Spring Campaign Takes Shape

Next year is ‘election year’ in the UK and candidates from all political parties will be eager to find out what matters to UK residents. We want to take this opportunity of politicians actively listening to us to raise awareness of the problems we face in getting a quick and accurate diagnosis and treatment based on individual needs.

Whilst Bridgend’s MP Madeleine Moon has been active in supporting this society’s aims, now is the time for you to raise these issues with the candidates where you live.

The spring campaign will first be targeted at existing MPs and we will need your help to ensure that our message gets across to as many MPs as possible.

The first thing that will be happening is that we, the PA Society, will be hosting a Parliamentary Reception within the House of Commons—you may remember that we hosted one of these in 2008. Arrangements are still being made and no dates have been decided as there are various stages that any request to host such an event has to go through. We will let you know when firm arrangements have been made.

Once we know the date and venue we will then want all members who live in the UK to get involved.

We will provide a letter on the website that you can download and print off. This letter will inform your MP of the Reception. We then want you to send this letter to your sitting MP and ask him or her to attend the event.

At the event we will give a short presentation that will be based on the results of the Survey that was published earlier this year. We will also provide every attendee with a Briefing Sheet and Further Information Pack that will further highlight the problems that we face in getting diagnosed and treated.

If you are unsure of your MP please just give the office a call and we can tell you who your MP is and how to contact him or her.

Later, during early May, we will also be providing downloadable Briefing Packs that you can hand to any other candidates during the election campaign.

New Guidelines Start to Work

As we reported in the last newsletter the new guidelines on Cobalamin and Folate Deficiency (B₁₂ and Folic Acid) have been published by the British Committee for Standards in Haematology. These guidelines are an enormous step forward in that they acknowledge, for the first time, that there are serious problems with the current test used to determine B₁₂ Deficiency. Although there are still issues that need to be addressed, and they make no recommendation on treatment they are, hopefully, the first step towards the issues surrounding diagnosis being addressed. And we can report one positive outcome.

One member, who lives in Gloucestershire has been complaining of a whole raft of symptoms of B₁₂ Deficiency for years but, because her serum B₁₂ levels were above the threshold to determine deficiency she was refused treatment. She recently telephone the office; “My doctor has just telephoned me to tell me that she has just returned from a training session on the new guidelines. She apologised and told me that the new guidelines tell GPs to treat patients who have the symptoms even if their test results are above the threshold that shows a deficiency. “She told me to come straight to the health centre where she would immediately give me an injection”.

© The Pernicious Anaemia Society 2014. Reg. Charity No. 1147839
RESEARCH UPDATE

New Developments and On-going Projects

Project 1: Some bad news. The research project that is looking into why some patients need more frequent injections than others didn’t get approved by the Medical Ethics Committee relevant to the University that is overseeing the research. The main stumbling block was that the committee wants the research to include a ‘control group’ of healthy individuals whose B12 is normal. This isn’t a real problem but it will need us to recruit more recruits to the study who do not have any deficiency of B12, but it has delayed the start of the project. We just have to be patient.

Project 2:

This involves developing a sub-cutaneous implant that will deliver a daily dose of B12 into your bloodstream. The research team are still applying for funding and hope to have some positive news soon.

Project 3:

This is the project that is looking at the B12 levels in patients in or attending Psychiatric Units in the UK. The society is a Partner Applicant but we have nothing new to report on this—the lead applicant is still identifying doctors who are interested in the project and who would like to take part in it.

Project 4: This is the project that will promote the provision of an automatic endoscopy and biopsy for all newly diagnosed patients with Pernicious Anaemia to identify any early signs of stomach cancer. We are now collecting data for the lead researcher with regards to what tests patients had at diagnosis. If you haven’t taken the survey please do so via the website.

Project 5: A new project that will be looking at “Cognitive Function of Patients Before and After Injections”. The lead researcher is a member of the society and has just secured funding for the project. More of this in the next edition.

