MPDlife

The newsletter for people with MPNs
May 2016

Successful review by NICE for use of ruxolitinib in Myelofibrosis (MF)

We reported via the MPN Voice website in March that we were delighted to share a very positive outcome from the NICE review of ruxolitinib.

Readers may recall that back in February 2013, in an initial review of ruxolitinib, The National Institute for Health and Care Excellence, NICE, had ruled that it would not recommend ruxolitinib (Jakavi, Novartis), for the treatment of disease-related splenomegaly (enlarged spleen) or symptoms in adults with primary MF, or MF secondary to polycythaemia vera (PV) or essential thrombocythaemia (ET). This decision was based on uncertainties in the data used by the manufacturer to estimate the degree of survival benefit as well as the conclusion by the Committee that ruxolitinib was clinically effective but could not be considered a cost-effective use of NHS resources compared with best available therapy for treating disease-related splenomegaly or symptoms in adults with MF.

Since that time, further clinical evidence to back up the effectiveness of this drug for MF and ongoing discussions between clinicians and NICE, and MPN Voice advocacy initiatives to ensure NICE listen to the patients' voice, have led to a more favourable outcome.

What has NICE said?

Ruxolitinib (Jakavi) is now recommended as a possible treatment for treating disease-related splenomegaly or symptoms in adults with primary myelofibrosis (also known as chronic idiopathic myelofibrosis), post polycythaemia vera myelofibrosis or post essential thrombocythaemia myelofibrosis only if they have intermediate-2 high risk disease.

What does this mean for patients?

- If you have an enlarged spleen or symptoms caused by one of these types of MF, and your doctor thinks that ruxolitinib is the right treatment due to stage of disease, blood counts and other factors, you should be able to have the treatment on the NHS.
- Ruxolitinib should be available on the NHS within 3 months of the guidance being issued which was published on 23 March 2016. If you are not eligible for treatment you should be able to continue taking ruxolitinib until you and your doctor decide it is the right time to stop.

MPN Voice would like to extend particular thanks to everyone who responded to information requests, our patient attendees, patient advocacy teams and clinical experts.

For full guidance notes you can visit the NICE website **www.nice.org.uk/guidance/ta386/ifp/chapter/what-has-nice-said**

Advocacy: MPN Horizons

Jon Mathias, chair of MPN Voice steering committee, updates on plans and successes.

We have previously reported about our growing involvement and commitment to being an influential voice on behalf of MPN patients. The past six months have seen some major steps for international MPN Patient Advocacy. Thanks to support from fellow advocates in the CML (Chronic Myeloid Leukaemia) world, we held a successful meeting in London alongside our Living with MPNs day in November 2015, where I, Caroline Thomas and Professor Claire Harrison, represented UK patients.

At the meeting, advocates from the US, Germany, Italy, Holland, Switzerland and Israel committed to creating a major international conference later in 2016 to be titled "MPN Horizons". We plan to bring together patient advocates and representatives from around the world and the idea is that we will be able to share best practice between the more established organisations. Ultimately we want to help patients in less developed countries create support groups as we have done in the UK with MPN Voice. The steering committee of this new international network met again earlier this month to begin the detailed planning of the event.

Jon Mathias and Caroline Thomas – winning battles on behalf of MPN patients

It is clear from our discussions so far, that MPN patients face similar challenges wherever they live in the world and have similar concerns regarding access to expert advice and emerging therapies. We hope that through collaboration with our overseas colleagues, we will give MPN patients a more powerful voice and serve their needs more effectively.

MPN voice

GUY'S & ST THOMAS' CHARITY

Charity number 1160316-15

MPN in young patients

patient story

Myleproliferative neoplasms (MPNs) are usually associated with older patients, but here we share patient stories from two younger people

Diagnosed as a teenager

Claire, a mum in her 30s was diagnosed as a teenager and shares:

'I was 17 when I was diagnosed. I was continually tired and after complaining a lot to my mum, she took me to see the GP. At first they thought that I may be depressed but after a follow-up appointment and insisting that I didn't think I was depressed they agreed to run blood tests to check my full blood counts and thyroid function. That night I was phoned to tell me to get to hospital as my platelet count was over 2000! After A LOT of tests, I was finally diagnosed with essential thrombocythaemia (ET).'


