

REACHING OUT

Spring 2011

A Publication of the Myalgic Encephalomyelitis
Association of Ontario

Words from the President

Canadians have a great history of “helping out”. To those of you who are able to volunteer to help MEAO, we salute you and remind you that it is only with your help that we can be successful.

Volunteers in today’s world want to be challenged and be able to contribute in a meaningful way. Tell us what your talents are and we will try to utilize them to everyone’s benefit.

Over 600 individuals took the time to complete our recent on-line questionnaire. This quickly gives us more data to advocate for the community. Thank you for taking the time!

We will be undertaking a Spring Fundraising Campaign and ask our supporters to generously donate to the MEAO to help us help you. Many thanks to our May 12th Volunteer Committee who are very busy planning another great day at Queen’s Park to increase awareness of ME, FM and MCS.

We encourage all of you to continue to tell your personal stories to your MPs and MPPs. They need to be reminded of how ME, FM and MCS affects over 400,000 Ontarians. Many of you passed along your thoughts about the Special Diet Allowance to government officials. It is only with our collective actions that we can raise awareness and support for research and clinical management of individuals with ME, FM and MCS.

You can contact Mr. Keith Deviney directly at president@meao.ca



Snow drops are the first sign of spring!

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RDSP – What's it all about?

For many years, individuals and their families have sought the best way to ensure long-term financial security for their family members who are sick. The Registered Disability Savings Plan (RDSP) helps to address this issue.

Who is Eligible? Any person can be a beneficiary (the person to whom the benefits accrue) if they:

- are eligible to claim the Disability Tax Credit and
- have a valid SIN and
- are a Canadian resident and
- are under the age of 60.

Who Can Contribute to an RDSP? Anyone can contribute provided that they have the permission of the beneficiary. This can include a parent, a guardian or even an institution for a minor. When the beneficiary attains the age of majority, they can become the plan holder and can make contributions along with the others mentioned above.

Contributions and Grants. The government has made some very generous sums of money available. If the beneficiary's family (or the beneficiary themselves if old enough) net income is less than about \$78,000 (it increases each calendar year) the government will make a Canada Disability Savings Grant (CDSG) of \$1500 on the first \$500 (\$3 for every \$1 contributed).

On the next \$1000 contributed, the CDSG is \$2000 (\$2 for every \$1). In total, that is a grant of \$3500 for \$1500 contributed.

The maximum lifetime CDSG is \$70,000 and no grants are available after the year in which the beneficiary turns 49. The lifetime contribution amount is \$200,000.

For families or individuals with incomes less than about \$22,000 (this amount increases each calendar year), a Canada Disability Savings Bond (CDSB) of \$1000 is available and a pro-rata amount is available for incomes between \$22,000 and \$38,000. No contribution is required to receive the CDSB. Lifetime maximum CDSB is \$20,000 and no grants are available after the year in which the beneficiary turns 49.

Withdrawals from an RDSP. There must be at least 10 years after receiving a grant before starting to receive payments or else the grants must be repaid to the government. Payments can start anytime but no later than 60 and the payout is geared to the expected lifetime of the beneficiary.

Tax. Tax is always a big consideration but fairly reasonable given the amount of the grant. If everything goes as planned and according to the guidelines, then there will be no tax on the contributions (after-tax money was contributed in the first place), but any income, growth, CDSG or CDSB will be considered income and attract tax in the hands of the beneficiary. It is expected that any payments received from an RDSP will not reduce or eliminate or disqualify a beneficiary from other government plans.

One of the first items on your agenda should be to make sure that the beneficiary qualifies for the Disability Tax Credit (DTC). Even if you have no income, the DTC may be of benefit to the beneficiary.

This is a very basic description of an RDSP. You should consult your advisor or accountant or a bank before proceeding. If you are an experienced investor, note that the selection of investment options varies widely between participating banks.

Improving your life with ME Therapeutic Pool Program

By Jeanne Samonas, Certified WaterArt
Arthritis Instructor Water and Land



The goal of the Therapeutic pool program is mobility. The idea is to spend 40 minutes in a warm pool moving your body using equipment like stairs, gloves, paddles, wands, dumb bells and noodles, to increase mobility while keeping your program interesting and challenging. Aside from physical improvements there are positive social and emotional benefits as well.

The body is composed of over 200 bones, more than 600 muscles and 68 joints, thus the first step in any program should be muscular conditioning and balancing strength with flexibility. This will prevent muscle soreness and overuse as a result of trying to do too much. Flexibility is important for safely moving through activities of daily living. Another key component of the program is cardiovascular conditioning. All these points should be addressed in an effective pool program. The physical benefits for people with ME, FM and MCS are that the warm water allows the tight tense muscles to relax, which removes stress on the body. The rotations of body movement in warm water are twelve times that of movement done on land. Buoyancy reduces stress from body weight and increases ease of movement in the pool, making walking in warm water one of the most beneficial activities you can do. This simple activity strengthens the legs, improves balance and mobility, and achieves endurance over time.

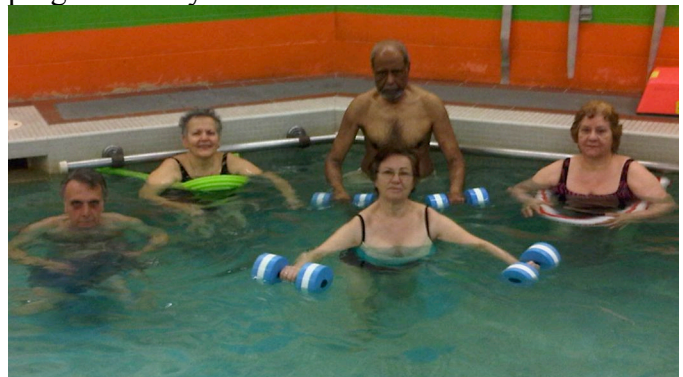
To participate in a therapeutic pool program you'll need medical approval. To locate a program

in your area check with local pools and recreation complexes, YMCA's, or Senior Centres. Then contact the program asking them to send you information about their program and requirements. Inquire if the pool program has classes for people with ME, FM and MCS. Program instructors should have current certification with a recognized Water program, CPR training and be taking educational courses throughout the year. To meet the complex needs of participants a good understanding of their individual situations is required. For example, the Arthritis pool program is required to educate its staff about ME, FM and MCS, as well as other arthritic conditions. The cost of a class varies but is around \$5 per class or \$40 per 8-week program. Other programs will charge a flat rate for a number of classes. Water shoes are recommended for foot support and a nylon bathing suit is advised as it won't be affected by chlorine.

