

COBALAMIN NEWS

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Society at Critical Crossroads

The Pernicious Anaemia Society is asking for members for their help to ensure they can continue its work to raise awareness of the condition and its treatment, as well as support sufferers and their families.

“Telephone enquiries that lead to letters of support and complaint have now reached a level that have stretched the society’s resources to breaking point and this, together with the need to keep pushing our cause onto the health agenda means that the time has come when it is no longer possible for us to rely on the small band of volunteers to meet the increasing demands of our continually growing society, said Martyn Hooper, chair of the society.

“Unless we are able to secure funding to employ professionally qualified specialist administrators and a Chief Executive it is highly likely that the society will cease to exist in the New Year,” he added. The society needs to secure funding to employ three part time positions. It hopes to employ specialist help to secure vital funding and grants to make it possible to get the society in shape to face the challenges ahead.

Said Martyn, “We thank all those who have supported us over the years and please know we do appreciate that not everyone can commit to a regularly contribution, but hopefully many can and even just £1 a month can add up if enough of our members can help.” £1 a week from those members who can afford it will enable the society to answer more calls and emails from those sufferers that need advice or a sufferer in total despair because their injection has been stopped or reduced. It will also allow the society to continue to engage with the medical community and legislators.



Annual General Meeting

The Pernicious Anaemia Society is holding its annual general meeting at 10:30am on Saturday, 31 October 2015 at the Macdonald Burlington Hotel, Burlington Arcade, New Street, Birmingham B2 4JQ.



Our new ambassador, Dr Chris Steele will be attending the event. There will also be representatives from the B12 Deficiency Support-Group; the Chair, Mrs Susan Peacock, and Chief Executive, Dr Hugo Minney.

We hope you can come along and find out more about the work of the society and meet fellow members and volunteers.

How you can help

- Download a standing order form from the society’s website . £1 a month could make all the difference and a standing order is the most cost effective way for the society to receive funds).
- If you prefer you can donate to the society directly via [Just Giving](#) or [support one of our fundraisers](#).
- Alternatively, check out our [website](#) for other ideas like collecting mobile phones, cartridges etc.
- Producing and sending paper versions of the newsletter is more costly than sending them by email. If you now have an email but still get a paper version please consider changing your delivery option.
- Still want a paper version? Please consider making a donation to cover the cost of your newsletter.

Calling all students

Do you have Pernicious Anaemia and are concerned your teachers or tutors don’t understand?

The Pernicious Anaemia Society has published a new leaflet to help address this issue. It explains some common symptoms of the condition that may impact on students.

Any educator who wants to know more about the condition or who has concerns about a student can contact the society for more information.

In this issue

- Parliamentary update
- Fundraisers success
- New PASOC leaflet
- Martyn Hooper’s new book
- Support group news

Fundraisers' Gallery

Tough Mudder Successes

Well done and grateful thanks to Katie McMullin and Ryan Lane who both completed the Yorkshire Tough Mudder Challenge on behalf of the society.



Katie gets stuck in

Thames Path Challenge

Jessica Sandi raised over £500 for taking part in 100k Thames Path Challenge for PAS in September. A big thanks and well done.

Unfortunately Jessica was forced to pull out halfway through the challenge thanks to a dislocated knee. She had gone 10 miles in this state. Ouch! Hope it feels better now Jessica.



Jessica and friends

Get in touch

If you're planning on raising funds for the society please let us know so we can give you the credit you deserve.



What you **NEED** to know!

33% of patients waited five years or more for a diagnosis

44% of patients were initially misdiagnosed

64% of patients are unhappy with their treatment¹

Get informed: the new Pernicious Anaemia Society leaflet available from October

New Leaflet

The Society has produced a handy new leaflet about Pernicious Anaemia. It introduces the latest BCSH Guidelines, symptoms of B12, treatment options and also shares some of the latest B12 statistics in a bid to dispel some of the commonly held misconceptions about the condition.

Useful to share with health professionals, family members and friends – as well as those who may have the condition and want to know more. Leaflets will be available to collect at the society's AGM in October.

News from the Midlands

The inaugural Leicester & East Midlands support group meeting has been heralded a great success and further meetings are planned for Saturday, 26 September and Saturday, 24 October.

The monthly meetings are open to all of the East Midlands or the surrounding Counties of Leicestershire and all are welcome.