London Coffee Morning

We know that one of the worst consequences of Pernicious Anaemia is the feeling of isolation that comes from non-sufferers not really understanding how the disease can impact on the patient’s everyday life. And we also know that the Coffee mornings that we hold at the society’s offices in south Wales are awkward for some people to get to.

So we have arranged a Coffee Morning to be held in London which will be the first of a series of regional events over the next year. These events will provide the opportunity for patients to meet other patients and relate their own experiences, not only in getting diagnosed but also it allows patients to exchange details on how they develop various ‘coping strategies’ that allow them to manage their everyday lives. A short Presentation of recent developments will also be given. If you identify a suitable venue for a meeting near you please let us know. The London event takes place at:

CAN Mezzanine
49 - 51 East Road
London
N1 6AH on Saturday 25th October between 10am and 2pm. Tea, coffee and advice are free!

Please Update Your Profile

It’s so important that we have the correct contact details for you. It may have been many years since you first joined us and not only may you have moved during that time, but you might have also changed your email address or telephone number (which is the preferred way of us contacting you). Please ensure that your details are up to date by logging into your account and entering your new details. If you are one of our paper members please write to us with your new details.

Incidentally, your details are kept on a secure website server and are subject to our Data Protection Policy which can be viewed on the website. We will NEVER reveal your details to any third party, and we are registered with the UK’s Information Commissioner’s Office and are entered on the Register for Data Protection (registration Reference Z1928059). One of the requirements of the registration is that our information is up-to-date so please ensure that it is.

If you have any problems with logging in to your account please note that you will need to do so using the original email address that you joined with. You will be able to change your email address once you have logged in.

© The Pernicious Anaemia Society 2014. Reg. Charity No. 1147839
Treatment Issues

We are increasingly being asked for advice and help by members whose treatment has been stopped. There are various reasons why this has happened but it is usually because their doctor, or nurse, has requested a serum B₁₂ test that then shows that the patient has a high level of B₁₂ in their blood. Treatment is then suspended until the B₁₂ levels return to ‘normal’. This is extremely ‘bad medicine’ as patients who have Pernicious Anaemia will need treatment to address their B₁₂ Deficiency for life. Here’s what the new Guidelines on B₁₂ and Folate from the British Committee for Standards in Haematology say:

“Patients suspected of having pernicious anaemia should be tested for intrinsic factor antibody. Patients found to be positive should have lifelong therapy with cobalamin.”

But what if you have been told your B₁₂ is low but you don’t have the Intrinsic Factor Antibody that is used to diagnose ‘classic’ Pernicious Anaemia? Well the Guidelines state that you should still receive life-long injections:

“Patients negative for intrinsic factor antibody, with no other causes of deficiency, may still have pernicious anaemia and should be treated as anti-intrinsic factor antibody negative pernicious anaemia. Lifelong therapy should be continued in the presence of an objective clinical response.”

Remember, vitamin B₁₂ injections are cheap, very safe and it is impossible to overdose on B₁₂ as any excess is excreted in urine. Left untreated B₁₂ Deficiency leads to a wide range of problems including Psychosis, Behaviour Changes including mood changes and erratic and irrational behaviour. We have now produced a short one-page bulletin on this for patients to give to their doctor if their injections are stopped for whatever reason. The bulletin is now on the website Library section and is called “Treatment Bulletin”.

Medical Negligence

Unfortunately some of our members have suffered from negligence in their care and treatment. We have now briefed a team of solicitors about members experiences. This team is led by a former Haematologist who may be able to help you to right any wrongs. Please telephone the office or contact us via email for more information about this. Please note that this route should only be explored when all other avenues have been explored.

New Survey on Tests at Diagnosis

It’s not a subject that many people like talking about but it is well known that patients who have Pernicious Anaemia stand a greater risk of developing stomach cancer than those who do not have the disease.

