

Chairman's Annual Update

2014 began with the PA Society having to deal with a serious problem with the core of our service - our website. Tastic Multimedia, our webmasters and who had been responsible for the setting up of the charity since its inception went into receivership the day before Christmas Eve 2013. It meant that for the first part of the year all activity and resources were channelled into ensuring that the website remained operational. In the spring of 2014 we were able to source funds to revamp and modernise the website and in June all was back running perfectly. Unfortunately the forum, which had been such an important source of advice and guidance was unable to be moderated and we had to take the decision to make all of the posts 'read only' but perhaps the society had grown too big to support what was proving to be quite a labour intensive service. It was a very shaky start to the year but one that we survived and we continue to grow stronger.

Milestones

It is easy to forget that two important, very important milestones were passed in 2014. The first of these was the publication, in a highly respected health Journal of the results of our survey of members experiences. Dr Andrew McCaddon had written up the results into an established format had previously submitted the paper to two other journals, both of which meant altering the format of the paper before finally the British Journal of Nursing accepted the paper for publication in April. The survey was originally designed and produced by Dr Fiona Porter, a Welsh GP and a member of the society. For the very first time here was the evidence that there were serious problems with the way in which Pernicious Anaemia is diagnosed and treated. 14% of our members waited over ten years for a diagnosis which is quite a shocking statistic on its own, but when it is also known that 21% waited two years or more for a diagnosis and 19% waited five years or more to be told what was wrong with them the numbers are not only shocking but quite shocking when you take into consideration that left untreated a deficiency in B12 leads to serious and irreversible nerve damage. The paper is not without faults - respondents would have been members of the PA Society and therefore would have likely had a troublesome time which is why they joined the society. However 5% of respondents rated their care as 'excellent' and so not all members would have been diagnosed and treated badly. The main thing to remember about the paper is that it shouldn't be viewed as a stand-alone document but rather it is a statistical piece of evidence that reflects the postings and interactions on the many social media sites that have sprung up in the past few years. And the fact that the paper was accepted for publication by a respected journal means that its integrity was subject to careful evaluation. This was an extremely important milestone and one which is being discussed by medical professionals.

The second important milestone was the publication, in June, of the new Guidelines on Cobalamin and Folate that had been produced by the British Committee for Standards in Haematology. These new guidelines were commissioned by the committee following a meeting with the Department of Health in May 2012. The new guidelines are a bit of a curate's egg in that there are good parts and disappointing parts. The good bits centres around the current assay (test) that is used to determine the patient's B12 status - the guidelines acknowledge, for the first time, that there are serious shortcomings in the test. The guidelines actually tell doctors that, if there is discordance between the patient's symptoms and the test result then the test results should be ignored and treatment began to prevent any neurological issues developing. This is an extremely important milestone that is nothing less than an admission that the current assay is not really fit for purpose and that doctors should resort to doing what doctors had

previously done for more than half a century - diagnosing by listening to the patient and not relying on the results of the laboratory test. Sadly, doctors are not heeding this advice simply because they haven't and probably will not read the new guidelines. I was surprised at this and on investigating why doctors wouldn't take the time to read the publication I was told that it was due to there being so many new guidelines being issued that GPs simply don't have the time to read through every new set of guidelines. In July of 2014 I received a telephone call from a senior figure in the Dept of Health who asked if the society would like to help produce a downloadable app that GPs can access which will be based on the new guidelines and will involve the doctor answering a series of questions based around the guidelines. If he or she gets them right they can then claim Continuing Professional Development (CPD) Credits. Thankfully one of the society's supporter who is a GP has taken on this project and we are extremely grateful for her so doing. On New Year's Eve I had a telephone call from a member whose mother, who is in her 80s has all of the symptoms of PA including pins and needles and some numbness. Both the caller and her sister have been diagnosed with having classic, intrinsic factor antibody PA. Her mother's serum B12 levels is at or around 230mg/ml with the laboratory threshold being 200. Despite the caller printing off the summary of the new guidelines that are on the Medical Professionals part of the website the GP is refusing to treat the elderly lady. The family now have no alternative but to by-pass their healthcare system and purchase Methylcobalamin from suppliers in the north of England. Thankfully the caller's sister is a nurse and so will be able to administer the injections in a professional manner. These incidents of doctors refusing to depart from normal clinical practice and treat patients who have all the symptoms of PA but whose serum B12 is not below the threshold stated by the laboratory happens all the time which proves the need for the downloadable app. The new Guidelines also, for the first time, acknowledges that some people will test negative for the intrinsic factor antibody but WILL still have Pernicious Anaemia; in short the guidelines admit that the way in which PA is diagnosed is nothing less than a mess.

