COBALAMIN NEWS
The Newsletter of the Pernicious Anaemia Society

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Chairman’s Update

My first duty is to apologise for the late appearance of this newsletter. I know that many of you look forward to hearing what has been happening and that you rely on this newsletter to keep you informed. There are two reasons why this edition is later than usual. Firstly I have found it difficult to find the time to actually sit down and write this edition. I have been busy attending events around the UK where health professionals and politicians are keen to know what our problems are and what they can do to try to change things. Secondly we are waiting to hear the results of other activities.

There are two activities in particular that we are anxious to hear about. The first of these relates to the British Committee for Standards in Haematology which has delayed issuing new guidelines on vitamin B12. These guidelines were originally intended to be produced in June of last year. We understand that the new guidelines have been produced in draft form and have been sent to interested health professionals for their comments. The society hasn’t, to date, been approached by the committee. The Scottish Parliament has suggested that we should be contacted and perhaps we may be approached as part of the process. We have been holding back publication of this edition hoping that we could bring you details of the new findings.

The second development that we were hoping to bring you details of relates to the publication of the results of our survey which has now been produced as a serious piece of research by Dr. Andrew McCaddon, Dr. Fiona Porter and Peter Hudson. The paper was submitted to a highly regarded medical journal three weeks ago and the editors have yet to decide whether they will publish it. We expect to hear their decision any day now. If it is rejected then it will be submitted to other relevant publications. Please check the society’s website where details of the publication will be posted. Until then we just have to be patient.

NEW WEBSITE ‘GOES LIVE’

Back in the autumn, Sarah Griffiths, who is a member and a volunteer with the society applied for a Big Lottery Grant from Awards for All England. The grant was for the development and maintenance of a new website. Happily the grant for £10,000 was awarded and the difficult task of designing the new website began.

The result is a website that is now more responsive to the needs of our members. And we know this because the content was the result of two exercises.

The first thing we had to do was to commission a Search Engine Optimisation report which listed the search terms that people entered into internet search engines that led them to our site. We learned,


PASoc Chairman - Martyn Hooper

RESEARCH NEWS

The society is currently engaged with two research programmes. As we have signed ‘non-disclosure agreements’ we are limited in what we can report.

The first programme is looking at just how vitamin B12 is absorbed at cell level. Whilst some members will manage perfectly well on their prescribed treatment regime others will feel no relief from the symptoms of PA even after treatment has commenced. Any blood test taken will show that the patient will have adequate or high levels of B12 in their blood - yet they will still be experiencing the symptoms of B12 Deficiency. This research will seek to understand why this is so.

The second research programme we are involved with relates to the most common complaint by our members and is in some way related to the first research programme outlined above. Whilst many members manage to live a normal life on the usually prescribed treatment (three monthly in the UK - one monthly in North America and Europe) others need much more frequent injections to find relief from their symptoms. Nobody knows why some need more frequent injections than others. And this second collaboration is looking into just why some patients need higher doses of B12 and more frequent injections than others.

Members who have registered to take part in future research using the online registration form will be contacted in the future if their co-operation is needed.

If you would like to register to take part in future research please register using the form that can be found in the ‘Get Involved’ section of the website. If you do not have a computer but would like to be added to the register then please contact us so that we can take your details and add you to the register.

SPONSORED EVENTS

From running marathons to walking Hadrian’s Wall - our members find various ways to raise money for the society.

London-based Ngozi Aniagwuna will be running the Run To The Beat London half-marathon on behalf of the society on the 8th September this year. Ngozi who is a member and fellow sufferer is studying for a Masters Degree in Management was diagnosed in 2010. You can sponsor him by going to his just giving page: http://www.justgiving.com/ Ngozi-Aniagwuna  Runners are encouraged by loud music along the entire route—hence the name of the half-marathon.

Gordon and Gloria - a tea party then a walk! An altogether quieter affair will take place on the afternoon of 2nd June at the Saint Peter’s Heritage Centre, Aberdeen where from 2pm to 4pm Gordon Anderson and Gloria Duguid will be holding an informal tea and coffee afternoon.

And then on the 13th and 14th July the intrepid pair will be walking 25 miles along Hadrian’s Wall aiming to raise £1,500 for the society. You can sponsor Gordon and Gloria by going to their Just Giving page: http://www.justgiving.com/ Gordon-Anderson

Good Luck to Ngozi, Gordon and Gloria - and thanks!

AWARENESS WEEK & AWARENESS DAY

This year’s Awareness Week will take place between 21st October and 25th October. We are busy organising various events but we have already decided on including a comprehensive campaign of political lobbying which will include, parliamentary questions, petitions and perhaps a demonstration.

There is, however, only so much that we can do from the office and the success of the week will depend on you getting involved. We want you to think of how you can help us raise awareness of the problems we face in getting diagnosed quickly and treated adequately. Everyone can help - think about writing to your elected representative whatever country you live in. Or maybe you would like to contact your local radio station or newspaper to make them aware of what we are trying to do.

