



Forget-me-not

SSB Contacts: Like to talk to someone?

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

Jo will visit members who live within a reasonable distance of Kings Heath.

Jenny: 0121 689 0777 Text only 07785 958 872

And don't forget you can now:

- join Facebook (Official Solihull and South Birmingham ME Support Group)
- get in touch with someone on your SSB Contact List

Read the latest news on the new website: <http://ssb4mesupport.weebly.com/news.html>

Member's news, thoughts or articles for our newsletter or website are very welcome. Post to Jenny Griffin: 59 Cartland Road, Stirchley B30 2SD or email to jennylg@live.co.uk or just give us a ring on the numbers above

National Organisations:

ME ASSOCIATION 01280 818 968 www.meassociation.org.uk

The MEA '**me connect**' helpline is **0844 576 5326**.

(Available every day of the week - phone between these times: 10am-12noon, 2- 4pm and 7- 9pm.)

The 25% ME Group (severely affected) **01292 318 611** www.25megroup.org

The TYMES TRUST (young pwme) **0845 003 9002** www.tymestrust.org

INVEST in ME **02380 251719** www.investinme.org

ME Research UK **01738 451234** www.meruk.org

ACTION for ME **0845 123 2380** www.afme.org.uk

Local Organisations

Birmingham Disability Resource Centre (Yardley) :

0121 789 7365 www.disability.co.uk

Carers Centre Birmingham: 0121 678 8000

www.birmingham-carers.org.uk

Princess Royal Trust Carers Centre Solihull: 0121 788 1143

Freshwinds (includes local DIAL office) [Selly Oak]

0121 415 6670 www.freshwinds.org.uk/

DIAL Solihull 0121 770 0333 www.dialsolihull.org.uk

Disability Info & Resource Centre (Erdington) -

Lisieux Trust (including **DIAL** office): 0121 382 6660

[**DIAL** provides a **FREE**, impartial and confidential information and advice service for disabled people and their carers. The service is run by people with disabilities for people with disabilities and their carers.]

Shirley & Solihull Citizens Advice Bureaux - advice line: 0844 826 9716

Birmingham Law Centre (provides legal advice and casework

services to individuals and communities in need). 0121 766 7466

Home visits available. www.birminghamlawcentre.org.uk

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 March 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



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



December Newsletter 2012

"Supporting sufferers and their families"

*Wishing you all a peaceful Christmas
and better health in 2013*

Researchers find no link between XMRV and CFS/ME - the results of the Lipkin Study

The National Institutes of Health, the Centers for Disease Prevention and Control and the Food and Drug Administration commissioned a study under the direction of Ian Lipkin, a professor of neurology and pathology and director of the Center for Infection and Immunity at the Columbia University Mailman School of Public Health, to definitively answer the question.

Senior investigators from the original studies were involved in the design of the new study. It was "overpowered,"

involving 147 patients with the syndrome and 146 matched controls, recruited by researchers at six sites across the country. Analysis was blinded. Genetic tests that looked for the virus in the blood of the subjects "found no evidence of XMRV or related viruses," said Lipkin. It is "a very clean result that is impossible to misinterpret." The answer was delivered at a September news conference in New York City, and published in the online journal - mBiol.

More on this and links on p 17

Judge grants judicial review of Work Capability Assessment



The High Court has granted permission to two disabled people to bring a claim for judicial review against the Secretary of State for Work and Pensions to challenge the operation of the Work Capability Assessment (WCA).

The case concerns some of the problems with the system as experienced by people with mental health problems.

More on this story on p 16

Christmas meetings!

Don't forget our

Christmas Social

at Shirley Community Centre on
Monday December 10th
starting at 7.30pm



We also have an

extra Christmas meeting

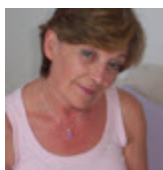
On **Tuesday December 18th**

at 59 Cartland Rd B30 2SD

"drinks, mince pies and a chat!" starting at 1pm

Everyone is very welcome!

Jenny Writes...



Dear Members,

When we filled in the application form for the Comic Relief Grant the theme was very much about the social isolation of people with ME. This theme was further underlined in Sam Strong's fascinating dissertation on ME which appeared in our Autumn newsletter.

I have had lots of phone calls and emails from you over this last year and I know that many of you are struggling with benefits and trying to find some help from the NHS or Social Services. Once again the battle for recognition for this illness and to get any sort of appropriate help has taken its toll on our health. Far from placing people back into the mainstream of society, the government's vicious cuts of support for disabled people have resulted in yet further isolation from any sort of life at all. The lack of any informed medical knowledge on ME only reinforces this situation.

At no time is this isolation felt by sufferers of ME more apparent than at Christmas. At a time when everyone else seems to be

celebrating it is hard for pwME to join in and maybe still hard for others to understand why we cannot.

Our hearts go out to those who have been severely affected for yet another year and we hope that next year will be your year to improve.

Please remember all of you, if you feel isolated then we have the Contact List and our Facebook where you will find someone to talk to and of course we have our usual contact numbers (below). Keep in touch.

No denying that this has been a difficult year all round for all pwME and for the group. As you will see from the committee page (p19) and group news (p6) we have had some tough times and some tough and unprecedented decisions to make.

In the ME world depressing news abounded with NICE accepting the PACE Trial and CBT & GET and apparently absolutely nobody in the government, the DWP or the NHS prepared to actually listen to us. The XMRV research fiasco created headlines for all the wrong reasons.

The benefit cuts and the new ESA were every bit as bad as we feared. No doubt that pwME have suffered more this year.

However as you will see from our ME News pages, the fight back is beginning. We are not going to give up or sit back and accept inferior and irrelevant research such as the PACE Trial. Thankfully the Medical Research Council have finally made available some funding for ME research and there are some interesting developments in the US with Prof Lipkin giving his views on the need for more research on ME.

I am very grateful to all of you who have contributed to the group this year with articles, feedback, book reviews and news - and a special thank you for all your fantastic fundraising and generous donations Well done! And, of course, another big thank you to those who have helped us out this year like Flea for doing the newsletter labels, and Gurminder in raising funds for ME Research.