Claire

Claire continues 'I had a very mixed reaction; it took me a long time to get my head around what it all meant and I had lots of questions. I spent a week in hospital whilst they got my platelet level down and during that time, I don't really remember reacting much about it. It was later on down the line as I started to learn more and realised that I would have it for the rest of my life that I'd sometimes get upset or feel frustrated and it seemed people didn't understand, because to them they couldn't see anything wrong with me.'

When asked how her parents handled the diagnosis, Claire says; 'my parents, to me, were brilliant; if they had a big reaction, they certainly kept it from me! I used to get embarrassed at my haematology appointments because of the amount of questions my mum used to ask! I realise now that was just their way of being supportive and trying to understand. Even now, as a woman in her 30s with my own family, I still have to text my parents after haematology appointments with my latest count so they are still involved!'

Ongoing treatment

'At diagnosis I was put onto Hydroxycarbamide for around 18 months. Anagrelide was licensed after my diagnosis, so wasn't an available treatment at first but when it became available I was moved onto that for around a year and my platelets remained stable around 350–400. However, I started to get problems with circulation so was taken off that and fortunately my platelets remained at the same levels and have done ever since, so I am now just on low dose aspirin and am seen every 6 months in clinic.'

Challenges of being a young person with an MPN

Claire shares; 'that to everyone around you, you look 'normal' so I found it very difficult to talk to my friends about it and when I did they were quite dismissive. You want to be out all the time and doing what your friends are doing and I personally continued to do that, but I know from speaking to others who have more severe symptoms than I did, that this can be difficult and something that your peers don't understand.

I would also say that another big challenge is when you start to form long-term relationships as you get older, make sure your partner understands your condition and the effects it can have on yours and their life. When I met my now husband, I was in my early twenties, and when we became more serious, I took him to a forum and asked him to read various things so he could understand more.'

Claire's advice to parents of a child diagnosed with an MPN is; 'talk to them! Ask them how they feel about it and be supportive. Read all you can and appreciate that they may not want to know everything about it right then and there, and that however they react or feel about it, it's ok. Everyone reacts in different ways, including parents, so it's so important to keep talking to each other.'

Diagnosed at four years old

Jen, mother of Grace, soon to be nine, shares some of her MPN journey as a parent of a very young child.

'Grace was diagnosed with ET at four years old after a neurologist initially diagnosed her with migraine. As her mother I wasn't happy with the diagnosis as no tests were done and my GP suggested we investigate further starting with a blood test which picked up that her platelets were high. A follow up blood test three months later showed that the platelets were still high and at that point my GP referred us to a haematologist at a Dublin Children's Hospital. The tests showed Grace was Jak2 positive and a bone marrow biopsy led to a diagnosis of ET. Grace's haematologist also got her heel prick/Guthrie card from birth and had it tested and this showed that Grace was Jak2 positive at birth, which means she was in utero.'


Grace

How did you react as parents?

Jen recalls; 'Initially we did not understand much about ET and coming home to 'investigate' online did not help. The first word you see is the one word no parent wants associated with their child – 'CANCER'. The first few months were a blur after diagnosis. We tried to get as much information as possible. It was devastating and took a full two years to even accept her diagnosis.

For Grace it was a lot easier, she just accepted she has ET, 'busy blood' is how we explained it to her. Now she's a little older she understands she has too many platelets in her blood and that's what can cause her headaches.'

Challenges of having a young child with an MPN

Jen continues; 'Grace is currently on no treatment, not even aspirin and her platelets remain stable at 700–800. However there is a lack of information and we have no one to compare Grace to; all the information regarding MPNs online is in relation to adults with the

disease. We have no idea how her life is going to pan out with ET. Sometimes it feels we are looking at her just waiting on something to 'go wrong' and this is something we still struggle with and find frustrating. Even health care professionals can't help us as ET is so rare in children so we have no one to answer our questions.

