

Survey Results Published

Special points of interest:

- Research Paper Published
- Groundbreaking Development
- Rejected Twice
- First Reference Point for Patients' Experiences
- Over 1,300 Responses

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For nearly two years members were asked to complete a survey that would provide numerical data to support our claims that there is a serious problem with the way in which patients are diagnosed (and often treated) with Pernicious Anaemia.

The survey was designed by Dr. Fiona Porter who is a fellow sufferer and Trustee of the society. Once we had over 1,300 responses it was time to carefully analyse the raw figures in order to eradicate any double-counting and ensure that the responses gave an accurate picture as was possible. The job of 'cleaning' the data was undertaken by Peter Hudson, a biochemist with a particular interest in statistics and after a few weeks

Peter was able to present us with accurate figures of our experiences in getting diagnosed. Then it was necessary to write-up the paper in a format that would appeal to medical journals. In charge of preparing the paper was Dr. Andrew McCaddon who wrote-up the findings for publication in various journals (every journal favours a particular style of presentation). The introduction was written by society chairman Martyn Hooper and after two rejections the paper was finally accepted for publication (subject to some further information being included) by the British Journal of Nursing. This highly respected journal published the full article in April and now we are awaiting re-



sponses by medical professionals to our findings. This is an enormous leap forward in achieving our objective of getting the way in which we are diagnosed and treated thoroughly reviewed. *Patient journeys: diagnosis and treatment of pernicious anaemia; Martyn Hooper, Peter Hudson, Dr. Fiona Porter, Dr. Andrew McCaddon; British Journal of Nursing, Volume 23, Number 7.*

We hope to have a downloadable version of the paper available on the website soon—subject to obtaining the necessary permissions. Our thanks go to the authors for all their hard work.

NEW GUIDELINES ON B12 & FOLATE

The British Committee for Standards in Haematology (BCSH) regularly reviews existing guidelines and produces new guidelines for diagnosing and treating various diseases. It produced a set of guidelines on Vitamin B₁₂ and Folate in 1994 and a revised set of guidelines was due to be produced in June 2012. In May 2012 we met with the then National Director of Pathology and the immediate past chairman of the BCSH in the Department of Health offices in Skipton House, London. The meeting was very productive and lasted nearly two hours (it

was scheduled to last just 20 minutes) and the publication of the revised guidelines was postponed. In February we were sent a copy of the new Draft Guidelines on B₁₂ and Folate and were pleased to note that there are now serious concerns about the quality and accuracy of the current test to determine B₁₂ status in patients—the Combined Binding Luminescence Assay. The new guidelines also accept that the tests for Methylmalonic Acid and Homocysteine are not routinely available and that these tests could be a more accurate measure of

patients' B₁₂. And whilst the new guidelines do not recommend the immediate introduction of the 'Active' B₁₂ Test they do acknowledge the existence of the test and suggests that a more thorough evaluation of this new test be conducted. This is an enormous step forward in the society's quest to get medical professionals to review current diagnostic methods. We understand the Draft Guidelines have now been submitted for publication in the British Journal of Haematology. A summary of the new guidelines is available on the society's website.

New Developments and On-going Projects

Project 1:

We are aware that a number of members are concerned that they have not been contacted by the various researchers that we have been working with even though they registered to take part in the projects over a year ago.

The reason is that the team looking into why some patients need much more frequent injections than others is still going through the process of obtaining medical ethics approval for the research to begin.

We are pleased to report that this process is now almost complete and the research

team will begin the study in the next few weeks. We are still looking for patients who manage perfectly well on the three-monthly treatment regime to take part in the research.

Project 2:

This involves developing a subcutaneous implant that will deliver a daily dose of B₁₂ into your bloodstream. The research team are still applying for funding for this and do not expect any developments until the autumn.

Project 3:

This is a new development and is centred on a major re-evaluation of how B₁₂ Deficien-

cy affects those who are currently being treated in Psychiatric units. Whilst it used to be well known that B₁₂ deficiency causes psychotic episodes very little work has been done in this field since the late 1960's. This is a national project in the UK and the society has been asked to be a 'partner applicant' for the study. More on this as it develops.

Project 4:

A new 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.

B₁₂ Injection Shortage in the UK

We became aware of a serious shortage of B₁₂ injections in the UK in January following a number of telephone calls to the office. Patients were being given a prescription for their injections but when handed to the pharmacist they were told that there was a national shortage. Obviously this caused panic among our members who turned to the society for help. We immediately contacted the

Department of Health and informed them of this development. Within three days we were telephoned back with an explanation—it appears that the company manufacturing the generic form of B₁₂ had simply stopped production due to "problems with the manufacturing process". We were impressed with the

response of the Dept. of Health who swiftly ensured that there were plentiful supplies of the two branded form of B₁₂ injections used in the UK, Neo-cytamen and Cobalin H. If your doctor tells you there is a shortage of the injection please tell him or her that it is only the generic injections that are in short supply and there are plentiful supplies of the branded forms of injectable B₁₂ available in the UK.

B₁₂ Injection Shortage Canada and USA

There have been reports of shortages in Canada and the USA—here's the latest developments.

CANADA:

Owing to a widespread shortage of injectable cyanocobalamin in Canada, PA/B12 Deficient patients are unable to get their injection from their doctor. This situation should resolve shortly because Sandoz Pharmaceuticals have provided a release date of the end of March for the 10 ml vial of cyanocobalamin. Cytex Pharmaceuticals, the other supplier of cyanocobalamin in Canada has given April 15th as the expected date of delivery of a shipment of the 10 ml vial of

cyanocobalamin. It still may be the end of April before we actually see the vials of cyanocobalamin back on the shelves at the pharmacy.

