MPDlife

The newsletter for people with MPNs
May 2015

Order matters

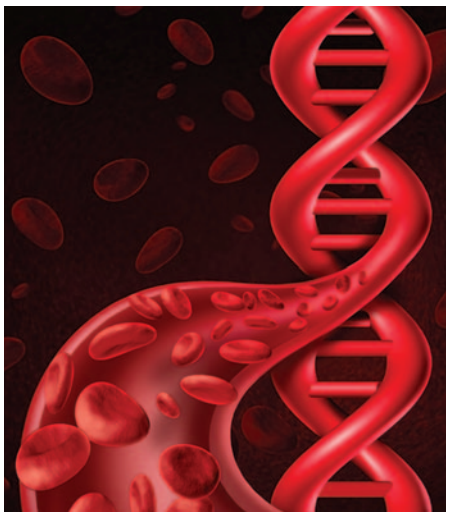
Dr David Kent and Professor Tony Green share new research findings

Professor Tony Green

Dr David Kent

Research shows that the order of mutation acquisition drives different disease sub-types.

Myeloproliferative neoplasms (MPNs) are thought to arise from a series of mutations in blood stem cells that result in an overproduction of blood cells accompanied by a growth advantage over non-mutant cells. Historically, researchers believe that each disorder reflects the sum of the mutations that have been accrued by that patient (e.g., A+B+C = MPN), but no studies have asked whether disease behaviour is affected by the order in which mutations arise.



Double helix DNA with red blood cells

Recently, we undertook a series of studies to address this question and discovered that mutation order makes a big difference. Approximately one in ten MPN patients carry mutations in both the JAK2 gene and the TET2 gene. By studying these individuals, we determined which mutation came first and were then able to ascertain the effect of mutation order on the clinical disease and also on the behaviour of single blood stem and progenitor cells.

Using samples collected primarily from patients attending Addenbrooke's Hospital, part of the Cambridge University Hospitals, we showed that patients who acquire JAK2 prior to TET2 (JAK2-first patients) display aberrant blood counts over a decade earlier, are more likely to develop polycythaemia vera than essential thrombocythaemia, are more likely to develop a blood clot, and may respond differently to JAK2 inhibition.

These surprising and exciting results may allow doctors to offer more accurate prognoses to MPN patients based on their mutation order, and to tailor potential therapies for individual patients. For example, our results predict that treatment with JAK2 inhibitors may be more effective in JAK2-first patients and less effective in TET2-first patients. However further studies including a prospective clinical trial, would be required to confirm this prediction.

From a broader research perspective, this is the first time that mutation order has been shown to affect any cancer, and it is likely that this phenomenon occurs in many types of malignancy. Our results appeared last month in the *New England Journal of Medicine**.

* *New England Journal of Medicine*
(Ortmann, CA and Kent, DG et al.
Effect of Mutation Order on Myeloproliferative Neoplasms.
N Engl J Med 2015; 372:601-612. February 12, 2015.
DOI: 10.1056/NEJMoa1412098).

Current MPN trials

Professor Claire Harrison writes

Professor Claire Harrison

Support from the MPN community to help recruit patients into available trials this year has been fantastic. Our epidemiology study and sample banks continue to recruit yielding much important information. The MEASURES study asks questions about quality of life and symptoms. The MAJIC trial, (administering ruxolitonib) is fully recruited for ET and we are now keen to recruit more PV patients and open new trial centres. Recent data from the RESPONSE study suggests ruxolitinib may reduce the risk of thrombosis in PV patients making the MAJIC study very important to see if we find the same signal. Significantly, MAJIC is the only ongoing study with ruxolitinib in ET in the world.

We have the opportunity to answer the question about which is better, hydroxy-carbamide or interferon (pegasys) in the MPD RC112 study in newly diagnosed ET and PV; this is a key question as to the effectiveness of the two for patients.

The PT-1 study is no longer open to more patients but we are in an intense phase of data gathering and analysis.

For MF we continue to test ruxolitinib in combination with other agents, including pre bone marrow transplant, along with other JAK inhibitors like pacritinib and momolotinib. To date there are very positive results coming from the PERSIST-1 study and other agents altogether like the smoothened inhibitors, the pentraxin analogues PRM-151 and imetelstat.

MPN voice

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MPN trials and research

The last few years for MPN patients have been exciting in terms of the rapid development of research and new drug options that have been available.