I would like to say a heartfelt thank you to all those families, friends and carers, who have supported and cared for us all year.

I wish you all a very happy and peaceful Christmas and and lots of good health for 2013

Take care & keep in touch,
Love Jenny

YOUR MEMBERSHIP RENEWAL IS NOW DUE!

Your membership renewal form is enclosed with this Newsletter!

Bearing in mind the current economic climate and the extra financial difficulties faced by many members at this time, the committee have decided not to increase the subscription fee this year and it will remain at £7 until 2014.

Please try and return your renewal form as soon as you can.

**Your 2013 meeting dates
are on page 5**

And on our website:

<http://ssb4mesupport.weebly.com/meetings.html>

Poetry Corner



Fecund, thrusting up
into gentle mists, fungi
edible stillness

michelle bint

Inside This ISSUE

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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**

On Facebook: **Official Solihull and South Birmingham ME Support Group**

By textphone: **07785 958 872**

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

*Many thanks to Michelle for her lovely Haiku.
For those of you, like me, who had not seen this
type of poetry before, I have put a short
description below:*

Haiku is a poetic form and a type of poetry from the Japanese culture. Haiku combines form, content, and language in a meaningful, yet compact form. Haiku poets write about everyday things. Many themes include nature, feelings, or experiences. The most common form for Haiku is three short lines. The first line usually contains five syllables, the second line seven syllables, and the third line contains five syllables.

...group news ...group news

Meetings News



Say cheese? That's what attendees at October group meeting did - to celebrate the receipt of Comic Relief Funding via Birmingham & Black Country Community Foundation.

September meeting

We had a lovely meeting in September at Shirley catching up with both old and new faces. Everyone got on really well and there was a lot of chatting going on! Lovely to meet member, Amanda, for the first time (well done Amanda!) and to meet new contact Michelle and her Mum. Welcome to Michelle. We had much excitement as we had the first draw for the SSB Lottery! See the Lottery results on p 5...

October meeting

We were all back at Shirley in October (see picture above) having received the news of the Comic Relief grant from the Birmingham & Black Country Community Foundation. As you see we had our photo taken, courtesy of Alison our newly appointed head of the digital media working party - wow. This caused much hilarity as Alison kept running backwards and forwards to get in the picture before the timer went off! We are going to use this photo for publicity for the grant and so far we have sent it to the B'ham Post with a brief article - did anyone see this, because I didn't ??! The photo is also on our new Facebook page and our website.

We welcomed new member Rosie and new contact Melody. Again there was a lot of chat and it was very good to see that everyone talked to the new people as well, making them feel part of the group straight away. We finished the evening with another exciting SSB Lottery Draw.

Yvonne: 'Really good night with a lovely crowd!'
Melody: 'It was lovely to meet you and the group on Monday evening. Having a good laugh was a unexpected joy too.'

November meeting

Another good and interesting meeting - this time at 59 Cartland Road in the daytime. No new members this time but it was great to see long time member, Nayyar, who had not been to a meeting for some years since returning to work part time. As she said you can only do so much when you have ME - sadly it nearly always seems to be our social life which has to go when we have to work or have other necessary commitments. The library was out on display at this meeting and we finished the meeting with our SSB Lottery Draw.

...group news ...group news

SSB LOTTERY DRAWS and the winners are ...



September Lottery Draw:
Number 18 - Glennis Hill

October Lottery Draw:
Number 6 - Dennis Gardner

November Lottery Draw:
Number 26 - Sara Griffin

CONGRATULATIONS!!!

**I have enclosed an updated Lottery List for the Lottery members as we now have 5 new members!*

MEETING DATES

SSB Christmas Socials
Monday December 10th
At Shirley Community Centre



7.30 pm

&

Tuesday 18th December
an extra Christmas
get together

at 59 Cartland Rd B30 2SD
1pm

All are very welcome!

Remember there is
NO MEETING in JANUARY!

Monday February 11th 2013
at 59 Cartland Road B30 2SD
1pm

Dates for Meetings 2013

NB The meetings are at Shirley Community Centre starting at 7.30pm unless otherwise specified

No meeting in January

Monday Feb 11th at 59 Cartland Road Stirchley B30 2SD [1pm - 3pm]

Monday Mar 11th AGM!

Monday April 8th

Monday May 13th - at 59 Cartland Road Stirchley B30 2SD [1pm - 3pm]

Monday June 10th

Monday July 8th - at 59 Cartland Road Stirchley B30 2SD [1pm - 3pm]

No meeting in August

Monday Sept 9th

Monday Oct 14th

Monday Nov 11th - at 59 Cartland Road Stirchley B30 2SD [1pm - 3pm]

Monday Dec 9th Christmas Social

...group news ...group news

Group update 2012

We have had our ups and downs this year. It has been a difficult year for the **committee** what with serious illnesses, house moves and resignations which have caused more than our usual share of problems on top of just trying to keep going with ME... On the plus side we have had two new members on the committee, Yvonne and Alison both of whom have proved to be great assets to us.

One of our highlights was getting **funding** from Comic Relief via the B'ham & Black Country Community Foundation. This has taken a lot of the financial worries off our shoulders and will enable us to maintain and hopefully improve our services for this year and next year.

Another highlight was the fantastic amount of **fundraising** the group has achieved in the last twelve months - well over £700 raised for ME biomedical research. Well done everyone!

We have also been well blessed with **donations** from individual members - thank you so much - and a large donation from the Redditch Masonic Lodge once again.

The group **birthday cards** have proved to be very popular and we intend to keep this going - thanks to Jo for making sure everyone who has given us their birthday date gets their card on time!

Meetings have been well attended this year on the whole and have been both interesting and uplifting.

The **Contact List** has gone from strength to strength and well over half of the group members have now joined.

The **Newsletter** continues to be well received and we are very happy that lots of members are now contributing with their articles, poems and pictures.

We had a problem with **Facebook** as we had to close down the old page due to circumstances beyond our control. We are more than grateful to Alison for volunteering to help out and re-launching the new Official SSB Facebook. Lots of the old members have re-joined but we are hoping that many more of you will come on board. The new FB page is now a closed group and by invitation only, which means that only the group members can join and can see it.

