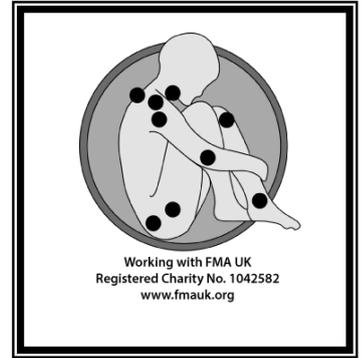




Welcome to Our October 2015 Newsletter.

Note from the Editor Maxine: October the month of the trick or treaters. Love them or loath them I've got the poster for you to use. Please support Caroline with her head shave!



Monthly focus.

Please read the article about hydrotherapy ASAP, as registration for the initial course closes on 9th October. It isn't possible to register yet for the next continuation course in January, but you can email them to express interest.

Also, ignore the information about having to be a Bolton resident: any member of our group is eligible, as we are members of BNV for this financial year.

Dates For Your Diary:

Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are now held at The Wildlife Trust Centre, 499/511 Bury Rd, Bolton, BL2 6DH.

They occur on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). The building is past Morrisons/Home Bargains/Brightmet Health Centre on the right hand side as you go into town, very near the junction before you turn onto Crompton Way from Bury Rd.

Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, orange squash, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

Thursday October 15th 7.30pm: Hannah Carrington Bolton CCG's Engagement Officer

Thursday November 19th 7.30pm: Bring and Share Supper Our very popular pre-Xmas supper. Please bring a dish to share with fellow members. Don't worry, as there is always plenty of gluten, wheat and dairy free dishes and you won't go hungry!

No main meeting in December, but please join us at Prestwich!

Issue: 111 Registered Charity number is 1161356. October 2015

Yoga Classes: Are 3:15pm-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. Please contact our instructor Lisa Heaps Mobile: 0770 803 66 36 Email: lisayogatori1@gmail.com. **Our yoga classes are currently being funded by The Big Lottery Fund.**

Prestwich Socials: Our Prestwich socials are now at **The Church Inn, 40 Church Lane, Prestwich, M25 1AJ.** This has level access and free parking outside. We meet on the **second Wednesday** of the month at 2pm, the next meeting is **Wednesday 10th November 2015** The attendance at Prestwich has been doing better lately, but do please try not to turn up too late in case numbers are low.

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.



DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Trustees, nor the Bury & Bolton ME/CFS & Fibromyalgia Support Group (Registered Charity Number: 1161356). Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Bury Bolton ME and FM group talk for September 2015: Marie Oxtoby, Bolton Neuro Voices, about the Hydrotherapy Project

Marie began by giving a brief history of her work with the Neurological Alliance, set up to support the large groups, eg. multiple sclerosis and stroke, but especially people with rarer conditions who would have difficulty meeting another person with their condition, but who would share common concerns, and some symptoms, with someone with another neurological condition. Working together made for a louder voice.

In 2007, the Greater Manchester Neurological Alliance, of which our group was a member, was heavily involved in consultations for the reorganisation of neurological services in Bolton. Unfortunately, the GMNA was wound up a few years ago, but Bolton Neuro Voices

arose from the ashes. In around 2012 Bolton One opened (now also called the Jason Kenny centre). It is right in the centre of the town and boasts a large public swimming pool, but, more importantly, a large hydrotherapy pool. At that time, there was no ongoing physiotherapy whatsoever for neurological conditions, but, as some people had noticed a benefit from warm water on holiday, we decided to set up a course of hydrotherapy and find the funds to pay for specialist neurological physiotherapists. A private session of hydrotherapy (more properly aqua therapy, but I'll carry on using "hydro") would cost £80-100, but Susan Pattison and her team at Susan Pattison Therapy Services agreed to work with Bolton Neuro Voices (BNV) at a greatly reduced cost, didn't charge for travel time or cost, provided one physiotherapist free, and did much of the (very time-consuming) preparation free, too. The courses have been running ever since, constantly being modified based on feedback from participants, which was collected after each session and at the end. The levels of satisfaction were extremely high, The team and BNV are now inviting applications for a new initial course starting in November, and a continuation programme in January. The courses are on Wednesdays, between 12 and 2pm, depending on your group.

