



PMR-GCA UK NORTH EAST SUPPORT
(Polymyalgia, Rheumatica & Giant Cell Arteritis)

Patrons: Professor Bhaskhar Dasgupta, Southend Hospital
Dr V Saravanan, Queen Elizabeth Hospital, Gateshead.
Mr D Anderson MP, Blaydon

NEWSLETTER June 2009

THE NATIONAL LAUNCH

When the famous 5 PMR Fighters, Wendy, Pam, Kate, Jayne and Mavis first meet they were determined that there should be a registered charity for PMR & GCA. Their gruelling trip to London (by taxi for 2 of the fighters) in March 2008 to meet Professor Bhaskar Dasgupta was with that sole intention.

On the 9th March, Pam, Mavis and Margaret set off down to London by train to represent members the North East Support groups at the Launch, They stayed at the Premier Inn with lovely views of the London Eye and that night joined by Wendy, Jayne and Kate reflected on the time gone by of that first meeting and how they had all moved forward. Wendy as acting Chair of the National Charity soon to hand over to Kate, Jayne as National Secretary, Pam, Mavis and Margaret with their support groups and other exciting projects.

On the 10th March 2010 they saw the fruition of that meeting come to life with the launch of the First National Charity PMR-GCA UK. We travelled to the Wellcome Centre, Euston Road, where Mavis was whisked away to talk on the RNIB National Radio, The Launch was well attended by group leaders from around the country, trustee directors and other interested parties.

Professor Dasgupta gave an excellent talk about his work and hopes for the future, Wendy about living with PMR and Jennifer Nott from East Anglia Support Group about support groups and finally John Gibson about the need for fund raising.

Also in attendance was Dorothy Byrne who works for Channel 4 TV and at only 50 yrs old suffers from PMR and GCA. She has joined us and has already penned two wonderful articles which appeared in the Daily Mail during March and April. Dorothy is set to "shout it from the Rooftops" :-
<http://www.dailymail.co.uk/health/article-1262172/Wendy-thought-muscle-aches-signs-ageing-fact-days-going-blind.html>

<http://www.dailymail.co.uk/health/article-1246075/TV-boss-bed-thought-overdone-In-fact-crippling-disease-blind-you.html>

After a lovely reception and opportunity to talk to others we returned to our hotel exhausted and very excited about the future of the National Charity.

Thursday morning brought a bright start to the day and some rested whilst other took a walk along the embankment, Pam, Jayne and Margaret took to the sky on the London Eye.

Many people from around the southern region had contact us either by email or telephone seeking advice and enquiring about support groups in their area. So, Mavis and Pam sent all an open invitation to meet us at 2pm in the hotel. We where overwhelmed by the attendance, people travelled from far and wide. Over lunch, coffee nibbles and the odd glass of wine we were able to exchange experiences, give support and advice in helping them find funding and set up their own support groups in their area.



At 8pm we returned home, exhausted, excited at the events' of the last three days and boy did that glass of wine or two on the train taste good!

OUR BIG DAY IN THE NORTH EAST

When we three (that is Pam, Mavis and Margaret or as the medical team now call us “the Wicked Witches from the North”) first got together in May 2008 we talked about our own experiences with the medical profession, how we could support those who were helping us, setting up support groups, advertising our existence, creating a web site, making a DVD for newly Diagnosed patients even holding a medical seminar. Our first application was to the National Lottery for funding to help us on our way and in that application we ended with our dream for the future, to launch our DVD and Web site and hold a medical seminar for Ophthalmologists and Rheumatologists lead by the world leading research scientist in PMR and GCA Prof Bhaskar Dasgupta in the hopes of making the North East of England a leading light for those who suffer from PMR and GCA. At that time, little did we know just how much support with the invaluable help of Dr. Vadivalu Saravanan, Queen Elizabeth Hospital in Gateshead, and Dr. Mike Plant from James Cook Hospital, Middlesbrough together with , Dr. Daya Ashock Durham University Hospital Dr Margaret Dayan Newcastle RVI, Dr. Shazir Abdulla and others from the medical profession would give us.