Unfortunately we have had to discontinue the **U25** group.

The **website** continues to be a valuable tool, not only for others to find and learn about our group but also where we can post news and up to date messages for the meetings etc.

We continue to monitor and move forward with our **Quality Assurance** programme and we are working hard to be as inclusive as possible, actively seeking and welcoming your ideas, thoughts and involvement. Please keep in touch!

Jenny



In touch...your page...your news



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**

Message from the Contact List Working Party!

Message from Jo

In the feedback from our Quality Assurance survey on our services last year, a few people asked if there was any possibility of meetings on another day than Monday. Unfortunately when we arranged the meeting dates for 2013 it was not possible to change the day. However, I have been thinking about this, so if anyone is still interested in occasionally meeting up on a different day, please get in touch with me and I will see what I can do.

0121 679 8103
(Sun - Fri :12 noon - 7pm)

We have enclosed a full updated copy of the **Contact List** with this newsletter.

This is because there have been some new members and quite a few updates in information.

We thought it would be helpful to have a completely new version rather than lots of updates on various little bits of paper!

Please dispose of all your old Contact Lists - either shred them or burn them, but be careful!

Best wishes
Jo & Tarsam

ME RESEARCH UK

2012 Christmas cards



ARE STILL ON SALE!

tel: **01738 451234**

(using a debit or credit card)

or go to:

www.mereseach.org.uk/support/cards.html

Victoria C tells us that she has written to the DWP about the new **PIP** and in their reply they said: "The new Payment will maintain the key principles of DLA. It will be a **non-means-tested** cash benefit available to people in and out of work, but it will be delivered in a fairer and more consistent manner." Thank you Toria for this reassurance that PIP will be non means tested.

In touch...your page...your news

SSB Annual General Meeting March 11th 2013

Our Annual General Meeting will be held next March. We will have an annual report from the Chair and the Secretary and a full financial report from our treasurer.

It will also provide the opportunity to elect the committee for the next year.

Voting Slips

A voting slip is enclosed with this newsletter.

Please use it to vote for next year's committee, if you are not well enough to come to our Annual General Meeting.

Quality Assurance - Code of Conduct Message from Jo

Hi All

Quality Assurance is all about moving forward at a manageable pace and deciding priorities for improvement annually. Our priority for 2012/2013 is to develop a code of conduct for the group.

If anyone has anything they wish to contribute or would like to join a working party (we won't be meeting until early 2013) then please give me a ring.

Best wishes to you all
Have a good Christmas and a Happy New Year
Love Jo
0121 679 8103

Alistair M has sent a message to recommend the U-tube clips below. They explain the results of the PACE Trial in a way that is easily understood.

- 1: The Pace Race <http://youtu.be/Sa3LyYxu49s>
- 2: 60 – the new 75 <http://youtu.be/PJf27ExfyMA>
- 3: Not So Bad <http://youtu.be/qXMZv0MzFCo>
- 4: The force of LOGic http://youtu.be/b3_mjQe-t1M

I must say that although I was aware that the PACE Trial was unacceptable, it was a revelation to me to see in such a simple and graphic way just how the results has been seemingly manipulated to give a much better impression to the media than was justified by the actual results.

NB I have also put these on our website so that you can get a direct link there- see:

<http://ssb4mesupport.weebly.com/news.html>

Happy Birthday to:

DECEMBER – Louise Palfreyman; Alan Griffin; Janet Houghton; Steph Byrne; Patrick Leahy; Sandra Oliver; Cecilia Rabb; Lynn Zielinski; Denise Lynch

JANUARY - Joe Farnell; Shaun Murray; Marjorie Preston; Julie Large; Mark Taylor; Emma Williams; Tom Bourne; Umair Hussain

FEBRUARY – Eve Headland; Roy Lampitt; Donna Newby; Michael Tudor; Yvonne Troth; Trevor Higgs; Jimmy Curry



Ask Alison...ask Alison...



Hello, I'm the newest member of the group's committee. I was recently co-opted to assist with communications and digital media. The first thing I did

was to set up and manage the new facebook page – 'Official Solihull & South Birmingham ME Support Group'.

A little bit about me I have had ME for a number of years, although, only formally diagnosed around 3 years ago. Like a lot of people with ME, my health is very up and down and I try to manage my condition as best I can – although often it manages me!

I have been a member of the group for around 4 years and have attended quite a few monthly meetings. I strive to keep my sense of humour in the face of adversity and for those of you who use facebook – members often share their funny stories and brain fog moments on the group's page.

For my first column, I thought it would be useful to highlight some good practice guidelines for staying safe on Facebook and list some of the commonly used jargon on

the site, which is included in a fact sheet with this newsletter. I hope members will find this useful and hopefully, I haven't scared or put off people from joining the group online!

To join us, you will need to set up a personal profile on facebook and then ask to join the group. Jenny has kindly put a guide to joining the group on our webpage, which can be found by using the below link: http://ssb4mesupport.weebly.com/uploads/8/0/5/0/8050248/how_to_join_a_closed_group_on_facebook.pdf.

The group's facebook page is entitled 'Official Solihull & South Birmingham ME Support Group' and has been set up as a closed group so only members who have joined the group will be able to see content and contribute to the page. All group members (over 16 - see below) and their carers/family are encouraged to join, so hope to see a few more faces there soon.

Well, that's enough waffling from me for now. Any topics/comments for my digital media/communications page in the next newsletter would be gratefully received.

Best wishes
Alison

Would you like to join our NEW Facebook Page?

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

'Official Solihull & South Birmingham ME Support Group'

Detailed instructions on how to join are enclosed with this newsletter along with some very useful guidelines, compiled by Alison, for staying safe and explaining commonly used jargon.

SSB GROUP NOTICE

Young people under 16 are very welcome to join our group

- Please note that you must be over 16 to join the Facebook page or the Contact List, but parents/guardians of younger members are very welcome to join.
- Young people under 16 should be accompanied to meetings by a parent or guardian.

Our committee apologises for any inconvenience, but we do not have a Child Protection Policy and we do not have the resources to implement one at this time. The safety and well being of all our members is our prime concern.

