

Special Yule-Tide Issue

Cobalamin News



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SPECIAL POINTS OF INTEREST:

- **Axis-Shield** develop new B₁₂ test.
- **Welsh Assembly Reception**
- **MP re-tables Early Day Motion**
- **Chris Parker to run London Marathon for PAS**
- **PAS achievements of the year**

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New Active B₁₂ Test

A new test has been developed that distinguishes between the two types of vitamin B₁₂ in blood.

As reported in the last newsletter this test provides a much more accurate indicator of the amount of B₁₂ that is *active*.

Axis-Shield is the company responsible for developing the test. "It has long been known that the measurement of the total amount of B₁₂ in a patient's blood is not a reliable indicator of vitamin B₁₂ status", says Edward Valente, Marketing Manager at Dundee based Axis-Shield Diagnostics. "This new Active B₁₂ test distinguishes between the biologically active B₁₂ (holotranscobalamin) and the inactive B₁₂ (holohaptocorrin). We know that normally only around 20% of circulating B₁₂ is in the active

form and that the levels of this form change much quicker than the inactive form", says Edward.

This breakthrough in diagnosing B₁₂ deficiency might explain why some of our members may display all the symptoms associated with Pernicious Anaemia and B₁₂ Deficiency whilst their total serum B₁₂ levels are well above the lower threshold used to traditionally diagnose deficiency.

This new diagnostic tool has been subject to intensive evaluation by Axis-Shield and collaborators in clinical laboratories worldwide. The test has been adopted for use in Germany, Switzerland, Holland, and Australia amongst others.

The Pernicious Anaemia Society thoroughly endorses this active B₁₂ test and we shall start cam-



paiging in the New Year to get the NHS to adopt it as a replacement for the existing total serum B₁₂ test that is 50 years old.

The biochemistry involved in the new test is, as you'd expect, incredibly complex. However, we do have hand-outs that explain the test in greater detail and these are available to members of the PAS society on request. Please see contact details on the back page of this newsletter and please consider making a donation towards the postage costs involved.

PAS Aims for *Information Standard*

This society provides an enormous amount of information about Pernicious Anaemia to sufferers of the condition and to their family and friends. This information, along with advice and support, is available in many formats including our leaflets, telephone helpline, online information and the online forum.

Along with many other charities working with patients we do our best to ensure that all information that is available is accurate and reliable.

A new initiative by The Department of Health aims to ensure that all information distributed by charities and patient groups is trustworthy.

This society is about to start the process that will hopefully lead to it achieving the **Information Standard** awarded by The Department of Health. This is given to charities that have a robust quality control system in place that guarantees only accurate information about Pernicious Anaemia is provided to its members.

“The assembly now makes all decisions relating to health in Wales.”

“Over 70 MPs have already supported the call for a Review of the Symptoms, Diagnosis and Treatment of PA.”



Chris Parker

News from the Welsh Assembly

Martyn Hooper, Chair of The Pernicious Anaemia Society, along with a few volunteers from the charity, attended a reception at The Welsh Assembly Government building in Cardiff on Wednesday 25th November 2009.

The reception was headed by Martyn who offered a presentation to several Welsh Assembly Members (A.M.s) that called for a Review of the Diagnosis and Treatment of Pernicious Anaemia. Amongst the A.M.s was Peter Black,

South Wales West Liberal Democrat, and Dr. Dai Lloyd, Plaid Cymru Spokesman for Social Justice, Local Government and Regeneration. Dr Lloyd also tabled a Statement of Opinion that calls for a review of the diagnosis and treatment of P.A.



The betterment of ‘the lives of people in Wales’ is a key ingredient of the Welsh Government’s objectives.

As a result of Wednesday’s reception, which offered a thorough update on the wishes of The Pernicious Anaemia Society, is just one step further to the charity’s push to renew the treatment of PA and the quality of the lives of patients that could hopefully become an international accomplishment.

Early Day Motion & e-Petition

We are pleased to report that Doug Naysmith, MP, has re-tabled the original Early Day Motion in the UK’s Parliament.

The original Early Day Motion (EDM) acquired 87 signatures from MPs, which was a much higher number than we had originally hoped for. However, it had to be withdrawn when Parliament went into recess. Thankfully Mr. Naysmith re-tabled the EDM

and at the time of writing 81 Members of Parliament, who are not members of the Government, have called for the Review into the Symptoms, Diagnosis and Treatment of Pernicious Anaemia.

Please write to your MP and ask him or her to support Early Day Motion number 49.

You, your family and friends might want to show your support for the society’s no. 10 e-Petition that calls for the

introduction of a treatment regime based on the individual needs of the patient. If you haven’t already signed the petition you have until the 18th February 2010 to do so. The petition can be found online by copying and pasting the following link into your Internet address bar: <http://petitions.number10.gov.uk/B12Treatment>

Unfortunately only UK citizens can sign.

Chris Parker to Run London Marathon 2010

The Pernicious Anaemia Society has paid £345 towards being allocated a place in the London Marathon on 25th April 2010.

The running entry we have been given is to be filled by Chris Parker. Chris Parker is a 25 year old Masters graduate from King’s College in London. Upon learning that

his mother had been diagnosed with PA, Chris was inspired to find out more about the condition.

“If I can raise awareness and support for the condition ultimately benefitting my mother and other sufferers, then I will endeavor to generate as much money as possible and run my heart out”,

says Chris.

