COBALAMIN NEWS
The Newsletter of the Pernicious Anaemia Society

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NEQAS B12 Alert

The Pernicious Anaemia Society have been aware for over a year that there are serious problems with the current test used to determine the B12 status of patients. Now, the United Kingdom National External Quality Assessment Scheme for Haematinic Assays has published a B12 alert.

NEQAS exists to help ensure that clinical laboratory tests are accurate, reliable and comparable.

The B12 alert is titled "False normal B12 results and the risk of neurological damage".

This alert states that B12 assays may be vulnerable to interference, resulting in ‘normal’ test values despite severe cobalamin deficiency.

Their advice, therefore, is to treat patients with B12 replacement therapy where there is a discordance between clinical neurological features and test results—BUT—only when the patient has developed nerve damage.

In short the advice has been to treat the symptoms and not the test—but only if the patient has already developed nerve damage. This seems ridiculous to us as it means that a patient with all of the symptoms of B12 Deficiency will not be treated until he or she develops nerve damage.

Here is the complete bulletin: False normal B12 results and the risk of neurological damage.


OCTOBER CONFERENCE

Our Autumn Conference was held on October 19th in the PASOC Headquarters in Bridgend, South Wales.

The day was a hit, with people coming from many miles away in order to attend. We also had our first foray into live-streaming and people all over the world tuned in to the stream in order to watch live.

With nine different talks on offer, attendees left knowing all of the latest news surrounding cobalamin deficiency and Pernicious Anaemia.

Our Chairman, Martyn Hooper, began the day with a talk about all the recent developments with the society. This included the news that we have now secured enough funding to go ahead with our latest research programme that is investigating why some patients need more frequent injections than others (this is still the biggest cause of complaint by our members).

Petra Visser from the Dutch B12 foundation flew in to be with us and her talk highlighted how, regardless of geographical location, the same problems are experienced with B12 deficiency and Pernicious Anaemia.

Dr. Hugo Minney of B12d.org also made an appearance, as well as the ever popular Dr. Joseph Chandy.

Professor David Smith also gave a talk, showing that baseline homocysteine seemed to be related to brain shrinkage and explored the relationship between B12 and Dementia/Alzheimer’s Disease.

Dr. Anna Guildford (a member) from the University of Brighton presented her proposal for better, more frequent replacement therapy for B12, while Dr. Siddharth Banka gave an update on the genetics of PA.

Dr Allison Wilde of Oxford Biosciences made the conference aware of a new form of Methylcobalamin B12 which she supplies in powder form and that is mixed with sterile water to become injectable. If you are contemplating contacting Oxford Biosciences please discuss this with your doctor.

Dr Willemina Rietsema told the conference about her experiences of treating PA and B12 Deficiency as a practicing GP.

We have now uploaded the talks onto YouTube so that those unable to attend or watch the ‘Livestream’ will be able to enjoy the fascinating information that was shared.
MEETING WITH SIR MICHAEL RAWLINS

On July 1st we had a meeting with Sir Michael Rawlins, the founder of NICE and its last chairman. He is also currently the President of The Royal Society of Medicine.

Carrie-Anne, a volunteer, and Martyn, our chairman, met with him to discuss the challenges that exist with the current treatment and diagnosis of Pernicious Anaemia. He was extremely interested in hearing about sufferers’ struggles and the difficulties they face.

His suggestion was for Martyn to write to as many people in instrumental positions as possible to make them aware of the current situation.

At present, the letters have been written and sent out to decision makers across the UK and we hope to hear back soon.

Our volunteers in the office have been busy sending out the letters and a list of people we have written to is as follows:

- Alex Niel, MSP (Cabinet Secretary for Health and Wellbeing, Scottish Parliament), Carwyn Jones AM (First Minister, Welsh Assembly), Rt Hon Jeremy Hunt MP (Secretary of State for Health) and Professor Dame Sally Davies (Chief Medical Officer for England.) We have also written to Edwin Poots MLA (Minister for Health for Northern Ireland), Mark Drakeford AM (Minister for Health for Wales) and Dr Ruth Hussey OBE (Chief Medical Officer for Wales.) and the Chairman of the Diagnostic Technology and Screening Panel—part of the Health Technology Assessment Programme.

So far only six replies have been received and only two of these made any useful comments although we know that they have been read by the recipients. We suspect that the letters are being discussed.

NEW GUIDELINES

“The Petitions Committee of the Scottish Parliament requested that the BCSH contact the society.”

New guidelines on diagnosing and treating B12 Deficiency are currently being drawn up by the British Committee for Standards in Haematology. The new guidelines were due to be published in June of 2012 but were delayed until June of 2013 and we now understand that these new instructions for doctors are now due to be published in 2014—sometime late spring or early summer.

The society has written twice to the Chairman of the committee but we have not had a reply—even though the Petitions Committee of the Scottish Parliament requested that the committee contact us.

Obviously the committee will be aware of the failings of the current test used to ascertain the serum B12 levels of patients and it is reassuring to know that the committee seems to be weighing up all alternatives.

And we know that the committee will be investigating the accuracy of the ‘Active B12’ Test and whether Methylmalonic Acid and Homocysteine are better at identifying any deficiency than the current test that is giving false high results in up to 35% of patients who are deficient. And this is leading to patients remaining undiagnosed or wrongly diagnosed for many years.

