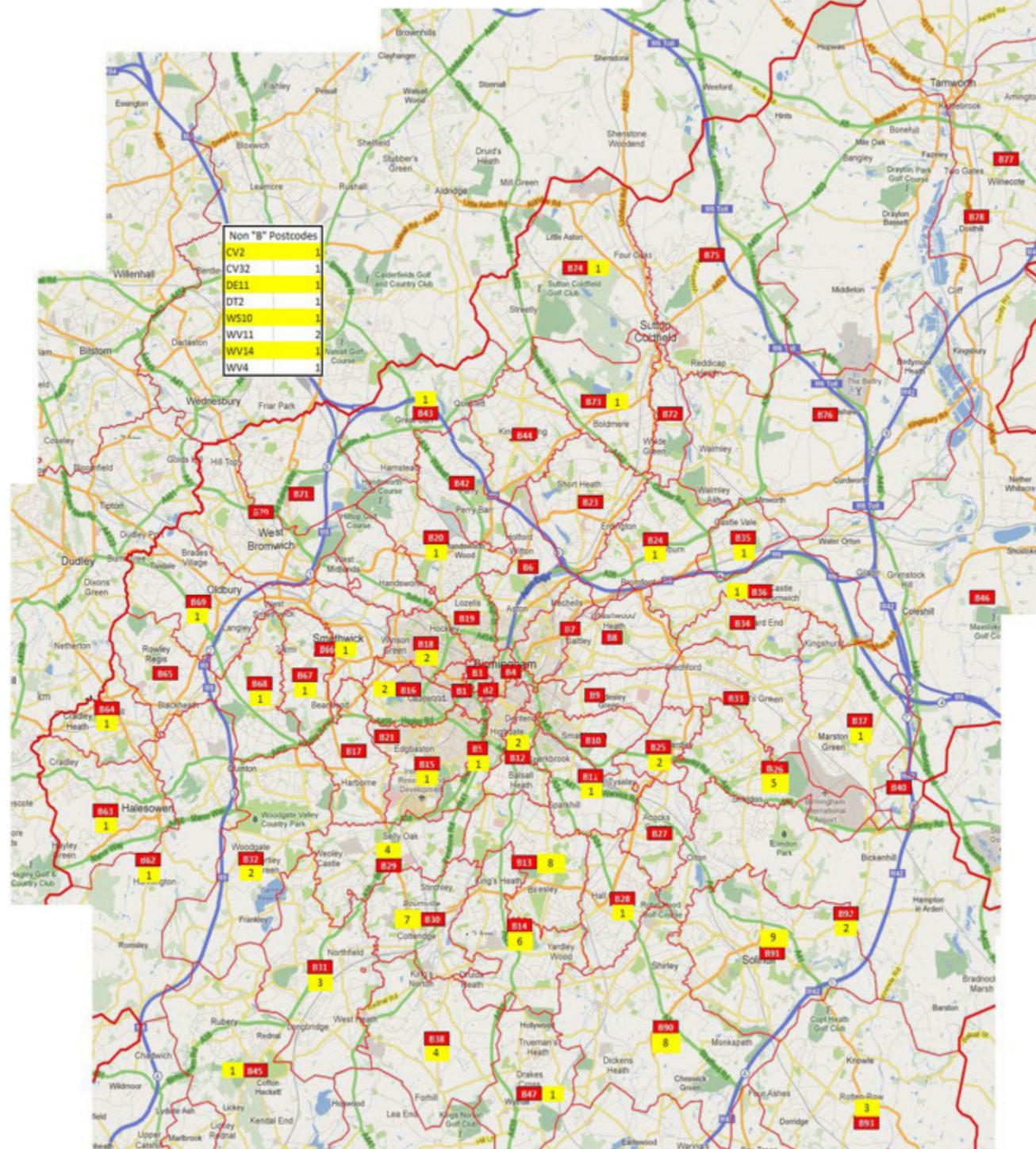


## WHERE DO WE ALL LIVE?

Many thanks to Tony Bradstock for 'mapping' the first part of all our postcodes (numbers in each postcode in yellow box)



### Other Websites:

**Benefits and Work:** useful site about benefits and how to claim them  
<http://www.benefitsandwork.co.uk/>

**Disability Alliance:** helpful site with lots of information on disability rights, benefit information, campaigning updates, and advice lines.:<http://www.disabilityalliance.org/>



Your next newsletter will be in September. Take care, Jenny

### Disclaimer:

Solihull & South Birmingham does not endorse or recommend any treatment/therapies/practitioners but merely reports on discussions or information received. The views expressed do not necessarily reflect the views of the group. The reader should always make their own enquiries before acting on any information contained in this newsletter.

## SOLIHULL & SOUTH BIRMINGHAM ME SUPPORT GROUP

birmingham & black country community foundation

Partner group of The Young ME Sufferers Trust  
 Group Friend of ME Research UK  
 Member of the West Midlands ME Groups Consortium



<http://ssb4mesupport.weebly.com>

FUNDED BY COMIC RELIEF

# ME Awareness Week

## Newsletter May 2013

*"Supporting sufferers and their families"*

### Launch of the UK ME/CFS Research Collaborative

The UK CFS/ME Research Collaborative [UK CMRC], chaired by Professor Stephen Holgate, is a new initiative by the country's leading experts in the field to expand medical studies into this complex set of disorders by facilitating greater expertise and improved co-ordination of wide-ranging research activities. Researchers at the launch discussed some of the key issues they are facing and the areas that are making progress. They explained



some of their thoughts for future research and their latest preliminary findings. The launch was also attended by leading UK research funders and representatives from some ME Charities.

It was a shame that this exciting research initiative was let down by a poorly worded press release before the event, which quoted figures of 600,000 UK sufferers and headlined with 'chronic fatigue' - do they never learn?

See Pages 16 & 17 for more news on this

### Your SSB Lottery membership form is enclosed in this newsletter.

This year's SSB lottery finishes in July. If you would like to join our Lottery club which is starting again in September for 2013/14 please fill in the form and return it as soon as you can.

All those already in the Lottery Club are cordially reminded that they will have to renew their membership for 2013/14.

**The subscription is £10 and this gives you ten chances to win the prize!**

Many thanks to all those who joined last year and raised £185 for 'Invest in ME', also for all the fun we have had at the meetings doing the draws and sending prizes to the winners!

### Gurminder is raising funds for ME Research again



I have heard from our very own Gurminder that she has managed to persuade her company, Salts Healthcare, to make ME Research UK one of their two sponsored

charities for the next year. Fantastic news as we already know from Gurminder's splendid samosa sale last May that they raise lots of money.

Thank you Gurminder & everyone at Salts Healthcare!!



### Don't forget our ME Awareness COFFEE MORNING

at 59 Cartland Road B30 2SD  
 Monday MAY 13th 2013 - from 1pm until 3pm  
 What are you wearing?! see page 4...



## Jenny Writes...



Dear Members,

I hope you have all managed to cope with the unbelievably long and harsh winter that we have just endured. It seemed never ending, but as I write there are signs that Spring is on its way as the daffodils in my garden start to flower at long last. Lets hope we have some warm and sunny weather soon - goodness knows we all need it.

We had a good Annual General Meeting in March and it was really encouraging to see you, the members, contributing with your thoughts comments and ideas. We hope to continue to give opportunities for you to have your say. We would like to say thank you to Tarsam for being a great Chair for the last year or so (see p 22). We were very pleased to welcome Alison as our new Chair. We have no doubt that Alison will bring her own unique perspective to the role (or that

we will have a few laughs along the way!) It's our **ME Awareness Week edition** again and it would seem looking at the contents that we still need to raise awareness and fight our own corner just as much as ever. Traditionally the May newsletter has a more 'serious' content and we have lots of **updates on benefits** this time - an issue that we know concerns you all greatly. Many thanks to Alison for her really helpful article on her journey through applying for ESA to appeal.

We also have lots on **research news**, including the latest news on a **new national research collaborative**. This shows promise and there are already some good research projects in this initiative, but what a pity they had to issue such a contentious press release before the launch event. (see p 16) How can this help sufferers to have confidence that they are actually looking at ME and not 'fatigue'? I hope the participating ME charities will try to put right this damage and find ways to stop it happening again.

It's our **annual ME Awareness Coffee Morning on May 13th** and, as you will see on **p4**, we

have some great ideas to help us to raise some money for biomedical research and have a little bit of fun (not too energetic!) at the same time. I hope we will see as many of you there as possible.

Thank you to those who have already returned your **benefit surveys** - please keep sending them in if you haven't done yours yet. There is a quick summary of the information gathered so far on **p23**.

Don't forget to rejoin the **SSB Lottery** for our next year and we hope lots more of you will now join as well - the more that join the more we raise for Invest in ME biomedical research!

Take care & keep in touch,  
*Love Jenny*

### YOUR ME AWARENESS Coffee Morning POSTER

is enclosed with  
this newsletter.

It would be fantastic if you could put it up somewhere locally or in your window so as to make sure we reach out to as many ME sufferers as possible.

