

## JAK inhibitors “superior” to standard therapies

Dr Claire Harrison describes results of recent trials, and explains what's ahead in drug research

Researchers have reported the results of the first JAK inhibitor study in Europe, and there is good news: the results were very positive. This study, called COMFORT 2, showed that a JAK inhibitor gave superior results to standard treatments for patients with myelofibrosis. The drug controlled symptoms and reduced spleen size in these patients. We expect full results of the study to be released in mid-2011.

A number of other studies are set to open in the UK, including several studies with JAK inhibitors in myelofibrosis.

There is good news for people with polycythaemia vera (PV) as well: the first trial of a

JAK inhibitor in people with PV has now opened. If you would like more details you can contact us at [info@mpdvoice.org.uk](mailto:info@mpdvoice.org.uk)

Another drug being tested is a modified form of interferon called PEGASYS. Two studies of this drug will open soon for people with essential thrombocythaemia (ET) or PV. The study compares PEGASYS to hydroxycarbamide in patients who cannot take hydroxycarbamide.

MPD Voice will offer updates on our website as information on study results becomes available. You can find further info on the US National Institutes of Health website at:

[www.clinicaltrials.gov](http://www.clinicaltrials.gov) or email us at: [info@mpdvoice.org.uk](mailto:info@mpdvoice.org.uk) ■

### National Patients' Day, London, 19th November 2011

Please join us for a “Living with MPDs Day on 19th November 2011. This full-day event will take place in London. People with myeloproliferative disorders (MPDs) and families and friends are welcome to attend

Researchers in the field of MPDs from across the UK and around the world will join our own Dr Claire Harrison of Guy's and St Thomas' Hospital to discuss the current state of MPD research.

People affected by MPDs speak about their experiences, and a health psychologist will offer tips on coping with stress in chronic illness. People attending will be able to talk with experts directly during break-out sessions.

You can find more info on [www.mpdvoice.org.uk](http://www.mpdvoice.org.uk) or you can register online by visiting the website of the event organisers at [www.hartleytaylor.co.uk](http://www.hartleytaylor.co.uk). The cost to register is £10 per person. Space is limited to 180 persons. ■

### Open or forthcoming trials

**RESPONSE TRIAL** First study of a JAK inhibitor in patients with PV.

**Study arms** People enrolled in the study will be assigned at random to one of two groups (or “arms”). They will take an oral JAK inhibitor or the best PV therapy currently available.

**Who is enrolled** Patients with PV who cannot tolerate hydroxycarbamide; patients with PV resistant to hydroxycarbamide; patients who continue to need venesection and have an enlarged spleen.

**RESUME TRIAL** Trial of an oral pomalidomide (a thalidomide-like drug) versus a placebo.

**Who is enrolled** Patients with myelofibrosis who need regular transfusions (at least 2 units every 28 days).

**UKOSS TRIAL** Observational study of pregnancy in MPDs.

**PT-1 AMENDED** The two PT-1 trials look at treatment of low-risk and intermediate-risk ET patients.

**Who is enrolled** In the low-risk study, ET patients aged below 40 with platelets less than 1500 and no previous clotting or bleeding events. In the intermediate-risk study, patients with ET between the ages of 40 to 60 with platelets less than 1500 and no previous clotting or bleeding events.

You can read more details about the PT-1 study on page 4.

# House of Lords gala raises funds for MPD research

Hazel Butler talks with Ann Marie Jahn about how she and her husband raised £40k for research

Mr and Mrs Geoff Butler support the work of many charitable associations, and so when Mrs Butler's daughter and the mother of her grandchildren was diagnosed with polycythaemia vera (PV), the Butlers decided to take action.

"When I learned my daughter had been diagnosed with PV, I became determined to do something to fund research," explains Mrs Butler. The Butlers thus set a goal: to raise £35,000 in 2010 for research into the causes and treatment of myeloproliferative disorders (MPDs).

