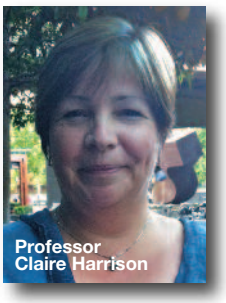
MPDlife

The newsletter for people with MPNs
November 2017

MPN trials and research

Professor Claire Harrison shares the latest updates on what's happening to improve the understanding and management of MPN patients


Professor Claire Harrison

Currently available trials in the UK for patients with myeloproliferative neoplasms (MPNs) range from those where there is no treatment intervention to those where very new therapies are used either alone or in combination. These types of studies are known as phase 4 when it's just observation with no intervention, to phase 1 where completely new drugs are used.

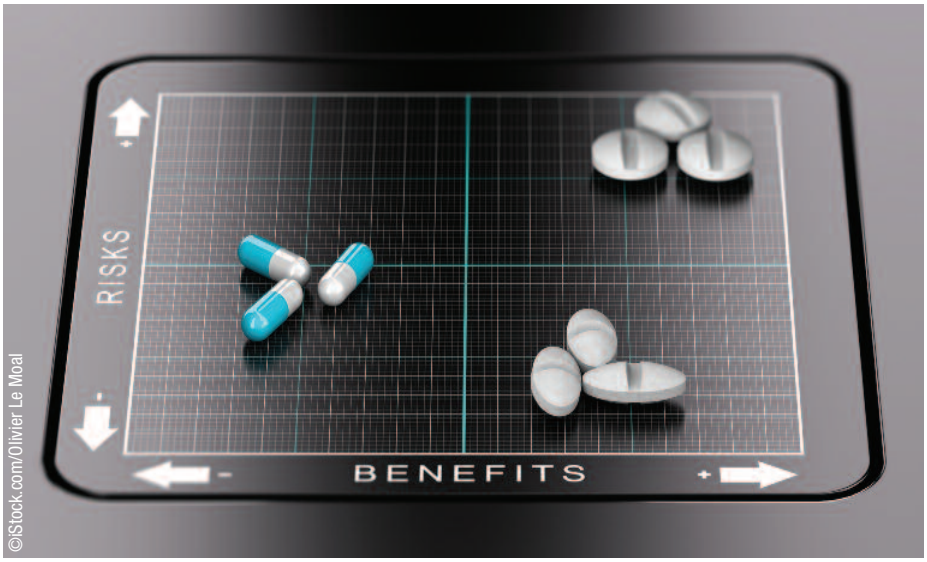
We are very excited to announce that along with France the UK will be running a study to test the JAK inhibitor ruxolitinib in patients with PV as a first line therapy. This is the first study of its kind and it is part funded by MPN Voice. It is set to answer very important questions about the role of this therapy. This study has been named MITHRIDATES referencing an antidote to poison.

At present in Myelofibrosis (MF) there will soon be studies with pacritinib (a JAK inhibitor), luspatercept (a drug we hope to be effective for anaemia) and ruxolitinib in combination with navitoclax.

A listing of the current studies in the UK is regularly updated on the MPN Voice website. One of the most important current studies is known as "MEASURES". This study was designed in collaboration with Professor Ruben Mesa to evaluate the impact of all the current therapies in relation to patient symptoms and quality of life. Recruitment in the UK is progressing extremely well which will mean that we will soon be able to analyse the UK data.

Other important and interesting studies include TAMARIN which follows up on important data showing that oestrogen (a female sex hormone) is significant for maintaining abnormal MPN stem cells in mice. In TAMARIN we are testing whether Tamoxifen, a drug that inhibits oestrogen, can reduce the amount of abnormal MPN stem cells in patients. The Phazar study is testing ruxolitinib with azacytidine in MPN patients who have developed leukaemia.

Soon a trial will begin, MOMBAT, which tests if methotrexate which is used to treat arthritis, can control blood counts and symptoms.



Meanwhile we await results from studies such as PT-1, MAJIC-PV and studies with agents like Imetelstat and PRM 151 which are currently still gathering data.

A little bit of MAJIC?

