



# Worldwide Association for ME/CFS

## Awareness and Research

### Words of Welcome!

Welcome to the first issue of WAMCARE's newsletter! In our inaugural issue we felt it was important to introduce our organization's purpose and vision and the volunteer Board of Directors. Our newsletter strives to provide accurate, up-to-date scientific information and resources on ME/CFS and related illnesses, support for care-givers, friends and family of those with ME/CFS, and a forum for anyone involved with ME/CFS to have their voices heard. We welcome feedback about our newsletter and are happy to make changes to best accommodate the ME/CFS community we serve. Please send your suggestions and comments to [newsletter@wamcare.org](mailto:newsletter@wamcare.org)

#### About the Worldwide Association for ME/CFS Awareness and Research

WAMCARE has the following goals: to raise awareness and funds for ME/CFS and biomedical research into ME/CFS. We support any reputable organization or individual who works towards these same goals. We promote public knowledge of these facts: ME (Myalgic Encephalomyelitis) and CFS (Chronic Fatigue Syndrome) is the very same biological disorder, and not a psychological somatoform disorder. (The World Health Organization has defined them both together as a neurological/nervous system disorder). That ME/CFS affects 28 million people worldwide and their families and communities, which is all of us. That ME/CFS is a serious disorder that can be so severe that persons are unable to move a muscle, speak or eat, and deserves serious governmental support and funding.

In July 2009, WAMCARE applied for and received official non-profit status in the US state of Nevada (non-profit no. E0388962009-4. This is the first step in becoming an

Internationally Registered Non-Profit Charity. The next step is Federal Registration in the U.S. Please [donate](#) to help us with the application fees. Though we are registered in the U.S., we are a group of volunteers from several countries worldwide, and have provided information and services for the international ME/CFS community since our inception. We will, of course, continue to do so!

WAMCARE operates under the assumption and fervent belief that an organization is a group of people, not a name, label or individual person, regardless of the roles individuals play in the organization. We adamantly believe that people always come first. This includes respecting and promoting the rights of our members, volunteers, ME/CFS sufferers worldwide, their families and communities. In addition, our People First mandate requires us to put the health and well-being of each individual before any organizational concern. We encourage our volunteers to be committed to their own self-care, to ask for help, and to express their needs and concerns freely and openly. We will support and assist every member in any way we can. We never ask anyone to work beyond their own capacity and desire. For more information about WAMCARE, ME/CFS resources and volunteer opportunities please visit our newly designed and launched website: <http://www.wamcare.org>.

We would also like to take this opportunity to thank our donors and volunteers for all their hard work and support since campaign month, May 2009, when WAMCARE was formed. Generous donations have made possible our official incorporation and funded supplies for our up-coming bracelet fundraising campaign (which will be launched in the next issue of our newsletter). We would especially like to thank Joe Cassels for arranging our website and domain as well as Anja Rusewald for designing our fabulous new logo and graphics. Many hands have been involved with ME/CFS Awareness, and many more hands [volunteer@wamcare.org](mailto:volunteer@wamcare.org)

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## Introducing the WAMCARE Board of Directors



**Laura Dunks**  
President, BOD  
Writer



**Michelle Martin**  
VP, BOD; PR Officer  
Newsletter, Website



**Darlene Blair**  
Secretary, Treasurer,  
Writer



**Nicola Baker**  
Director, BOD;  
Merchandise

## Upcoming ME/CFS Events Around the World

Please Note: WAMCARE is working on a more comprehensive events list for their website, which will include local support and association meetings from community ME/CFS groups in North America, Australia and the U.K. If you know of any meetings, groups or conferences coming up, please email us at [info@wamcare.org](mailto:info@wamcare.org)

### Fantasy Football – AYME League kicks-off!

Written and submitted by [The Association of Young People with ME](#)

A fun fundraising idea to raise money for The Association of Young People with ME, AYME, has been set up by footy-fan and member, Chris Theobald. AYME is the largest charity for children and young people with ME/CFS, providing vital support to those in need and breaking the isolation through its varied support services. [Click here for full details](#)

### National Chronic Invisible Illness Awareness Week ([www.invisibleillnessweek.com](http://www.invisibleillnessweek.com))

From the Press Release: “September 14-20, 2009 is National Invisible Chronic Illness Awareness Week. The theme is “A Little Help Gives a Lot of Hope.” It is a major public awareness campaign sponsored by Rest Ministries, an organization that offers a supportive environment for those who live with chronic illness or pain. Sept 14-18 NICIAW features a free virtual conference with 4 seminars each day available to listen to live or download later.”

[Click here to read the full press release](#)

### 2nd annual ME/CFS Conference Myalgic Encephalopathy Association Belgium

19 Sept 2009 in Brussels. [Click here for more information](#) (written in Dutch, to translate: [http://babelfish.yahoo.com/translate\\_txt](http://babelfish.yahoo.com/translate_txt))

### Meeting: Federal Chronic Fatigue Syndrome Advisory Committee (CFSAC)

(U.S. Department of Health and Human Services) October 28-29, 2009, Washington, D.C. USA. [Click here for more information](#)

### ME/CFS AUSTRALIA (VICTORIA)

Self Help Course on Managing ME/CFS and Fibromyalgia via SKYPE – 5 weeks starting 12 August 2009. A similar course is available via teleconference starting in November. For these and other up-coming ME/CFS Australia events, [Click Here](#)

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## ME/CFS in the News

- [Local author shares Fibromyalgia, CFIDS self-help info in book](#)
- [Play explores fatigue illness in marriage](#)
- [Under the microscope: Shirley Conran on sleepless nights and why she refuses to live to 100](#)
- [Illness and Medical Twitters Get a New Social Network](#)
- [With chronic fatigue syndrome, my life is a glass box](#)
- [Switch off, switch on \(B-Cell Depletion Therapy\)](#)
- [PR chief \[with ME/CFS\] takes East Lancashire Hospitals to tribunal](#)
- [Teenager took his life after suffering years of ill health](#)
- [Mum brings Pokémon closer to her son](#)

