NATIONAL ME/FM ACTION NETWORK

Quest
Newsletter

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In this issue we are featuring the voices of people whose lives have been impacted by ME/CFS and FM. We dedicate this issue to all who are affected by these illnesses.

Dear Friends:

1. Unheard Voices: My Story;
2. Unheard Voices: The Forgotten; and
3. Between You & M.E.- Part I Lydia's Story
4. Between You & M.E.- Part II The Journey

I am working on the above stories and have published everything on our website that has been edited. As some of you may not be familiar with these projects, I thought I would highlight what it is all about.

1. Many people who are ill have never had an opportunity to voice how they feel and what they have experienced. Through these trials and tribulations, you have learned what works and doesn't work for you. If you are like most of us, these trials were fought on your own and rather than just bury them, here is an opportunity to tell your story. With relating your story, it also brings healing and lets you close that chapter to the past.

   Some of you have written me expressing that they didn't feel their story was different from others and therefore felt nothing they would say would contribute to others. That could not be further from the truth. Someone out there feels like you do and seeing your story might give them the courage to go on. Never underestimate your value. We may have the same illness but how it reacts to you may be completely different from someone else. It is your uniqueness that someone else might recognize and relate to.

2. There are other silent voices and stories that need to be told. Those are the people who care or live with someone who is ill. They are familiar with people asking them about the sick individual but feel completely ignored about what they themselves may be going through. In a sense, they are forgotten. Very few will discuss their feelings as they are not ill. How do they cope with what has changed in their lives because of the ill person?

   As you know, those who are ill and those who live with them seldom will let each other know how they feel. By seeing their stories, we will have an opportunity to understand both sides of the story and thereby make changes to our lives for the benefit of everyone.

3. I also wrote my story which is in two parts. The first part is about how I got ill and what I experienced and the second part is about what I have learned over the years, both as myself and as an activist. By telling you the mistakes I've made and what I learned from them and how, through those mistakes, I was able to start making my life meaningful again. By finding meaning in life, I realized that my fulfillment lies in helping others. We are all on this earth for a reason, finding your reason brings peace in your heart. Having a talent, gave us a job but now you need to discover what is your gift.

Please let me hear from you and send me your story. There is no minimum or maximum length, no deadline or age limit. I have included some stories, in no particular order or importance. As always, your story is handled with the utmost confidentiality and your identity will not be disclosed. For those who do not use the internet and want their story told, all you need to do is send it to me and I will include it in Unheard Voices: My Story or Unheard Voices: The Forgotten.

Remember that you can send your story by mail, fax, or email. Before publishing, I will check with you for your approval of your story for publishing. I look forward to hearing from you.

Email me at: lydia@mefmaction.com

Lydia

Contents

“Tom’s” Story

This is a comforting concept to write our stories, in a way - because having ME means being misunderstood.

Just to keep it short, I was knocked out in a car accident at age 8. A few months later, I had muscle tremors, chronic fatigue, and other symptoms - like heart palpitations - that increased with age. I was misdiagnosed by each medical specialist that I visited. And being male, I have been told that I have a “woman’s disease.”

I finally got a diagnosis of fibromyalgia by various rheumatologists in 2000 which is over 20 years after my accident. The first rheumatologist tried to sell me a book he wrote (which he actually copied from a book called The Artist’s Way). Various health food stores always have some kind of elixir, vitamin supplement or product to sell to me (none of which do much -- I call these people “placebo pushers”).

Having ME turns a patient into a marketing target. Furthermore, I had an appointment with a naturopathic doctor, at a leading naturopathic college in Canada (in Don Mills, Ont.). After wasting my time and Dollars with a blood test and earnest check-up, I was told to “take a cold shower” by the supervising “doctor.”

I am too sick to work. I had a successful fashion design biz, doing my sales/promo/press in New York City. Now, I can barely get any understanding from my mates and family - because I don’t look sick.

Thus fibromyalgia is insidious and destructive both due to the physical harm, and the psychological.

ANON from Toronto

Paul's Story

I am a 59 year old male retired because of chronic 24-7 pain.

In my late 20's, I had some bladder problems and was told I had a small irritable bladder. This bothered me my entire life and a few years ago I was diagnosed with a bladder disease called Interstitial Cystitis. I found out later that this disease is related to Fibromyalgia. Also, at the same time I was told I had an enlarged prostrate.

I have worked in construction for 35 years, the last 15 owning my own company. In 1985 I started to have back problems and, as a result, I learned to live with chronic everyday lower back pain. Little did I know back then that if that's all I would ever have it would truly be a blessing.

Twenty years ago I started to notice my skin on my entire body was very sensitive, especially my legs and scalp. It actually hurt to comb my hair. Also I began to develop chronic joint and muscle pain. I am not one for going to a doctor but the pain began to affect my work so I have seen a few doctors over a period of years. They all told me the same thing. Your pain is job related and you need to quit. Obviously being married with young children this was not an option.

I pretty much gave up on doctors. I spent thousands on natural supplements and any kind of remedies found on the internet, all with zero positive results.

Because I was self employed, I could work around the pain at its worst. It worked for several years and when the pain became too much I asked my family doctor for some pain meds, the first time in my life. He gave me medications for Fibromyalgia which did not work for me. Finally I asked for some heav-duty pain medication just to make it through the day. I am now addicted to percoset and drink more than I should.

I have pain 24/7 in every square inch of my body. Luckily not always at the same time. As a result I am also suffering from depression. I have also been told I have gout, arthritis in my knee, neck and shoulders, chronic fatigue syndrome and irritable bowel syndrome. The latter two are quite common for people who suffer from Fibromyagia.

My worst symptom, is having a splitting headache non stop for over 2 years. If the pain in my head would go away, I think I could handle the rest.

I have distanced myself from family and friends, only because it's too hard to try to have to explain myself why I cant do anything. I do not feel sorry for myself but I have accepted my fate. It is the people who love me I feel sorry for. Nobody can understand what I'm going through unless they are in the same boat.

I come from a small city where doctors won't even say the word Fibromyagia. I really dont know if I have Fibromyalgia. All I know is the pain I feel every day of my life is real, at least to me. Having chronic pain may not be a death sentence as may cancer but anyone of you who suffer from this disease know your quality of life is zero!!!!!!!!!!!