## POETRY CORNER

I write  
as if somehow words could take my pain,

as if letters on a page could be enough  
to ease the sharp, blinding fire

]that burns  
inside, out.

But they do not.  
I could speak a million words.  
I could paint the sky with countless poems;  
spell them out in clouds for all to see to ease this  
craving  
to feel understood,

but still burn. Still cry out; wordless,  
with a mind that does not understand.

So why write? Why say these words over and over?  
Why paint poem after poem with all of this hurt?  
Why sit, with this page, with all of this pain,  
and think maybe this could make it easier,

when I know that it does not.

I have no answer.

Maybe it always comes down to the same thing:  
craving.  
Craving for someone to take the pain away.  
Craving for something to take the pain away.  
Desperation when I don't know what else to do,  
or maybe I do, but don't feel like I have the  
strength to do it.

Or maybe I've been wrong all along,

and in some strange, unfathomable way,  
these words do help,

not by easing the fire, but helping me see it,  
and feel it,  
without turning away.

I don't know.  
The more I learn about myself, the more I realise I  
do not know.  
The more I see a mass of confusion,

## Inside This ISSUE

- 2 Jenny writes
- 3 Poetry Corner
- 4 Group News
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- 8 Update on Personal Independence Payments (PIP)
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- 12 Ask Alison
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- 18 Research News
- 21 Comedy Central
- 22 Committee News

*Continued...*

All I know is that I *do* write.  
I write to reach out, to understand, to express,  
and maybe to achieve none of these things.

But in the midst of fire, all one wants is for  
the burning to somehow stop.  
Or, if not, to somehow find a way to be with it  
without turning to ash.

By Lucinda Troth

### KEEP IN TOUCH!

For any thoughts, feedback, comments, ideas or just to have a chat  
you can contact us:

By phone: **Jenny 0121 689 0777**

**Jo: 0121 679 8103** Sun - Fri -12 noon - 7pm

By email: [jennylg@live.co.uk](mailto:jennylg@live.co.uk)

On Facebook: [Official Solihull and South Birmingham ME Support Group](#)

By textphone: **07785 958 872**

By post: **59 Cartland Rd Stirchley B30 2SD**

# SSB ME AWARENESS COFFEE MORNING!

## What will you be wearing?

We will be wearing our dressing gowns to remember that many of our members are so severely affected that they often have to choose between getting dressed or another activity like just having a wash or eating breakfast.

Please join in if you can (it's optional) - doesn't have to be your dressing gown it could be a pair of slippers or your bed socks!



at 59 Cartland Road B30 2SD

Monday MAY 13th 2013

1pm - 3 pm

There will be cakes & samosas on sale!

All donations of cakes are welcome.

Please bring them along on the day.

There will be a small table sale

Any small items you would like to sell? Bring them along on the day.



There will be a game of SSB Bingo with PRIZES!

(not too cognitively challenging - trust us!)

And a RAFFLE with PRIZES - 1st Prize £25 M&S voucher!!

(tickets £1 per strip)

(If you aren't able to come and would like some raffle tickets

get in touch with Jenny BEFORE May 13th)

Please come along and help raise funds for ME biomedical research - bring your family & friends.

All are welcome!

### News on NHS services in our area

#### Dudley CFS/ME Psychology Speciality Service

Dudley Psychology Counselling Services, Physical Health Team, Cross Street Health Centre, Cross Street, Dudley, DY1 1RN  
Tel: 01384 366249

#### The Barberry Centre

After enquiry, we understand that the new consultant neuropsychiatrist for the CFS/ME services is Dr Kanu Achinivu who has a clinic on Tuesdays starting at 7pm. There is also a daytime triage

service with therapists (nurse & OT).



Dr Kanu Achinivu

The updated phone number is **0121 301 2280**

## SSB LOTTERY DRAWS and the winners are ...



March Lottery Draw:  
Number 15 - Mike Tudor  
April Lottery Draw:  
Number 14 - Steve Lund

CONGRATULATIONS!!!

## MEETING DATES

On Monday...

MAY 13th

ME Awareness Coffee Morning

1 - 3pm

At 59 Cartland Road B30 2SD

JUNE 10th

at Shirley Community Centre

7.30 pm

JULY 8th

Sam Strong is speaking at this meeting (see below)

At 59 Cartland Rd B30 2SD

1pm

N.B NO meeting in August!

SEPTEMBER 9th

At 59 Cartland Road B30 2SD

1pm

## Meetings News

### March Meeting

This was our AGM and the minutes are enclosed with this newsletter.

### April Meeting

For once we had reasonable weather at this meeting although it was very cold at least it wasn't snowing! A range of topics were discussed, in-

cluding: the Group's ME Coffee Morning (in the afternoon) on 13 May; supplements and vitamins; advances in digital/social media; coping strategies and mechanisms; craft making for charity ..... to name a few. All in all a very enjoyable and helpful meeting

## Sam Strong - July 8th meeting!

Unfortunately Bobby Bradstock is still awaiting ethical approval for her project on the use of Skype for counselling for people with ME, so she won't be able to come and talk to us in June. Hopefully she will be with us later in the year (maybe October)

Sam Strong is coming to talk to us at the July 8th meeting. Many of you may remember helping with Sam's dissertation - 'Cultural landscapes of chronic illness: M.E.taphor, confinement and invisible illness' in 2012 It was a very interesting and original take on ME from a geographical perspective and demonstrated how physical confinement can lead to social isolation and political marginalisation.

After gaining his degree at Cambridge, Sam went on to do a PhD continuing his research on the geographical aspects of ME. We have asked him to come along and give us an update on his latest research which I know many of us found fascinating.

Read Sam's dissertation at: <http://ssb4mesupport.weebly.com/all-about-us.html>

## Continuing Yvonne Troth's review of

CHRONIC FATIGUE SYNDROME 2<sup>ND</sup> EDITION By Erica F Verrillo (Kindle)

Part two (part three of review will be in next edition)

### Chapter 2

#### The nervous system and Limbic Hypothesis.

Dr Goldstein a psycho pharmacologist has developed a theory that ME is the result of problems with the limbic system which relates to the hypothalamus/hippocampus, and amygdala which are situated deep in the brain just above the brain-stem, and involves memory, emotion, and regulation of the autoimmune nervous system (ANS). The ANS is important to the regulation of appetite, body temperature, blood pressure, blood sugar, sleep, heart rate, and digestion – in short nearly every function necessary for maintaining life. Dr G's theory is that ME is a communication problem between the limbic system, and the rest of the nervous system. He maintains that whatever the cause of the illness the result is injury to the limbic system, which goes on to cause problems in the neuroimmune, and then affects the central nervous system. As a doctor with enormous knowledge of the workings of the brain his views must gain respect. Psychologists have performed cognitive tests to measure overall performance of patients, while neurologists use MRI scans to discover brain activation. SPECT to measure blood flow, PET scans to measure glucose uptake and MR spectroscopy to measure biochemical's associated with inflammation inside the brain. It has been discovered by tests that ME patients cannot focus on a particular task while receiving input from somewhere else. Also tests on memory proved that there were problems in this area. When presenting with mental tests involving attention and working memory, it was discovered that the greater the brain activity the greater the fatigue. SPECT scans measure blood flow in the brain and a high percentage of ME patients have been discovered to suffer with this, and so this tends to explain the neurological aspects of the illness. It has also been discovered that many ME patients appear on MRI scans to have unidentified bright objects within the brain, and also reduced grey matter volume in the prefrontal cortex.

**Immune Dysfunction** The reasoning behind looking at the immune is that after exposure to infection or toxin the immune fails to recover, but fights on as long as it perceives a threat. This then is responsible for the malaise, flu-like symptoms, and inflammation involved in ME. The immune system is highly complex and responds to everything the body comes into contact with.

**Vascular system and diastolic dysfunction.** Talks about heart dysfunction and its impact on ME. Blood

pressure can be maintained at the cost of restrictive flow of blood and therefore the demands for blood are not properly met. Dr Cheney, a respected ME specialist, believes that this lies at the literally, heart of the illness, and is the reason why so many suffers feel it tremendously energy draining to get from lying down or sitting down into a standing position. The body responds to this loss of output by restricting blood flow to other organs, such as the gut, which in turn causes malabsorption. This lack of blood flow affects the immune system, but also the liver which relies heavily on blood flow. The liver therefore loses its ability to detox the body sufficiently, which leads to a build up of toxins. Obviously under these conditions any attempt at exercise would put too much of a strain on the system and could be highly dangerous. The response to exercise would therefore be not only fatigue but an exacerbation of all body systems. The use of beta blockers does not seem helpful as energy is lacking. Treatment consists of mitochondrial support which includes CoQ10 and other supplements, including B12 and magnesium.