Secondly, we are always second guessing. Children pick up everything in school and even the common cold can push platelets up. Grace still suffers with headaches, sometimes she gets pains in her legs and sometimes her energy levels aren't great. As parents we are constantly worried there is something ET related going on.'

Asked what advice Jen would give to other parents of a child who is diagnosed with MPN Jen says; 'Don't believe everything online as the information is not related to childhood ET. It is normally talking about adults 50 plus.' She continues; 'it takes almost two years to come to terms with the diagnosis and each individual MPN case is different; what applies to one patient does not apply to another. When I look at Grace now, she's been living with ET for almost nine years and she's doing okay with no disease progression.' Finally Jen advises; 'as a parent you are your child's representative/their voice. Ask questions, follow your instinct and educate yourself.'

Professor Claire Harrison comments

One of the commonest reasons for a conversation between specialists is to discuss the management of difficult or challenging patients. I think few patients realize that their doctors often seek informal or formal opinions all the time from their colleagues in either the same or a different speciality. In the MPN field a common scenario for discussion is the young patient and I am so pleased to see that some of this newsletter is dedicated to this. Of course ones definition of a "young" patient will change relative to ones own age, but there is no getting away from the fact that MPN can occur in the very very young; (two years old is the youngest I have seen). As the patients and families featured in this edition reflect, this can be extremely challenging for the young person as well as their family.

Editor's note: Information for MPNs in children is scare, however we are looking to include more on this area of living with MPNs on our website, so please do contact us if you are or know a young person who has been diagnosed with MPN – **info@mpnvoice.org.uk**

Celebrating 10 years of buddying!

MPN Voice offers many types of support to patients and families affected by MPN, one of which is the buddy system, originally driven by the vision, "No one should ever feel alone" of a group of MPN patients including Ann Marie Jahn, Marjorie Leonidas, Jon Mathias, Tim Ellis, Tamara Kosta and Nona Baker. It is now expertly administered by Maz Campbell-Drew.

Tamara recalls; 'I felt very strongly that a newly diagnosed person should not feel alone, as I did aged 26. The feeling of being 'like a rabbit caught in headlights' is something that seemed to resonate with a lot of newly diagnosed patients and the idea was that you could share your feelings with someone who had already been through the initial fear and who could also share information with you about the condition. More knowledge means more power, which in turn alleviates so many fears we have all had and still have. It was particularly important to have more knowledge about the condition in the early days, as often some haematologists and GPs did not have many answers.'

Nona adds how important it was that the buddy support was developed with the professional input of a specialist clinical psychologist at Guy's and St Thomas', Nicky Thomas, and that is still the case today, with ongoing support from clinical health psychologists. The main objective was and continues to be, to provide MPN patients a friendly, non judgmental and 'non medical' ear to share concerns and to bounce questions off, for a rare condition that at that time had little information available to help understand outcomes and treatment options.

Since then the MPN Voice buddy system has helped buddy over 200 people affected by MPNs, not only patients, but the family members and friends involved in caring or supporting patients. Buddies come from all types of backgrounds but all have had the experience of living with MPN, so that they can offer support from a position of real knowledge, emotional stability and have their own MPN under control.

Nona stresses that MPN buddies are not counsellors or medical experts but rather a person who can listen and support the person who needs a buddy, especially as some MPN patients find it difficult to share their real concerns with close family and friends.

Buddies support each other by phone, email or face to face, whatever is appropriate and over the years MPN Voice has matched up MPN buddies all over the world, not just in the United Kingdom.

Maz Campbell-Drew
Buddy Administrator, MPN Voice

Two current buddies share their involvement as MPN Voice buddies...

Chris Harper

Chris, aged 63, had a stem cell transplant (SCT) five years ago after being diagnosed with myelofibrosis (MF) in 2010. He started being a buddy six months post transplant when someone who needed to have a transplant but was unsure, wanted someone to talk to. Chris says he agreed to help 'in a heartbeat'.

He continues; 'I do it because I have always enjoyed helping others and I know how it is to tackle this alone as I had no one to help me other than my wife when I was diagnosed. The best thing is helping people to understand more about their condition and dispel some of the fears that are generated by reading misinformation on the Internet or from Joe down the pub, and showing that things might not be as bad as first thought.