Paul

Keli's Story

In 2006 someone filled my shoes with concrete and threw me into a tank of jelly – so I have to drag myself around slowly whilst constantly fighting oxygen as if it were made of lead.

I was a busy, active, healthy 31 year old with a demanding job and hectic social life. I was happy, healthy and loving life. Then in 2006, in what felt like a flash, I was ill and my life changed.

It started with what felt like constant trips to my Doctor, despite hardly ever needing to go before. I'd go each time with a long list of ailments and come away with random drugs each time – none of which ever worked. After a few weary months and a noticeable decline in my health, I started to self-diagnose using the internet and eventually went back to my Doctor to tell him I thought I had got thyroid issues. My own Doctor was on holiday and a new

Doctor was covering his work. She was literally a saint and saved me (physically and emotionally). It was this Doctor that went on to diagnose the ME and signed me off work for 3 months. She was so positive and seemed to know so much about ME that I felt finally believed and supported.

I look back at the point of being diagnosed and wonder how I managed to function. I was a zombie, in pain, in depression and desperate. The migraines, lock-jaw sensation, swollen glands, sickness and exhaustion were the main symptoms and almost paralysing.

A few years on and I still have ME. However, I am much 'better' than 2006 and do manage to work full time and look after my family. It isn't without challenge and there are sometimes tears of frustration. I am constantly tired, but don't give in and push and push through the fog. The migraines and sleep pattern have been made HUGELY better by a medication called 'amitriptyline' – which I started in 2008 at 175mg. This drug isn't without its own horrible side effects, so I have found with a good diet, sensible life style and good support network I have been able to reduce to a lower dose of 25mg

More recently I have become curious again as to other symptoms of ME as I found my old symptoms (Migraines, sickness, sore throat, lock jaw sensation, dizziness) are better than ever, but new ones have replaced them! I get terrible pains in my stomach where the liver is. I have recently had an ECG due to constant chest pains (ECG clear), bowel issues and terrible skin! Great!

All in all, I feel I manage amazingly considering the wall of issues I deal with each day, but it's not like I'm living a normal life and I often feel very bitter about the way I feel. But, I am petrified that if I stop for a moment and give in then I'll be swallowed into a black hole and the real me will be lost forever.

I would love to be in a financial position to give up working and go live in Turkey (my husband is Turkish) because I feel so much better without the stress of work. In Turkey I'd have lots of sunshine , organic food, fresh air, supportive network and a sedentary lifestyle built around your own pace. I once saw a documentary about 'locked in syndrome' and I can honestly say that having ME is like having a version of that! You are the same YOU, have the same dreams and desires but suddenly you can only do what a 120 year old can do and at a slower pace!

I live in hope that one day a cure will be found and it will be like someone can flick a switch and bring me back again. The real me, who I used to be and not the woman currently being controlled by ME who moans a lot and wants to scream HELP!

Keli

New Zealand

Janet's Story

I developed shingles in 2000 at the age of 56 and simply never recovered. It was not residual pain and numbness that was the major problem but continuing to feel very ill. At the time I could only describe it as flu-like yet it was not entirely like flu. Two years later I was diagnosed with CFS. Emotional, intellectual or physical activity all left me drained with severe frontal headaches and a racing heart. I felt well in the morning for one to two hours depending on how I slept and what I was doing. Each day I developed a numb tongue that was, and still is, a red flag telling me to slow down, calm down, stop and rest. I continue to feel less well as the day progresses.

My Family Doctor has been very supportive through this now fourteen year journey. He referred me to a neurologist, internist, naturopath, and acupuncturist - looking for a cause. All of my numerous tests were normal except high levels of lead and an acidic body. I tried acupuncture which made me worse, nutrients, and chelation therapy. The only thing that has helped me on a day to day basis is careful pacing along with reminding myself not to rush, to keep calm, and to plan regular periods of meditative rest.

Early on I was my own worst enemy because I did not believe that I would not get better. I told everyone that I had post shingles syndrome, leaving off the Chronic Fatigue Syndrome part. I had been a healthy high energy involved person in both my professional and personal life and felt there was a stigma to admitting that I had CFS. I was a college teacher and administrator and tried to continue working for five years. I tried a variety of part time roles with reduced workloads - all of which left me terribly ill. I realized finally, that I could not continue to work. I needed to get control of my health and my life.

Although I was believed and supported by my doctor, colleagues, my husband and children, I found the experience with my disability carrier very humiliating. It was easier for me simply to retire rather than try to prove how sick I was. Once I accepted the diagnosis, I discovered the National ME/FM Action Network which gave, and continues to give me so much support emotionally. I no longer feel alone. I feel fortunate that I have gained some resilience and some vitality. Occasionally, I have a day or two of feeling "normal" and I feel better, I believe, when I am in a sunny climate. Generally speaking, friends and acquaintances have difficulty understanding how ill I am because I do not look ill.

I now find peace and serenity in my paced lifestyle. Some days are better than others and I go with how I feel. Socializing wears me out so I limit and rest before and after, monitor the length even of phone conversations. Working at the computer and reading I do in very small bits. I love listening to classical music and that is healing. I have discovered the joys of bird watching, photography and painting which give me a sense of accomplishment. I walk every day and have learned exactly how far and at what pace so that I am not left drained. I save my energy for the most important people in my life - my husband, our children and their spouses.

In summary, the challenge of ME/CFS has prompted me to listen to my body more carefully, explore new opportunities for learning and growth, clarify priorities and appreciate more deeply all that I have.

Janet, RN

David's Story

As far back as high school, a residential school for the blind, I felt Lazy,-easily tired. I just figured I must be as lazy as some people implied. I often would fall asleep, and just doze off in class. I'd be up at 6:45 and in school by 8:00 but by 9:30 am, I'd get tired. Sometimes, in the afternoons after about 2:00 I'd get sleepy again.

I worked for a time as a medical transcriptionist. It's one of those jobs blind people seem to fall into. I noticed quite often that I'd suddenly become sleepy and exhausted. I had a neurological evaluation to rule out narcolepsy and sleep apnea. I had to resign from my transcriptionist position but I still thought that if I had a better sleep routine, things would improve and I would be able to work.