Some important factors to keep in mind:

a) find a program that meets all your needs so you keep attending, b) understand that everyone in the pool will be doing the same program but at their own level of ability, and c) listen to your body and STOP if something you are doing hurts. There are many ways in which to move and stretch muscles so ask for suggestions from your instructor.

On a personal note I started as a participant over seven years ago. There have been many changes, but what remains constant is my commitment to my pool program, my class and myself. I believe I am better because of the warm water pool program and hope to always continue with it. I hope you can enjoy a warm water pool program near you!



**Special thank you to T.S. Arthritis Pool Program
Participants Wednesday morning**

Research Findings

John Prescott DVM PhD, Professor University of Guelph The PACE Study: More CFS Controversy



PACE is the acronym for “**P**acing, graded **A**ctivity, and **C**ognitive behaviour therapy: a randomized **E**valuation”. This long-anticipated four-group randomized study of different “treatments” of adults with CFS has just been published in *The Lancet*, a respected international medical journal. It has set off a firestorm of controversy that may continue for years. Unfortunately, the results of this study have been newspaper headlines screaming “Got ME? Just get out and exercise, say scientists”. This is **not** the conclusion of the paper but it plays into the hands of groups who think that CFS is a psychological illness of some type, which it isn’t. Because this is such a sensitive issue, it’s worth understanding this study in some detail.

The largest study of its kind, costing \$8 million, PACE tested the safety and effectiveness of four interventions: Specialist Medical Care (SMC), Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET), and Adaptive Pacing Therapy (APT). 640 participants were selected from over 3000 new outpatients attending specialist CFS clinics of the UK National Health Service. These 640 patients met the “Oxford criteria” for CFS and achieved a certain score on questions about fatigue and about physical function, as well as being over 18 years old and able to speak and read English. Participant’s mean age was 39, with three-quarters being women (sound familiar?). The patients were randomly assigned to four treatment groups: APT, CBT, GET, and SMC. The study was done with impeccable monitoring, record keeping and standardization, and lasted 12 months for each patient.

The least intensive treatment, SMC, was 3-6 sessions of specialist medical care. The other three treatments each involved at least 14

sessions during the first 23 weeks of enrollment, with a booster session offered at 36 weeks. APT was designed to allow patients to adapt optimally to their illness, and involved keeping a diary that recorded links between activity and fatigue, and encouragement to do as much as they could without triggering fatigue. Most CFS patients will be highly familiar with such adaptation, but the study developed a detailed manual (in conjunction with the national CFS association) for use by their occupational therapists. CBT was conducted by clinical psychologists or nurse therapists and involved trying to change the behavioural and cognitive factors assumed by this school of thought to be responsible for perpetuation of CFS symptoms and disabilities. It involved establishing a baseline of activity, rest and regular sleep, then collaborating with the therapist in planned gradual increases in mental and physical activity. GET was conducted by physiotherapists to gradually increase patient physical activity to address the exercise intolerance and deconditioning assumed by this school of thought to be the basis of CFS.

The effect of these treatments was scored through questionnaires filled in by the participants themselves, who recorded fatigue and physical function against standard scales. Patients knew the group to which they belonged. The only objective outcome was how far patients could walk in 6 minutes. Safety was assessed by recording all serious adverse responses to treatments. Responses between the 4 groups were compared by careful statistical analysis of results at 0 (baseline), 12, 24 and 52 weeks after the start of treatment.

Patients treated with CBT or GET had statistically highly significant reductions in fatigue and increases in physical function scores compared to patients treated with APT or SMC, which did not differ from each other. For example, compared to SMC, GET treatment had a more significant ($p=0.0005$) effects on increased physical function compared to CBT ($p=0.007$), though fatigue scores were similar. (To understand statistical significance, anything over $p=0.05$ is chance). Improved scores over baseline were seen at 12, 24 and 52 weeks. Patient-rated assessment of positive change in

their overall health was: SMC 25% positive change; APT 31%; CBT 41%; GET 41%. This showed a significant advantage of CBT or GET over APT ($p=0.03$) but no advantage of APT over SMC ($p=0.3$). Contrary to other reports that CBT or GET is not well tolerated by CFS patients, there was no difference in adverse effects between the groups; about 9% of patients in all groups showed serious deterioration. Using “international criteria for CFS” or the “London criteria for ME” (which reduced the number of patients) gave equivalent results.

Although these differences between the CBT or GET and the APT and SMC groups were significant, the extent of the improvements based on the scales used were relatively little. The authors describe the improvements through CBT or GET as “moderate”. The improvements of CBT or GET over APT as a percentage of the 33-point fatigue scale were about 10% and as a percentage of the 100-point physical function scale were about 8%. Overall, 58% of patients treated with CBT reported “no change or worse” after one year compared to 70% of APT-treated patients. In other words, an additional 12% of patients were helped by CBT or GET but the majority were not helped by any treatment.

