

SPECIAL POINTS OF INTER- EST:

- **PAS Conference a success**
- **A call for members to write to their MPs**
- **Chris Parker needs your support**

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Spring Conference a Great Success

The PAS conference held on the 13th March 2010 that was based around the theme 'Developments in the Diagnosis and Treatment of B12 Deficiency' was a resounding success.

The conference received a very impressive turnout of members, doctors and scientists. An analysis of the seventy completed Evaluation Forms showed that sixty attendees found the conference 'Completely Met their Expectations & Needs'.

All presentations offered by the conference speakers fully engaged with attendees

through question and answer opportunities and group activities. One of the most interesting parts of the



Hugo Minney acts as facilitator during the group session

day was when the delegates were split into groups to formulate a response to the official answer given by the

UK Government to the Adjournment Debate held by Madeleine Moon M.P. The response that this Society will make to the Government will now have the added credibility of being formulated by over 100 of the society's members. It is hoped that the involvement of patients in such activities as this will further increase awareness of the problems with the diagnosis and treatment of PA.

Please find enclosed in this edition of the newsletter a full write up of the Spring Conference.

PA Soc. Election Campaign

Now that the U.K. General Election has been called for 6th May 2010 the society has launched its own crusade to ensure that all candidates in the campaign become aware of our problems.

"This is the best opportunity we will have to make our voices heard" says society Chairman Martyn Hoop-

er. "We want every member to write to every candidate asking them what they would do to end the needless suffering that is happening due to outdated Diagnostic tools and inadequate Treatment regimes" he says.

Please write to **all** parliamentary candidates in your constituency.

Should you require any help

in identifying and contacting your potential MP please telephone 01656 724163 or email chair@pasoc.org.uk.

A template for the letter has been included in this edition of the newsletter and is also available as a PDF file from the Downloads section of the PAS website.

Kevin Byrne's B₁₂ Deficiency Debate



Kevin Byrne

At The Pernicious Anaemia Society's conference on Saturday 13th March a paper on 'The Enterohepatic Circulation of B₁₂' was published. The paper was written by Kevin Byrne and was presented at the conference by Dr. Hugo Minney, Business Development Manager for the Shinwell Medical Group.

Kevin Byrne's paper is very interesting as it states that "the time at which B₁₂ deficiency signs/symptoms begin seriously to make their presence felt is a reflection of the point at which an individual's enterohepatic cycle ceases to cope – i.e., the point at which recycling/resupply ceases adequately

to support the body's demands which can be due to any failure at any point in the enterohepatic cycle".

Kevin also debates the pros and cons of B₁₂ "supplementation". He differentiates between "oral administration" and "subcutaneous injection". However, Kevin does indicate "three findings in common". One of these conclusions includes the statement that "cutting back on B₁₂ supplementation causes an immediate worsening of signs/symptoms". Kevin believes that "what physicians are taught, believe, and practise is absurd; or it would be, if it didn't con-

demn millions of people to the living death of inadequate and incomprehensible treatment with no discernible justification in research, theory, or therapeutic results".

Kevin Byrne's paper was made available for conference attendees to take away with them and consisted of both a professional and simplified version. The professional version of the paper could be very useful to your GP. Should you require any copies of either versions of 'The Enterohepatic Circulation of Vitamin B₁₂' then please telephone 01656 724163 or email kim@pasoc.org.uk.

"We understand that some people with Pernicious Anaemia believe that insufficient heed is paid to their particular wishes regarding the nature and frequency of treatment."



Number 10 Petition Response

Further to the Number 10 E-Petition issued mid-November 2009 a reply has been written by the UK Government.

The Number 10 petition called for the development of "a more cost-effective and patient centred treatment regime" and received over 400 signatures by 18th February 2010.

Unfortunately, the reply

offered to the petition is very generic and is very similar to the responses issued by Health Ministers and Ann Keen MP to Madeline Moon's MP Adjournment Debate and a letter written to the society's Chairman.

The Number 10 petition reply states that the diagnosis of B₁₂ deficiency in relation to Pernicious Anaemia "is not generally difficult". The reply unwittingly explains that "most patients respond well to treatment through quar-

terly injection of vitamin B₁₂ and are able to get on with their lives very well". However, The Pernicious Society has daily contact with members who can prove this statement otherwise.