## Latest Online ME/CFS Research

- [Hypothalamic–pituitary–adrenal axis in chronic fatigue syndrome](#)
- [GH resistance in a group of chronic fatigue syndrome patients](#)
- [Infectious mononucleosis, chronic fatigue syndrome, adolescents](#)

- [Clinical impact of B-cell depletion with the anti-CD20 antibody rituximab in chronic fatigue syndrome: a preliminary case series](#)
- [Increased d-lactic Acid intestinal bacteria in patients with chronic fatigue syndrome.](#)
- [Chronic fatigue syndrome after infectious mononucleosis in adolescents](#)
- [Use of medications among people with chronic fatigue syndrome and healthy persons: a population-based study of fatiguing illness in Georgia](#)
- [A Gene Signature for Post-Infectious Chronic Fatigue Syndrome](#)
- [The economic impact of chronic fatigue syndrome](#)
- [A two-year follow-up study of chronic fatigue syndrome comorbid with psychiatric disorders](#)
- [Cardiac function fluctuates during exacerbation and remission in young adults with chronic fatigue syndrome and “small heart”](#)
- [Chronic Fatigue Syndrome: EGCG Ameliorates CFS Behavioral and Biochemical Changes in Mouse Model.](#)
- [Anticardiolipin \["anti-mitochondrial"\] antibodies in the sera of patients with diagnosed chronic fatigue syndrome](#)

## Research Feature: Prof. Kenny De Meirleir: Hydrogen Sulfide

Article by Laura Dunks and Michelle Martin

In May 2009, Prof. Kenny De Meirleir, an ME/CFS researcher from Belgium, called a press conference to announce his research on Hydrogen Sulfide (H2S) and a urine test he has since made available for purchase via [Protea Biopharma's website](#). His announcement was met with controversy and diverse reaction from the ME/CFS community. The focus of this article is not to add to the controversy, but to summarize the research and what it means for ME/CFS. A more comprehensive article about the research on H2S and its effects has been written by [Dr. Sarah Myhill](#).

H2S is normally produced by bodily cells and play a role in the regulation of many body systems including the cardiac, muscular, immune and central nervous systems. An abnormally high amount of H2S in the body, however, is toxic - it causes dysregulation of these systems - systems that, in ME/CFS, seem to be dysfunctional & symptom-causing. De Meirleir's research shows that the ME/CFS patients he tested have bacterial overgrowth in the gut, causing food to ferment and produce excess toxic H2S. The responsible bacteria include: streptococcus, enterococcus and Prevotella. His research also shows that the amount of overgrowth is positively correlated with severity of symptoms.

De Meirleir also found heavy metal toxicity in his subjects, and suggests that these toxins combine with the bacterial overgrowth/H2S to produce a synergistic effect, worsening symptoms produced by either. H2S also blocks mitochondrial function, which other research has suggested may account for the lack of energy production in ME/CFS patients. According to Myhill, H2S may also be the culprit in the chronically low levels of glutathione found in ME/CFS. De Meirleir's research suggests that improving the balance of flora in the gut and removing the heavy metals could significantly reduce symptoms of ME/CFS. A return to healthy gut levels of bacteria and acidity may in fact "cure" ME/CFS.

The urine test De Meirleir has made available tests the amount of H2S that has spilled over from the gut into the urinary system. It should be a good indicator of excessive levels of H2S. It is not, however, a direct indicator of the presence of ME/CFS. More research needs to be done to confirm de Meirleir's conclusion that excess of H2S actually causes ME/CFS. In other words, it is theoretically possible to have excessive H2S without having ME/CFS. However, the test can be useful as it points to a

treatment - re-establishing a health gut. As Myhill suggests, the test can also be used to monitor the effectiveness of treatments directed towards lessening H2S in the gut. Several ME/CFS patients have taken the urine test and blogged about their experiences (see below). These anecdotal results seem to confirm that H2S is correlated with ME/CFS.

De Meirleir [claims](#) that "if you do not have this bacterium, you do not have ME". However, scientific method dictates that further studies need to be done to assess whether all cases of ME/CFS show bacterial overgrowth and/or an excess of H2S, or if these markers appear in a subset of ME/CFS patients. Dr. Charles Sheppard, advisor to the ME Association, raises this and other [cautions](#). There is a [preliminary abstract](#) of De Meirleir's yet-to-be published (in a peer-reviewed journal) research; however it is impossible to judge the validity of his research without more information. We at WAMCARE view the current state of H2S research with cautious optimism and interest. Despite the controversy, and the lingering questions De Meirleir's announcement raises, it gives reason to hope that significant improvement can be achieved in ME/CFS patients who show these markers by following de Meirleir's treatment recommendations.

### References & Resources:

[Prohealth Article including Preliminary Abstract of De Meirleir's Research](#)

[Protea Biopharma's Information on the Urine Test](#)

[Dr. Myhill's article on H2S](#)

[Daily Telegraph Article on De Meirleir's Announcement](#)

[Dr. Shepard's comments on De Meirleir's Research](#)

[De Meirleir's Slideshow Presentation](#)

[Alternate version of slideshow](#)

[Prof. De Meirleir's profile on InvestinME.org](#)

[Resource Article from Fighting Fatigue.com](#)

Urine Test Bloggers: [Ashy's Living With M.E cfs/me blog](#)

[Dr. Logan on H2S, Fiber and the Gut](#)

[ME/CFS Breakthrough – Diagnostic Test Announced](#)

[Chronic Fatigue Syndrome Breakthrough: What is Hydrogen Sulfide?](#)

## Voices of Youth: Young People Speak Out about ME/CFS

### Alysha Tatum: My Experience of M.E.

Alysha with her older sister.