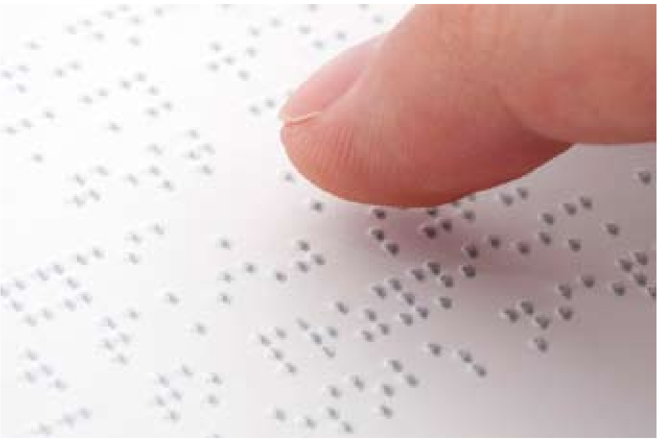
I tried another job - this time teaching Braille. It was a part-time job and I could just about manage it. However, the stress of a supervisor caused me to leave after two years.

I attended library school and was often sick, tired, and very stressed. It was not a supportive environment and even my guide dog suddenly died from cancer one evening while I was at the library attempting to find work in my field but I was unsuccessful.

In 2004, my brother, hearing some of my health complaints thought I had fibromyalgia syndrome - I exclaimed that was not possible as that is a women's disease. I saw a rheumatologist who tentatively diagnosed me, after the appropriate blood tests.

It's been a crazy game after that. The diagnosis is bizarre because it's more a ruling out of things, not a test that says, "Oh, you have FMS" though I understand there seems to be some sort of test in the U.K. for it.

Being totally blind, I certainly did not need this as well.



It’s exhausting and trying to handle it and blindness is ghastly!! Blind people are taught that we should be independent and that can be hard when you have a chronic health condition.

I did some online research and found newsletters put out from the FMS-community which outlines the ups and downs of this crazy syndrome. I have also have talked to the people in the ME/CFS community which was very helpful in coping techniques.

I live on a very limited income so don’t have the big amounts of money many practitioners require to treat FMS/CFS. I have tried water exercises and physical therapy. One physical therapist actually told me he didn’t think I had FMS because I did not meet the characteristics i.e. fat, female, forty-something, fatigued, and frustrated. I was not amused.

I have not ever found that physical therapy was really good. All the bending and pulling is very painful and I never seem to become any more flexible. I see a chiropractor but can’t say it’s helped greatly. I may consider an acupuncturist again, but am not sure about that. I also take anywhere from 45-65 pills or tablets or capsules a day when I can afford them. I think some help, I notice something when I’m not taking them. I have to label the many bottles in Braille so I know what is what. Some help would be nice but when I applied for a PCA, I was declined because I did not meet the criteria.

At present, I am just trying to live a meaningful life and not hate this syndrome for taking what I could expect to accomplish away from me. The complicated treatment protocols, the different strokes for different folks ideas, confuse me at times. The brain fog, the tiredness, the anxiety and jitteryness are soul-numbing.

In 2008, I suffered a severe fall from a third floor fire escape. I had become extremely disoriented while taking a 13-day prednisone taiper prescribed by a walk-in clinic for a dramatic rash I suddenly caught. I badly hurt my lower back, fractured my pelvis, and even hurt my tailbone. I am still in pain and think the FMS has negatively impacted my ability to heal. Added to this, the doctors’ seeming indifference to me, and I just get so disgusted, I could stay in bed and never come out again.

A friend has told me about the raw foods lifestyle. I am going to watch to determine how she makes out because I sure need to do something. I feel like life is just slipping away and I am slipping slowly down the path toward more disability and breakdown!

I live alone in a subsidized apartment, use Medicare for my insurance, and just get so lost and feel purposeless at some times. I am one of the few totally blind people I know who has a MLIS or Masters Degree in Library and Information Science but can’t use it, can’t give back much, have to spend most of my time, remembering what not to do:

- Don’t do too much;
- Don’t overdo it:
- Don’t get too excited;
- Don’t get too anxious;
- Don’t get too manic,

And to remember what to do:

- Maintain a standard bedtime;
- Eat good food; and
- Explain to any and all people who won’t understand it anyway what FMS/CFS is.

They think I am just a supplement-taking nutcase!

I wish I had found a niche and had one thing that I was amazingly good at. One thing, I could do for say 3 or so hours a day and make enough money to live well on.

I feel so suddenly tired and exhausted.

David F, Louisiana, U.S.A.

Bonnie's Story

In the spring of 1989 I was laid off from my job as a computer programmer. The following fall, I had a series of viruses. I remember rain and dampness and feeling tired. By the next year I was feeling exhausted and wiped-out. I had low-grade cold symptoms. I was blessed to have a doctor who not only knew about, but also treated Chronic Fatigue Syndrome. She diagnosed me over the phone and asked that I come into the office so she could run tests.

By this time I had a job doing tech support. A big part of my job consisted of moving around and setting up PCs. I lasted ten, very difficult and exhausting months, doing this work. I had more sick days than work days. I was looking to get out of the computer field and planned to go back to school and to get my MSW.

A friend suggested I get acupuncture treatments to help with my fatigue. It was the first step in discovering a path that would forever change my life. Two years later I was back in school studying acupuncture. It took me five years to complete a three-year program. The illness waxed and waned. I would go through many months without any symptoms, only to have the illness return. I wanted to get better and was willing to try anything that I felt would do no serious damage to my body.

I tried subcutaneous shots of an herb called iscador, shots of gamma globulin, intravenous vitamin C, CoQ10, nitroglycerin, herbs, photooxidation, and nutritional supplements. The whole time I was getting weekly acupuncture treatments.

After about 8 years of living with the illness, I noticed that there was a seasonable component to it. I tended to do better during the summer. I invested in a 10,000 lux bright light – the kind used for seasonal affective disorder. On a weekend vacation in Rhode Island, when I was particularly sick and exhausted, I went to the local herbalist who recommended a supplement called NADH. This was the fall of 2000. I started sitting in front of the light for a half an hour every day and taking NADH when I woke up in the morning. The illness subsided and has never returned.

In the past ten years, I have earned a Master's Degree in Acupuncture, met my soul mate and got married, moved to a new area, bought a house, changed jobs several times, found community… I work out about an hour a day and roller blade, bike, ski, kayak, and hike.

I hold out the possibility of complete recovery from CFS, tempered by the information that it took me nine years with excellent medical care and a good reason not to be ill – my desire to work as an acupuncturist.