The initial "taught" course is 5 x 30 minutes (though you can rest if 30 minutes is too much), with a specialist physio, Heather, and a therapy assistant in the pool with you, demonstrating the exercises and helping anyone who needs it, and they modify the exercises week by week based on feedback and observation. One important point to note: you are never pushed to do more than is comfortable: in fact, the physio told me several times to step out and rest.

The continuation programme, for "graduates" of the initial course, and anyone who has previously done hydrotherapy with a physio, is 8 or 10 weeks, and the therapists attend the first week and another session (to check we're doing it properly). We are given individual laminated exercise sheets for each programme, with easier and more strenuous variations, with warm-up and cool-down exercises. Some of the exercises are done individually, some as a group, but again you can opt out of anything.

The pool and changing area is very warm, there are volunteers who can help carry belongings, pass out cups of water etc., and a really friendly lot of people. You are placed in a group depending on ability (physical not swimming) and level of water confidence, rather than condition, and the average group size is 6-8. If you have a blue badge you can park outside for 2 hours, but you must get a ticket from the machine even for a disabled space. Otherwise the car park across the road at the Mecca bingo hall is the best. The cost of the courses will be approx. £25 or £30, payable in advance: we get nothing from the NHS, but subscriptions such as that from our group and others, and grants from Bolton CVS, and local fundraising, subsidise the cost.

If you are interested, please go to Susan Pattison's website: www.neurologicalphysio.co.uk, click on Our Services, then Hydrotherapy in the drop-down box. There is a flow-chart to decide which course you should register for. If you don't have internet access, please contact me, Maria Sale, on 01204 575613, and I'll enquire about alternative arrangements. If you have any questions, please phone me, email on aria113@talktalk.net, or through Facebook: I would prefer the last two, please.

Please note: registration for the initial course closes on 9th October. It isn't possible to register yet for the next continuation course in January, but you can email them to express interest. Also, ignore the information about having to be a Bolton resident: any member of our group is eligible, as we are members of BNV for this financial year.

Caroline's Close Shave!



At the end of October, group leader Caroline will be shaving off her long locks in aid of the Bolton Destitute Animal Shelter. She has wanted to do it since earlier in the year, but thought I needed to be longer. Now it's over 18.5 inches, probably the longest it's ever been, it's time to chop. Would anyone like to sponsor her? There will be pics of before and after!

The Bolton Destitute Animal Shelter means a lot to Caroline, as that's where they adopted their two cats from. The mother and daughter duo consists of Amber, a 12 year old tortoiseshell white and Jade 11, a ginger-white. They were left in a cardboard box on the shelter doorstep overnight.

They are our constant companions, hot water bottles and bottomless pits. Jade knows what "ham" and also "vet" means, and can hear you open a packet of treats from six gardens away. Amber cries if it gets too quiet and also likes to pretend she is deaf when it's time to come in at night. They each have a child's doll bed for a bed (and five or six more, each), and refuse to go near the very expensive cat house outside, so that it remains purely ornamental.

Caroline's head shave pro's:

No hair to brush every day, or wash once in a blue moon.

Save lots of money on dry shampoo

Money raised for the homeless animals

When it grows back, it will be my natural colour again so I can finally get to dye it purple.

I already own a cupboard full of warm hats, so well prepared.

Will hopefully donate hair to make wigs

Caroline's head shave con's:

I will be very, very cold, in winter time.

Husband will not recognise me for about week (and neither will I).

I will miss my copper blonde hair.

Again, so very, very cold.

Caroline is hoping to donate her hair to The Little Princess Trust, a charity which provides real hair wigs to boys and girls across the UK and Ireland that have sadly lost their own hair through cancer treatment.

Sponsorship info from Caroline:

I have a sponsorship form to record all donations. **You can remain anon if you wish.**

Cheque: Send to Caroline, payable to "Destitute Animal Shelter". Please send to: 53 Denstone Crescent, Harwood, Bolton, BL2 5DE.

