

## First UK national patient day a great success

The first ever MPD Voice patient day recently took place on 19th November 2011. Over 250 delegates comprising patients, family and friends travelled from far and wide in the United Kingdom and Europe to hear a wealth of knowledge from leading experts in the field of MPDs.

The day was packed with talks covering the individual MPD conditions, treatments and the latest medical options as well as fascinating updates on the latest research initiatives, managing stress, why MPDs cause blood clots and an overview of current and future drug trials.

Patients heard the latest news and thinking from leading MPD and medical specialists: Prof Tony Green (Addenbrookes, Cambridge), Dr Steven Knapper (University Hospital of Wales, Cardiff), Dr Nauman Butt (Arrowe Park Hospital, Wirral), Dr Claire Harrison and Dr Nicky Thomas (Guy's and St Thomas' NHS Trust, London) and Prof Mary Frances McMullin (Queen's University, Belfast). International medical expert presenters included Prof Jean Jacques Kiladjian (St Louis Hospital, Paris), Prof Ruben Mesa (Mayo Clinic, Arizona, USA) and Prof Tiziano Barbui from Bergamo, Italy.

One patient commented, 'How encouraging it is for patients with MPDs to see and know that such an auspicious group of experts are working together to find better ways to understand and manage our conditions and ultimately find a cure for these rare disorders.'

The day included a very moving session, where 3 patients and one mother of an MPD teenager (diagnosed at 8) shared their personal and varied MPD journeys. Their stories were honest and challenging, demonstrating that living with MPDs is not always easy.

The afternoon offered breakout sub-groups for the main disease areas of ET, PV and MF. In these sessions, patients had the opportunity



**Professor Ruben Mesa**  
spoke about  
measuring and  
managing symptoms



**Professor Tony Green**  
spoke about MPDs  
and why people get  
them

to share their own experiences and ask even more detailed questions of the medical experts.

It was clear that patients appreciated the chance to network and support or empathise with other people who had similar medical challenges. Since the day, feedback to the organisers has been extremely positive, demonstrating the need for this type of event in the UK. Jon Mathias, one of the charity's founders, said:

'This event represents a huge milestone for us – it shows us how much we can achieve as a team... Judging from the feedback that people were giving as they left, it delivered exactly what MPD Voice was originally created for.'

For more information and a selection of slides from the presenters at the event please visit [www.mpdvoice.org.uk](http://www.mpdvoice.org.uk)

### Exciting developments, trials and drug launches in 2012

Dr Claire Harrison is excited about the year ahead and writes:

This year is tremendously exciting for those of us in the field of MPD. 2011 ended with the FDA approval of Jakavi (or ruxolitinib, or INC424) for the treatment of myelofibrosis. We hope that EU approval will follow shortly, probably mid to late 2012.



Awaiting EU approval and launched in the US

In the meantime we have had the chance to assess the results of the first ever randomised studies in myelofibrosis – the COMFORT trials (CONtrolled MyeloFibrosis study with ORal JAK inhibitor Treatment). These studies will soon be published in the New England Journal of Medicine. They show that when compared either with placebo, (COMFORT 1 in USA, Canada and Australia) or doctors choice of standard treatment, (COMFORT 2 in Europe,) the drug led to spleen size reduction and large improvements in quality of life with patients being able to walk further, return to work, gain weight etc.

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# MPD voice

GUY'S & ST THOMAS' CHARITY  
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At the annual ASH meeting in San Diego further data from these studies showed that patients benefited from the drug regardless of whether they had a JAK2 mutation or several other influencing factors such as age, gender, size of spleen and whether their MF occurred after PV, ET or was primary MF.

### Does it really work?

There is much discussion about whether the drug prolongs survival. Data from the COMFORT-1 study suggests that ruxolitinib treatment, when compared to placebo, may prolong life, a finding supported by a study from the MD Anderson Cancer Centre. However there is conflicting data reported from the Mayo clinic in Rochester.

At the current time, the jury is out on some of the issues raised. The Mayo clinic patients were treated with a lower dose and were taken off the study much more rapidly, perhaps before the drug had the chance to deliver a benefit. It is important to remember that ruxolitinib alone is not curing patients and clinicians will need to try to partner the drug with other treatments or procedures such as bone marrow transplant.