Now for the criticisms. 1) Other studies have not shown significant benefit of CBT over APT, but they were much smaller. 2) There are questions about the precision of patient selection. Did they all truly have CFS? Patients were selected on the basis of “Oxford criteria” that do not include some important features that define CFS. The “international criteria” used for a subset of patients were those of Reeves and others (2003), not the CDC criteria. About one-third of patients did not meet the international criteria used, which could have a significant effect on outcome. 3) Except for the timed walk, the scores are all subjective. The improvements are modest. Others have shown that CBT increases higher perceived activity and an increased sense of control, in the way that GET decreases symptom focusing rather than fitness. 4) The Chalder scale of fatigue is probably inappropriate. 5) APT as practiced in the study is not quite the pacing recommended by the British ME Association.

Despite the criticisms listed above, if CBT and GET really did improve CFS symptoms in a small way over the other interventions, how did this work? The “firestorm” of controversy is not only for some of the reasons listed but also because of the assumptions on which CBT and GET are based. In Britain, there are two radically opposed ideas about what causes CFS. CBT, which together with GET, is the only treatment approved under the National Health Service’s NICE guidelines, assumes that failure to recover from CFS is because of patient’s “fear, and avoidance, of mental and physical activity” which in some unknown way links with “physiological processes” to perpetuate fatigue. It has no logical mechanism. The assumptions behind use of CBT are in stark contrast to the other school of thought, that sees CFS as a complex multi-system disease that, likely because it is mostly initiated by an infection of some type(s), strikes ordinary people out of the blue and has serious and often long-lasting consequences. The big fear in Britain is that this study will be used to reduce insurance and disability benefits to CFS patients. This may be the reason for what seems to me to be a defensive over-reaction to this complex study.

My conclusion about this enormous study is that it has flaws: In the erroneous assumptions on which it was based; in some of its design, including patient selection; in its definition of APT; and in the subjectivity of patient self-evaluation. The benefits of CBT and GET, if true, were similar, which to me demonstrates that the assumptions behind CBT must be incorrect. Overall, the overall beneficial effects of CBT and GET were minor or at best modest. These were definitely not “cures”, but resulted in an overall 8-12% improvement in self-assessed health. By way of comparison, CBT has been shown to reduce the nausea and pain associated with cancer chemotherapy, but is obviously not a treatment for cancer itself.

There is so much to be done to understand CFS. It is likely that only true understanding of what causes this complex illness will lead to effective treatments. The PACE study is definitely not the answer to CFS. The search continues.

Dr. Bested on the Oxford Criteria

The patients in the PACE study published in *The Lancet*, were selected using the Oxford criteria which excludes patients whose illness started with a viral infection. In comparison when using the “Canadian criteria” most patients get ill with ME/CFS after having an infection or flu-like symptoms. Since the Oxford criteria excludes ME/CFS patients that have been diagnosed using the Canadian ME/CFS diagnostic criteria, this research article does not apply to patients diagnosed using the Canadian ME/CFS diagnostic criteria.

It’s like trying to get orange juice from an apple. If you want orange juice you have to go to an orange grove and pick oranges. They were picking out of the wrong orchard to study patients diagnosed with Canadian ME/CFS criteria – so this study is irrelevant for them.

Patient Survey Results

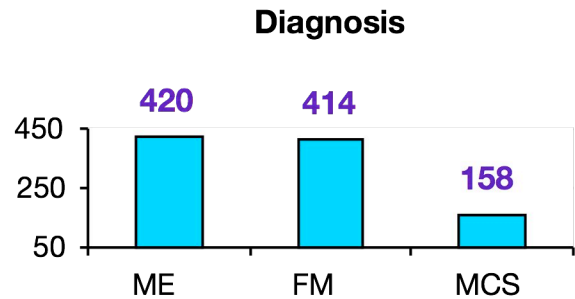
Here are partial results from the survey sent out February 19th, 2011 by the MEAO and the National ME/FM Action Network. It was administered by internet-only to minimize resources and turnaround time.

A complete summary of the results will be sent by email and posted on website soon. The MEAO and National ME/FM Action Network will analyze the data in more detail and ensure constructive conclusions and recommendations. We ask readers to be cautious in drawing conclusions until then.

The main purpose of the survey was to gather information from individuals with ME, FM and/or MCS regarding their experiences with physicians. We recognize that the questionnaire had its limitations and was designed for simple and timely analysis. As some of you wrote, the questionnaire did not always allow full and precise description of an individual’s situation. The summary does not show the individual stories.

Who answered the survey?

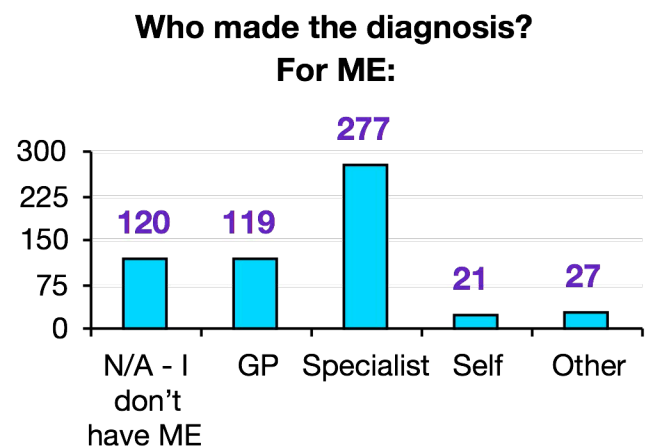
We received 612 responses: 267 were from Ontario, 91 from BC, 93 from Prairie provinces. The rest came from other provinces and 132 from outside Canada. The distribution by diagnosis can be seen in graph below.



The median for current energy levels (on good days) is about 5.5 (on the Functional Scale of 0 to 10) while median (good days) at time of diagnosis was about 3.5.

Who made the diagnosis?

The diagnosis was made in a variety of ways as shown in the graph below. A similar distribution was seen for FM. MCS was diagnosed by a specialist in 50%, self in 25% and GP in 15%.