Cash: At a meeting or drop off at my house. I can give you a receipt if needed.

Paypal (online): Please send to chigson47@gmail.com (Caroline's personal account), using the "friends and family" option so no fee is taken off. You will get a receipt off paypal and I will also acknowledge receipt. I will then send the Shelter a cheque of the total amount received.

GoFundMe: www.gofundme.com/carolineheadshave

Note, I have been DBS checked, so have full confidence it's going where it should!

4 Tips for Dealing with Unsolicited Health Advice **Handling unsolicited health advice with grace is a challenge.**

We have all be given “advice” on how to get well from ME/CFS and FM; “Go to bed earlier”, “eat more fruits and vegetables” and “do more exercise” are ones I’m sure you’ve all heard? Writer Toni Bernhard, whom we have featured before, has written about her experience with those helpful “tips”.

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*. Her newest book is called *How to Live Well with Chronic Pain and Illness: A Mindful Guide* (Fall, 2015). Before becoming ill, she was a law professor at the University of California—Davis. Her blog, “Turning Straw Into Gold” is hosted by *Psychology Today* online. Visit her website at www.tonibernhard.com.

Here’s the most distressing piece of unsolicited advice I’ve received to date. It showed up in my Inbox two days after I’d completed a course of radiation for breast cancer. The email was in response to an article I’d written about this new, unexpected turn my life had taken; the article included the fact that, at the time, I was in the middle of a course of radiation treatment. Here’s what the woman said in her email: “I’m sorry to hear you have breast cancer. However, because you’re already chronically ill, do not, under any circumstances, continue with radiation. It will destroy your immune system.”

In the article she’d read, I emphasized that my intention in writing it was to share my experiences in a way that would be helpful others. I didn’t ask for treatment advice, but I received a lot of it, including this email, which had the effect of making me anxious and worried about a treatment I’d just completed.

I know that the woman had good intentions, but I wish that before she’d given me that advice, she’d reflected on a version of the last line from a favorite movie of mine: *Gosford Park*. It’s spoken by the ladies maid, Mary, as she’s contemplating whether to share some damning information that, while true, could lead to a miscarriage of justice. Deciding against revealing the information, she reflects: “What purpose could it possibly serve?” I often repeat this phrase to myself if I’m uncertain whether what about what I’m about to say would be helpful to the person I’m addressing.

Over the years, I’ve received a lot of unsolicited advice about my health, but I assumed it was because I’ve been diagnosed with a little understood illness: Chronic Fatigue Syndrome (aka ME/CFS, SEID). I was sure that having an illness that’s so misunderstood and mysterious accounted for all the advice I was getting on how to cure myself, advice that’s ranged from jumping in a cold swimming pool of water every day for six months to swishing oil around in my mouth each morning and then spitting it out (along, supposedly, with any viruses in my body).

But it turns out that unsolicited health advice comes in just as fast and furious when the diagnosis is cancer.

Some readers may welcome advice from others. That’s fine. This piece focuses on those of us who’d rather not be given advice unless we ask for it. It suggests some ways to respond skillfully to that unsolicited advice.

I recognize that the options available to each of us differs depending on our relationship to the advice-giver and to the medium through which the advice is given—for example, in

person (where we're a "captive audience") versus via an email or even in a public Facebook comment. That said, here are some suggestions:

1. Shove it under the bed (literally or metaphorically).

Twenty years ago, my dear friend Anne was in the final stages of cancer. She was a therapist by profession, but she decided to see one herself to help her cope with what was happening.

One of her ongoing difficulties was that almost everyone who came to visit brought her some kind of treatment, whether it be a supplement, an herbal tea, or a crystal to wear around her neck. She told me that sometimes she wanted to scream: "I'm in the hands of good doctors; we're doing everything we can to keep me alive; I don't want or need your advice!" But she didn't because she didn't want to hurt people who were being kind enough to visit.

When Anne raised this dilemma at a counseling session, her therapist suggested that she smile and say, "Thank you very much," and put the item down. Then, as soon as the visit was over and the person had left, shove it under her bed. It turned out to be just the advice she needed.

