

ARTHRITIS

CHRONIC FATIGUE SYNDROME

ENDOMETRIOSIS

FIBROMYALGIA

IRRITABLE BOWEL SYNDROME

M. E.

FOGGEY'S

EST. 29 JUNE 2012



"INVISIBLE ILLNESS" SUPPORT

NEWSLETTER 21

12th SEPTEMBER 2012

www.butyoudontlooksick.co.uk

**GROUP FOUNDER
DEB COOKE**

deb.cooke@butyoudontlooksick.co.uk

0844 887 2377

0844 887 2485

BETWEEN 12PM – 4PM

ANN

BARBARA

MONDAY – FRIDAY

CORRESPONDENCE ADDRESS ONLY:

112 ELBOROUGH ROAD

SWINDON SN2 2LP

PERIPHERAL NEUROPATHY

RHEUMATIC CONDITIONS

POLYMYALGIA RHEUMATICA & GIANT CELL ARTERITIS

SEASONAL AFFECTIVE DISORDER

TRIGEMINAL NEURALGIA

Hi

We had good turnouts to our latest Swindon meetings. As you know we've moved the evening one to the Haydon Centre and gained new faces. It's great to be getting a steady number of people.

Meetings now are £1. We don't like to charge however, fundraising is, as and when we feel able to, and the halls need paying.

If you've not been before, or not been for a while, you're always very welcome. It's lovely to sit and chat with people in very similar, if not the same situations as yourself.



Salisbury meeting this week, 14th September 2012, is now a catch up meeting. Our speaker Trish Cowie from Active Health Classes has had to defer until October. It will be lovely to catch up after the Summer holidays.



We have a fundraiser in Swindon on Saturday 15th September 2012 at Empowers' Fun Day, The Manor Pub, Cheney Manor Road, Swindon 12pm – 6pm. Please come and say hi.



Conference info. and booking form is attached. There are 4 of us Foggy's going, if you'd like to join us, please complete the form and return the form to me, with payment asap. You can pay in instalments, last payment due 6th February 2013. If you want your own room, (if there's one still available), it's an extra £50.



The website is always being updated, don't forget to look in on it. If you're a paid member, please ask for login details for the members' area !!

Membership is £10 web lifetime membership and £12 for postal members as we have to pay for printing and postage etc.



Look on UK Fibromyalgia Forum as they have interesting advice about DWP & a Solicitor you can ask questions of !!

FMA UK has a benefits helpline:

0844 887 2450

0844 826 9033

An FMA UK run helpline that provides information in relation to all aspects of benefits.

Please note this is a national rate call charge

Opening times:

Mon 10.00 am - 12 noon; and

Fri 10.00 am - 12 noon.



I'm very proud to announce, that I have been appointed Acting Regional Coordinator for FMA UK, for Wiltshire and Gloucestershire.



I've been trying to arrange a Bingo night and as I type it is set for Tuesday 18th September at Swindon's Gala Bingo, Greenbridge. Meet outside at 6pm (at the latest). It's free to play and you get a free dabber when you register !! I thought it would be nice to socialise for free ☺



I've finally tracked down the website link for the free NHS LIFT Psychology "Coping with" courses <http://lift.awp.nhs.uk/all-courses/browse>



Please can you check to see if your doctor, community centre, etc. have posters. Please find enclosed our latest posters and leaflets. Or contact me to arrange to send them some.

Take care and soft hugs

Deb x

ENCLOSED:

- ³⁵/₁₇ Conference info.
- ³⁵/₁₇ Conference booking form
- ³⁵/₁₇ Diary 2012
- ³⁵/₁₇ Swindon and Salisbury Posters
- ³⁵/₁₇ Swindon and Salisbury Leaflets

4th NATIONAL FIBROMYALGIA CONFERENCE CHICHESTER 26th - 29th APRIL 2013



**PLEASE SHARE THIS WITH YOUR MEMBERS. THANK YOU.
WE CAN RESERVE A NUMBER OF ROOMS FOR YOUR GROUP IF REQUIRED.**

Last Easter the conference was the best yet with overseas speakers including Professor Muhammad Yunus, the 'Godfather' of Fibromyalgia who came from the USA. From Canada we had the humorous Dr Kevin White, author of an award winning book and specialist on Fibro Fog. Dr Gary Lee, a consultant from Southampton University, was another great hit with his down to earth explanations on pain and FM. AND we had rave reviews from our delegates.