National Pernicious Anaemia Awareness Day has been set for Wednesday 23rd October. Please think of how you can help us to make this a successful campaign. We now have nearly 8,000 members and if everyone did just one thing to raise awareness success could be guaranteed!
Autumn Conference - Saturday 19th October 2013

This year’s Conference will be held on Saturday 19th October at the society’s offices in Brackla House, Bridgend south Wales.

There will be a round table conference and dinner for medical professionals associated with the society on the evening of the 18th and many of those attending will be speaking at the conference the next day.

The complete list of Guest Speakers is still being drawn up and we will be able to confirm the format of the event in the next newsletter.

For more up to date details please go to the website where details of the event will be provided as and when they are confirmed.

As in previous years the annual conference provides an opportunity to meet fellow members and sufferers and it allows for the dissemination of best practice in managing Pernicious Anaemia - you’d be surprised how some people have developed ingenious coping strategies that allow them to best manage their condition.

Bridgend is just off the M4 motorway and is on the London to Swansea intercity train line.

If you would like to attend this ever popular event please telephone the office to reserve a place. Please note that there are a limited number of free car parking spaces at the office.

By holding the conference at the society’s large office suite it means that it will be free of charge but please let us know if you will be attending as we will be providing lunch and we don’t want anyone to go hungry! Similarly please advise us at your time of booking if you have any special dietary requirements.

AWARENESS RAISING

In April of this year the UK’s new National Clinical Director for Pathology was appointed. Professor Joanne Martin is Professor of Pathology at Queen Mary’s College at the University of London. At the end of April society chairman Martyn Hooper and Support Group Coordinator Carrie-Anne Carr met with the new Director and explained that there were serious problems in the way in which B₁₂ deficiency in general and Pernicious Anaemia in particular is being diagnosed and treated.

The meeting lasted over two hours and ended with Professor Martin asking for any information that the society has been forwarded to her which of course we are happy to do. We expect there to be some important developments to take place soon in this area.

At the beginning of July Martyn will be speaking to a class of trainee nurses about the problems faced by our members. This is the first time we have been asked to speak to trainee medical professionals.

In December Martyn gave a presentation to around forty doctors who are members of the British Society for Ecological Medicine in London.

MORE SUPPORT GROUPS ESTABLISHED

At the end of last year just one patient Support Group was active. Since January we now have support groups in the following areas of the UK: Aberdeen; Hertfordshire; London; Suffolk; Sunderland; south Wales and Surrey.

If there isn’t a Support Group near you then please consider setting one up. We have a specially written leaflet that will provide you with the necessary information you will need to go about arranging a group near you. Basically we provide you with an email address and then we email all members in your area asking them to get in touch with you. If you want to use an existing email address then you can. You will need to provide us with a telephone number.

Please note that as yet we don’t have support groups anywhere outside the UK. If you are a member who lives outside the UK please consider setting up a support group for people living near you. We will help you to do so in any way we can. For further details email: carrie@pasoc.org.uk

The Pernicious Anaemia Society was formed in 2006. It is based in Bridgend, south Wales in the U.K. It is a registered charity (No. 1147839) and is a limited liability company (Reg. no. 07904047). Overall responsibility for the society rests with eight trustees. The society is run entirely by volunteers. Day to day decisions are made by the Executive Chairman.

Main Contacts

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Please contact us for details of overseas delegates. Email: info@pasoc.org.uk

NEWS IN BRIEF - a round up of recent developments.

New Spray
A new Sub-lingual Methylcobalamin spray has been launched which many of our members have reported using to supplement their prescribed injections. The spray is manufactured by Sheffield based Better You (www.betteryou.uk.com). The spray is available from JG Supplements (www.jgsupplements.com) who now offer a 10% discount to members. Their telephone number is 0161 4081544. Quote PAS10 to receive your discount. Please talk to your doctor before taking any supplements as it will interfere with future blood tests.

New Conference
The next big conference that centres around B₁₂ will be held at Trinity College Dublin between 8th and 12th September 2013. The 9th International Conference on Homocysteine and One Carbon Metabolism will bring together clinicians and researchers with an interest in the many complexities of B₁₂ metabolism. The society will be present and will host an exhibition at the event for two of the five days.

More Meetings
Chairman Martyn Hooper and Carrie-Anne Carr will be meeting with the recently retired chairman of the UK's National Institute for Health and Clinical Excellence (NICE), Sir Michael Rawlins. The pair were originally supposed to meet Sir Michael in April but unfortunately the meeting had to be postponed. The meeting will now go ahead on July 1st.

New Test
Word reaches us that a new test to diagnose B₁₂ deficiency (though not Pernicious Anaemia) is being developed in Florida in the U.S.A. The test doesn’t examine blood but uses a sample of breath to determine the patients B₁₂ status.

New American Guidelines
The American Institutes of Health are meeting in Washington in December to develop new guidelines on diagnosing and treating B₁₂ deficiency.

Dr. Riar
Dr. Riar would like to thank all members who wished him well following his stroke. We are pleased to report that he is now back at work.