



photo by Ken Beattie

# inforME Magazine

**InforME Magazine is an informal publication for people concerned with ME, CFS and CFIDS.**

*(ME: myalgic encephalomyelitis, CFS: chronic fatigue syndrome, CFIDS: chronic fatigue & immune dysfunction syndrome)*

**Autumn 2010**

## **The Anatomy of Hope**

*By Bruce Campbell*

Sourced from: <http://cfidselfhelp.org/library/the-anatomy-hope>

### **Inside this edition:**

**The Anatomy of Hope .....1**

**Editor's Letter.....2**

**Heart to Heart Stuff in ME/CFS.....4**

**UARS: The Hidden Sleep Condition.....8**

**Health On The Line.....9**

**Indian Vegetarian Curried Fried Rice.....10**

**Greek Panzanella Salad.....10**

**You Must Be Well By Now .....11**

**I Still Survive.....12**

**XMRV, MLV... the alphabet soup thickens.....14**

**Alena's Tips for a Happy Life.....15**

**DNR course.....15**

**Upcoming Events.....16**

If you are like most people with CFIDS and fibromyalgia, you have probably felt discouraged or even despairing at times. Perhaps it happened when you learned that you had an illness with no cure. Or maybe it crept over you slowly as came to suspect that you were unlikely to restore the life you had before becoming ill. In any case, you may have wondered how to keep hope alive when faced with long-term suffering.

A recent book by Dr. Jerome Groopman of Harvard offers some answers (*The Anatomy of Hope: How People Prevail in the Face of Illness*). Based largely on his experience with cancer patients, the book describes different approaches to living with serious illness.

### **Resignation**

Some people are passive in response to their diagnosis. Dr. Groopman describes a patient named Dan who refused treatment even though he had a curable form of cancer. Groopman eventually learned that Dan's refusal was based on the assumption that he would suffer the same fate as a friend who had died of cancer after a series of debilitating treatments. Feeling helpless and hopeless, Dan resigned himself to dying.

Dr. Groopman was able to persuade Dan to undergo treatment. By uncovering Dan's mistaken belief about his situation, the doctor was able to convince him that his situation was different than his friend's. Also, he encouraged Dan to see his treatment as a series of small steps in which his life would improve gradually. And, last, Dan was inspired to continue his treatments after meeting a woman who had recovered from the same cancer he had. Dan persisted and recovered.

Like Dan, CFIDS and fibromyalgia patients can fall into helplessness after years of suffering, but they can help themselves using some of the same strategies Dan employed. By taking a series of small, realistic steps, most patients can help themselves to feel better. In our self-help course, we teach how you can improve quality

Hello Readers! It is a privilege to spend this time with you. I hope this letter finds you at peace and not too hot. June was a rough month for me, but I have also had some wonderful times motoring around in the ocean and sitting in my garden this summer. I have to remember: even healthy people don't have all good days. I have had some lovely chats with some of you over the summer time that have inspired and encouraged me and I hope I have done the same for you. I talked to someone who mourned the loss of her energy, which I totally get. I would love to have even half the energy I use to have. I have fun just thinking of all the adventures I could be having, at work and at play.

Even though I didn't have much energy at the June event, it was quite nice. Jen Nemeth did a wonderful thing for us that afternoon. She set up a painting table and if anyone wanted to participate they were free to express themselves with paint on paper. I'm pleased with my painting; I will have to show it to you sometime. Thank you Jen for being willing to do that for us. Jen has just recently published a very attractive book about color, titled, 'Color For The Real World'. Well done Jen! [www.desitterpublications.com/ColorForTheRealWorld.html](http://www.desitterpublications.com/ColorForTheRealWorld.html). Ken Beattie was there taking photos and some have made their way onto these pages. See the one of my kitty sniffing Jen's paintbrushes. Thank you Ken your photos lend a look of quality to our magazine. Thanks to all who are part of the InforME team. I would like to take some time to mention people like Phyllis Griffith who is great at sending me news feeds, Margaret Sherwood who is our organized mailer, Kim Cutler the detector, Christopher Heppner for writing such up to date and informational articles, Lorraine who makes it all look pretty on paper, and of course, there is Krissoula Vincent and Beth Politano who will send me all their best recipes as I need them

I was very impressed by the variety of salads at the barbecue in August. Thank you for your delicious contribution. Thank you Tina for being such a gracious host at this event; and thank you to Chris Karch, a.k.a. the barbecue guy, for doing the cooking that afternoon. While at Tina's I had a chance to admire her new kittens. Oh my, they were so cute!

For those that are interested in RDSP's: go to [www.forthefuture.com](http://www.forthefuture.com). It is worth the work. It's free \$\$\$\$.

The MXRV debate lives on! There is some pretty compelling evidence that CFS is virus related. I am not an expert on this topic. Chris Heppner does keep up with the research and has a lay understanding, but he could not give any medical advice, as he is not a qualified professional. If you want any further discussion on this topic e-mail [chris.heppner@shaw.ca](mailto:chris.heppner@shaw.ca). I bet you have been wondering who won the gift certificate for the Blue Fox? Well, it was Teresa Craig-Morgan.

Congratulations! Well this June we had two generous donations for our draw. Margaret Sherwood was also a lucky

# InforME Magazine

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For people concerned with ME(Myalgic Encephalomyelitis), CFS(Chronic Fatigue Syndrome), and CFIDS(Chronic Fatigue and Immune Dysfunction Syndrome)

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## Publication Disclaimer

The purpose of InforME Victoria is to offer a wide variety of information about coping strategies, research issues and possible treatments for ME, CFS and CFIDS. There is yet no agreement in the scientific and medical communities with regard to the causes and optimum treatment for conditions. We make every effort to use only responsible sources but some information may be speculative. We recommend that readers consult with a health professional with regard to their own treatment plan.

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winner! She won a half hour 'Befriending the Body', session with Connie Frey. Thank you Roz and Connie for supporting MEVA! Roz has been a proud supporter for three years now. I sure do appreciate all MEVA supporters. Life is good.