A potential partner agent is the histone deacetylase inhibitor panobinostat and exciting animal data was shown at the ASH meeting. Such is the pace of progress that 5 patients are currently enrolled in a study with these two agents 4 of them being treated in the UK.

### JAK inhibitor studies

Other exciting data is appearing with other JAK inhibitors. The Sanofi Avenis compound SAR302503, currently being trialed in the UK and elsewhere, shows promises of potentially reducing the amount of mutated JAK2 and maybe even bone marrow fibrosis. Further developments are that these drugs are now being studied in ET and PV.

### And finally....

UK MPD experts are thrilled that, after many years, they will be able to start on the launch of PEGASYS trials in ET and PV later this year.

Dr Harrison concludes, 'Plenty of basic science, more mutations and the MPD Voice supported study into the Epidemiology of MPDs (read more inside) are all highlights to come this year'.

# Say what you mean and feel

**Dr Nicky (Veronica) Thomas, Consultant Health Psychologist advises on some of the communication issues MPD patients and their families face**



**Dr Nicky Thomas, Department of Haematology, Guy's and St Thomas' NHS Trust**

### All change

The diagnosis of MPD has far reaching effects within the family and it is quite often reported that roles and responsibilities within families can change as a consequence. People with MPD often have the added challenge of communicating in a useful way with their family.

People with MPD often say that they don't have the energy to carry out existing roles, and this could be as a result of MPD itself or due to treatment.

Trying to get other people such as your family and friends to understand can be difficult, because there are no visible aspects of the MPD communicating itself to them, and although they may want to understand they have no frame of reference i.e. they do not share the same perspective as you. Therefore it's really important to explain that you don't necessarily show all your symptoms to everyone. When others see you it is usually when you are feeling well enough to go out or go to work etc and not when you are feeling unwell.

### No-one can mind read

In our intimate and close relationships, we have a tendency to think that our loved one "should know my needs" but the truth is the only one who can really know our needs is ourselves. Therefore it's important to be explicit to your partner about how you feel and what you expect from him/her.

*E.g. 'I'm feeling really tired at the moment, so I can't do all the things I said that I would do this week. It would really help me if you could do the shopping /or help me by supervising the children's homework.'*

### Independence

It's equally upsetting to feel "wrapped up in cotton wool" by family members, because this just serves as a reminder of the MPD and its threat. Therefore it's important to inform family how not to do that.

*E.g. 'I'm learning to live with MPD as normally as I possibly can, and I'm going to need your help. Please allow me to carry on with the things I have always done and when I'm feeling tired or unwell I'll let you know.'*

### Emotional stability

Sometimes you can feel anxious because the uncertainty around your MPD and speaking to your medical consultant may have left you a little confused or overwhelmed. If you don't explain this, the anxiety can be expressed to your family and partner as irritability which is unhelpful. So it's important to find a way of communicating this emotion in a way that allows him/her to support you.

*E.g. 'I'm feeling upset/confused about the last consultation with the haematologist but I don't want to talk about it at the moment, it's just nice to know you are here for me'.*

### Support

Giving your partner or close family member a role in your MPD is very useful to them and supportive for you. For example, ask your partner to come along to medical consultations to be your ear because it's very hard to keep in memory all that you're told in consultations. Your partner can then remind you of what has been said later on and it also helps them to appreciate what you are going through.

## National patient forums in 2012

Originally initiated by patients based in the south, MPD Voice now represents a national/international audience. As part of its commitment to representing and helping MPD patients in every part of the country, in

2012, patient forums are planned for Newcastle, Cardiff, Cambridge and London. See the website for details and dates. Please feel free to contact us if you would like to be involved in helping at a forum in your area.

# Count your blessings – don't give up!

Pauline Collis speaks with Alisia O'Sullivan about managing the ups and downs of PV

**W**hen I heard Pauline Collis speak at the recent Living with MPDs day, I was inspired and moved by her honesty about how she had coped with her condition and a brief time of mild depression.

Interviewing her for MPDLife, the first thing that impressed and encouraged me was hearing that Pauline is 71 years young! She is still very active, working part-time in a responsible role as a quality advisor for her local Citizens Advice Bureau where she has held various key roles for the past 25 years.

