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Historic Survey Launched

For the first time a comprehensive survey of the issues surrounding the Symptoms, Diagnosis and Treatment of Pernicious Anaemia has begun,

The survey will provide hard evidence of what many of us already know—that the way in which Pernicious Anaemia is diagnosed and treated needs to be urgently reviewed by medical professionals.

“One of the major problems this society faces is that the vast majority of doctors, and other medical professionals, are genuinely unaware that there are serious issues relating to the way in which patients are diagnosed and treated” says society Chairman Martyn Hooper. “Gathering information that proves such problems exist will allow the society to present doctors with the hard evidence

of misdiagnosis and non-diagnosis that they are asking for in order to be convinced that an urgent review be undertaken” he says.

The survey has been developed by doctors, who are members of the society, and other members. It is largely based on the experiences of members who have posted on the online forum.

The forum is an excellent resource where members can gain peer support and advice. The postings clearly show major problems with the diagnosis and treatment of Pernicious Anaemia. In the past, doctors who have asked for evidence of these problems have been referred to the online forum but we know of only one medical professional who has trawled through the postings. Producing hard evi-

dence that can be sourced and proven will go some way towards changing the way in which most doctors diagnose and treat Pernicious Anaemia.

The survey automatically pops up on the website when you log in. So if you haven't been on line for a while visit our website and take the survey.

If you are reading this as a hard copy you should have also received a paper copy of the survey that you are asked to complete and return using the addressed envelope also enclosed. Should you require further copies please contact us so that we can help.

The first analysis of the survey will be completed in two months time—ready for publishing around the same time as the next round of political lobbying takes place in November.

Documentary Update

Over the summer one of our employees, Kim Epton, and her friend Laura Fry, have been busy travelling around the U.K. to capture video footage of interviews with various doctors and members of the society. This footage will be used to produce an hour-long documentary that, for the first time, will expose the problems faced by our members during and after diagnosis.

The film will not only provide a

platform for airing the many grievances held by our members, but will also explore the views of the vast majority of medical professionals.

“I am determined that the film will not be a propaganda tool for the PA Society” says Kim. “I will ensure that the arguments and counter arguments are given equal amounts of exposure. It will be up to the viewer to make up his or her mind whether there are serious is-

sues to be addressed” she says.

Filming will continue into early October. If you would like to be interviewed please contact Kim—see contact details on back page. We are especially keen to interview members who were wrongly diagnosed before finally being told they had PA.





New Political Campaign Planned

Last year saw the society, for the first time, actively engaging with politicians and civil servants in both Westminster and Cardiff.

Raising awareness of the serious issues relating to the diagnosis and treatment of Pernicious Anaemia among politicians has meant that Pernicious Anaemia is truly on the political agenda. But it is only by launching another Autumn campaign that we can hope to capitalise on what we have achieved so far.

Whilst filming for the documentary various politicians have stated that none of their constituents have contacted them and they are blissfully unaware that there are even the slightest problems with the diagnosis and treatment of Pernicious Anaemia.

Please write to your MP and tell him or her about any problems you have had with being diagnosed and treated. And if you are outside the UK please write to your political representatives to make them

aware that this is a global issue affecting members from all corners of the earth.

The Autumn campaign will centre around another Early Day Motion, and hopefully a Westminster Hall Debate. We have already started to lobby members who signed last year's EDM urging them to get involved in this year's campaign. It would make our campaign even more effective if you raise awareness of the problems we all face with your MP before the campaigning begins in earnest.

The New Campaign will once again focus on the UK Parliament

“Hopefully this is the beginning of the end of all of our problems with the diagnosis and treatment of PA”

Juvenile and Infant Pernicious Anaemia may be more common than originally thought.



NICE set to carry out review

One of the most frustrating obstacles faced by our members is the fact that their GP attributes the symptoms experienced by his or her patient *after* replacement therapy treatment has started as being imaginary.

That is why so many of our members heave a sigh of relief when they find the website and realise that they are not alone in still suffering after receiving treatment.

The hard fact is that doctors

simply do not know that patients can still be symptomatic after treatment has started.

Why some patients still experience symptoms after treatment has started and why some do not is a question that has not been answered. What we do know is that it causes distress and frustration and often leads to misdiagnosis of another medical condition.

Following a meeting with Dr.

Stephen Hunter, the Director of the NHS in Wales and the society, Dr. Hunter will be writing to the National Institute for Clinical Excellence to ask them to conduct a thorough Review into how PA is Diagnosed and Treated.

NICE turned down the society's request for a Review in March of this year but have since written to us stating that if there is new evidence we should re-submit our request.

Paediatrician's Duet

Some good news for our younger members.

Earlier in the year we sent a copy of our Review of the Diagnosis and Treatment of Juvenile PA to the Medical Standards Committee of the Royal College of Paediatrics and Child Health (RCPCH).

After two months we had a reply from the Chair of the committee thanking us for the

Review and stating that she would be sending the report to the Database for Uncertainty of the Effectiveness of Treatments (DUETS).

The letter also suggested that we refer this matter to the British Paediatric Survey Unit and kindly offered to refer this on our behalf should we want that to happen. Of course we took advantage of

her kind offer and the matter has been referred by her.

The way in which babies are treated for B₁₂ Deficiency is particularly harrowing because the medical professionals continually monitor the baby's blood before injecting. Treatment is based solely on Serum B₁₂ levels as it is for many adult members.