One of the most challenging things is dealing with the raw emotions and fear that are generated by diagnosis and helping to move

this on to positive inquisitiveness and self advocacy. Sadly there will be successes and there will be losses. We all know that there are risks with SCT and I have lost some good friends. Having said that I have also lost MF-ers who chose not to go the SCT route. You have to be prepared to deal with both. Sometimes you may buddy a family member and not the actual patient as some prefer not to discuss their illness but still want the research done.'

You can help

Chris says; 'I'd encourage others who have a stable MPN and have learned to deal with their condition well, to consider becoming a buddy because you have a great deal of first hand knowledge to pass on that is not coming from a book but from experience. It is rewarding to help someone as you may well have been helped by others.

And for those who think a buddy might help them in their MPN journey I'd say you should try it. I have buddies who come to find information and then do their own thing and I have buddies who are still in touch/friends four years later.'

Ange Watson

Ange was diagnosed with polycythaemia vera (PV)(JAK2+) nine years ago, aged 40 after many years of feeling unwell. She says that; 'It wasn't a shock, but an enormous sense of relief knowing I wasn't a hypochondriac! At that time, there was so little information available, so peer support and MPN Voice was my only means of comfort and reassurance. I soon learnt to deal with my condition and what the future meant for me. My levels remain good, with venesection every six weeks and hydroxycarbimide treatment.'

Becoming a buddy

'When I was diagnosed, Nona, my buddy, was an amazing inspiration. She listened to me, reasoned with me and gave me an enormous amount of emotional support. I felt being a buddy was the least I could do for others, so I signed up!'

Support from MPN Voice

'Once I enrolled, the advice and guidance from MPN Voice focuses on giving emotional support. We are not trained counsellors or medical professionals, but fellow patients. It was important to learn how to listen, which is often all people need.'

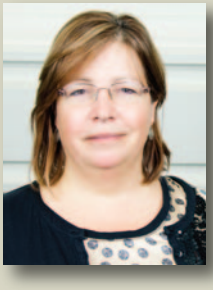
What things do you enjoy about being a buddy?

'Speaking to patients who are initially distraught is heart wrenching. But soon after peer support, the transformation becomes apparent. It's a great feeling hearing those individuals become increasingly confident and less anxious with their condition. I hope I have managed to reassure others to remain positive.'

If you think you could be a buddy to someone who needs encouragement and will benefit from your MPN journey, please do contact Maz who can give you more advice on what is required. We particularly need a few more buddies with experience of MF – **buddies@mpnvoice.org.uk**

Latest updates

Professor Claire Harrison writes:



Drugs and trials

As reported on page 1, it is so encouraging that the NICE appraisal of ruxolitinib (or JAKAVI) has led to the approval of this drug for patients with intermediate and high risk myelofibrosis (MF) in England. This time there was much more data available for assessment including analysis from our European wide study COMFORT-2 showing a survival benefit with the drug for patients with intermediate-2 and high risk MF who were enrolled in that study when compared with standard therapies and also a study led by Adam Mead (who writes in this issue) and myself. We were very much supported by the MPN Voice team of patient advocates, Colin Clayton and Caroline Thomas who were armed with information gathered from surveys and personal quotes. These two did a fabulous job of making sure the patient perspective was well heard. This is tremendously important for patients not only in England but also elsewhere as many other health economies may well now follow in approving this drug – for example Wales and Ireland as well as countries much further afield. A huge thank you to our clinical experts and patient representatives.

On to other drugs news; Dr Adam Mead writes about drug safety and recent events with the JAK inhibitor pacritinib. This has been a very hard few months for the patients globally who either stopped taking this drug, or who suffered a side effect either due to the drug or indeed to stopping it. A tricky time too for their families. Quite what will happen with pacritinib is yet to be seen but it is very disappointing since the drug seemed effective and to help a population of patients who don't benefit well from ruxolitinib. I remain hopeful that the drug will complete evaluation and be made available.