The promise of recovery is important, but more important in my mind is the ability to learn to live with Chronic Fatigue Syndrome. Recovery is possible but uncertain. Living with the illness is an attainable goal. I am not suggesting the Chronic Fatigue Syndrome or any chronic illness is good or something to be sought after but what I am suggesting is that there are lessons and skills to be learned from the illness. These include:

- setting limits on your time and energy;
- resting when you need to rest;
- listening to your body – it is always speaking to you;
- asking for and accepting help;
- eating foods that sustain you;
- getting an appropriate amount of exercise;
- choosing the things in life that are important to you;
- setting simple, achievable goals; and
- using trial and error to determine which treatments improve your condition.

The most important lesson is to start living the life you want now. This doesn't mean running a marathon, traveling to a Greek island or finding your dream job. It means being creative in bringing positive experiences and people into your life. It means finding joy in life. I love to cook and I love to ice-skate. When all I had the energy to do is lie on the couch, I would be watching PBS's cooking shows and figure skating competitions.

The tools that are so helpful in dealing with chronic illness are the same skills necessary in meeting with any of life's challenges.

One of my favorite quotes is from the book Learning to Fall: The Blessings of an Imperfect Life by Philip Simmons:

"We have lived long enough to discover that life is both more and less than we hoped for. We've known Earth's pleasures: sunlight on a freshly mowed lawn, leaves trembling with rain, a child's laugh, the sight of a lover stepping from the bath. We've also seen marriages sour and careers crash, we've seen children lost to illness and accident. But beyond the dualities of feast and famine we've glimpsed something else: the blessings shaken out of an imperfect life like fruit from a blighted tree. We've known the dark woods, but also the moon. We are ready to embrace this third way, the way through loss to a wholeness, richness, and depth we had never before experienced."

May you bring health and contentment, joy and happiness into your lives. May you learn from tragedy.

There is Power in telling one's story

Know that there is hope.

Bonnie

Edna's Story

I am a retired US Navy nurse practitioner. I was commissioned into the Navy in 1996, immediately after completing my bachelors in nursing. I caught a flu while at work at in 1997. My temperature went up to 103.8 degrees Fahrenheit. I believe this is when I first became ill with ME/CFS. It took seven years to be diagnosed, even with wonderful doctors all around me. Then I was ostracized and tormented about my illness until I managed to retire but only after having to hire my own attorney at a whopping $15,000.00 – my entire life's savings.

I managed to retire with my soul barely intact and moved to be closer to my sister and family, and find a part-time job which I love. However, I now see ME/CFS day in and day out in my own patients. These Veterans often became ill during their military service or deployments. One barely middle-aged man has been ill for 20 years without a diagnosis.

There is not only a lack of knowledge of ME/CFS, but an ignorance in diagnosing and treating. Even when the diagnosis is handed to another provider on a silver platter, it is often either ignored or simply refused acknowledgement. Patients continue to suffer, and I get more and more frustrated. Patients are diagnosed as bipolar, depressed, anxious, and psychosomatic and ME/CFS is never even considered in the differential. It is abhorrent.

This is just a touch of my own story, but I wanted you to know how my own illness has affected my desire to help others, and how my ability to help others continues to be blocked due to lack of appropriate knowledge.

Edna

U.S.A.

Lesley's Story

Walk Just A Little with ME ...

I thought that if I just waited a little longer and focused on being patient, that our medicos would have it all worked out. So I waited and kept my trust in the learned world of medicine.

And I grew weaker and sicker.

I comforted myself by thinking that everything was being done behind the scenes and that in time an answer would be found ...and so I waited.

I couldnt physically endure my early morning beach walks anymore or my evening aerobics to the incredible Annie Lennox.

I encouraged myself to be patient and wait

I look out my windows at home and watch the birds and the trees blowing in the wind. I sit in my car parked at the beach and watch the sea and ships in the shipping channel and daydream myself into the picture of a day on the beach. I wind down the window and breathe in deeply. Happy but sad.

The isolation of this disease knows no bounds and reaches into every facet of my life, making me aware with a clarity that defies questioning that I am in this on my own.

All sufferers Are.

So what has this disease that has bypassed the rigors of biomedical research and jumped straight into Guessiatry and Thinkology - taken from my everyday life?

My ability to study at University;

My Physical strength and dexterity;

My ability to earn a living;

My chance to create personal wealth within a free enterprise system;

Holidays;

Family outings;

Dining in restaurants;

Shopping for birthday presents for my family;

Going to the hair dressers;

Being at school presentations when my children receive academic awards;

Walking down the street to get the weekend papers;

Walking the dog;

Generally being free to create a life of my own design.

I am housebound. Sometimes couch bound - Sometimes sleeping days away. No not depressed. Just too weak to function like a physically healthy person can.

Lesley

John's Story

Although much of the public feels some one such as myself is defective, I think my current lifestyle is typical of CFS patients. For that reason, I want to focus on one aspect of my CFS:

For many months circa 1999/2002, I was more or less back to full health during the months I was close to the equator (except when at high altitudes). The location/good health co-relation was very clear. There was nothing special I had to do, or avoid, or ingest to be well when close to the equator.

Nothing I did in Canada/US could make me well. I asked other CFS people who'd been close to the equator how they'd been. Well over half reported being in good health during their time close to the equator!

Being near the equator no longer makes me well, except for perhaps the first few days. I don't know what caused my earlier good health there - or what caused it to end.

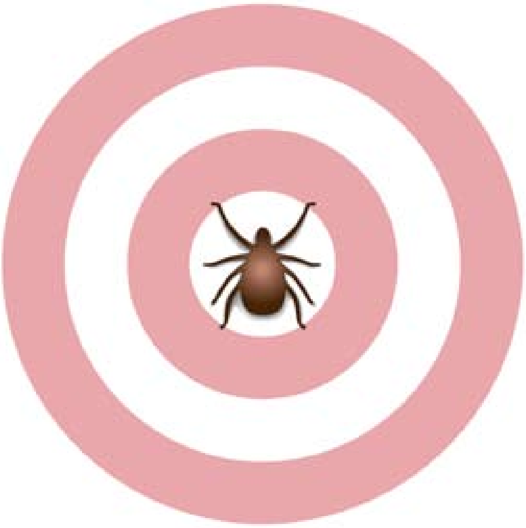
My impression is that perhaps mould, magnetism or EMF factors are at play.