I've found this to be a valuable strategy. When I get unsolicited advice via email or a private Facebook message, sometimes I answer by simply saying, "Thanks for thinking of me." And that's it; I purposefully don't address the substance of the advice. I've found that if I engage someone on a suggestion that's clearly off-base for me by responding with something like, "Thanks, but I'm aware of that treatment and I'm sure it won't work for me," it invites the person to continue the dialogue—sometimes to try even harder to convince me that he or she is right. I don't want to have to defend my treatment decisions; it takes up too much of what precious little energy I have. So, as an act of self-protection and self-compassion, I answer politely, but briefly, and avoid addressing what the person is suggesting that I do. In other words, I metaphorically shove it under the bed.

2. Ignore it.

This strategy is often only available when, unlike in the example above with Anne, the unsolicited advice arrives in a non person-to-person interaction—via an email or in a Facebook comment for example. In those circumstances, you can always choose not to respond at all.

I used to answer every single online communication that came my way (and I still do if it's about my books or other writing). Now, if it's unsolicited health advice, even though I appreciate that people are trying to help, I admit that I might simply ignore it.

For example, one person told me to forgo all future breast cancer treatments and start eating lemons because acid kills cancer. That's a piece of unsolicited advice I decided not to respond to. If that person is reading this, please understand that I appreciate that you were thinking of me, but I consulted multiple doctors and spent many hours online doing research before I settled on a treatment plan. It's better for my peace of mind not to second-guess that plan unless some change in my health requires re-evaluating it.

3. Be honest about how you feel about being given unsolicited advice.

This is an especially good option to consider when you're offered in-person advice from well-meaning family and friends. I've been given lots of health advice that's of no use to

me whatsoever. I often just mumble, “Thanks,” but sometimes I muster the courage to say: “I appreciate your attempt to help, but I’d rather talk about something other than my health”; or “I appreciate your suggestion, but my doctor and I already have a treatment plan and I want to stick to it.”

To my surprise, so far, this response has been well-received. I think I know why. Family and friends who offer unsolicited advice have the best of intentions. Their hearts are in the right place: they’re as frustrated as I am that I’m chronically ill. And so, when I get up the nerve to be honest with them about not wanting unsolicited advice, they’re actually relieved, as if they’d felt obligated to try and help in this way, but have been let off the hook.

Being honest may not always be the best strategy, but I’d keep it in mind as a possibility. Let’s face it, some family and friends can’t resist giving advice or bringing us cures. For them, that “Thank you” followed by shoving it under the bed (metaphorically or literally) works better.

4. Work on accepting that people won’t always behave the way you want them to.

This is good advice for everyone, whether chronically ill or not. We can’t control other people’s behavior. Despite our attempts to be honest with family and friends about not wanting advice, as I mentioned above, some may continue to give it. This calls for self-protection in the form of compassion for ourselves. We can gently remind ourselves what a burden it is to have to add to our ongoing pain and illness the work of having to access how to skillfully deal with what others are telling us to do about our health.

Dealing with unsolicited advice also calls for equanimity. This means, first, accepting that people won’t always treat us the way we want them to and, second, *having that be okay with us*. This is the essence of equanimity—being okay with our life as it is, knowing it won’t always be pleasant and it won’t always unfold the way we’d like it to.

As for that unsolicited health advice I received about radiation? I ignored it and, instead, turned my attention to self-compassion and equanimity. That was better use of my time.

Salford Royal NHS Foundation Trust

I wanted to let you know that we are currently restricting referrals to our Salford CFS service due to huge referral numbers and lack of capacity within the service for provision of both diagnostic assessments and treatment programs. We are hoping to achieve the necessary expansion to re-open the service but currently we can only see patients registered to Salford GPs/with Salford postal addresses.

I have attached the letter that GPs and specialists will receive if their patient does not fit current criteria for referral.