People can view the full response to the Number 10 petition by going online and copying and pasting the following link into the Internet address bar:

<http://www.number10.gov.uk/Page23052>.

Chris Parker Runs for Pernicious Anaemia



The Pernicious Anaemia Society has paid £345 for a place in the London Marathon that takes place on Sunday 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. This may be Chris's first at-

tempt at running a marathon but he is clearly a very active individual who enjoys "rock climbing, snow boarding and surfing".

Apart from being very active Chris has also travelled the world, visiting South East Asia, Australia, New Zealand and the Pacific. "Indeed, it was upon my return from a recent trip to Central and South America that I learnt my mother had been diagnosed with Pernicious Anaemia", explains Chris.

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 benefiting my mother and other sufferers, then I will endeavor to generate as much money as possible and run my heart out", says Chris.

Any support that the society members can offer will be greatly appreciated by Chris and his mother as well as everybody at The Pernicious Anaemia Society. To sponsor Chris please visit the PAS website or contact our office on 01656 724163 or email kim@pasoc.org.uk.

Health Technology Assessment Panel

On Thursday 8th April 2010 Society Chairman, Martyn Hooper, presented a research proposal to the Diagnostic and Technology Screening Panel. This is a Panel made up of experienced and highly respected medical professionals. The Panel seeks to continually update the technology that is used for screening and diag-

nosing diseases and other medical conditions. It is part of the National Institute for Health Research.

Martyn's proposal was to investigate whether the use of the Active and Inactive B₁₂ test would result in a quicker and more accurate indicator of B₁₂ Deficiency. The Panel members were both interested and

intrigued by the research proposal and requested more information relating to the research that has been conducted into the Active and Inactive B₁₂ test. The Society is now busy assembling evidence of the reliability of the test and how the current B₁₂ test that is used can often lead to misdiagnosis or non-diagnosis.

"The Panel were both interested and intrigued by the new B₁₂ test."

Prescription Charges Alliance

The Society has been playing an active part in the Prescription Charges Alliance that is a coalition of registered charities representing patients with long term medical conditions.

The issue of charging for prescriptions for injectable B₁₂ is not straight forward. It is usually the case that if the patient

with PA attends his or her local surgery to receive the injection then no charge is made. However, if the patient prefers to self-inject or get a family member to inject him or her at home then there is a charge for the prescription.

This is further complicated because of regional differ-

ences.

In Wales and Northern Ireland all prescriptions are free, whilst in Scotland a small charge is made, and even this will be phased out in the next year.

England still has prescription charges.



Methylcobalamin Infusions

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

Requests for information by members to the society's office regarding Methylcobalamin infusions and the use of self-administered small injections are constantly increasing.

The Pernicious Anaemia Society does not *recommend* this particular treatment but believes that members should be made aware of this alternative method of treating B₁₂ Deficiency that is only available in the private sector in the UK.

Methylcobalamin is a 'purer' form of B₁₂ and is administered by a 'drip' straight into the bloodstream. The patient then 'tops up' his or her blood using small injections sometimes as many as three times a day. The needles used are the same size as those used by diabetics.

Many members have reported almost miraculous improvements in their wellbeing after receiving an infusion while a few have reported 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 subject 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.

If you require any information on Methylcobalamin infusions please telephone 01656 724163 or email chair@pasoc.org.uk.

Create a PA Support Group in Your Area

If you are interested in meeting with other PA members in your area then we can help you set up a support group.

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

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 members permission for us to provide the voluntary

organiser with his or her contact details.

We can also help you to promote your support group by providing you with posters and flyers for you to display in your



vicinity.

We would also like to establish groups outside of the United

Kingdom so if you are one of our many readers that live outside the UK please consider setting up a group with your fellow countrymen and women.

The PA Society is hoping to get these support groups up and running by June and through to December. If you would like to organise such a group in your area or would be interested in attending such an event please contact us so we can help and advise you further. Please telephone 01656 724163 or email kim@pasoc.org.uk.