Most respondents had both positive and negative experiences with physicians. Almost 80% strongly agreed or agreed with the statement “I have been to doctors who did not believe my symptoms”. Similarly, 80% agreed or strongly agreed with the statement “I have encountered doctors that are accepting of my symptoms”.

Interview with the Pacific Fatigue Lab

On March 16th, we recorded a phone interview with the Pacific Fatigue Lab (PFL), in the Department of Sport Sciences at the University of the Pacific in Stockton, California. PFL is a research, clinical and teaching laboratory focused on the functional aspects of CFS/ME and other fatigue-related disorders.

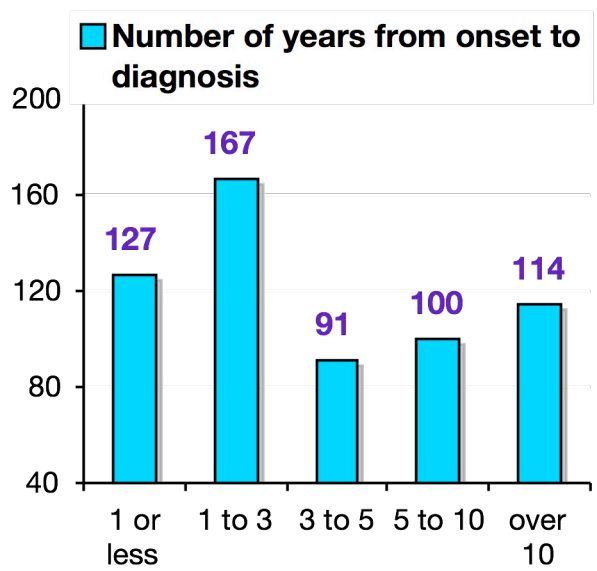
Staci Stevens is the founder of the PFL. She is the current Vice President of the International Association of Chronic Fatigue Syndrome/ME, which is planning a national conference in Ottawa this September (see separate notice for this event in Reaching Out). She is also the developer of the test-retest protocol for CPET (Cardio-Pulmonary Exercise Testing) evaluation for ME patients. Christopher R. Snell, Ph.D. is a Professor and Chair, Sport Sciences at the University of the Pacific. He is also the chairman of the Chronic Fatigue Syndrome Advisory Committee, which was chartered under the public health services act of the US.

Highlights from the interview are published below. Both audio (about 1 hour) and transcripts will be available in their entirety on www.meao.ca in April.

Ralf (MEAO): Let's start by asking for thoughts on the upcoming conference in Ottawa.

Staci: It's the first time the International Association of CFS/ME has had a conference outside of the US. So we're really excited to be coming to Ottawa on September 22-25. There will be a one day patient conference and a clinical and research conference that follows. For all your listeners and readers, I would encourage you to come and please invite any clinicians that you know or researchers that may be interested. We would love to see you there.

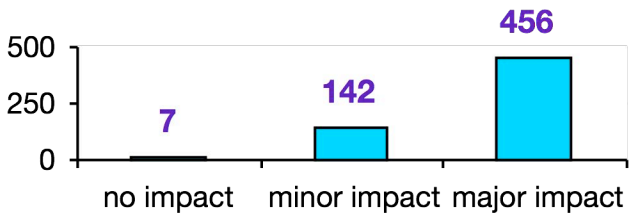
R: In a recent letter to Lancet, Kimberly McCleary, President of CFIDS said that it's biological basis has been objectively demonstrated. She gave a number of citations and then wrote "Using exercise testing,



What is the impact of the illness?

Over 75% of respondents indicate that the illness had major impact on relationships.

Impact of illness on relationships



In Summary

Mostly specialists not GPs are diagnosing these illnesses. There is large variability among physicians in their ability or willingness to diagnose. Individuals have consulted many physicians before a diagnosis was made. The illness had a huge impact on relationships.

Dr. A. Bested: "This survey is a great start. It documents the ongoing difficulties that Ontario patients have in getting diagnosed, getting access to treatment and the many other difficulties that can result from these potentially extremely debilitating illnesses."

We thank the participants and those who helped distribute the survey. We have some interesting data for the analysis still ahead. Comments are welcome at survey@meao.ca

researchers have identified physiological responses that persist for days or weeks.” Can we today describe ME as having an accepted diagnostic? Are we there yet?

Chris: We get a lot of similarity in terms of the measurements we get from a number of patients. Whether we are at a point of having an algorithm that diagnosis CFS I don't think we can say that. But the similarities are very striking and we also see that in testing done at other labs along similar lines to ours. The classic post-exertional detriment in performance up to this point appears unique to CFS. The idea that people are unable to repeat their performance on consecutive exercise tests seems to be a hallmark of the illness.

S: I would add to that that cardiopulmonary exercise testing in general is a great diagnostic tool. It's been used for 50 years for the diagnosis of cardiac disease, pulmonary disease and metabolic disorders. So it's not a new test. In terms of CFS/ME it's a great diagnostic tool because it excludes cardiovascular and pulmonary disease. It allows us to look at metabolic function from day to day. I think it's a perfect evaluation tool because ME is a diagnosis of exclusion at this point.

R: It's not ready to be stand alone yet but it can be part of the compliment.

S: Absolutely

R: Describe the assessment and interventions that go on at PFL.

S: What we do is a two day evaluation. This started out as a research project and patients started to find out about it and started to contact us to ask if they could use it for disability evaluation. The test consists of two days on a bicycle. We have a number of tests that surround the actual exercise test. We do resting EKG, resting lung function testing, and a reaction time test as well. The actual exercise test itself only lasts about 8 minutes. It starts out with a resting phase of 3 minutes. We do a minute of unloaded cycling with just the movement of the legs. Then it goes into a very gradual ramping protocol that gets harder and harder throughout the test until the patient can no longer peddle. And then

we ask them to come back and do the test again the next day.

