



# Phoenix

Newsletter of The Central Lancashire ME/CFS Support Group

Patron: Doctor J Roberts

July 2012 issue

Charity no. 1106333

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**Welcome** to the “summer” issue of the newsletter. A **big thank you** to all those who have renewed. To those who are yet to renew, please either send back any reminder you receive as soon as possible, or contact the office, who will be happy to help.

Part of our “conditions” within the Lottery funding is for us to attain £1800 this year ourselves through subscriptions & donations. With your help, we have made a good start. Whilst there is no compulsion or expectancy, we have been moved by the kindness of many members who have paid additional amounts over the renewal cost. Also a **big thank you** to those who have made/donated items to sell for the group.

At the AGM on the 13th June, all of the committee was re-elected. We would like to thank those who voted both by post, and particularly those who were able to attend the AGM. However, no-one accepted our offer for others to “throw their hat into the ring”, so to speak. Whilst we are pleased to have the confidence of members and will carry on trying to do our best for them.... this cannot go on indefinitely. Apart from the fact that nearly all of the committee are ME sufferers themselves, new blood and new ideas are welcome... and needed.

Colin, our Chairman, has said for quite a while, that after seeing through the successful lottery funding bid, he would hope to see a successor come forward, prior to him standing down at the latest by 31st July 2014. The idea would be for a willing and suitable candidate to work alongside Colin, so that person could be eased in gently.

Another very important role, which we desperately need help with, is in relation to helping with future funding bids. We would particularly welcome help from someone who has had experience in obtaining funding for a charity, but if you feel you might have a skill to offer... or have a family member or friend who may be able to help... do please give the office a call!

With the extra funding from the Lottery, the group is in a healthier position than it has been for a long while and so will be able to offer greater help and support to members than ever. We are confident that our new “Lifeline” programme is as good as anything available for ME sufferers. It is already growing in popularity and it has the huge advantage of being run “at ME pace”.

You are able to attend the monthly ‘modules’ in any order, with opportunities available to “catch up” on any missed. The course is free for members, but non-members are more than welcome to join on the night!

Finally, we can report that there are positive changes to the NHS ME Clinic in several aspects. We have had the opportunity to meet patients about to start treatment and introduce them to the group. Watch this space for updates!



### Disclaimer

**The views represented in this Newsletter may not necessarily represent the views of the committee. Therapies, treatments, techniques etc, are described for information only and inclusion in this Newsletter should not be taken as a recommendation. Items featured are for information only.**

## Open Meetings and Social Lunches 2012

### Preston Open meetings

**Bamber Bridge Methodist Church,**  
Station Road, Bamber Bridge. PR5 6ED  
Wednesdays 7-9pm.

1st August  
3rd October  
5th December

**Galloway's, Howick Park Dr,**  
Penwortham, PR1 0LS

**LIFELINE PROJECT**  
12th July      Life Coach  
15th November Homeopathy

### Other Preston meetings

#### Minerva Centre coffee/tea Mornings:

**WRVS Café,** PNE Football Ground, Low-thorpe Road, Preston, PR1 6SB. **Last Friday of the month, 11am onwards.:** 27th July, Aug 31st, Sep 28th.

#### Coffee morning—New venue

**Tootsies, Liverpool Road (A59)**  
**Much Hoole PR4 5JT**  
Wed 23rd May from 11am

**Craft/Coffee Sessions 2- 4pm Roccoco**  
**Coffee Lounge, Church Brow, Leyland PR25**  
**3NH.**

**Weds: 25th July, Aug 29th, Sep 26th**

**Lunch: Wed July 18th, 12pm**  
The Hungry Horse/Lea Gate  
Blackpool Road, Lea PR4 0XB

### East Lancs meetings

#### Wilpshire Methodist Church Hall

Ribchester Rd, BB1 9HU - Mondays 7-9pm  
**30th July - showing recorded Lifeline talk**  
- Gail Sumner

#### Lunches

**Wed 25th July –Game Cock 12.30pm**  
Whalley Road, Gt Harwood BB6 7UH  
**Simply Classic Bistro** (Shuttleworth Mead  
Business Park, Padiham BB12 7NG—J8 M65)  
**12.30pm onwards    Tue 25th September**  
**Wed 5th December**  
(Christmas Lunch—booking required)

**Coffee/Lunch from 11.30am**

**Tues 25th Sep The Bistro, Padiham**

### St. Annes meetings

#### Ansdell House Clinic, 261 Church Rd, St Annes, FY8 3NP

Open meetings - Wed 7-9pm **12th Sep - recorded Lifeline talk, Life Coach Joan Short**  
Next meeting 14th Nov

**Coffee Thurs 2nd Aug, 2pm Hotel Dalmeny, Bar Indigo (left of Reception) South Promenade**

## Support Group News

### Additional “Lifeline” information.

We make no apologies for starting the third page by again mentioning the Lifeline course. We hope members will take advantage of what it has to offer and just as importantly.... give us your feedback and suggestions.