Current other agents under investigation include Momelotinib for which the studies have recently closed and three other options are presently available for other patients with MF for whom conventional therapy does not seem to be working; these include Imetelstat the telomerase inhibitor, PRM-151 the pentraxin analogue and a three way combination study with ruxolitinib. At present the latter two are highly investigational and only open in our unit at Guy's and St Thomas' whereas the imetelstat study is open in many centres in the UK and globally.

For patients with PV it is difficult to get treatment with ruxolitinib although the MAJIC study is still open with about 25 slots still available until the beginning of July. Results are just being analysed for the ET patients in this study and hopefully we can share these with you soon.

We very much hope that the MOSAICC study, initially funded by MPN Voice, will be open soon. MPN Voice should be very proud of everything the team running the MOSAICC pilot have achieved.

Forums and fundraising

I was so very pleased to see the large number of patient forums and events happening under the MPN Voice umbrella over the past 18 months. Much gratitude to local health care teams and MPN patients, in particular, Maz and Nona, for supporting these.

And finally… I couldn't sign off this article without saying the most enormous THANK YOU to Marilyn who has been the most wonderful fundraising co-ordinator for MPN Voice. It's great that she will still be part of the steering committee even though she will soon be hands on with her first grandchild. Marilyn – you inspired so much and gave us so much energy and time – thank you!

Drug Safety

How drug trials are designed with patient safety at their heart

Recent drugs trials, some of which involved MPN patients, have been put on hold. Adam Mead, Associate Professor of Haematology University of Oxford writes:

Dr Adam Mead

No medicine is 100% safe. Indeed, all medicines can cause side effects, and if you read the patient information leaflet (PIL) for many drugs, there is often an alarmingly long list of possible side effects.

Treatments for myeloproliferative neoplasms (MPNs) are no exception. This can be a particular issue when considering the possibility of taking part in a clinical trial of a new treatment, when side effects may not be fully understood, and a number of widely publicised safety concerns have recently emerged from clinical trials in MPNs. For patients this raises a number of important questions when faced with the possibility of starting a new treatment either as part of a clinical trial or not. How are the potential side effects of new treatments assessed? What are the important side effects of a drug to look out for? How do you know whether a new symptom might be related to a new treatment, or not?

In order to provide robust drug safety information for patients and doctors, side effect data is systematically collected during the clinical development of a new treatment.

Safety monitoring of medicines during clinical trials

Drug safety is rigorously assessed in a series of clinical trials before any new treatment becomes available. All phases (phase 1–4) of clinical trials collect drug safety information, and even after a drug is licensed, the process of collection of side effect data continues and the PIL is updated accordingly. When a patient on a clinical trial develops a new symptom or problem, we as investigators must assess the relationship of the 'adverse event' to the drug treatment and also the seriousness of the event. Often it can be quite difficult to distinguish between a side effect of a treatment and symptoms of the underlying condition, and careful assessment of the likely relationship to the study drug is based on timing, previous knowledge about the drug and details of the patient's underlying condition. This process of collecting safety information about a new treatment is known as 'pharmacovigilance' and occurs over many years with regular review of side effects that are reported by a "drug safety monitoring board". If evidence of a new toxicity of a drug emerges, investigators and patients are informed so that any necessary steps can promptly be taken.

Occasionally, serious side effects are observed during a clinical trial, necessitating in some cases a 'clinical hold' where patients may be asked to discontinue the treatment whilst more information is gathered about a new side effect. This may even result in permanent discontinuation of the clinical development of a drug. The unfortunate consequence is that even if patients are clearly benefitting from a treatment, they may have to discontinue the treatment if the trial is placed on clinical hold. A number of recent drug trials in myeloproliferative neoplasms have been placed on a clinical hold. For example, the development of the JAK2 inhibitor Fedratinib was discontinued in 2013 due to severe neurological toxicity encountered by a small number of patients receiving the drug. More recently the clinical trials of the JAK2 inhibitor pacritinib were placed on clinical hold whilst further information about safety is collected, although some patients may continue to receive the drug as part of a 'compassionate use programme'. The very nature of clinical trials investigating a new drug treatment means that emerging new safety concerns are not uncommon, and the robust systems for safety reporting ensure that patient safety remains paramount.