**Digestive System.** The gut has been described as the most important organ in the body as it is responsible for the intake of nutrients without which we could not survive for long. It contains 100 million neurons and very importantly serotonin, which originally was thought to be produced only in the central nervous system. But in fact 90% is produced in the gut. The gut also produces 400 times more melatonin than the brain and other neurotransmitters. There is a close communication going on between the gastrointestinal tract and the brain and so when we get a 'gut feeling' about something this should be listened to. The large intestine contains trillions of bacteria which destroy foreign microbes, making them harmless. When not working properly harmful microbes enter the bloodstream – a condition called 'leaky gut'. This is an area of ME which is well worth further investigation and Dr Sarah Myhill has a great deal to say about this in her book.

#### Note from Yvonne:

*As I said at the beginning, this book is quite large but contains enormous amounts of information in a great deal of detail. It would mean I have to go on through many pages more to cover everything included, and am sure that those with ME are exhausted with all of this already. If anyone wants more information about the book let me know.*

Yvonne Troth

([yvonnetroth@btinternet.com](mailto:yvonnetroth@btinternet.com)) 0121 745 2923



**JO'S TRANSPORT**  
 If you would like a lift to a meeting, please phone Jo Taylor on **0121 679 8103**. We will do our best to arrange this. If you can offer a lift to meetings please phone Jo on **0121 679 8103**

## CONGRATULATIONS!!!



Love & best wishes  
to Nic & Adam  
On the birth of  
Flynn Brian Hogarth  
On April 22nd  
7lbs 13ozs

Another lovely baby from  
our ME Mums!

Discovered this website:  
An online community of & for disabled people  
<http://www.youreable.com/>

The ATOS National  
phone number is:

**0800 2888 777**  
Thanks to Tony B  
for this  
information

Message from the  
Contact List  
Working Party!

We would like to give everyone who hasn't  
joined another opportunity to join our  
**Contact List.**

If you haven't joined you will find a  
membership form enclosed with your  
newsletter in case you are now ready to  
join or are a new member and haven't  
received a form yet.

### Would you like to join our NEW Facebook Page?

All our members (over 16) are cordially invited to  
join our new Facebook Page:

'Official Solihull & South Birmingham ME Support  
Group'

Detailed instructions on how to join are on our  
website page:

<http://ssb4mesupport.weebly.com/about-our-group.html>

## Happy Birthday to:

**MAY** - Jo Draysey; Elaine Samworth; Glenys Thomas;  
Raga Abdi ; Barbara Emery

**JUNE** - Jo Taylor ; Wendy Vincent; Judith Jones; Dan Longley;  
Simone Dorsett; Rose McCready; Susan Hrubis; Michael Dyer

**JULY** - Lin Cook; Hugh Jones; David Slater; Victoria Cox; Laura Arrowsmith;  
Marianne Hicks

**AUGUST** - Mary Denby; Mark Holland; Rebecca Greenhill; Stephen Moss;  
Sheila Tompkins



## Update on Personal Independence Payments (PIP)

With thanks to Benefits & Work website:

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

**Please note:** this guide is based on the most reliable information available at the time of writing.

**Personal independence payment (PIP)** began replacing disability living allowance (DLA) for working age claimants from 8th April 2013. The assessment for PIP of all current working age DLA claimants is expected to be completed by March 2018. The government have claimed that the introduction of PIP will ensure that resources are targeted where they are most needed. They have also clearly stated, however, that one of the intentions behind the introduction of PIP is to reduce the cost of the current benefit by around 20%. This means that the DWP expect 55% of all current working age DLA claimants to be worse off under PIP (29% will have had their award decreased; 26% will have no award at all

### PIP vs. DLA - similarities and differences

- Like DLA, PIP is not means-tested, doesn't require national insurance contributions, can be claimed whether you are working or not, is non-taxable and acts as a passport to other benefits and premiums.
- Like DLA, PIP is divided into two components: a daily living component and a mobility component.
- Unlike DLA, each component has only *two rates*, a lower paying standard rate and a higher paying enhanced rate – DLA has three rates to the care component.
- Unlike DLA, PIP awards are based on a points system, meaning that the method of assessment has more in common with employment and support allowance (ESA) than with DLA.
- Like DLA, there are special rules that apply to people with a terminal illness.
- Like DLA, PIP can give some claimants access to the Motability scheme and automatic entitlement to a Blue Badge.
- Unlike DLA, the vast majority of awards are intended to be time limited – the majority will be for either two years or five years. So most PIP claimants can expect to have regular reassessments for as long as they remain on the benefit.
- Like DLA, people who qualify for the benefit below the age of 65 can continue receiving it beyond 65 provided they still meet the eligibility conditions.

### Qualifying period

For PIP, you need to have had your current level of needs for at least three months and be likely to continue having them for a further nine months. The three months test does not apply if you are transferring from DLA to PIP.

### Length of awards

All PIP awards are for a fixed period, except in exceptional circumstances. Short-term awards of up to two years are given where your condition is expected - by the DWP - to improve significantly. Awards of 5-10 years are made where changes in your condition are possible but less likely. Ongoing awards will only be given in a very small minority of cases where you are unlikely to get either better or worse. A claim can be checked at any time while the award is still in force, to verify that there has been no change of circumstances.

### Timetable for introduction of PIP

The transfer of claimants from DLA to PIP is expected to take five years, ending in March 2018, with DLA claimants with indefinite awards being the last to be assessed. The DWP have published a timetable for the transfer, which we have set out below.

**From April 2013** the new timetable began with a pilot from 8th April 2013 for new claims for PIP in the North West and part of the North East of England.

**From June 2013**, all new claims from anyone aged 16-64 will be for PIP instead of DLA throughout the whole of Great Britain. The only exceptions will be renewal claims from a fixed-term DLA award which is due to expire before the end of February 2014. In these cases the renewal claim will still be for DLA rather than PIP.

**From 7th October 2013** the following DLA recipients will begin to have to claim PIP:

- Children turning 16 will have to claim PIP when their existing fixed-term award is coming to an end.
- People reporting changes of circumstances which might affect their rate of payment, such as an improvement or deterioration in their condition, but not issues like going into a care home or hospital or changing address.
- People with a fixed-term DLA award which expires from the end of February 2014.

Anyone who chooses to make an application for PIP, including people who have a fixed-term or indefinite award of DLA, can make a claim from this date. However, you cannot make a claim for PIP if you are in the course of making a claim for DLA and no decision has yet been made on your claim.

**From October 2015**, all other working age DLA recipients will have to make a claim for PIP.

Claimants will be selected randomly rather than by area or age, although the DWP say that they will "invite claims as early as possible from recipients who have turned 65 after 8 April 2013, when PIP was first introduced." The DWP does not now expect to complete the reassessment of all existing working age DLA claimants for PIP until March 2018.

## Update on Personal Independence Payments (PIP) continued

### PIP components, rates and scores

PIP has two components:

- daily living component
  - mobility component
- Each component has two rates:
- standard rate
  - enhanced rate

Claimants who are assessed as having:

- 'limited ability to carry out daily living activities' (minimum score 8 points) are paid the standard rate of the daily living component, currently £53.00
- 'severely limited ability to carry out daily living activities' (minimum score 12 points) are paid the enhanced rate of the daily living component, currently £79.15
- 'limited ability to carry out mobility activities' (minimum score 8 points) are paid the standard rate of the mobility component, currently £21.00
- 'severely limited ability to carry out mobility activities' (minimum score 12 points) are paid the enhanced rate of the mobility component, currently £55.25

### ADDITIONAL INFORMATION

#### Variable and fluctuating conditions

Taking a view of ability over a longer period of time helps to iron out fluctuations and presents a more coherent picture of disabling effects. Therefore the descriptor choice should be based on consideration of a 12 month period.

Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in the 12 month period. The following rules apply:  
If one descriptor in an activity applies on more than 50 per cent of the days in the period – i.e. the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen.

If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.

Where one single descriptor in an activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days – for example, descriptor 'B' is satisfied on 40 per cent of days and descriptor 'C' on 30 per cent of days – the descriptor satisfied for the highest proportion of the time should be selected.

#### Reliably, in a timely fashion, repeatedly and safely

An individual must be able to complete an activity descriptor reliably, in a timely fashion, repeatedly and

safely; and where indicated, using aids and appliances or with support from another person (or, for activity 10, a support dog). Otherwise they should be considered unable to complete the activity described at that level.

**Reliably** means to a reasonable standard.

**In a timely fashion** means in less than twice the time it would take for an individual without any impairment.

**Repeatedly** means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

**Safely** means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

#### Risk and Safety

When considering whether an activity can be undertaken safely it is important to consider the risk of a serious adverse event occurring. However, the risk that a serious adverse event may occur due to impairments is insufficient – there has to be evidence that if the activity was undertaken, the adverse event is likely to occur.

#### Aids and appliances

The assessment will take some account of aids and appliances which are used in everyday life. In this context: **Aids** are devices that help a performance of a function, for example, walking sticks or spectacles.

**Appliances** are devices that provide or replace a missing function, for example artificial limbs, collecting devices (stomas) and wheelchairs.

The assessment will take into account aids and appliances that individuals normally use and low cost, commonly available ones which someone with their impairment might reasonably be expected to use, even if they are not normally used.