Our youngest member is now three years old (she became a member at 18months when her brother joined aged four.

New Offices



At first he refused to believe what he was hearing, but when society chairman Martyn Hooper was offered a vast new office as a base for the society's operations he leapt at the chance to occupy the recently refurbished accommoda-

The New Office is big enough to be used as a conference venue tion—after all, it was being offered for free! “I had the initial telephone call when I was in Spain and told the caller on the other end of the line to contact me after I had returned to the UK. The second time she called she told me to go and visit the office and speak to the owner. This I did and it was he who told me about a new scheme whereby if a landlord makes available a large office space

to a charity, the landlord would not have to pay 80% of the Business Rates that has to be paid to the Local Authority in the area the office is based. The Local Authority can then decide to waive the other 20% of the rates” says Martyn.

The new office is so large that it can accommodate up to 150 delegates for future conferences and seminars—and it is all free.

Our thanks also go to Fortitude Furniture of Bridgend for their kind donation of desks and other office furniture. Thanks Julian!

The New Coalition Government in the UK means a new Health Team.

New Government Health Team

The results of the UK General Election held in May produced a coalition government—just as most people had expected.

The Coalition Health Team will be the main target for the political lobbying that will take place in the Autumn.

The team is headed by **Andrew Lansley** who is the new Secretary of State for Health and is MP for

South Cambridgeshire. Chelmsford MP **Simon Burns** is another Conservative and has been appointed Minister of State (Health) and Lib-Dem MP **Paul Burstow**—the MP for Sutton & Cheam has been appointed Minister of State (Care Services). It is Mr. Burstow who is responsible for Long-Term Conditions including P.A. Conservative MP for Guildford

Anne Milton (with a nursing background) is appointed Parliamentary Under Secretary of State for Public Health.

Earl Howe takes on responsibility for Health Quality.

If any of the above are your MP please write to them and make them aware of the problems we are facing. Focus your letter on the problems with the Diagnosis and Treatment of PA.

Methylcobalamin Infusions

There has been a dramatic increase in demand for information about Methylcobalamin Infusions.

Many members have reported a remarkable change in their well-being after receiving an infusion. A few members have reported no change in their condition.

The procedure is not licensed in the UK and we know of no country that uses this form of treatment. It is not available on the NHS in the UK.

We understand that most members of the British Society for Ecological Medicine proffer Methylcobalamin Infusions.

Methylcobalamin is a ‘purer’ form of B₁₂ and the patient is connected to a ‘drip’ containing the Methylcobalamin. The procedure takes between 45mins and an hour to complete.

Once ‘saturated’ with B₁₂ the patient is then taught how to self-inject just below the skin (sub-cut)

however often he or she wishes.

This society has a policy on this alternative treatment method. This policy states clearly that, before making enquiries or contemplating this treatment, members should discuss this procedure with their GP. You should also ensure that the practitioner giving the infusion is a qualified doctor.

This society does not recommend this alternative treatment but we believe that we should make you, our members, aware of it.



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MMA/Homocysteine/B₁₂ Research Problem.

Over the past few months, the society has paid the travelling costs to many of our members who travelled to Cranfield University to provide a sample of their blood. These members all suffered from a return of all their symptoms well before their three-monthly injection was due.

A research team led by Prof. David Hunter were going to test the donated blood to investigate why these patients were suffering from a return of their symptoms. The blood would be tested to determine the level of Methylmalonic Acid and Homocysteine present and then the patient's serum B₁₂ would also be tested. The tests were being done to determine whether the MMA and Homocysteine levels were in some way related to the patient's B₁₂ levels.

The donated blood was tested for MMA and Homocysteine at Cranfield and was then frozen. The B₁₂ test would be conducted at the Princess of Wales Hospital in Bridgend.

We recently received an email from Prof. Hunter informing us that the research project had been halted because of a serious issue. It may be that the project will need to be restarted.

An enquiry into what happened is underway at Cranfield and we will let you know of the outcome when we are told.

NEW FACES AT THE SOCIETY

When the society moved into The Old Fire Station in September 2008, it was with the intention of recruiting local volunteers to help deal with the administration of the charity.

Using the Bridgend Association of Voluntary Organisations (BAVO) we were able to access the pool of volunteers held by BAVO and begin to recruit volunteers who needed to gain experience of office administration in order to enter the world of work.

We have become one of the most successful charities in the Bridgend area in acting as a steppingstone to help volunteers find full-time work.

In the last year alone no fewer than seven of our volunteers have gone on to find full time paid work.

Abigail, Fiona, Bethan, Jane, Kirsty, Anna and Jan have all found full-time work.

Kirsty was a particular success story because she had been our first paid



Miranda—our latest recruit using *Future Jobs*

employee using the Welsh Assembly Government's *Future Jobs* scheme.

Kimberley Epton was also employed by us under the scheme and has

used the last four months of her contract to produce and direct the documentary—thus building on her background in Media.

Another *Future Jobs* employee who started with us this month is Miranda Holmes who will be concentrating on maintaining our Social Network of online sites (we are on Facebook and Twitter).

Three more volunteers will be joining us soon. One is a Marketer, another is a GP whilst the third volunteer is a Dentist.

Another GP is to become a Trustee when we incorporate the society later this year.

We can still recruit more volunteers—after all—we have the room