The main reason for adding yet another reminder here however, is that “word has spread” that our Patron Dr Roberts has kindly agreed to host a couple of sessions and by the number of people who have asked, these will prove to be very popular. For those who do not know Dr Roberts, she has a wealth of medical and scientific knowledge, along with having knowledge of M.E. that is second to none. She is also a sufferer herself.

Dr Roberts will be hosting the September and October Lifeline sessions and we are looking forward to welcoming her back to the meetings.

### A member’s update

Whilst we are unable to personally recommend any particular treatment or medical professional, we welcome any updates from members, regarding any successes or failures that might help others, which provided that there are no harmful effects, we can pass on for individuals to make their own choices. One member, who wishes to remain anonymous, sent us the following feedback:

*“Just wanted to thank you for the information about The Perrin Technique and the loan of the book, which I’m still finding useful. I’ve been attending Perrin treatment sessions for a few weeks - it’s really helping and has given me real hope of recovery, so I’m very grateful.*

*There’s a lot of self-treatment involved, which was a big effort at first, but it is getting easier and more comfortable all the time. Some ‘getting worse before you get better’, but it’s so great to feel positive and feel that you’re on the road to recovery... and have help on the journey. It’s made a huge difference to my outlook already.”*

It is really good to hear such feedback and indeed we appreciate receiving it, but we must issue the standard caution that some things work better for some people than for others. It’s very difficult to make a judgement from a tiny excerpt such as we’ve included here. It’s also true that very few people could afford to pay for every treatment that gets mentioned as possibly helping with M.E.

Therefore, what we can and indeed do advise, is for members to check the meetings page opposite and come along when they are able to personally share experiences with other members.

You will get the benefit of sharing knowledge, enjoying social functions and lunches.... and of course.... being able to take part in our “Lifeline Programme!!”... we did mention our Lifeline Programme didn’t we?!!

### A personal thought

Despite the positive steps taking place regarding how people view M.E., particularly with the World Health Organisation’s acceptance that it is a neurological illness, do you still dread telling anyone that you have M.E.? What do you do, or what ideas do you have that can help beat the stigma that still exists. Would a change of name help for instance (for the illness, not you!)? Send us your thoughts.

One ‘mantra’ to tell yourself could be....”I didn’t ask to have this dreadful illness... I don’t want it for a second longer... so don’t expect me to apologise or feel guilty for having it too!”

### Where has the year gone?

Whilst looking through some old paperwork, I came across some handwritten notes that were given to me by “someone”, to offer some natural alternatives to conventional drugs. At that time, the other person and I were both attending hospital appointments. The other person was offering help, despite being unwell herself. This person was our own Christine Marshall, who sadly lost her battle with cancer one year ago.

I just thought it was pertinent to remember someone who did so much for the group. She certainly had her own character and ways!.... but it goes without saying that we all miss her and won’t forget her.

## National News

### News from the "ME Awareness Week", May 2012

#### **All in the Mind? Why critics are wrong to deny the existence of M.E./CFS** *From the Daily Mail Online website, 8th May 2012 (story by Sonia Poulton)*

This week (May) is M.E. Awareness Week. That may not mean a great deal to you. Certainly, it didn't to me. Oh wait, yes it did. Based on no personal knowledge whatsoever - fortunately neither I or my loved ones have M.E. - my judgement was gleaned from how the world has portrayed the illness. Like millions of others, I have seen M.E. through the eyes of the medical establishment, the Government and the Media. The picture has not been good. Here is what I have previously "understood" about M.E. and those who have it.

M.E. sufferers are workshy malingerers. They whine, constantly, about feeling tired. They are annoying sympathy seekers. Damn it... we're all tired! Especially those fools like me who work all hours God sends (and even some he doesn't) to support the type of people who say they are too tired to work. Oh, and mostly, importantly, M.E. is 'all in the head' and can be overcome with a bit more determination and a little less of the 'poor me' attitude. That, generally, is what I thought about M.E.