We also had a Harley Street consultant Professor Richard Powell, a specialist in allergies, food and Fibromyalgia. Professor Basant Puri, busy with FM research and brain imagery, came from Hammersmith Hospital. Other speakers included Dr Andrew Dilley from the Brighton & Sussex Universities, a well-known lecturer with an interest in chronic pain. Other speakers included Dr Ian Treasaden, a Consultant Forensic Psychiatrist. Dr Prem Bajaj spoke about the use of acupuncture point stimulation with manual electro acupuncture device combined with auto-relaxation and behavioural techniques with good effects in the alleviation of musculoskeletal pain for last 20 years.

Other speakers included a hospital nutritionist Deepti de Araujo and Pam Gully, a specialist counsellor. Among the biggest attractions was the Friday afternoon benefits presentation and forum with Wes Wright and John Stevens from Front Line Debt Services. We were so impressed we have invited them back.

THIS YEAR, NEXT YEAR

In April 2013 we hope to have another great line-up. We are still planning the programme for 2013. Simon, another FMS SAS trustee, worked with the FibCon Team this year and we will all continue for 2013. Sarah will become more involved as conference coordinator and Simon remains booking manager. They made me President to keep me out of their hair, but that did not work. As a Fibromite among 'normals' I will still have several fingers in this pie.

The 'darling' of the weekend was the oh-so-funny Dr Kevin White, the Canadian doctor with an acute sense of humour and great knowledge about Fibro fog. He has been invited to come back next year by public demand.

Dr Gary Lee, a Southampton Consultant in Long Term conditions, specialist in Chronic Pain, was also warmly welcomed and will be back with news of a new FM clinic and brain scans results. Dr Kim Lawson, an international researcher and lecturer, is joining us again following his great reception in 2010.

We have high hopes that Hal Blatman, from the USA, the Myofascial pain expert, will make it this time. Professor Mark Cropley from Surrey University has done in depth research on sleep and could be solving some of our problems. We are hoping Dr Andrew Holman who gave a successful lecture in Chichester on the compression of the cervical spinal cord and other facets of Fibromyalgia might come back.

We have a DVD on this topic pro videod by Dr Holman, which is available direct to the delegate at £6. Please write to info@follypogsFibro.org with DVD in the subject line.

<http://www.king5.com/health/60008882.html>

While at conference we will learn more about our invisible disability by day, we intend to have some fun and laughter in the evening.

Friday afternoon at 3pm will be a repeat of our successful benefits forum and presentation - not to be missed. Fibro Fillies race night is back again and we are already looking for some unusual names for the horses and pigs. You can own a horse or sponsor a race for the evening or name that winning pig with the woolly jockey. This is a fund raising night for the Folly Pogs research charity. Posh hats can be worn for the Ladies Day Frills & Flummeries Race at our Chichester races. Our original race team - Bill, Brian, Stuart and Peter with their black suits and bow ties will be back again with their ladies, running the fun filled race night. For details email conference@follypogsFibro.org

Saturday Night is Music Night with a Jam Session for those with guitars and ukuleles and a cabaret with Dr Kevin White on guitar.

Sunday we will repeat the successful fun dance competition. Last time the chosen music came from Ireland, Greece, with dancing to YMCA and belly dancing. The Team will be finding more dance challenges with Lee, our Music Master and a karaoke.

So if you want to book the April FibCon 2013 for 4 days, full board, accommodation, the conference, wall to wall lectures, gentle exercises, evenings filled with fun and laughter, with a great indoor pool, steam room, Jacuzzi, exercise equipment at the weekend at £199 per person please complete the booking form and send to your Group Leader. We have already sold almost half the accommodation so book now to save your place.