It is difficult to find exact figures for the percentage possibility of patients being likely to develop gastrointestinal cancer as there has been no thorough investigation into this, but studies carried out in the 1970’s and 1980’s suggest that patients with Pernicious Anaemia will have a 3 to 6 fold increased chance of developing cancer than those without PA.

It stands to reason therefore that newly diagnosed patients should undergo investigative procedures to detect any early signs of cancer in order that treatment can begin as soon as possible. In some parts of the UK doctors routinely offer the patient the option of having a Endoscopy and Colonoscopy (commonly referred to as the ‘camera up’ and the ‘camera down’). We think that every patient diagnosed with Pernicious Anaemia should be offered these tests as a matter or routine and we are not alone. A Professor of Gastroenterology and his team from a University in the north of England wants to find out whether this is feasible and the first part of this study is to gather evidence about how many people had these tests at or around diagnosis. That is why there is a new survey on our website that asks members to complete a short online questionnaire on what tests they had at diagnosis. If you haven’t already done so please take a few minutes to complete the survey. If you don’t have internet access please write to us and request a paper version of the survey.
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
Executive Chairman - Martyn Hooper
chair@pasoc.org.uk
Secretary - Michael Stevenson
secretary@pasoc.org.uk
Treasurer - David Connell-Smith
treasurer@pasoc.org.uk
Membership Secretary - Alex Black
membership@pasoc.org.uk
Surrey Support Group - Carrie-Anne Carr
carrie@pasoc.org.uk

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

NEWS IN BRIEF - a round up of recent developments.

PREGNANCY
We have recently had a number of very worrying reports of members who are pregnant having their B₁₂ injections stopped because their blood test showed that they had high levels of B₁₂ in their blood and were told that this would harm the baby. Thankfully all incidences were resolved but please be aware that if you are pregnant it is more important than ever that your B₁₂ levels are kept satisfactory.

THYROID UK
Chairman Martyn Hooper is one of the keynote speakers at the 2014 conference of Thyroid UK

The title of his talk is: “Hypothyroidism and Pernicious Anaemia: Similarities and Differences”. The conference takes place at the National Motorcycle Museum in Solihull on Saturday October 18th.

Meeting with the new Chairman of NICE:
In May the Chairman of the Society and Carrie-Anne Carr met with the new Chairman of NICE, Dr David Haslam. The meeting was mutually beneficial and we were able to tell Dr Haslam about the problems our members face. In return we were given valuable advice on how to tackle these issues further. Dr Haslam has asked that he be kept informed of any developments and offered to help in any way he could.

Newsletter:
A big thank you to all of our paper members who responded to our request for a financial contribution towards the cost of producing paper versions of this newsletter. Those who have not yet made a financial contribution, however small, please consider doing so.

POSTERS
We are currently waiting the outcome of a grant application of £5,000 to launch a new Poster Campaign to make people aware of us and to make medical professionals and patients aware of some of the misinformation about Pernicious Anaemia— that you can overdose on B₁₂ etc. The new posters will be designed by professional graphic designers who will have been given a specific brief of what the posters are intended to do. They will then be available to download or as hard copies in a variety of sizes.

PODIATRISTS
Following two successful presentations to two groups of Podiatrists and Chiropodists we have raised awareness among these professionals of peripheral neuropathy being a strong indicator of B₁₂ Deficiency.

Design a T Shirt Competition
Win a Free T Shirt!
We need your help in designing a striking T Shirt for us to have printed for use to raise awareness of PA. Please send your entries to us online or by post. Entries will be judged in January 2015 and the winner will be notified and sent a T Shirt with their winning design. These will go on sale on our eBay shop to raise funds for the society too. We look forward to receiving yours soon.

Exam Success
Congratulations to our A-Level student volunteers who achieved their required grades for their chosen courses: Danny and Anna start Medical school in October, Megan begins her Nursing Degree and Nicole starts her Law Degree. Well Done all—you will be missed.