Individuals who use or could reasonably be expected to use aids to carry out an activity will generally receive a higher scoring descriptor than those who can carry out the activity unaided.

\* \* \* \* \*

#### Please remember:

1. *These are just a few helpful (hopefully!) extracts from the B&W site, a new full PIP Guide in PDF is now available from Jenny via email and copies of the new points guide are also available via email or as written copies through the post.*

2. *We are here for you. We know that the introduction of PIP will be yet another awful & distressing experience for many of you, so please don't suffer this alone - call us or email us on any of the usual contact numbers or talk with each other via the Contact List or Facebook..*

## Changes to other benefits in 2013

There will be some important changes to a number of other benefits in 2013.

- Disability Living Allowance will be replaced by Personal Independence Payment from 2013.
- Council Tax Benefit will be abolished in April 2013. Local councils in England (and the Scottish and Welsh governments in the devolved nations) will be bringing in their own Council Tax Support Scheme to replace it.
- A cap on the total amount of benefits that can be claimed will be introduced from April 2013.
- From April 2013, the Bedroom Tax (officially known as the under-occupation penalty) will cut the amount of benefit you can get if you are considered to have a spare bedroom in your council or housing association home.
- Community Care Grants and Crisis Loans will be replaced in April 2013 by financial help provided by your local authority in England. In Scotland they will be replaced by the Scottish Welfare Fund delivered through local authorities. The Welsh Government will be bringing in their own scheme to replace them.
- Budgeting Loans will be replaced by a new system of Budgeting Advances from April 2013 onwards, as people are moved onto Universal Credit.

**For changes from DLA to Personal Independence Payments see pages 15 & 16.**

### Universal Credit

Will be launched in October 2013 and will replace:

- income-based Jobseeker's Allowance
- income-related Employment and Support Allowance
- Income Support
- Child Tax Credits
- Working Tax Credits
- Housing Benefit

Payment of all the benefits mentioned above will be 'rolled up' into one monthly payment paid to the 'claimant' a month in arrears. This means Housing Benefit or as it will be known 'the housing element' of your Universal Credit will be paid directly to you. You will therefore be fully

responsible for paying your rent personally. You may want to make sure you have a bank account in place to help you receive your benefits. Universal Credit is being introduced from April 2013, in selected areas of Greater Manchester and Cheshire. It will be rolled-out gradually over the next few years, and completed by 2017. At this time, your eligibility to claim Universal Credit will depend on where you live and your personal circumstances. If you already claim a benefit, you'll continue to do so as normal and you'll be told when the changes will affect you. The first people to claim Universal Credit will be newly unemployed jobseekers. As Universal Credit is gradually rolled-out, it will be extended to more groups of people.

By 2017, anyone who is eligible will be paid Universal Credit.

You won't be eligible for Universal Credit from April 2013 if any of the following are true:

- you're already claiming Jobseeker's Allowance
- you live with your partner
- you have children you're responsible for
- you own your home or have a mortgage on it

You'll be asked further questions to check your eligibility when you make a claim for Universal Credit. If you're on a low income, you will probably still get Universal Credit when you first start a new job or increase your part-time hours. The maximum a single person will receive a week is £350 and for couples it will be £500. This amount will include the money (a.k.a. Universal Credit 'Housing Component') that you are expected to use to pay your rent.

### Housing Benefit

From April 2013 Housing Benefit paid to you will be paid in relation to the number of bedrooms the Government deem appropriate for the size of your family (see Bedroom Tax for further details).

Your Housing Benefit levels will be reduced if you have other adults living with you. These people are known as non-dependants. They are assumed to be contributing to rent. The amounts, which are set down by law, are to increase significantly over the next few years. In April 2012 the lowest rate increased from £9.40 per week to £11.45 per week. If these adults work, the money deducted from your benefit is much higher.

## Changes to other benefits in 2013 continued...

### Bedroom Tax

#### What do the changes mean?

The size criteria in the social rented sector will restrict housing benefit to allow for one bedroom for each person or couple living as part of the household, with the following exceptions:

- Children under 16 of same gender expected to share
- Children under 10 expected to share regardless of gender
- Disabled tenant or partner who needs a non resident overnight carer will be allowed an extra bedroom

#### Who will be affected?

All claimants who are deemed to have at least one spare bedroom will be affected. This includes:

- Separated parents who share the care of their children and who may have been allocated an extra bedroom to reflect this. Benefit rules mean that there must be a designated 'main carer' for children (who receives the extra benefit). The other parent will not get housing benefit to cover their extra room.

- Couples who use their 'spare' bedroom when recovering from an illness or operation
- Foster carers because foster children are not counted as part of the household for benefit purposes
- Parents whose children visit but are not part of the household
- Disabled people including people living in adapted or specially designed properties.
- Parents whose children visit but are not part of the household
- Families with disabled children

#### How much will people lose?

The cut will be a fixed percentage of the Housing Benefit eligible rent and service charge/s. The Government has said that this will be set at 14% for one extra bedroom and 25% for two or more extra bedrooms.

The Government's impact assessment shows that those affected will lose an average of £14 a week. Housing association tenants are expected to lose £16 a week on average.

## Useful tip from Black Triangle

Black Triangle says thousands of people are currently at risk of serious damage to their health because – as a result of their WCA – they are being forced to carry out work or work-related activity that they are not well enough to do. Black Triangle believes that persuading GPs to refer to regulations 29 or 35 – which date back to 2008 – could even save lives. The two regulations state that a claimant should not be found fit for work (regulation 29), or placed in the work-

related activity group (regulation 35), if such a decision would pose "a substantial risk" to their "mental or physical health".

<http://blacktrianglecampaign.org/2012/11/28/two-regulations-could-hold-the-key-to-winning-esa-appeals/>

On this site you will find a link to a useful letter showing what your GP could write on your behalf.





## Ask Alison...ask Alison...

This is my account of claiming Employment & Support Allowance (ESA) and the journey through the Work Capability Assessment (WCA) and subsequent appeal at tribunal. *Alison*

When I first started claiming ESA, I was put in the assessment phase, where all new claimants are allocated to whilst their claim is processed and incidentally, this is the lowest amount of ESA available.

The next stage in the process is the completion of an ESA50 form, which is a Department for Work and Pensions (DWP) Limited Capability for Work Questionnaire (a 20 page document) for completion and return and this acts as the basis for a decision on whether or not you will be called for a WCA to determine whether or not you are deemed eligible to receive ESA.

Unfortunately, I never received an ESA50 form from DWP and when ATOS (the company contracted to carry out WCA assessments on behalf of DWP) phoned me to arrange an appointment for a WCA. I advised that I had not yet received an ESA50 form to complete, to which the caller told me not to worry and it didn't matter as the WCA could proceed without this. When I arrived for the WCA at the Birmingham assessment centre (5 Ways House in Edgbaston), I advised the healthcare assessor (a nurse) that I had yet received an ESA50 form to complete from DWP, I was again told not to worry and it was not essential. The series of events that followed were very stressful and had connotations of a farcical comedy, from the outside looking in.

In preparation for the WCA, I prepared a list of the medications I was taking and a list of all consultant/specialist and hospital visits/admissions and I also took my medication with me. So, I endured the half an hour WCA with the ATOS healthcare assessor that mainly consisted of a series of questions being asked via prompts from a computer database and the representative almost continuously inputting their interpretation of the answers I gave, into the database. I was told that their report would be completed that day and sent to DWP to inform a decision about whether or not I was deemed eligible for ESA. I was advised that DWP would be in touch via letter within the next few weeks.

Approximately 2 weeks after the WCA, I received a letter from DWP informing that they had decided that I was not entitled to ESA because I had been found to be capable of work following my recent WCA. It went on to explain that I would get a further letter explaining how they had arrived at the decision and that if I thought the decision was wrong that I should get in touch with them by phone or in writing within one month of the date of the letter. There was also reference to the GL24 – Decision Making and Appeals leaflet, if I thought the decision was wrong.

On the same day as the above letter, I received a separate letter from DWP entitled 'about your assessment

for ESA'. This letter contained information about the decision maker's reasons for the decision on my claim for ESA. A breakdown of the points allocated for physical functions and mental, cognitive and intellectual functions was attached and I was scored a grant total of 0 points throughout the assessment.

It was at this point that I completed the GL24 leaflet to appeal against the decision. This form asks for basic information about you and asked you to tell DWP why you disagree with the decision, why you think the decision is wrong – there is a Reasons area on the form in which to explain further. Instead of writing in the reasons area, I attached a printed A4 sheet, giving 3 examples of the many reasons why I thought the decision was wrong. I also asked DWP not to ask me to give further details of my ground of appeal at this stage, until I have been provided with more information about how the decision was reached and have had the opportunity to try and get independent advice and support. I also asked that I was only contacted in writing concerning this matter and that I did not wish to receive any telephone calls as I consider welfare benefits too complex to be discussed over the telephone. I also stated that under no circumstance I would withdraw my appeal verbally and that any suggestion that I have done so would be mistaken. I also expressed my wish for an oral hearing, so that I could explain the full effects of my condition to a tribunal and answer any questions they may wish to ask. Finally I advised that I wanted to remain in the assessment phase of ESA whilst my appeal was being considered. I also enclosed a letter asking to be provided with copies of all the evidence used by the decision maker in reaching the decision at the WCA and that this evidence should include the ESA85 medical report form and any evident as to whether the report was audited and whether any amendments were made as a result; the ESA113 – if one was acquired in my case; any medical evidence from health professionals such as my GP or consultant and any other information held on me under the Data Protection Act 1998.