Concessionary Bus Pass

Did you know that Network West Midlands offers a concessionary bus pass for people with a disability/illness (fulfilling certain criteria)? I heard about it from a friend, and this is where you find the information and application form to download:

<http://www.networkwestmidlands.com/mobility34/concessionary.aspx>

I recently applied successfully and it has made a heck of a difference to me – no, I am not living it up, zooming around the country at the corporation's expense or rolling in the money I am saving. It means that I can get to the shop/doctor/friends house, knowing that I can get back. It means that there is more chance of me continuing with physio at the gym if I don't have to include the effort of getting there on top of doing the exercise. It means I am more able to keep up some level of activity rather than hibernating at home because I will walk one way and ride the other if I am up to it. It means I don't have to choose between any of the above, and being able to feed the family because of the cost of transport. It helps me to pace out my energy expenditure and therefore be a little more in control of an independent life.

Initially I did not apply because I didn't think that my problems would make me eligible, ME/CFS didn't seem to fit in their criteria (there are 7), but if you have a condition that is restricting your ability to function in the outside world it is worth giving it a go, and this is how I went about it:

- I applied under the criteria of a walking disability (I have osteoarthritis in the knees, and chronic foot problem – I can walk but it is always painful), and mental health (anxiety and depression – both of which are influenced by ability to go out). I could not see a box which ME would fit in, so it is mentioned in the following letter to my GP.
- A friend who is familiar with ME, is experienced in constructing strong letters, and whose brain is working better than mine helped to write a letter to my GP giving



my reasons for applying, and how a bus pass would be of benefit to me – both socially, physically, mentally and financially, and asking her to write a letter of support. We also asked for copies of letters in my record which backed up my claims. This takes time to arrange, and staff are not necessarily familiar with searching records for specific information. It is of great benefit to you to always request copies of letters sent by health professionals to your GP – it will save you loads of hassle when you need evidence. When the appointment for my assessment came through there was not much notice given so it would be helpful to collate all your evidence before you actually get a date, to save panicking.

- My GP wrote a letter. This was not a medical report (which costs lots), it was a little letter just asking them to look favourably on the application and my GP charged £7 for it.
- I was taken to the assessment by a friend. This is important because it shows that you need help.

by Elisabeth Strachan

- I had highlighted relevant sections in my evidence letters (it doesn't hurt to make life easier for the assessor). These included letters from consultants/physio **and** an appointment at the ME clinic. I also submitted a copy of the letter I had sent to the GP with all my reasons for applying in it, and mentioning the chronic fatigue.
- The interview was conducted by an occupational therapist, she was very nice, not at all aggressive or obstructive. It was carried out in a different building to the waiting room – I suspect this was so they could observe my mobility. She discussed the information on my application form, and **this is the part that made the most difference:**
- I started to talk about how ME affects me – not just about the ability to physically move around, but about the cognitive problems. So when she was asking about the possibility of me driving (I haven't for years) I could hand on my heart talk about how I would be a danger behind the wheel. I can hardly cross the road safely at times because I will read a green light as meaning I can step into the road. It also helped that because of the stress of the day I was also not functioning very well. I misunderstood her directions to go to a particular room. I had to keep going over certain things she was saying to make sure I understood. I was having trouble making words, so, she could see the cognitive disfunction.
- She then talked about 'when I applied for a renewal' (did this mean I had succeeded?) that I should apply under section 7 (Other disabilities which prevent you from driving a car as this would be dan-

gerous to both you and others). She pointed out that applications under that category also do not have to attend for assessment.

So I got my bus pass!

Even though ME/CFS does not fit into any of their boxes I think that is more to do with a poorly designed form rather than an institutional non-recognition. The form makes it look like you have to have certain documents for particular conditions (ie DLA/mobility component). You don't, you just tick the box if you have it. Also, section 7 is laid out poorly – you do **not** have to fulfil the first option 'I have another medical condition that is not mentioned above which means I cannot have a UK driving licence' to then go onto other options under that category. You can go straight to the 'Other disabilities which prevent you from driving a car as this would be dangerous to both you and others'. For applying under this category they require you to fill in a brief supplemental questionnaire which also does not encompass ME, but I didn't fill one in. The OT just asked me to tick the previously mentioned 'dangerous to drive' box. Perhaps the evidence of an appointment at the Barberry was enough – that, and seeing me (not) in action.

Many thanks to Elisabeth for giving us such a clear and detailed account of how she got her concessionary bus pass -especially since she tells me she wrote it under her duvet whilst waiting for her heating to be fixed. That is real dedication!

This is very useful article to read not only for getting a bus pass but for almost any other benefit or help you are applying for, as it gives a very good idea of how to present the difficulties faced by people with ME.

Jenny

Report on the 2012 ME Association's 'ME Question Time' by Yvonne Troth

The annual ME Question Time was held on October 6th this year in Shrewsbury and hosted by the Shropshire ME Group. The format consists of a panel of experts who all give short talks and then take questions from the audience.

Our Committee member, Yvonne Troth, managed to attend the meeting and has written a report of her experiences for us. It is rare that you get the opportunity to listen to and ask question of so many ME experts gathered together at the same time. She said that she was inspired by the meeting, especially the talk by Jane Colby.

Many thanks to Yvonne for this article and to Shropshire ME Group for organising and hosting the meeting so well. There is another excellent report from Daphne Caton of Shropshire MESG on the ME Association website: <http://www.meassociation.org.uk/?p=13541>

The panel:

Dr Charles Shepherd,



Medical Adviser for ME Association

Dr. Sarah Myhill,



ME specialist

Dr Nigel Speight,



Paediatric Adviser, ME Association

Jane Colby,



The Young ME Sufferers Trust & Ex head teacher

Simon Toghil, Shropshire ME/CFS Service

The venue and refreshments for this event were free and were paid for by the ME Association and donations were welcome. The afternoon meeting consisted of questions and answers to the panel. This could be related to the many medical aspects of the illness, the problems of benefits, NICE guidelines, the political side of ME and research into ME. The panel all introduced themselves with a very brief introduction to their work and then questions were taken.