Interpreting side effect information

The PIL supplied with a routinely prescribed medicine (outside of a clinical trial) will list its known side effects based on the information gathered during clinical trial development of the drug, and subsequent safety reporting. If you no longer have your medicine's PIL, you can find a copy on the *electronic Medicines Compendium (eMC)*. Usually side effect information will be classified according to the frequency, type and severity of possible adverse effects of the treatment. Common side effects are those that occur in more than one in ten of patients receiving treatment. Rare side effects are defined as those occurring in less than one in a thousand patients receiving the treatment. The risk of developing side effects varies from person to person, and patient groups at particular risk are highlighted in the PIL as some drugs should only be used cautiously in certain circumstances. Sometimes a drug might interact with another medication to increase the risk of side effects, so it is important to discuss any other changes to your medications with your doctor or pharmacist.

What to do if you think you have developed a side effect to a new treatment

If you get any side effects that may be related to a new treatment, even if you are unsure, it is sensible to discuss this with your doctor or pharmacist. You can also report side effects of a medicine through the Yellow Card Scheme. This includes possible side effects that may not be listed in the product leaflet.

In essence, all treatment decisions made by patients and their doctors must balance the potential side effects of a treatment against the possible benefits. This decision can be particularly challenging when dealing with clinical trials, where the side effect profile and potential benefit of a new treatment may not be fully documented. Sometimes this decision is clear and in other cases more nuanced but in all cases informed discussion of risk-benefit is the key to making good treatment decisions.

2016 is definitely going to be an amazing year for MPN Voice Fundraising!

Marilyn Webster, fundraising co-ordinator writes

We've had so many MPN Voice supporters contact us, telling us about the fantastic events they are organising, including a fashion show, craft fair and comedy evening. We've also had a great response to the new events, some in association with Guy's and St Thomas' Charity, that are on the MPN Voice website events page. I can't wait to see our 20-strong MPN Voice Abseil Team, abseil down St Thomas' Hospital tower on 13 May!

We love to hear about what you are doing, no matter how small or large an event you are organising, or if you have got a place on one of the events in association with Guy's and St Thomas' Charity, please let us know by emailing **fundraising@mpnvoice.org.uk**

New challenges for Marilyn

I would like to take this opportunity to say a huge 'Thank You' to all the MPN Voice supporters who have helped MPN Voice raise an amazing amount of money over the last 3 years, to fund research and support for the MPN Voice Community. I have had a wonderful time being MPN Voice fundraising co-ordinator and have had the privilege to work with some amazing people. Due to a change in family circumstances, (I'm excited about becoming a Grandma for the first time and all that will entail), it's now time to hand over the role but I will still be continuing as a member of the steering committee and attending forums so you will still see me around.

Thank you so much for all your wonderful support and fundraising achievements.

Marilyn Webster

Dates for 2016...

- **13 May** Abseil Challenge, in Association with Guy's and St Thomas' Charity
- **30 May** BUPA London 10k
- **31 July** Ride London, in Association with Guy's and St Thomas' Charity
- **September** Blood Cancer Awareness Month
- **11 September** Great North Run
- **30 Sept–1 October** Guy's Urban Challenge, in Association with Guy's and St Thomas' Charity

... and 2017

- **March 2017** Adidas Silverstone Half Marathon, in Association with Guy's and St Thomas' Charity
- **April 2017** Virgin Money London Marathon, in Association with Guy's and St Thomas' Charity
- **May 2017** BUPA London 10k, in Association with Guy's and St Thomas' Charity

These events will be bookable shortly, via the Guy's and St Thomas' Charity Events website **http://www.supportgstt.org.uk/get-involved/events**
Please remember to state that you are fundraising for MPN Voice.