I received a response to my letter from DWP a few days later and was advised that they would look at the decision and if they could not revise it in my favour, they would send my appeal letter and papers giving their reasons and evidence for the decision to the Tribunals Service and that they would also send me a copy of the papers. To date, I still have not received a copy of the appeals papers from DWP.

The next communication was received from HM Courts & Tribunal Service, approximately 3 weeks later, enclosing an enquiry form for completion and return and information about the appeals process. At this point, the

## My Journey through ESA from the beginning to the Appeal at Tribunal

paper trail goes cold and I didn't hear from anyone again until some 7 months later when HM Courts & Tribunals Service wrote to advise that my appeal would be heard 5 weeks later.

I had previously tried to obtain legal advice via CAB and was signposted to local law centres. I contacted 3 of these, who all advised that they were not taking on benefits cases at the moment, for various reasons. I admit that I left it quite late when I contacted CAB again and was signposted to Community Legal Advice, who allocated a solicitor to look at my case. I liaised with the solicitor, who was very helpful and put together some information for the tribunal.

I attended the tribunal on the allotted date and time (still not having received a copy of the appeal papers from DWP), only to be told that the panel had decided to hear my appeal earlier in the day, without me! I was told to go home and wait for a letter containing the decision. Around a week later, I received the Tribunal's decision advising that the appeal had been disallowed due to no points being scored at WCA.

Subsequently, the decision was set aside (which means that it was disallowed and the hearing would be reheard completely) and I was invited to appear at Tribunal again, some 5 weeks later.

In the meantime, DWP stopped my benefits twice as their processing systems appeared to be very slow and cumbersome and did not keep up with the paperwork being issued by the Tribunals service and guess what? Still no copy of the appeal papers. This caused me an untold amount of stress, not to mention increased ME symptoms, as like a row of dominoes, a knock on effect from this was that my other benefits also ceased, so on top of preparing for tribunal, I was also contacting DWP and the local authority, to try and sort out the resuming of my benefits. My solicitor finally received a copy of the appeal papers, after the first tribunal hearing and I got sight of these, via my solicitor around 6 weeks prior to the second appeals hearing.

I was again contacted by the Tribunal Service and asked to attend for appeal a few weeks later. My solicitor wrote to my GP and asked for supporting information for the tribunal. My solicitor managed to process the information provided some 3 days prior to the tribunal hearing and decided that it was not adequate to support my case and regrettably had to withdraw his services. Although, he did give me some invaluable advice about how to prepare my paperwork to table at the tribunal.

So, here I am, 3 days to the hearing and I have to prepare a submission, arguing the points made by the assessor at WCA. Suffice to say that I created a 16 page document containing the assessor's findings against my actual findings. This was tabled at the hearing, which delayed the process for 30 minutes or so, whilst the tribunal panel had time to read it.

I was invited into the hearing room, which was set out in a meeting style with a table between the panel (a judge and a doctor) and me, with the court clerk at the end of the table, taking notes. I was asked a series of questions and, as I had taken a file containing all the information to do with the appeal, I was able to refer to this. I was then asked to leave the room whilst a decision was made and within 5 minutes or so, I was back in the room. I was advised that the Tribunal had allowed the appeal and that the original decision made some 11 months previously had been set aside and I was entitled to ESA with the support component. I was handed the appeal decision notice within 15 minutes of leaving the hearing room and went on my way.

It then took DWP around 7 weeks to change my benefits to reflect the decision and I also had to prompt them a couple of times within this period to ensure this was done. Incidentally, I have still not received a copy of the appeal papers from them!

The some of the lessons I have learned from this dreadful experience are:

- You can ask for the WCA to be recorded. This may delay the WCA but DWP/ATOS are obliged, if asked to record the session on your instructions.
- Keep your GP in the loop and ask for a letter of support, if possible. Also, take a list of specialist/consultant/medical appointments with names, dates and a little detail about the visit.
- Take your medication with you and if you can, take your repeat prescription or a list of medication including dosage and frequency.
- Take someone with you to the WCA – you may find 2 heads are better than one and at least post WCA, when the paperwork arrives, you will be able to discuss it with someone.
- When answering questions, you may be asked to consider what you can/can't do on an 'average' day. If most of your days are not good – base your answers on this.
- Seek legal advice as soon as you are aware of a negative decision – it is never too soon to prepare. The old phrase 'failing to prepare is preparing to fail' comes to mind.
- Try to keep all contact for your appeal in writing, so that you have a paper trail to refer to.

There are lots of other hints and tips and useful resources for this topic and I will be preparing further information for the next newsletter.

*Many thanks Alison for all your hard work- this is so helpful and well written , Jenny x*



## Professor Derek Pheby speaks out for the first time about his family's terrible ordeal

Taken from the All Party Parliamentary Group (APPG) on ME Minutes 13th March which focused on severe M.E. and received presentations by Professor Derek Pheby, Visiting Professor of Epidemiology, Buckinghamshire New University and others. The full minutes can be read here: <http://www.meassociation.org.uk/?p=15092>

Extract: In Professor Pheby's own words:

### 5) Impact on lives

"In respect of this, I can speak from personal experience, which I think exemplifies and illustrates in extreme form many of the problems that occur for people with severe ME and their families. My son fell ill at the age of eight; he is now forty-two. When he became ill, we immediately became public property, and there was no confidentiality. Social services, without our knowledge or consent, got involved from the outset. We were threatened with care proceedings, and our son fell into a nest of paedophiles. A secret case conference was held, which was minuted, and at which the county solicitor was present. The County Council lied repeatedly about this, and for twenty-five years denied it had even taken place. Eventually, the minutes were disclosed to us under the Data Protection act, and we found we were one day out in our estimation, on the basis that there had been a sudden upsurge in activity at that point, as to when it had taken place. The county solicitor then argued that this had not been a 'formal' child protection case conference, which was hypocritical, as this took place in 1979, and it was a further ten years before the distinction between formal and informal case conferences was enacted in the Children Act 1989.

This whole affair dominated our lives for years. It blighted the careers of both my wife and myself, and our children's social and educational development. For example, the university applications of our younger son, who had never been ill, was undermined by the Principal Educational Psychologist for the county, who muddled him up with our other son, seven years older, and proceeded to tell his school about his alleged history of "school phobia", which none of our children ever had. Fighting off these attacks cost us a million pounds that we did not have. As a result, we have not been able to do any of the things we wanted to do in life, and given the amount of time this has taken out of lives, we now know that we never will.

The threat to break up our family was real, and we determined that we would not permit it to happen. We kept our cars permanently topped up with petrol, and our

passports at the ready, with a view to my wife removing our children to France at the least indication that the threats were to be acted upon, so that I could stay behind to fight contempt proceedings, to which I would have been party, rather than care proceedings to which I would not at the time have been party. Our French friends were very supportive, including Amnesty International, which promised us succour if need arose, but questioned what else we could expect from 'la perfide Albion'.

In England, by contrast, as whistle-blowers we were treated with contempt at all levels from cabinet ministers down to local managers in social services. There seemed no end to the dirty tricks, and we even found forged documents, including for example a letter sent to a consultant psychiatrist in her private capacity, ostensibly from my wife, thanking her for her psychiatric care. This was a crude forgery, the handwriting bore no relation to my wife's, and it was written at a time when my wife was in hospital, where she remained for five months following a serious hand injury as a result of which she was at that time unable to write.

Eventually, after twenty-six years, an alternative dispute resolution process took place, following which public letters of apology were sent to all five members of the family from Sir Nigel Crisp, the then Chief Executive of the NHS, and also on behalf of nine NHS trusts and agencies. The County Council was not party to this. I am not at liberty to disclose other aspects of the settlement, and cannot even say whether I am subject to a gagging clause or not. I would like lessons to be learned, and would make the general point, however, that may or may not be applicable to my case, that gagging clauses should not be used to cover up criminal wrongdoing."

Many of you will remember Professor Pheby and his wife, Anita, who came to our group meeting to speak to us about the National Disease Register and the ME Biobank in September 2011. I was completely shocked when I read this as I am sure you all will be. I was aware that Derek and Anita had a son with ME, but had no idea of all the suffering the family had gone through. They are really lovely people and both of them spoke with many of our members on that evening in a very caring and compassionate way. We can only hope that the MPs present who listened to this horrendous account will find it in their hearts to do something to stop it happening again and again. Jenny

## £53 a week? Prove it IDS!

This is what Dominic Aversano challenged Iain Duncan Smith to live on for a year in his petition on line.