Charles Shepherd (CS) spoke about the problems experienced with the NICE guidelines and the way doctors were restricted to following these guidelines as opposed to using their own clinical knowledge and experience. He felt that they had a duty to their patients, which tended to get overlooked by the strict adherence to the NICE dictates. The panel seemed generally agreed with this.

There was then quite a lengthy discussion on the problems with claiming benefits particularly in relation to the Work Capability Assessment. The Harrington Report had pointed out the importance of the fluctuating nature of ME symptom and its variability from day to day. CS had been closely involved with a compilation of A 50 page report on this and although it appeared to be taken on board it has still not been implemented in ATOS assessments. It is hoped that this would happen some time next year. Sarah Myhill (SM) pointed out the significance of mitochondrial failure in ME patients and felt that the laboratory test she could arrange could be an important piece of evidence in the claim for benefits. CS emphasised the importance of submitting all medical evidence with the initial claim form, although ATOS did not necessarily take it completely on board, but it was still useful to include it as it could be of influence.

Someone pointed out that although failing the medical her son had gone to appeal and was informed that although they accepted he was genuinely ill, none of his symptoms coincided with the tick box system. I think everyone felt at this point the unsatisfactory nature of the Work Capability Assessment, certainly as far as ME is concerned.

continued...

Report on the 2012 ME Association's 'ME Question Time'

Lord Freud has actually recognised the validity of the fluctuating nature of ME and it may be helpful to mention this in an appeal.

It was suggested that patients try to get a body such as the Citizens Advice Bureau to help with claim forms for the Employment Support Allowance.

In response to a question from the audience SM spoke again about mitochondrial failure which leads to lack of energy production at a cellular level.

Low cardiac output can be a result of this, and this leads patient to be forced into resting more and more. The brain requires very large amounts of energy to function properly and the lack of energy production causes the symptoms of brain fog and can lead to other neurological conditions, including light sensitivity. She also commented that certain types of brain scans can actually reveal areas within the brain where energy is lacking.

CS then spoke about the ME biobank, patient database and post-mortem tissue bank. This was funded by charity donations and the 1st year had run into £160,000 and the 2nd year the same figure. He pointed out the need to bring the various institutions together to share knowledge in this important area. There had already been 4-5 post-mortem studies, which so far had not revealed a great deal.

The question regarding the documents hidden away in the National Archives at Kew was mentioned and why had it been hidden away from public view until 2072 (78 years). CS replied that he did not think there was anything particularly sinister about this and said that there had been some input from himself included. He also replied that he thought it was mainly about the definition of ME/CFS and felt that by calling the illness CFS it had been downgraded in importance. The title ME means brain inflammation which makes it a far more serious condition. The question regarding the ME/CFS title was discussed with most panellists preferring to refer to ME. However for practicality reasons they were usually forced to refer to the condition as ME/CFS in order for recognition purposes.

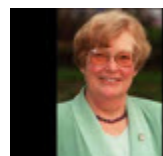
The subject of Rituximab used to treat lymphoma, a type of cancer which involved the immune system was discussed and its relevance in treating ME patients. CS said that it had been used experimentally on patients with ME. (More details on this were included in Jenny's December 2011 newsletter.) CS said that although there had been some success with the drug it could not be released for ME patients due the dangerous side effects that could even prove fatal. He also pointed out that it was very expensive.

Jane Colby (JC) talked about the stress often put on child sufferers, when they were forced to attend school on a 9-4 basis. Parents were often forced to wake children up and send them to school, even when due to delayed sleep patterns, they had obtained very little rest. She spoke about her leaflet called 'Don't Wake Me Up'. She said that this was such a common problem.

I was eventually successful in putting a question to the panel about unusual sleeping patterns, and found that in response there was some disagreement between SM and JC. SM has a preference for establishing as a priority a normal night-time sleeping pattern in order to regulate proper hormone production, whereas JC took a different view that daytime sleep should not be considered a problem as it is important to 'live within the rhythm of the brain' as it works to heal itself. It was cruel to wake children while asleep unless there are some really pressing reasons to do so. It may be inconvenient and result in reorganisation of timetable, but it will assist the body into returning eventually into a normal sleeping pattern. (I must admit that, although I do have a high regard for SM I do prefer to take on board JC's comments).

The final question was in regard to Vitamin D supplementation and what was considered to be the widespread problem of shortage of this vitamin due to having such a poor summer and so little time spent outdoors especially with ME patients. It was considered good advice to request a blood test for this from your GP, which should be available at no charge, although you often needed to push for this. Vitamin D is needed to protect against viruses.

Countess of Mar criticises the PACE Trial results in Lords debate



The Countess of Mar spoke out in November about the results of the PACE Trial at a House of Lords debate about Neurological services in the NHS.

The Countess said: "I would like to be able to go into the facts behind this research in more detail, but this is not the occasion. However, I must say that the spin on the results has had a very deleterious effect on the public perception of the illness and on the provision of health and social care for people with ME. What is happening to these frequently very sick individuals? There is still a great deal of scepticism surrounding the reality of this illness, despite pronouncements from government, the CMO and NICE."

She went on to say: "It is acknowledged that if the condition is caught in the early stages and dealt with conservatively, it can improve and patients can recover. Instead, patients and, particularly, children are pushed by medical practi-

tioners or, in the case of children, by teachers, social workers and carers, to keep going to work or school on the basis that it is good for them, until they collapse and what was a mild, treatable condition becomes chronic and untreatable. They are then encouraged to undertake programmes of cognitive behaviour therapy and guided exercise training which, at best, may help them to cope with their illness or, at worst, may exacerbate their symptoms, and they are blamed for not wanting to get better

"There is no indication in the trial results that one single person fully recovered after a year of CBT and GET. There is no indication that any who were not working went back to work or, in fact, that there was more than a very modest improvement in those whose health was deemed to have improved."