We will keep you informed of any developments as we hear of them.

B12 & DIABETES

A new paper has been written regarding Pernicious Anaemia and Diabetes.

The paper has been written by biochemist and member of the PA Society, Dr. Zeena Nackerdem. To read the paper in full, please find it in the library section of the website. The library section is found under “sufferers”.

The paper goes into detail about how these two conditions interact. It also mentions the fact that Metformin, a popular anti diabetic medication may contribute to vitamin B12 deficiency.

The paper also discusses how stomach problems that occur concurrently with Pernicious Anaemia can sometimes be a clinical sign of damage to other organs, such as the pancreas.

Another point made is that autoimmune gastritis and Pernicious Anaemia are increased up to 5-fold in Type 1 diabetics. This is a significant issue.

As concurrent autoimmune diseases are far from rare, this paper is valuable in understanding the need for a holistic approach to the management of Pernicious Anaemia and co-occurring illnesses.
MEMBERS SURVEY UPDATE

Members may remember our Survey that was conducted from 2010-2011. This survey asked members a wide-ranging number of questions, first establishing the different demographics of sufferers, for instance age and sex. The survey then went on to ask questions about such diverse aspects of people’s lives as what age (if at all) their hair went grey to what symptoms they suffered prior to diagnosis.

The question was also included of whether members also suffered from other medical conditions associated with P.A. This was to establish concurrent disease occurrence. Another section of the survey covered diagnosis and treatment of P.A. Many different aspects of the illness were covered and much data was collected.

The survey was written up by a team of doctors, aided by a statistician, who analysed all the data collected. Once it had been fully written up, we began searching for a paper to publish it.

Unfortunately it has been turned down by two major publications for being too large, however we are continuing to search for somewhere to publish it as we feel the results are incredibly important and need to be widely read to increase understanding of the challenges faced by members.

MORE FUNDRAISING EVENTS

The last newsletter featured Ngozi, Gloria and Gordon who were all raising money for the Pernicious Anaemia Society by holding or participating in sponsored events. This newsletter brings the news that we have more events to report and we are thrilled that so many people are representing the society.

Our thanks go to Emma Nelson who gave a presentation to Leith Rotary club about pernicious anaemia and skydive for us.

Our thanks also go to Philip Pierce who ran the Chester Marathon for us in October.

Emma Chesswas has also been allocated a place to run the London Marathon for us in 2014! We wish her the best of luck and have our fingers crossed as other applicants may still get the chance to run—if you have applied, we will keep you updated as and when we know if we will have additional places available.

To sponsor Emma please go to her JustGiving page.

Please let us know if you are planning to raise funds for us—we can supply you with various publicity materials and help publicise your event.

http://www.justgiving.com

ROUND TABLE DISCUSSION

The evening before this year’s conference saw twelve of the most distinguished experts on B12 assemble for a Round Table Dinner and After Dinner Discussion at a country hotel not far from the society’s offices. This was a new venture for the society and it was designed so that the various clinicians and scientists could interact with each other and share ideas and knowledge.

This discussion was designed to lead to greater cross-discipline understanding of Vitamin B12 and Pernicious Anaemia and it was hoped that the researchers would forge links for future research projects.

We presented the guests with five questions which we wanted answers to and the debate that these questions stimulated went on into the small hours. It was a great success with three collaborative research projects now underway between the guests. And each of these collaborations focuses on answering some of the questions set by us at the event.
This meant that all duplicate entries, bogus members and any other corrupt data was removed and as a result we now have a much more accurate and up-to-date database of our members. In three years, since we introduced paid membership, nearly 5,000 people have joined the society. Most members are sufferers but some are family members of patients. Our membership continues to grow by an average of 2.4 per day.

Future Plans
The trustees of the society met in Birmingham (UK) in August and agreed plans for the future needs of the society. Demands on our services are now so great that we are unable to function using volunteers only. The new strategic plan outlines the requirement to employ four part-time development officers based in the four constituent countries of the UK. We are about to submit two funding applications to pay for these posts.

American Institutes of Health
We hear that there is to be a meeting of all fifty of the American Institutes of Health that will take place in Washington in the new year. The meeting has been called to examine the problems with diagnosing B12 Deficiency.

New Merchandise
We launched new merchandise at our autumn conference and these are now available to purchase from our e-Bay shop. T-shirts, college jackets, Car Stickers and Pens are all now available at very low prices.

Volunteers Needed
We are desperately short of volunteers to help in the following areas: Website Maintenance; Database Management; General Administration. If you are able to help with any of the above please get in contact using the email: info@pasoc.org.uk

Happy Christmas!
We wish you and your families a Merry Christmas and a Happy New Year.

NEWS IN BRIEF - a round up of recent developments.

Recruits wanted
We are still short of research participants for the research investigating why some of us need more frequent injections than others. If you live in the UK and are prescribed an injection of hydroxocobalamin by your doctor every three months and you manage perfectly well for those three months we would like to hear from you. You must experience no return of symptoms before your injection is due. Please contact the office or email anna2@pasoc.org.uk.

‘Cleaned up’ Database
During the summer, the society’s database was thoroughly examined and cleaned.