Iain Duncan Smith to live on £53 a week right to their doorstep.

When Dominic started the petition I didn't think that he would actually take up the challenge, although there is nothing to prevent him from doing it. The point was to highlight the hypocrisy of our politicians living lives of real privilege while lecturing others on what poverty feels like.

The petition is still open:

<http://www.change.org/en-GB>

The response was overwhelming and in a very short time the number signing had grown to nearly half a million!

**460,000 people is a lot of people!**

On Monday April 8th the Department of Work and Pensions found out just what that looks like when Dominic delivered [the petition](#) calling on



Iain Duncan Smith still refuses to respond to the petition but I have no doubt he felt its impact. In fact his department was so surprised by how many journalists turned up at the delivery they went into lockdown for 15 minutes before they conceded they had to open the doors and let us in! Looking forward to seeing IDS trying to live on £53 a week!! Jenny

## ALL FALL DOWN FOR ME!

On Sunday 12th May at Old Palace Yard opposite Houses of Parliament in London, the organisers of the event call on all family, friends of people with ME, as well as people with ME, if well enough, to **fall down at 3pm and lie silent and still for 2 minutes**. This is to represent the brain/body collapse and pain people with ME have to suffer day in and day out, year in year out with no end in sight just to survive with this devastating disease.

**'This is not a life, it is a living death'**

The event is organised by the parents of children with ME, London ME Support Groups.

For more details see: [www.me-alivingdeath.org.uk](http://www.me-alivingdeath.org.uk)

## Wow factor for ME Awareness!



On May 12th, 2013 we are raising awareness. The Niagara Parks Commission of Niagara Falls Canada has confirmed that **Niagara Falls** will be illuminated in blue from 9:45 to 10:00 PM EST representing Myalgic Encephalomyelitis. They have also confirmed that Niagara Falls will be illuminated in purple from 10:15 to 10:30PM EST representing Fibromyalgia. Our voices are getting louder.

Wendy Boutilier to Invest in ME

## The 8th Invest in ME International ME/CFS Conference

**"Infection, Immunity and ME - Mainstreaming ME Research"**  
31st May

Chair - Dr Ian Gibson

Speakers include:

Professor Mady Hornig

Rakib Rayhan

Dr Sonya Marshall -Gradisnik

Dr Carmen Sheibenbogen

Dr Amolak Bansal

Dr Andreas Kogelnik

Professor Olav Mella and Dr Øystein Fluge

Dr James Baraniuk

Professor Greg Towers

And -

Dr Clare Gerada (Chair of the Royal College of General Practitioners) who is speaking on:

Government NHS Reforms: Implications for long term chronic conditions such as ME – for GPs and Patients

Launch of inclusive UK CFS/ME Research Collaborative

Monday, 22 April, saw the launch of the new UK Chronic Fatigue Syndrome/Myalgic Encephalitis Research Collaborative (CMRC). Set up by Stephen Holgate, MRC professor of immunology, and backed by the UK's main research funders (MRC, Wellcome Trust and NIHR) it aims "to create a step change in the amount and quality of research into chronic fatigue and ME". The launch featured some eye-catching provisional results that got good media coverage, particularly the [study from Newcastle](#) showing differences in lab-cultured muscle from CFS patients versus healthy controls. And an [fMRI study](#) found that patients had to use more brain regions to accomplish the same mental tasks as controls, confirming earlier work in this field.

**Not everyone is happy**

What's not to like? Well, although it's backed by most ME charities and almost all the UK's biomedical researchers, the collaborative is deliberately a broad church including all types of research, including psychological research. And that has upset a good number of patients - "read and weep..." was one pithy objection).

\*\*Many patients objected to the wording of the CMRC press release - for example this paragraph: "No certain cause has been established, which perhaps reflects its heterogeneous nature, but established immediate causes include certain infections, such as Epstein-Barr virus (EBV). (10-13 per cent of patients with a primary EBV infection develop CFS six months after onset. Predisposing factors include female sex, functional somatic syndromes, and prior mood disorders. For treatment purposes, important maintaining factors include comorbid mood disorders, beliefs about causation, and either

pervasive inactivity or swinging from inactivity to over-activity (boom and bust pattern of behaviour)."

The ME Association acknowledges these concerns, but its Chair Neil Riley argues: "*The Research Collaborative is a big tent covering a wide range of views on causation, definition, epidemiology and management. We believe it is far better to be inside the tent discussing and debating these issues - as happened during the discussion session on Monday - than sitting outside where we would not have a voice. ...Provided the Collaborative drives forward and promotes research into the biomedical causes of ME then we shall be in there, taking an active part and supporting its efforts.*"

Action for ME, AYME, the Chronic Fatigue Syndrome Research Foundation, The ME Association and ME Research UK all agree. The most significant ME charity choosing to remain outside the tent for now is Invest in ME, who have voiced their scepticism, arguing that what's needed is exclusive focus on biomedical research. - see: <http://www.investinme.org/IIME-Newslet-1304-01.htm> Nonetheless, it was an extraordinary achievement to bring together such diverse views into a single collaborative. As Stephen Holgate says, "It is the first time this has ever been done anywhere in the world—to get buy-in from these different communities".

[http://phoenixrising.me/archives/16786?utm\\_source=feedburner&utm\\_medium=feed&utm\\_campaign=Feed%3A+aboutmefsb+\(Bringing+the+Heat%3A+An+ME%2FCFS+\(Chronic+Fatigue+Syndrome\)+Blog+From+Phoenix+Rising\)](http://phoenixrising.me/archives/16786?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+aboutmefsb+(Bringing+the+Heat%3A+An+ME%2FCFS+(Chronic+Fatigue+Syndrome)+Blog+From+Phoenix+Rising))

\*\* Insert by SSB editor ref:

<http://www.actionforme.org.uk/Resources/Action%20for%20ME/Documents/CMRC%20launch%20media%20statement.pdf>

**A new era of Research in the UK?**

Extracts from *Phoenix Rising* article by Simon McGrath

For the last twenty years, the study of CFS in the UK has been dominated by researchers with a biopsychosocial perspective, so it's notable that the CMRC emphasises the need to do things differently. CFS is "a field that is in desperate need of new science", says Stephen Holgate. At the meeting he highlighted several new areas and opportunities:

- The application of state-of-the-art research methodology, including [Genomics](#), [Proteomics](#) and [Metabolomics](#).

- Using the new Networks approach as powerful tools for integrating and modelling biological data. This systems-based medicine approach focuses on how biological systems interact within the body, rather than looking at changes in individual genes or proteins. Nancy Klimas's Neuro Immune Centre in Florida, with Gordon Broderick providing network modelling, is a great example of this.

*Continued on p17*

- *Continued from p 16...*
- Emergence of large collections of biobanks. eg [The UK ME-CFS Biobank](#) and the [CFI bio-bank in the States](#). Such well-characterised patient groups, with clinical and biological material, open the way to large-scale studies probing any number of biological mechanisms.
- Holgate also wants to engage a wide range of new fields such as maths and environmental science who could all add to the party.

This looks to me like an agenda for cutting-edge biomedical research, particularly as he says:

By coming together in this way, the application of state-of-the-art research methodology... will greatly increase the chance of identifying pathways linked to disease causation and novel therapeutic targets.

As he's said repeatedly in recent years: "The key to success will be the engagement of scientists outside the field", drawing new blood into CFS research, bringing insights from other diseases, and encouraging young new researchers to study ME/CFS. Similarly, the MRC stresses the importance of proposals for research funding to include at least some researchers new to the field. And the MRC, who were at the launch, has a [highlight notice encouraging specific biomedical areas](#), including neuropathology and immune dysregulation.

One other important area discussed was heterogeneity and case definitions, which is a big issue for the whole field. Stephen Holgate referred to CFS/ME as a 'complex group of conditions' ie multiple conditions with different aetiologies, and so 'phenotyping' - dividing patients into different groups on the basis of clinical information, or even biomarkers - is a priority too.

**Biological breakthrough offers fresh hope for ME sufferers**

Hannah Devlin Science Editor

Scientists have found compelling new evidence for an underlying biological cause for the constant fatigue suffered by ME patients.

The study revealed abnormalities in the muscle cells people suffering from ME which are likely to contribute to feelings of tiredness and the inability to cope with sustained physical activity that many experience.

An analysis of muscle biopsies suggested that the cells had undergone substantial changes making them less able to cope with exertion.

The finding shows that whatever the initial trigger for ME, the condition leads to a cascade of physical changes right down to the cellular level.

Despite a growing body of evidence that ME has real physical symptoms, some patients still report facing stigma due to popular misconceptions that the condition is "all in the mind".

Professor Julia Newton, dean for clinical medicine at Newcastle University who led the study, said that the latest science was changing the way people view ME.

"You change people's perception of this terrible symptom," she said.

She added that in some cases the patients reported feeling vindicated by the findings which reveal basic biological differences between patients with ME and healthy volunteers.

Professor Newton presented the findings in London yesterday at a meeting marking the launch of a UK ME collaboration aimed at generating more high quality research into the disease.

