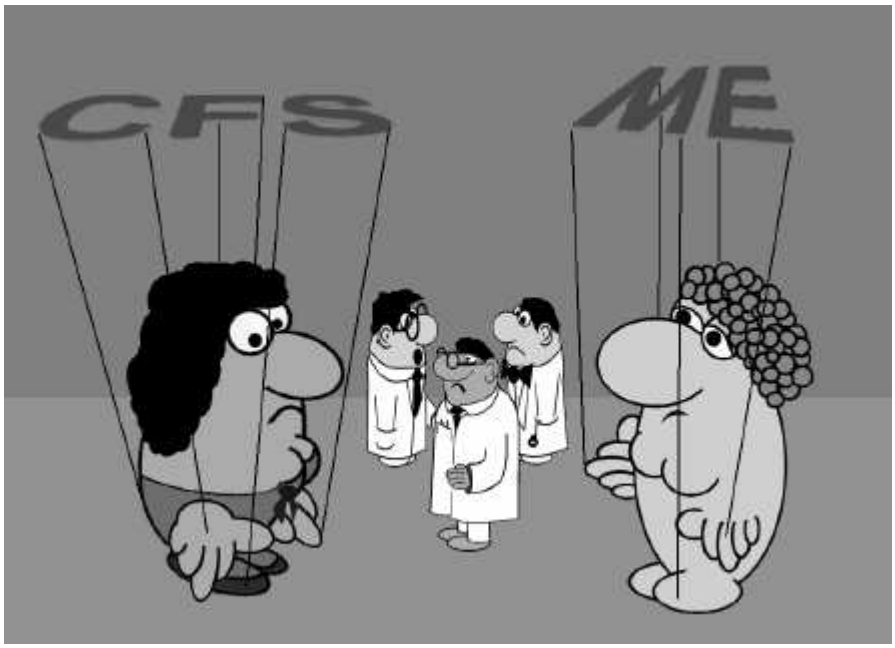
BBME

Support Group

"Breaking the Isolation"

Welcome to Our January 2014 Newsletter

A Note from Maxine: Hope you all have recovered from the festivities. I am still recovering from New Years Eve. I cancelled the family coming around for New Years day meal. What resolutions did you make? Or are you like me and made one year's ago to never make any more!



They all say that CFS/ME controls their lives so there's obviously more to it that meets the eye.

With thanks to Invest in ME (www.investinme.org) for their kind permission to reprint this cartoon from the calendar available to download from their website.

Contents of January's Newsletter

DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Committee, nor the Bury/Bolton ME/CFS Support Group. Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Dates For Your Diary

Longsight Meetings Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). There is a car park and blue badge parking on the street and the building is wheelchair accessible. Entrance is £1. Tea, decaf coffee, water, biscuits, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

Thursday 16th January 7:30pm. **Community Care Assessments**: Jeff Glasser, group member and former social worker will talk to us about community care assessments from Social Services, from ringing up to ask for an assessment to how to complain when things go wrong. A member has recently been awarded care services after being wrongly denied for many years, and can offer her experience as well.

Neuro Support Groups: These groups, run by Greater Manchester Neurological Alliance, provide information, advice and support for people with any type of neurological condition and/or their carers. Call 0161 743 3701 or visit www.gmneuro.org.uk for information about meeting times and locations.

Yoga Classes: Are **3:00pm-4:15pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX**. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Contact Olivia on 07746 197511, or olivia@oliviayoga.co.uk for more information. **Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.**

Radcliffe Socials: No meeting in February 2014 due to the refurbishment for the Sparkling clog. Next social to be confirmed.

Prestwich Socials: Unfortunately, due to poor attendance, our Prestwich socials at the Orange Tree are in danger of being cancelled. We understand people may be unwell, or have other things on that day, but they were set up in response to demand and if numbers do not improve, we may have to stop these and just have our Harwood and Radcliffe meetings. Now the weather is going colder, numbers may drop even further.
Someone has to commit to attending every month to be there, and on more than one occasion, they have been the only one there, and due to their own poor health, this is not fair on them. Februarys meeting is provisionally set for the usual second Wednesday of the month- **Wednesday 12th February at 2pm. Please check on Facebook first to check it is still going ahead, as that's the quickest and easiest way, or call Maria on 07867862341 if you are not on Facebook.** We are sorry to have to do it this way for now, apologies those not online, but it is either this, or stop them altogether.