I am dismayed that the doctors, schools, health ministers, organizations I contacted were uninterested in following my observations up!

I hope someone with clout will get interested in the location/CFS co-relation! I'd be delighted to co-operate!

John

A LYME DIAGNOSIS STORY



I am including our family story here to encourage anyone who has been diagnosed with ME/CFS or fibromyalgia to consider the possibility of Lyme disease.

I was “diagnosed” 30 years ago, in my mid 30’s, with ME/CFS and fibromyalgia. My son, at the age of 17 very suddenly became quite ill and was diagnosed at first with Mononucleosis. After about 2 years of steady decline he was diagnosed with CFS/ME, by one of Canada’s pre-eminent CFS doctors. My daughter, also at the age of 17, likewise became suddenly very ill and received the same diagnosis. No medical person ever suggested Lyme disease to us at any point. None of us ever had the classic “bulls-eye” rash.

On our own initiative we were tested in a Canadian lab for Lyme disease but it came back negative so we kept on searching, not knowing at that time how unreliable Canadian Lyme testing was and still is. After 6 years of devastating illness for my son, and 4 years for my daughter, we all tested positive for Lyme in a US lab. By this point my daughter was completely house-bound and my son was bed-ridden, both with serious gastro-intestinal and neurological symptoms.

We found a private MD who would treat us and with his expertise and that of others in our medical team, all at our own expense, we started to make progress.

We have had the wonderful care of our private physician here in Canada, but have also travelled to a clinic in the US repeatedly for additional care. We have included many different healing modalities in our journey, each with different degrees of effectiveness.

We all three have steadily improved. At the time of writing, my daughter has reclaimed her life. She is in Medical School now and back to playing ice hockey. I have also improved tremendously. My son is still struggling. He has been sick for 11 years now and still is unable to live independently. He has gained a huge amount of ground, but still has a way to go.

I strongly urge anyone with an ME/CFS and fibromyalgia diagnosis to look into the possibility that their symptoms might be due to Lyme disease.

ANON

BETWEEN YOU AND M.E.: Lydia’s Story

The Beginning

It was a Friday, October 17, 1986 and although I did not know it at the time, the last day I worked for a living. I had just come back from my boss’ office and had given him my doctor’s note stating that I had to go on sick leave for an indefinite period of time. “Indefinite” was an understatement. How about an infinite period of time would have been more like it. I did not know what was wrong with me, nor did my doctor but she did acknowledge I was too ill to work.

I had noticed at work that by the time 12 noon would arrive, I was unable to go upstairs where I needed to go all day long as my boss’ office was upstairs. Trying to hide this was practically impossible as working in a busy law office, there were clients to bring upstairs, and varied other unforeseen happenings which invariably would lead me to have to go upstairs. This 20 step stairs had become as gargantuan as a mountain and not having a diagnosis made me think the worst.

It all started In December 1985 as one of the law clerks had become ill which she at first ignored. However, after several days it became obvious she wasn’t getting any better so she decided to visit her doctor. Her bloodtests indicated she had extremely high titres of the with Epstein-Barr Virus. It took her a good six weeks to get over that before she could return to work. We were not particularly concerned about this as we were told by our physicians that we pretty well had all been exposed to EBV.

Except for that particular incident which resulted in all of us being ill in one stage or another, nothing else out of the ordinary was going on. Although the whole office had been ill, everyone pretty well recovered in about six weeks time. All that is, except me. Instead of recovering, I was starting to experience more and more symptoms I couldn’t ignore. However, I did manage to more or less continue working. Like many families, we needed both my husband’s and my salary to run our household.having two boys to raise. My youngest 9 at the time and my oldest 13.

What was the most frustrating, however, was not only the physical symptoms I was experiencing but also the mental deterioration I was starting to notice. Working in a law office you are very aware of dates being very important and therefore many steps are taken to make sure that no dates are missed. Both the client and the lawyer rely on your doing your part of your job. First I noticed I was starting to reverse numbers and so any date I wrote down I had to check, double check and triple check my information to make sure that this was not one of those occasions where my mind was playing tricks on me. If I was not having stress enough about that, I started to feel spaced out, almost like I was on something but no clear understanding about what was happening to me.

I was unable to multi-task, was distracted by any sounds around me and even crossing the street became a nightmare. I would look in one direction and then to the other, only to have forgotten whether or not it was safe to cross the street. What should take a few seconds became an albatross of events and it looked like I was watching a tennis match.

Foods that I would previously enjoy I was now unable to tolerate, nausea became a frequent companion. These symptoms I would relate to my doctor but there was nothing that stood out to give her some idea into which direction she should be looking. She had sent me to many specialists as well as special tests and all that did was make me feel like a hypochondriac and probably in the eyes of my physician also. Thankfully she never expressed that view.

Due to having problems tolerating most foods, I lost over 20 lbs which I could ill afford to lose. Some of my friends stated that they wished they were in my position to have a chance to lose that kind of weight. Even they were perplexed by my frequently having to cancel plans to go out with them and it became their habit to actually call me on the day of the outing to make sure I was coming. Later on I had to adopt that approach as until the day arrived, I had no way of knowing what kind of shape I would be in on that particular day.

This all came to a head on October 17th, 1986 when I had no choice but take my doctor's advice and take a leave of absence. By this time I had trouble getting out of bed in the morning, if I could get out of bed at all. No matter how long I slept and no matter how many breaks I took, I was unable to get any relief from the constant exhaustion I was feeling. I am basically a morning person and do my best work at that time. I absolutely dreaded mornings and the constant struggle I faced in talking myself into getting out of bed.

I was not prepared for any of these events. I was never ill except for the occasional cold. Like any healthy person, your health is the last thing on your mind. I must confess I took it for granted. I don't think any of us think about what we would do if we got seriously ill. You can plan an escape plan in case of a fire, but whoever makes an escape plan in case of illness?

As my doctor felt I was just needing a break, the indefinite time off work meant I would be going on sick leave under employment disability which was good for 15 weeks, money at this point was not a problem and so taking time off work gave me some relief from stress. Not for one moment did I think I would need the 15 weeks of sick leave.

Now What!

