

## Exciting and rapid change in MPN treatment options

Professor  
Claire Harrison  
comments on the  
pace of change  
in the world of  
health care  
professionals  
dedicated to  
helping patients  
with MPNs



The world for patients with MPNs changed significantly with the description of the JAK2 V617F mutation, dramatically improving the accuracy and speed of diagnosis as well as therapy, especially for patients with myelofibrosis (MF). Readers of this newsletter will have been following here and elsewhere the rapid development of Jakavi or Ruxolitinib as the first approved JAK inhibitor from its first use in 2007 to its license in 2012.

In the UK this drug was, and still is, available in clinical trials later becoming approved in some, though not all regional cancer drug funds. The current routes for accessing this drug, aside from in clinical trials, is via the national cancer drug fund exactly as for its licensed indication MF patients with symptoms or splenomegaly. However for patients in Scotland, Wales and Ireland the situation is not the same, since the new national cancer drug fund does not cover these regions and here access to drugs is more challenging. Earlier this year we were disappointed that NICE made a final recommendation that although this drug was clearly clinically effective, its cost effectiveness was not well enough demonstrated in the company submission. At this point I would like to pause and give my extra special thanks to patients Max and Colin who represented MPD Voice and so convincingly emphasized the

benefits of this drug to the NICE committee. Next year NICE have invited a resubmission and hopefully this, with newer published data will be successful. The situation for reimbursement of this drug is currently similar in many countries in Europe, Australia and Canada.



Re-submission to NICE  
planned for 2014

### New drug data

In June 2013 three-year trial data was evaluated at a large haematology meeting demonstrating a survival benefit for Ruxolitinib treated patients and on-going benefits in spleen and symptom response. An increase in risk of latent prior infections such as shingles, hepatitis and TB reactivating were also seen, but not at high levels. The UK guidelines for management of MF have been updated to recommend Ruxolitinib as first line therapy for patients with troublesome spleen and symptoms and to raise awareness of how best to monitor

and manage this drug. We also suggest the use of the myelofibrosis or myeloproliferative neoplasm symptom assessment form (MF or MPN SAF)\*\* in patients with symptoms.

ASH, the American Society of Haematology and the largest blood meeting in the world, will be held later this year. Here I know we will hear very positive data for Ruxolitinib but also the phase 3 trial results with Fedratinib (SAR302503) another highly effective drug, as well as news of other agents and advances in the science and biology of MPNs. We will bring you an update of this data early in 2014.

\*\*The MPN-SAF is available as a downloadable form on our website [www.mpdvoice.org.uk](http://www.mpdvoice.org.uk)

## What's in a name?

### All change for MPD Voice

MPD Voice will soon be known as MPN Voice. This is to bring the name of our charity in line with the WHO re-classification of MPDs as MPNS (Myeloproliferative Neoplasms). Apart from the acronym change we remain dedicated to providing support, information and investing in research to better the future of patients and families affected by MPNs.



Our website will soon be updated with the new name and some exciting new sections so do look out and give us any feedback on what else you would find useful for MPD Voice to include on our website.



Charity number  
251983

# Coping with hair loss

health update

Editor of *MPDlife*, Alisia O'Sullivan shares her experience of hair loss



**M**y personal experience of hair loss is that about three years into being treated for ET, and having been “successfully” taking Interferon Alpha to control my platelets, I noticed a thinning of my hair and then over a period of about a month more than usual loss when I washed or styled it. I was devastated and for a few days on realising this was a real problem, very upset. I had visions of having to wear a turban/hat or hairpiece for the rest of my life and with two young daughters was very challenged by the feelings I experienced. Would that embarrass them? How would my husband feel or react? It was very hard and I wasn't sure how to deal with the emotions. Having an MPN brings all sorts of challenges and I had so far dealt with them with by pressing into my faith and by prayer and the support of good Christian friends. This was a new thing to deal with and I did shed a few tears as yet another thing to do with my body seemed to be out of my control.