If you are thinking of attending any of our socials, whether you are a new member or a member who hasn't been able to attend for a while, please remember that you can bring along your carer or a friend. We don't bite, but we understand that meeting new people or if you have been house bound for a while, it can be quite daunting going out by yourself and we look forward to seeing you.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.

Reminders

Social Media. Please follow us on twitter on: @BBMECFS
Also our Facebook page just for members is www.facebook.com/groups/buryboltonmecfs/
Don't forget our own web page http://www.mesupportgroup.co.uk/

Urgent Volunteers needed for: Writing up an overview of what speakers said at the meetings, there is a tape recorder to help. A short summary is fine with highlights of important bits. Someone still needs to write this please and we really struggle on the night to do this. We are looking for volunteers who can help with all activities of running the group, if you have a particular skill (or just a pair of hands!) you think you can contribute, or are up for a certain task, please contact Caroline. **We are really struggling to keep the group going; we are just a small number of sufferers, so we need all the help we can get please. Please contact Caroline on caroline@mesupportgroup.co.uk or 01204 525 955 for more information.**

Newsletter Articles: Please carry on sending us anything you would like to share with the rest of the group, whether it is a whole page, or just a few lines, it all counts! It could be recipes, tips, experiences, book reviews, etc. Please send your contributions to: maxine@mesupportgroup.co.uk, or if you are unable to email, post to Maxine Fairhurst, 33 Heath Avenue, Summerseat, Bury, BL0 9NU

Equipment to Borrow: We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846.

Amazon: The group gets 5% commission when you shop at www.amazon.co.uk, but only if you follow the link from our own website www.mesupportgroup.co.uk. Please remember this when spending your Christmas money in the Sales.

Benefit and Work guides: Remember, for anyone filling in benefit forms or if you have appeals/tribunals, we have excellent guides available via post or email (saves us funds). Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk.

Radar keys: We have Radar disabled toilet keys available at cost (£2.35, plus 50p if posted, or you can pick up at our Harwood meetings). Small headed or large headed (for those with dexterity problems). Contact Caroline on 01204 525 955 or email caroline@mesupportgroup.co.uk

Helpful GP's. Don't forget, we have a list of helpful GP's! There are only 13 on it at the moment, but if you have a sympathetic or helpful GP, please let us know, as people ask us for one in their area all the time. 01204 525 955, caroline@mesupportgroup.co.uk.

February Breathworks Course.

We are delighted to confirm we have organised a Breathworks course to be run at Longsight Methodist Church Hall in Harwood, (BL2 3HX) starting Monday February 17th 1:30pm-4pm for 8 weeks. This is mindfulness for living well with pain and illness. Quite a few of our members have been on the course and have benefitted from it, but the course is run in Manchester, so people have difficulty in getting there, so we thought we would try and obtain funding to run a course in Bolton and see how it goes. Annie and Sue, the course trainers have been very kind to do this for us.

This course usually costs £180, concessions are £140, but the trainers run it for £50 a head, at cost, including the course materials which costs £35. We have obtained a grant from the Provincial/Walsh Trust for Bolton to further subsidise the course, and we can offer places at only £40 per place. This includes all the books and CDs. Places are very limited and can only be offered to members with M.E/C.F.S and not carers unfortunately, although carers are welcome to come in their carer role to assist.

PLACES ARE ON A FIRST COME, FIRST SERVED BASIS. You must send your booking form and cheque back ASAP to reserve your place. I know from when I asked last year, there was lots of interest, so please do not wait to send in your form, as you may be disappointed.