The MAJIC study is the first non-company study of ruxolitinib in patients with ET and PV. Later this year we expect to be analysing MAJIC-PV and await the data with great excitement. In the last year we've been analysing the results from MAJIC-ET. These show that ruxolitinib is as able as standard treatment to control blood counts in patients who have already been treated with many other agents for their ET such as interferon, busulfan and hydroxycarbamide. Importantly there was no greater risk of thrombosis, haemorrhage, or disease transformation with ruxolitinib and patients had better control of their other symptoms. We will be continuing our evaluation of blood and bone marrow samples to further understand the biology of the disease and how treatments affect it from this study. Many thanks to all patients and their families who have been taking part to date.

Hydroxycarbamide versus interferon. The great debate.

When a patient requires treatment the debate is often whether to start treatment with interferon or whether to use hydroxycarbamide. Both have many pros and cons and for some patients there is clearly one drug which would be preferred over another. For example, for a woman wishing to become pregnant within the next year, interferon would be the drug of choice.

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MPN voice

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However this might not be the case if the patient had a very active autoimmune disease or depression. Many patients and clinicians are attracted to the idea of interferon therapy as a more biological agent which has the ability to reduce the amount of abnormal MPN stem cells measured, as for example the JAK2 mutant allele burden. Nonetheless for clinicians a lack of clarity and comparative information makes the decision difficult.

Data from two studies is currently helpful in this regard. The first study MPD RC112 was open in the UK and compared the two agents for high risk ET or PV. Final analysis of the data from the study is currently underway but in the interim, information from the first 75 patients recruited was presented at the American Society of Hematology (ASH) meeting. Interestingly response rates in terms of controlling blood counts were similar between the two arms of the study. However for me, the most important data was that review of bone marrow biopsies at 12 months showed some improvement with a return to normal architecture with both agents, but more often with hydroxycarbamide. We also showed that both drugs can reduce the amount of JAK2 mutant allele burden, an important reminder that clinical studies are really required to properly compare therapies.

The second study included only patients with PV and is known as 'The Proud PV' study (a wonderful name for a study don't you think?). Here a new form of interferon known as Ropeginterferon Alpha-2b was used. An extremely exciting form of interferon which is much purer in its composition than other types and perhaps has a much better side-effect profile. In this study patients were randomised to receive the new interferon or hydroxycarbamide. It was found that at one year both agents can deliver complete control of blood counts in about 43% of patients. This is known as a non-inferiority study and was the planned outcome. We are excited about this form of interferon because many patients only required an injection every four weeks and the side-effects, which are common with other types of interferon such as mood disorders, immune and endocrine diseases, were very uncommon.

Long-term data from both of these studies will be incredibly important to inform decisions made by patients and their doctors in years to come.

New initiatives in managing MPN patients

Alisia O'Sullivan shares her experience of telephone appointments


Alisia O'Sullivan

I was diagnosed with essential thrombocythaemia nine years ago. My initial platelet counts were just under 3,000 and I was immediately put on hydroxycarbamide to reduce the risk of a stroke. Since that time I have been seen at a specialist MPN hospital clinic, initially quite regularly and then maybe three times a year.

Gradually my platelet count reduced, but after a few years, I became intolerant to the medication I was taking and my platelet count began to rise again, so in consultation with my haematologist I decided to try interferon alpha. I was advised about the side effects and knew that many MPN patients didn't always get through the initial phase of feeling rubbish, but I tolerated the drug quite well and it worked in bringing down my platelet count. After about 18 months there was a time when the drug made me feel really rubbish, emotional and confused. This led to a 60% reduction of the dose and fortunately my blood counts have remained steady ever since. Therefore when the possibility of having a telephone consultation was offered, being in full time employment, I jumped at it, as a hospital visit could sometimes take me most of the day to attend. It works really well, I have my bloods taken at my local GP surgery who then send the results to the consultant. About 10 days later I have a telephone appointment with the specialist MPN nurse, who has discussed the results with the consultant and talks through any issues/questions and if happy with the results and discussion then arranges for a repeat prescription to be issued.

