

Cobalamin News

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NOVEMBER 2009

SPECIAL POINTS OF INTEREST:

- **Early Day Motion signed by 79 MPs**
- **Over thirty members made their way to London to attend the event.**
- **Seventeen members from all parties asked for more information about the problems faced by our members.**

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Parliamentary Lobby A Resounding Success

After months of planning and intense networking within Westminster the Society's Parliamentary Reception took place on October 28th.

Held in The Jubilee Room in the House of Commons the Reception began at 9.00 a.m. and almost as soon as the doors opened the first M.P. who had



Martyn makes his point

been asked to attend by one of his constituents (and our member) approached

the Chairman of this society asking what the whole event was about.

"For two hours it was non-stop explaining to MPs the problems that we sufferers of Pernicious Anaemia relating to the Sym-

ptoms, Diagnosis and Treatment of the condition" said Chairman of the Society Martyn Hooper.

Members of the society also attended the event with several staying in London for two nights. Around thirty of our



The Event was recorded

members attended and many used the event to meet

other members of the society to exchange stories and experiences.

A total of seventeen MPs attended and it was reassuring to note that members from all political parties were genuinely surprised at the way in which Pernicious Anaemia is diagnosed (or undiagnosed /misdiagnosed).

Many agreed there and then to sign the Early Day Motion that had recently been tabled by Bristol MP Doug Naysmith.

We were looking forward to receiving ten and maybe fifteen signatures on the Early Day Motion that called for an urgent Review of the Diagnosis and Treatment of Pernicious Anaemia. At the time of going to press over 80 members had supported the call for a Review to take place.

The Early Day Motion has been kept open and so it is still not too late to write to your MP (if you haven't already done so) and ask him or her to support the motion by signing it.

The society would like to say a special thanks to Madeleine Moon MP and Mary Southcott for their hard work and support in making the reception a resounding success.

Private Cinema Screening - Photoshoot

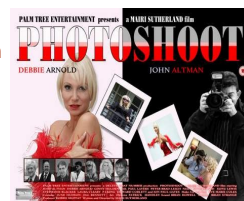
When Mairi Sutherland was diagnosed with Pernicious Anaemia she thought that all the problems associated with the disease would fade away. Unfortunately this didn't happen. She didn't receive any loading doses and was prescribed an injection of Hydroxocobalamin every three months. Like many of us on that treatment regime she struggled and her requests for more frequent injections was, as is usual, turned down. When she was told that she no longer needed

any medication whatsoever her condition deteriorated and she struggled to complete the most basic day-to-day living tasks.

"I own my own film and production company and I was really having problems directing my latest film *Photoshoot*. I had to hand over to the Assistant Director in the afternoons" says Mairi. "When I discovered the website of the PA Society I realised I was being badly treated and was immediately put back on the injections by another doctor".

Mairi has organized a Private Screening of her latest film. Just fifty tickets are available at £15 each. The Screening will take place at the Empire cinema in Leicester Square, London on Thursday 26th November. The show starts at

6.30 pm. Tickets are available online or by telephoning the office. Please support this unique event.



New Merchandise Available

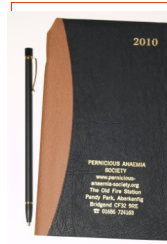
“The growing selection of gifts are perfect for Christmas and other special occasions”

Just in time for the Christmas Festivities we can now offer readers the opportunity to purchase some of our newly available merchandise.



Kirsty and Abigail model the new Polo-shirts - Just £10. S, M, L and X L in Black or White.

All merchandise can be ordered by post or email kirsty@pasoc.org.uk



New for 2010 these diaries come complete with a presentation gift box and a pen that is held in the spine of the

diary. They have a week per two page and have a quotation form notable celebrities from past and present. The cost just £4.99

Our ever-popular wristbands - £1 each or 5 for £3



Help to raise awareness of the society using our car window stickers.