R: And some of them are pleased to do that? I can't imagine.

S: We'll tell you about the client we had yesterday. I asked Chris to come down and have this discussion with the patient. Because She did the test on day 1 and showed severe functional impairment, which means that she didn't have to do it the second day. But she wanted to do it anyway.

C: As researchers we're very interested to see what happens. As human beings we're resistant to putting people through more pain than really is necessary. The key thing is we don't always need the second test because there's a floor effect. They're sick enough on the first test to demonstrate disability, so we don't expect to see a decrement on the second test. There's nowhere further that they can drop to so generally we won't require the second test. This person was really willing to put herself through the second test just to learn a little bit more about the illness.

R: How would you summarize the main findings of your research?

S: I'll take you through a little story of how this all evolved. Dr. Snell was my graduate thesis advisor. And our very first presentation, I was working with CFS patients and prescribing exercise. So we presented at a little conference on 'The impact of an exercise program with a patient – a single case study'. I went off and I happened to be involved in clinical trial with Ampligen and was doing testing at multiple sites in the US. I ended up doing 1200 tests. I came back and asked Dr. Snell if he'd look at the data and publish it. As I was traveling over the six years, what came up over and over again was that the patients could do an exercise test on a single day but rarely did they recover from it immediately or even days later. So I came back to Chris and said we're not asking the right question. The questions isn't what can someone do on one day, but how quickly do they recover from it. After looking at that original data set of 200 patients we found that half of them were moderately to severely functionally impaired. But the other half looked like they had no impairment or just mild impairment.

And even though they were all disabled according to their physicians, it wasn't being captured on a single exercise test. And that's how the two-day test protocol sort of emerged. We weren't capturing the post-exertional malaise and the delayed recovery response with a single test, we started the second test and what we found was a decline in metabolic function on the second day. And this doesn't happen – at least in the literature – in heart disease, in lung disease, in late-stage renal disease patients can reproduce exercise test results from day to day, but our CFS patients could not.

C: Two things came out of that: one of them was obviously our test-retest protocol. The other was we became strong advocates for using an exercise challenge to precipitate symptomology because a lot of the other research in CFS is equivocal. One set of researchers will get one set of results that find one thing and another set of researchers will get another result that seems to contradict that. It seemed logical to us that if a primary symptom of the illness was, this post-exertional exacerbation of symptoms, that people might want to start looking at patients when the symptoms are present. That that might be the best indicator of what's going on. And over time we've actually convinced a significant portion of the CFS research community to include an exercise challenge in their research protocols. Essentially what they're doing is looking at the person downstream of an event designed to induce symptoms. We're quite proud of that along with our test-retest protocol. That's where we're working now, is to get the idea of using multiple tests and to get the protocols involved in cardiopulmonary exercise testing.

R: What are you planning for future research studies at the moment?

S: Certainly, I think, the symptom of post-exertional malaise is so important in this illness. And no one understands what it even is. To further characterize that is one thing we would love to do. Chris and I have been talking about the importance of hypothesis driven research and I'll let him comment further on that.

C: Two things, 1) One bandwagon that we've been on is the idea of sub-typing for chronic fatigue syndrome. Often the patient groups, or subject

groups in research, are not very clearly defined. We would either like to clearly define groups by the results from the exercise testing that we get and then look at other parameters. Or we get groups that are defined by another parameter, be it a virus or a particular symptom complex and then we look at the exercise test data. So we start to test some hypothesis for what might be causing the fatigue and the other symptoms. And you really need a very clearly defined population. So all the hullabaloo about XMRV, if you want to look at that further, you need a subset of CFS patients that have evidence of XMRV to determine how important that is in the etiology, you know, the sequence of the illness.

R: What are the main benefits that the PFL can offer to patients that visit them?

S: I think the main benefit – when I sit down and go over results with a client – is that it offers them hope. I can tell them two things: I can tell them objectively what is going on and then give them hope for functioning better based on the results of the exercise test. And for the first time, often patients have never had any objective results or any positive findings. They're quite relieved when I can sit them down and say, "You've got metabolic dysfunction, this is why. Here's your heart rate at your anaerobic threshold which will allow you to pace your activities because when you exceed that heart rate, it's the beginning of the end." That's where fatigue and pain will set in. Most patients are exceeding their threshold just doing their daily activities. So knowing that this occurs is an extremely useful tool for management.

C: So when we can quantify why having a shower can wipe you out for a few hours then patients realize that there is an underlying biological cause for the symptoms and for their performance.

R: So this suggests that it is possible to manage ME using CPET. Is it good enough to just have the CPET doing it once or is it something that will require repeated checking?

C: The problem with one test is that it really doesn't take into account the effects of activity. The symptoms are cyclical and they may depend on a variety of different things including how much

you've exerted yourself. But there's probably other factors that determine how sick anybody is on any given day given that it's a multi system illness. Even if we look at just one aspect of the immune system, your immune system varies just in terms of its functionality from day to day and also your exposure to external pathogens. Like everybody else, people with CFS are susceptible to illness from outside so it's extremely variable. What we can tell them with the two-day test is, this is what you'll look like at your worst. And if you avoid going into that territory, if you avoid things that are guaranteed to make you feel sick, then your life should improve. You should see less instances of symptomology and you should be able to function. We've even had people that have been able to function in a work environment given certain guidelines.

R: What services are offered and what are roughly the costs at your facility?

S: Right now we are only offering disability evaluations as a service with a stipulation that we are allowed to use that data for research purposes. Unfortunately at this time we just don't have the personnel to do anything beyond that. The costs are \$2000 for the two-day tests. It includes a 10-page report that gets sent to the referring physician as well as to the patient.

R: Do you need a referral from a Doctor?