Kind regards,
Annice

Dr Annice Mukherjee
Consultant in Endocrinology & Honorary Senior Lecturer
Salford Royal NHS Foundation Trust
0161 206 5153

Late edition - September 2015

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

Researchers used an exercise tolerance test, called Bruce ET, to identify which severe CFS/ME patients would respond to Rintatolimod (also called Ampligen). Rintatolimod produced significant enhancement in exercise tolerance and quality of life indicators in patients able to complete more than 9 minutes exercise. Rintatolimod also reduced deterioration in exercise tolerance compared to a placebo in patients with the poorest initial exercise tolerance. - Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME): Characteristics of Responders to Rintatolimod – Prohealth - September 27

Dan Moricoli was a business owner, internet marketer, motorcycle racer, skiing enthusiast, international traveller and deep-sea fisherman . However, he suddenly got ill on a fishing trip and endured many years of severe CFS/ME. He split up with his wife and lost his business, but he didn't lose hope. He saw Dr. Nancy Klimas in 2008 and she started on improving sleep hygiene and some medication (although the medication was ineffective). However, things really changed with a strict pacing/exercise programme called VO2 Max testing as well as diet changes and yoga. It was never a quick process taking years before he recovered. This was definitely a "tortoise" approach to recovery, but it worked. - On the Path: Dan Moricoli's Remarkable Chronic Fatigue Syndrome Recovery Story – Prohealth - September 26

Adrienne Dellwo, a CFS/ME blogger, discusses the positive impact of yoga on people with CFS/ME and fibromyalgia. She quotes some studies which have had positive results, although there isn't enough data to be 100% conclusive. For example, in one study there were improvements in physical and psychological symptoms for fibromyalgia patients as well as people who had other neurological conditions, including multiple sclerosis, Alzheimer's disease, epilepsy, and stroke. - Yoga for Chronic Fatigue Syndrome – About.com - September 29

This article seeks to describe the psychiatric aspects of a patient who suffers from CFS/ME. It aims to help psychiatrists with their patients and gives a short appraisal of the issues. It emphasises that CFS/ME is an invisible disease, and that people may suffer from psychological issues as their lives have changed so much. It also makes recommendations to psychiatrists, such as, putting yourself in the patient's shoes: 'We are trained as psychiatrists to be good listeners'. 'This enables us to see things from our patients' perspective. Listening deeply and being empathetic are the foundations of our profession.' - The Psychiatrist's Role in Treating Unseen Diseases – Psychiatry Advisor - September 29

This is a summary of a report aimed at drug companies who market drugs to treat fibromyalgia: The 3 main drugs used for fibromyalgia are Lyrica, Cymbalta and Savella. All have been approved in the US while only the former is approved in Japan. These drugs are also available in the EU for other reasons, so they may be prescribed as off-label therapies. A handful of other generic products also provide off-label usage including antidepressants, anti-epileptics, opioids and muscle relaxants. Although Lyrica, Cymbalta and Savella can provide an effective treatment regimen, there are ample opportunities for the development of alternative treatments. By 2023, there will be four new entrants to the market (Lyrica CR, TNX-102 SL, DS-5565 and TD-9855). - PharmaPoint: Fibromyalgia – Global Drug Forecast and Market Analysis to 2023 by ReportBazzar – Medgadget - September 29

Sorry

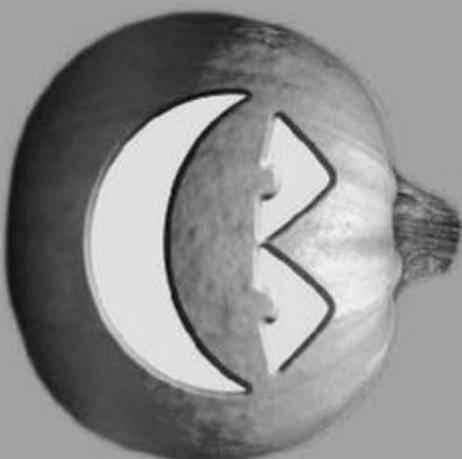
No Trick or Treaters Please



*There are no treats here.
Please be polite on Halloween night.*

Hello

Trick or Treaters Welcome



*There are treats here, but remember
be polite on Halloween night.*

TREACLE
safe4autumn.com

