

MPD Voice funds new epidemiology study

Dr Lesley Anderson, lead investigator of the study, explains what this research is all about

Why are we doing it?

There is little information on the causes of myeloproliferative disorders (MPDs). In 2010 we conducted a review of all published studies which have investigated a wide range of potential medical, environmental and occupational risk factors that could contribute to causing MPDs. However, these studies vary widely and have some limitations. We hope to identify potential factors that could be responsible for causing MPDs and assess quality of life issues of patients. This pilot study would then provide the information and assessment of technology to take forward to a full comprehensive investigation of the causative factors in MPDs in a large group of patients across the UK.

What are we doing?

A large multi-centred UK-based study is planned following a pilot study recruiting 100 MPD patients (cases) under the care of Prof Mary Frances McMullin, Belfast City Hospital and Dr Andrew Duncombe, the University Hospital Southampton NHS Foundation Trust. People in the general population, without MPDs (controls), will also be invited to participate in the study to compare lifestyle, occupational and environmental risk factors that may increase one's risk of developing a MPD. The pilot study, supported by a grant from MPD Voice will be at the leading edge of research in this area.

How will we do it?

The study will aim to evaluate the best recruitment procedures, response rates, the development of a telephone administered questionnaire, compare occupational exposure assessment using OccIDEAS, a novel web-based program, with a job-exposure matrix (FINJEM) and evaluate the feasibility of collection of DNA from saliva and dried blood spots compared to blood samples.

Are there any other similar studies and how did they help treatment plans?

Studies investigating the causes of MPD are limited. We are actively working with a group of researchers undertaking a study investigating causes of polycythaemia vera (PV) in Pennsylvania, USA. Collectively we hope to be able to understand the causes of MPDs and by doing so identify potential targets for the prevention and treatment of these conditions.

Who are the key people involved?

Dr Lesley Anderson, a lecturer in Cancer Prevention at Queen's University Belfast with more than 10 years experience in conducting case-control studies is leading the investigation in conjunction with a multi national team. In addition to Professor McMullin, and Dr Duncombe, Dr Frank De Vocht, Lecturer in Occupational and Environmental Health at the University of Manchester, will oversee the assessment of occupational exposure within the study.



Dr Lesley Anderson



Prof Mary Frances McMullin

Collaborators from the Mayo Clinic, Texas, USA (Prof Ruben Mesa), National Cancer Institute, Bethesda, USA (Dr Mark Purdue), Western Australian Institute of Medical Research (Prof Lin Fritschi) and Drexel University Pennsylvania (led by Dr Arthur Frank) will be involved in developing the study protocol and analysis. These collaborators have been specifically

Timescale/plan

- Start date: 1st July 2012
- MPD patient/control recruitment: Jan 2013
- Target numbers achieved: Dec 2013
- Data analysis/protocol development: 2014/15
- Applications for funding for the UK wide study: Beginning 2014

chosen as they are the leading experts in their fields and their expertise will ensure the successful implementation of the project.

What steps will the research go through?

The development of the study protocol and questionnaire are well underway with input from our local and international team of investigators. Patients with MPDs will be approached and asked to participate in the study in addition to members of the general public. Participants will be asked to undertake a telephone interview lasting approximately 1–1.5 hours and to provide one or more of the following biological samples: whole blood, dried blood spots, saliva, urine and toe-nail clippings (for elemental analysis). Following the recruitment phase the team of investigators will analyse the outcome of the pilot study and finalise the UK-wide study protocol.

What might determine the success or failure of the study?

Participation in the study by patients with MPDs and the general public is fundamental to the success of this project. Sufficient funding for the pilot study and later the UK-wide study will ultimately determine its success.

Editor's note: We are launching a fundraising campaign to reach a target of £100,000 towards this exciting research – visit our website for further details.



Charity number
251983

Health matters – Pruritus

At patient forums, questions about itch are probably one of the most common, and it's well documented that itchy skin is a common symptom of MPDs, in particular in polycythaemia vera (PV).

Pruritus is defined as an unpleasant itching sensation that leads to intensive scratching.

MPD patients often suffer from water-induced itching, (aquagenic pruritis). Patients report feeling moderate to severe itching, burning, pricking or stinging after contact with any type or temperature of water. A bath or shower, a swim in the sea or a swimming pool, and even sweat can provoke the symptoms. Arms, legs and trunk are usually the worst affected. Symptoms can be seasonally dependent and vary from summer to winter.