On a personal note, this has been really difficult to organise for me and I am ill, just like you. My M.E/Fibro brain really struggled to sort everything out that needed doing. I have done this so that people can benefit from it as I have heard nothing but good things about this course. Please understand that everyone helping with the group is very ill and doing it so that others can benefit from help and support. Things to do not just appear, so much work goes unseen behind the scenes, sometimes it is taken for granted all that committee and helpers do, at the expense of their own health.

Please see the enclosed flyer for details on the course and return it to me with your cheque if you wish to attend. Caroline.

How does Rituximab Relate to Other ME Research?

(sorry its long, but we think it's worth the read in full rather than over two newsletters. Maxine)

This article first appeared on Phoenix Rising, republished with thanks. http://phoenixrising.me/archives/18544.

Andrew Gladman *explores the current research climate of ME/CFS, discussing how existing research ties into the emerging autoimmune hypothesis.*

Throughout the history of ME it is safe to say that understanding of the condition and the research itself has been somewhat fractured at best and lacking significance in many areas. In the last 30 years, following the Lake Tahoe outbreak which piqued the interest of doctors and media, little progress seems to have been made in terms of physiological understanding of the disease processes involved, perhaps due to the stigma of ME as a purely psychological entity which is only in recent years being shaken off.

This struggle clearly speaks to both the complexity of the illness in general and the misunderstanding that many researchers and doctors still have of it to this day. The causal theories proposed range from chronic viral infections, mycotoxins, stress, psychological stress,

immune dysfunction and many more; yet none of these have been shown to adequately represent the patient population as a whole or to account for the presented symptoms and varying degrees of disability.

The fractured and inadequate biomedical research to date has left the majority of patients with treatments such as Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) as recommended by the National Institute of Health and Care Excellence (NICE). However, the heavily promoted PACE Trial – which endorses these treatments – has itself come in for a large amount of criticism with regard to various aspects of its design, data management and conclusions: and is seen by many patients as being unrepresentative of their own experiences. This leaves the only other option for patients as specific symptom relief, which many GPs are still unwilling to prescribe; alternative psychological treatments, such as the Lightening Process and Mickel Therapy – coming with a costly price-tag and no guarantee of success; and off-label treatments such as Valcyte or Ampligen, which while of anecdotal benefit to some, are not yet approved for use, and can attract another heavy cost and the risk of quite serious side effects.

A positive change in momentum…Despite this we do seem to be witnessing a positive change in momentum for ME research and in terms of official recognition that ME has a physiological foundation. In 2011 the Medical Research Council (MRC) announced that more than £1.6m was specifically available for biomedical research into ME/CFS – funds that have now been allocated to specific projects. Alongside this came the establishment of the CFS/ME Expert Group chaired by Prof. Stephen Holgate with the aim of exploring new ways in which to encourage research into ME/CFS; while in America, the Chronic Fatigue Initiative has been pivotal in encouraging collaboration between researchers in many different areas and trying to raise awareness of ME.

Prof. Holgate's Expert Group has undoubtedly helped with the establishment of multiple initiatives including the UK CFS/ME Research Collaborative (UK CMRC) in April this year, and as a joint charity initiative we have seen the forming of an ME Biobank at University College London – which received a welcome boost from the US National Institutes of Health recently. The annual Invest in ME International ME (ME/CFS) Conference is at the forefront of this momentum change, meaning there are now more opportunities to present and showcase the latest research from new and experienced ME scientists from across the world. Other than something of a misfire in the form of XMRV, the growing research community seems to be going from strength to strength, despite the slow action of other groups such as the US Centres for Disease Control and Prevention (CDC).

Undoubtedly one of the most recognised presences in recent years at the Invest in ME conference has been the Norwegian Doctors Oystein Fluge and Olav Mella. In 2009 Fluge and Mella's Rituximab pilot study seemed to show major transient improvement for all 3 patients and in doing so attracted quite a lot of attention. A follow up study published in 2011 built upon this, showing further transient improvement rates of 67% in a double-blind placebo controlled study. These results created a clear buzz in the ME community and with data from the maintenance trial of Rituximab presented at the 2013 IiME Conference and due for publication soon – promising positive results gained by extending the treatments over a longer period and aimed at maintaining improvement – it is clear that Rituximab is one of the most positive developments in ME research for decades. Positive, not only as a potential treatment for some, but also as a breakthrough in understanding of the physiological cause of ME: implying as it does that autoimmunity may lie at the root of the illness.