Of course the society will be offering lots of support to Chris in his running of the marathon.

To sponsor Chris please visit the PAS website or contact our office on 01656 724163.

A Call to Members of the PAS



If you are one of the 3,000 odd members who joined online, you may have had an email from Jan, one of our volunteers, asking you to supply us with your telephone contact details.

The reason we are doing this is to allow us to contact you quickly

should something be happening in your area. For example, if a support group was forming in your area then we would telephone you to ask if you would be interested in going along to the first meeting.

Telephone numbers tend to remain the same, while email addresses change and there is no sure way that we are able to establish if you have received our email.

Telephone contact details are asked for when members sign up to The Pernicious Anaemia Society, but it is left to the discretion of the applicant as to whether or

not that information is given.

As a society we operate within our Data Protection Act policy and we are registered on the Data Protection Register at the Information Commissioners Office. We never ever pass on your information to third parties unless you specifically request that we do so.

Please consider providing us with a telephone contact number so that we can contact you speedily should we have reason to do so.

Please contact Jan on 01656 724163 or email

jan@pasoc.org.uk.

“3 out of the 4 objectives from the last Strategic Plan were met.”

Future Strategic Plan

At the time of writing a new Strategic Plan is being written. The Strategic Plan sets out the aims of The Pernicious Anaemia Society for the next three years.

As part of the process the previous Strategic Plan is reviewed and a report is produced for the Trustees of the society.

Three years ago the Strategic Plan focused on four main goals. The first of these goals was to be the

development of an interactive website, the second, was raising awareness amongst medical professionals (and now politicians) of our common problems. The third goal was the establishment of an office that would be staffed by volunteers recruited from our local association of voluntary organisations. All three of these objectives have been met.

Unfortunately, the fourth objective of the previous Strategic Plan

was not met, and this has now become the first priority in a new Strategic Plan.

The recruitment of a full-time Development Officer with the experience, skills and knowledge to drive the society forward is now our next major objective. Applying for funds to finance this post has already begun and hopefully our first employee will be in place by June.

Mairi Sutherland Screens *Photoshoot*

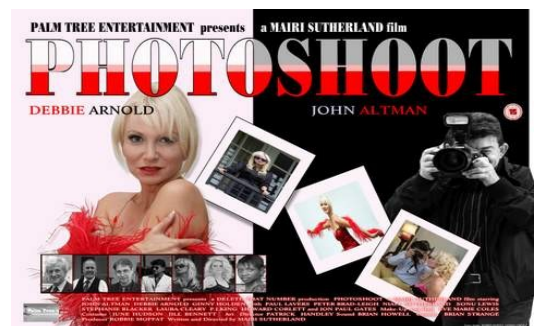
Mairi Sutherland, member of The Pernicious Anaemia Society, has held a private screening of her feature length film, *Photoshoot*. The premiere took place on Thursday 26th November 2009 at the Empire Cinema in Leicester Square, London.

The film's plot follows the interests of a magazine photographer in the life of an aging movie star,

played by Debbie Arnold. John Altman, famously known for his role as Nick Cotton in *Eastenders*, plays the character of the egotistic photographer.

The screening was a charity based event in aid of The Pernicious Anaemia Society. Martyn along with Kirsty and Kim attended the screening in order to promote the charity to several

stars and crew members of the film.



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Volunteers Still Needed

There is still time to do your bit in the name of science. Volunteers are needed for the research programme into the connection between B₁₂ deficiency and Homocysteine levels. Being conducted at Cranfield University.

There has been a slight delay in the start trials for this search programme, which are due to occur early in the New Year 2010 due ethics approval.

It has been fantastic receive so many of your applications.

Some people have requested application forms to be involved in the research but have not yet returned them, so if that is you, then this is a gentle reminder.

If you would like to apply to volunteer for this research programme please contact carrie@pasoc.org.uk and put 'B₁₂ Research' in the subject box. Or call the office on 01656 724163 and ask for an application form to be posted to you.

Thank you again for all your support, it is great that we can all work together to help ours and our families futures.



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PAS Achievements This Year

2009

As 2009 draws to a close it's interesting to reflect on what we, as a society, have achieved in the past 12 months. It has been an incredibly busy year.

This time last year we had no volunteer help in our office based in Bridgend, South Wales. Since December 2008 we have recruited 10 volunteers, who gain various administrative skills as they help in the running of the society.

Three of the volunteers have gone

on to full-time employment and it was a pleasure for us to provide these young people with positive references and to note that their CVs were a lot fuller than when they first joined The Pernicious Anaemia Society.

In February 2009 the first ever Seminar was hosted by the PAS and that event is still being talked about today.

The profile of the society was raised during the Summer of 2009 when we travelled around the country to set our stand at various county fairs where we offered members of the public our 'Could You Be B₁₂ Deficient?' test. It was during the Summer that we received our first legacy.

Our telephone helpline was also introduced and continues to be popular and a genuine life-saver for some.

Alternative treatment therapies were discovered and evaluated during the course of the year, and the Chairman's Review that was published in March summed up the known issues surrounding Pernicious Anaemia.

The flurry of political lobbying that characterised the late Autumn is still taking place and promises to continue well into next year.

Lessons have been learnt and discoveries made that have all contributed to what amounts to a highly successful year for the society. Hopefully with the continued hard work of all the society's volunteers, 2010 will be even more successful.