S: Yes. The paperwork is available on our website at <http://web.pacific.edu/x31814.xml>. We require a physician referral. We do cardiac risk stratification – we want to make sure that patients are at a low risk for a cardiovascular event. We have a medication list and a few forms that need to be filled out and returned to our office before we can set up an appointment.

R: What would you say are the most significant agreements and disagreements with other research papers on the subject?

C: We don't have a lot of people that are doing our test-retest protocol. There are some people in Europe that are doing it and their results seem to replicate ours. They have fairly well defined samples and fairly large groups, so we find that

encouraging. When using very small groups that are not clearly defined in terms of the illness you may lose the effect and not see it.

S: That's tremendously encouraging. With all of these potential biomarkers, very rarely do you see them replicated and they're not readily available in labs around the world. Cardio pulmonary exercise testing as a tool has been around for 50 years – it's nothing new. And if done properly it can potentially be replicated anywhere. There was a study done that was replicated by the De Meirleir group in the Netherlands. That's exciting!

C: And the protocols are clearly defined by the American Heart Association and the American Thoracic Society and they have pages and pages on the protocol so it's relatively easy to replicate for people that know what they're doing. Then you know that patient A in Holland is doing exactly the same protocol as patient B in California or C in Ottawa.

R: I thought Nancy Klimas was doing something with multiple snapshots, looking at all kinds of blood tests at multiple intervals post exertion?

C: Nancy is onboard with the exercise challenge. Our main reservation is that a lot of people are not doing a maximal exercise test. And if you don't do this you can't equate the level of challenge. There's a body of literature on the effects of exercise on the general population and it's extremely variable in terms of the level of stress that you put somebody under and that person's level of initial fitness. What we do is we can equate the level of stress across individuals and we can say that person A who does not have CFS was put under the exact same level of stress as person B who does have CFS. Therefore any differences downstream of the exercise test are not due to different levels of exertion. So if you don't do a max test, you don't know how hard someone was working to achieve whatever your goal.

R: Are you able to provide advice in terms of exercise to those who can't come to your center?

S: Only really in broad strokes. Unfortunately we are not at this time doing individualized exercise or activity management consultations. We've got two lay publications that we can make available to

patients that are interested; “When working out doesn’t work out” and “A realistic approach to exercise and CFS.” There are some resources for patients that we have developed and we hope in the future that we will be able to offer more services in this area.

C: We have the knowledge to do it but we don’t have the capability to do it.

R: Would you see a potential to one day be able to extrapolate the CPET findings to something more readily available? Something cheaper and faster?

C: We’ve been dreaming of that for a long time and you can actually do it with a normal population because people function pretty much the same way when you give them an exercise test. People with CFS don’t. So it’s very hard to extrapolate without getting the data that we need to get. The thing with a max test is that it allows us to equate a number of things. A key thing is something called the anaerobic threshold. This is the point at which anybody in the world, if they exceed their anaerobic threshold, the time that they can continue to work is going to be limited and there’s going to be some payback. It’s the use of energy borrowed against future supplies of oxygen. It’s the emergency energy system used for fight or flight. It appears that a great many people with CFS rely solely on this emergency energy system because their normal, aerobic energy system, their long-term energy system, is malfunctioning and not working properly. If you can’t find that point, and that’s where we think people precipitate symptomology. but unless you do a full test and then go back to see where that point was, you don’t know for anybody where it is. You can guess for general individuals that it’s going to be 50-70% of their max output so you can run somebody at a predicted 50% max test and look at that, but we can’t even predict endpoint for CFS patients. A lot of people use predicted max heart rate, but even the American Heart Association say not to use it because it doesn’t work. It’s based upon a normal, healthy individuals max heart rate, 220-their age. We get blunted heart rates frequently that don’t even approach 60% of predicted max.

R: Other centers are offering exercise testing and therapies What would you look for from

centers to make sure they were providing reliable results?

S: I think there are several things. Firstly, personnel that are familiar with working with CFS patients and have an understanding of post-exertional malaise. What it’s going to cost a patient to do this testing, having somebody who’s sympathetic is extremely important. And having somebody that’s competent. You need to have good staff that knows how to do this testing. Ideally having an exercise physiologist do the testing is the best case scenario. Other things to look at are maintenance of the equipment and quality control. A mistake that often medical providers make is that they assume that if the equipment calibrates at rest then it’s working properly. They may or may not be maintaining the equipment. Basic equipment quality control and maintenance is important but beyond that biological validation, which means having a healthy individual do three steady state workloads, so three workloads of 3-6 minutes at different work rates, and making sure that every other week they’re getting the same results to make sure that their machine is reading appropriately.

C: And we’ve had experience where we’ve consulted with other entities on exercise testing in clinical settings where we’ve not been present during the exercise test and when we look at the results it’s clear that the equipment was not calibrated properly or they didn’t follow the appropriate ramping protocol for the patient. And essentially you’ve got to throw the data away. You’ve just put a sick person through 2 twelve-minute periods of purgatory and what you have is of absolutely no use. So it’s got to be taken seriously.

S: We would say do it right or don’t waste your time. Sadly, because it’s an exercise test most researchers and clinicians just assume that they can go out and buy the equipment and they can do it because it’s just a walk on a treadmill. This is an entire field that has manuals and textbooks on the proper ways to do exercise testing that you need to hire a professional in those areas to do that. And beyond that you need to have someone that can interpret the results. Most cardiologists don’t know how to interpret gas exchange or may not use a metabolic cart. So you need somebody that’s familiar

with the gas exchange side of the equipment and isn't just looking for a cardiac abnormality.

S: Chris and I have been doing this for years and it still takes us at least an hour or more to do a good solid interpretation and write the report. I know that in most medical centers physicians just don't have that kind of time, they don't have that luxury to sit down and do a complete analysis. So those are the road blocks to doing this well.