It's been about two years now, and I have the reassurance that if I do feel concerned about anything or changes in my health, I can arrange for a face-to-face appointment at any time or call the specialist nurse for advice. It does seem like a win-win option in that I can manage my care and save time in the busy clinic for other MPN patients to see the consultant as needed.

Telephone appointments for MPN patients at the Royal Bournemouth Hospital

Louise Wallis, MPN Specialist Nurse at the hospital explains how the system works there.

We offer patients the chance to have telephone appointments rather than attending the hospital. However this does not suit all patients and there are some who should be seen face to face, and some who would rather come to the hospital.

We may organise these appointments in a slightly different way to some other hospitals. We have two nurse-led MPN clinics a week, and I have added some telephone appointments on to the end of these. This means that I am in a clinic room with access to the notes and blood results that I would have in a face to face appointment.

We have been offering these appointments for the last two years. I have tried to group most of the ad-hoc telephone calls into these clinics so that the activity can be seen.

There is an expectation from me that patients will have their blood taken prior to the appointment, and it also means that the patient knows when to expect a phone call.

If either the patient or I feel that the telephone appointment is not the right method of monitoring for them, or I feel that the patient would benefit from being seen in the hospital I will revert back to a traditional out-patient appointment.

I hope that this option gives patients more choice in how they access care from us. It may mean that there is less impact on their work and home life, and they are not having the additional worries of travelling to an appointment or paying for car parking.

A double gift

patient story

Francis Hallinan shares how being diagnosed with PV brought him the chance to be a better doctor.

Any doctor will tell you that the very worst patients are doctors. They delay seeking help for absurd lengths of time, wrongly diagnose themselves and refuse well meaning advice from colleagues to get themselves treated. So it was with me. In my late fifties I started to bruise easily, a mild tap on the skin would produce a huge purple patch which took ages to fade. Ludicrously I dismissed it as getting older. Even when the bruising extended into both thighs and I was finding it more and more difficult to walk I still ignored it. I was a doctor after all, doctors did not get ill.

It was not until a clot the size of a small orange developed deep in one thigh making it impossible to climb the stairs I decided to surrender. With extreme reluctance I allowed my wife to take me to my local hospital.

'Since when?' asked the medical registrar opening the curtains of the cubicle in Accident and Emergency, my blood tests in her hand, 'Have you been going around with a haemoglobin of twenty grams?'

It took a few minutes for the significance of this to dawn, I had noticed lately I was getting a bit slow on the uptake. A haemoglobin that high meant my blood must be as sticky as toffee.

'Polycythaemia' I muttered.

'Yes, polycythaemia' said the registrar severely. I was on the medical naughty step, and richly deserved it.

'You must have known the risks you were taking?'I felt like the Scotsman who died and found himself at the Pearly Gates.

'Oh Lord I dinna ken,' says he.

'Well you ken the noo.' thunders The Lord.

Another doctor came and took a bag of my blood. In a few hours the world began to resume its sharp outlines and I realized that for months I had been within an ace of a stroke. Definitely not a case of 'physician heal thyself'.

After a bone marrow biopsy which showed I had the primary form of the disease, I was discharged on hydroxycarbamide and aspirin with instructions to come back for a blood test in a couple of weeks. The test turned out to be normal, life could go on as before. I carried on smoking my pipe which was about as mad as lying down on the hard shoulder of a motorway on the grounds that not many cars use it.

A week later one moment I was sitting on the toilet reading 'The Spectator', the next I found myself in a critical care bed back in my local hospital. I remember nothing of what had happened in between. I don't remember the ambulance ride, blue lights flashing, or that I was embarrassingly rude to a doctor in Accident and Emergency. It still remains a mystery to this day how my wife, a tiny woman, managed to open the narrow toilet door against my eighty kilos and pull me out onto the landing.

My platelet count, which a week before had been a normal 350 was now over 1,000. The level was fluctuating up and down from a low of 123 to a high of around 1,000. The last two blood tests had been taken when they were deceptively low. Had I had the test a week later they would have been high. That, and smoking, did the rest. I had had a TIA, a fortunately reversible mini stroke.