For patients however, the choice and terminology surrounding the whole area of trials and research may be confusing so we have tried to summarise what's involved and included an update on current trials and eligibility.

You may think that MPN research is primarily focussed on investigating new drugs for better blood control in ET, MF or PV and ones that offer patients a longer and better quality of life. However there are also a number of projects researching why patients get MPNs and also the science behind the diseases, for example the discovery of the JAK2 and calreticulin mutations.

Clinical trials supply doctors and healthcare professionals with evidence about what treatments actually benefit patients. Trials look at the safety, possible side effects and the benefit of newer drugs against established ones.

All trials have to follow specific medical protocols which are designed to protect patient safety and provide meaningful results.

All trials offered to patients will have been through several approval phases beforehand, in particular approval from an independent research ethics committee which will review safety and monitoring as well as whether the study is considered to be needed. The committee protects the rights and interests of patients who enter trials.

Funding of trials

In the NHS trials are funded in a variety of ways which include: the National Institute for Health Research, (NIHR), the Medical Research Council, (MRC), the Department of Health and other government departments, medical research charities and pharmaceutical and other healthcare representatives.

When research is published, the method of funding will be declared and when a patient is asked to take part in trials, they should be told how it is being funded. For MPN patients some funding for trials has been donated by MPN Voice – e.g. the MOSAICC and MEASURES studies.

Different trial phases

Clinical trials using new medicines are normally classified into four phases.

Phase one trials

These are early trials in the development of new medicines. Primarily concerned with safety and are given to a small number of subjects, sometimes these are healthy volunteers and sometimes they are patients with the disease. To minimise the risk, dosage levels are small at the start of the trial and increased if minor side effects are demonstrated.

Phase two trials

These are performed on a larger number of patients to evaluate the side effects and benefits for the condition, a clear dose range for the drug is identified. Some phase two studies may be randomised; i.e. a computer decides what treatment a patient gets, and compares the new treatment to another existing treatment or placebo (dummy pill).

Phase three trials

These are for medicines that have passed phase one and two. Larger numbers of participants are included at this stage and new drugs are compared with existing treatments or placebo. Results will consider side effects and outcomes. Most of these studies are randomised. Depending on the design of the research, patients not on the trial drug may sometimes cross over to receive the trial drug at a defined time point in the trial.

Phase four trials

Once new medicines have successfully passed through the first 3 stages, the medicine will then be given a marketing licence, which means that the drug is available on prescription. Ongoing monitoring will occur on safety, side effects and long term risks and benefits, such ongoing monitoring is usually the job of a phase four study, these are often very large and are not randomised.

Questions to ask

If you are asked to consider being part of a trial, or want to investigate trials that are available, it is sensible to consider a number of issues…

- Why is the trial running?
- What are the questions being asked?
- How is it expected to help me or other MPN patients?
- How long is the trial planned to run for?
- How much time would be needed to attend for appointments and what frequency?
- Will I need to take time off work?
- What extra tests/appointments might be required?
- Will the cost of travel to take part in the trial be covered?
- Where will I get the drugs? Hospital/GPs or by post?
- Who needs to be contacted if there are any questions or problems?
- What happens if I want to stop the trial before the end of the research period?
- Is there any potential impact on future treatment options?
- What are the potential side effects – physical or emotional?
- What paperwork will I have to do – questionnaires/diary etc?
- How long will it be before the trial results are published and how do I find out the results?
- How is the trial funded?

Consent

Patients who are asked to take part in a trial have free will to say yes or no. The doctor organising the trial should discuss why you should consider being involved and the potential risks and benefits. In particular, before deciding, you will be offered a patient information leaflet. This contains information about why the study is being done, what is already known, what the potential side effects are, how frequent your visits would be and who to contact for more information.

Eligibility

There are many new drug trials planned or running for MPN patients and your haematologist will be keeping abreast of these opportunities to best manage your condition. However, unfortunately sometimes it is not possible for MPN patients to take part in trials when they do not fulfil the specific eligibility criteria: e.g. age or physical fitness or other medical conditions may make a patient less suitable for a drugs trial. These issues will all be discussed at the time of considering trials and ongoing treatment options and may be tested for in the so-called screening phase of the trial before treatment is begun.

A selection of currently available trials

ET/PV

First line therapy

MPD RC112

A randomised study of pegylated interferon versus hydroxycarbamide in high risk ET or PV patients. Planned participating hospitals: Cambridge, Oxford, Birmingham Heartlands, Liverpool, Belfast, Guy's, with more to be added.