Once again I hope you enjoy this edition. If you have any ideas, topics, photos or anything you would like to share with us, please contact me at 250-370-2884 or [gmgrey@hotmail.com](mailto:gmgrey@hotmail.com). Thank you. I hope this summer has left you with some happy memories. I wish you well in your journey.

Gloria Gray, Editor

*continued from front page*

of life by making different choices than in the past. We also believe that the model offered by patients who have improved provides inspiration. That's why we focus in our course on what works and why we have a series of success stories in our Library. We don't offer a cure for CFIDS or FM, but the strategies we teach have a good chance to decrease suffering and increase quality of life.

### **False Hope**

Another response to serious illness is to hold out unrealistic hope. Groopman says he did this himself early in his career. He describes a case in which he and a colleague misled a patient named Frances, who had a colon cancer. Even though Frances' cancer was rated at Stage D, meaning rarely cured, she was given an optimistic interpretation of her situation. The doctors used the term "remission," which meant to them a short-term reduction in tumor size, even though they knew that Frances would hear this as "cure." When, inevitably, the cancer worsened, Frances was understandably angry that the doctors had misled her and lost trust in them.

Groopman now believes that offering patients false hope was wrong and that doing so showed a lack of confidence that it is possible to have both hope and a realistic view of illness. The problem with false hope, he says, is that it does not acknowledge the risks and dangers facing a patient.

False hope can be an issue for CFIDS and fibromyalgia patients, too. I have often seen people spend great amounts of time and money in search of a miracle cure, something that will give them their old life back. While some people are able to recover, recovery is rare and repeated failed attempts at recovery can produce the same sense of helplessness as resignation.

### **Realistic Hope**

Groopman describes a third way to respond to illness, which he calls true hope. True hope, he says, "takes into account the real threats that exist and seeks to navigate the best path around them." Hope can flourish when you believe that your actions make a difference, that they can create "a future different from the present." To have hope

is to "acquire a belief in your ability to have some control over your circumstances."

He illustrates this approach by describing a patient named Barbara, who had an aggressive form of breast cancer. Barbara acknowledged that the cancer was likely to kill her, but she also wanted to treat it aggressively. She told Groopman: "I wish to live as long as possible, so long as there is quality to my life." And Groopman was impressed at how much quality of life she had. Barbara had a wonderful sense of humor and many good friends. She enjoyed travel, and found meaning in her faith and in working as a volunteer at her church.

Groopman was impressed with Barbara's acceptance of her situation. He found she had a calmness that was rooted not in surrender but in a "steady realism." She "set the parameters on her care with a clear-eyed vision of what was possible, what made sense to her, how she wanted to live, when it was time to die." Even with the limits imposed by her illness, Barbara was able to live her life on her own terms.

Barbara's approach is similar to what we call combining acceptance and hope. Patients with this attitude acknowledge that life has changed. Instead of living as if they were well or searching a miracle cure to restore them to health, they accept that their lives are different and, in some ways, more limited. At the same time, they have a fierce determination to improve and a conviction that they can find ways to make their lives better.

### **Hope for CFIDS and Fibromyalgia**

What is realistic hope for someone with CFIDS or fibromyalgia? While it is realistic to hope that a cure may be developed some day, at present neither illness has a cure. Some patients recover on their own, but their numbers are small. So for most people, it is prudent to assume that CFIDS or fibromyalgia will be long-term conditions.

But it is also realistic to believe that you can find things to help you feel better. Medications and self-help strategies may not cure CFIDS or fibromyalgia, but they can help reduce pain and discomfort, bring greater stability, and lessen psychological suffering. This approach requires that you assume responsibility for the day-to-day

management of your illness.

Living well with long-term illness means living differently from before. CFS patient JoWynn Johns describes her journey to a new life by saying in an article on recovery, “If recovery means returning to the way of life I had before CFS, I have not recovered. But in other and to me equally significant ways, I have recovered.” She describes regaining control over her life, regaining physical comfort and learning how to control her symptoms through living within her energy envelope. She writes, “I apply the word ‘recovery’ to myself because I have regained a satisfying life. It’s just not the life I had before CFS.”

Realistic hope can have physical effects as well as boosting your spirits. Groopman describes experimental evidence that hope can reduce symptoms. Hope appears to trigger the production of endorphins, the body’s own pain killers. “Belief and expectation, cardinal components of hope, can block pain by releasing the brain’s endorphins and enkephalins.” Hope sets off a chain reaction. “Hope tempers pain, and as we sense less pain, that feeling of hope expands, which further reduces pain.”

Students in our program echo JoWynn’s sentiment, saying that they believe it is possible to create a joyful and rewarding life while living with long-term illness. While not the life they had before becoming ill, it is a good life. They observe that, even though they would not have chosen their illness, they have learned valuable lessons from it and even, in some cases, consider themselves to be better persons now than they were before becoming ill. I hope that, even if you have a different life than you expected, you see it as a good life.



## **Heart to heart stuff in ME/CFS** *By Chris Heppner*

*(Note: I have supplied PMID numbers where feasible so that anyone interested can go to*

*PubMed and type the number into the search function to access at least the abstract of the essay referred to; in some cases, the entire text is available free)*

There is no getting away from the centrality of hearts in our lives, and CFS is no exception to that—indeed, we may well die of heart disease. Leonard A. Jason examined the records to find out what kills us (PMID:10910366), and discovered that heart failure, suicide, and cancer are in a virtual tie for the top three places, each at around 20%. In the case of heart failure, the mean age of death among those with CFS was conspicuously low (58.7) compared with the population average age of death from heart failure, which is 83.1. CFS does not often appear on death certificates, but hides its dirty work under the names of other conditions.