I was soon to learn that MPN is a form of permanent haematological exile. There is no way to go back to normal. However it is not all bad.

'It is like having to move from a huge continent like Africa to a nearby island like Madagascar, but the rules say 'once you move you cannot go back.' said my haematologist, 'Your blood will never be normal again, but there are lots of ways we can help.'

He was ten times as good as his word.

It was a struggle to get my platelets to behave. The more hydroxycarbamide I took the more they bounced up and down, eventually on a modest dose they now bounce from a low of 150 to a high of 800.

A clot in my abdomen five years on, some wrestling with anticoagulants and eighteen years later I am still holding down two different jobs as a GP and journalist. I travel a lot, and work until two in the morning when deadlines demand. Tiredness is the worst symptom as well as occasional bouts of itching. It is important not to be beaten by the tiredness, but to keep going.

It may be a bizarre thing to say but had it not been for polycythaemia I am sure I would not be alive today. I had to give up smoking, and a few years ago while having a CAT scan of my abdomen a sharp eyed radiologist noticed a small tumour on my right kidney. It was burnt off with a catheter guided hot wire. It has not come back.

Polycythaemia brought me another gift, the chance to be a better doctor. The best training a doctor can ever have is to be a patient himself, and thanks to the example of the haematology staff, doctors, nurses, admin, everyone, their unfailing courtesy and patience, sitting in the day unit watching them at work helping some very sick people is one of the most important lessons I have learnt since leaving medical school. A double gift then.

(Francis Hallinan is a pseudonym)

Photograph: ©iStock.com/Niyazz

Can you help us?

Volunteer Regional Fundraising Organizer

Would you like to be part of our fundraising team? We are looking for volunteer regional fundraising organizers to aid and support fundraisers, and hope to have an organizer in each county. You don't need to have experience, just lots of enthusiasm for getting involved with fundraisers and their supporters, however, if you do have experience that would be great. As a regional organizer you would look after fundraisers in your area by communicating with them about their event and providing resources, attending events if possible to support and encourage participants, identifying events for fundraisers to take part in and reporting back to the fundraising co-ordinator and fundraising committee. The role is voluntary, with no set amount of hours per day/week/month, the time you spend as an organizer will depend on how many fundraisers and events there are in your area.

If you are interested in becoming a volunteer regional fundraising organizer please email **info@mpnvoice.org.uk** to request a role specification and application form.

Corporate, Grant and Charitable Funding

We are also looking for someone to source and apply for corporate, grant and charitable funding for MPN Voice. If you have experience of applying for funding and grants and would like to take on this voluntary role for MPN Voice please email **info@mpnvoice.org.uk** to request an application form.

Communications support

MPN Voice produces a number of publications, including this newsletter which are aimed at keeping MPN patients and their families up to date on what is happening in the world of MPN treatment and research. If you would like to be involved and have time to volunteer to help with our communications we would love to hear from you if you can write, proof read, or edit. Contact **editor@mpnvoice.org.uk**

FUNDRAISING UPDATE

Throughout 2016 and this year we've seen an amazing range of fundraising events. It's wonderful to hear about the variety of ways that MPN Voice supporters have raised money to support us. So many people have taken part in activities including cycle rides, walks, marathons, 10K runs, abseiling, craft fairs, evenings with bands, hosting lunches, open gardens, themed parties, 3 Peaks challenge, special forces challenge – the list is endless and MPN Voice would like to say thank you to all of you who have organized and/or taken part in an event.

If you are taking part in, or organizing a fundraising event, whatever it is, we would love to hear about it, so do tell us about it by emailing **fundraising@mpnvoice.org.uk**

Fundraising heroes

Virgin Money London Marathon Sunday 24 April 2016 a total of £6,920.53 was raised

They did it! After many hours of pounding the pavements to get fit and ready, **Helen Bass**, **Samuel Beevor** and **Trevor Buckley** all completed the London Marathon, thank you and well done to you all and thank you to everyone who sponsored you.