Hi, My Name's Alysha Tatum and I'm 12 years old. I have had M.E/C.F.S for 2 years now. I'm from Southampton [U.K.]. My hobbies before I got ill were hanging out with my friends, having sleepovers, going to the forest, dancing, and doing gymnastics. Now that I have become ill, I cannot do most of those things anymore. So I like to go to the forest sometimes in my

wheelchair, and play/walk with my dog Maggie. We got Maggie because of my ME/CFS. My mum said it could help, and it did at first, I was around 20% but when I got Maggie I went up to 30% and I started to recover. I was going to school again, part-time and seeing my friends again, but I over-did it in school and because they didn't believe me or support me, I had another relapse. So now I am down to 30% again sadly. I have just got over being semi-bed-bound and attacks from the illness, but I'm slowly starting to recover again.

My doctors aren't very good at all, they think I'm faking so the only person who supports me and helps me is my mum. My dad isn't much help; he also thinks I'm faking. My older brother, Clive who is 18, he helps me. When I had the relapse and I couldn't use the stairs, he carried me. He helped me borrow my wheelchair. The doctors did not provide me with a wheelchair, so he asked one of his teachers and he borrowed it from her. My older sister Lara who is 15 doesn't really help, she takes after my dad, so the people who support me would have to be my mum and brother. None of my school friends support me; they all ditched me so I don't really have anything else to do with them anymore. I'm not at school at the moment, but I'm having online learning called 'E-Learning' - it's an online classroom. I have only just started within the past month.

I haven't properly thought of what job I would like yet but I wouldn't mind being a gymnastic teacher, teaching children and either working full-time or part-time helping/saving animals. I have also wanted to open an animal rescue centre, and help all the homeless and injured animals.

[Click here](#) to read more stories from young people with ME/CFS

## Cormorbid Condition: Fibromyalgia Syndrome (FMS)

Article by Laura Dunks

*Co-morbidity refers to two or more illnesses occurring in the same person at the same time. There are many co-morbidities associated with ME/CFS, which means that if you have ME/CFS, you are more likely to also suffer from one of a long list of other ailments. Each issue we will feature an illness related to ME/CFS.*

The term "fibromyalgia" means pain in the fibrous tissue of the body: *fibro* (Latin for fibrous tissue) – *myo* (Greek for muscle) – *algia* (Greek for pain.). It is characterized by musculoskeletal pain throughout the body, as well as various tender points - specific points in the body, that when pressed, elicit an extreme pain response. Other symptoms of fibromyalgia include fatigue, cognitive difficulties (often referred to as "fibrofog"), muscle aches, twitches and/or spasms, and non-restorative sleep. (A comprehensive symptom list can be found [here](#)).

Controversially, fibromyalgia is considered by some to be a rheumatic condition, like arthritis. Though rheumatic conditions do involve chronic pain and impairment of the joints and/or soft tissues, FMS does not involve obvious inflammation and damage to the bone, joints and muscle tissues. The illness is more likely neurological in origin, involving disordered pain processing in the central nervous system which leads to amplification of pain. Fibromyalgia is a "syndrome", which means that it is a collection of signs and symptoms that occur together but without a known, identifiable cause. However, at present it is classified by the World Health Organization as a musculoskeletal disease.

### Prevalence

According to [UK Fibromyalgia](#), between 1.3 and 7.3% of the U.K. population have FMS. [The National Fibromyalgia Association](#) estimates that fibromyalgia affects 10 million people in the U.S. and 3-6% of the worldwide population. Fibromyalgia is at least three times more common in women than men and can strike people of any ethnicity and age, however, it is most often diagnosed in people aged 20-50. Relatives of people with fibromyalgia are more likely to be diagnosed with FMS, but it is unknown whether this is due to environmental factors, genetics or a combination of both.

70% of people with Fibromyalgia also have CFS/ME. Read about the similarities and differences between fibromyalgia and CFS/ME [here](#). People diagnosed with fibromyalgia also often suffer from other ailments, including Irritable Bowel Syndrome, Lupus, Myofascial Pain Syndrome, Multiple Sclerosis, Depression, Multiple Chemical Sensitivities and allergies (including food allergies/intolerances).

### Causes

Fibromyalgia is a multi-factorial illness, which means that it does not have a single known cause but seems to be caused by several factors acting in combination. The loss of non-REM sleep is believed to be a very important factor in fibromyalgia. Research has shown it is possible to create a fibromyalgia-like syndrome in healthy volunteers by depriving them of non-REM sleep.

Fibromyalgia can be 'triggered' by traumatic life events such as a bereavement, car accident, or serious illness. Scientists have theorized that there may be genes in people with Fibromyalgia which cause them to feel pain in response to stimuli that healthy people would not normally find painful.

### Diagnoses and Treatment

FMS is usually diagnosed by a rheumatologist, who must find a minimum 11 of 18 tender points (where pain is felt with only slight pressure) on the body in the neck, spine, hips, arms, legs, and shoulders. You can see a map of the theorized tender points [here](#). [The American College of Rheumatology](#) diagnoses fibromyalgia when these tender points exist alongside a history of widespread pain which lasts more than three months and is present in all four quadrants of the body (both right and left sides as well as above and below the waist). Diagnosis of FMS usually and most responsibly occurs after other possible diseases, such as thyroid disorders, have been ruled out by blood tests.

