

# Cobalamin News

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## PA Soc. Hosts March Conference

The Pernicious Anaemia Society will be holding a conference at Bryngarw House, Brynmenyn, Bridgend, South Wales, UK on 13th March 2010 at 9:30am-3:30pm.

Following on from the highly successful Spring seminar that was held last February the PA Society is hosting another event that will, this time, be more in the form of a conference.

The conference will be about recent developments in the treatment and diagnosis of Pernicious Anaemia. The event aims to bring together scientists, doctors, patients and other interested parties so that ideas, innovations and examples of best practice can be disseminated.

A list of speakers includes: Dr. Edward Valente, Marketing Manager of Axis-Shield, Dr.

Siddharth Banka who is conducting research into the genetics of PA at Manchester University, and a Medical Negligence Solicitor who was a consultant Haematologist before becoming a

lawyer. Dr. Chandy will also be there. The event has been organised by volunteers of the society who were successful in obtaining a grant that has helped to pay for what will undoubtedly be a highly successful conference.

There are a limited number of places available and the conference is free to members. Free Refreshments will be provided Lunch is available at a cost. We will need to know if you plan to attend and if you would like the



Bryngarw House—the conference venue

buffet lunch. If you would like to reserve a place please contact us as soon as possible as places will be allocated on a first come, first served basis.

**You can reserve your place or places by either telephoning the office on 01656 724163 or emailing Kim using the email address [kim@pasoc.org.uk](mailto:kim@pasoc.org.uk).**

When you contact us please inform us of any special dietary needs that you may have or if you have any other special requests.

## Methylcobalamin Infusions

The society has been receiving many requests for information about Methylcobalamin infusions. The society has now produced an information leaflet that gives details of the process along with a contact point that can provide a list of practitioners who offer infusions.

The Pernicious Anaemia Society does not recommend this par-

ticular treatment but believes that members should be made aware of this alternative treatment that is available only in the private sector in the UK. Many members report almost miraculous improvement in their well-being after receiving an infusion while other report no change in their condition.

Your doctor is the best person

to advise you on any medical matters, including Methylcobalamin infusions, and you should always discuss this matter with him or her before proceeding. You should also ensure that the persons providing the infusions are qualified doctors and members of a professional medical organisation, such as the G.M.C.

## Petition and Government Responses



Readers may well remember the flurry of political lobbying that took place in Autumn last year. As well as a Number 10 e-Petition we also held a Parliamentary reception in the House of Commons and another reception at the Welsh Assembly. We also had an Early Day Motion tabled that attracted over 80 signatures from MPs and led to an adjournment debate by Madeline Moon MP.

The Number 10 petition led to the Department of Health issuing a reply that stated, quite categorically, that the National

Health Service should treat each individual according to his or her needs. The reply suggested that the treatment patients receive should not be 'narrow' and individuals shouldn't be made to fit into locally produced treatment regimes.

All of this political activity has helped raise awareness among politicians of the plight of many patients of Pernicious Anaemia. This awareness raising provides the society with credibility and has led to letters being written to the Secretary of State for Health and the Chief Medical

Officers for England, Northern Ireland, Scotland and Wales pointing out the problems with the symptoms, diagnosis and treatment of PA.

Another Early Day Motion (number 49) is also currently available for MPs to sign. Please ask your MP to sign the petition if you haven't already done so. We will let you know the responses we receive to the letters that have been sent.

The e-Petition can be found online by copying and pasting the following link into your Internet address bar: <http://petitions.number10.gov.uk/B12Treatment>

*"Thank you to all those members who have made donations to The Pernicious Anaemia Society."*

## Generous PAS Members

The Pernicious Anaemia Society are exceedingly grateful to the number of members who have donated money to the charity.

Over the past month we have been the beneficiaries of the generosity of many of our members who have made donations to the society. Following our urgent appeal in the last edition of the newsletter these donations have allowed us to keep pro-

viding information, advice and guidance to our members for the immediate future. However, the medium and long-term financial viability of the society is still precarious.

A special thank you to a member, who wishes to remain anonymous, who donated a whole months rent for our small office.

We appreciate every penny that was donated by everyone

and we will ensure that by keeping running costs to a minimum all of our income will be used to benefit our members.

As well as donations from UK members many of our supporters were from outside the UK including three separate donations that were the result of special fundraising events.

If you would like information on how you can hold such an event please contact us so we can help.

## PAS Gets its First Employee

The Pernicious Anaemia Society is pleased to report that on the 4th January we received our first employee.

Kirsty Perkins is the lucky candidate that has made the leap from volunteer to employee through the Future Jobs Fund.

The Future Jobs Fund is run by the Department of Work and Pensions (DWP) in order to create additional jobs aimed at 18-24 year olds.

A number of candidates applied for the administrator position along with Kirsty. Kirsty went through the same application and interview process as the other candi-

dates and we are pleased to say she came head and shoulders above the rest.

"Working for the PAS is a very interesting experience and I am glad I got the vacancy", Kirsty admits.

Our congratulations go out to Kirsty from everyone at The Pernicious Anaemia Society.

**Kirsty Perkins  
hard at work  
in the PAS  
office**



# Active B<sub>12</sub> Research Application



The PAS's constitution states that as well as providing information, help and support to our members the society is also obliged to identify researchers and research programmes to instigate research into the diagnosis and treatment of Pernicious Anaemia.

The society has been busy in fulfilling its obligations to research and has placed three research suggestions with the National Institute for Clinical Excellence.