Some patients have found non-medical ways to relieve these symptoms. There are no guarantees that these will help everyone, but if you do suffer with itch, it may be worth considering some of these ideas submitted by MPD patients.



Louise Broughton

Louise Broughton, a PV patient diagnosed 2 years ago says, 'Aqua/aquagenic pruritis is a big pain in the butt! Since I was diagnosed, I've gradually eliminated anything that makes

me itch. At its worst it has been known to reduce me to tears. (Not easy for someone who gave birth to a ten pounder without pain relief... I would choose the latter over pruritis anytime).'

Louise shares some tips that have helped:

- Not showering/bathing but using either a bidet, or if unavailable/away on holiday, just a couple of inches in the bath to sit in. Legs, arms, neck, torso and back are cleaned/wiped gently with baby wipes.
- Washing hair over the bath.
- No swimming.
- Avoid leg waxing. Even shaving legs can spark off a bad bout of itching. A spoonful of Piriton about 30 minutes beforehand helps.
- Always use some sort of cream daily on arms and legs – e.g. Vaseline Intensive Care.
- Drink at least 2½ litres of still water a day, on top of other hot/cold beverages.
- EXERCISE!
- Avoid excess sugar. Chocolate in a large quantities seems to start off itching, as does constipation.

- Tights. 7 denier cool wear for summer, and in the winter the 'Nora Batty' type 100% cotton.
- Rubbing/massage/spa treatments are a no-no, with the exception of facials.
- SUN! After a week in Andalucia the itch disappeared (see editorial on Phototherapy).
- Piriton syrup. One teaspoon, not every day, but when the itch starts up.
- Avoid rushing about and try to avoid stress.
- Overheating in bed and scratchy bed linen can also set off a bout of itching. For holidays, Louise ensures that she packs a low tog duvet and Egyptian percale sheets and duvet cover, washed in Eco organico anti allergy liquid detergent.
- Her final tip is 'If you do itch – try not to scratch or rub the affected area, simply press firmly – or go for a run!'

Phototherapy alleviates Aquagenic Pruritus

Lynda Taylor, another PV patient shares her experience of managing itch. Lynda says, 'I was diagnosed 6 years ago and in the last 18 months have had a very severe form of pruritus – a stinging, pricking and burning pain as soon as my skin gets cool or cold. Ordinary daily personal tasks became difficult and painful, e.g. dressing and undressing, getting into a cold bed or entering a cool or air-conditioned space. Worst of all was bathing or showering. In fact I had to give up showering, swimming and wearing summer clothes. Even the cooling effect from my own sweat drying on my skin made my body hurt.

At the suggestion of my haematologist, I tried various medications and all the advice available about ways to take a bath in the hope of reducing the reaction. We even tried doing fewer venesections as he thought that I might be mildly anaemic and people with anaemia sometimes experience pruritus. None of these treatments worked and we seemed to have run out of options.

In desperation my husband and I went back to the internet for help and did some searches on aquagenic pruritus. After a while he found two very helpful reports/papers which we took to my GP. She agreed to refer me to a consultant dermatologist who in turn agreed that my condition was severe and that I should start a course of narrow band UVB phototherapy.

I have been attending a dermatology unit since then and have two treatments per week. You undress completely and enter a lightbox. The first treatment lasts 15 seconds and then is increased each time. The aim is to produce a mild reddening of the skin without burning.

Once some reddening started to happen, my symptoms began to lessen. This took about 12 treatments. Before phototherapy, on a scale of 1–10, the pain that I experienced I would rate as a 9 or 10 and after 20 treatments it reduced to about 1.

I completed a course of 25 sessions but found that when I stop having the phototherapy, within two weeks the pruritus returns to full strength. However, if I continue with the therapy, the amount of discomfort can be kept to a manageable level and I can get on with normal life. Bathing or showering are still difficult, but I am much more comfortable than I would be without the treatment. So, even though phototherapy has not been a cure, it has improved my quality of life substantially.

For me this result is fantastic and if you know of anyone who is struggling with this condition, then perhaps narrow band UVB phototherapy will help them too.'