In the study, scientists took muscle biopsies from ten patients and from ten healthy but sedentary volunteers.

The muscle cells were grown into small pieces of muscle in culture, and subjected to "exercise" in the form of electrical im-

pulses.

The cells from ME patients produced on average 20 times as much acid when exercised, suggesting an underlying cause for the aching muscles that patients often experience as soon as they begin to exercise.

The cells also showed other abnormalities, such as reproducing more slowly.

"We have found very real abnormalities," said Professor Newton.

The Newcastle team now hopes to use the muscle samples as in-vitro test beds for potential medications that could help reverse the symptoms of ME.

However, she said that scientists are still struggling to understand what causes the condition in the first place.

The disease affects more than 600,000 people in Britain with a quarter of those cases unable to perform even basic activities or look after themselves. Current treatments on the NHS include talking therapy and exercise. ■

## Evaluating the DePaul Symptom Questionnaire in the ME Research UK cohort

Prof. Leonard Jason at DePaul University, Chicago has been in the forefront of research into the development and application of diagnostic criteria for ME/CFS for more than a decade. In 2010, he developed a standard questionnaire (The DePaul Symptom Questionnaire, DSQ) to assess core symptoms of ME/CFS, with the aim of ensuring that symptoms are assessed in a consistent way across settings to aid in diagnosis. This questionnaire has now been refined (Jason et al, American Journal of Biochemistry and Biotechnology <http://thescipub.com/html/10.3844/ajbbasp.2010.120.135> and is being made available to other research groups for operational testing on existing ME/CFS cohorts. Importantly, the DePaul Symptom Questionnaire (DSQ) now comes in a format which scores symptoms and SF36 data, and produces a "diagnosis" based on several of the more common definitions of ME, CFS and ME/CFS. If this instrument is found to be sufficiently sensitive, it could greatly assist patient diagnosis, saving time (as it can be completed in the patient's home and brought to the clinic for scoring) and improving confidence in the diagnosis.

In the course of the ME Research UK-funded patient cohort study at Newcastle University, the researchers have collected a large volume of clinical, autonomic and symptom data, and they have available full data sets from almost 200 patients who have attended the Newcastle ME/CFS Service and been referred to their research programme. Each of these patients has been assessed on the basis of the Fukuda 1994 CFS and the Canadian 2003 ME/CFS definitions as part of their clinical examinations, but through the timely development of the DSQ an opportunity has arisen to compare the clinical diagnoses of patients in the Newcastle ME Research UK cohort with those derived from the more structured DSQ instrument. The results obtained will also be shared with Prof. Jason's group in Chicago, adding to the data on the usefulness of the DSQ which he hopes to acquire from research groups around the world in different populations of patients. Considering the importance of the ME Research UK cohort and its well-characterised nature, the results could throw valuable light on diagnostic categories and on the utility of the DSQ in practice.

See more: <http://www.mereseach.org.uk>

## The neuropsychiatric and neuropsychological features of chronic fatigue syndrome: revisiting the enigma.

**Abstract from paper by Y. Christley et al.**

School of Health, Nursing and Midwifery, University of the West of Scotland

The aim of this article is to provide a comprehensive and updated review of the key neuropsychiatric and neuropsychological complaints associated with chronic fatigue syndrome (CFS). Neuropsychiatric and neuropsychological difficulties are common in CFS and are linked primarily to disorders of mood, affect and behaviour. The neuropsychiatric complaint most frequently encountered amongst CFS patients is depression and in particular major depressive disorder (MDD).

Despite decades of research, the precise aetiological relationship between CFS and MDD remains poorly understood. This has resulted in the development of a number of interesting and polarised hypotheses regarding the aetiological nature of CFS. Recent scientific advances have however begun to unravel a number of interesting inflammatory and immunological explana-

tions that suggest CFS and MDD are distinct yet interrelated conditions.

The possibility that the overlap between CFS and MDD might be explained in terms of shared oxidative and nitrosative (IO&NS) pathways is an area of intense research interest and is reviewed in detail in this article. The overlap between CFS and MDD is further differentiated by variations in HPA axis activity between the two disorders. Important immunological differences between MDD and CFS are also reviewed with particular emphasis on antiviral RNase L pathways in CFS. In addition to the presence of neuropsychiatric complaints, CFS is also associated with neuropsychological symptoms such as impaired attention, memory and reaction time. The key neuropsychological problems reported by CFS patients are also included in the review in an effort to understand the significance of cognitive impairment in CFS.

<http://www.prohealth.com/library/print.cfm?libid=17902>

## Further research in the US links Gulf War Syndrome to physical illness

**Researchers in Washington say they have found physical proof that Gulf War illness is caused by damage to the brain — and that proof may ultimately help civilians who suffer from chronic fatigue syndrome and fibromyalgia.**

Using fMRI machines, the Georgetown University researchers were able to see anomalies in the bundle of nerve fibres that interpret pain signals in the brain in 31 Gulf War veterans.

The research is published in PLOS ONE journal:

<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0058493#s1>

The findings are "huge," because an fMRI allows doctors to diagnose a person with Gulf War illness quickly, said James Baraniuk, senior author and professor of medicine at Georgetown University Medical Center. The research, he said, also shows that Gulf War illness is not psychological.

Over 25% of the 697,000 veterans deployed to the 1990–1991 Persian Gulf War and 15% of nondeployed veterans have developed a symptom complex of widespread pain, fatigue, headache, gastrointestinal, bladder, and other "functional" nociceptive and interoceptive complaints. Gulf War veterans were exposed to a wide variety of exposures that include binary nerve agents, acetylcholinesterase inhibitors, organophosphates, other pesticides and herbicides that may have initiated their symptom

complex. This syndrome has been termed Gulf War Illness (GWI). An initial analysis defined these subjects as Chronic Multisymptom Illness (CMI) based on ≥2 complaints of (i) fatigue, (ii) musculoskeletal or (iii) mood and cognitive dysfunction for ≥6 months. Deployed Gulf War veterans met criteria for Chronic Fatigue Syndrome (CFS) (odds ratio = 40.6) and Fibromyalgia (FM) (odds ratio = 2.32) indicating extensive symptom overlap. All of the veterans who met CMI criteria in this study also met CFS criteria, and 52% met FM criteria.



Dr James Baraniuk of Georgetown University spoke at the Invest in ME conference in 2012 on 'Systems Biology of Interoceptive Disorders'. His research into cerebral spinal fluid proteomics (the study of proteins) can be seen at:

<http://www.research1st.com/2011/02/23/the-promise-of-the-proteome/>  
Rakib Rayhan, Researcher at Chronic Pain and Fatigue Research Centre Georgetown University Medical Centre Washington, who works with Dr Baraniuk will speaking at this year's IiME con-

## Cognitive deficits in chronic fatigue syndrome and their relationship to psychological status, symptomatology, and everyday functioning

<http://www.ncbi.nlm.nih.gov/pubmed/23527651>

**Method:** The current study compared the cognitive performance (reaction time, attention, memory, motor functioning, verbal abilities, and visuospatial abilities) of a sample with CFS (n = 50) with that of a sample of healthy controls (n = 50), all of whom had demonstrated high levels of effort and an intention to perform well, and examined the extent to which psychological status, CFS symptoms, and everyday functioning were related to cognitive performance. **Results:** The CFS group showed impaired information processing speed (reaction time), rela-

tive to the controls, but comparable performance on tests of attention, memory, motor functioning, verbal ability, and visuospatial ability. Moreover, information processing speed was not related to psychiatric status, depression, anxiety, the number or severity of CFS symptoms, fatigue, sleep quality, or everyday functioning. **Conclusion:** A slowing in information processing speed appears to be the main cognitive deficit seen in persons with CFS whose performance on effort tests is not compromised. Importantly, this slowing does not appear to be the consequence of other CFS-related variables, such as depression and fatigue, or motor speed.

# Research news... research news...

## Lipkin and Hornig go hunting for ME/CFS pathogens

Taken from the article by **Simon McGrath**, *Phoenix Rising* February 2013

Full article here: <http://phoenixrising.me/archives/16081>

Professor Ian Lipkin was the scientist who skillfully handled the XMRV 'rediscovery' study (which Mady Hornig worked on too). Despite disproving a link with XMRV, Professor Lipkin made clear his belief that ME/CFS was a serious disease that had not received the serious attention it deserved. Even more important - given his stellar record as a scientist - was his commitment to playing a serious role in trying to solve the illness. He's asked Mady Hornig to lead their hunt for the cause of ME/CFS. Professor Mady Hornig spoke at the recent CFS and Gulf War Illness Conference which was hosted by Nancy Klimas.