On the whole I felt I had managed to have an even approach to the many side effects of the condition, including the erratic fatigue and bone pain which are not visible, but this was an outward manifestation of being affected by MPN and not that welcome. The best help was a neighbour's suggestion to speak with the Macmillan nurses. They were great in suggesting practical solutions and remedies to help. For example my usual style was in an 'up-style' using elastics and until that time I had regularly coloured my hair, both of which I changed. Since then I have not used a chemical hair colour and sparingly resort to the old 'up-style'. I also took their advice that shorter hair gave

an illusion of fuller hair – a seeming paradox but surprisingly it worked as I bravely cut my already thinned hair into a shorter style. I was also careful to use gentle hair cleansing products and for a while took a supplement for hair, nails and bones. Over a period of 18 months I was relieved that the loss lessened and, although having afro-caribbean hair means that my hair grows slowly to any length, it did regain its thickness.



Try to minimise use of heated hairstyling products

For those facing this particular challenge I would definitely recommend contacting the Macmillan Cancer Support Line on 0808 808 0000, visiting their website [www.macmillan.org.uk](http://www.macmillan.org.uk) or getting hold of their booklet, *Coping with Hair Loss* from [www.be.macmillan.org.uk](http://www.be.macmillan.org.uk)



Some people find it easier to talk to someone they don't know about hair loss. Talking to a support specialist may help or maybe your GP can offer information about counselling in your area.

An online community may be helpful. [Macmillan.org.uk/community](http://Macmillan.org.uk/community) offers the opportunity to chat with others who have hair loss and our own patient forum MPD Voice Health Unlocked puts patients in touch with others facing similar challenges. Dealing with hair loss or changes is a topic that has been raised on recent occasions.

Using a wide-toothed comb is more gentle and has less of a pulling effect on the hair.



## Looking after your hair

Here are a few practical tips reproduced with kind permission from Macmillan's booklet.

If your hair is brittle or dry due to medication/hormone changes:

- Only use gently hair products and non-medicated shampoo.
- Brush or comb your hair gently using a brush with wide prongs or a wide-toothed comb.
- At night, wear a soft cap or turban around your head to stop your hair becoming tangled. Women may find it easier to wear a hairnet.
- Avoid using excessive heat from hairdryers, straighteners or heated rollers as this may cause further hair drying/damage.
- Avoid wearing hair in a tight band and if plaited, plait gently.
- Avoid perms/hair colours.
- Avoid massaging the head as it's unlikely to stimulate new hair growth and could wear away any fine, new hairs.

## Other useful organisations

- **Institute of Trichologists –**  
[www.trichologists.org.uk](http://www.trichologists.org.uk)

The foremost professional association for trichologists (hair health specialists) in the world. Gives information about hair health and hair loss.

- **My New Hair – Trevor Sorbie**  
[www.mynewhair.org](http://www.mynewhair.org)

A charity with a network of salons that provide a wig styling service for people with cancer and medical hair loss. The site lists recommended salons that offer advice and styling and also has information about hair loss and wigs. Consultations are free and some salons offer their services free.

- **Look Good...Feel Better**  
[www.lookgoodfeelbetter.co.uk](http://www.lookgoodfeelbetter.co.uk)
- **Hairdressing and Beauty Suppliers Association**  
[www.hbsa.uk.com](http://www.hbsa.uk.com)

# International buddies – ‘a win-win’ solution

patient  
story

**Although thousands of miles away in Hong Kong, MPD Voice enabled 3 patients with PV to ‘buddy-up’, providing vital support and encouragement to each other.**

## Anna’s story

Anna, a Caucasian Australian who has lived in Hong Kong for most of her life was diagnosed with PV 5 years ago after tests to discover why she was feeling ‘out of sort’ with symptoms that included severe itching, migraine-strength headaches and heavy fatigue. Results showed an elevated red blood count and a raft of further tests including a bone marrow biopsy confirmed the JAK2 mutation and diagnosis of PV.