- **Inclusion criteria:** High-risk PV or ET. PV (but not ET) must be JAK2V617F positive and diagnosed within 3 years and either received no cytoreductive therapy or less than 3 months of hydroxycarbamide.
- **Exclusion criteria:** JAK2V617F negative PV, prior treatment other than hydroxycarbamide or for more than 3 months.

Second line therapy

MAJIC

A randomised study of best available therapy versus JAK inhibition (ruxolitinib) in patients with high risk PV or ET who are resistant or intolerant to hydroxycarbamide. Open at 33 sites.

- **Inclusion criteria:** High-risk PV or ET who have met criteria for intolerance or resistance to hydroxycarbamide, JAK positive or negative.
- **Exclusion criteria:** ECOG performance status more than or equal to 3, uncontrolled atrial fibrillation, uncontrolled/unstable angina, myocardial infarction in the past 6 months or acute coronary syndrome or any clinically significant cardiac disease higher than NYHA (New York Heart Association), Class II, previous treatment within the last 12 months with ruxolitinib, previous or current platelets less than 100 x 10^9/L or neutrophils less than 1 x 10^9/L not due to therapy, inadequate liver or renal function. **Currently only recruiting PV patients.**

MAJIC

TAP

From Leukaemia & Lymphoma Research

MAJIC is funded through the TAP programme which aims to get clinical trials open in an accelerated manner.

MF

PERSIST-2 Pacritinib

Running in multiple sites. A randomized controlled Phase 3 study of oral pacritinib versus best available therapy in patients with MF.

- **Inclusion criteria:** Intermediate or high-risk prognostic group, splenomegaly bigger than or 5 cm, platelet count under 100, active symptoms of MF according to MF symptom assessment form (1 score of 4 other than fatigue, or 2 of at least 3), peripheral blast count less than 10%, absolute neutrophil count more than 500/L, no lower limit platelet count. Adequate liver and renal function, at least 6 months from prior splenic irradiation and 12 months from prior 32P therapy, prior treatment with a JAK2 inhibitor or transplant permitted.
- **Exclusion criteria:** Splenectomy, other malignancy within last 3 years, inflammatory or chronic functional bowel disorder, impaired cardiac function.

Pfizer study: B1371013

Running at Guy's Hospital, a phase 2, double-blind, randomized trial evaluating safety and efficiency of PF-04449913 against placebo in patients with MF previously treated with one JAK inhibitor.

- **Inclusion criteria:** Symptomatic MF with palpable splenomegaly (more than 5cm below costal margin); prior JAK inhibitor treatment; adequate liver and renal function; age18 years and over.
- **Exclusion criteria:** Prior experimental smoothened inhibitor (SMOi); evidence of significant cardiac disease, prior myocardial infarction, uncontrolled inflammatory bowel disease, peptic ulcer disease or gastro intestinal bleeding within 6 months, any condition requiring oral steroid treatment; active second malignancy.

SIMPLIFY-1

A randomized, double-blind trial, evaluating momelotinib against ruxolitinib in patients with MF (PMF, PPV-MF or PET-MF), at multiple sites.

- **Inclusion criteria:** patient with MF intermediate-1 (if symptomatic or unresponsive to available therapy), intermediate-2 or high-risk prognostic score; older than 18 year; palpable splenomegaly (at least 5cm below costal margin); platelets higher or equal to 50 x 10^9/L; less than 10% blasts in peripheral blood; adequate liver and renal function.
- **Exclusion criteria:** Previous splenectomy or splenic irradiation within 3 months; patient eligible for transplantation, uncontrolled current illness, previous malignancy.

SIMPLIFY-2

A Phase 3, randomized trial at multiple sites to evaluate the efficacy of momelotinib against best available therapy in MF anaemic and/or thrombocytopenic patients previously treated with ruxolitinib.

- **Inclusion criteria:** age 18 years and over; palpable splenomegaly (at least 5 cm below left costal margin); currently or previously treated with ruxolitinib and experienced haematological toxicities; (transfusion needed, equal to or over Grade 3 anaemia, thrombocytopenia or haematoma) related to drug; symptomatic intermediate-1, intermediate-2 or high risk prognostic group; less than 10% blasts in peripheral blood; Adequate liver and renal function.
- **Exclusion criteria:** Previous splenectomy or splenic irradiation within 3 months; uncontrolled current illness; previous malignancy.