Abseil St Thomas' Hospital Friday 13 May 2016 raised over £25,000

Well Friday the 13th was certainly not unlucky for the MPN Voice abseilers and didn't stop this amazing team taking part and having a lot of fun, raising over £25,000 between them! Half of the abseilers have been diagnosed with MPN, and the other half were family and friends. We would like to say a massive thank you to: **Camilla Baker**, **Portia Baker**, **Lara Budgen**, **Christine Ray**, **Fiona McBain**, **Sian Miles**, **Ruth Barnett**, **Helen Scott**, **Simon** (aka Spiderman!) and **Charlotte Fox** and 'Team Altro' – **David Brailsford**, **Laura Brewer**, **Rebecca Dermott**, **Ros Austin**, **Ed and Sarah De los Rios**, **Domingo Lopez-Dean**, **Valerie Brinson**, **Kathryn and Levi Nicholson-Brown**. Have a look at the video of the abseil: **http://www.mpnvoice.org.uk/about-us/videos/abseil-2016**


Camilla, Laura and Portia getting ready

South West Coast Path Challenge 17 May – 16 July 2016 raised £1,789.50

On 17th May 2016 **Elise Walsh and her dog Fergus** set off on the 630 mile South West Coast Path, taking 10 weeks to complete the challenge she had set herself. Elise has ET and wanted to raise funds for MPN Voice to support funding for research for MPNs. Elise raised an amazing £1,789.50, which includes £447.75 collected in an MPN Voice collection pot which she tied to her rucksack! Well done and thank you to you and Fergus.


Elise Walsh with Fergus

Saigon to Angkor-Wat Cycle Ride November 2016 raised £4,668.71

On 10th November 2016 **Sammy-Jo Nelder** set off on her bike to complete the 280 mile Saigon to Angkor-Wat cycle ride in memory of her dad, David, who had PV, and sadly passed away shortly before she began her ride. Sammy-Jo wanted to raise money as well as awareness of MPNs. She hopes that with the money raised, MPN Voice can continue to fund vital research. A massive thank you to you Sammy-Jo; your dad would be so proud.

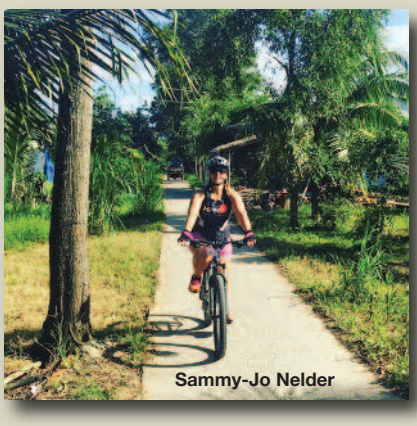
Craft Fairs in Bristol November 2016 raised £3,419.89

Adrienne Knight has a craft sale every year, making all the items she sells. In November 2016 she had a stall at two craft fairs in Bristol and donated all the money she raised to MPN Voice as her husband, Jeremy has MF. Adrienne was very ably helped to run the stalls by Jeremy and her friends Jacky, Mary and Felicia. Thank you so much Adrienne for all your handiwork which looks absolutely amazing.


Adrienne Knight on her stall

The Adidas Silverstone Half Marathon March 2017 and The Vienna Marathon April 2017 raised £700

Rebecca Paling took part in both of these half marathons to raise money for MPN Voice as her friend Theresa has a MPN. She said she enjoyed both courses especially running across the River Danube to the strains of the Blue Danube Waltz.


Sammy-Jo Nelder

Fundraising heroes

Virgin Money London Marathon 2017: a total of £10,320.72 was raised by our runners

MPN Voice was represented by **Thomas Caron**, **Catriona Coulthurst** and **James White**. Everyone achieved very good times and all thoroughly enjoyed the marathon and the atmosphere. Thomas even got a 'high five' at the finish line from the Duke and Duchess of Cambridge!

Abseil St Thomas' Hospital May 2017 raised a total of £9,212

The MPN Voice 2017 abseilers were: **Suzanne Canavan**, **Colin Aitkenhead**, **Louise Broughton** and her daughters **Rosie** and **Claire**. They said they all thoroughly enjoyed the abseil and the views. Thank you all so much.