The full story can be seen here:

<http://www.meassociation.org.uk/?p=13776>

Editor's comment: *Good for her - everything she said is true.*

'ME: bitterest row yet in a long saga'

Taken from an article in the Independent November 25th



Professor Simon Wessely, one of Britain's foremost experts on ME, won the John Maddox Standing up for Science honour earlier this month. The prize was created by the journal Nature and the charitable trust Sense about Science. It was given to Professor Wessely for "courage" in speaking out about his studies into ME in the face a pro onged hate campaign and death threats.

But critics protested against the decision last night. They said the professor's work perpetuates the idea that myalgic encephalomyelitis, also known as chronic fatigue syndrome (CFS), is a mental health problem, trivialising what they claim is a largely physical illness. Malcolm Hooper, emeritus professor of medicinal chemistry at Sunderland University, said: "He's responsible for trying to make ME into a psychiatric condition when it's not. He has done very poor science."

Another opponent, the Countess of Mar, said: "I was absolutely horrified when I read he'd won the award and I would like to see it retracted."

Dr William Weir, a retired consultant physician who says ME is caused by a chronic viral infection, called the decision "almost satirical". "If the scientific data is properly examined it will be seen that Professor Wessely's doctrine is wrong and it will be proved to be wrong in about five years' time," he said.

But Professor Wessely, head of psychological medicine at King's College London's Institute of Psychiatry, said: "I have published several hundred papers on this over the last 20 years. These have been published in world-class journals such as the BMJ and The Lancet, subject to rigorous peer review. I have never said that CFS is all in the mind. I do not believe that, and have never written that. I have said repeatedly the exact opposite. I have published many papers on possible infectious triggers to the illness." *Editor's comment: Unbelievable - both the award and the SW comment!*

<http://www.independent.co.uk/news/science/me-bitterest-row-yet-in-a-long-saga-8348389.html>

Possibly the 10 worst Christmas cracker jokes?

1. What is Santa's favourite pizza?
One that's deep pan, crisp and even.

2. On which side do chickens have the most feathers?
The outside.

3. What kind of paper likes music?
(W)rapping paper.

4. What's white and goes up?
A confused snowflake.

6. Did you hear about the man who bought a paper shop?
It blew away.

7. What's furry and minty?
A polo bear.

5. What do you call a woman who stands between two goal posts?
Annette.

8. How do snowmen get around?
They ride an icicle.

9. Who hides in the bakery at Christmas?
A mince spy.

10. What do you call a penguin in the Sahara desert?
Lost



ME news...ME news...ME news

“ME isn’t ‘all in the mind’, but it’s still a mystery”

Daily Telegraph talks to Dr Charles Shepherd

Extracts from the [Daily Telegraph](#) 26 November 2012 (story by Caroline Lavender).



As medical adviser to the ME Association and an ME sufferer, Dr Charles Shepherd has spent the past two decades vigorously fighting the dismissive attitude still common among the medical profession. Here, he talks about the latest research into the disorder. It was in the late Seventies that Charles Shepherd became ill with myalgic encephalomyelitis, or ME as it is better known. It was an era, he recalls, when the condition was still dismissed as “hysterical nonsense” by most clinicians. Working as a young doctor at Cirencester Hospital, he had contracted a severe case of chickenpox from a patient with shingles. Shepherd says he has never been truly well since. He “plods along”, though managing to enjoy life: he regularly walks Polar, his snow-white Labrador, near the Cotswolds home he shares with his wife Pam, a nurse.

.... the debate over the cause of ME continues. Is it biological, psychological or a combination of both? The controversy flared up again in September, with the publication of findings finally disproving the theory that ME is linked to XMRV and mMLV, viruses that had previously been isolated in tissue samples taken from ME patients.

ME researchers now view the illness as having three separate components: first, a (probable) genetic predisposition; second, a precipitating factor – which for 75 per cent of patients is an infection, usually viral, although occasionally other immune stressors such as immunisation may be a trigger; and finally the development of the condition itself. Other signs include fainting, low blood pressure, and irritable bowel syndrome. The origin of such symptoms remains a mystery. One theory gaining favour is that ME patients have an aberrant immune response which fails to “switch off” after the original infection has resolved itself.

Another theory is that an auto-immune response (in which the immune system produces antibodies that attack the body’s own

cells) may be involved. Other research is looking at potential abnormalities in the muscles of ME patients, with evidence that some sufferers produce excess acid when they exercise. One study at Liverpool University is examining potential structural abnormalities in the mitochondria – cell components which produce energy in a usable form – in skeletal muscle. A further focus of research are abnormalities in the hypothalamus. This tiny pea-shaped gland in the brain regulates a number of functions including hormone secretion (via the pituitary and adrenal glands). Problems here could help explain symptoms as diverse as sleep disorder, low blood pressure, temperature disturbance and heart, bowel and bladder problems. “A large number of papers demonstrate that ME patients have abnormalities in the hypothalamic-pituitary-adrenal axis,” says Shepherd.

In particular, he says, ME patients have been found to have lower levels of cortisol, a hormone secreted by the adrenal glands. He concedes that ME researchers are still “fitting together the jigsaw puzzle”, with some way to go before treatments are developed. “We have reached a point where there are drugs that would be worth trialling,” he says. But clinical trials are expensive to run and the pharmaceutical industry, the only realistic source of such funding, has shown little interest. In the meantime, can graded exercise (a programme aimed at building up activity levels) and cognitive behavioural therapy, advocated by NICE, help with the symptoms? “The NICE guidelines on ME are not fit for purpose,” Shepherd argues. “They reflect the belief that this is a psycho-social illness.” He himself is a fan of pacing – a technique which involves listening to your body to find the right balance between rest and activity. “I go swimming and walking, but within the limits of what I can do.”

“I have no problem,” he replies, “with the idea that the mind affects the body and the body affects the mind. Of course, people who are chronically ill get depressed and have psycho-social stress. But the point is that too much energy and money has gone into research based on the belief that ME is psycho-social – when the right route is biomedical.” Full article can be seen at:

<http://www.meassociation.org.uk/?p=13809>

Judge grants judicial review of Work Capability Assessment - cont'd from page 1

The reasonable adjustment to the process that the claimants seek is for medical evidence to be sought by the Atos HCP and the DWP at the very outset of the claim. This would ensure that very sick people for whom having to go through a WCA would be extremely distressing are exempted from the process, and for those that do attend a WCA, the assessment of fitness to work takes place in the correct medical context, so that dangers associated with forcing people back to work are correctly identified.