Based in Hong Kong, Anna describes the medical care she received as, ‘Excellent. I’ve always felt totally confident and happy with the care I received from the oncologist and my treatment was recently fully endorsed by a top haematological-oncologist professor in Australia.’ She added that she valued family and friends’ support and understanding along with information and friendship from MPD Voice which she discovered whilst searching on the internet.

Anna still deals with symptoms such as frequent severe itching and infrequent headaches but feels that in the scheme of things, these are very small issues. Since diagnosis her PV has been managed and stable and, along with regular phlebotomies her lifestyle, diet and daily exercise have ensured that she has continued to live a very active, healthy, fulfilling and positive life.

Several years ago she became buddies with Alison and Maureen who also live in Hong Kong and have been diagnosed with PV. Anna is enthusiastic about the benefits of having and being a buddy in a community where PV is even more rare than in the UK or the US. She says, ‘It has been wonderful to meet two lovely ladies who (unfortunately) share the same diagnosis, issues and concerns. We have all benefited greatly from meeting each other and sharing our stories, offering support and friendship. As much as family and friends have given loving support, meeting someone with the same rare incurable disease has been a very positive and beneficial experience. I’ve also been in touch via email with MPN buddies in England and France which has encouraged us to be positive. I truly treasure these friendships and exchanges and am so very thankful for MPD Voice for helping us get in touch.’

Anna’s final words to anyone who may be considering becoming a buddy or contacting a buddy are, ‘Don’t “maybe consider” it ... don’t delay ... do it immediately! It’s a win-win situation on both sides. Be a buddy, or have a buddy – today!’.

## Alison’s story

Alison was diagnosed in 2010 after investigations into an ‘over red complexion’. Various tests confirmed a diagnosis of PV. At the same time Alison was in a lot of pain following gynaecology surgery and a diagnosis of PV hit her hard.

She recalls being fearful while the treatment options were explored and how it would affect her life, suffering regular panic attacks while trying to recover from the surgery. It was a tough time and the emotional turmoil seemed to make the physical pain even worse. She recalls, ‘I could see no end to the state I was in, both physically and emotionally. I couldn’t determine what was the PV and what was reasonable to expect as I recovered from surgery. I went from being a capable calm teacher to being on the verge of severe depression. This was the state I was in when I met Anna my PV buddy.’

The healthcare system in Hong Kong is excellent and you can see a doctor or specialist very quickly, however the haematologist I saw refused to do venesection and had few PV patients. He put me on drugs which made me feel terrible so I stopped taking them and seeing him and sought information on the internet which is how I found MPD Voice.’ Alison read the website from start to finish and then contacted Maz who put her in touch with Anna.

Alison describes Anna ‘as a breath of fresh air and a lifeline. She had walked the PV route and the first thing she said was “I am well, you will be once the blood levels are lowered and you have got over the abdominal surgery pain”. I clung onto her every word and she helped me to cope again. She was so strong when I was weak and I felt supported. Anna told me she was receiving venesection only and it was working for her so I decided to find another doctor who would offer more than drugs to treat PV.’



Alison

I found another haematologist who offered venesection and now see him every 3 months. After a few months and a few venesections I started to feel better. Now I am very well and very fortunate to be asymptomatic.

The buddy system works well for us and I would encourage anyone to have a buddy. You can ask all the questions you need from someone who has been in the same situation’.

## MPD Voice buddy system

The buddy system was originally set up in 2003 by Nona Baker and Tamara Kosta with advice and input from the clinical psychology team at Guy’s and St Thomas’ and the other founding members of the charity. There are currently 42 buddies registered.

Marion Campbell-

Drew aka Maz has been a buddy for 3 years and is the MPD Voice administrator for buddies. Nona and Tamara still help her run the scheme.