It seems that every time I turn around another symptom appears. This has become so embarrassing. This reminds me of a story I had read in Highschool where this hypochondriac was looking up symptoms in a medical dictionary and realized the only disease he didn't have was housemaid knees. I do not recall the book nor the author but in an effort to find out what was wrong with me I looked up many diseases simply because of some of its symptoms. I felt that my biggest problem was not the illness itself but the fact that no one knew what it was. I figured once that was known I would be well on the way to recovery. I think back of that time now and I can't believe how naive I was.

I thought I was getting smart by keeping a list of the symptoms that seemed to be coming and going. The list became depressing, and no end in sight. I went from seeing my GP once a year for an annual check-up to sometimes so often that she probably didn't need any other patient to pay her office expenses. None of these visits brought any results. All I know is that every new medical expert she sent me to, all of them were of the opinion was that I was depressed. I started accumulating tons of sample anti-depressants and prescriptions. Depressed? Yes, I was depressed because I was ill – not ill because I was depressed.

In addition to being ill, my first dilemma was to fill out an application for disability benefits. Easier said than done. Try to get benefits when the doctor is not able to give you a diagnosis. Eventually the doctor called it Epstein Barr Virus. Although it took some doing but eventually I did get my 15 weeks of benefits. As the law firm I worked for did not have insurance covering its workers, that is all the benefits I got. Once I left work, except for the usual vacation pay, no other salary was forth-coming. What I did get was lots of phone calls wondering when I would be back at work. The law firm had hired a temp and as the temp earned more than I did, they obviously wanted to put that at an end as quickly as possible. This added extra stress to what already was a stressful situation for me as well as my family.

On my visit to my doctor's office as the 15 weeks unemployment disability was coming to an end, and because of my frequent enquiries from my employer, I asked my doctor for an approximate date when she thought I may be ready to return to work. She told me that in her experience with EBV patients, most were able to return to work within a short time. However, I was not responding the same way and she didn't see any improvements in me. My husband and I decided at this point that to at least relief the stress of my employer's request for answers, I should resign from my position so that they could hire a replacement and they would leave me alone.

I thought I would feel a sense of relief but instead it resulted in me feeling lost and useless. Not only was I unable to really take proper care of my family but now I could not even contribute to their financial wellbeing. Everything was now shoved onto my husband's shoulders alone and all I was doing is what – existing.

The Good News and the Bad

My daily routine consists of getting out of bed and moving to the sofa in the livingroom. This effort leaves me totally exhausted, even though I have spent the whole night in bed. I cannot believe that anyone can sleep so much and still not feel rested. How is that possible? I cannot watch TV or even listen to the radio. My whole life consists of pillows and blankets. I can't remember the last time I looked in the mirror. Sometimes I comb my hair, sometimes I wash myself but any kind of even daily personal hygiene is so exhausting that even just thinking about it puts me into a panic.

What gives me encouragement is that I am noticing slight improvement and by February 1988 I am going for a follow-up appointment advising my doctor that I finally was starting to to see improvement from EBV. My husband dropped me off at the door what I thought was my doctor's office and as it usually takes some time, he had gone on some errands. Once I got in the building, I realized that I had written the number down wrong and after checking the number realized I had to walk about six blocks to the proper location.

It was extremely cold that day and by the time I was at the doctor's office I was completely out of breath. It is this episode, in my opinion, that not only erased any progress I had made but it also brought me into a completely different phase of what I thought was EBV. It is the second onslaught of something that took me out of the chance of recovery to what I know now as ME/CFS.

For the next two years, my daily routine was back to the beginning of bed and sofa and sofa and bed. It is difficult to remember one day from the next at the point. The only constant was I saw my GP on a regular basis, at which time I would get to leave the house. The only thing that stands out from that period of time is that in addition to the symptoms I had gotten from the start, I developed panic attacks that I was so afraid of that I always wanted to be within 30 minutes of a hospital. The first time I had an attack I ended up in the emergency department as I thought I was going to die as I had trouble breathing. Little did I know that it was my panic that stopped me from breathing normally. Later on I learned how to deal with them but at this time I struggled with them and would panic until the attack was over.

On one particular appointment to my GP and my incessant complaint about being exhausted, she told me that she had just received a letter from a Dr. Byron Hyde who, on a recent flight out of the country had met a British doctor who told him about an illness named Myalgic Encephalomyelitis which they originally named in 1953 when doctors at the Royal Free Hospital in England and nurses all came down with an illness they did not recover from. In describing the symptoms, Dr. Hyde felt that the people who were coming into his office were displaying similar characteristics. He decided to research it further and was writing doctors in Ottawa alerting them to this illness. He asked if they had any patients displaying these symptoms to send them to him for further studies.

As my GP did not know what else to do asked if I wanted to see Dr. Hyde and see if this could be what I had come down with instead of EBV. At this point I figured that I had nothing to lose and got an appointment with Dr. Hyde. This appointment changed my life forever. Dr. Hyde asked questions that nobody else had asked and I was believed for the first time that what I was experiencing was real. That in itself did a lot for my self-esteem. What was interesting was that he looked at the bloodtests that I was told were normal and he told me that although they were in the normal range, they were either borderline high or borderline low. In other words, almost abnormal. All this was news to me. I knew nothing of bloodtests or anything remotely medical at this stage. That eventually would change, first out of necessity and then to help others.

A few weeks later, Dr. Hyde held a meeting in Ottawa where there were hundreds in attendance who were in a similar state of illness as I was. What I thought was only me turned out to be nothing of the sort. Person after person stood up relating similar horror stories as my own. Although of course I felt bad they were ill, at the same time it was a relief to know I was not alone. Many of the people I met on that day I still am acquainted with today.

One of the first things I learned that day is that it is important not to isolate yourself from others. If you have an illness, find others to connect with. It doesn't have to be a support group. It can be a simple get together where you accept each other as people who may be ill but still stay don't lose site of who you are. It is important not to become the illness and be identified by it.

It was reassuring to know that my illness had a name. That was the good news. The bad news was that there was nothing at this stage that could be done for it.

No Longer Alone But…….

I thought I had made progress by getting a diagnosis. I imagine doctors apologizing to me for not believing me and the thought of this brought a smile to my face. I was brought back to reality when I heard a doctor calling my name over and over again as I was imagining this different scenario. The doctor was talking about listening to my body and taking time to rest, making sure I had enough sleep blah blah blah blah blah. He was talking as if I had any choice in the matter. I had done nothing but sleep, and my body and mind decided when I would be up and about when I would be down. Listen to my Body? I had done nothing but listening to it. If that was the only thing I needed to get cured, I should by now be running in the Olympics.