Planned studies

In the next 6 months the following studies will open:

- **Phazar** – a study for patients developing leukaemia after MPN or patients whose disease is close to leukaemia. This is another TAP study and will be open in 13 centres.
- **Imetelstat**: a study with this telomerase inhibitor will open shortly in several centres.
- **PRM-151**: A drug which inhibits fibrosis will also be studied.

Trial recruitment often uses international medical scoring conventions, some of which have been referred to above: NYHA (New York Heart Association), IPSS, QT interval

Useful websites

Visit any of these websites to find more information about trials.

- **http://www.crn.nihr.ac.uk/can-help/patients-carers-public/how-to-take-part-in-a-study/**
- **http://www.patient.co.uk/clinical-trials**
- **https://clinicaltrials.gov/ct2/help/for-patient**

MPN studies

Please visit our website for updates on research trials and for a link to the recruiting sites for MPN trials.

	Closed trials in follow-up	Current trials
MOSAICC	Epidemiology: (looking for causes of MPNS)	
MEASURES		Symptom & quality of life observations/ assessments
First-line ET/PV	Low and intermediate risk PT1 closed after a recent extension for follow up	MPD RC 112 PEGASYS versus hydroxycarbamide just about to recruit
MF	JAKARTA1 and JAKARTA2 with fedratinib closed. LBH589 panobinostat and ruxolitinib fully recruited. RESUME pomalidomide in transfusion-dependent MF Oral pacritinib versus best available therapy in MF – PERSIST-1	LDE225 and ruxolitinib in MF Harmony: BKM120 and ruxolitinib in MF PERSIST-2 pacritinib versus best available therapy with platelets less than 100 SIMPLIFY-1 ruxolitinib versus momelotinib
Second-line ET/PV and MF	ARD12042 for ET/PV closed RESPONSE data at EHA 2014 and RELIEF Novartis commercial portfolio completed	MAJIC ruxolitinib versus best available therapy in ET and PV BKM120 and ruxolitinib in MF PERSIST-2 pacritinib versus best available therapy, platelets less than 100 SIMPLIFY-2 momelotinib versus best available therapy PF study Imetelstat study
AML/MDS post MPN		Phazar about to open (ruxolitinib plus azacytidine)
Observational		ERNEST

Going on a drug trial

patient story

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

MPN voice

When traditional medications failed to help Edgar's condition the opportunity to take part in a drugs trial offered new hope.

Edgar's story

Edgar Mortimer, aged 59 and a lecturer in Construction and Bricklaying shares his experience

'I was first diagnosed in 2003 when I went into hospital for an operation on a Pilonidal Sinus. After the operation I bled a lot and my bloods were then checked leading to my MPN, PV being diagnosed.

Edgar given a new life line

At first me and my wife Anne didn't know what was what. We came home and looked on the Internet and got confused by all the information. On returning to hospital the staff at the Macmillan unit were able to answer all the probing and unsure questions we had and they explained all the issues, medications and treatment processes.

The first drug offered was hydroxycarbamide but I didn't tolerate this well. The side effects were like having flu. I also lost about two stone in weight in about three weeks. I was taken off and the process of finding a drug I could tolerate began; anagrelide, interferon and pegylated interferon are the ones I can remember but I built up a tolerance to all of these after a period of time.

Then my consultant decided to refer me to Guy's Hospital as they were offering further new drug options. While on these drugs I was also having venesections to reduce my haemaglobin levels.' He adds, 'it's a good job I don't have a needle phobia having to inject myself! My wife began my injections as she is a Phlebotomist and a good one, but then after a period of time, I thought I can do this, and one night I injected myself with no issues and have carried on since then until new drugs were implemented.'

When asked how he felt about considering going on a trial Edgar says, 'I was nervous once I had completed the trial protocol and met all the criteria. Then to be included on the trial felt fantastic as I was being given another possible lifeline.' He continues, 'the trial drugs and procedures were explained and discussed at the onset of the trial. The monitoring of my progress has involved blood tests and urine and weight tests with all of this information being recorded. I have an MRI scan about every six months to check my spleen for possible enlargement, (part of the trial), also I still need a venesection to control my blood levels. The trial so far has met of all my expectations, (not knowing what to expect).' He adds, 'all the staff have been superb and very supportive; they can't do enough in terms of providing information or settling any doubts. I can't fault any of my treatment or information given since the beginning of my journey and all the medical staff have been knowledgeable and supportive at all times. They make me feel part of a family.'