Until, that is, a reader sent me a DVD of a British-made film about the illness titled '*Voices From The Shadows*'. I receive dozens of clips and films each month, and I try and see as many as I humanly can, but there was something about '*Voices...*' that stopped me in my tracks.

One of the reasons the film had such an impact is because it challenged my deep-seated preconceptions about M.E. Through '*Voices...*' - and subsequent research I conducted - I came to realise that what I thought I knew about M.E. was a fallacy but, more importantly than that, was actually detrimental to those affected.

So, as a naturally curious individual (I'm not a journalist by mistake) I began to question why I had been furnished with one version of events - and inaccurate ones at that. The more I began to delve into the subject the more curious it all became. So, to this end - and seeing as it is M.E. Awareness Week - here is my personal guide to shattering the myths and blatantly-peddled untruths about M.E.

**Myth No. 1: ME is a mental illness** - Not so. It is a neurological one, as accepted by the W.H.O. in 1969.

**Myth 2: ME is just extreme tiredness, right?** - Wrong. Despite falling under the Chronic Fatigue Syndrome category - as does Fibromyalgia - it is entirely wrong to assume that M.E. is merely about lack of energy.

**Myth No. 3: M.E. is just like a bad flu** - Oh, if only. As one doctor put it, comparing M.E. to an illness like flu is like comparing Emphysema to a chest infection. It seriously undermines the true extent of M.E.

**Myth No. 4: M.E. sufferers should just 'pull themselves together'** - M.E. is **not** in the mind.

**Myth No. 5: Only adults have M.E.**

**Myth No. 6 - You can 'catch' M.E.**

**Myth No. 7: Real M.E. sufferers are few and far between** - There are currently 250,000 recognised cases of ME in the UK. That's 1 in 250 so that's hardly an insignificant number, is it?

**Myth No. 8: Only severe cases of M.E. are worth acknowledging** - Terrible misconception. M.E. ruins people's lives even if the patient is not entirely bedbound.

**Myth No. 9: Children with M.E. have neglectful parents**

**Myth No. 10: Physical exercise will benefit M.E. sufferers** - Absolutely not true. Worse, still, enforced 'graded exercise' can escalate the condition to dangerous and irreparable levels for the patient.

**Myth No. 11 - M.E. is not life-threatening**

**Myth No. 12: M.E. is an excuse not to work** - M.E. sufferers face a battery of controversial fit-to-work assessments and often have benefits removed and are plunged into poverty. Let us be clear, M.E. is comparable to AIDS and cancer and all the other vicious and uncompromising diseases that savage the body and, in some extreme cases, kill it completely. I believe that we, as a nation, deserve to know the truth. Not only for those still battling the disease, but for those poor souls who have already been lost to it.

*(For those who can get online, the full article can be found on the Mail Online website...and also on the ME Association website. It is far more comprehensive than the summary above and is well worth a read. For further details on Voices from the Shadows: <http://voicesfromtheshadowsfilm.co.uk/shop-dvds/>).*

## CRAFT GROUP NEWS

Craft group get-together with visiting specialist Stephen Watson demonstrating Origami in Accrington. We meet the last Wed of every month at the Roccoco Café, Church Brow, Leyland PR25 3NH. Please join us for chat and drink/cake (some gluten free) and (craft if you want to).



## Sudoku (fairly easy)

Complete the grid so that every row, every column and every 3x3 box contains the numbers 1-9  
(and remember, if you would like more difficult puzzles or no puzzles at all, you need to let us know!)

<b>8</b>				<b>3</b>	<b>1</b>	<b>2</b>		
	<b>5</b>			<b>7</b>	<b>2</b>	<b>9</b>	<b>6</b>	
					<b>4</b>	<b>3</b>		<b>7</b>
					<b>3</b>	<b>5</b>		
		<b>9</b>		<b>6</b>				<b>8</b>
		<b>8</b>				<b>6</b>	<b>1</b>	<b>3</b>
<b>7</b>							<b>5</b>	
<b>6</b>	<b>9</b>	<b>5</b>			<b>8</b>		<b>3</b>	<b>4</b>
<b>1</b>		<b>2</b>		<b>4</b>	<b>5</b>			

## Let's lighten the mood!

### Mr Grumpy returns

Actually, I'd rather not "lighten the mood!". This is my first 'piece' since just before Christmas (a time when I pay tribute to my favourite characters like Scrooge and the Grinch, along with spending my afternoons heckling at pantomimes).