The disappointing aspect of the New Guidelines concerns the treatment of PA with the guidelines simply stating that the whole issue of how often injections should be given is not a matter of the committee but for the British National Formulary. And that is why in November I met with the Director of the BNF to address this issue. At the meeting I was able to describe in detail what happens when members who need more frequent injections than the one given every twelve weeks are refused additional shots by their doctor. There was much eyebrow raising and not only from the Director. When I mentioned that the BNF recommended (not dictated but recommended) that a 1mg injection of Hydroxocobalamin be given every month in the 1960s and that this was changed to every two months in 1974 and then to every three months in 1984 I suggested that these changes were the result of a whim in an effort to save money. I was told that I was wrong, and that the changes were made based on scientific knowledge and only after a great deal of discussion. This would make sense but it was my turn to raise my eyebrows when I was told that the BNF were under pressure from some doctors and others to change the guidelines to every four, five or even six months, fortunately the same scientific evidence that was presented to change the treatment frequency in the past was not forthcoming to secure any further changes to an even less frequent duration between injections. On a positive note I was told that if we, as a society, can provide the BNF with evidence that some doctors were giving more frequent injections than every three months then "the wording of the guidelines could be changed". As yet I haven't figured out how to gather and provide this evidence - the main stumbling block is getting GPs to admit that they depart from the guidelines; after all the consequences could be that they might be censured for so doing. What we really need is some hard, scientifically robust evidence why some people need more frequent injections than others, and this brings me to my next disappointment.

Research *(please note that only the briefest details can be given due to the society having signed 'Disclosure Agreements' with the researchers.)*

In the summer, the research project being led by a leading Gastroenterologist failed to gain approval by the East of England Medical Ethics Committee. The main reason was because the research team believed that, because the project involved only 20 patients no 'control' group was needed. There were a few other

'niggling' recommendations which have also been addressed and the project has now been re-written and will be re-submitted to the committee in the near future. This is such an important piece of work because it will provide some robust scientific evidence about B12 take-up. It is a small project because it is a 'proof of concept' undertaking which will (hopefully) lead to a larger and more comprehensive investigation.

Again, in the summer, we were approached by another Gastroenterologist who wanted our assistance in a project that aims to ensure that anyone diagnosed as having Pernicious Anaemia would automatically undergo a colonoscopy and endoscopy (gastroscopy). The reasoning behind this is that patients with PA will stand a bigger chance of developing stomach cancer than those who do not have the disease. The figures relating to the chances of someone with PA developing stomach cancer are not reliable but it is generally accepted that those of us with PA stand a greater chance of developing stomach cancer. Performing the procedures at diagnosis and then every three years will allow doctors to detect any abnormalities quickly thereby giving the patient a greater chance of a full recovery if there is anything sinister. If you haven't already done so please complete the survey on the society's website.

In September I came across a press release which was about how a team of scientists in Bristol University had identified the gene that switches off (or on - I'm not sure which or perhaps it is both) the gene that causes autoimmune diseases and the sequence (not sure what that is but it's to do with genes) that causes MS and Type 1 diabetes have already been identified. I contacted the Professor leading the research and went to meet him in early November. I told him that all the society can do is raise awareness of the plight of our members and he replied that I was "doing a damn good job because I hadn't even thought of investigating the sequence that triggers PA". He then assured me that he would now be concentrating on looking for the genes or sequences that cause PA. And this means that for the first time in the history of the disease somebody is actually going to investigate a potential cure for the disease instead of just treating it.

Another research project which is making steady, if slow progress is led by a senior researcher at a south coast university who is also a member of the society. She is looking at a much more effective way of treating our B12 deficiency. This project is still in the formative stage but does sound promising and holds out the hope that patients will be treated according to their individual needs.

Finally, and another project led by one of our members and fellow sufferers, a Psychologist has successfully applied for funding to work with the Pernicious Anaemia Society to investigate the psychological impact of the disease relating to how it affects day to day living - something that we are in a unique position to provide information about. Work started on the project in the late summer and preliminary reports are expected later this year.

Presentations

At the start of the year, following on from a series of presentation I had given to classes of nursing students we were deluged by nursing tutors to give presentations at various universities. There were so many requests that I stopped giving them they were taking up too much of my time. Following discussions with Carrie it was decided to make an hour-long video of my presentation which could be used by nurse tutors and another video that can be used by doctors in in-service training sessions. Somehow these projects never came to fruition but events in the last three weeks have made us realise that there is a need for these videos to be produced and we aim to get these completed by late spring.

I have also made three presentations to Podiatrists (they are interested in the peripheral neuropathy that can develop due to late diagnosis) including one that was attended by several hundred. I am already due to give another three groups of podiatrists my presentation between January 18th and March 5th. I also gave a presentation at Thyroid UK's 2014 Conference.