Now that I had a diagnosis of ME/CFS and having met others at the meeting, I started to feel a different sensation. One of anger. I was angry that this illness had been around for a long time and had been known by many names but no one sought to get to the bottom of it. We were treated as invisible patients with invisible illnesses and I decided at that point to put out signs on bulletin boards in stores and libraries announcing that anyone with certain undiagnosed symptoms might want to come to my meeting to see whether or not ME/CFS should be considered as a possible diagnosis for them.

I think what became the biggest setback for all of us who were either just diagnosed with EBV and eventually Myalgic Encephalomyelitis was the U.S.A.'s 1988 Holmes etal definition entitled The 1988 Holmes Definition For CFS.: Chronic Fatigue Syndrome: A Working Case Definition AnnInternMed.1988:108:387-389. We now not only had to deal with yet another label but it belittled the exhaustion experienced by us along with other symptoms.

From what I was able to determine in interviews Dr. Holmes had done, he noticed that what the patients all had in common was the feeling of constantly being tired. After all the media comments based on doctors' interviews established that this was an illness related more to a psychiatric condition rather than a medical one, it trivialized the tiredness of the individuals and made us objects of ridicule. A doctor whose name I cannot recall stated aptly calling ME chronic fatigue is calling pneumonia a chronic cough.

There is of course the extra difficulty of having this name of chronic fatigue used by the media and family and friends who supported us. They started telling us what they had heard and now viewed us as people who did not want to work. They would tell us that they probably also had CF as they were tired. We started to turn more into ourselves and saying less and less about our illness in order to avoid being dismissed as malingerers.

If that was not bad enough, this same attitude by the public was also felt when sent for doctors and specialists' appointments. More anti-depressants were described,and strange questions were asked:

- are you happy in your job or marriage?
- were you sexually abused as a child?
- are you depressed?

In the end, I got so frustrated that I told the doctor that I was depressed because I was ill – not ill because I was depressed. However, if I would relate a new symptom, the doctor would say it was part of my illness. You mean the illness I'm imagining?

Give Me A Break!

I am sick and tired of being told I am depressed and that the symptoms I am experiencing will go away, once I take the anti-depressant. Having met people who are severely depressed, it is a disservice to those who really are and their depression should not be belittled in any way. I am no doctor and am only talking like a person who had a full life, loved her life and had a great job. I come down with an illness and as it progresses it turns from an illness into a depression? All I have to do is think positively and the symptoms will go way? Give me a break!

I can say that now but at the time it was happening I was not positive about anything anymore. I didn't know what and whom to believe. Common sense tells you that if enough doctors give you the same diagnosis, then it must be so. That may be true when backed up by science, research and proper tests but when it is not, then on what are you basing your diagnosis?

From what I have observed over the years, my opinion is that medical professionals have come to rely on tests so much that they do not look at the obvious. The patient in front of them. A ME/CFS and FM person does not look normal nor even walk normal. True it is not obvious to the average man on the street but surely a professional who sees illness every day should be able to see what is so obvious to those who take the take to observe the person.

I bet most, if not all of us, if given the chance to say what they thought, would say what I am saying. It was always the same routine. Saw the specialist who is sympathetic, listens and orders tests. You go back for the follow-up appointment and the whole attitude of the doctor has changed. The doctor tells you that everything was normal. Then the spiel of what is going on in your life that makes you so depressed you're ill. This pattern never changed, just the doctor's name.

When people become ill then they want to know what is wrong and of course want to get treatment. When none of that is forthcoming, you get upset and be sad but if the pattern were to change and treatment and support were given, no anti-depressant is necessary in that case. These are life events you will overcome. Sadness doesn't make your ill.

Depression, on the other hand may be similar to sadness but on a much larger scale and more profound. It is not a normal emotion like sadness is. Depression is an out of control emotion and is not a normal reaction to human difficulties. There are tests that comfirm that diagnosis but interestingly although I was told many times I was suffering from depression, no tests to confirm that diagnosis was never done. At that time I didn't know any better.

I know if just one of those medical professionals would have taken the trouble to really listen to me and I felt at least some empathy from one of them, then at least I would walk away from that appointment uplifted. Unfortunately at that time that never happened when I needed it most. The only good thing that came out of that was that I learned what it must be like to be ill and not be believed. It has helped me a lot over the years with others.

A Time To Grieve

I had a hard time dealing with the different emotions I was experiencing that did not make sense to me. In addition, the reaction of my family and friends also left me baffled. A friend dropped in to see me who was telling me how she was having a hard time dealing with her grief after she lost her husband. She started to tell me about a book someone gave her which dealt with grieving and the different emotions that a person goes though. The book was authored by Elizabeth Kubler-Ross On Death and Dying.

I am an avid reader, and had read it. In reading it the second time, I realized although it was about people who were terminally ill, this time the book affected me in a completely different way. Although we are not losing our lives the way a terminally ill person does, we are in effect losing who we used to be. Grieving is necessary in any loss. I came to the realization that the stages I was going through was grieving for the life I used to know. Until I had dealt with that, I was not able to continue on my journey of a new kind of life. Once I understood that, my reactions and those of others to my illness made sense. Eureka!

I now understood that as she was grieving for the loss of her husband, I was grieving for the loss of the life I used to have and the loss of me as I used to be. I now also understood that my family and friends were also experiencing these same grieving stages. I did not realize that they had trouble dealing with the new me as they did not know me. They had to reacquaint themselves with this new personality whom they knew nothing about.

As time went on, I started realizing everyone was coming to grips with their feelings of loss at their own speed and we collided simply because I was going through one stage while they may be going through another stage. If I'm dealing with anger and they're going through denial, it is no wonder we cannot connect. This helped me to understand not to take what my family and friends were displaying as personally as I was. This helped me tremendously because if you take away the personal from the situation, you can then look objectively at what they are actually expressing. With time I came to recognize and be able to understand their feelings.

I know that before you can close a chapter of your life, you have to deal with whatever is stopping you from closing that chapter. You cannot move on if you're continuously looking back. Some people call it closure but I just simply call it moving on and coming into the present.

I was not at this point of time in a position or will to want to re-establish a life but I did want to understand what I was going through. Grieving is for mourning of a loss. Now that I understood I was grieving, I turned to experts who have written on this very subject.