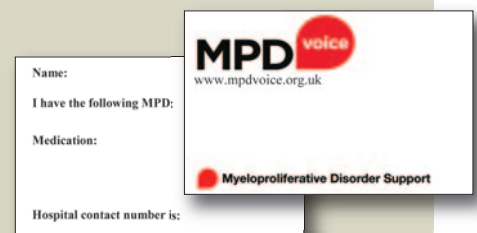
Thanks to Louise and Lynda for sharing their tips and experience of this side effect of MPD. If you have any other suggestions please remember to share them with us – email: info@mpdvoice.co.uk – subject 'itch tips'.

Visit the MPD website for more hints and tips on this topic.

Editor's note: If you do have problems with itch and can persuade your GP that this is related to your MPD, you may have a case to obtain certain itch creams/remedies as part of a prescription, which for MPD patients should be free/exempt from charges.

Get the latest newsletters, patient leaflets and new medical alert cards

Treatment leaflets and newsletters can be downloaded from the website or we can post copies to you. We also now offer patient information/medication cards.



Name: _____
I have the following MPD: _____
Medication: _____
Hospital contact number is: _____

MPD voice
www.mpdvoice.org.uk

Myeloproliferative Disorder Support

This is credit card sized and a useful way to ensure MPD patients are treated appropriately if they need emergency medical care. If you would like a medical alert card, please contact info@mpdvoice.org.uk

Drug trials

Dr Claire Harrison updates MPD Voice on one of the latest new trials...



'A new trial is starting very soon using the JAK inhibitor ruxolitinib. This study, so-called MAJIC, will be open in lots of centres in the UK and we hope to reach some patients via MPD Voice.

In previous articles we have covered the benefits of ruxolitinib for patients with myelofibrosis (MF). Now we want to move forward and test this drug in patients with polycythaemia vera (PV) and essential thrombocythaemia (ET).

Ruxolitinib is a tablet that is very well tolerated. It reduces and controls blood counts and can help greatly with symptoms of MPD such as itching, weight loss and sweating. We are looking to test the drug compared with standard treatments in ET and PV patients who are not getting good control of their disease, e.g. a high platelet count, increased need for venesections or a blood clot, despite treatment with hydroxycarbamide (or hydra). Patients with side effects from hydroxycarbamide, such as mouth or leg ulcers will also be eligible. Plus you won't need to have had these problems right now, you could have had them a while ago.

The study will last for 5 years and will be carried out at between 25 and 30 centres in the UK. It will start in June 2012 and 290 patients will be recruited.

Dr Harrison concludes, 'This is a very exciting opportunity to test this drug in a real setting and compare it to everyday therapies.'

Editor's note: Visit the MPD Voice website for more details and an update list of participating hospitals.

The study is partly funded by Leukaemia and Lymphoma who fund a TAP initiative (therapy acceleration programme), which aims to bring treatments to patients faster. This is the first study in this programme.

MAJIC

TAP
From Leukaemia & Lymphoma Research

Don't worry! Be happy!

patient
story



Tim Ellis, 52, married and a proud father of 3 children aged from 6 to 23, shares the background to his decision to have a bone marrow transplant...

After the birth of our first child Gemma in 1988, I started to feel very tired and apathetic. Believing this to be normal for such a change in lifestyle, like most would do, I just carried on. Fortunately, my elder brother Simon was not convinced and as a rather unique Christmas present sent me off for a full private health assessment. My blood tests revealed an elevated platelet count.

At St Barts, the myeloproliferative disorder essential thrombocythaemia (ET) was confirmed and, with a platelet count in excess of 1.1 million, I was quickly prescribed hydroxycarbamide (HU). I was somewhat concerned, given the close links it has with leukaemia and the fact that my father died at St Barts at 48 from acute myeloid leukaemia.

Over the following years I was prescribed various drug options available to manage my condition including hydroxycarbamide, anagrelide and interferon, the latter which I took for 8 years before experiencing tiredness, irritability and becoming withdrawn.

17 years later, I was told that my ET had progressed to myelofibrosis (MF). Five years after that my blood counts became unstable and I was told that my MF condition had deteriorated to the point where it was becoming unmanageable with drugs alone.

The latter half of that year was very worrying as we explored what best to do. By this stage I was feeling particularly poorly and the

prognosis was that it could be mere months before I died.

I had two choices: blood transfusions or a bone marrow transplant (BMT). Given that transfusions could only ever be short term and may also lead to a more risky BMT later, I opted for the BMT.