Edgar recommends that MPN patients considering a trial should; 'Discuss everything with the staff as they will reassure you of the best options and treatment open to you. Also speak to other patients to get information in plain English. It's worth its weight in gold. I would say go for it as it will help you and others around you as it did me.'

Concluding, Edgar remembers some of the lows of living with a MPN as, 'Why me? What happens next? What will happen with the next drug offered?' Fortunately he now feels optimistic that with the current change of drug he can start to enjoy a positive outcome.

Anne's view

Anne, Edgar's wife adds a MPN patient partner's perspective to drug trials

Anne says, 'When Guy's Hospital said "Edgar you can go on the trial drug", I had never been so happy! Watching Edgar struggle so much with his previous treatments and all their side effects such as weight loss, major headaches aches and pains, was just awful and there seemed nothing I could do to help… it was a dream come true!' Adding, 'Edgar's sense of humour and determination have been amazing he's been the one supporting me.

Deciding that Edgar should join the trial was a no brainer. We trusted the consultant completely and once she said to me "I was to stop worrying about Edgar, that was her job", I tried to take her at her word. In the early days I took a lot of time off work to go with Edgar to appointments but as my confidence grew in all the decisions and seeing him get better so very quickly with his blood levels settling down, I left it to the consultant and Edgar and she was only an email away if we needed her.'

A trial was a 'no brainer.'

Anne concludes that, 'Without our family and friends I would never be as strong as I am. I had worried so much, not sleeping at night feeling sick with worry. Being able to cry when the results were bad and very happy when we had good results everyone around us was beginning to understand the result levels … amazing really! It was the support I needed and I could never thank them all enough, our family and friends are wonderful.'

MOSAICC update

Glen Titmarsh

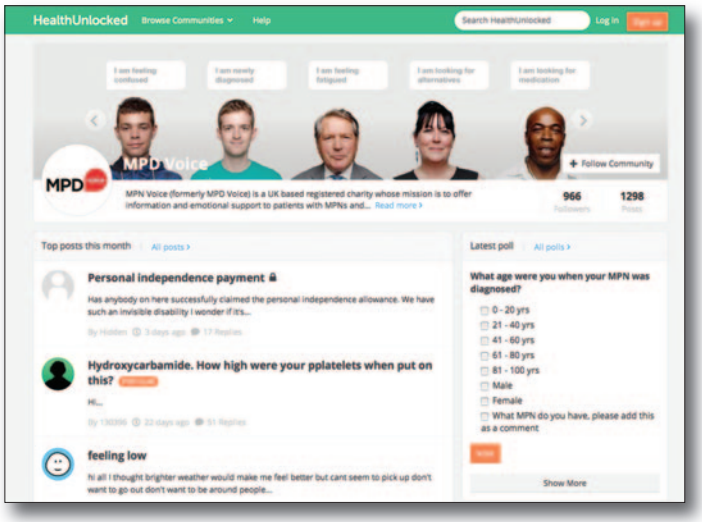
The MOSAICC Pilot Study has now closed and statistical analysis is currently being undertaken by PhD student Glen Titmarsh. In addition to analysis, Glen is writing up his PhD thesis which incorporates all aspects of the MOSAICC study. Information regarding results of the study will be published in peer-reviewed articles and made available via our study website in the coming months (**http://mosaicc.qub.ac.uk**). Once again the team would like to thank all those who took part.

The MOSAICC Study team met in December 2014 to discuss results of the MOSAICC study and plan a strategy for implementing a larger study. Funding for a future study has been applied for and the team are currently awaiting feedback. Glen spent a week in February 2015, working with occupational expert Dr Frank de Vocht to finalise occupational results for the pilot MOSAICC study.

MPN Voice online community

Have you visited HealthUnlocked on the MPN Voice website? This offers MPN patients an opportunity to ask questions of and support other patients who may be recently diagnosed or who just enjoy the chance to share their MPN journey. Moderated to ensure medical accuracy and content, many MPN patients value the unique forum and count the community as an extended family of MPN friends. Why not visit today?

https://healthunlocked.com/mpdvoice



Fundraising update

Marilyn Webster, fundraising co-ordinator writes


Marilyn Webster

2015 has already started as a really exciting year for MPN Voice Fundraising. We have had so many requests for fundraising packs, T Shirts, balloons and flags.