One of the first things I learned was that even though there are stages of grieving, the length of time you may take for each stage of grieving is solely dependant on you. There is no set period, just as the grieving stages for someone who lost a loved one is different for each one of us.

Slowly but surely I now started to understand how grieving affects how you act or react or think about anything. When I think about it now, I find it very appropriate to grieve before you go on to the next episode in your life. I know the author, Elizabeth Kubler-Ross had made that observation and her book helped me in so many ways, with both my husband's illness and death.

My husband's passing was very traumatic but I think that going into shock and denial is a good thing. If everything were to have hit me all at once, I doubt my mind would have been able to grasp it. Below are the stages of grieving I experienced.

On our website, is a more detailed explanation of the stages of grief.

No Test – No Illness

Acceptance of my illness was not easy. At first I felt by accepting, I was giving up but eventually the Dutch stubbornness in me thankfully took over. I started hounding my doctor requesting to be sent to all kinds of specialists as I didn't believe that if they did the proper test, they would find what was wrong. Although I may have accepted my illness, I had not accepted that a test wouldn't indicate it.

I thought all my troubles were now over. Fat chance of that! I didn't know they were just beginning. Although I had a diagnosis, except for my GP, no one believed me. The names of the doctors were different, but the results were always the same. The protocol would go like this: At first sympathy, followed by utter disbelief and a convincing that my illness was nothing that a good anti-depressant couldn't fix, then followed by a quick .guiding out of their offices.

One doctor who stood out though was one I had been sent to by employment insurance. This doctor was working at a very well known teaching hospital but also saw patients sent by their insurance companies for verification that they were ill. He did believe I was ill and that my symptoms were real. He even went so far as to tell me that he had seen others with the same illness. However, he explained that although he understood my illness, he had a nice little practice and couldn't afford to have patients who would take up valuable time that he was unable to do anything about. The staff had also been told by the hospital not to talk about CFS. This was not the first time I had been told that. A nurse who befriended me at another hospital told me the same thing.

I had never had that much experience with doctors as I never needed any. I had this belief that as their mission and motto stated they 'would do no harm'. If only doctors thought about how what they say will hurt. You expect to walk out better than when you walked in. A sympathetic word goes a long way when your life has been pushed upside down.

I found that the bottom line simply was that if it doesn't show up on a test, then it simply doesn't exist. No longer listening to a patient and observing their demeanor plays a role in many doctors' lives. In many cases it has become like a referral service for tests and then you're told you are perfectly fine, the tests are normal. As the tests you are sent for are specific, of course they would come back normal if you haven't got what the test is supposed to determine. The failure of the test is that it cannot determine what it isn't asked. That doesn't make you healthy, just you haven't got whatever. How about if you haven't designed a test yet that would determine the illness? How about research?

Right now only the symptoms are treated. With me it was a question of choosing which symptoms I wanted treated more than any other. Then there would be the side effects. Sometimes they were worse than the symptoms the drug was covering. Drowsiness? Check. Nausea? Check. Fatigue? Check. And the list goes on. Why would I want to take a drug that would amplify the symptoms I already had?

There came a point all tests that could possibly be made, had been made. Alternative or homeopathy did not help me either. One doctor I saw was so convinced that she could cure me put me on a cereal and grains regimen. I lasted three weeks on that and became so sick I ended up in the hospital once again. Diagnosis - malnutrition. That particular episode set me back months.

It finally registered that there was nowhere else to go or things to try. Once again, anger took but with that came resolve but that's another story.

From Anger To Action

It soon became obvious that I would be better off not saying anything about ME/CFS as what appeared to be a sympathetic doctor would turn nasty and incredulous. They all admitted hearing about CFS, not ME, but they said it was an illness caused by stress rather than a physical illness. More anti-depressant added to my collection. That and tranquillizers. I could start a pharmacy.

I would go to the follow-up appointment with optimism and hoping that this time there was something they could fix. I could not believe I felt so ill and still the tests come back normal. The doctor would look at me with an I-told-you-so expression and would then start talking about depression and anti-depressants.

As I was becoming more and more disillusioned with the medical establishment not being able to help me and hearing others voicing the same pessimism, I couldn't understand why no one was doing anything to find a solution. I even called the medical associations asking why no research was being done on ME/CFS and FM. I was still at the stage where I naively believed that researchers researched illnesses that needed to find the cause of the illness and once established treatment and a cure would be studied. Unfortunately, research needs funding and without funding there is no research.

More and more the healthy friends I used to know started disappearing and my only contacts were those with similar illnesses. By that time I had met both people with ME/CFS and FM and realized they too were in the same position of not being understood and believed than those with ME/CFS. The only thing is FM sounds better than Chronic Fatigue Syndrome but that didn't seem to make a difference in that case.

When my husband and I were talking as he would drive me to the meetings I started for both ME/CFS and FM locally, he got to hear others that sounded just like me. Any doubts he had about my illness completely disappeared and from that moment on he became my staunchest supporter and helped me everything I undertook to bring ME/CFS and FM into the open.

I went from Somebody Needs To Do Something to I Am Going To Do Something. Although I didn't know it yet how I was going to do it and what but I no longer was willing to sit on the sidelines and let our people go it alone. An idea was coming but did I have the strength and perseverance to do it?

It became very obvious that if we wanted support, it would come from the ME/CFS and FM community. At first I started volunteering when I could at national organizations in Ottawa that were already established. However, although they were helpful, what I and others were experiencing was not being taken care of. We needed sympathetic doctors who were willing to help as well as people in other professions to help with disability matters as well as information to help them. It is then I decided to start the National ME/FM Action but that's another story.

Lydia

UNHEARD VOICES

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Consensus Documents for ME/CFS and FM

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols [Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004 ISBN:0-7890-2207 9] and The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4]] can be viewed on our website at www.mefmaction.net and is also available at Amazon.com or at Chapters.ca

Or view the Consensus Documents on our website at www.mefmaction.com

ME/CFS and FM Overviews - $7.00 each

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents entitled Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols and The Fibromyalgic Syndrome: A Clinical Case Definition for Practitioners.

Overviews can be ordered from Marjorie Van de Sande via email at mvandesande@shaw.ca or by regular mail at 151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 Canada, or from the NATIONAL ME/FM ACTION NETWORK Or may be viewed on our website at www.mefmaction.com

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