The Butlers launched their six-month fundraising drive with a thrilling event: Mrs Butler and her daughter abseiled



L to R: Mr Eric Underwood (event sponsor), Baroness Knight and Mr Geoffrey Butler

down Guy's Tower during our 2010 fundraising events and together they raised over £15,000.

"Stepping over the edge of a 35 storey tower was a challenge,

but I wanted to help my daughter and everyone with an MPD," she explains.

Mr Butler was also keen to make a contribution to the charity.

He recently retired as vice-chairman of an American firm, after 41 years with that company. To commemorate his retirement he asked that in lieu of a personal gift, the firm's board should make a donation to a fundraising event his step-daughter is organising – a cycling event from London to Paris. The firm is expected to donate about £3000.

Funds were coming in quickly, but the Butlers still needed to meet the objective they had set.

The next event Mrs Butler organised was a garden party in September 2010. The party was held in the private home of Mr Raymond Sawyer,



L to R: Mr Raymond Sawyer, Mrs Hazel Butler, Michael and Chrissi Bradbury



whose house is surrounded by magnificent gardens and brought to life by exotic “residents” including pink flamingos, wallabies, meerkats and exotic birds. The garden party event raised a further £5000 in a single afternoon.

In March 2010, Hazel Butler’s friend Baroness



Persuasive auctioneer  
Mr David Ford

Knight of Collingtree graciously agreed to sponsor a charity dinner in the House of Lords, to be held on December 15th. As a Peer of the Realm, Baroness Knight was the hostess of the event, while Mrs Butler was responsible for all the organisation, and Mr Jack Scrutton acted as event sponsor. It was agreed that all proceeds from the evening would be donated to MPD Voice (then MPD Support).

The evening opened

with champagne served in the Cholmondeley Room, where the festive atmosphere was enhanced by beautiful harp music. A sumptuous dinner was served on the terrace, which afforded stunning views over the River Thames, the London Eye and (appropriately) St Thomas’ Hospital.

Each table was entertained by magician “Magic Mikey” who performed astonishing tricks. After dinner television entertainer Mr David Ford auctioned off an array of prizes including a dinner cooked in the winner’s home by celebrity chef Mr Reza Mohammed.

The House of Lords gala raised £20,208, increasing the total amount the Butlers raised to £40,208, and



Dr Jill Owen with event sponsor Jack Scrutton

exceeding their target by £5,208. The money they raised will go towards an epidemiological study of MPDs that researchers had long hoped to run, but that had not been possible until now due to lack of funding.

MPD Voice is immensely grateful to Mr and Mrs Butler, to their daughter, to Baroness Knight, to the Hathaway Foundation and to Mr Sawyer for their generosity and unstinting efforts on behalf of MPD Voice. ■



MPD Voice steering committee member Ms Tamara Kosta, celebrity chef Reza Mohammad, Mrs Hazel Butler, and Mrs Kosta (senior)

## Expert Briefing

### Von Willebrand Syndrome

**Q**I have essential thrombocythaemia (ET). My haematologist tells me I have low-risk ET, so I only take aspirin, but I bruise easily, and minor injuries such as a cut tend to bleed a lot. Should I be worried? – TJ

**A** While your haematologist feels that you have a low risk of experiencing a clot at this time, you may be feeling a bit perplexed because you have bruises and you have a tendency to bleed.

Your haematologist can order a simple test for a condition called von Willebrand Syndrome when you next have your blood drawn. Some people with ET have this condition, which causes them to bleed slightly more if they have an injury than other people do. This condition isn't a major concern but it will explain why you are experiencing these symptoms despite being a low-risk patient.

Von Willebrand Syndrome may be inherited, although when it occurs in conjunction with MPDs, it is not inherited, but associated with the disorder itself. Your haematologist may suggest that you stop aspirin therapy or that you consider taking medication to lower your platelet count if bleeding is a problem.