There are going to be so many events up and down the country organised by the MPN Voice Community in support of our work; coffee mornings, tea parties, cake bake-offs, fêtes and raffles, walks with friends, pamper parties and a sponsored silence, some amazing challenges as well as dress down days at work and schools!

We love to hear about what you are doing so please do let us know or to get a fundraising pack, please email Marilyn at **fundraising@mpnvoice.org.uk**

Thank you as ever for your amazing support and contribution to MPN Voice.

Future events

2015

- **May 17th**
  Hyde Park Superheroes – run or walk 5k or 10k
  Sky-diving in association with Guy's and St Thomas' Charity
- **26th/27th June**
  Abseil Challenge in association with Guy's and St Thomas' Charity
- **September**
  MPN Voice Coffee, tea and cake month in support of MPN Voice Rare Blood Cancer Awareness Month

2016

MPN Voice is delighted to announce that we have secured guaranteed places in the following iconic events;

- **2016 London Virgin Marathon**
- **2016 Adidas Silverstone Half Marathon**
- **2016 London BUPA 10k**

Anyone interested in taking part in the above events please email **fundraising@mpnvoice.org.uk**

Fundraising heroes

Virgin 2015 Marathon success!

This year we were delighted to have two runners raising funds for MPN Voice.

John Messenger, diagnosed with ET, finished in 5hrs 13mins 56secs and **Giovanni Maso** who secured a place through GSST, but fundraised for MPN Voice finished in an amazing 3hrs 32mins 41 seconds! He whizzed by so quickly that he had gone before the shutter came down for a picture to be taken! Their efforts have achieved almost £7,000 along with the invaluable benefit of raising additional awareness of MPNs

David Brailsford

Diagnosed with ET in 2009, turning 50 prompted David to do 50 new things or go to 50 new places which included embarking on the London to Brighton off-road cycle ride. The thrill of crossing the finishing line has now inspired him to cycle 1,234 miles in 2015 to raise money for charity, including MPN Voice. His first ride raised £240 and this amazing challenge includes a variety of charity rides including the three day London to Paris off-road in June. MPN Voice wishes him ache free riding and puncture resistant tyres! Visit **www.justgiving.com/David-Brailsford** to support David's fundraising year in the saddle.

David Brailsford

Paul Foulke

Paul, whose sister has ET, was diagnosed with PV two years ago. Along with his wife Lara and their friends Jill and Ian, they were delighted to raise £470 by completing an alcohol free January, well above their original target. Paul says he was also pleased to raise the awareness of MPNs as 'most people do not know or understand what they are'.

Paul Foulke

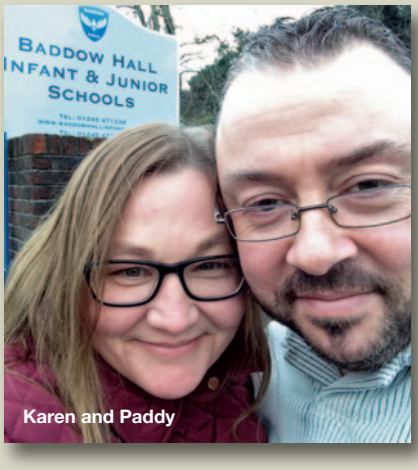
Chloe Lloyd

Chloe Lloyd

Diagnosed with ET three years ago, Chloe decided to fundraise for MPN Voice by asking for a donation instead of gifts for her 40th birthday. She is thrilled to have raised over £1000 and is thankful for the generosity of her friends and family.

Paddy Miller

Raised over £500 by running the Adidas Silverstone half marathon. Paddy's partner Karen was diagnosed with an MPN in 2014. Describing the experience as rewarding, Paddy says that the fundraising was made up of work mates, friends, family and MPN well-wishers and would like to thank them and Karen, who he admires for being a great mum and devoted grandmother whilst holding down a successful career.



Karen and Paddy

Michelle Russell

Raised over £600 by taking part in the Silverstone Half Marathon. It took her 3 hours and 5 mins and she describes crossing the finish line as 'a proud moment with a few tears and achy joints'. Michelle, diagnosed with PV in 2013, will be taking part in the Bupa 10k in May and says, 'I know this money will go to help in the trials and the research and generally those affected by MPNs. Without the supportive messages and opportunities to take part in these runs I would have given up on myself by now. MPN Voice, those that support it and those that need it are the ones that keep me going! Here's to the next run'.