Diagnosed with ET over 10 years ago, Maz says, ‘I think back to when I was first diagnosed and didn’t know much about MPD/Ns. If I had been able to speak to someone who could understand what I was going through it would have made such a huge difference to me at the time.’

To be a buddy you will need to want to help other people and be able to listen and give help, advice and support. Having the same MPN and to be taking the same medication as the person you are buddying does mean you can give help from the perspective of someone who really does understand what it feels like to live with a MPN. This is a very important factor as we all have medical help and advice from our haematology departments and GPs but if you don’t have a MPN then you don’t really understand how it feels when someone describes being fatigued, dizzy, itchy etc. You need to be able to listen, to encourage the person to find ways to cope, be understanding and non-judgemental, and always always remember that being a buddy does not mean you are a counsellor, you are a “mentor”.’

We always need more buddies so please do get in touch for more details – [info@mpdvoice.org.uk](mailto:info@mpdvoice.org.uk)



Maz Campbell-Drew



## Need a buddy or think you could be a buddy?

MPD Voice's Peer Support Programme offers individual support to all people with MPNs and to their partners and families. The goal of the programme's mission is to help patients cope with the common and emotional side-effects of an MPN diagnosis. These include feelings of fear, confusion, isolation or any difficult emotion related to having a chronic illness like an MPN.

## Need support?

Often the best person to speak to is not a relative, partner or friend but instead to someone who also has an MPN, a "buddy" or peer group supporter. A buddy can give support either via email or phone during what can be a difficult time. They will empathise and answer questions you might have about everything that comes with having an MPN, as they themselves have already experienced it. The relationship helps both the person offering support and the recipient.

## Want to become a buddy to someone else?

If you would like to offer support to a newly-diagnosed person, you do not need any particular skills to become a buddy. However you must have had your MPN diagnosis for at least two years. If you would like to have a buddy or indeed be a buddy yourself, then please contact us.

To register as a buddy or to request a buddy, please email [buddies@mpdvoice.org.uk](mailto:buddies@mpdvoice.org.uk)

## International buddies

MPD Voice has been contacted by an MPN patient in Switzerland who would like to contact other patients in Europe who may be interested in setting up a support group.

Anyone else in Hong Kong who would like to be put in contact with Anna, Alison or Maureen or find out more about the European needs for buddies and support please email Maz on [info@mpdvoice.org.uk](mailto:info@mpdvoice.org.uk)

# Current trials

## Professor Claire Harrison updates on the many latest drugs trials

**MOSAICC** an epidemiology pilot study for MPNs is now open in Southampton and Belfast. If successful this will lead to a bigger study (see inset).

**MEASURE** another study supported by MPD Voice will assess quality of life in MPN and is planned to open later in 2013.

## Trials for ET and PV patients

MPD RC112 is the only trial ever to compare hydroxycarbamide (HC) with interferon and is opening at Guy's, Cambridge, Birmingham, Belfast, Oxford and Liverpool.

The MAJIC study is the first academic study with ruxolitinib and is the only ongoing study of this drug in ET patients. Over 100 patients are now enrolled but more are needed. Who is eligible? ANY PV or ET patient with inadequate control of blood counts; symptoms or spleen enlargement on HC or any patients who have unacceptable side effects with HC such as mouth or leg ulcers. This study is open in over 30 hospitals in the UK.

For PT-1, our long-running (since 1997) and the world's biggest ET study, we are currently completing analysis of the PT-1 low and intermediate risk arms but are no longer recruiting patients.



## Trials for MF patients

Last year we completed JAKARTA, a phase 3 study with fedratinib (SAR302503), which will be presented at ASH 2013. However, there are important questions remaining in MF, eg might other JAK inhibitors be better? Currently open is PERSIST -1, a study with pacritinib which is an agent that appears to cause less anaemia and thrombocytopenia. In addition there is an observational study for all MF patients and plans to open a study using ruxolitinib prior to BMT. Later this year a study comparing ruxolitinib with momelotinib (a fourth JAK inhibitor) will also open. We are also assessing ruxolitinib in combination with other agents in 3 phase I studies, these are more time-demanding studies with slightly more risk, though aiming to deliver more benefit.