Heart issues have been central to CFS research for many years, with perhaps two chief avenues that have engaged researchers. The first is the possible role of viruses in damaging the heart and vascular system. Here A.M. Lerner is the most prominent name. As early as 1988 Lerner wrote a short paper on “A New Continuing Fatigue Syndrome following Mild Viral Illness” (PMID: 3180889), describing “prolonged nondescript courses of a fatigue syndrome similar to that caused by acute Epstein-Barr virus (EB) or cytomegalovirus (CMV) infections.” This, more or less, is CFS. By 1993 Lerner noted “repetitively negative to flat T waves” during 24 hour ECG monitoring in patients with CFS, and proposed that the fatigue of CFS might be related to subtle cardiac dysfunction (PMID:8222798). A year later he wrote about dilation of the left ventricle and “segmental wall motion abnormalities” among a group of CFS patients (PMID: 7955743). By 2002, he was trying valacyclovir (an antiviral) on a small group of patients with EB but not CMV; a control group had both. The group with only EB improved, that with both viruses did not (PMID:12582420). A follow-up of the EB patients at 36 months showed that tachycardias decreased, cardiac wall motion improved, and patients resumed normal activities (PMID:18019402). Very recently Lerner

has reported upon a longer study of 142 patients with EB, CMV or HHV-6 (Human Herpes Virus, type 6) singly or in combination, treated with long-term valacyclovir and/or valganciclovir; the result was that 74.5% “returned to a near-normal to normal life... cardiac, immunologic, and neurocognitive abnormalities improved or disappeared” (Subset-directed antiviral treatment of herpes virus patients with chronic fatigue syndrome; not in PubMed yet).

Montoya also found valganciclovir helped most of a small group of CFS patients with HHV-6 and EBV (PMID:17276366). Viruses can and do affect the heart, causing fatigue and other symptoms. Cytomegalovirus, for instance, has recently been shown to promote both high blood pressure and atherosclerosis (PMID:19436702). Not all antivirals are active against all viruses, but it has become clear that they can help substantially in some cases. Artesunate, a wormwood derivative, has shown it can deal with CMV as well as the herpes family (PMID:18419454). Research is ongoing, and of course XMRV (Xenophobic Murine Leukemia Virus Related Virus) is still being actively investigated; though there are reports that several antiretroviral drugs are active against it, it is too early to begin asking for such therapy.

Another important line of research into cardiac issues began with the work of A. Peckerman et al. whose paper, Abnormal Impedance Cardiography Predicts Symptom Severity in Chronic Fatigue Syndrome (PMID:12920435) showed that patients with CFS had significantly low cardiac output, both when supine and when standing. This finding was picked up by Dr. Paul Cheney and became a cornerstone of his influential 2006 recorded conversation, “The Heart of the Matter,” easily accessible on the net, and well worth reading. I wrote about this in a review of recent research for this magazine a while back, so will offer only the briefest of summaries here. His view is that we are all in diastolic heart failure, a view that he has maintained and elaborated up to the present; I offer here a summary of his present thinking, based upon his 2009 DVDs, “CFS: Is Oxygen the Problem?” These are still available

very cheaply from [www.dfwcfd.org](http://www.dfwcfd.org), and well worth watching, though sometimes tough to follow. Cheney refers to an essay based on Mayo Clinic statistics (Owan TE, The Epidemiology of Diastolic Heart Failure, PMID:16003647) that shows that the prevalence of diastolic heart failure, or heart failure with preserved ejection fraction, has been rising steadily since the late 1980s, without a clearly agreed upon cause; the rise in CFS may be partly responsible, while another possibility is the wide use of statins, which damage mitochondria and thus, probably, diastolic function. Cheney explains that the diastolic or filling part of the heart’s pumping action actually takes more metabolic energy than the systolic or squeezing part of the cycle, which he likens to the opening of the Hoover dam gates to release the backed up water in order to generate electrical power. In the diastolic phase, the myocytes, the energy producing cells of the heart, have to pump out calcium through the ion channels in order to prepare for the next squeeze that pumps blood throughout the body.

Anything that damages or hinders the functioning of mitochondria will be reflected in the performance of the heart, since it is densely packed with mitochondria—necessarily, since mitochondria are the prime sources of all of the body’s energy, and the heart is at the centre of the production of energy. If the heart cannot refill with blood preparatory to the next systolic squeeze, we die. There is some research showing that cardiovascular dysfunction in CFS is associated with small heart size (K. Miwa, PMID:19881233), and that the size of the left ventricle improves “during the remission phase,” suggesting that this is not necessarily a permanent state, but is a response to a dysfunctional dynamic condition. In my own case, the diameter of the left ventricle at diastole has diminished significantly over the last years, but I hope that it may increase if and when my condition improves.

Miwa speculates that the symptoms are due partly to diminished venous blood return. There is good evidence in CFS for venous blood pooling in the legs and even more the gut, for which G-suits are a possible solution. A few brave

women posting on the Phoenix Rising website have resorted to this tactic, with good humour and apparently good results! Compression pantyhose represent a more acceptable path, and compression socks help maybe a tiny bit in the process by which blood is returned to the heart.

Such venous pooling is associated with the orthostatic intolerance so many of us have. One can perform a simple home made version of a tilt table test to check one's status in relation to POTS (Postural Orthostatic Tachycardia Syndrome) and OI by going to <http://www.oiresource.com/oitest.htm> and following the instructions there, if you have a blood pressure monitor at home; this will give you some idea of where you fit into the spectrum.

Orthostatic intolerance is also associated with the autonomic dysfunction that comes with CFS. Blood pressure regulation also is often disturbed; it is often low, but sometimes high pressure spikes arise, suggesting attempts at regulating blood perfusion to key areas in compensation for low circulating volume. Cheney notes that as the volume of circulating blood drops, a variety of body systems develop problems, in a sacrificial sequence designed to protect the most valuable at the cost of the less. Skin circulation drops, leading to problems with temperature regulation; then skeletal muscle, leading to fatigue and exercise intolerance; then the liver and gut, bringing malabsorption and food intolerance; then the brain is rationed leading to brain fog, etc. All of this before things get really serious, with kidney and lung function compromised and finally the heart itself.

One surprising symptom of the heart's desperate attempt to keep up the production of energy despite difficulties is Cheney's finding that a very high percentage of us have Foramen Ovale Patent (FOP), literally a hole in our hearts between the left and right atria. This seems to be caused by the heart's high pressure squeeze to pump out the reduced volume of blood that inadequately fills the left ventricle in diastolic dysfunction; the squeeze raises the pressure between the atria, the upper chambers of the heart, enough to blow open the more or less

sealed flap that was necessarily left open while we were in the womb so that blood could bypass the lungs, which obviously did not work then; normally the flap closes shortly after birth, though some 25% of the general population have FOP. It does not usually result in serious consequences, and no surgical remedy is recommended by Cheney, though he does advise it may give rise to migraines, and warns against high altitudes, which may exacerbate any symptoms.

