping – why Monday morning, of course!
(Thanks Katherine for this tip!)

ON THE FUNNY SIDE



Growing old ain't for Sissies

A couple in their nineties are both having problems remembering things. They decide to go to the doctor for a check-up. The doctor tells them that they're physically okay, but they might want to start writing things down to help them remember. Later that night while watching TV, the old man gets up from his chair. His wife asks, "Where are you going?" "To the kitchen" he replies. "Will you get me a bowl of ice cream?" "Sure." "Don't you think you should write that down so you can remember it?" she asks. "No, I can remember it." "Well, I'd like some strawberries on top, too. You'd better write it down because you know you'll forget it." He says, "I can remember that! You want a bowl of ice cream with strawberries." "I'd also like whipped cream. I'm certain you'll forget that, so you'd better write it down!" she retorts. Irritated, he says, "I don't need to write it down, I can remember it! Leave me alone! Ice cream with strawberries and whipped cream - I got it, for goodness sake!" Then he grumbles into the kitchen. After about 20 minutes, the old man returns from the kitchen and hands his wife a plate of bacon and eggs. She stares at the plate for a moment and says - "Where's my toast?"

Success usually comes to those who are too busy to be looking for it.
- Henry David Thoreau

FROM OUR KITCHEN TO YOURS

SCALLOPED POTATOES

Ingredients:

6 – 8 medium white potatoes, thinly sliced
4 tbsp. flour
pepper
onion salt
garlic salt (or powder)
dried oregano
4 tbsp. butter
2 ½ cups milk, scalded

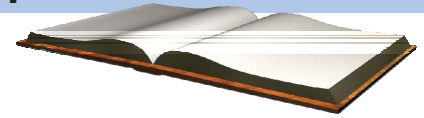
Directions:

Layer approx. ¼ of the potato slices on the bottom of a greased casserole dish (2 quart size). Sprinkle 1 tbsp. of flour, a dash of pepper, oregano, onion salt and garlic salt over the potatoes. Add a tbsp. of butter. Arrange another ¼ of the potato slices on top, and once again add the flour, pepper, oregano, onion salt and garlic salt. Repeat with a 3rd and 4th layer of potatoes. Over the final layer pour approx. 2 ½ cups of scalded milk. Cover and bake at 350 degrees F. for 30 minutes. Uncover and continue baking for 60 – 70 minutes. During the 2nd baking, use the back of a spoon to nudge the top layer of potatoes down once or twice. Allow casserole dish to stand for about 10 minutes after taking it out of the oven. About 6 – 8 servings.

HANDY HINT

Flexible vacuum: To get something out of a heat register or from under the fridge, add an empty paper towel roll or empty gift wrap roll to your vacuum. It can be bent or flattened to get into narrow openings.

RESEARCH



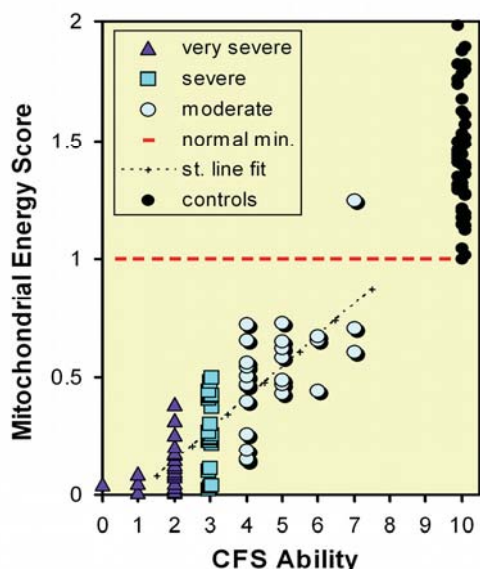
Research Findings on M.E./CFS

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

“Cellular hypoxia” is a likely underlying problem in CFS, and is a term that describes an inability to produce adequate energy through oxidative phosphorylation at the cellular (mitochondrial) level. Mitochondria are the busy energy factories in every cell in the body that allow us to live normally. Over the course of a day they can produce up to 100 kilograms of the basic energy unit, called ATP. A recent paper from the United Kingdom, available from <http://www.ijcem.com/files/IJCEM812001.pdf> represents what **looks like a major breakthrough in CFS research.**

What Drs Myhill and others did was simple but profound. They developed 5 tests for mitochondrial efficiency based on analysis of mitochondrial activity in neutrophils extracted from a small blood sample of 71 patients with CFS and from 59 healthy controls. An “ATP Profile” of 5 tests was developed based on mitochondrial functions. The tests measured: ATP availability; the ATP fraction complexed with magnesium; the efficiency of oxidative phosphorylation; the transfer efficiency of ADP into mitochondria; and the transfer efficiency of ATP out of mitochondria. The other part of the research was to classify the 71 patients into categories of severity of CFS based on the Bell CFS Ability Scale. The tests chosen separate mitochondrial energy generation and recycling into 5 crucial steps. The scientists then multiplied the results of the 5 tests together to produce what they called a Mitochondrial Energy Score (MES). Once they did this, an extraordinary picture emerged. This graph, shown here with permission of the authors, shows a remarkable and statistically dramatically

significant correlation between the severity of CFS symptoms and the MES.