Louise Broughton (centre) with daughters Rosie and Claire

Suzanne Canavan and Colin Aitkenhead

The Marie Curie Etape Caledonia 2017 Cycle Challenge 2017 raised over £6,000

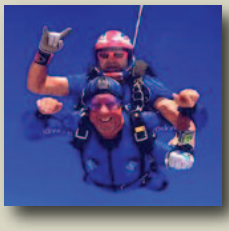
Tricia Marshall participated in the Etape Caledonia, an annual challenge attracting 5,000 riders. It is claimed by former Olympian Chris Boardman, who also takes part, to be the UK's 'most sportive cycling event' – a gruelling cycle ride of 81 miles with 4,000 feet of ascent.

Tricia said "Despite all the training, I still found the course very tough – especially as it rained for the last two hours of the six-hour ride. However, the morale and financial support from family and friends was a huge motivation, and my husband Alan, who is a race veteran, stayed with me until we crossed the finishing line."

Tricia's sister, Sheena, was diagnosed three years ago with MF. Sheena has been active in raising money for the charity both personally and by inspiring friends and family to take on their own challenges and Catriona Coulthurst (see marathon report above), is the partner of Sheena's son, so well done and thank you to you all: what an amazing family!

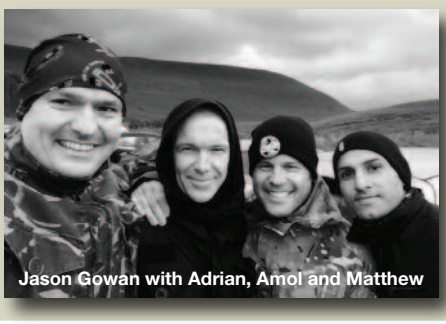
Skydive Sunday 18 June 2017

Ray Matthews did a very brave thing to support MPN Voice and his wife Annette who is due to have a bone marrow transplant this year. He took part in the skydive in Salisbury, strapped to a professional and skydived 10,000 ft. So far Ray has raised £2,141.



The Fan Dance Challenge Saturday 1 July 2017 and July 2016

In July 2016 **Jason Gowan** took part in the Fan Dance Challenge with his friends Adrian, Amol and Matthew and raised over £600 for MPN Voice, and has just done it again this year! The Fan Dance Challenge is a 24 km non-navigational race in the Brecon Beacons. The route is used by the SAS and the SBS as part of their selection course! Jason says "I carry over 40 lbs in my backpack, the route is a real lung buster, with steady slopes, shocking inclines that have you almost on your hands and knees and tracks through forested areas. Getting to the end of the route is an accomplishment and something to be proud of." Well we totally agree, you should be extremely proud, and doing it twice is amazing!



Jason Gowan with Adrian, Amol and Matthew

We would also like to say a big thank you to the following wonderful fundraisers:

Sarah Tattersall for the skydive in Dubai in April 2016; her dad Andy has an MPN so Sarah wanted to show her support to him and others with MPNs. What an amazing place to float over!

Barbara Coryn, **Lucy Hawkin**, **Claire Hutchings**, **Angela Watson**, **Louise Simpson** and **Maria McMahon** who all took part in the London BUPA 10K in May 2016. Unfortunately Angela couldn't take part so her friend **Leanne Naylor** took her place. And Angela's dad, **David Potter**, did his bit for fundraising for MPN Voice by taking part in the 5 mile Hayling Billy race in June 2016.

Lesley and Rob Thompson and Lesley's sister for running the Great Manchester 10K, in May 2016. Lesley has MF and wanted to raise funds and awareness.

Chelsey Rydzinski for a sponsored silence in March 2017. Chelsey didn't utter one word for seven days, which as a self confessed loud chatty person was tough.

Joanne Bartles for running in the Liverpool Half Marathon in April 2017 in memory of her granddad John.

Andrea Headech for the Glow in the Park 5K event in April 2017, Andrea completed the 5K course dressed in her MPN Voice T-shirt, frilly skirt and neon face paint.

Freya French, her younger sister and step-dad who took in the Edinburgh Marathon Festival running 5K in May 2017.