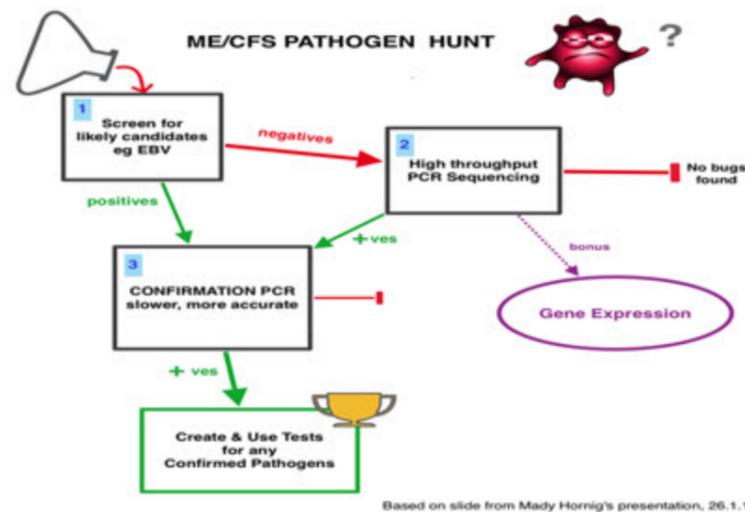
### Huge initial studies look for pathogens or tell-tale signs of infection

Work has already started with around 400 patients *plus* controls, including 200 patients + controls from the CFI pathogen study by Professor Hornig the Principal Investigator for CFI's Pathogen Discovery and Pathogenesis. If that's not enough, they are hoping to get funding for up to a further 400 patients and controls - that makes a mind-boggling maximum of 1,600 subjects: 800 patients and 800 controls. This is a big step up for ME/CFS research.

The major part of the study is looking for pathogens - viruses, bacteria or protozoans both known and unknown. But they are also looking for protein/immune abnormalities in patients, and they even plan to take a look at gene expression too to see if that throws up any clues.

The pathogen hunt has three steps:

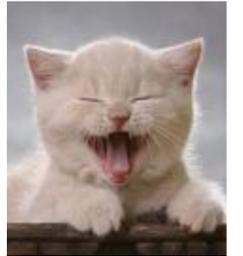
- Screen for a panel of 18 specific pathogens already implicated in ME/CFS, such as EBV.
- If no such pathogens are detected, they move to the heavy-duty phase, basically sequencing all DNA/RNA in the blood, which should identify both known and unknown viruses. This technique has been successfully used by Ian Lipkin in the past to discover new viruses.
- To be thorough (and these people are nothing if not thorough) any 'finds' from the first two steps will be confirmed by a smaller-scale but more accurate technique.



Finally, once they have confirmed candidate pathogens - assuming they find ones that have a statistically significant link with ME/CFS - they will develop new tests specifically for these pathogens. The team will also try to define 'host profiles', looking for a unique protein signature associated with the illness. If the study does find a robust CFS signature, it could be used for diagnosis - and a validated diagnostic test is almost the Holy Grail of ME/CFS research. The signature could also be used to measure treatment progress.

They are using a fancy technique called 'multiplexed immunoassay' to look at over 50 specific proteins that are markers of immune/inflammatory changes, or oxidative stress. For a smaller sub-sample, they will look more widely for any abnormality in protein profiles using "Target proteomics Mass Spectroscopy"

# COMEDY CENTRAL...



## DOG RULES

1. The dog is not allowed in the house.
2. Ok, the dog is allowed in the house but only in certain rooms.
3. The dog is allowed in all rooms but has to stay off the furniture.
4. The dog can get on the old furniture only.
5. Fine, the dog is allowed on all furniture, but is not allowed to sleep with humans on the bed.
6. Ok, the dog is allowed in the bed but only by invitation.
7. The dog can sleep on the bed whenever he wants but not under the covers.
8. The dog can sleep under the covers by invitation only.
9. The dog can sleep under the covers anytime.
10. Humans must ask permission to sleep under the covers with the dog.



OUCH!

# Group News... committee news



Tarsam Jo Jenny Alan Yvonne Alison

## Annual General Meeting March 13th.

Your AGM report is enclosed in this newsletter. Thank you to everyone who attended the AGM. The 'business' bit of the meeting ran through smoothly and we had time to relax and have a chat afterwards.

Welcome to Alison our new Chair!

## Committee meeting April 26

All the committee were present. We firstly thanked Tarsam for his work as Chair and welcomed Alison as our new Chair. We then spent some time discussing the **ME Awareness Coffee Morning** and what we were going to do this year - you can see the results of this on page 5! We also discussed the **Facebook** page and agreed that non members of the group (as long as they were known to us) could

join for a 3 months trial, at the end of which they would be invited to join the SSB group or would be asked to leave FB if they didn't want to join. We also finalised our SSB **code of conduct**, which you will see below. This will be sent out every year with the membership form from now on. We thank everyone for their contributions to this. We are looking at all aspects of **equality** next and welcome any thoughts from members on this. We decided to get more members' input at the meetings and on FB to try and make our group as inclusive as possible. We had the usual updates on communications, newsletter, finances and the general day to day business of the group. Next committee meeting is in July

## Thank you to Tarsam!

Tarsam Singh has stepped down as Chair of the committee after a year (2012 - 2013). You will see his letter on the back page of the AGM notes (enclosed). Tarsam very kindly stepped into the breach after Jo Taylor finished as Chair and always made it clear his position was temporary until someone else felt that they could take on the role. As it turned out Tarsam had the unenviable task of guiding us through some of the most troubled times we have ever had in the group. This he achieved with great diligence and unfailing dedication to the members' safety and well being, in spite of his own fluctuating health. We thank Tarsam for all his hard work and his fantastic contribution to the group and assure him that he can leave with the knowledge of a job well done.

## SSB Quality Assurance Working Party

### Code of Conduct

The committee would like to ensure that our Group provides a safe place for all its members. Our aim in developing a Code of Conduct is to give guidelines applicable to all areas of the Group e.g Newsletter, Contact List, Meetings, Facebook page, Website.

Members should:

- Show respect for others as individuals – their viewpoints, beliefs and different experiences
- Maintain confidentiality of other members' details and shared personal stories
- Be non-judgmental and non-confrontational
- Allow others time to talk

Any member experiencing any difficulties with the above has the right to notify the committee, who will seek to resolve any issues.

# Group News... committee news

## A quick look at the results of the SSB Benefits Survey so far

- 13 people returned surveys so far
- 11 applied for (or were migrated to) ESA
- 1 judged not entitled to ESA
- 1 asked for a revision and was successful
- 1 went to appeal and was successful but had benefits reduced while waiting

Of these 11:

### 3 people had outside help filling in ESA50 and were placed directly into the support group

- They used AfME helpline (rated good); Advocacy matters B'ham Settlement (rated good); Freshwinds (rated good)

### 3 people had outside help filling in ESA50 but were *not* placed directly in the support group

- They used 25% group (rated good); CAB (rated good); Age Concern (rated not good)
- 1 of the 3 had to attend a Work Capability Assessment (WCA)
- 1 appealed without help and was successful
- 1 appealed with help (B'ham Law centre - rated good) but had decision revised to Support Group before Appeal
- 1 person had benefits stopped whilst waiting for revised decision
- 1 asked for revision (refused) and then appealed but decision revised to Support Group before Appeal

### 2 people had no outside help at all

- 2 had to go for WCA
- 1 placed in WRAG

### 2 people had filled in ESA50 but are still awaiting decisions

### 1 person filled in ESA50 (no help) and placed in support group but then placed in WRAG

- Appealed but unsuccessful (helped by MIND - rated good)
- Currently does not have to do any work related activity

### 4 people had Work Capability Assessments

- 2 saw a doctor
- 1 saw another health professional (nurse)
- 1 not sure
- 

It appears from the figures received so far, that only 3 out of 11 or just 27% of members were awarded ESA in the support group without having to ask for revision or appeal. More encouragingly almost everyone succeeded in getting in the support group after a revised decision or appeal, however this all came at a cost to our members' health. We will include more results and some of your comments & thoughts in the next edition.

## Some Commonly used Abbreviations

APPG = All Party Parliamentary Group  
 BACME = British Association of CFS/ME (formerly the CCRNC = CFS/ME Clinical Research Network Collaboration)  
 CNCC = Clinical Network Coordinating Centre  
 DLA = Disabled Living Allowance  
 DoH = Dept of Health  
 DWP = Dept of Work & Pensions  
 ESA = Employment and Support Allowance  
 IB = Incapacity Benefit  
 ICC = International Consensus Criteria  
 LMDT = Local Multi Disciplinary Team  
 MRC = Medical Research Council  
 NICE = National Institute of Clinical Excellence  
 NIH = National Institute of Health (USA)

PACE = A comparison of Adaptive Pacing Therapy (APT), Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET)  
 PIP = Personal Independence Payments  
 PWME/pwme(s) = Person(s) with ME  
 RCGP = Royal College of General Physicians  
 RCPCH = The Royal College of Paediatrics and Child Health  
 SSB = Solihull & South B'ham ME Group  
 UK CMRC = UK CFS/ME Research Collaborative  
 WCA = Work Capability Assessment  
 WMMEG = West Midlands ME Groups (consortium of West Mids ME support groups)  
 WRAG = Work Related Activity Group (ESA)