C: A lot of people look for the simple explanation. If you're starting with the premise that this person is not really sick, and I've just got to show that they're not really sick, then you're going to approach the test very differently than from the idea that this person's got a definite diagnosis, that these symptoms are real and not imagined, let's see if we can shine a little more light on why that might be happening. If there's nothing there then we're not going to say that there is. If we don't get the results that you hope we get then that's what we're going

to say, and we have to stand by that. We get a number of other conditions other than chronic fatigue syndrome where we don't get a clear disability based on the data that we use.

R: You also evaluated patients with other conditions. What are the similarities and differences between them and ME?

S: FM is interesting - some people consider it a co-morbidity, some people consider it the same illness. We've had people that have had a primary FM diagnosis that look classic CFS. So clearly they have CFS with whatever symptomology is required to diagnose FM.

The MEAO would like to thank Christopher and Staci for taking part in this enlightening interview.



**Success of
"Intro to Therapeutic Yoga"**

By: Lynn Holmes (Co-facilitator of the Scarborough ME, FM and MCS Support Group)

As advertised in the last issue of "Reaching Out", on February 10, 2011 East Village Yoga studio, in Pickering, conducted a "free" special class for the ME Association of Ontario for people with ME, FM and MCS.

Due to the success of this class, and the incredibly positive feedback received after the class, a series of classes are being offered for the month of April.

Classes are specifically designed to help support the recovery process for people dealing with ME, FM and MCS. A series of very gentle Therapeutic Yoga poses are combined with breath exercises to help enhance the participant's path to healing.

There are four one-hour classes over 4 weeks where you will build on skills learned in the previous class, in addition, you will also receive a home program to be practiced daily between sessions.

April's classes will be offered on
Wednesday, April 6th to 27th, 2011

Future classes will be offered dependent on interest and attendance. For more information and to register: contact Nicole Ablack-Ramkay via email at nicole@eastvillageyoga.ca

Or call the studio at 905-250-0173

More Exciting News!!! East Village Yoga is currently considering the development of a "Therapeutic Yoga" DVD to assist those who cannot attend the sessions at their studio.

Many thanks to Nicole and East Village Yoga for their support of our ME, FM and MCS Community.

Spotlight on Carolyn Swirsky Polisuk

BUT YOU DON'T LOOK SICK

A regular visit to the Periodontist: no problem, right? Well, it started off that way when I arrived early and enjoyed a little time to myself reading: People magazine - but that serenity quickly changed. I was called in and after some friendly banter the hygienist began to apply a topical anesthetic to my gums to work on my very sensitive teeth. I've had this identical procedure before with no difficulties, however this time, as the topical anesthetic was applied to my gums, I had a terrible reaction. My tongue started to burn, and suddenly my mouth was on fire. I calmly described to the hygienist what was happening and she gave me some mouthwash to rinse with (making it worse) and finally some water. Waiting twenty minutes or so for the discomfort to subside, I sensed the hygienist's frustration but I held my ground.

My Periodontist then came in and advised me that I couldn't be allergic to the topical anesthetic as my mouth was not red or inflamed. *Sound familiar? "But you don't look sick." "All of your test results have come back normal."* I tried to explain that I have multiple chemical sensitivities and that it wasn't their fault as I had used the topical anesthetic before with no problems. I just went on and on.

*Was I hearing myself correctly?
Why was I trying to appease them??
Shouldn't they have been taking care of me?
Why was I having such a hard time with self advocacy? Isn't this what I so very clearly advocate in my workshops for people with chronic conditions, at my monthly FM/CFS support group, and to all of my coaching clients?*

The appointment continued and an alternate topical anesthetic was used resulting in the same reaction. Finally it was decided that the hygienist would just use the regular cleaning instruments as opposed to those specifically designed for deep cleaning and apply topical toothpaste for sensitive teeth over my gums. Sounds wonderful! However the suction caused my mouth to feel like there was a deep freeze. As a last resort the scaling and cleaning

resumed minus the cold suction air. Finally, the ordeal was over!

Looking back, I initially did not handle this situation as well as I could have. It was as if the past few years of practice and preaching a positive mantra flew out the window and I gave permission to the old messages to take over. Images of that desperate woman; unheard, misunderstood and alone seeking to hear the diagnosis" You have CFS and Fibromyalgia" flashed before me. Eventually I did manage to change that negative picture and get back into a positive frame of mind; choosing to put an end to my self doubt and to the negative voices.

Firstly I realized that I did not owe the hygienist or the Periodontist anything except to explain my situation once. This is who I am and while it took extra time to accomplish the 'cleaning', no apology was necessary. Then I reached deep inside for my strengths of *patience* and *understanding* ...ironically the two qualities that I yearned to receive for so many years from the many unreceptive doctors. Just repeating these two words calmed me down and allowed me to regain focus. Finally, I chose to believe that the Periodontist and hygienist were indeed sympathetic as the appointment progressed. They indeed did hear me and documented what happened for future reference and forwarded the information to my dentist. It makes me feel better to see the best in people and harboring resentment only breeds harm to the one feeling the negativity; in this case, me.

Well, I am relieved to say that I have a 6 month window until my next appointment. I can't say that I am looking forward to it but I *can* choose how I will show up. And I have already decided that it will be with a clear vision of how I want to respond if something goes awry and with a firm notion of who I am!

Lesson learned: I am who I am with no apologies.

Cheers, Carolyn

Carolyn Swirsky Polisuk is an Adler trained Life Coach with a special interest in helping people with chronic conditions and their care giving partners adopt strategies to help them with their self care goals.