From International Journal of Clinical Experimental Medicine 2009; 2: 1-16.

There are several reasons why this research is extraordinarily important.

Firstly, it strongly implicates mitochondrial dysfunction as the immediate cause of CFS. The tests details are given in the paper such that they could easily be reproduced in clinical biochemistry laboratories. Secondly, they provide objective and relatively simple tests to demonstrate mitochondrial dysfunction. Up to now, CFS has been largely clinical diagnosis. Thirdly, they show that not all patients are affected in the same way, since there are differences between patients in some of the scores of the individual tests that make up the MES. Some of these different biochemical “lesions” may be amenable to different treatments. Fourthly, these tests and the MES might provide objective ways to measure the effect of treatments.

The results of this study of course need to be confirmed, as indeed the authors themselves suggest, in well-designed and properly funded studies by other groups around the world. If they are, this research will be seen to be a significant advance in helping sort out the enigma of CFS, not least by providing

objective diagnosis that can convince skeptical physicians and others.

Nevertheless, mitochondrial dys-function is not the actual cause of CFS. The cause appears to relate to a post-viral persistent immune dysregulation that increases mitochondrial ribonuclease activity that in turn breaks down RNA, the message responsible for making the enzymes that actually produce ATP.

HELPFUL WEBSITES



fmcfsme.d-3systems.com A comprehensive website with many valuable links.

www.mercola.com Dr. Mercola, an American, talks about healthy living, helping those with chronic illnesses. There is also a newsletter you can sign up for.

<http://phoenix-cfs.org/> a good M.E. web site that will send weekly newsletters.

<http://www.cdc.gov/cfs/cfsdefinition.htm> The web site for the Centers for Disease Control in Atlanta, has pages on M.E./CFS.

A few links from ARCH's web site:

Community Living Ontario,
<http://www.communitylivingontario.ca/>
 Fibrotalk: An online support community for people with debilitating diseases,
<http://www.fibrotalk.com/>
 Ontario Fibromyalgia Association,
<http://www.hwcn.org/~aq226/>
 Ontario Human Rights Commission,
<http://www.ohrc.on.ca/>
 Canadian Human Rights Commission,
<http://www.chrc-ccdp.ca/>
 Disability Rights Promotion International (DRPI), <http://www.yorku.ca/drpi/>
 Disability Awareness in Action,
<http://www.daa.org.uk/index.htm>



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www.meao-cfs.on.ca



Kelli-Ann Woulfe

DISABILITY CLAIM DENIED?

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

"After my surgery, I tried to go back to work - against my doctor's advice. But I just couldn't do my job any more."

"So I applied for disability benefits. I couldn't believe it when they turned me down! I was very sick, as well as depressed and broke.

"My case was deemed to be without merit by several law firms. Then I found David Share Associates. They were a Godsend.

The settlement allowed us to pay off our mortgage and has enabled me to live at home with dignity."

If your disability benefits have been wrongly denied, call 416-488-9000 or Toll free 1-888-777-1109.

You will receive a Free Booklet 'Benefits Denied - What To Do When Your Insurance Company Denies Your Claim' by David Share.

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GENERAL INFORMATION

If you know of an event that may be of interest to our members, please call us on our INFO LINE number below. THANKS!

CONTACT US

Our mailing address:

The Myalgic Encephalomyelitis Association of Ontario, P.O. Box 84522, 2336 Bloor St. W., Toronto, Ont. M6S 4Z7.

Our INFO LINE is:

416 222- 8820, or 1 877 632-6682.

Call to receive information on M.E./CFS, Support Group and doctors.

Our email address:

info@meao-cfs.on.ca.

MEMBERSHIP AND DONATIONS

Our annual membership is \$20.00. Donations are greatly appreciated, as they help us increase education and awareness of M.E./CFS throughout Ontario. Donations of \$10.00 and over are issued a charitable tax receipt. We also welcome those who request a Complimentary Membership!

Members receive our quarterly newsletter '**Reaching Out**' with news on M.E./CFS, Research, Coping Tips, Recipes, Upcoming Events, and much more! Members with emails are also notified regarding updates on: Conferences, Television Programmes on M.E./CFS and special M.E./CFS events. See our Membership / Donation Form below.

As a resource group, the function of our organization is to provide you with current information on M.E./CFS. As we are not medical professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your health with your attending physician.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
P.O. Box 84522, 2336 Bloor St. W.
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