Best wishes,  
Dr Claire Harrison

*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.*

## PT-1 study improved treatment of ET

Dr Claire Harrison explains the results of this important study

PT1 is the largest ever study involving patients with the myeloproliferative disorder essential or primary thrombocythaemia (ET or PT).

This study opened in 1997, and well over one thousand patients have been enrolled to date. Prof Green and I are leading the study, which continues to recruit patients throughout the UK, Northern Ireland and in additional sites in Australia, New Zealand and France.

Results of the PT-1 study are helping guide therapeutic choices for patients. The study uncovered some unexpected risks with new drugs such as anagrelide, and aided us in identifying better treatment plans for high-risk patients.

In addition, we collected clinical and biological samples during the study (samples of blood and bone marrow), and these have allowed us to make important observations:

- We've learned that there are similarities between JAK2-positive ET and PV
- We've discovered information suggesting why some patients with ET develop leukaemia or myelofibrosis
- We've learned more about whether patients with MPL mutations are different than other people with ET. (MPL mutations are a recently discovered genetic change found in small percentage of people with MPDs.)

- We've learned about other changes in the JAK2 gene (called "46/1")
- We've discovered better ways to interpret bone marrow biopsies

The PT-1 study is also helping us determine whether hydroxycarbamide causes long term damage or increases the risk of leukaemia. You can find detailed information with articles about the PT-1 trial on this website:

<http://www.haem.cam.ac.uk/pages/pt1/publications.html> ■

### Who is high-risk?

Patients enrolled in the study were considered at high risk of clotting events if:

- They were over sixty years of age
- Their platelet counts were greater than 1000
- They had previously experienced a clot (heart attack, stroke or DVT)
- They suffered from diabetes treated with medication in addition to ET
- They had high blood pressure

The high-risk arm of the PT-1 study closed in 2004. The results have been published and are available on the PT-1 website.



# Runner braves the Spartathlon, raises £1550

Ramona Thevenet-Smith's challenging run raised needed funds, friend Hazel Butler explains

Every September in Greece runners compete in an event called the Spartathlon, an historic ultra-distance foot race.

MPD Voice fundraiser Ramona Thevenet-Smith, 50, competed in this race, which celebrates the famous run by Athenian messenger Pheidippides. Pheidippides is said to have run 154 miles from Athens to Sparta to secure reinforcements for the Athenians in their battle against an invading Persian army during the Battle of Marathon in 490 BC.

In 1982, British RAF Wing Commander and student of Greek

history John Foden and four RAF colleagues ran the first modern Spartathlon, retracing the steps of Pheidippides and proving that a man can indeed run 154 miles in two days.

Ms Thevenet-Smith trained for the Spartathlon by running 2.5 hours each day. "To prepare, I ran to and from work every day with a rucksack on my back," she said.

Ms Thevenet-Smith originally entered the Spartathlon because of her interest in ancient Greek history, and was inspired to use the proceeds to help MPD Voice (then MPD Support). She first became aware of the charity through her friend and colleague, Mrs Hazel Butler.

Ms Thevenet-Smith and the other runners set off from the Parthenon in Athens with the aim of running until they kissed the feet of the statue of Pheidippides in Sparta the following evening. Only one third of all contestants are able to finish the race due to the raw terrain and exposure



Ramona runs in Pheidippides' steps

to the elements. She completed much of the race but was disappointed not to complete the entire 154 miles. We at MPD Voice are extremely impressed with her resilience and courage. We thank Ramona on behalf of all of us with myeloproliferative disorders (MPDs) for raising £1550. The entire amount she raised will go towards needed MPD research. ■

## "Most gruelling race"

The International Spartathlon Association explains that only about a third of the runners who leave Athens end the course in Sparta. "The Spartathlon runs over rough tracks and muddy paths, crosses vineyards and olive groves, climbs steep hill-sides and, most challenging of all, takes the runners on the 1,200 meter ascent and descent of Mount Parthenio in the dead of night. It is a trial for human stamina and mental strength.