Symptoms of FMS can be managed to varying degrees by medications, lifestyle management and alternative therapies. Usually the first thing doctors recommend is regular exercise and a healthy diet. Specific recommendations can differ, but generally exercise that is easier on the body, such as walking, yoga and swimming are considered beneficial. It is essential to start with short periods of gentle exercise and very gradually build stamina. If you have CFS/ME and fibromyalgia, be extra careful about exercising, as it can make ME/CFS symptoms worse. Gentle movement practices like Tai Chi and Qi Gong are excellent for people with fibromyalgia and/or ME/CFS. A well-balanced diet is essential for symptom management, especially one that includes lots of fruits, vegetables and protein such as fish. As many people with fibromyalgia have food sensitivities, it can be helpful to be tested for food allergies and/or attempt a "rotation-diet" to identify potential intolerances. Supplements are often important as well. Some of the more helpful include: a good multi-vitamin, calcium and magnesium, Omega 3-rich oils (such as salmon oil) and B vitamins.

[Click here to read the full article](#) and for Fibromyalgia Resources and Support

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## Amy Kiel: An FMS Sufferer takes on The Overnight Walk for Suicide Prevention

Fibromyalgia is not the only illness close to the heart of Amy Kiel. Despite pain and the risk of permanent damage, Amy decided to participate in The Overnight Walk – an all-night fundraiser for suicide prevention. She raised the \$1000 entry fee and travelled to Chicago to take part in the event. WAMCARE interviewed Amy before and after the Walk, to highlight the concerns and struggles she willingly endured as an FMS sufferer undertaking a major physical challenge in order to help others. Her optimism and diligence despite the pain and fatigue makes her a real every-day hero.



Amy is very active online in advocating for both fibromyalgia and mental illness issues. About her online activities, she says:

As a person living with a chronic illness and dealing with mental health issues, I have chosen to reach out to others dealing with similar issues as well as to people who may not understand. I do

this both to help myself and to help others. I believe the only way to end the stigma associated with these issues is by speaking out about them and also by living a life that is non-judgmental and expressing love and acceptance of others. I am on a path, a journey, seeking wellness and knowledge. I share my experiences and thoughts, insights, etc on my blog at <http://unavitabella.com>. I am also very active on twitter at <http://twitter.com/abeeliever>. I am a big fan of the American Foundation for Suicide Prevention <http://afsp.org> where you can find great information about their efforts to prevent suicide as well as helpful statistics, warning signs, etc. You can see my fundraising page for the walk at <http://tinyurl.com/theovernight> or you can learn more about The Out of the Darkness Overnight at <http://theovernight.org>.

[Click here to read Amy's pre- and post-walk interviews!](#)

To find out if a community walk is being held near you go to <http://outofthedarkness.org>.

For information about suicide prevention you can go to <http://afsp.org>

## Helping Hands: Care-givers, Family & Friends of People with ME/CFS

### Support Is Simply Being There - No Strings Attached -by Darlene Blair

Do you know, love or care for someone who has ME/CFS? Are you just learning about ME/CFS or has your loved one or friend had this terrible condition for several years? If you have answered yes to any of these questions, then some of the following suggestions can assist you to help your loved one during their difficult times. I had a friend years ago who had CFS. This was long before it was even considered a real medical condition. The medical community considered it just a lack of vitamins, over work, stress, depression or even an imaginary ailment. Doctors are finding out how wrong those theories are, due to the mounting scientific evidence that ME/CFS is a biological disorder, marked by inflammation of the spinal cord (Myalgic Encephalomyelitis). Some doctors are admitting their error in judgment, but there are many who refuse to admit their mistake. I lost my friend because of a doctor's ignorance. She died due to the lack of proper medical care and complications arising from the use of medications, drugs that only made her condition worse.

How did I help her cope with her illness while she was alive? In many ways, some of which are so simple, you may not realize how much difference they can make to a person with ME/CFS. For instance, whenever I would cook meals for my son and myself, I would make extra and bring her a meal. Luckily, she lived fairly close by, and after feeding my son I would load him and the meal in my car and bring it to her. I would then sit with her and make sure she ate. With all the pain she felt and the medication she was on, it could be difficult for her to eat when she had no appetite or the food had no taste. I always tried to make things with lots of flavor but low on sodium. There were times when she could not eat the entire meal but I knew that at least she had eaten something healthy that day. We would sit together while she ate and my son would watch TV and we would talk. I did most of the talking since even that small action could tire her out. When she shared her feelings with me I always made sure she

knew she had my undivided attention. It would sometimes take her an hour to eat even half of the meal but that was okay. I had patience. I would then clean up for her, since cleaning even a few dishes was very difficult.

Other days, while my son was in school, I would go to her home and help her clean her apartment, do laundry and/or any other household chores that needed to be done. She would work beside me even though it took a lot of energy. I was not allowed to do it alone - as with most people she was very independent and needed to feel that she was pulling her own weight. We'd spend the day making jokes and laughing together, and that would make the work fun. I also stayed while she took her showers, since that was often scary for her - a few times when she tried to shower on her own, she had fallen and hurt herself. I made sure to be there so that would not happen again. She could drive, but only during the day, and only on really good days and for short distances. The times she couldn't drive, I would take her shopping or to the doctor. If it was a local doctor I would run errands while she was there and go back to pick her up, but if it was a doctor far from our home, I stayed and sat in the waiting room. Afterwards, we'd have lunch at a restaurant near the doctor's office and then drive home. These were special occasions for the both of us. Even though no one likes to go to the doctor, we made an adventure out of it. We both felt like we were two single girls out for the day, playing hookie from school or work, and we would flirt with guys knowing we would never see them again! These trips usually lasted most of the day - the majority of the time was spent in the doctors' office, but the few hours we spent after that was great fun.

The most important thing you can do for a loved one with ME/CFS is to listen. [Click here to read the full article!](#)

## Simon Overton Takes on Eiger Mountain for ME/CFS Research



*Simon Overton has a generalized dysautonomia and suspected hereditary spastic paraplegia. He credits his diagnosis to "ME Research UK's efforts in funding research to identify sub-groups of ME/CFS and missed diagnoses in patients with fatiguing illnesses". About the organization, he says, "ME Research UK have played a leading role in funding the work of my own consultant Prof. Julia Newton. Thanks to her intervention I am doing very well on the drug midodrine and have seen a massive*

improvement in my condition. As a driven and dynamic individual I am now able to move my life and career forward." [To raise funds for ME Research UK](#), Simon planned a tandem skydive jump down the North Face of the Eiger Mountain, part of the Bernese Alps in Switzerland. Simon has graciously written his story for WAMCARE in response to our email interview questions.