At present, the DWP do not routinely ask for expert medical report from an applicant’s communi-

ty-based doctor. The judge has held that it is arguable that this failure is a breach of the duty to make reasonable adjustments, and is therefore unlawful.

Editor’s comment: Although this review has been sought by people with mental health problems, it could have far reaching implications for all disabled people - certainly people with ME could argue that they also find the whole process unfair and equally distressing for the same reasons. We will await the review with great interest.

<http://www.dpac.uk.net/2012/07/judicial-review-of-work-capability-assessment-granted-2/>



Research news...research news

News from the Lipkin Study (continued from page one)

The research, at Columbia University in New York, found no evidence that sufferers are infected with the rare viruses XMRV or pMLV, which are distantly related to HIV.

A 2009 paper by Judy Mikovits published in the journal Science,2 and a subsequent paper by Harvey Alter in Proceedings of the National Academies of the United States of America that identified a similar murine retrovirus, claimed to have established a causal relation with chronic fatigue syndrome. Attempts by others to replicate the findings of a link failed to do so, and many came to believe the initial work had been sullied by contamination. But questions remained because the confirmatory studies often used different methods and were underpowered.

Genetic tests that looked for the virus in the blood of the subjects “found no evidence of XMRV or related viruses,” said Lipkin. It is “a very clean result that is impossible to misinterpret.”

“It took extraordinary courage” for the original investigators to participate in this study Lipkin said. “I cannot think of a single instance where an investigator came back, went through this sort of

a process, and then stood up and said ‘I made an error here but am committed to moving forward.’”

“One has to resist the temptation to keep the murine retroviral hypothesis alive,” he said. “This study was really quite definitive.”

Read more: <http://www.meassociation.org.uk/?p=12891>
The media tried to imply that there was no viral link at all to ME - the Daily Mail headline, for example, was: “Viruses ‘are not to blame for ME’: Study rules out old theory ‘once and for all’”.

This is not what Professor Lipkin was saying - in fact Professor Lipkin said he believes chronic fatigue syndrome “is likely to be a constellation of disorders, not necessarily a single agent, be it viral, bacterial, or otherwise.”

He called the samples gathered during this process “an extraordinary resource for addressing questions related to the causes, the treatment, the management, the pathogenesis, the basic sciences of these disorders.” The NIH has established a process by which qualified investigators can access the stored samples and it is funding further examination of them.

Virus Behavior Insight Offers Hope For New Drugs

Written by Christine Kearney - Medical News Today

An important stage in the life-cycle of viruses such as the common cold and polio has been discovered by experts at the University of Leeds. This breakthrough may pave the way for new methods of battling viral diseases.

According to the study, published in the Proceedings of the National Academy of Sciences (PNAS), the researchers were the first to notice, at anatomic level, how the genome that creates the core of a single-strand RNA virus particle accumulates in its outer shell of proteins.

Accepted thinking about the process has been overturned by these results, lead researcher Professor Peter Stockley said. This could be a way into exploiting a chink in the armor of several types of viruses. Stockley said, “If we can target this process, it could lead to a completely new class of anti-virals that would be less likely to create resistant viruses than existing drugs, which tend to target individual proteins.”

Certain viruses, such as polio and the common cold have genetic material made up of ribonucleic acid (RNA) instead of DNA. The recent findings have discovered that the RNA in the viruses have considerably more volume than the virus particles made after they are “packed” inside their protein shell.

Dr Roman Tuma commented: “We realized that the RNA genome must have to be intricately folded to fit into the final container, just like when you pack to go on holiday and need to fold your clothes to fit into the space in your suitcase.”

When proteins were added to the viral RNA by the researchers, they observed an instant fall in the RNA’s volume. “It seems that viral RNAs have evolved a self-folding mechanism that makes closing the ‘viral suitcase’ very efficient. It’s as though ‘the suitcase’ and the clothes’ work together to close the lid and protect the con-

tent,” Tuma said.

Stockley added, “The viral RNAs, and only the viral RNAs, can do this trick of folding up to fit as soon as they see the ‘suitcase’ coming. That’s the important thing. If we can interfere in that process we’ve got a completely novel drug target in the lifecycle of viruses.” He continued: “At the moment there are relatively few antiviral drugs and they tend to target enzymes that the virus encodes in its genome. The problem is that the drugs target one enzyme initially and, within the year, scientists are identifying strains that have become resistant. Individual proteins are extremely susceptible to this mutation. A fundamental process like the one we’re looking at opens the possibility of targeting the collective behaviour of essential molecules, which could be much less susceptible to developing resistance.”

The report adds that the same effect is seen in plant and bacterial viruses as well. Stockley said, “While we have not proved it yet, I would put money on animal viruses showing the same mechanism too.”

Researchers utilized state of the art machinery tailor-made at the University which let them to produce the first single-molecule measurements of viral assembly ever. This allowed the experts to analyze the viral particles individually. “The specific collapse, which can only be seen in such assays, was totally unexpected and overturns the current thinking about assembly,” said Stockley. Stockley concluded: “We’re now perfectly positioned to pursue questions about how this mechanism works in other viruses and we’re already thinking about ways to start designing new antiviral drugs that would target this newly recognized feature of viral life cycles.”

<http://www.medicalnewstoday.com/articles/251757.php>



Research news... Research news

Experiences of young people who have undergone the Lightning Process to treat chronic fatigue syndrome/myalgic encephalomyelitis – a qualitative study

Silje Endresen Reme; Nicola Archer; Trudie Chalder

Objectives

Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is a serious condition characterized by debilitating but unexplained fatigue. Treatment alternatives are few, and especially so for young people. The aetiology of CFS/ME is still unclear and controversial, but rehabilitative interventions seem so far most promising. The Lightning Process is a 3-day training programme that has recently become available, but no outcome studies have yet been published. It is a non-medical training programme that combines concepts from Neuro-Linguistic Programming, Life Coaching and Osteopathy. The aim of this study was to explore the experiences of young people with CFS/ME after they had undergone the Lightning Process.