XMRV has taught us not to get carried away before the data is published and reliably replicated, but it's clear that these studies are incredibly important going forwards – with the

potential to change the way researchers and doctors alike approach ME. The importance of these further studies is underlined by the impressive response some of the Norwegian pilot study patients experienced. When asked how they were doing 4 years after the pilot study took place, one of the patients said, “Right now I’m living an active, normal life as a full time student and I really appreciate that the doctors at Haukeland gave me the chance and the health to do what I want in my life, I will never take this lifestyle for granted!” Considering she has received no further Rituximab treatments, it is clear that this drug has a lot of potential!

Autoimmune theory and other research findings…One important question that the autoimmune theory does raise is how all the other research findings tie in with it. There are numerous researchers currently looking into a plethora of different aspects of ME and it is important to give each one careful consideration. Each area has the potential to represent one piece of a very complex puzzle and only once each is weighed against the others can we discover where each piece goes and indeed whether the piece we are looking at is even a part of the overall puzzle.

For example, Montoya and the Stanford ME/CFS Initiative (Summer 2013 Update), and the projects from Lipkin and Hornig, are looking in detail at the presence and prevalence of pathogen involvement in ME. Given the historical and current causal theories posited by pathogen involvement, many patients and doctors are looking forward to the results once they are published.

It is perhaps difficult to make the initial connection of pathogens to an autoimmune theory and it is of note that many of the pathogens commonly identified or associated with ME are prevalent in similar numbers within the general population. Therefore the question may be why the immune system suddenly starts to respond to them, and becomes a compounding problem for ME patients.

This logically leads to further questions as to whether these pathogens are re-activating and hence require an ongoing immune response or whether the immune system is over-responding to otherwise inert pathogens. Perhaps this could point to an important part of the underlying disease mechanism whereby the immune system is overreacting to the mediators released by the chronic low level pathogens everyone harbours – although as yet these theories are speculative. Another answer could come in the form of dysregulated sensory gating. A recent study in Japan (Health Rising Article by Marco) discusses the possibility of troublesome sensory gating in ME at some length, specifically the potential for this to explain the sensory overload many patients experience. It is interesting to note that this could come as a result of the autoimmune process targeting the neurones of the sensory nervous system – as was originally proposed by Fluge and Mella following their 30 patient trial.

Another researcher undertaking ground-breaking work in the ME field is Professor Julia Newton. Her studies looking into the muscle dysfunction along with the effect of lactic acid upon these muscles and the effect of low blood pressure in ME patients are areas that have not received much research attention in recent times. However both represent intriguing possibilities for physiological problems in ME, possibly even pointing towards the vascular system as a potential autoimmune target bringing with it possible direction for treatment – this is one of the reasons why her results promise to make some very interesting reading. This is one area of research however where the link with autoimmunity would appear to be more subtle – for this reason it is all the more exciting that Professor Newton has been looking into Rituximab herself.

Of all the links between different research areas and the effects of rituximab, Dr. Amolak Bansal’s work into B-cells represents one of the strongest: as would be expected considering

the B-cell depleting action of rituximab. Published in March 2013, his research was aimed at intensive B-cell immunophenotyping in order to identify whether there were any consistent B-cell abnormalities in the general ME/CFS population. It is very interesting to note that this study came about as a direct response to positive results shown in rituximab trials – underlining the importance of the rituximab trial in shaping new research directions. Prior to this study the research literature on the topic of B-cells in ME, like many areas of ME research, was inconsistent and sparse. The results of this study however led Dr. Bansal and his team to conclude that there was perhaps a "subtle tendency to autoimmunity."