They sit inside the window and show our telephone number and website address. Just £1 each or 10 for £5



These beautifully crafted and engraved pens make writing a

real pleasure. They come with gold gift box and cost just £4.49



We Have An Entry for the Virgin London Marathon 2010

Virgin London Marathon

We have been allocated a running entry for the 2010 Virgin London Marathon.

Following an administrative error we were unable to enter last year and our entry was allocated to another charity.

Earlier this year we paid £345 to the London Marathon to ensure that our place was still available.

If you know of anyone who is

looking for a place in the 2010



Marathon please ask him or her to contact us.

Obviously the runner would be competing on behalf of the society and would need to

raise at least £345 to cover the cost of the entry.

The society will offer administrative support and publicise the details on our website.

We will also provide a running vest with our logo and any other support that the runner feels he or she needs.

And of course our entrant will receive all our members' support!

New Telephone Help-Line Launched

Following on from a successful pilot scheme that the society ran last year, a new dedicated telephone help-line has been set up.

The service, which is only available to members, has a dedicated telephone number - 01656 724810 within the U.K. and 441656724810 from outside the U.K.



The Helpline is manned by Jane, our specialist nurse counselor. If Jane is unavailable when anyone calls (which is most likely as she is a busy Community Nurse, the

caller's contact details will be taken and Jane will 'phone the caller back usually within an hour. If nobody is available then the caller can leave a message and Jane will call back as soon as she can.

We receive an average of three calls a week about a wide range of subjects - but most are about the treatment regime used to treat PA.

A new dedicated telephone helpline has been set-up.

Invitation to Welsh Assembly Reception

Following on from the successful Westminster Reception the society is hosting another such event at the Welsh Assembly Buildings in Cardiff, U.K. in Conference Room 24 on the 25th November starting at 12 noon and ending at 1.30.

All Welsh Assembly Members (or AMs as they are known) have been invited to attend the Reception where they will be made aware of the problems faced by sufferers of Pernicious Anaemia. We appeal to all of our Welsh members to write to their AMs (there will be more than just one AM per constituency) and ask him or her to attend the

event. An even better arrangement would be for our Welsh members to request a meeting with their AMs at the Reception.

If you live outside Wales but have relatives who reside in the Principality you might like to ask them to write to their AM or arrange to meet their representative at the event.

It's vital that everyone in a posi-



tion of public responsibility is aware of the unnecessary suffering that is being experienced by our members because of an antiquated diagnostic process and old-fashioned treatment regime.

At the same time as the Reception is being held, two Assembly Members have signed a Statement of Opinion calling for an urgent review of the diagnosis and treatment of Pernicious Anaemia.

If you need help in identifying and contacting your AM please contact the office so we can help. Contact details are on the back page.

"If you live in Wales please join us or write to you're A.M. We need you to get involved"

Research into Genetics of PA & MMA/Homocysteine

Volunteers are wanted to participate in a Research Programme being conducted by Prof. J. Hunter at Cranfield University near Bedford, U.K.

Prof. Hunter is looking for patients who have been clearly diagnosed as having Pernicious Anaemia and who feel that the three-monthly treatment regime is not suitable for them and who feel their symptoms returning after

just a few weeks.

You will be asked to present yourself to Prof. Hunter at the site in Bedford where your levels of Homocysteine will be checked. As well as the Homocysteine level, the Professor will also check the amount of Methylmalonic Acid in your urine.

The hope is that even though your B₁₂ levels will be fine (although see the article on the back page re-

garding this), the reasons why the patient still experiences all the symptoms of P.A. is because of abnormal levels of Homocysteine or M.M.A.

The society may be able to pay your travel expenses and even arrange transport. If you would like to get involved please contact the office so we can send you a form or email carrie@pasoc.org.uk

Thanks

Society Writes Statements on Cyanocobalamin

Tablets and Methylcobalamin Infusions

There has also been rumours circulating that governments are considering using alternatives to administer B₁₂ other than the usual intra-muscular injections.