At the root of all these problems lies the production of energy, and here Cheney refers to the work of Marin Pall, who has proposed that mitochondrial function has been compromised by several mechanisms that produce an excess of peroxynitrate and other noxious substances. This theme has recently been taken up by Maes and Twisk (Why ME/CFS may kill you: disorders in the inflammatory and oxidative and nitrosative stress (IO & NS) pathways may explain cardiovascular disorders in ME/ CFS, PMID:20038921). They support the thesis of Jason's essay reporting the early death of patients with CFS from heart failure, and attribute this to chronic low grade inflammation with extended production of nuclear factor kappa B and COX-2 and increased levels of tumour necrosis factor alpha, increased peroxide levels and oxidative damage, decreased levels of specific antioxidants, i.e. coenzyme Q10, zinc and dehydroepiandrosterone-sulphate, bacterial translocation as a result of leaky gut, decreased omega-3 and increased omega-6 and saturated fatty acid levels, and the presence of viral and bacterial infections and psychological stressors. In this view, the heart and vascular system simply participate in the general situation created by a systemic malfunction at the cellular level.

So where does this leave us? CFS is a multi-system disease with multitudes of possible and probable symptoms. It is the result of systemic problems that are not focused in one organ but operate at the most general level: in the mitochondria that are present in virtually all cells of the body, in the digestive processes that feed all the other bodily processes, in the heart and vascular system that distributes that food plus

oxygen to every organ of the body, including of course the brain. So at the heart of this complex distribution system is the heart itself. There is no way that it could be excluded from the general course, and in turn it affects the function of every other organ of the body. It is indeed as Cheney says “The Heart of the Matter.”

We may well test out more or less OK on an echocardiogram, and may even do reasonably on a treadmill test, but there are still problems lurking in our hearts, such as the diastolic dysfunction Cheney reports on so well, that is however likely to be overlooked or underestimated by most cardiologists. The second most likely symptom is the sense of discomfort around the mid section caused by the pooling of venous blood, splanchnic pooling. If we had access to impedance cardiography, the situation would become clearer to cardiologists; I proposed it to my cardiologist, but have not had a reply. Cardiologists do not have an answer for diastolic dysfunction and so do not like giving that diagnosis; they are for the most part ignorant of the supplements that offer a little help, such as Q10 and acetyl L-carnitine, though they have been written about by Dr. Stephen Sinclair, a legitimate cardiologist.

If we are unlucky enough to get atherosclerosis, cardiologists will want to help, though none of those I have met have proposed the obvious—the strict dietary control outlined by Drs. Dean Ornish and Caldwell Esselstyn. They will propose statins, which do some damage to mitochondria and are generally not recommended by specialists in CFS. They will also propose meds to control high blood pressure, if we are among the small but not insignificant percentage of CFS patients who have that as a symptom.

So what to do? Some doctors attack the viruses that seem to be one root of all these problems; Cheney likes Artesunate, which has demonstrated some activity against HIV, as well as good activity against the herpes family of viruses, and may well have some efficacy against XMRV, though that has yet to be demonstrated. Cheney does report that Artesunate has been able to reverse, I assume partially, diastolic

dysfunction and that is exciting. I assume that is because it has dealt with the viruses that were at the root of the metabolic dysfunction causing the diastolic problem. Other doctors use more familiar antivirals, most of which can have significant side effects; I do not know how available they are in BC.

One can follow the path outlined by Martin Pall in his book or on his website (<http://sprident.com/martin-pall/cfs.htm>), using supplements designed to reduce the inflammatory processes that can damage the heart and vascular system among others. One can buy into the related theory of Rich van Konynenburg and try to restore what may be a broken methylation cycle. I dealt with this option in my earlier essay.

Or one can be a little more radical, and go with Cheney along the path of his latest exploration, stem cell therapy. The least radical way to pursue this channel is to buy some Stem-Kine, described as a stem cell mobilizer, a blend of substances shown to speed the natural supply of one’s own stem cells into the blood stream. These are mostly endothelial progenitor cells, whose function is to improve and repair your circulatory system, including of course your heart. At [www.stem-kine.com](http://www.stem-kine.com) you will find information on this, and typing “stem-kine” into PubMed will take you to two essays supporting the claims made on the website. The company sells capsules that contain, not stem cells, but a proprietary mix of Vit D, ellagic acid, beta glucans, and other substances all fermented together, that have been shown in those small studies to increase the number of stem cells circulating in the blood. I will only say that I have been taking them for a couple of months, and think I notice a small improvement.

Cheney has gone further, and has sent patients to a clinic in Panama, run by the man at the head of the company making Stem-Kine; results have ranged from modest to very good. A few brave souls have now gone directly to these clinics on their own, and are reporting results on the stem cell thread in the Phoenix Rising Forums. Stem cell therapy clearly works, and is here to stay, though still experimental and changing and developing fast. Some American

clinics are now getting into the act, while clinics in Germany, India, China and elsewhere have been busy for some years, and researchers at the University of Montréal have very recently used stem cells garnered from a patient's own body, injected them directly into his heart to heal severe cardiomyopathy as he was otherwise destined for transplant or death.

Maybe we will eventually become like the newts described in Robert Becker's fascinating *The Body Electric*, which can re-grow half of a heart overnight. For the time being, however, we will have to be content with slower progress. I will give a fuller account of stem cell therapy in a future report.



## UARS: The Hidden Sleep Condition

by Dr Steven Park

*(Sourced from <http://doctorstevenpark.com/uarsthehiddensleepcondition>)*

*Dr. Park is an otolaryngologist who practices integrative medicine and surgery in New York city and has a very informative website.)*

You've gained some weight over the years and you're just not sleeping well. Your husband says you've begun snoring. You know that your father has obstructive sleep apnea and is doing well with CPAP. You mention this to your doctor and she orders a sleep study. The sleep study comes back completely normal. Now what?