Of all the research mentioned, this has the clearest link to the autoimmune theory and its importance is underlined by the desire of Professor Jonathan Edwards and the team at UCL to undertake a similar trial as a preliminary stage of their planned UK rituximab trial – a preliminary trial that thanks to the fundraising efforts of Invest in ME is able to begin in the near future. Professor Edwards, in a recent interview with Phoenix Rising, explained that one of the primary aims of a UK rituximab trial would be to connect the data from the Norwegian study with the B-cell abnormalities Dr. Bansal has reported.

The immune dysfunction hypothesis is nothing new in ME/CFS, being proposed numerous times throughout the history of the disease – certainly the signs have always been there that the problem may stem from the immune system. Many of the drugs patients use off label such as Ampligen and Imunovir act primarily through modulation of the immune system and its aberrant responses, while drugs such as Valcyte act through antiviral properties but still exhibit an immunomodulatory effect. There are many reports of patients improving on these drugs and it's difficult to not encounter the remnants of the outrage many patients feel towards the denial of Ampligen approval numerous times over the years.

Valcyte itself has been heralded many times by patient subgroups as a treatment that has helped them turn the corner. However a recent study by Kogelnik and Montoya has had disappointing results – perhaps the antiviral properties help a sub-group for whom chronic viral infections are a major factor but these results do not confirm many patients' beliefs that viruses are to blame. The results simply do not appear as positive as many hoped for. There is the possibility that immunomodulation might explain the improvement in patients for whom the proposed autoimmunity may be the problem, however more research will be required to confirm or deny this. The multi-armed trial involving both Valcyte and rituximab, proposed by Dr. Kogelnik and OMI-MERIT, could be the best way to determine whether Valcyte has a role as an ME treatment.

Future UK Rituximab trials…Of all the changes Rituximab and the autoimmune theory can and have been making, the most striking is likely the discussion and thought it has provoked among researchers, doctors and patients the world over – influencing the way researchers consider new trials and how patients view the future of ME. Many organisations have taken note of this through public declarations, and the ME Association in the UK have pledged both their interest in this emerging research area and a not insignificant sum towards a UK trial.

Dr. Charles Shepherd has made many comments regarding Rituximab and has partaken in online question-and-answer discussions on the topic. The ME Association issued the following statement early in July for example, "we have consistently maintained that the positive results from the initial case study reports indicate that Rituximab could form a very significant development in finding a drug aimed at treating the underlying disease process in at least a sub-group of people with ME/CFS". While Dr. Shepherd had this to say regarding the autoimmune hypothesis: "I'm not yet convinced that ME/CFS is what doctors term an autoimmune disease. This is because from what we know so far there is no consistent and

robust evidence relating to autoimmunity in ME/CFS that links specific autoantibodies and autoimmune tissue/organ damage or functional change to actual symptoms."

Dr. Shepherd went on to explain that a "wide range of immune system abnormalities have been reported in ME/CFS. These include the presence of low levels of autoantibodies in some people", and concludes that "a sub-group of people with ME/CFS have what I think is best described as an autoimmune component". Dr. Shepherd has also made it clear that the ME Association is very much in favour of supporting a UK rituximab trial proposal from a financial standpoint, provided that such a proposal meets the standard peer review process required by the Ramsay Research Fund.

Conclusion…It is clear then that research into ME seems to have made a positive turn, with more unique directions than ever and many initiatives to help researchers and patients alike. Certainly there is still work to be done in interpreting how evidence such as muscle fatiguability possibly due to excessive lactate build up, Post-Exertional Malaise and mitochondrial dysfunction fit into the puzzle; but now the evidence of physiological abnormalities is mounting, the interpretation and conclusions can begin to be made.

In Rituximab there is not only the offer of a potential treatment even if only for some, but also evidence for an autoimmune causation which could form the central trunk in the tree of ME research for the next few years, and from which all other areas could form the varying branches. The importance of Rituximab research in ME is clear from the comments of researchers, doctors and charities alike. With a phase III multicentre trial now close to being fully funded in Norway and due to commence early next year; plans in place for a smaller replication and exploratory trial at University College London; and early plans for further trials in America at the Open Medical Institute: it is clear that this development is being taken seriously.