Parliamentary Reception

Just as Parliament was going into recess and with the help of Bridgend MP Madeleine Moon we applied to have use of the Jubilee Room in the House of Commons. These two hour slots are extremely popular with any organisation, individual or groups of individuals who want to host an event where MPs, including Ministers and members of the House of Lords can meet the hosters and learn more about their cause. We applied for a two hour slot, but it was an application that we didn't expect to come to anything - after all this is a General Election Year and demand was going to be even greater than usual. Well, it was a nice Christmas Present when we learned that we had indeed been

granted a two hour slot on Tuesday 3rd February 12-2pm. This is an excellent opportunity to raise awareness among politicians of the problems that we, as patients face in getting an accurate and quick diagnosis and adequate treatment. Go to the website of the PA Society and you will be able to access a template of a letter that you can complete and send to your MP inviting him or her to attend the event. I will give three 5-minute presentations to all Members who attend. Please write to your MP and ask him or her to attend the event. Thanks once again to Madeleine Moon and her team for their continued support of the society.

Raising Awareness

In the late summer I wrote to a variety of senior figures and institutions in the UK Healthcare system including:

The British Medical Association, the Medicines and Healthcare Products Regulatory Agency, the Royal College of Pathologists and the Royal Pharmaceutical Society. Following those letters I met with either the President or Chief Executive of the organisations face to face to make them aware of the problems faced by our members. All meetings were extremely useful and I was told on each occasion that the individuals or organisations concerned were unaware of the issues that I had raised. I was also told to contact two other individuals whom I will be writing to in the next week or so requesting a meeting. In the summer I, along with Carrie, met with the new Chairman of the National Institute for Health and Care Excellence (NICE) who was very supportive of our cause and requested that he be kept informed of developments.

This round of awareness raising was highly successful in that I became aware that the vast majority of medical professionals are completely ignorant of the plight of our members and I was very pleasantly surprised with the way not only was I received but also was listened to. It's all too easy to forget that these people have chosen their individual healthcare careers because they want to help people, genuinely want to help alleviate suffering. Only by raising awareness can we provide them with the evidence,(and I choose that word very carefully because evidence aren't necessarily facts until they are accepted as such) upon which they can come up with a solution. That's why the new guidelines are such a success story - we raised awareness that there were problems with the way in which our members were diagnosed and treated and those problems were addressed albeit without any firm alternative solutions - yet.

Another way in which we helped raise awareness was via letters to newspapers - I had four letters published in the national press this year including one that was addressed to a newspaper doctor who printed my response to her response to a letter she had received about the frequency of injections.

It would be all too easy to simply throw our arms in the air and run around shouting "it's not fair" which is what some groups content themselves with doing. If we did that nobody would take any notice of us and we would become even more frustrated. What we are trying to do is to make medical professionals aware that there is a dire need for someone who knows what they are doing to get the way in which patients who

have Pernicious Anaemia are diagnosed and treated thoroughly reviewed and, hopefully modernised and overhauled. And we do this in competition with other patient support groups who all have their own agenda. Shouting "unfair" will get us nowhere; presenting decision-makers with evidence that is other than anecdotal in a reasoned and logical way using established protocol and procedures will pay dividends in the end - though that end is still, I'm afraid, a long way off. I have always said that this will be a long journey and my shoulder, along with others, is at the wheel; yet the wheel turns only very, very slowly - but it is turning. And one of the ways in which we can get it to turn a little quicker is to get the backing of politicians to push our issues onto the political and research agendas which is why in the immediate future we shall be concentrating on the Parliamentary Reception and then on our Autumn Conference that Carrie is applying for grants as I write this. And I have decided that it is at the conference that my next book, *What You Need To Know About Pernicious Anaemia & B12 Deficiency* will be launched. You are the first to know this as my publisher originally wanted it to appear in June - I suppose I will have to speak with her soon.

All of the above took place alongside the day to day activities of the society. On average we receive around six telephone enquiries per day which often leads to me getting involved in Employment Tribunals, Divorce proceedings though thankfully, and touch wood there have been no cases this year involving children being taken into care or (again touch wood) members having been detained under section 3 of the Mental Health Act following their treatment being stopped altogether. There have been unfortunate incidences where patients have been told that they no longer need injections and that their treatment will now revolve around buying oral supplements from high street stores. I like to think that we deal with these everyday incidences quickly and professionally and although it these incidences are rare they do happen and of course, we only get to hear about some of the malpractices that take place almost on a daily basis.

Thank you for all your continued support and for any help that you have given the society in the past year - be it by organising coffee mornings, running marathons, organising a local support group or posting on the Health Unlocked website. Any help in whatever form is always most welcome.

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