I haven't the time to cover a fraction of all the things currently annoying me, but for starters... there's the stuff that's been on TV. First football... then tennis... and no, I'm not referring to the games or players.

No... what has left me traumatised... was seeing 100's of cheering people wearing Wayne Rooney... and then Andy Murray masks in the crowd!! My poor eyes! Now we've got the Olympics due to start... a fortune spent... to watch us finish a lap behind... and that's just the 100 metres!

On another TV topic... does anyone watch that "Embarrassing Bodies" program? How is it, that someone has been too shy or ashamed to show "anyone" some 'awful' personal problem for 10, or even 20 years... not even their doctor... but feels OK to show several million people what the problem is on national TV?! The world's gone mad!

### <--Apology...& inspiration!

The committee wishes to distance itself from Mr Grumpy's comments! We congratulate Andy Murray on his brave performance... and wish the British Olympic team much success over the next few weeks. If they can improve on Beijing... that would be superb. It will also be very exciting to see the likes of Usain Bolt...and indeed... whether his team-mate and training partner Johan Blake can beat him again, as he recently did in both 100m and 200m races at Jamaica's national trials!

However... if you want to see **real** bravery and talent... don't forget to take a look at the Paralympics. Their achievements can be awe-inspiring. Not just the likes of Oscar Pistorius (AKA "Blade-runner"), but also our own athletes Ellie Simmonds, Sarah Storey, David Weir, Dave Roberts and many others (and we mustn't forget past heroes, such as Dame Tanni Grey-Thompson). The Paralympics website is well worth a look: <http://www.paralympics.org.uk/gb>

Finally, for anyone who isn't aware (or convinced!)... just take a look at the times etc. that the top paralympians achieve. Very few able bodied people could come near to them... even very fit ones! They are truly amazing athletes in their own right.

## Absolutely awful joke corner (and it's not even a corner!)

A panda walked into a bar and said, "A pint.....of beer please".  
The barman asked, "Why the big paws?"

"Doctor, Doctor, I think I'm a moth"

"I'm sorry you've come to the wrong place. You want the psychiatrist next door"

"Yes, I know, but your light was on"

### You know it's 2012 when...

You accidentally enter your PIN on the microwave.

You haven't played solitaire with real cards in years.

You have a list of 15 phone numbers for 3 people.

You email the person who works next to you

You pull up in your own driveway and use your cell phone to ask someone inside to come out and help carry in the groceries.

You get up in the morning and go online before you even make a cup of coffee.

You notice that 4 out of 5 TV adverts involve Payment Protection, Accident Claims, ask you to donate money... or are advertising a rival TV company! The 5th is unknown, as by then, you finally realise you've recorded the program and so can fast forward/skip it.

### Healthy recipe - Banana cake

#### Ingredients & instructions:

3oz margarine or butter  
6oz sugar (I use a white/brown mix)  
cream together with  
2 eggs  
3 bananas mashed and added to the mixture  
Fold in 8 oz S R flour  
3oz coconut  
Add 1 tbspn treacle  
1 tbspn of nuts if liked  
You could also add 1 to 2 oz oats  
Mix all together  
Put in a lined 2lb loaf tin bake in centre of oven  
140 degrees  
Bake approx 1½ hours..... delicious!!!

(Many thanks to Viv for this recipe)

## By popular request (well...a request!)

At least one member wanted to have the poem "Warning" by Jenny Joseph included in the newsletter. It has also occasionally been known almost as "Lady in Purple". We try our best to help, so here it is:

### Warning

*by Jenny Joseph*

When I am an old woman I shall wear purple  
With a red hat which doesn't go, and doesn't suit me.  
And I shall spend my pension on brandy and summer gloves  
And satin sandals, and say we've no money for butter.

I shall sit down on the pavement when I'm tired  
And gobble up samples in shops and press alarm bells  
And run my stick along the public railings  
And make up for the sobriety of my youth.

I shall go out in my slippers in the rain  
And pick the flowers in other peoples' gardens  
And learn to spit.

You can wear terrible shirts and grow more fat  
And eat three pounds of sausages at a go  
Or only bread and pickles for a week  
And hoard pens and pencils and beer mats and things in boxes.

But now we must have clothes that keep us dry  
And pay our rent and not swear in the street  
And set a good example for the children.  
We must have friends to dinner and read the papers.