I am 37 and teach English at Cockermouth School in the Lake District, Cumbria, England. Before being ill I was a mountaineer and climbed here in the Lakes, Scotland, the Alps and on expeditions. When first ill, I recovered, only to relapse climbing at altitude in the Tien Shan. I was rescued by my climbing partner Jon Gay. Before coming back to the UK I was seen by a neurologist who found that I had a problem with the blood supply to my brain. Back in the UK the local neurologist wouldn't listen and said I had a functional neurological disorder, in other words conversion disorder caused by "something that happened when you were a little boy". I went private and with the help of Prof. Terry Daymond, Dr. Byron Hyde and Dr. Vance Spence I was eventually seen by Prof. Julia Newton at the Royal Victoria Infirmary in Newcastle. She

did tilt table tests and showed I have a problem with the blood supply to my brain just like the neurologist in Kazakhstan said.

I also had tests on my bladder and bowel as I have problems there. They showed I have pelvic autonomic dysfunction and systemic autonomic dysfunction. I also have problems with spasticity in my legs. I am seeing a great neurologist called Dr. Grainne Gorman who thinks I have hereditary spastic paraplegia. All my problems began following a viral infection. I am a wheelchair user though some days my mobility is quite good because of all the medication I take. Without medication - baclofen & midodrine - I would be permanently wheelchair bound and unable to sit up without supports on my chair. I am due to have surgery in the form of a sacral nerve implant now the NHS have provided the £10,000 funding.

I decided to help ME Research UK because they fund Prof. Newton's research. She is a wonderful person. I also know Dr. Vance Spence who is chair of ME Research UK. This charity has made a big difference to my life so I wanted to give something back. Vance is a great, great man, profoundly intelligent and deeply caring.

I chose to do the skydive after I went for a job interview and the head at the school (The Bede Academy) said I wasn't driven enough to get the job. All my colleagues thought this was hilarious as I am the most driven person they know. I saw the skydive on TV so e-mailed the company and within a few hours was booked. Like I say I am very, very driven and when I say I am going to do something- I do it. I don't know fear- seriously, I don't.

I am also a writer and editor. I have written a book "Charcot's Bad Idea" about how patients with ME, CFS and other illnesses are often not properly investigated and given labels such as "functional" and "conversion disorder/hysteria". My book is available from Amazon.com, [amazon.co.uk](#) and [lulu.com](#). I am also the editor of Dr. Byron Hyde's book "Missed Diagnoses". This book is available from the same sources. Byron is a genius and it will be many years before his contribution to medicine is properly recognized. He is also a great doctor and some of the things he has said to me have stirred me on to fight my illness and I quote him a great deal in my own book.



Due to unfortunate circumstances (see below) Simon Overton was not able to undertake the sky dive as planned. However, he did manage to endure an extreme trek across the glacier instead. He would be very grateful if you could still donate to ME Research UK (featured in WAMCARE's spotlight below). Simon sent the following message to members of the Facebook Group North Face of the Eiger: Skydive for ME Research UK:

"Dear friends- due to adverse weather the jump as planned could not take place. Instead Fiona and I crossed the glacier from jungfrauoch to the monchshutte. A journey that would normally take an hour...it took us several. This was an amazing achievement that really shows what can be achieved despite disability. I would therefore ask that you pass this e-mail to as many people as possible and ask them to give generously to <http://www.justgiving.com/eigerjump/>. Fiona and I are currently recovering in the hotel - just wish wheelchair access in the hotel was a bit better."

WAMCARE would like to thank Simon for his story, and acknowledge his courageous effort in crossing the glacier on behalf of research for ME/CFS.

## WAMCARE Kitchen Corner

### Recipes & Tips for ME/CFS patients and their families

*Welcome to WAMCARE Kitchen Korner! With your input, we will be providing easy-to-make, healthy meals, to help make our time in the kitchen fun, simple and quick. One of the things I have learned in over 50 years of cooking is that cooking can and should be fun. Everyone makes mistakes -- I have thrown away many meals myself, overcooking or even burning food. But fear not! There are ways to salvage any malfunctioning meal, or to make something different out of the messed-up ingredients. And, even if it doesn't taste that great, it can still be good for you. Each time you will learn valuable lessons to improve your cooking results. Have fun with trying out our recipes, and don't forget to send in your own favorites!*

*-Darlene Blair*

For the first edition of Kitchen Korner, I will be addressing some easy tips and ideas on how to prepare food for more than one meal and keep it from going bad in the freezer.

**Always double or even triple wrap your food items.** If I am making something that I think might not be eaten for more than 2 weeks, I use re-closable sandwich or gallon-size freezer bags. First, put the food item in one bag and make sure you squeeze out as much air as possible before sealing tightly. One way to remove air is to close the bag almost completely, and then take a straw and suck the air out until the bag collapses. Then quickly finish sealing the bag. Next, seal that bag inside of another bag, removing enough air to flatten it. If I think the food may be in the freezer for a month, I do the same thing with a third bag. This may seem extreme, but the two outer bags can be reused, since they do not touch the food. When you want to use, just remove the top bag/s and put in your frig to thaw. If you want to reheat in the microwave while still frozen, remove all the bags, and put the food on a plate or bowl (we don't recommend putting anything plastic in the microwave – various sources say it can cause the plastic to leech into food, and it is better to be safe than sorry), cover with a paper towel or other microwave-friendly cover. Be very careful of steam and remove from microwave with a potholder or towel. Remember: safety first! Trial and error

is the best way to learn anything - the lesson learned will stay with you.