If anyone is interested in taking part in any of the events listed for 2016, please contact us at **fundraising@mpnvoice.org.uk**

Editor's note: On behalf of MPN Voice we would like to say a MASSIVE thank you to Marilyn for all the dedication, hard work and time she has invested as a volunteer, enabling supporters to raise much needed funds for MPN Voice. It's great she's not disappearing and please do take time to thank her personally for all she's achieved. If you or anyone you know would like to become involved as a volunteer fundraiser please contact us on **info@mpnvoice.org.uk**

Fundraising heroes

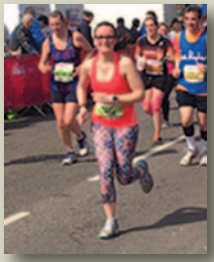
Jacqueline and John Graham Charity Fashion Show, 14 March – raised £1,400 for MPN Voice and a further £1,270 for the Herriot Hospice Homecare.
Jacqueline who was diagnosed with Myelofibrosis (MF) organised the fashion show, attended by over 145 ladies said 'when I've recovered I may do something else next year!'

Cara Martin and Iain MacLelland Inverness Half Marathon 13 March – raised £1,153
Cara, her family and friends have been raising money and awareness of MPNs for a number of years after her father was diagnosed with myelofibrosis (MF). She says 'I am very pleased that my friends and I took part in the Inverness half marathon and 5K fun run. My friend Gail and her six year old son Ryan took part in the fun run event that was held on the same day. We were all so proud when they crossed the finish line! We hope the money raised will go a long way to help research and perhaps even a cure for MPNs.

Henry Long **Surrey Half Marathon, 13 March – raised £1,203**
Henry knows a lot about MPN Voice. As the teenage son of Professor Claire Harrison he was trained from an early age, attending events and selling fundraising merchandise at the Living with MPN Patient days. He says to those who recently sponsored him 'thank you for all the support. Admittedly it was a bit tougher than I had thought (I did not train!), but your very kind donations spurred me on to a pleasing time of 1hour 44 minutes. I love being active and am glad I could turn this passion into a means of raising a great amount of money for a superb charity thanks to your generosity.'

Kirstie McClatchey **Mount Kilimanjaro, March 2016 – raised over £800**
Kirstie wanted to fundraise for MPN Voice as her father, Professor John McClatchey, who was diagnosed with polycythaemia vera (PV), sadly died last year of a heart attack. Kirstie says 'I managed to successfully reach the summit on the morning of the 31st March. It was absolutely incredible.' Kirstie is fundraising in memory of her father and to raise funds for research and awareness.

Jessica Hart
Reading Half Marathon, 3 April – raised £150
Jessica and her sister Janet's mum was diagnosed 18 months ago with MPN. Janet says, 'My sister did all the hard work, and I collected the money.' Sounds like great team work!



Forthcoming events

MPN Voice Marathon Runners
Virgin Money London Marathon, 24 April 2016
Thanks to all the hard work and training from the fantastic team of **Helen Bass, Samuel Beevor, Trevor Buckley** and **James White** over the past nine months or so. Unfortunately James has had to pull out on doctor's orders due to knee ligament damage, but we will be reporting how the other three got on in subsequent newsletters and on the website.

Sarah Tattersall **Skydive Dubai, 28 April**
Sarah's dad has an MPN and in his youth he participated in parachuting and skydiving. Sarah is skydiving over the Palm in Dubai to raise funds for MPN Voice. We look forward to seeing the pictures!

Elise Walsh **South West Coast Path Challenge, starting 7 May**
Elise plans to walk 630 miles with her dog, starting in Minehead, Somerset and finishing in Poole, Dorset from 7 May for 10 weeks.

Sandie Ostler **Great Manchester 10k, 22 May**
Sandie has never run before but was inspired to fundraise for MPN Voice after her aunt was diagnosed with MF.

Lesley Thompson **Great Manchester 10k, 22 May**
Lesley is full on fundraising this year for MPN Voice. Not only is she planning to run the 10K Great Manchester run, but she is also planning a fundraising comedy night on 19 November.

The Abseil Team **160ft down the Tower at St Thomas' Hospital, London, 13 May**
We are delighted that over 20 people will be taking part in this challenging event. Some of the line up includes: **Christine Ray, Fiona McBain, Simon and Charlotte Fox, Sian Miles, Ruth Barnett, Helen Scott, Camilla Baker, Lara Budgen and Portia Baker**. Please go along and cheer them if you are in the area and visit the MPN Voice website for further details of their individual Just Giving pages.