On the 12th of May our dream came true, with further funding from **Awards for All**. Our day started at 10am with coffee on arrival and guests were entertained with light music from 12 young people from Durham Music Services Supersonic Strings who had previously held a fund raising event in our honour.

We were delighted to be joined by the Mayor of Gateshead, Mr John Eagle, as Gateshead Metropolitan Borough Council were the first to give us a grant and allow us use of the Civic Centre facilities for the filming of the DVD.



Group members who had travelled by coach from Middlesboro with Karen Faughey from the Evening Gazette.



These were joined by members from our Gateshead branch, as well as others who had travelled from all around the UK, Italy and Holland were free to view our story boards, snippets from our DVD and Web site before going into the lecture theatre. Short talks were given by all the medical profession who had appeared on the DVD.



We were delighted to welcome Hans Kruyswijk. from the Marijke Foundation in Holland who research into GCA who also gave a short talk on their work



and Professor Dasgupta gave an excellent presentation on the history of GCA and his research into GCA and PMR.



Dr Daya Ashock received the cheque for £600 from the Supersonic Strings Orchestra. An open session took place where the medical professionals took questions from the guests.



At 2pm over 100 doctors specializing in Rheumatology and Ophthalmology attended a closed seminar. Mavis Smith our Chair welcomed the guests and explained our work and how we could support them in their work. Members of the public were then asked to leave and the seminar commenced where they heard lectures from Professor Bhaskar Dasgupta and other experts in the field of PMR and GCA in the North East.

Our hopes and dreams have been achieved and many thanks to everyone who make this possible and those who attended to make this event such a success.

Mavis, Chair of PMR&GCA UK North East Support thanked everyone who attended the event and particular mention was given to those who had given their time/services free or for “pennies” – Frank Auffret Desktop Solutions for the website, Edward Gainford of GDA Designs for the design work, Alan Evans, AE Video, Wendy Garratt Photography, GMBC for the free use of the Civic Centre for Filming, and finally to Dr Sarvanan (Sara) for his friendship and support – amazing where his love for cakes takes him!

The event was well attended by the local media, BBC Look North (TV), BBC Radio Newcastle, the Middlesbrough Evening Gazette, Northern Echo and Whitley Bay Chronicle.

Link to Evening Gazette article:-

<http://www.gazettelive.co.uk/news/teesside-news/2010/05/15/campaigner-launches-dvd-in-bid-to-help-other-sufferers-84229-26448131/>

Link to Whitley Bay Chronicle Article:-

<http://www.newsguardian.co.uk/latest-news/Friends-looking-to-help-other.6311402.jp>

Sharon Barbour from BBC TV Look North arrived at Kibblesworth the day before the event for filming. We had fun filming and received about 2 mins air time on BBC TV the following day. Here are some photos of the day:-



More information & photographs (thanks to Wendy Garrett www.wendygarrett.com)
on our website www.pmr-gca-northeast.org.uk

New Treasurer

Our thanks to Dorothy Reed for the work she did whilst we were setting up. Dorothy has now left us and we introduce Alan Tailford our new Treasurer:-



Alan Tailford (Treasurer)

Alan is 60 years of age. He retired from Northumbria Police in 1999 and has since had two roles with the Office for National Statistics.

Alan was impressed with the positive approach of all those attending a meeting in Teesside and recognised the commitment of Margaret, Mavis and Pam.

Alan volunteered to act as treasurer and is pleased to be associated with the dynamic team who steer PMR-GCA NE.

New Logos

You will notice the new logo on the top of the newsletter, also some may have noticed the design work at our launch. These are thanks to Edward Gainford of GDA designs

AREA 1 (Cleveland, S Durham and N Yorks)

Area 1 had a change of venue – now Marton Country Club, Stokesly Rd, Middlesbrough. Meeting to be held every 3 months – January, March, June and September.

Funding

Area 1 has been awarded £904 from Tees Valley Community Foundation to cover, room hire, postage, printing, expenses for guest speakers etc for this year. A big thank you to them

CAPS (Call a pal scheme)

Our scheme continues to be used but not to the full. Anyone who wishes to add their details to the list to help others – please get in touch (01287 623334 or pmrgcafightersne@googlemail.com) and any member who feels they would like to talk to someone who understands do not hesitate to use the scheme