It is important to remember that we are still likely dealing with multiple diseases under one larger heading as Prof. Stephen Holgate has outlined on numerous occasions. Rituximab is unlikely to help everyone with ME, however initial trials are incredibly positive and imply that for perhaps a significant sub-group, autoimmunity may be the causal disease mechanism. And it is not beyond the realms of possibility that there may be several different autoimmune conditions under the heading of ME/CFS.

If an autoimmune group can be identified within the larger ME/CFS group in the future, there is a strong possibility that this autoimmune group would be removed from the ME/CFS label and identified as a unique autoimmune entity. This group would likely be given a new name more befitting of the clinical findings. This could benefit those remaining in the ME/CFS group by removing those suffering from an autoimmune disease and allowing more relevant research to continue. Undoubtedly the research going forward has a direction that has been lacking in the past and with this, the potential for new treatments in the near future must surely follow. Who knows where we could be in another 5 years!

Six Common Misconceptions About the Chronically ill

What those who are healthy rarely understand about those who are sick or in pain

Toni Bernhard is the author of the award-winning "*How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers"* and *"How to Wake Up: A Buddhist-Inspired Guide to Navigating Joy and Sorrow"*. Until forced to retire due to illness, Toni was a law professor and served as dean of students at the University of California—Davis. Her popular blog,

"Turning Straw Into Gold" is hosted by *Psychology Today* online. She can be found online at www.tonibernhard.com.

More often than not, chronic illness and chronic pain go hand-in-hand, so when I use the term "chronically ill," I'm including people who are in chronic pain. My hope is that it won't be long until these common misconceptions become uncommon ones, as people become educated about what life is like for those who suffer from chronic illness (130 million in the U.S. alone).

Misconception #1: If people look fine, they must feel fine Whether healthy or sick, it's good for most people's morale to try and look nice when they go out. I go out so seldom that I make an effort to look my best when I do. Sometimes I feel like a young child again, playing dress-up. That said, I always hope that if I see people I know, they'll remember that looks can be deceiving.

I've had people say to me, "You look great." I know they're trying to be nice, so I make an effort to respond graciously (with something other than, "Well I don't *feel* great," spoken in an irritated tone of voice). But the truth is...there I am, "looking great," while my body is pulsating with flu-like symptoms, my muscles are aching, and my heart is pounding so hard that sometimes it feels as if it must be visible to others on the outside of my body!

When people see someone whom they know is struggling with his or her health, I hope they'll remember that they have days when they leave the house looking great but feeling terrible, perhaps from a bad night's sleep or from lingering symptoms of an acute illness. If they understood that this is how most chronically ill people feel all the time, this common misconception would be well on its way to becoming an uncommon one.

Misconception #2: If people's illness or pain were truly physically based, their mental state wouldn't affect their symptoms If you're not sick or in pain, I invite you to try this simple two-part exercise, so you can test this misconception out for yourself.

Part One. The next time you feel under stress—maybe you're angry at someone or worried about something—stop; close your eyes; and pay attention to how your body feels. Can you feel that your muscles have tightened? In addition, your heart may be beating faster and your whole body may be pulsating. You may even have broken out in a sweat. These are just some of the ways that mental stress manifests in the body of a healthy person.

Part Two. Keeping that stressful mental state in the forefront of your awareness, now imagine that you suffer from chronic pain and/or illness. What would happen? Your body would respond to the mental stress the same way it did for you as a healthy person. But now, that response would be *in addition to* your chronic, everyday symptoms. And if those symptoms happen to overlap with the physical symptoms that accompany mental stress—tightened muscles, racing heart, pulsating body and maybe even sweating—you can see how a person's mental state can easily exacerbate the physical symptoms of chronic illness.

This is why keeping mental stress to a minimum is so important for the chronically ill. It's important, but often impossible. Why? Because we live in the same stressful world that healthy people live in.