Becky McDonald for taking part in The Cotswold 113 Middle Distance Triathlon in June 2017, Becky's dad was diagnosed with MF last year, so she did this for him.

David Smith for competing in the Windsor Triathlon in June 2017. His partner has ET and he wanted to raise money for MPN Voice to help us progress the search for a cure.

Eleanor Hutcheon who celebrates her 50th birthday this year and is marking the occasion by swimming 50 miles over the course of the year in various places.

And for those of you who have events coming up soon we would like to say good luck and thank you!

Forums

2017 has been the busiest year yet for MPN Voice patient forums. The very first MPN patient forum which took place in London in 2005 was attended by 12 patients and three specialist Doctors. This year a total of 9 regional forums, including our first one in Birmingham have taken place attended by almost 700 patients and family members.

Forums are a way to keep MPN patients and families up to date with the latest on MPNs, treatment and research as well as to meet others living with MPNs. A combination of talks by MPN medical specialists, patients and break-out groups for patients to share experiences and support each other, these are a popular element of how MPN Voice supports the MPN community.

The forums would not have been possible without the local teams of Doctors and Nurses who have been involved and it's always really encouraging to find out how far people will travel to get to a forum. At Inverness some patients and their families travelled from the Scottish Islands and in Belfast several came from South of the border as far away as Limerick.

Here's a selection of comments from people who have recently attended MPN Voice forums:

'I was able to ask my questions and concerns and my worries have been relieved.'
'Very professional all round – sympathetic approach, informative, practical, well led and organized.'
'The sessions were just right, enough information, but not too complex. Helpful and informative.'
'It was great to talk to other patients.'
'Very valuable forum. There is clearly a need for wider dissemination of info in MPN among some medics as well as patients and carers. More power to your efforts!'

A really big thank you all the medical professionals who have given their time to be involved in the forums this year and a special thanks to Maz and Nona who have travelled far and wide to represent MPN Voice.

Keep an eye out for the 2018 MPN Voice forum locations and dates which will be confirmed soon.

Visit our **News and Events blog**: www.mpnvoice.org.uk/news-events or visit our Facebook and Twitter pages

MPN Advocates Network – update

patient power

Jon Mathias, chair of MPN Voice shares an update on the latest activities


Jon Mathias

Over the past couple of years, MPN Voice has been involved in an initiative to collaborate with MPN patient organisations in other countries.

Initially, we had a few phone calls with people from similar groups to MPN Voice in the Netherlands and Spain. It took a while to get properly organised but about 18 months ago, we created a new organisation called MPN Advocates Network. From a legal point of view, this is part of a larger group called the Leukaemia Patient Advocates Foundation, a charitable organisation based in Switzerland. This is important because it enables the new group to obtain independent funding from sponsors and does not rely on financial support from member organisations like MPN Voice.

The mission of the international network is to build collaboration between MPN Patient groups internationally. MPNs themselves do not recognise national boundaries so we patients also need a voice that speaks for us all, wherever we happen to live. Together, we can have a louder voice when it comes to dealing with governments and the pharmaceutical industry.

Our first goal is to expand the network so that we can truly represent MPN patients around the world. From our first phone calls with a few people in Europe, we now have over 15 members from literally all over the world. At our first international conference last year, we had delegates from patient organisations in Australia, Brazil, Japan, the USA and, of course many European countries. We will continue to expand and a 'sister' organisation, one that supports patients with Chronic Myeloid Leukaemia (CML) has well over 100 members (so we still have a long way to go!).

One of the first projects we are planning to undertake is to conduct a global survey of MPN patients' needs. We are hoping to be able to show how different patient experiences are, depending on where they come from, and to be able to highlight issues like access to treatment, participation in trials and the availability of MPN specialist doctors. It is our hope that the national organisations will be able to use the information we gather to put the case for their patients in their own countries. The work on this survey has just got started and we hope to be able to tell you more about it before long.

The other benefit we are seeing already is the value of sharing ideas and practices between patient support groups, whether they are ideas for fundraising, how to operate a buddy system or set up social media channels.

MPDlife

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

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


Alisia O'Sullivan

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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 or visit their website for more information: www.gsttcharity.org.uk