**To freeze vegetables and fruit, prepare like this:** Clean and cut to size first. Dry completely and then put uncovered on a cookie sheet in your freezer. If, like me, you don't have room in your freezer for a cookie sheet, use a pie or cake pan, or a dinner plate covered with aluminum foil. Lay the pieces of veggies or fruit on the pan or plate, put it in the freezer, and allow to freeze completely. This usually takes only a few hours depending on how big the pieces are. Once frozen, remove the vegetables or fruit and wrap as described above. Since this can be very time-consuming, you can buy veggies and fruit a little under-ripe and prepare one item a day. That way you can spend what time is needed to clean it well and cut it to required size. These frozen vegetables can be used in salads, stir fries, sauces or for cooking in crock pot (stews and roasts).

**Easy, one-at-a-time cupcakes!** Have you ever had a craving for chocolate cake so bad you can almost smell it cooking? And even if you felt like making a cake or cupcakes with a mix, you REALLY don't need the whole thing? Here's a solution. When I make up a batch of cupcakes, I use paper cupcake liners and undercook them just a little. Take them out of the oven a couple minutes before they are done – when you poke them with a toothpick, it should still be a little coated with batter. As soon as the cup cakes are cool enough to handle, quickly take them out of the cupcake pan and freeze them

by placing them uncovered on a flat pan or plate in the freezer. Once they are frozen through (which will take about 4-5 hours), then double-cover each cupcake individually in air-tight reusable sandwich bags (as described above). This process freezes the cupcakes with just the right amount of moisture. The next time you get a chocolate craving; you can take a cupcake out of the freezer, thaw it out in the fridge or unwrapped on medium power in microwave. One warm cupcake, just like that.

Wait, what about frosting? There are lots of healthy things you can use in place of sugary frosting, such as yogurt, honey, preserves (jam), ice cream, brown or white sugar, nuts, peanut butter or marshmallow. Any of these ingredients can also be combined to make a great frosting. I like mine plain with a sprinkling of confectioners' sugar.

*Have any other tips, ideas or recipes? Is our information unclear? Have any input on how to improve our Kitchen Korner column? Please send us your comments! Let us know if you've tried some of these tips, and how they worked for you. Watch for cooking contests coming in the near future!*

*Take care and be safe. Darlene Blair, Kitchen Korner Ed.*

## Podium: Your Stories of ME/CFS

### If a tree falls in the forest By Jody Smith (<http://www.ncubator.ca>); Reprinted with permission

If a tree falls in a forest, and no one hears it ... does it make a sound? To the chronically ill, this is more than just a philosophical question.

We are people living out of the loop and our connection to the rest of the world can be tenuous. Some of us have more of a social network and some of us have less.

Some people with a chronic illness are very much alone.

Most people don't want to hear the long descriptions of symptoms, the loneliness, the feelings of isolation and alienation. They don't want to be the sounding board for the person who feels they've lost any normal semblance of having a "witness" to their life and existence.

The invalid is very self-absorbed. They have to be. It is a full-time job rebuilding their life and they can't afford NOT to be very, very focused upon this. And they will repeat, and repeat and repeat the things that they need someone to hear.

When the sick one has a revelation, and no one wants to hear it, they are lessened. Their sense of self, of their place in this world, becomes precarious.

I remember being told by a well-meaning friend a few years ago, that I should not think that my value as a person was any less now that I was not able to "produce".

But she was wrong.

Should my value be less? Should my life be less significant than the life of someone who is healthy and productive, connected to others through activities, who makes an impact on the world and other people? No, of course not. But it is less. I started out believing otherwise but over the last four years, I have had it pounded home to me.

In a family gathering, the sick kid may be in the background, on the outskirts. He is the least able to draw attention to himself, because he is weak and easily tired. And he has, really, very little to say. He has no stories about school or work to tell. He has no achievements to share and be praised for.

His biggest achievement lies in the fact that he managed to get out of bed and dressed, and now is curled up in a corner of the couch, while the people around him share their normal life.

Lucky is the sick person who has a champion in their corner. And that champion is likely carrying a heavy load. Because the sick one has a great need to be heard. To be affirmed and acknowledged. To talk about their symptoms, their fears and their hopes. They fear that, like the vampire, they have no reflection. They do not have an effect on the world around them. They throw a pebble into the pool and the ripples are so insubstantial that ... they fear that they may be disappearing. And that they may disappear without anyone even noticing.

That's why I'm here. Because I fell, a long time ago, and I want to be heard.

Can I get a witness?

For more about Jody, please visit her [blog](#) or read her [interview on Bringing the Heat](#)

### How I describe ME/CFS by Rachel Miles

For four years I've been suffering with Myalgic encephalomyelitis (M.E.) and for four years I've been trying to describe it to non-sufferers. I've compared it to a permanent flu, to a never-ending marathon, to insomnia with eventual pointless sleep.

Now that it's been part of me for so long, I realized how I could get the point across. I've not only been living with it, I've been battling with it.

The only thing I can think to compare to is living with an abusive and unpredictable partner.

He tells me what I spend my day doing.

He makes me cancel on friends, and cancel appointments.

He decides whether I can read a book, or listen to music.

He gives me false hope; lets me think that I can achieve an unprecedented step forward, then pulls me back down to his level.

He tells me what I can eat and drink.

He's indecisive, sometimes he lets me do something then changes his mind midway.

He plays tricks on me, and punishes me when I read his mood incorrectly.

He makes me feel sick in the same day that he let me be happy.

He controls how long I sleep, or if I'm allowed to sleep at all.

He makes me feel weak, when inside I know I'm strong.

He makes me feel pain for no reason.

He makes me afraid of what will happen if I defy him.