## MOSAICC – MPD Voice funded epidemiology study update

**T**he MOSAICC Pilot Study recruitment phase is well underway with 115 participants successfully recruited to date. Patients in Belfast and Southampton will be invited to take part by their clinician who will provide them with an invitation letter and information booklet. The MOSAICC Study team encourage as many patients as possible to participate in this study as the results will aid in the design of the UK-wide study planned to commence in 2014/2015. The MOSAICC Study team are also seeking to recruit 100 non-blood relatives or friends of the MPD patients taking part in the study as a comparison group.

Further details can be found at <http://mosaicq.qub.ac.uk>.

The MOSAICC Study added second year Cambridge medical student Chris Tapper to their team for the summer. PhD student, Glen Titmarsh, obtained a travel scholarship to attend a four week Cancer Prevention Course at the National Cancer Institute, Washington D.C., where he met with collaborators and agreed access to using the US Veterans Affairs (VA) database, to investigate potential causes of MPNs. Collaborators of the study will also meet in London at the Myeloproliferative Neoplasms advances day in November.

Sponsor Glen in his fundraising efforts for MPD Voice – see our fundraising page.

# FUNDRAISING 2013 update

## Goodbye... and welcome

After several years as fundraising co-ordinator for MPD Voice, we are sorry to report that Rachel Bridgman is moving onto other projects.

During her time as co-ordinator, Rachel personally raised over £15,000 and oversaw many successful events including abseiling, skydiving, sponsored walks and bike rides which contributed over £135,000 to MPD Voice's funds. The most recent, the prestigious Young Musicians Savile Club evening in July raised almost £11,000. Factoring in the many other events that Rachel helped others to organise it's clear that she has been a key contributor to our current healthy financial position which allows us to provide ongoing support and information for MPN patients and their families.



Goodbye Rachel, Welcome Marilyn

Stepping up to continue in this vital role we are delighted to introduce Marilyn Webster. An ET patient herself, Marilyn attended the MPD Voice patient day in 2011 and, having benefited from the support and help of the charity, wanted to share her fundraising experience gained working with the NSPCC, Breast Cancer Care and Marie Curie. She says, 'This is my way of taking back a little control, helping other people with MPDs as well as helping myself'.

On behalf of *MPDlife* we would like to say a BIG thank you to Rachel for all her input and support, we will miss you, and to Marilyn, welcome and all good wishes for future fundraising initiatives and events.

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 heroes

We know that lots of supporters are fundraising all the time on behalf of MPD Voice. Please do let us know so that we can say thank you and maybe feature your success, no matter how large or small either on the website or in our newsletter. We really do appreciate it ☺

### Thanks to...

**Martin Garbutt** who raised over £300 on behalf of MPD Voice. Martin, a non-runner, recently completed the Henley half marathon, despite the awful weather.



Martin Garbutt – running on behalf of his mother-in-law who was diagnosed with ET

**Glen Titmarsh** the PhD student working on the MPD Voice funded MOSAICC study is taking part in Movember (growing a moustache and not shaving for the whole of November). He will be donating all the proceeds to MPD Voice. He has already raised £250 and will be taking weekly photos to document his hair growing journey.



Glen Titmarsh

Readers can donate through the online donation form on our website.  
[www.mpdvoice.org.uk](http://www.mpdvoice.org.uk)

## Savile Club success

A wonderful evening of music performed to the highest standards was enjoyed by guests attending the last fundraising event organized by Rachel. Taking part in the magnificent Savile Club ballroom the evening was an amazing mix of talented musical performances and also included a short talk by Will Self, an auction of donated prizes that 'money could not buy' and a raffle of additional gifts donated by generous MPD Voice supporters. The evening concluded with a thank you and short talk by Professor Claire Harrison on why MPD Voice are funding an epidemiology study, with the profits from the evening being committed to this research.