But maybe I ought to practice a little now?  
So people who know me are not too shocked and surprised  
When suddenly I am old, and start to wear purple.

*Taken from the book*

*When I Am An Old Woman I Shall Wear Purple*

*Edited by Sandra Martz*

*Papier Mache Press--Watsonville, California 1987 (ISBN - 1576010785)*

### What does CLancs ME/CFS Support Group mean to you?

We would love to hear from you about what kind of difference and meaning we make in your lives. Feedback will be used to help with vital future bids for support and funding which help to keep this charity going.

If you would rather we did not use your name with any feedback for submission, you can make your comments anonymously. We'd also welcome any thoughts, articles or ideas that you may like to see in the newsletter.

Also, if you disapprove of something... you need to inform us AND tell us why! Please email us with any comments you have, or send them to the office (full details under 'Contacts' on back page of this newsletter).

## Carers' Contacts

**Carers Lancashire:**           **0345 6887113** Ring the central number and you will be put through to the Carers' organisation covering **your area**.

**Blackpool Carers' Centre:**           01253 393748   [info@blackpoolcarerscentre.co.uk](mailto:info@blackpoolcarerscentre.co.uk)  
Covering **Blackpool**

## Useful Contacts



### Central Lancashire ME/ CFS Support Group

Howick House  
Howick Park Avenue  
Penwortham  
Preston. PR1 0LS

**Office:** 01772 751254

For all enquiries, please contact the office at the address above

**Web:** [www.clancsme.org.uk](http://www.clancsme.org.uk)

**Email:** [info@clancsme.org.uk](mailto:info@clancsme.org.uk)

**Chairman:** Colin Briggs

**Deputy Chair:** Vivienne Henderson

#### Support Workers:

Helen Crossan:  
[helen@clancsme.org.uk](mailto:helen@clancsme.org.uk)

Lynn Green

#### Committee Members:

Shelley Burrows

Harriet Fairhurst

Kath Grannell

Pat Iddon

Paul Leeming

Keith McNicholas

Moira Portman

#### Newsletter:

Keith McNicholas

#### Volunteers:

Dave Berry

Claire Tracey

Brenda Wilson

Rob Edwards

Pat & Albert Hardaker

Phil Green

#### Council for Voluntary Services (CVS)

Preston 01772 251108

## Help and Advice



Accrington: 01254 394210

Blackpool: 01253 308400

Preston: 01772 682588

Chorley: 01257 279807

Blackburn: 01254 671211

Burnley: 01282 450535

Kirkham: 01772 682588

**Welfare Rights:** : 0845 0530013

You will be connected to your local office in Lancashire

Except: Blackburn with Darwen: 01254 583350

Blackpool: 01253 477488

**Help Direct For Practical Support:** 0303 333 1030

**Benefit Enquiry Line:** 0800 882200

#### Samaritans:

**National:** 08457 909090

**Preston:** 01772 822022

**Chorley:** 01257 266881

**Blackburn:** 01254 662424

**Burnley/Nelson:** 01282 694929

**Blackpool:** 01253 622218

#### Useful Websites:

[www.afme.org.uk](http://www.afme.org.uk)

Action for ME

[www.meassociation.org.uk](http://www.meassociation.org.uk)

The ME Association

[www.tymestrust.org](http://www.tymestrust.org)

Young ME Sufferers Trust

[www.ayme.org.uk](http://www.ayme.org.uk)

Young people with ME

[www.investinme.org](http://www.investinme.org)

Invest in ME

[www.mereseach.org.uk](http://www.mereseach.org.uk)

Research & scientific info

[www.drmyhill.co.uk](http://www.drmyhill.co.uk)

GP - specialising in ME

[www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)

Benefits advice/forms etc

[www.turn2us.org.uk](http://www.turn2us.org.uk)

Benefits advice

[www.lancashirecare.nhs.uk](http://www.lancashirecare.nhs.uk)

Adult Services for CFS/ME

#### Disability Equality North West (formally known as DISC):

Get Advice on Filling in Benefit Forms

Preston

01772 558863

#### Shop Mobility:

Preston 01772 204667

Chorley/South Ribble: 01257 280888

Burnley: 01282 450684

Blackpool: 01253 476451

#### PACT (Patient Advice and Liaison Service):

Chorley and South Ribble

0800 032 2424



LOTTERY FUNDED



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Patron: Doctor J Roberts