TEAM ALTRO – headed up by David Brailsford
David Brailsford has already amazed MPN Voice readers with his year in the saddle, cycling over 1,200 miles to fundraise in 2015. This year the fundraising is stepping up several gears ☺ and Team Altro, which includes **Laura Brewer, Rebecca Dermott, Ros Austin, Ed and Sarah De los Rios, Domingo Lopez-Dean, Valerie Brinson, Kathryn** and **Levi Nicholson-Brown** will be raising much welcome funds on behalf of MPN Voice in 2016 as part of the abseil challenge team!

London BUPA 10k, 30 May
We have several fundraisers taking part in this event including Barbara Coryn, Lucy Hawkin, Claire Hutchings, Angela Watson, Louise Simpson and Maria McMahon

We really are overwhelmed and grateful for all achievements and plans for fundraising on behalf of MPN Voice. Remember to send pictures and let us know how you have got on or if you are planning an event: **fundraising@mpnvoice.org.uk**

Patient forums – give them a go!

MPN Voice has been committed to supporting patients with regional forums and recently ran one in Belfast, Northern Ireland. Caroline Kerr, the Clinical Nurse Specialist (CNS) shares her experience of how the forum went

'From a CNS point of view it was amazing to see so many people engaging with the forum. There were a wide range of ages represented and many patients had brought family members which was lovely. It was a great opportunity for the CNS team to get the message out to patients that we are there to support them and their families throughout their illness too. We can answer any questions or queries that they may have about their treatment. Sometimes patients don't like to ask medical staff in case they look silly. Patients and relatives used the forum to ask these questions. It was amazing to see how many people had travelled from Southern Ireland for the forum. Maz, one of the representatives for MPN Voice is approachable and friendly at the desk which automatically puts people at ease.

The feedback from the presentations was fantastic. The medical staff tried to keep it as easy to listen to as possible and people who attended said that they managed it wonderfully! I watched the audience as the patients' stories were being told, and you could see the relief on people's faces when they realised they weren't the only ones who had these feelings. It was very moving. The breakout sessions gave everyone a chance to ask questions about their disease in a 'safe' environment. I helped facilitate the friends and family breakout session and it was a privilege to be able to give reassurance, support and advice to the people who felt they always had to be strong.'

Asked what Caroline would say to patients and family considering attending an MPN Voice forum she said; 'Give it a try. Many fed back to our forum that they were sceptical about attending, but were glad they did. Many patients may have not met their CNS for various reasons, and at the very least, it gives you an opportunity to do so. There is a wealth of information and support available to you through local centres, MPN Voice and other patients. Use it!'

Confirmed dates for other forums in 2016 are shown below and do look out on our website for additional forthcoming dates of regional forums.

Regional forums – forthcoming dates

- **Manchester** 25 June 2016
- **Bothwell, South Lanarkshire** 30 June 2016
- **London** – Summer date TBC

Continued thanks to the Samuel Sebba Charitable Trust for the funding to expand our range of regional forums.

If you think your hospital/clinic would be a suitable place to organize a regional forum please contact us on **info@mpnvoice.org.uk**

Website update

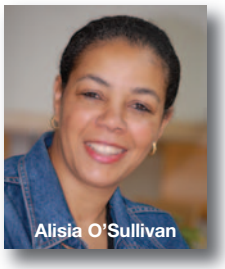
We are pleased to announce that our new website is finally up and running!

Thank you to everyone who fed back compliments, ideas for improvements and additions and helped to iron out the glitches. We are currently working through these and will incorporate them into future development plans. Please do continue to email your ideas though as MPN Voice is here to support you and the website is an integral part of that commitment. A big thank you to everyone who submitted stories, (we do welcome more), helped in proof reading and generally encouraged the development team through to the end of the update. And a final thanks to Matt Davis and Itineris, the web developers for their patience and advice and for the final results.

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.



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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.