He knows I dream of leaving him, and reminds me that I'm foolish for doing so.

But what I don't let him know, is that I will one day be free of him, and that his power over me will slowly diminish.

M.E. is a hugely complicated illness, and like abusive people, each form has it's own tricks and tortures. It lets you appear capable and healthy but inside you're constantly physically and mentally exhausted. Remember, next time you see a sufferer, that in energy terms, he or she may have just climbed a mountain. But all they've done is sat and smiled at you. That's what M.E. does.

It fools the body into thinking that it's just run a marathon, climbed a mountain, built a house, gone a week without sleep, but all it's actually done is made lunch.

When a sufferer tells you he or she is a little tired, they sometimes mean is they are so exhausted they could weep. It's a trickster that sleep won't stop. Whether it's got you in a weak or strong hold, it's still powerful.

So please, when you see your sufferer friend, remember that they are fighting a constant battle with their oppressor. If you can't imagine it yourself, don't try. Just support them. They'll need it.

Read Rachel Miles' interview on our website:

<http://www.wamcare.org/rachelmiles.html>

## ME/CFS Org. Spotlight: ME Research UK (<http://www.mereseach.org.uk>)

In each issue of the WAMCARE newsletter we highlight another exemplary ME/CFS Organization. ME Research UK kindly provided us with the following information about their organization, mission and activities. We'd very much like to thank ME Research UK for their co-operation and effort!

### Aims

ME Research UK sees its principal aim as commissioning and funding high-quality scientific (biomedical) investigation into the causes, consequences and treatment of ME/CFS. Recognizing that much of the existing research into ME/CFS has concentrated on psychological interventions designed to "manage" the illness, ME Research UK believes that a program of biomedical research is what is needed, and is what most patients and their careers want to see. To achieve this, researchers with fresh, novel ideas have to be recruited and encouraged to undertake research in this field. This is the most difficult task of all — not least since government funding via the established research agencies is hard to access for groups wishing to research the illness. It is at this leading edge that ME Research UK sees its role: to give help to biomedical scientists for novel research projects that would otherwise not be funded, and to support research groups to the stage where they can apply, on the basis of their previously published work, to major funding agencies for support. The other objectives of the Trust are to provide education about the illness and the need for research (by, for example, producing high-quality professional reviews and reports, and presenting research at meetings and conferences), and to support sufferers by providing information on accessing the services they require. In general, the Trust considers that its mission is to "Energize ME Research" globally.

### Research Projects

The charity funds the work of a growing number of scientists in the UK and worldwide, whose research covers several different areas of interest. To date, ME Research UK has invested over half a million pounds to support biomedical research, and some of the funded projects are shown below. Full details of these and other projects, including the resulting scientific papers, can be found at the [research pages](#) of our website:

- Evaluation of pain and therapeutic interventions. Dr Lorna Paul, School of Health and Social Care, Glasgow Caledonian University
- Autonomic nervous system dysfunction – a clinical study. Prof. Julia Newton, School of Clinical Medical Sciences, University of Newcastle (with co-funding from the John Richardson Research Group and the Irish ME Trust)
- The effect of exercise on the immune and sensory systems. Dr Jo Nijs, Department of Human Physiology, Vrije Universiteit Brussel, Brussels, Belgium
- Non-invasive neuroimaging of the brain. Prof. BK Puri, MRC Clinical Sciences Centre, Imperial College London (with co-funding from ME Solutions and the MRC Clinical Sciences Centre)
- Plasma vitamin D status in ME/CFS. Dr Faisal Khan, Institute of Cardiovascular Research, University of Dundee
- Interleukin-6 and its receptors. Prof. Myra Nimmo, Department of Applied Physiology, University of Strathclyde, Glasgow
- Biochemical and blood flow aspects of ME/CFS in children. Dr Gwen Kennedy, Institute of Cardiovascular Research, University of Dundee (with co-funding from The Young ME Sufferers (TYMES) Trust and Search ME)
- Gene expression studies. Dr Jonathan Kerr, St George's Hospital, University of London (with co-funding from the Irish ME Trust)
- Exercise tolerance and post-exertional symptoms. Prof. Brian MacIntosh and Dr Eleanor Stein, University of Calgary, Alberta, Canada

### Other Activities

The charity's most recent conference was the New Horizons 2008: International Conference on ME/CFS Biomedical Research took place on 6th May 2008 at the Wellcome Trust Conference Centre on the Genome Campus at Hinxton near Cambridge, UK, an outstanding custom-designed venue. The aim of the day was to bring together researchers working towards understanding the biomedical basis of ME/CFS, and the full day's program consisted of invited keynote lectures from scientists from Scotland, England, USA, Canada, Belgium, Sweden and Australia. The media coverage of the conference was far greater than in previous years, and one thousand copies of a 4-DVD set of the conference presentations was produced by ME Research UK, and free copies sent to key supporters, including those who give standing orders to the charity. Other copies were available to interested parties for a nominal cost of £5. The main aim of the DVD was to "energize ME research", and allowed patients who were unable to travel to meetings to hear about the biomedical work in the comfort of their own homes, or to have a copy of the film sent as a gift direct to their GP or consultant.

As well as publicity and fundraising, ME Research UK produces a bi-annual 16-page glossy magazine, Breakthrough (previous issues can be seen [here](#)). Each issue describes aspects of biomedical research, and explores more fully the research that ME Research UK funds, and has a print run of 4000.

### Location, Staffing and Income

ME Research UK was founded by Dr Vance Spence and Mr. Robert McRae in 2000. With Roger Jefcoate CBE as founding patron and The Countess of Mar as patron, its official opening was in May 2001. The office is based at 'The Gateway', a purpose-built centre in Perth, Scotland, which is home to a range of voluntary organizations under the auspices of Perth and Kinross Association of Voluntary Services (PKAVS).