### **The Real Reason for Your Chronic Fatigue**

Before you begin searching for other reasons for your chronic fatigue, don't rule out a sleep-breathing problem too quickly, even if you don't have obstructive sleep apnea. In fact, a sleep-breathing problem can cause if not aggravate conditions such as hypothyroidism, chronic fatigue syndrome, depression, insomnia, and even irritable bowel syndrome.

Sleep doctors have defined obstructive sleep apnea as having at least 5 apneas or hypopneas every hour on average. An apnea means you stop

breathing completely for 10 seconds or longer. Hypopneas are similar 10 second or longer pauses but with restricted airflow. But what happens if you stop breathing 25 times every hour but each episode lasts only a few seconds?

In the early 1990s, Dr. Christian Guilleminault of Stanford University looked at young, thin men and women who were tired all the time, no matter how long they slept. These people were found not to have obstructive sleep apnea after undergoing formal sleep studies. However when they placed thin pressure catheters in their chest and throat, they found that they had frequent episodes of partial obstruction that led to subtle, but significant limitation of nasal airflow, along with very negative vacuum pressures in the throat. Most of these minor episodes were not apneas or hypopneas, but still lead to an arousal—from deep to light sleep. What was happening were multiple partial obstructions and arousals that were not severe enough to be called apneas or hypopneas, but enough to wreak havoc on deep sleep quality.

It's been shown that even very subtle levels of restricted breathing can lead to deep brain stimulation and arousals that prevents your ability to stay in deep sleep. These reflex signals to the brain can be so weak that it doesn't even reach the outer layers of the brain where standard scalp electrodes can pick up these disturbances.

### **Blame It On Your Parents (And Your Jaws)**

The fundamental problem in UARS is due to smaller upper airway anatomy, caused by having smaller jaws and dental crowding. The smaller the space behind the tongue, the more likely you'll obstruct while breathing when on your back (due to gravity, the tongue can fall back), and when in deeper levels of sleep (when your muscles relax). This is why most people with UARS can't, or prefer not to sleep on their backs. The problem is that you can still have breathing problems despite sleeping on your side or stomach, just not as bad as being on your back.

Lack of sleep and especially lack of deep sleep has been found to cause a whole host of physiologic changes. In general this happens due to chronic over-stimulation of your sympathetic

nervous system. This is the fight-or-flight half of your involuntary nervous system. Since your body thinks it's under attack, it heightens your nervous system, making you on guard, edgy, hypersensitive or over-reactive to normal situations. This also leads to diversion of blood flow, energy and resources away from less essential body parts and organs, such as your digestive system, reproductive organs, skin, hands, feet, and other "end organs."

Due to this "hypersensitivity," the nose and sinuses can be overly sensitive, reacting to stimulants such as weather changes, chemicals, scents, and even allergies. Chronic stress that results from sleep deprivation also can heighten your immune system. Is it Hormones or Your Breathing?

A number of other studies point out that UARS patients are more prone to have cold hands or feet, hypothyroidism, irritable bowel syndrome, depression, chronic fatigue, and various other "somatic" syndromes. I see this all the time in my practice. In fact, a recent study even showed that chronic long-term sleep deprivation caused significant lowering of the TSH and T4 levels, with women being much more susceptible to this effect compared with men.

With time, as people age, and especially as they gain weight, most people will progress into true obstructive sleep apnea. You'll find that most younger, thinner people with UARS will have one or two parents with significant obstructive sleep apnea.

Now that you're convinced that you may have this condition, what can you do about it? For the most part, it's treated just like obstructive sleep apnea. You should start with all the conservative options first, such as weight loss (if you're overweight), diet, exercise, improving your nasal breathing, and not eating late. If these options don't work, then all the formal options for treating obstructive sleep apnea are possible including CPAP, oral appliances, and even surgery.

Unfortunately, if you don't officially have a sleep apnea diagnosis based on a sleep study,

then insurances generally won't cover any of the treatments. The irony is that our health care system won't treat or prevent diseases in the early stages, and would rather wait until it's much more severe before covering for medical services.

If you think you may have upper airway resistance syndrome, you may be disappointed to find that the medical community in general will not be responsive to your queries. With a few exceptions, many sleep doctors are not convinced that UARS is even a legitimate condition, and would rather lump it into the spectrum of snoring to obstructive sleep apnea. Time after time, whenever I see patients who are told they don't have obstructive sleep apnea and I treat the upper airway narrowing and inflammation, patients almost always feel better. Your best option is to continue to educate yourself and be persistent. Your first priority should be to be able to breathe better so that you can sleep better.



## Health on the Line

Dr. Alison Bested was a guest on "On the Line", a live TV phone-in show on CTS-TV August 23, 2010 addressing the problems patients with ME/CFS, FM and MCS have with access to medical care. Dr Bested also took questions from the public. Unfortunately this program is only available live here in Victoria if you are connected to satellite providers Bell and Star Choice. So we were unable to call in questions. However you can view recordings of all the "On The Line" programs by using this link <http://ctstv.com/ontario/tuningin.php> First select "Online Player" from the tabs at the top of the page and then the program "On The Line" from the list on the left. Below the video window is a list of pre-recorded shows. Select "ME/FM/MCS Problems with Access to Medical Care" to view the video of this program. Also scroll through some of the other topics previously recorded. Some looked interesting: such as; "Hormonal Imbalance & Adrenal Fatigue" broadcasted on July 26th.

## Indian Vegetarian Curried Fried Rice

Serves: 4

Prep Time: 17 minutes

Cook Time: 4 minutes



### Ingredients:

3 tablespoons peanut or vegetable oil, divided

1/2 cup chopped onion

1 tablespoon minced ginger

1 cup chopped mushrooms

1 cup julienne green, red and yellow peppers

1 cup green beans, cut into 3/4-inch pieces

1/2 cup 1/4-inch diced carrots

1 tablespoon curry powder

3 cups cooked brown rice

1 cup canned chickpeas, rinsed and drained

1 cup halved cherry tomatoes

2 tablespoons low-sodium soy sauce

1/8 teaspoon freshly ground black pepper

### Directions:

Heat a 14-inch flat-bottom wok or 12-inch skillet over high.