Even the finest athletes start hallucinating as they cover the final stage of the race, descending into Sparta. Having lost all sense of time and reality, they push their weary bodies on towards the finishing line at the statue of Leonidas. Those who succeed in reaching Sparta have trouble finding words to describe their feelings."



Map courtesy of the International Spartathlon Association

# Integrative care: new ideas offer options for feeling better

Ann Marie Jahn talks with the Mayo Clinic's Dr Brent Bauer about proven treatment strategies

Dr Brent A Bauer, MD (medical doctor) is Director of the Complementary and Integrative Medicine Program at the Mayo Clinic, a leading hospital in the US. He is a specialist in the relatively new field of integrative medicine.

We asked him some questions to learn more about this new and innovative approach to medical care.

*Integrative medicine is a new field. Can you tell us about it?*

For many years Western medical practitioners have looked at medical treatment as divided into two camps: conventional and alternative medicine. However, people can benefit from many different treatment traditions.

What we call "integrative medicine" is medical care that brings together the best in alternative, complementary and conventional therapies.

*How did you yourself develop an interest in this field?*

When I began practicing medicine, I was surprised to find that many of the people I treated came to me asking about supplements, herbal therapies and other treatments that they were taking, sometimes with jar in hand.

My colleagues at the Mayo Clinic and I decided not to immediately discount the ideas that patients brought to us. Rather, we elected to take a rigorous and scientific approach, by studying the potential benefits of alternative therapies and supplements. No one really knew what worked and

what didn't, so we decided to take a closer look.

*Based on your research, what can you recommend for people with myeloproliferative disorders (MPDs)?*

At the Mayo Clinic we of course treat patients with conventional medicine. In addition we recommend that every patient (indeed every person) focus on three key areas of self-care: diet, exercise and stress reduction.

*What have you discovered about how people can reduce stress?*

Research being done at both the Mayo Clinic (US) and at Sloan-Kettering (US) has demonstrated the value of massage. A study of massage following open-heart surgery found that patients had a reduction in pain and muscle tension if given regular massages. These benefits apply to patients suffering from cancer and receiving chemotherapy as well. If you have an MPD, you may wish to seek out massage as a complementary treatment.

*Are there other stress reduction techniques that people can try?*

Yoga is an ancient practice that has been shown to reduce stress and fatigue and promote well-being. The effects are significant and proven: researchers Mustian, Palesh, Sprod et al recently published a report on the effect of yoga on sleep, fatigue, and quality of life. Patients in the yoga program reported a 42% reduction in fa-

tigue, compared with a 12% reduction in fatigue among patients who received conventional care alone. (This was a randomised, controlled clinical trial among 410 cancer survivors. You can find the study in the *Journal of Clinical Oncology* 2010;28 (15 suppl):abstract 9013.)

*People with MPDs are often interested in supplements and alternative therapies. What have you discovered at the Mayo?*

At the Mayo Clinic we take a rigorous scientific approach to studying the potential benefits of different approaches. We have not been able to prove that there is any benefit to many vitamin supplements and herbal treatments.

Indeed, some studies in cancer patients have indicated that large doses of antioxidants can in fact increase the growth rate of cancer tumours. I recommend to my patients that they should exercise a good deal of caution before adding supplements to their diets.

*Any other recommendations you'd like to offer our readers?*

In our Western culture people are often under a great deal of stress. Meditation offers immense relief. I wish that all my patients would find 15 minutes to meditate every day.

You can try any technique that works for you as an individual: inspirational readings, prayer, or guided meditation. You can also view a video on guided meditation at [www.mayoclinic.com/health/meditation/mm00623](http://www.mayoclinic.com/health/meditation/mm00623) ■



# Upcoming events: Walk, Skydiving, Forums

Rachel Bridgman tells us about fundraising events planned for 2011, in the air and on the ground

We're looking forward to two exciting MPD Voice fundraising events for 2011 – a tandem skydive from 10,000 feet and (for those of us who like to keep our feet firmly on the ground) a sponsored walk followed by a family picnic in beautiful Richmond Park.