The Chairman of the society is a member of the National Institute for Health Research's Diagnostic Technology and Screening panel (part of The Health Technology Assessment programme). This panel identifies prospective research proposals presented by various individuals and organizations. The panel has an annual budget of over £75 million. All members of the panel are encouraged to produce three to four re-

search proposals every year. At the time of going to press a research request has been presented that asks for an investigation into the benefits of distinguishing between active B<sub>12</sub> (Holotranscobalamin) and inactive B<sub>12</sub> (Holohaptocorrin). If accepted this research proposal will be voted on when the panel next meets in April 2010. However, another two hurdles will have to be overcome before final approval is given. If any member identifies a potential research topic please let us know so that we can identify a suitable research programme to apply for.

**“We would like to establish support groups of fellow sufferers in your area”**

## Regional & International Groups

The membership of this society continues to grow by an average of three to five new members every day. We now want to encourage members to set up a regional or local support group based on a geographical area.

We already have one regional support group operating in Surrey where patients have benefitted enormously by talking to other members who face the same problems relating to the diagnosis and treatment of Pernicious Anaemia.

There is also an established B<sub>12</sub> Deficiency Support Group in Co. Durham that is independent of this society.

The society can help you establish a group by providing you with contact details of members in your area. We will, of course, seek each member's permission for us to provide the voluntary organiser with his or her contact details.

We can also help you to promote your group by providing you with

posters and flyers for you to display in your vicinity.

We would also like to establish groups outside the United Kingdom so if you are one of our many readers that live outside the U.K. please consider setting up a group with your fellow countrymen and women.

If you would like to organise such a group in your area please get in touch so we can help and advise you further.

## ‘Name the Teddy Bear’ Fundraising Event

A number of countrywide companies based in Bridgend, South Wales have been contacted by The Pernicious Anaemia Society in order to get them involved in a ‘Name the Teddy Bear’ fundraising scheme for the PAS.

This competition will invite members of the public to guess the name of a cute fluffy teddy bear that the winner can claim. The

Pernicious Anaemia Society relies entirely on donations to provide a much needed service so a fundraising event such as this is a very important opportunity to the society.

All companies that become involved in this ‘Name the Teddy Bear’ fundraising scheme will be publicised on our website and their kindness will also be re-

ported in future editions of our newsletter.

If you know of any companies that would be interested in becoming involved in this fundraising scheme for the society then please contact Kirsty on 01656 724163 or email [kirsty@pasoc.org.uk](mailto:kirsty@pasoc.org.uk).



The Pernicious Anaemia Society

The Old Fire Station

Pandy Park

Aberkenfig

BRIDGEND

CF32 9RE

U.K. **Tel. 01656 724163**

United Kingdom

Tel. (44)(0)1656 724163

Fax. (44)(0)1656 724810

#### Main Contacts

**Chair** - Martyn Hooper

chair@pasoc.org.uk

**Secretary** - Michael Stevenson

secretary@pasoc.org.uk

**Treasurer** - David Connell-Smith

treasurer@pasoc.org.uk

**Membership Secretary** - Alex Critchlow

membership@pasoc.org.uk

**News Editor** - Kimberley Epton

kim@pasoc.org.uk

**Canadian Delegate** - Pat Kornic

canada@pasoc.org.uk

**American Delegate** - Ian McLean

usa@pasoc.org.uk

**Mid-East Delegate** - Fatima Parker

mideast@pasoc.org.uk

**Australian Delegate** - Daisy Loader

aus@pasoc.org.uk

## New PA Booklets

A new development for the society has come in the form of a grant offer which will allow us to produce new information booklets on Pernicious Anaemia.

Last month the PA Society applied for and was successful in receiving a grant courtesy of the Big Lottery Fund. This grant is to be used to create updated bilingual information booklets on Pernicious Anaemia. These booklets will be distributed to both new and existing members. The booklets will also serve as literature to enlighten the public on the condition and treatment of PA.



**ARIENNIR GAN Y LOTERI  
LOTTERY FUNDED**

The booklets also offer an opportunity to the society's members to get their personal short stories on living with PA publicised.

If it's the truth we'll print it, we want your stories! Members who are willing to have their personal accounts published in the booklets should contact Kim with their stories via post to the Bridgend office address at the top of this back page or email [kim@pasoc.org.uk](mailto:kim@pasoc.org.uk).

## March Conference Schedule

We are pleased to confirm the following schedule for our Spring conference 2010

**Date:** Saturday 13th march 2010

#### **Timetable of Speakers:**

**8:45** Registration and tea and coffee

**9:20 Madeline Moon MP:**

**Welcome address**

**9:30 Chairman's address:**

**'PA Society membership update'**

**10:00 Dr. Joe Chandy**

Shinwell Medical Practice Co. Durham:

**'Vitamin B<sub>12</sub> Deficiency - Unresolved Issues and the Clinical Evidence'**

**11:00** Tea and Coffee

**11:30 Dr. Edward Valente**

Marketing Manager Axis-Shield Diagnostics Ltd:

**'Active B<sub>12</sub> - The Next Level of B<sub>12</sub> Testing'**

**12:30** Lunch and optional guided walk

**13:30 Dr. Siddharth Banka**

Department of Medical Genetics, Manchester University

**Update on the Research on the Genetics of Pernicious Anaemia**

**14:15 Mr. Andrew Thomas**

Medical Negligence Solicitor and former Haematologist:

**'Medical Negligence and Pernicious Anaemia'**

**15:00 Mr. Jeffery Spector**

Methylcobalamin Infusion Advocate:

**Closing address**

**15:10** Tea and coffee and evaluations

Following the conference at around 4pm there will be a meeting of the Trustees of The Pernicious Anaemia Society that you may attend should you wish.