Swirl in 1 tablespoon oil, add onion and ginger, and stir-fry for 10 seconds or until ginger is fragrant.

Add green beans and carrots; using a metal spatula, stir-fry for 1 minute or until beans are bright green.

Add mushrooms, and peppers.

Stir in curry powder and stir-fry for 5 seconds or until fragrant.

Swirl in remaining oil, and then add rice. Stir-fry for 1 minute, breaking up rice with a spatula until it's well combined with vegetables.

Add chickpeas, tomatoes, soy sauce, and pepper and stir-fry for 1 minute or until mixture is heated through.

Divide among 4 bowls and serve.

### Options:

Use all green peppers. Add in squeezed, drained cubes of tofu after the onion, and ginger sauteing for an extra minute.

Add in bean sprouts at the very end and stir-fry for another 1/2 minute or so...

## GREEK PANZANELLA SALAD

Serves 6

Extra Virgin Olive Oil

6 cups (1-inch cubes) French or Italian bread, fresh or day old

Kosher salt

1 hothouse cucumber (unpeeled)

1 red pepper, large-diced

1 yellow pepper, large-diced

1 pint cherry or grape tomatoes, halved

1/2 small red onion, sliced in half-rounds

1/2 pound feta cheese, cubed

1/2 cup Calamata olives, pitted

### FOR THE VINAIGRETTE:

2 cloves garlic, minced

1 teaspoon dried oregano

1/2 teaspoon Dijon mustard

1/4 cup good red wine vinegar

1/2 cup good olive oil

1/2 teaspoon freshly ground black pepper

1. Heat 3 tablespoons of olive oil in a large sauté pan. Add the bread and sprinkle with salt; cook over low to medium heat, tossing frequently, for 5 to 10 minutes, until nicely browned.

2. Meanwhile, cut the cucumber in half lengthwise and scoop out the seeds with a small spoon. Discard the seeds and slice the cucumber 1/4 inch thick and place in a large bowl. Add the red pepper, yellow pepper, tomatoes, and red onion.

3. Next, make the vinaigrette: Place the garlic, oregano, mustard, and vinegar in a small bowl and whisk together. Whisking constantly, slowly add the olive oil to make an emulsion. Add 1 teaspoon of salt and the pepper and taste for seasoning.

4. Add the feta, olives, and cooked bread cubes to the bowl with the salad and add the vinaigrette and toss lightly. Set aside for 30 minutes for the flavors to blend. Serve at room temperature.



# You Must Be Well By Now

*Are you tired of hearing that?*

*Lydia E. Neilson's sets the record straight on ME/CFS and exercise.*

Dear Friends:

A person who I have been communicating with suggested I forward my reply to her to others in the support network.....in the hope it will help someone going through something similar.

Lydia

Dear Friend:

First of all, I want you to understand that your reaction to exercise is normal for people who have ME/CFS. Until you are in the recovery mode, exercising will set you back. Even in recovery mode, you must be very careful. If you want to do any kind of exercise, keep it to careful stretches so that your body stays limber and just do plain walking. If it means only walking in your house, then do just that. I am sending you what happens to people who have ME/CFS and they exercise before they are ready to do so:

## RESPONSE TO EXERCISE

### Healthy People:

A sense of wellbeing

It invigorates them and acts as an anti-depressant effect

Resting heart rate is normal

Heart rate is at maximum workload and elevated

They get a maximum oxygen uptake and elevated

Age-predicted target heart rate can be achieved

Heart functioning is increased

Cerebral blood flow increased

Cerebral oxygen increased

Body temperature increased

Respiration increased

Cognitive processing is normal or more alert

Recovery period is short

Oxygen delivery to the muscles is increased

Gait kinematics is normal

### ME/CFS People

Feeling of malaise, fatigue and worsening of

symptoms

Resting heart rate is elevated

Reduced heart rate

Oxygen uptake approximately half of sedentary controls

Age-predicted target heart rate cannot be achieved

Heart functioning is sub-optimal level

Cerebral blood flow is decreased

Cerebral oxygen is decreased

Body temperature is decreased

Respiration, breathing irregularities occur i.e.

shortness of breath and irregular breathing

Cognitive processing is impaired

Recovery period at least 24 hours but can last days or even weeks

Oxygen delivery to the heart is impaired

Gait abnormalities

I hope that helps you to realize that what is happening to you is for a reason and why you feel worse after exercise.

Your mom's reaction to your illness is lack of understanding what a chronic illness is. She is not any different from most people who have not been exposed to chronic illness before. It is hard to believe how anyone can be ill for so long without getting better. I doubt very much that at one time you would think your illness could go on for so long.

When an illness is considered chronic, it means that it goes on for a long time and can wax and wane. Some days are better than others. That is with all chronic illness and ME/CFS is no exception. You have to get over the fact that you must have done something wrong or because you are not doing the right things and if you did you would be better by now. To get better you need treatment that is geared towards the illness. In our case, the treatment treats some of the symptoms. The only part you can influence is the stress and pace as much as you can. It is important that you do not go to the point of exhaustion and always stop much before you get there. That accomplishes two things. One, if you stop before you reach the breaking point, you make the decision to stop instead of the illness stopping

you. In addition, your recovery rate is better if you rest before you exhaust yourself.

How other people react to your illness is something you cannot control, just like you can't control what people think of you. You may have changed because of illness as to what you can do but you are not the illness and are still you. You need not be ashamed because others feel you have been ill long enough and it is time to shape up. It is hard for anyone to believe that in this day and age there is not something that a doctor can give you that will make you recover. We think that once we are diagnosed, everything will be fine and it is just a matter of time before we are as good as new. That is not reality.

From this day forward, hold your head up high and be yourself. Stop indirectly apologizing that you are not the way people think you should be. You are equal to everyone else and those who do not treat you with respect and caring, and make you feel bad about yourself, keep your distance from them. Go on with your life as best you can and know that the National ME/FM Action Network will keep working for you.