Michelle Russell

Patient advocacy

patient power


Jon Mathias

MPN voice continues a focus on building its profile as a voice for MPN patients both in the UK and Europe. The group we founded, MPN Advocates Net now has representatives from Italy, France, Germany and Israel and have secured some seed funding to hold an initial meeting of the expanded network later this year.

In April, Jon Mathias and Caroline Thomas represented MPN Voice at a round table meeting organised by the pharmaceutical company, Novartis. The subject of the meeting was "Sustainable UK patient access to cancer medicines". Representatives attended from several UK patient groups as well as Novartis and AstraZeneca.

As many MF patients will know, in situations where NICE decides that a particular treatment is too expensive, the drug can be made available to patients via the Cancer Drug Fund (the CDF). The CDF was introduced in 2011 in recognition of the fact that the cost of many new drugs would rule out their approval for use using the conventional NICE process.

However, the CDF was always intended as a temporary measure, and is due to come to an end in 2016, so proposals are being put forward for a longer-term solution to the problem. The meeting was convened to discuss one of these proposals being put forward by Novartis in consultation with other manufacturers.

The proposal provides a means by which the NHS could provide patients with access to certain high-cost treatments in advance of full conventional approval provided by NICE. One of the keys to this working would be for the manufacturers to share some of the cost, at least during an interim uptake period, while more data is gathered about the drug's effectiveness.

It must be emphasised that the proposal is only one of a number of possible outcomes and is very much in the discussion phase at the time of writing.

Encouragingly, one of the topics discussed was how patient groups like MPN Voice can become involved, firstly in the discussion about the future of the CDF generally, and then as part of whatever process may replace it. All the parties involved clearly recognise the need for patients to have a strong voice in debates about a drug's value for money and the extent to which a patient's quality of life is affected.

Given that many MF patients in England are benefiting from the fact that ruxolitinib is currently funded by the CDF, these issues are clearly a matter of great importance to patients, and MPN Voice will continue to participate in the ongoing discussions and future funding, and we will update you as further news emerges.

Forums for 2015

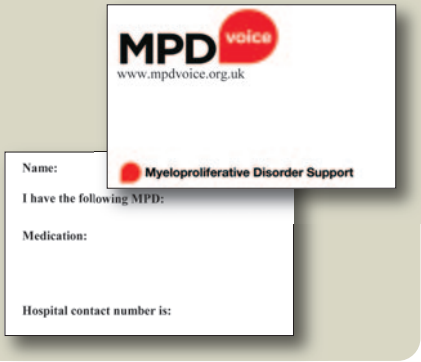
MPN Voice continues to support patients through regional forums. These are a great way to meet with MPN patients and their families and friends, and offer the opportunity to keep up to date on the latest research. Always friendly and relaxed, many MPN patients find these meetings invaluable as a way to feel less isolated and to network.

Our thanks as ever to the support of Samuel Sebba Charitable Trust which enables MPN Voice to offer more regional forums.

- **Inverness Friday 5 June**
  10 am–2 pm, registration from 9.45 am. To be held in Eden Court Theatre, Bishops Road, Inverness, IV3 5SA
- **London Wednesday 8 July**
  6 pm–9 pm, registration from 5.30 pm. To be held in the Robens Suite, 29th Floor Tower Wing, Guy's Hospital, Great Maze Pond, London, SE1 9RT
- **Edinburgh Wednesday 30 September**, 2 pm–5 pm, registration from 1.30 pm. To be held in The Carrington Suite, Scottish Health Service Centre Conference & Training Centre, Western General Hospital, Crewe Road South, Edinburgh, EH4 2LF
- We are also planning forums for **Liverpool** and **Nottingham** later in 2015
- **London 14 November**
  3rd Living with MPNs Day

Medical alert cards

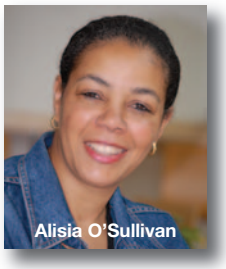
Don't forget, we provide credit card sized cards (free of charge) that are an invaluable way to ensure MPN patients are treated appropriately in a medical emergency. If you would like to receive a medical alert card, please contact **info@mpnvoice.org.uk**



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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