In the past, ME Research UK has been instrumental in forming a Cross Party Group on ME at the Scottish Parliament, to provide a forum for the concerns of patients and careers. In addition, has produced a range of high-quality documents, including an extensive response to the Chief Medical Officer's Working Group report on CFS/ME, an overview of ME/CFS research funding sources in the UK, and a document on Care Pathways which was submitted to the Scottish Executive of the Scottish Parliament. On the research front, it brings together a team of scientists to form a Scientific Advisory Panel to review the merit of applications to ME Research UK for research funding, and commissions and funds a number of research projects, the results of which have now been published in professional scientific journals, and are summarized on the website. It also has a Friends of ME Research UK scheme, and established links with other ME/CFS charities and groups.

At 2009, the charity has a group of trustees, and one full-time employee (Dr Neil Abbot), supported by a part-time administrator and part-time fundraiser. Fortunately, it also has the support of a core group of trusted volunteers who take on specific defined tasks, and staffing costs can be kept to a minimum. In 2007/8, ME Research UK's Income was £264,862, a figure that should be compared with Cancer Research UK's income of £476,559,000 for the same period. This comparison illustrates the scale of the task involved in unraveling the biomedical basis of ME/CFS. Experience has convinced the trustees and staff of ME Research UK that its funding strategy must mirror that of other illnesses, such as cancer research which obtains most of its revenue from private sources and ground-level fundraising. It is a huge task, but much can be achieved by a determined and collaborative ME community.

# WAMCARE Photo Contest

## Theme: COLOUR!

Welcome to WAMCARE's first international competition! This competition will be a photography competition on the theme of COLOUR! The Grand Prize for the best photo will be one month of FREE Wellness Coaching from Gyan Baird ([epiphanycoaching.com](http://epiphanycoaching.com); [twitter.com/TheDailyHerb](https://twitter.com/TheDailyHerb)). Gyan has been coaching women since 2000, and specializes in helping those with chronic illness in eight different life areas.

### Contest Rules:

- Members and volunteers for WAMCARE (with the exception of BOD members) and members of the public are eligible to enter the competition.
- Persons who enter may be of any age and live anywhere in the world.
- Entrants must ensure that the photo(s) they are submitting are their own work and they have full copyrights to their photos.
- Entries must be sent via e-mail attachment to [newsletter@wamcare.org](mailto:newsletter@wamcare.org) by October 1, 2009.
- Persons may enter up to 2 photos by the deadline; late entries will not be accepted.
- If an entry includes identifiable persons, then the photographer must get consent from all of these subjects before entering said photo/s.
- Entries must be no larger than 1MB and in JPEG format.
- Photos must not be created/alterd digitally using computer programs such as Photoshop, beyond basic lighting/red-eye corrections.

When submitting your entry(s), please include your name, age and country in which you live, a brief description of the photo, and the type of camera and if possible the type of lens used. These details will be kept confidential until after the winners have been announced, so as to not influence the voting. All photos entered into the contest will be displayed as they are received on the WAMCARE [website](http://www.wamcare.org) and any person can vote for their favorite photo.

The winner and 2 runners up will be notified by email on October 16, 2009 and all three winning photos will be displayed in the following issue of the WAMCARE newsletter and permanently on the [website](http://www.wamcare.org). Good luck, photographers! We are excited to see your entries. Further questions regarding the photo contest can be directed to [contest@wamcare.org](mailto:contest@wamcare.org)

# Have your voice heard!

WAMCARE exists to support the ME/CFS community. We love hearing from you! [info@wamcare.org](mailto:info@wamcare.org) or [newsletter@wamcare.org](mailto:newsletter@wamcare.org)

- **Tell us your story** – we'll post in on our website, and may feature it in the Podium Section of our newsletter!
- **Volunteer** – visit our [website](http://www.wamcare.org) for information on how you can help, or email [volunteer@wamcare.org](mailto:volunteer@wamcare.org) Volunteer activities can be as simple as "tweeting" our campaign promotions, participating in letter-writing campaigns, or as committed as becoming a volunteer member and having a big hand in all our organizational decisions and fundraising campaigns. View our [volunteer agreement](http://www.wamcare.org).
- **Write an Article** – we are always looking for well-researched articles on the latest treatments and research, experiences of ME/CFS, what it's like to have a friend or family member with ME/CFS (our Helping Hands section), how you cope emotionally with chronic illness etc. Tell us what you'd like to write about and we'll work with you! Newsletter article submissions should be approximately 500-750 words. Email [newsletter@wamcare.org](mailto:newsletter@wamcare.org)
- **Submit Recipes** and cooking tips to our Kitchen Korner! Email [newsletter@wamcare.org](mailto:newsletter@wamcare.org)
- Have a community ME/CFS support group, association or blog? Let us know and we'll add you to our [website resources](http://www.wamcare.org)
- **Give Feedback** – did we make a mistake? Is there information that is important for us to know? Have questions, suggestions, comments? Let us know so we can make changes that will serve you better. (*Note: our website does not yet have complete information – we are working on it* ☺) Let us know what you think of our newsletter – what do you like, what don't you like, what should we add?
- **Participate in our Photo Contest** – we'll be holding more contests as time goes on, including contests for art and crafts, writing and more. Have a contest idea? Let us know!
- **Donate** – we are currently raising funds to attain our 501(c), federal non-profit status. This accreditation will open more doors for us, such as allowing us to collect donations from our [Facebook Cause](http://www.wamcare.org) and registering our charity internationally. All excess funds raised goes directly to research and awareness campaigns – we have very little 'overhead' costs, being an all-volunteer organization run from our volunteers' computers.

*WAMCARE thanks you for reading this first issue of our newsletter. Please feel free to forward the email to anyone you think may be interested. To subscribe to our email version of the newsletter, just send a quick email to [newsletter@wamcare.org](mailto:newsletter@wamcare.org)*