Methods

Semi-structured interviews were conducted with an opportunistic sample recruited through open advertisements of nine young people, aged 14–26, who had undergone the treatment, and three

of their parents. Inductive thematic analysis was used to evaluate the content of the interviews.

Results

Mostly positive experiences were reported of the Lightning Process. Two reported dissatisfaction and no improvement, while seven were satisfied and were much improved. Particular helpful aspects were the theoretical rationale, practical exercises, and the technique they learned. Less helpful aspects were the intensity and short duration of the treatment with little follow-up, the secrecy surrounding it, and feelings of being blamed if the treatment did not work.

Conclusions

As this is the first report of young people's experiences with the Lightning Process, it will be important to consider the helpful and unhelpful treatment components for future refinement of interventions for CFS/ME

<http://onlinelibrary.wiley.com/doi/10.1111/j.2044-8287.2012.02093.x/abstract>

Editor's comment: *Interesting - not quite as convincing as one would have expected, considering the authors*

Prevalence of DSM-IV Personality Disorders in Patients with Chronic Fatigue Syndrome: A Controlled Study.

Kempke S, Van Den Eede F, Schotte C, Claes S, Van Wambeke P, Van Houdenhove B, Luyten P.

<http://www.ncbi.nlm.nih.gov/pubmed/23065435>

BACKGROUND: It is not yet clear whether chronic fatigue syndrome (CFS) is associated with elevated levels of personality disorders.

PURPOSE: This study aims to determine the prevalence of DSM-IV axis II personality disorders among patients with CFS.

RESULTS: The prevalence of personality disorders in CFS patients (16.3 %) was significantly lower than in psychiatric patients (58.7 %) and was similar to that in the community sample (16.3 %). Similar results were found for dimensional and pseudodimensional scores, except for the Depressive (DE) and Obsessive-Compulsive Personality Disorder (O-C) subscales. Patients with CFS had significantly higher levels of DE features compared to normal controls and similar

dimensional scores on the O-C scale compared to psychiatric controls.

CONCLUSIONS: Although the CFS sample was characterized by depressive and obsessive-compulsive personality features, this study provides no evidence for the assumption that these patients generally show a higher prevalence of axis II pathology. Given the conflicting findings in this area, future studies using multiple measures to assess personality disorders in CFS are needed to substantiate these findings.

Comment from Dr Charles Shepherd of the MEA:

'The prevalence of personality disorders in CFS patients (16.3 %) was significantly lower than in psychiatric patients (58.7 %) and was similar to that in the community sample (16.3 %).

Quite a few of my medical colleagues believe that people with ME/CFS have an underlying personality problem - so this is a useful conclusion that I will be referencing in the next edition of the MEA purple booklet'

Group News...committee news



Tarsam



Jo



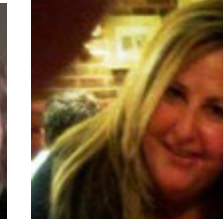
Jenny



Alan



Yvonne



Alison

Committee Meetings - September (Apologies from Jo). The committee had been informed on 23 August of the news concerning George Beech (GB) and we received his resignation on 30 August. This meeting was called to look at the implications of GB's resignation and discuss what the committee needed to do to safeguard the members. The committee immediately accepted GB's resignation. Because of the situation with our Facebook, Alison Jeavons had volunteered to set up a new FB page, we thanked her & co-opted her onto the committee to ensure that FB was accountable to the committee. Alison will be putting her name forward for election at the AGM 2013. At this time the committee agreed to withdraw all references to GB on our website & on any group literature and to inform the schools we had contacted that he was no longer part of the SSB group.

October - (Apologies from Yvonne) The committee met again in Oct to review the situation after GB's resignation and to complete the rest of the group business on the agenda. In the meantime the committee had in-

formed the police dealing with the GB case that GB was previously a member of SSB.

Our Chair, Tarsam, had contacted the NSPCC for advice. In view of this advice, the committee agreed to state clearly by name where necessary that GB was no longer associated with the SSB ME group and the reasons why. The committee would like it to be known that this was not an easy decision to make and that the fact that this meeting lasted for an unprecedented 3 hours shows just how seriously this matter was taken. The committee's overriding concern is the protection of young people in the group and any other young person with ME that may contact GB in the future thinking he was part of group.

Alison reported back that the new FB was now launched and the old page removed. Jenny said that all old literature had been destroyed, & website references removed where possible. Any previously contacted schools had been notified that the U25 contact was no longer available.

The resignation of George Beech

You may have seen the following in the Solihull News :

"Sep 7 2012 by Hannah Jennings Parry.

A MAN has been accused of grooming and sexually touching a 13-year-old girl from Solihull.

George Beech, 20, whose address cannot be revealed for legal reasons, allegedly groomed the young victim via Facebook between May 1 and June 10, culminating in the alleged assault on June 10, Solihull Magistrates Court heard. Beech has been bailed to appear at Warwick Crown Court for a plea hearing on December 6."

Message from the SSB Committee

George Beech has been asked to resign and is no longer a member of the SSB committee or the SSB group. Whilst the committee notes that George Beech is deemed to be innocent of the charges brought against him until proven guilty, the committee nevertheless has to take into account the nature of the charges and has a duty to safeguard the group and its members - particularly any members or other ME contacts aged under 16. In the interests of the members and of George Beech, we advise that no further contact should be made with George Beech. Any future contacts to the group should be made via our usual group contact numbers below. If you have any further concerns or enquiries please do not hesitate to get in touch with us.

By phone: **Jenny 0121 689 0777 Jo: 0121 679 8103** Sun - Fri -12 noon - 7pm; by email: jennylg@live.co.uk

SSB GROUP NOTICE

Young people under 16 are very welcome to join our group

- Please note that members must be over 16 to join the Facebook page or the Contact List, but parents/guardians of younger members are very welcome to join.
- Young people under 16 should be accompanied to meetings by a parent or guardian.

Our committee apologises for any inconvenience, but we do not have a Child Protection Policy and we do not have the resources to implement one at this time.

The safety and well being of all our members is our prime concern.