Diagnosed over 35 years ago, Pauline describes how she had aches and pains in her joints, headaches, very bloodshot eyes and itching. A familiar story was that because her GP was not at all concerned, Pauline had to insist there was something wrong. He referred her to a rheumatologist who in turn referred her to the Sutton Branch of the Royal Marsden where she has been a patient ever since.

I asked Pauline how she had coped with the initial diagnosis, which for some MPD patients can be a confusing and challenging time. Pauline recalls, 'I asked for a prognosis and was told "15–20 years was usual". So I set my sights on seeing my daughter Tamsin grow up, and hopefully see her happily married, (she was only 6 when it was diagnosed).



Pauline with her daughter Tamsin – now married!

In those days, we mothers thought that our daughters, if they wanted, could and should do whatever a man could, but that being married was still important! Also I wanted to see in the Millennium. From then on I have tried to live as normally as possible and follow my granny's advice, to count your blessings one by one – and I have had many – including a very good



Enjoying her fitness and travel opportunities

marriage and family and friends. I have also been fortunate that, on the whole, the symptoms are easily managed. I know that this not the case for some patients.'

Pauline generally has a monthly blood test and appointments to monitor and manage her PV. She was given Busulfan at the beginning, which resulted in premature menopause. Later Hydroxycarbamide was tried but she didn't tolerate that so the main treatment is regular venesections and daily low dose aspirin. The hardest thing for her is that the constant venesections have resulted in iron deficiency and increased fatigue, which then makes her feel unwell. However, reflecting over her treatment, Pauline comments that, 'I have been looked after extremely well.'

Working outside of the home has been a positive decision and help to Pauline throughout the years. She says, 'Some days I have gone in feeling very unwell but in no time at all I have forgotten about it. Unfortunately this does not work so well at the moment and I am considering giving up my job. Interestingly however, whenever I have felt like this in the past, all the doctors have always said keep working. At least 15 years ago one, young then, but now very eminent, haematologist slid his chair across the room, held my hands and said "coast for a while until you feel better, do not give up". I'm glad I took his advice.'

The death of her husband six years ago was a difficult period of adjustment and Pauline remembers that this, together with the length of time that she had had the disease, was the start of a downward trend. She says, 'It made it all too easy to think the future was very bleak.' Fortunately she was referred to a Consultant Health Psychologist who helped her to work through this dark time and she says, 'I can now feel comfortable with resting when I have to, and occasionally spoiling myself, but also making the effort to get out

and walk and try new things and most of all not to let the black thoughts take over; not always easy to do, but worth it.'

I asked her what advice she would give to patients who have been recently diagnosed. Pauline replied, 'If possible, continue with your previous life, keep busy but also rest. Try to keep positive and enjoy life. Give yourself treats and if you are finding it difficult, seek help! To quote Dr Nicky Thomas, "Live with the disease, do not let the disease live with you and take over."'

Our thanks go to Pauline for bravely speaking at the Living with MPDs day and also for her candid and encouraging advice about dealing with the emotional challenges of a chronic medical condition.

## Help! Volunteers needed All locations...

MPD Voice was set up almost 7 years ago by a small group of patients who wanted to help support and encourage others who had limited understanding or knowledge of their MPD. Through subsequent years it has grown and built its reputation as a reliable and essential resource to patients and their families. MPD Voice now has a website, a buddy system, patient forums and various patient leaflet information previously not readily available in the UK. In 2011 it ran the first ever Living with MPDs day (see page 1).

The group, led by Dr Claire Harrison and chaired by founder patient Jon Mathias, currently comprises a varied selection of volunteer MPD patients who donate their time to improve the information and support available for people who contact the charity. The number of requests for help and information continues to rise and we always welcome more offers of help. So if you have a skill, writing, editing, photography, fundraising, training, trust applications, think you could be a buddy or anything else, and can spare a few hours to help us to help more people affected by MPD please do contact us. [Info@mpdvoice.org.uk](mailto:Info@mpdvoice.org.uk)

Visit our **News and Events blog**: [www.mpdvoice.org.uk/news-events](http://www.mpdvoice.org.uk/news-events) or visit our Facebook and Twitter pages





# Fundraising events for 2012

**R**achel Bridgman, co-ordinator of fundraising for MPD Voice, would like to thank ALL the fundraising heroes who have contributed to the charity in 2011 through a wide range of events, whether big or small. Two of the larger events, the Richmond Park Sponsored Walk and the Oxfordshire Skydive resulted in an amazing £22,293.43 alone! The money raised from all contributions is vital to fund areas of education, patient support and research for the improvement of the lives of people affected by MPDs.