STAGE PAYMENTS

We are of course very aware it can be difficult for delegates to save for this weekend with so many demands on finances. We are once again offering a choice of stage payments at no extra charge that will total the cost for one person at the weekend. If your delegates are interested in paying monthly the following might be helpful. We also accept post-dated cheques to save on the extortionate cost of postage or direct debit.

Start September 5 x payments of £35 & 1 of £24, start now 4 x payments of £40 & 1 of £39 or 50% deposit (£100 per person) and balance (£99) to be paid no later than February 6th 2013 when all payments should be completed. The 50% deposit will secure your booking.

NOTES TO GROUP LEADERS

If you plan on collecting stage payments from your members and sending it to us monthly we are happy to hold the number of beds you have an interest in and add to them if you wish and allocate two to a room as they require. There are no single rooms and sadly the hotel levies a single supplement of £50 against one person in a double room. This is why we encourage them to bring a husband or a friend or for 3 friends to book a triple with 3 single beds. Just 5 of these are available.

So we could send you booking forms for each two people who will share a room together. It helps us if two names are on one form (or three if it is a triple). There are en suite facilities for folks to get changed in the bathroom and shower in private etc.

Everyone has to complete their details on the booking forms for Health & Safety but initially you could say you want e.g. six twin bed rooms and maybe one triple. Simon our booking manager will ask for a stage payment deposit from each person as and when you can collect it and then stage payments after that running up to Feb 6, which is the closing date.

There are rooms on the ground floor and first floor but no lift. We try to use the 1st floor for those capable with stairs and like to book group room close to one another for your convenience if they book at the same time. This is why it is good to work with a group to iron out these details.

So we please need to know twin or double beds or a triple, 1st floor or ground floor and initially their full name, email/telephone and the group please. The booking form does require full contact details - address, if Fibromite or carer/partner has diet requirements etc. Soft and hard beds are available if booked in advance.

There are no single beds available and we therefore encourage double/twin or triple bookings, albeit 3 single beds. There are a very limited number of the triple rooms as a number have already been booked but it does avoid the third person paying a single supplement for a double room. The hotel levies £50 and for every double room with one person. Sadly one delegate will miss out for each booking of this kind, if we sell out. As a result single supplement rooms have been limited and there are a very few left. The rooms are comfortable and have en suite facilities to wash and dress in private. As there is a television that could be left on low volume overnight, this would possibly allow anyone to get up in the night without disturbing anyone else.

GREAT WEEKEND

This can be a memorable weekend with the opportunity to talk to like-minded people, other GL's, make new friends, get close up and personal with the speakers and enjoy 1-2-1 conversations with the doctors. If you go nowhere else in the coming months you should spoil yourself, learn more about your condition from those who know (from the States and researchers) and talk with those who have the same pains as you do. If only we could do it on the NHS it would prove to be great medicine.

Fibromyalgia Conference

Booking Form
April 26th - 29th 2013

Title	
Surname	
First name	
Address	
Address2	
Post Code	
Home Tele.	
Mobile	
Email address	
<i>Give the names of those with fibromyalgia</i>	
a	
b	
c	
<i>Please state if ME/CFS or Chronic Pain</i>	
<i>Accommodation</i>	
Preference for ground or 1st floor accommodation - THE HOTEL DOESN'T HAVE A LIFT	
Female or Male	
Two Singles	
One Double	
Family room 3 or 4 beds	
All rooms have a bath with a shower	-----
If you cannot manage stairs please confirm? <i>Are you confined to a wheelchair? YES/NO</i>	
If you are travelling alone, will you share? Sole occupancy supplement fee of £50 Payment for double room is required.	
<i>Payments-</i>	
<i>Instalments, 50% deposit or full payment</i>	
Surname	
First name	
Amount Enclosed	
Signature	
Date	
Cheque number	

<i>Additional Guests</i>	Title	
	Surname	
	First name	
	Address	
	Address2	
	Post Code	
	Home	
	Mobile	
	Email address	
<i>Additional Guests</i>	Title	
	Surname	
	First name	
	Address	
	Address2	
	Post Code	
	Home	
	Mobile	
	Email address	
<i>Additional Guests</i>	Title	
	Surname	
	First name	
	Address	
	Address2	
	Post Code	
	Home	
	Mobile	
	Email address	
<i>Additional Guests</i>	Title	
	Surname	
	First name	
	Address	
	Address2	
	Post Code	
	Home	
	Mobile	
	Email address	