One such alternative treatment could be the introduction of Cyanocobalamin Tablets that contain an extremely high concentration of B₁₂. So high is the concentration that some, a very small percentage of the total, is ingested

in a part of the stomach. The society is against the use of Cyanocobalamin tablets as the favoured treatment regime mostly because they are based on cyanide and a Policy Statement has been produced.

Similarly a Statement has been produced and adopted on the use of Methylcobalamin Infusions which makes it clear that the society doesn't recommend this treatment, but will



Copies of the Statements can be ordered by contacting the office.

make our members aware of the alternative treatment but we recommend they discuss this form of replacement therapy with their GP first before undertaking any treatment and that the infusions be carried out by a qualified doctor.



The Pernicious Anaemia Society

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Mid-East Delegate - Fatima Parker

New Diagnostic Test Developed

A new Diagnostic Test has been developed by Axis-Shield, an international organisation that specialises in developing these types of tests. And the new test could explain why some members have serum B₁₂ levels that are above the lower threshold used to determine B₁₂ Deficiency and yet still experience the symptoms of Pernicious Anaemia.

The new test distinguishes between Active B₁₂ and Inactive B₁₂. The Active B₁₂ is playing its part in the complex biological process that takes place in blood. The Inactive B₁₂ plays no part in the biology.

A person can have up to 70% of their total B₁₂ made up of Inactive B₁₂, yet the total Serum B₁₂ would show healthy levels. For example let's assume that a laboratory's lower reference range for normal B₁₂ is 200ng/L. If a person has a total B₁₂ level of 210ng/L he or she would not be considered to be B₁₂ deficient. But, if that person's total B₁₂ level was only 50% Active B₁₂ then he or she would be B₁₂ deficient. The more accurate figure would give a reading of 100ng/L - well below the threshold for determining B₁₂ deficiency.

Until now it has only been possible to measure the total (active and inactive) B₁₂ in blood and this new, more accurate test explains scientifically why people with total serum B₁₂ levels within the normal range are still symptomatic of B₁₂ deficiency.

The test is already available in Australia and has been subjected to very strict trials in Germany. This is a very important development that needs to be promoted. The society is currently seeking further information and clarification from the developers of the test. It is worth noting that the new, more accurate and more comprehensive test costs about twice the price of the current test. More about this soon.

Please Help Us To Continue Our Work.

Like most other charities the society relies upon the generosity of our members to carry on our work. The society still relies on the generosity of volunteers to continue to meet the demands for our information packs and provide a voice for sufferers of Pernicious Anaemia and their families and friends. And just like most other charities money - or lack of it - is a continuing problem.

Please consider helping us financially. There are many ways in which you can help the society financially. Please take a moment to consider the different ways in which you might be able to help us to continue to fight our cause:

ONE-OFF DONATION:

These are always welcome and the society has received several of these over the past two years. The only downside to them is that they cannot be predicted and consequently they cannot be used to predict or

anticipate any cash-flow issues. Please ask us for a Gift Aid form so that we can claim even more money from the government.

SMALL REGULAR DONATIONS:

This is our preferred method of receiving money. By filling out a Standing Order Form (available by contacting us) you can make a small but highly valuable donation every month or at any other chosen time. We currently have three members who give a small amount every month - hopefully this number will grow.

PAYROLL GIVING:

A portion of gross income is donated every month. You donate £6 per month - we get £8! Only available to employees of organisations that operate the scheme.

ORGANISE A FUNDRAISING EVENT:

This could be anything from being sponsored to complete an event, organising a coffee morning or other social event.

E-Bay:

If you sell on e-bay you can donate a percentage of your sale to the society.

Easyfundraising:

By shopping online using easyfundraising.co.uk a percentage of your spend is automatically given to the society.

LEGACY:

There are different types of legacies including **Residuary Legacies** where your estate or percentage of it could be left to the society after all other financial commitments have been paid. **A Pecuniary Legacy** is a fixed amount that could be granted whilst a **Specific Legacy** is an item, such as a ring, that could be given. We received one legacy of £5,000 two years ago.



Have you considered a leg-