Misconception #3: Preparing for an event by engaging in "radical rest" will assure that when the occasion arrives, the chronically ill will be in better shape than had they not rested. I can "radically rest" for several days in a row before a commitment (I've had some events for my new book that I've been doing this for) and yet, on the day of the event, feel

terribly sick. Resting may increase the odds that I'll be less sick than usual on the day of the event, but it's no guarantee.

When my granddaughter, Cam, turned six in September, I asked my husband take me to her birthday party for a short time since it's only an hour's drive away. It would have been a treat to watch her interacting with her friends (something I rarely get to see) and to meet their parents. I rested for four days before the event. But that morning, I called my son in tears to tell him that I was too sick to attend.

This misconception can lead to serious misunderstandings. For example, a week later, I was able to attend an event for my book. This could make it appear that I was choosing the book event over my granddaughter's birthday party, but I was not (and thankfully my son understood this).

The truth is that the same amount of resting before each of the two events simply did not yield the same results. That's the unpredictability of living day-to-day with chronic pain and illness. Not only can it be a source of disappointment and sadness, but if we don't treat ourselves kindly and with compassion, it can lead to self-recrimination and be a source of terrible guilt.

Misconception #4: If chronically ill people are enjoying themselves, they must feel okay. When an important occasion arises, people who are chronically ill have learned to put up with the symptoms of illness, including terrible pain, so they can try to enjoy what they're doing, especially the enriching experience of being in the company of others. Please don't assume that a person who is laughing is a person who is pain-free, ache-free, or otherwise feeling good physically.

Misconception #5: Stress reduction techniques, such as mindfulness meditation, are a cure for chronic pain and illness. Stress reduction techniques can be effective tools to help with symptom relief and to help cope with the mental stress of ongoing pain and illness. However, unless a person suffers from a distinct disorder called somatization (in which mental or emotional problems manifest as physical symptoms), stress reduction techniques are not a cure.

Misconception #6: Being home all day is a dream lifestyle. This misconception arises because, when healthy people entertain this thought, they're not contemplating being home all day *feeling sick and in pain*! Put another way, would they say: "I wish I could be home all day with pain that no medicine can relieve"; or "I wish I could be home all day with flu-like symptoms that keep me from being able to read a book"? I doubt it.

My heartfelt wish is that people will become educated about what life is like for the chronically ill so that, some day soon, we can say that these are six **uncommon** misconceptions.

No Health & Safety

A backward glance at yesteryear.

- My mum used to cut chicken, chop eggs and spread butter on bread on the same cutting board with the same knife and no bleach, but we didn't seem to get food poisoning.

- Our school sandwiches were wrapped in wax paper in a brown paper bag, not in ice pack coolers, but I can't remember getting e.Coli. Almost all of us would have rather

gone swimming in the lake or at the beach instead of a pristine pool (talk about boring), no beach closures then.

- We all took PE ..... And risked permanent injury with a pair of Dunlop pumps instead of having cross-training athletic shoes with air cushion soles and built in light reflectors that cost as much as a small car. I can't recall any injuries but they must have happened because they tell us how much safer we are now.

- We got the cane for doing something wrong at school, they used to call it discipline yet we all grew up to accept the rules and to honour & respect those older than us. We had 50 kids in our class and we all learned to read and write, do maths and spell almost all the words needed to write a grammatically correct letter....., FUNNY THAT!!

- We all said prayers in school irrespective of our religion, sang the national anthem and no one got upset.

- Staying in detention after school caught all sorts of negative attention we wish we hadn't got.

- I thought that I was supposed to accomplish something before I was allowed to be proud of myself.

- I just can't recall how bored we were without computers, Play Station, Nintendo, X-box or 270 digital TV cable stations. We weren't!!

- Oh yeah ... And where was the antibiotics and sterilisation kit when I got that bee sting? I could have been killed!

- We played "King of the Hill" on piles of gravel left on vacant building sites and when we got hurt, mum pulled out the 2/6p bottle of iodine and then we got our backside spanked. Now it's a trip to the emergency room, followed by a 10 day dose of antibiotics and then mum calls the lawyer to sue the contractor for leaving a horribly vicious pile of gravel where it was such a threat.