STEP IN 2 COACHING /
www.stepin2coaching.ca / 905.889.0796 /
carolyn@stepin2coaching.ca

Upcoming events

*Please note these are all scent free events.
This includes no coffee or perfumes.*

An Introduction to Meditation

Tony Murdock, special guest speaker, has been practicing meditation and studying yoga since 1972 and teaching a blend of meditations from a variety of religious and spiritual traditions since 1998. He has Master's degree in Sanskrit and Hindu Religious History, with a Minor in Christian Studies from McMaster University. This is a **FREE** event brought to you by the Scarborough ME-FM-MCS Support Group. For more information contact me-fm-mcs.emails@bell.net

When: Thursday April 14th, 2011 from 1-3pm

Where: Fairview Mall Library, Meeting room 1
35 Fairview Mall Drive, Toronto M2J 4S4
(2 blocks N of Don Mills/Sheppard Ave E)

Environmental Health Clinic Presents:

It's a Chemerical!

When: Wednesday April 20 from 1:30-3:30pm

Where: Cummings Auditorium,
Women's College Hospital, 76 Grenville St.
Program: Film and panel discussion by EHC
physicians and Andrew Nisker, film director
Cost: \$5 – light refreshments included

Environmental Health Conference

When: Wednesday May 4 from 8:15am-4:15pm

Where: Cummings Auditorium,
Women's College Hospital, 76 Grenville St.
Program: A highly interactive day focusing on
multiple exposures and health effects; prenatal and
childhood toxic metal exposures; body burden,
plastics and pesticides; health impacts of poor
indoor air quality; diagnosis and management of
ME/CFS, FM & MCS and more!

Cost: \$100, breakfast & lunch included
\$50 half day, \$25 students

Advanced registration required

For further information call 416-351-3764

Dr. Kevin White on “Breaking Thru Fibro Fog”

Dr. White, author of ‘Breaking Thru Fibro Fog,’ will be speaking at the Mississauga support group meeting in April. He will speak about what made him write the book and all the research that has been done here and in the US.

When: Monday April 25th, 2011 at 7:00pm

Where: Loblaws 2nd floor, 5079 McLaughlin & Britannia, also known as Hearland Centre

MEAO Educational Seminar

The MEAO is excited to announce that we are in the midst of planning our next educational seminar for June 2011. We have not yet confirmed a date but will forward details as soon as they become available. If you have any requests or ideas for speakers you would like us to host, please send an email to info@meao.ca



The Ottawa Canada Conference

The Ottawa, Canada conference (hosted by the National ME/FM Action Network) will consist of a 4-day professional meeting (September 22-25) and a one day (September 22nd, 2011) patient meeting which will coincide with the professional meeting.

The professional conference themes focus on fatigue, pain, sleep, pediatrics, cognition and brain function in ME/CFS, Fibromyalgia and related illnesses and will be addressed in scientific sessions on assessment and treatment and original research in the fields of immunology, virology and neuroendocrinology. There will also be workshops for clinicians and researchers. Planning for the patient meeting is ongoing.

Registration will open in May, 2011. To receive conference updates, you can register your email at: <http://www.iacfsme.org/Home/ConferenceUpdates/tabid/451/Default.aspx>

Passing of Dr. van Hoogenhuize.

The MEAO is sad to share with the community that Dr. van Hoogenhuize died on December 8, 2010 after practicing medicine up to the age of 79. He was a Diplomate of the American Board of Allergy and Immunology and was a panel member at the 2008 MEAO Annual General Meeting. A number of MEAO members were patients of his and held him in the highest regard. Dr. van Hoogenhuize will be fondly remembered for his lifelong passion for medicine, studying medical journals and related texts for up to two hours a day well into his 70's. Dr. van Hoogenhuize was also known to spend an hour or more with individual patients and was a beacon of hope for some, having fully recovered himself from a diagnosis with ME

MEAO Disclaimer:

As a resource group, the function of our organization is to provide you with current information on ME/CFS, FM, MCS and related illnesses. As we are not medical or legal professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your needs with your doctors, lawyers and other professionals before making any decisions.

May 12th International ME, FM & MCS Awareness Day



Building on the success of last year Jeanne Samonas, May 12th Chairperson, and her volunteer committee are hard at work planning this year's event on the Queen's Park front lawn.

New T-Shirts with the May 12th logo (seen above) are available for \$20. Contact info@meao.ca to place your order or for more information. We will also be running a ribbon campaign (\$2/each) and encourage you all to purchase and wear one regularly.

Guest speakers will be starting on the Queen's Park south lawn at 10:00am.

With over 440,000 individuals in Ontario with ME/CFS, FM and MCS, think of what we could do if everyone gets involved. We hope you will all come out and support your cause!



CONTACT US:

Our mailing address:

Ste. 402, 170 The Donway West
Toronto, ON M3C2G3

Our website can be found at:

www.meao.ca

You can email us at:

info@meao.ca

OUR INFO-LINE IS:

416.222.8820, for callers in the Greater Toronto Area, or 1.877.632.6682 for toll-free calls across the Province.

Our Info Line is a message centre. Please leave your name, number and the best times to call you on our machine, and a volunteer will call you back to help with information and referrals.

MEMBERSHIPS AND DONATIONS:

Our annual membership is \$25.00, and we are able to give tax receipts for memberships as well as all other donations. Membership gives you our quarterly newsletter 'Reaching Out', filled with articles on Medical Research, Coping Tips, Legal Issues, Upcoming Events, Helpful Websites and Books and much more! Members who provide an email address also receive special monthly email alerts, full of the latest news and events. All members are eligible to direct the work of the MEAO and vote at our Annual General Meeting.

Paid memberships help support our charity and our mailings but we do have complimentary memberships for those experiencing financial hardship. See our Membership / Donation Form on our website or use the form below.

Donations are our lifeblood. Donations of \$10.00 and over are issued a charitable tax receipt. You can mail us a cheque or donate by credit card through CanadaHelps on our website.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

Ste. 402, 170 The Donway West, Toronto, ON M3C 2G3

Please go to our website for our full Membership Application or send us this form with payment
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for Memberships and Donations!**

I am requesting a free membership due to financial need

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