USA:

The cyanocobalamin shortage started in the summer of 2013. Normally a 30ml vial was about \$30 but the 30 ml vial was no longer available at most pharmacies. They were offering 10ml vials for about \$12-\$15 each depending on your insurance (or lack of). Heading to the internet things were a bit better, Amazon and a few other sites had 30ml vials for \$50+, expensive but

available. Currently the only place to get a 30ml vial is Mid-westernmedicalsupplies.com and the price has gone up to \$60 for a 30ml vial.

Methylcobalamin and hydroxocobalamin are also available for around \$100 for 10ml vials.

Many people in the US are just not getting their monthly shots or having to go longer in between injections. US people are showing up more on the PA Facebook page asking where to get supplies, also on the PAS forum.

Latest word is American Regent will start producing cyanocobalamin March or April.

EMPLOYMENT ISSUES—SOLICITORS BRIEFED

We, as a society, are increasingly being asked to provide letters of support or appear at tribunals when members find that their Pernicious Anaemia is affecting their work. In the last few weeks alone we have been contacted by Long-haul Airline Pilots, Police Firearms Officers, Teachers, Architects and manual workers who have all found that their continuing symptoms are having a detrimental affect on their work. Now, in a new development, we have briefed a team of Lawyers in the UK on how the symptoms of Pernicious Anaemia affect the everyday lives of some of our members.

During a series of meetings lawyers specialising in Employment Law have been made aware of the fact that even after replacement therapy injections have begun a great many patients still experience the worst effects of the symptoms of Pernicious Anaemia. They have also been made aware

of the wide range of symptoms and how these symptoms manifest themselves in individual patients. We cannot make any guarantees of success in any workplace issues, nor do we necessarily endorse these lawyers but we can say that the solicitors below are now aware of how PA affects patients' working lives.

We are still working to identify lawyers interested in being briefed about PA in Scotland. All of the following have already attended a briefing made by the PAS.



NORTHERN IRELAND:

Belfast

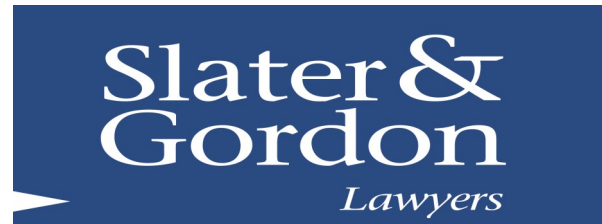
Contact:

Tom Johnstone

Within the MKB Law practice, Tom deals mainly with employment law cases and particular-

ly claims against employers. He is particularly interested in cases involving medical issues.

Tel. 028 9024 2450



In **Wales** contact **Rachel Harfield**

Tel: 0292 192 1818

London—Contact **Mohini Bharania**

Tel: 020 7657 1555

Birmingham—Contact **Sarah Evans**

Tel: 0121 233 8300

<http://www.slatergordon.co.uk/>

...these are the first lawyers who have been briefed about workplace issues faced by our members

Emma Runs the London Marathon for the PAS



Emma during the race

Congratulations to Emma Chesswas on successfully completing the Virgin London Marathon on April 13th.

Emma, from Reading in the UK ran the race on behalf of the PA Society and raised over £1,500 for us.

“It was the hardest thing I have ever done and the best thing I

have ever done at the same time” she said after the race.

Emma’s mother is a member of the society and so she is fully aware of the problems that patients with Pernicious Anaemia face on a day to day basis.

“I would like to thank the PAS for giving me the opportunity to take part in the race and I hope to be able to do the same again” says the 24yr old. Sports Devel-

opment Officer.

Emma is pictured wearing her PAS ‘Hoodie’ after the race. Our thanks to Emma and all those who sponsored her. Well Done!

If you would like to complete an event for the PAS please let us know so that we can help with clothing and publicity. Simply call the office or email (see back page for contact details).



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Reg. Charity No. 1147839

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

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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.

Trustees Meeting In Birmingham

The next meeting of the Trustees will take place in the Britannia Hotel, Birmingham on Saturday 10th May at 10 am. Members are welcome to attend but please let us know if you are going to attend by telephoning the office. The meetings usually last around three hours.

What the new Guidelines don't say.

The new guidelines from the British Committee for Standards in Haematology do not make any recommendations regarding the treatment of PA. Members being unable to receive injections according to their individual needs is

still the biggest cause of concerns. But the BCSH says that this is not a matter for them but for the British National Formulary—which is why we are meeting with representatives from the BNF in June to start the process of getting a one size fits all treatment regime revised.

Thyroid UK Conference:

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 Sat-

urday October 18th.

Meeting with the new Chairman of NICE:

A meeting has been arranged between representatives of the PAS and the new chairman of the National Institute for Care and Clinical Excellence (NICE). The meeting is scheduled for late May at the London headquarters of NICE.

Newsletter:

Due to the large and increasing number of ‘paper members’ (members who did not join online but by paper application) it now costs us over £400 to produce and mail our newsletter. If you are a paper member please consider sending us a money contribution to help us to cover the cost of producing Cobal-

amin News—any amount will help.

New Strategic Plan Written.

With membership approaching 10,000 the demands for our services are so great that we are now applying for funding to employ Regional Development Officers (RDO)s throughout the UK. We are also applying for funds to employ a part-time Administrator for the offices in Bridgend, south Wales. These developments have been incorporated into a new three-year Strategic Plan for the society and will be discussed, and hopefully adopted at the next meeting of the Trustees on the 10th May.