- To top it off, not a single person I knew had ever been told that they were from a dysfunctional family. How could we possibly have known that?

- We never needed to get into group therapy and/or anger management classes. We were obviously so duped by so many social ills, that we didn't even notice that the entire country wasn't taking Prozac!

Late Edition

Here's a brief roundup of some of the recent articles covering CFS/ME during December.

Jessica Taylor, 22, who spent years bed-ridden with CFS/ME has set up Share a Star to help children who spend their lives indoors due to the illness. Her sister Ruby helped Jessica set up the charity, and said the impact on the family was much more evident at Christmas time. They send special gifts and cards to the children, and treat them as special Stars. **Source: Jessica Taylor with ME begins 'Share a Star' charity – BBC – 18th December**

The 2nd International Symposium for CFS/ME took place in Australia and many researchers presented their work. They covered many topics including a description of how CFS/ME research in the UK is being co-ordinated under the UK CFS/M.E. Research Collaborative.

Researchers are also focussing on mitochondrial function, improving diagnostic tools and how diseases "talk" to the brain. As there was so many presentations, here's a brief summary of some of them:

- A study of 1,200 young people with CFS/ME in Australia found the average duration of illness was 5 years (range 1-16 years) and at 5 years, 60% had recovered, and at 12 years, 88% had recovered. 1/3rd said they had to consciously manage their workload. Of those recovered, some only rated their health at 8/10, but were leading relatively normal lives.
- Work by Richard Kwiatek showed ME/CFS may share biological features with anxiety and depression, although data shows they appear to be 2 distinct disorders.
- Dan Peterson reviewed the diagnostic and management plan for patients with CFS/ME and concluded there is insufficient home and medical care. He also observed CFS/ME appears to be similar worldwide, but the way it is treated is different. Dan estimated about 19m people have CFS/ME worldwide.
- Rosamund Vallings spoke about how she educates GPs on how to diagnose and manage CFS/ME. She pointed out that the average GP has a minimal grasp of immunology and biochemistry, and with time constraints (usually only 15 minute consultations) they also find the illness too complex to manage.

In her closing statement Dr Elizabeth Unger stated that CFS/ME is a big public health problem with a significant economic impact. Interventions are needed such as education of the public, primary care physicians, nurses etc.

She questioned the need for a case definition, as it will not solve the problem of diverse aspects of the illness. A multisite review of the illness is also needed, using a large number of measuring techniques.

She also discussed the PROMIS initiative measuring 471 patients in the US. There was less diversity than expected, and most respondents were white educated "upper class", in a higher income bracket. The duration of the illness was long, and some symptoms were common to all, but there was still a broad diversity of symptoms. The study is ongoing as the results will need to be combined with biomarkers, and compared with other illnesses e.g. chronic pain. **Source: The 2nd International Symposium For CFS/ME – ProHealth – 29th December**

The effectiveness of Gene-Eden-VIR, a dietary supplement, was recently tested on a sample of 100 people. They were infected with the Human Papillomavirus, Epstein Barr Virus, Herpes Simplex Virus, Human Cytomegalovirus, and Hepatitis C Virus. The subjects all reported a feeling of long-term fatigue at the start of the study. After taking Gene-Eden-VIR, 72 out of 98 people reported a decrease in general fatigue, 56 out of 90 reported a decrease in physical fatigue, and 36 out of 79 reported a decrease in mental fatigue. The study is now being used to promote Gene Eden VIR as a partial solution for CFS/ME. **Source: Gene-Eden-VIR is Effective Against Fatigue: Results of a Post Marketing Clinical Study Conducted According to the FDA Guidelines - The Centre for the Biology of Chronic Disease – 28th December**

Researchers recruited 30 patients with CFS/ME and 25 people without the disease to compare differences in immune system. They found significant difference between the 2 groups which suggest significant impairments in immune regulation in those with CFS/ME. They also concluded these differences may have similarities to a number of autoimmune disorders. **Source: The Role of Adaptive and Innate Immune Cells in Chronic Fatigue Syndrome – ProHealth – 28th December**