I was fortunate to achieve an excellent donor match and eventually received a stem cell transplant last June at Addenbrooke's in Cambridge – eleven months on I feel the best I have in many years! However, I know that my body is still in the recovery process and I face further treatment to fine tune my body's acceptance of the BMT.

In sharing my experiences with other MPD patients I would encourage them to be aware of the potential long-term effects of some of the medications available. I believe not having a bone marrow biopsy between 1989 and 2005 was a mistake and also question whether I should have taken anagrelide for the length of time that I did; although I realise that we are all different and that we tolerate and react to these various drugs in very different ways.

I'm remaining optimistic and know that I'm lucky to be the husband of a caring wife, Sally-Jane and the proud father of Gemma, Tristan and Theo and therefore have a lot to live for. I'm immensely grateful to the staff of Addenbrooke's, to my friends and family and of course, to my stem cell donor.'

Editor's note: I'd like to personally thank Tim for his openness, wisdom and encouragement to me on my own ET journey. Thanks ☺.



Fundraising – make a difference in 2012

MPD Voice currently funds regional patient forums, newsletters and patient information leaflets, as well as contributing to MPD research and drug trials. This is possible because of the many ingenious and challenging fundraising activities undertaken by our generous supporters. Often, we don't get to hear about what you've been doing, but we do regularly receive donations at events and via the website so THANK YOU and WELL DONE.

Top shot – Lady Captain, Trish

At a recent patient forum, we were delighted to receive a generous donation from Trish Sweeting for £2,705. Trish, a MF patient for over 5 years, raised the money in her role as Lady Captain in 2011, at The Oaks Golf Club, Aughton, East Yorkshire. The money was raised from numerous events and dinners, the main one being "Ascot at The Oaks" which was held in a marquee at the side of the golf course. MPD Voice would like to thank Trish for this great achievement particularly as, like many MF patients, she has had to deal with constant fatigue and health challenges, as her medication and treatment regime are revised and reviewed.



Patient and fundraiser Trish Sweeting – great golf and a superb result for MPD Voice!

Forums Listen... chat... be informed... get support...

Our forums are a great way to hear about the latest research, meet other patients and their families and feel part of a community. Here are some comments from one of our recent regional forums:

'I just wanted to email you to say what a great job you did on the first Cambridge regional event! Well done! It was excellent, superb, a really good night. ... It means a great deal to the patient group to have the forum and also the charity ... brilliant question and answer session ... brilliant night, good food and nice to meet other people.' **Scott**

'Just to say how much I enjoyed the Cambridge forum. It was interesting and informative plus I was able to talk to people who understood what it's like to suffer from PV.' **Cheryl**

'I found the session very informative. I think it helped me to put my situation in some perspective and I have taken some very positive messages from it.' **John**

Forthcoming forums 2012

Belfast 17 May 2012
London 21 May, 21 Nov 2012
Edinburgh 28 June 2012
Cardiff 4 October 2012

With thanks

MPD Voice would like to thank The Samuel Sebba Charitable Trust for their generous financial support, which has enabled us to increase the number of regional forums for patients in 2012.

Please do contact us with any ideas for other regional forums/fundraising events etc info@mpdvoice.org.uk

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



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
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We welcome your letters and feedback. Please send by post or to 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 or visit their website for more information: 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.



Alisia O'Sullivan

Stop press...

Eileen MacLennan, whose uncle has MF, has already raised over £1000 in sponsorship for a forthcoming 10k race in Glasgow. If you're not up to a physical challenge, why not sponsor her?

It's all for great cause. <http://uk.virginmoneygiving.com/EileenMacLennan>



Eileen MacLennan

Fundraising Diary Dates

Whether you feel energetic or want to nominate one of your family, colleagues or friends to fundraise for us we have an exciting range of events for you to choose from:

- **London to Paris Cycle Ride** Weds 6 – Sun 10 June 2012
- **The London Nightrider** Sat 9 June 2012
- **Sky-dive** Sat 16 June 2012
- **The Three Peaks Challenge** Fri 22 – Sun 24 June 2012
- **Abseil Kings College Hospital** Sun 1 July 2012
- **Mt Kilimanjaro Climb** Weds 11 – Sun 22 July 2012
- **London to Brighton Cycle Ride** Sun 16 September 2012

Details can be obtained from Rachel Bridgman who co-ordinates all our fundraising. Email her on fundraising@mpdvoice.org.uk or visit the website to register for any of these events www.mpdvoice.org.uk



Rachel Bridgman