Special Requirements - complete where appropriate	
Dietary requirements	
Please indicate your preference for either a soft or hard mattress. Please also indicate if you prefer blankets or duvets.	
<i>This information is required by Hotel. Please advise your waiter of your diet requirements.</i>	
Member of which FM Group	Foggy's "invisible illness" Support
Which beauty therapies interest you	
<i>There will be an additional charge for these</i>	
Which topics are you interested in ?	
<i>Your booking will be held on 50% deposit but full payment is required no later than 6th February 2013</i>	
<i>Cancellations after 5th February 2013, will not be eligible for refund.</i>	
Any cancellations made before Feb.5 will be subject to a £50 administration fee.	
Any comments you wish to make	
*****	*****
<i>Administration use only: -</i>	
HELP LINE Simon 07806 808862	
or 08433 828 829	
Email info@follypogsfibro.org	

VENUE	DAY	FROM DATE		GUEST SPEAKER OR MORE INFO.	TIME
SALISBURY	FRIDAY	14/09/2012			7pm - 9pm
	SATURDAY	15/09/2012	FUNDRAISING	EMPOWER FUN DAY THE MANOR PUB, CHENEY MANOR, SWINDON	12 noon - 6pm
SWINDON	MONDAY	17/09/2012			7pm - 9pm
SWINDON	WEDNESDAY	03/10/2012			
		06/10/2012	AWARENESS	WORLD OSTOMY DAY	
		10/10/2012	AWARENESS	MENTAL HEALTH - INTERNATIONAL DAY	
SALISBURY	FRIDAY	12/10/2012		TRISH COWIE ACTIVE HEALTH CLASSES	7pm - 9pm
		12/10/2012	AWARENESS	ARTHRITIS - INTERNATIONAL DAY	
SWINDON	MONDAY	15/10/2012	SPEAKER	PETER KIDD HELPING U SLIM	7pm - 9pm
SWINDON	WEDNESDAY	07/11/2012	SPEAKER	JACKIE WRAY SWINDON MS THERAPY CENTRE	1pm - 3pm
SALISBURY	FRIDAY	09/11/2012			7pm - 9pm
SWINDON	MONDAY	19/11/2012			7pm - 9pm
SWINDON	WEDNESDAY	05/12/2012		CHRISTMAS MEETING	1pm - 3pm
SWINDON	FRIDAY	07/12/2012	FUNDRAISING	FUNDRAISING - TESCO OCOTAL WAY, SWINDON	5pm - 9 pm
SWINDON	SATURDAY	08/12/2012	FUNDRAISING	FUNDRAISING - SAINSBURY'S - BRIDGEMEAD, SWINDON	12pm - 4pm
SWINDON	THURSDAY	13/12/2012	FUNDRAISING	FUNDRAISING - SAINSBURY'S - BRIDGEMEAD, SWINDON	5pm - 9pm
SALISBURY	FRIDAY	14/12/2012		CHRISTMAS MEETING	7pm - 9pm
SWINDON	MONDAY	17/12/2012		CHRISTMAS MEETING	7pm - 9pm
SWINDON	THURSDAY	20/12/2012	FUNDRAISING	FUNDRAISING - TESCO OCOTAL WAY, SWINDON	5pm - 9 pm

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EST. 29TH JUNE 2010



"INVISIBLE ILLNESS" SUPPORT

DEDICATED TO RAISING AWARENESS, PROVIDING SUPPORT AND PROMOTING POSITIVITY

We hold informal drop-in support meetings every:

first Wednesday Of The Month 1 – 3pm

third Monday Of The Month 7 – 9pm

at Liden Community Centre

Barrington Close
Swindon
SN3 6HF

at The Haydon Centre

Thames Avenue
Swindon
SN25 1QQ

www.swindon-support.co.uk

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The Pavilion
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SALISBURY
SP1 3GY

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