All who attended were pleased to meet others with the same condition, for most it was the first time they had talked to anyone with the same illness and found it really supportive. "We are not alone" as our saying goes and all found support in the fact that we had all encountered the same problems with lengthy diagnosis and treatment," said Frank Chafer, support organizer and coordinator.

You can contact Frank at the Leicester & East Midlands Support Group by emailing: leicestershire.pas@gmail.com

Other support groups include: Worcestershire worcestershire.pas@gmail.com, Isle of Man pas.b12iom@gmail.com

Countess's Parting Shot in PA Battle

We would like to record our thanks for the efforts of the Countess of Mar in seeking to get answers relating the diagnosis and treatment of Pernicious Anaemia in the House of Lords. Back in July, before she retired from campaigning, she asked further questions of Her Majesty's Government:

1. What action they are taking to address the problems associated with the late diagnosis of pernicious anaemia following the publication of the results of a survey published in the British Nursing Journal in April 2014.
2. How they propose to alert medical practitioners to the severe and irreversible nerve damage that can occur if pernicious anaemia is misdiagnosed as ME/CFS, depression, hypochondria or multiple sclerosis

The response from the Department of Health, represented by Lord Prior of Brampton, acknowledged the difficulty in early diagnosis and clarified the independent role of the BCSH and the evidence-based guidelines. He also referenced their acknowledgement that there 'no gold standard test for the condition' and that 'the clinical picture of a patient is the most important factor in assessing the significance of the test results.'

He did not, however, offer a solution to the problem of making primary care physicians aware of the BCSH recommendations. To find out what is being done to address this issue read our New App for GPs article.

The full response to the questions, made by Lord Prior of Brampton on behalf of the Department of Health, and Martyn's thoughts on it can be found on his blog www.martynhooper.com



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Martyn's New Book

Martyn's new book on Pernicious Anaemia will be launched at the AGM in Birmingham. '

What You Need To Know About Pernicious Anaemia and Vitamin B₁₂ Deficiency' is published by Hammer-smith Health Books and is available in advance of publication on Amazon. Martyn will be signing copies of the book at the AGM.

What You Need to Know About

PERNICIOUS ANAEMIA & VITAMIN B12 DEFICIENCY

Martyn Hooper

FOREWORD BY DR CHRIS STEELE MBE

New App for GPs?

The society is working on producing a downloadable app that GPs can use to get to know the new BCSH guidelines.

We'll keep you updated on the progress of this app so you can keep your doctor informed.



B12 Conference, Nancy, France

Back in July, Martyn Hooper represented the Society at the international B12 Conference, Nancy, France.

Over 140 delegates attended the 10th International Conference on One Carbon Metabolism, B Vitamins and Homocysteine at the Medical School at the University of Lorraine.

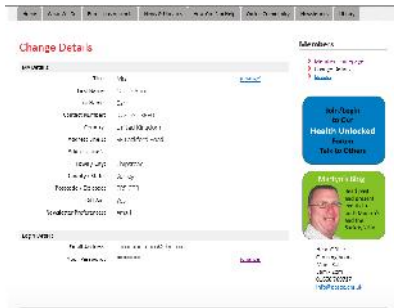
"Although a great deal of the science was above my head, it was great to attend the conference to gain awareness of the work that is going on around the world to improve our knowledge of this condition we all battle with," said Martyn.

A list of the papers presented at the conference can be found on Martyn's blog.



Online Members

Please login regularly to the PAS site to check your contact details are up to date and that you have looked around our members homepage and see if there are any surveys that you may like to take part in.



Having problems logging in?

We have received some correspondence from members saying they have had problems logging in recently. Please note that if you have not logged into the current website you need to log in using the **email address** you signed up with and your **password**. If you are still struggling there is an opportunity to be reminded or change these.

Volunteers needed

Are you an experienced corporate fundraiser or skilled at database analysis? We want to ensure the society is 'Fit for the Future' and need your help. If you can spare even just a little time please call for a chat to see how you can make a difference.

Got other skills you think can help the society? We'd love to hear from you too!

About us

The Pernicious Anaemia Society was formed in 2006. It is based in Bridgend, south Wales in the UK. It is a registered charity (No. 1147839) and is a limited liability company (Reg. no. 07904047).

Overall responsibility for the society rests with eight trustees. The society is run entirely by volunteers. Day to day decisions are made by the Executive Chairman.

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