## Walk for the Cure 2nd May

Our 2011 sponsored walk will be held on Monday 2nd May 2011 (a bank holiday weekend) at 10 am. People who attend will not only be helping to raise much needed funds for MPD Voice, but will be spending the day in Richmond Park, one of the oldest and most beautiful Royal Parks in the UK, with 2,500 acres of land and 650 free-roaming deer.

Families, friends, children, bikes and dogs are welcome. The cost of the walk is £10 per person to register and secure a place. Please bring a picnic.



Walk for the Cure in historic Richmond Park on 2nd May 2011



Skydive for MPD Voice in the skies over Oxfordshire on 2nd July 2011

## Skydiving 2nd July

If you have ever wanted to skydive, here is your chance! MPD Voice is offering a tandem skydiving event on Saturday 2nd July 2011 in Oxfordshire. We are looking for as many people as possible to be adventurous and take part in this breathtaking

special event.

Participants will complete a tandem jump from 10,000 feet, attached to a professional instructor. No experience is necessary and all training will be provided.

Just imagine standing at the edge of an open doorway in an aircraft flying at 10,000 feet with the noise of the engines and the wind ringing in your ears with only the outline of distant fields below.

Now imagine leaning forward out of that doorway and letting go – falling forwards into the clouds, diving down through the air as you start free falling at over 120 miles per hour!

## Registration information

Please call Rachel Bridgman on 07901 875910 or email [fundraising@mpdvoice.org.uk](mailto:fundraising@mpdvoice.org.uk) for further details and for registration and sponsorship forms. The cost of this event is £70 per person to register and secure a place. ■

# Editor says goodbye to MPD Voice

Ann Marie Jahn, our dedicated website and newsletter editor, is leaving MPD Voice after six years with the charity.

“Ann Marie has made substantial contributions to the charity and I accepted her resignation with regret,” said Dr Claire Harrison, chairman of MPD Voice. “We will miss her.”

Ms Jahn joined MPD Voice (then MPD Support) in 2005. One of her initial tasks was to develop the editorial direction for a newsletter dedicated to people with myeloproliferative disorders (MPDs). She focused the content on the lives of people with MPDs, creating a type of publication that had never before been offered to MPD patients.

Over the last eighteen months, Ms Jahn has focused her energies on rebranding MPD Support as MPD Voice and developing the charity’s new website.

She added a vast amount of all-new content, and worked in conjunction with an external agency to develop the new look, features and navigation of the site, with the goal of providing clear and accurate information



Website and newsletter editor Ann Marie Jahn

and emotional support to people with MPDs.

Ms Jahn contributed 75% of her time pro bono (and the external agency 50%), allowing a small charity with limited means such as MPD Voice to raise its profile and offer in-depth health information to people with MPDs worldwide.

“Our superb new website gives the charity the platform it needs to raise substantially more money for research,” says MPD Voice Vice-Chairman Mr Jon Mathias. “It’s an end result of which a much bigger charity could be proud.”

Ms Jahn is leaving MPD Voice to pursue other professional goals. She explained, “It has been deeply meaningful for me to serve all of you in some small way over these years and to be a part of MPD Voice. Thank you and the very best of health to you all.”

We wish her success in her future endeavours, and much health and happiness. MPD Voice will be forever grateful for her contributions. ■

## Find news fast

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**News & Events blog**  
[www.mpdvoice.org.uk/news-events/](http://www.mpdvoice.org.uk/news-events/)

And please visit our new  
**Facebook & Twitter** pages!



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### Upcoming Events

Holistic Fair, London  
15th May

London Patients' Forum  
20th May

Belfast Patients' Forum  
2nd June

Tandem Skydiving 2nd July

National Patients' Day  
19th Nov