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## **I Still Survive**

*Submitted by member with permission;  
originally from a magazine blog.*

In the words of E.R. Burroughs John Carter of Mars: *"I Still Survive!!"*

That small act of defiance to tweak the nose of my illness is a sort of anthem of mine. I wish that I could shout it from the top of a high mountain that I have climbed on my own two feet. Instead I whisper it in the night to the monster who steals my sleep. I chant it over and over in my head

while I struggle to walk across a room or across a parking lot. I say it with a sigh of satisfaction after a busy day when I push myself to my limits to enjoy every moment. "I still survive!!"

Some days it is very difficult to utter that phrase. Those days I just want to give up, days when I just want the pain to stop. Days when a fog of pain is all I know. Yet, "I still survive!!"

Having good friends helps to give me the strength and the want to hang on, to reply to the prods and jibes of the D\*mn Disease with: "I still survive!!"

Life is lived one day at a time, because every day is different for me. It is a difficult life, and 2010 is a milestone year for me. I have been "officially" severely disabled and practically housebound since 1990. Twenty years waiting in the hope that a cure will come, that maybe treatments will come that will at least free others from my fate. I would be happy if I could trade mostly bedridden for the practically housebound of twenty years ago. Any day that brings a smile and a bit of pleasure counts as a good day and that makes my good days more frequent than my bad ones and hence "I still survive!!"

I have traded hope in a cure for hope in more tangible things. I'm not advising anyone else to give up hoping for medical advances, but I will let them hold that hope for me. I cannot emotionally deal with hopes trashed any longer. Instead I put my hope into smaller things, things that allow me to take my life from that distant day when there is a medical miracle and place it in my own hands. Hope for a good day to celebrate a birthday. Hope of getting strong enough to board a plane and go and visit a friend in Florida, on the opposite side of North America from my home on Vancouver Island. Hope that I will find a dress that fits and looks good on me. Hope that I can sit in my garden and enjoy a few hours of peace and beauty. Small hopes, larger hopes. Hopes that I will someday cross things off of my "Bucket List" as done. As I do these things I smile and say with pleasure and pride: "I still survive!!"

It is a simple statement, but a profound one. This is my reply to those who ask me how I am doing: I Still Survive!!

# XMRV, MLV... the alphabet soup thickens

By Chris Heppner

Last December I wrote a short piece about the Whittemore Peterson Institute and the finding of a recently discovered retrovirus, named XMRV, in, initially, 67 % of patients with CFS—subsequent testing brought that up to 95%—and 3.8 % of healthy controls. There followed some promising sequels, including Canada's decision, clearly taken because they took the threat of viral infection seriously, to ban CFS patients from donating blood; several other countries followed suit, though the US produced a rather wishy-washy statement.

Then followed a discouraging series of negative studies, all deeply flawed in either methodology or patient selection criteria—that damned Centre for Disease Control empirical stuff again—which includes a large percentage of people with depression but not CFS, and excludes most of those seriously ill with ME/CFS. Judy Mikovits, the lead researcher for the WPI, expressed confidence in her work, which is ongoing. Then some months ago we were alerted to a forthcoming major study from the FDA and NIH that reportedly found the virus in a high % of patients with CFS, and in a significant % of healthy controls.

In the last week, there have been a series of important and interrelated events that move things much further, and, I believe, mark the turning of a big corner—or, if the corner was really turned last October, as I believe, the first major milestones on the new road opened up. I know that many of you old hands have been through this kind of thing before, and have become tired of being disappointed as well as sick—a bad combination. But read on, and remember that from the early days of Peterson and Cheney in the early 80s retrovirals were suspected, because of the nature of the symptoms; the De Freitas episode in 1991 was aborted by the CDC, but doubts still linger as to just what retrovirus she found.

The confirming paper from the FDA and

NIH was made public on August 23 (it had been held up because it disagreed with another negative paper from the CDC, which strangely was published the day after we were told that both papers were to be delayed.) This new paper (available free on the net at [www.pnas.org/cgi/doi/10.1073/pnas.1006901107](http://www.pnas.org/cgi/doi/10.1073/pnas.1006901107)) shows that not just one, but a whole family of mouse derived retroviruses has invaded us; you will be hearing more about MLVs and XMRVs and other initials as this story unfolds—it is by no means over. Harvey Alter, the discoverer of the Hepatitis C virus, and a big name in virology, is a lead researcher, and carries real weight. This team discovered that 86% of well-categorized CFS patients carried one or more of these beastly little things, and 6.8% of healthy controls—the blood bank people are disturbed, and there will be more meetings. Alter and his team are quite clear that this supports the central argument by Lombardi et al. [the Mikovits team] that MLV related viruses are associated with CFS and are present in some blood donors. They are also clear that they have not proved causality, but the ratio of percentages between CFS and controls is a strong argument. They also state that the possibility that these agents might be blood-transmitted and pathogenic in blood recipients warrants extensive research investigations of appropriately linked donor-recipient cohorts. The fat is in the fire.

A new serological test for XMRV and related MLVs was announced the next day by the VIP that licenses it from the WPI and is now attached to it; information on this can be obtained from <http://vipdx.com>. It is, I believe, around \$300.

A word of explanation of those acronyms: XMRV stands for Xenotropic Mouse Leukemia Virus Related Virus, which means that it is a virus related to a family of mouse derived viruses that cause leukemia in them; “xenotropic” means that this variant has mutated, and now cannot infect mice, but can infect other species—including, unfortunately, humans. MLVs are Mouse Leukemia Viruses that come in several types. So XMRVs—there are by now several subspecies identified—are a variant of the large group of already known MLVs. The Alter paper

does not in any way contradict the basic findings of the WPI paper, though it does complicate the picture. In response, the WPI has proposed a new name, HGRV, for Human Gamma Retro Viruses, causing HGRAD, HGR associated diseases. This may or may not play out—the WPI earlier proposed the term XAND for all diseases that proved to be caused by XMRV, but that seems to have fallen by the wayside; the future of the latest proposal is still unclear.

Doubtless further refinements of testing will follow, but for anyone seeking evidence with which to make the case for disability a positive result from the VIP test should carry some weight. The timing of the announcement of the availability of the test was no doubt deliberate, since it includes those MLVs that were only made public as having been found in humans on Aug 23. Serological means that it tests for antibodies, not the viruses themselves, which would demand more complicated and therefore expensive work. A serological test should be good evidence, though it has been suggested that in some cases of long-standing immune dysfunction, a negative response may mean only that the immune system has given up the fight and accepted the continued presence of the pathogen. A negative serology result could be followed by a culture test at increased cost to make quite sure, but a positive result should suffice.