Gifted young talent

## More Patient Forums in 2014 – help needed

Many readers will know that over the past few years we have increased the number of regional forums and support which is great news for those who cannot attend the London meetings.

Next year, we are delighted to announce plans for a further expansion to the number and locations of forums thanks to the ongoing generosity of the Samuel Sebba Charitable Trust and other kind supporters.

However, as we are a volunteer patient group more regional forums will require more help from people who may be able to co-ordinate the events. If you have some free time and would like to be involved visit the MPD Voice website for a patient forum volunteer role specification and to register your interest.



# MPD Voice backs advocacy initiatives for MPN patients

Jon Mathias, patient chairperson for MPD Voice recently represented the charity as part of a working party to explore ways of ensuring that patients have a voice in the fast changing medical world of treating MPNs.



Jon says, 'Advocacy means speaking on behalf of someone or something – in this case, we're saying that one of MPD Voice's roles, as our name suggests, is to speak out on MPD patients' behalf.

As funding for research and treatment comes under increasing pressure we believe that it will be important for MPN patients to be properly represented and, for that purpose, we have teamed up with similar patient groups in Europe in order that our collective voice will be louder.'

It's early days for this initiative and we'll provide an update on our progress in a future newsletter.

## Max Smith

With regret we report the sad death of Max Smith earlier this year in August 2013. Max was diagnosed in 1985 with MF and at that time given a 5–7 year life expectancy. Determined to prove the doctors wrong, Max underwent several leading edge drug research trials, many of which were self-funded in the USA and survived to the age of 74. Recently Max represented MPD Voice to NICE and was also interviewed for an earlier edition of MPDlife. Our sincere condolences go to his wife and lovely family at the loss of a special and inspirational person.



## Promote MPN Voice

Help us to raise awareness about our MPN patient support. New poster available to display in your haematology or hospital department. Either visit our website to download or email [info@mpdvoice.org.uk](mailto:info@mpdvoice.org.uk) for copies.



## November 2013 Living with MPDs day fully subscribed

As this newsletter is just about to go to print, we are delighted and excited that the second ever UK Living with MPNs patient day will be taking part in London on 16th November.

Patient delegates will be able to hear presentations from leading International MPN experts including Profs Nicolaus Kroger, Claire Harrison, Tony Green, Mary-Frances McMullin and Dr Gary Benson. The day will also include patient sub types of MPNs break-out groups allowing patients and families to exchange ideas and ask specific questions of the health care professionals.

A full report of the meeting will appear in the next newsletter and there are plans to include podcasts and copies of the presentation on the MPD Voice website.

## Want to make a difference for other MPN patients? Why not become a volunteer?

MPD Voice is 10 now years old and is proud of its many achievements since it was formed by a small group of MPD patients looking for information and reliable support. Since that time we have grown and are grateful to the dedicated help of a small team of patients and health care professionals who give up their time to develop the charity. For 2014 we have many plans to extend our reach and profile so that more MPN patients will benefit from the resources we offer, have access to a buddy or attend a forum BUT we need more help. If you have a few hours to spare and any ideas of how you could help us to grow, please visit our website to see if you have some of the volunteer skills and attributes to help us grow. [www.mpdvoice.org.uk](http://www.mpdvoice.org.uk)

## 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

Contact MPD Voice care of: Guy's and St Thomas' Charity  
FREEPOST LON 15724  
London SE1 9YA  
Email: [info@mpdvoice.org.uk](mailto:info@mpdvoice.org.uk)

We welcome your letters and feedback. Please send by post or to [info@mpdvoice.org.uk](mailto:info@mpdvoice.org.uk)

### 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.