This year, together with GSTT, MPD Voice will benefit from seven exciting events planned for dates throughout the year and in various locations. If you or your friends and family would like to sign up to any or all of them, please visit our fundraising section of the website or email Rachel Bridgman at [fundraising@mpdvoice.org.uk](mailto:fundraising@mpdvoice.org.uk) for more information and registration forms.



**Rachel Bridgman – a fundraising heroine! Rachel completed the 3 Peaks Challenge on behalf of MPD Voice**



**One step beyond! Skydivers raised over £15,000 in 2011.**

Rachel reminds readers that fundraising events do not have to be large scale and costly to organise or take part in, 'School or work cake sales, car-boot sales, dress-down Fridays, walks, runs, cycles ... whatever you like doing you can do it for us!'

MPD Voice needs your support and welcomes all fundraising ideas. So if you would like to talk through your ideas or need help with any aspect of fundraising please don't hesitate to contact Rachel at [fundraising@mpdvoice.org.uk](mailto:fundraising@mpdvoice.org.uk).

## Fundraising Diary Dates

- **Adidas Silverstone Half Marathon** Sunday 11th March 2012
- **Brighton Marathon** Sunday 15th April 2012
- **London Marathon** Sunday 22nd April 2012
- **Peru Trek** Monday 30th April – Thursday 10th May 2012
- **London to Paris Cycle Ride** Wednesday 6th June – Sunday 10th June 2012
- **The Three Peaks Challenge** Friday 22nd – Sunday 24th June 2012
- **Mt Kilimanjaro Climb** Wednesday 11th – Sunday 22nd July 2012

## Looking for a cause?

### MPD Voice charity backs new epidemiology research

**MPD** patients and carers often ask what may have caused this condition to develop. Unfortunately there is little information to give a definitive answer. A recent review of the various studies in this area does not provide any clear conclusions on the potential medical, environmental or occupational risk factors that could contribute to MPDs.

In 2012, MPD Voice has committed to fund a pilot study that will be the start of a potentially bigger investigation of this area. Comprising an International research group, the exploratory study will compare one hundred MPD patients with one hundred people from the general public.

The aims include the evaluation of the best patient recruitment procedures. The development of a telephone administered questionnaire. The comparison of occupational/job exposure assessment and the evaluation of the feasibility of saliva DNA collection compared to blood samples.

Following the pilot and depending on the

findings, researchers expect that the results will be used to develop information and technology enabling them to take forward a comprehensive investigation into potential causative factors for MPDs.

Prof Mary Frances McMullin, Queens University, Belfast comments that, 'This research is an exciting opportunity to investigate factors which may influence the development of MPDs. It is crucial to determine the best methods of obtaining information as a first step.'

MPD Voice will be launching a fundraising campaign to support this research – watch this space!

The study has participation from the International research team of Prof Mary Frances McMullin, Dr Andrew Duncombe, Southampton University Hospital. Frank De Vocht, University of Manchester, Lin Fritschi, Western Australian Institute for Medical Research, Mark Purdue, National Cancer Institute, USA and Prof Ruben Mesa, Mayo Clinic, USA



**Dr Lesley Anderson: Lead researcher**

## MPDlife

- Want to be featured in our patient story?
- Do you have tips to share with readers on managing MPDs?

If so, please email the editor at the address below.

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### MPD Voice

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We welcome your letters and feedback.  
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### Guy's and St Thomas' Charity

You can also contact the Guy's and St Thomas' Charity at [info@gsttcharity.org.uk](mailto:info@gsttcharity.org.uk) or visit their website for more information: [www.gsttcharity.org.uk](http://www.gsttcharity.org.uk)

Please note that nothing contained in this newsletter is intended to constitute professional advice for medical diagnosis or treatment. You should always seek the advice of your physician or other qualified health provider prior to starting any new treatment or consult them on any questions you may have regarding a medical condition.



**Alisia O'Sullivan**