On August 25 it is noticed that the CDC has begun a search for “Chief, [of] Chronic Viral Diseases Branch,” which includes primary responsibility for the direction and substance of the CFS research program. I do not know if the timing is coincidental or not, but an optimistic reading is that someone in charge has seen the writing on the wall, and has decided that 25 years of mayhem and misrule from this quarter must be brought to an end. We can realistically hope.

Finally, some people have already been trying antiretrovirals against their proved XMRV, and some are reporting excellent results; one such is a doctor, who has been using them on herself and her daughter (both seriously sick with CFS) for some six months now under a doctor’s care; you can read her latest blog reporting

major improvement at <http://treatingxmriv.blogspot.com>. Several antiretrovirals have shown activity against XMRV in the lab, and some commentators have stated that one of the best ways of determining causality is to try a treatment; if patients get better it strongly implies that a target has been reached successfully. Others however advise waiting for more research and the possibility of more benevolent treatments in the future.

What does all this mean? Well, you could order that test, and use it either to bolster a request for disability, or to try to persuade a cooperative doctor to order antiretrovirals. This last should not be undertaken lightly, of course; most of them can carry serious side effects, and there may prove to be other less damaging treatments down the road. There is still much to be learned about this family of retroviruses, and doubtless not all CFS sufferers carry these viruses, though it certainly looks as if most do.

At the least we are now seeing real movement and progress after 25 years of stasis. Things are happening, and happening fast. There are other ongoing studies yet to report, including a big one at Cornell that will try to trace out the paths of possible pathology between these viruses and disease symptoms. The next year should prove exciting for all of us. Best wishes for your better health, Chris



PHOTO BY KEN BEATTIE

## Alena's Tips for a Happy Life



*(a slightly altered version of a list included in one of the issues of InforME, and with a new title. Thank-you to whoever came up with the original list.)*

1. My purpose is to \_\_\_\_\_.
2. Clear clutter from your house, your car, your desk and let new and flowing energy into your life & give those “discards” a new purpose elsewhere.
3. Get rid of everything that isn't useful, beautiful or joyful. Share the things that are.
4. Don't waste precious energy on gossip, energy vampires, issues of the past, negative thoughts or things you can't control. Instead, invest energy in the positive present moment. Here. Now.
5. Whatever a situation is, it will change. Make the change a helpful one.
6. What other people think of you is none of your business.
7. Don't take yourself so seriously. No one else does!
8. Everyone is in charge of happiness.
9. Forgive everyone for everything.
10. Be thankful.

I just posted this on Facebook and I really wanted to share it with the local community, and any others that you are in touch with. Also, let people know that I would LOVE for them to add me as a friend on Facebook at [www.facebook.com/alenaw](http://www.facebook.com/alenaw) to join together in the healing and love.

My CFS, FM, and MCS have 99.99% disappeared because of what I only just realized, and engaging in this discussion, whether with me or anyone, will make a huge difference. We all matter, and we are all worthy of everything we have EVER been denied, and I am creating this with everyone who wants to join on Facebook, and in every conversation I have.

This said, feel free to be in touch, 250-995-1313, and I will connect with anyone who calls, if I'm not already doing that with another.

Love, Alena

“The best way to take care of me  
is to take care of we.”

## DNR System offered in Victoria

Annie Hopper, CEO and founder of the DNR System is coming to Victoria. A few of our members have taken this 3-day course and they have reported a mix of results. To see some testimonials from folks who have recovered, including MEVA member Alena's, go to [www.dnrssystem.com/testimonials.html](http://www.dnrssystem.com/testimonials.html). Also a friend of a member, Gayle who had MCS, has a video testimonial on this site. But we have also had reports from people who have shelled out the money, taken the course and have **not** become significantly better.

The **Dynamic Neural Retraining System** is a revolutionary neuro-rehabilitation approach that helps restore normal limbic function in the brain. Based on the premise, and some research, that damage to the limbic system in the brain is often at the very root of Multiple Chemical Sensitivities (MCS), Chronic Fatigue Syndrome, (CFS) Fibromyalgia or Anxiety Disorders and therefore you can recover through neuroplasticity – the brain's ability to change and heal itself.

If you believe that you can truly afford this course knowing that it is possible that it may “Rewire Your Brain, Transform Your Health and Reclaim Your Life” or it may **not**, and knowing that although many people get improvements during the course it still requires a deep commitment for 6 months of staying with the practice to re-wire your brain. Then you will need to mark the following date on your calendar and act now because spots are filling up fast. If you go please let MEVA know so we can share more results with others.

### Dynamic Neural Retraining System

**October 22 - 24, 2010**

At University Canada West

950 Kings Road, Victoria, BC

Price: \$995 + HST.

Early Sign-Up Discount (until Sept 10):

\$895 + HST.

Each program is limited to 10 participants. To register: fill out Steps 1a) and b) on the link below and return to Annie. [www.dnrssystem.com/forms](http://www.dnrssystem.com/forms). She will contact you to book a telephone interview to determine your candidacy. On the day of the interview, if accepted, full payment will be required to reserve your space. For more information about The Dynamic Neural Retraining System:

<http://www.dnrssystem.com>

# ***Up Coming Events!***

## **Thanks Giving Turkey**

At 1908 Stanley Ave. ~ October 6th at 2:00 pm.



We will be serving turkey with all the fixings.

You can bring a desert if you like.

Please join us for this special time  
as we celebrate all that we have to be thankful for.  
Energy not required.



## **M.E.V.A Christmas**

At 1908 Stanley Ave. ~ December 8th at 2:00 pm

Come share your goodies, your stories  
and maybe a greeting card to cheer one another.  
Bring a friend and sit back and enjoy!



If you want any information on events please contact us at 370-2884 or  
e-mail us at [me.victoria@shaw.ca](mailto:me.victoria@shaw.ca)



PHOTO BY KEN BEATTIE