

PAS Spring Conference: Developments in the Diagnosis and Treatment of Pernicious Anaemia and B₁₂ Deficiency

Following the success of The Pernicious Anaemia Society's first spring seminar, held February 2009, a second conference was arranged this March.

On Saturday 13th March 2010 The Pernicious Anaemia Society hosted a conference on



the 'Developments in the Diagnosis and Treatment of Pernicious Anaemia and B₁₂ Deficiency' at Bryngarw House, Brynmenyn, Bridgend, south Wales. More than seventy people from across the UK, mainland Europe and Canada attended the event at an idyllic country setting on a beautiful spring day. Conference attendees consisted of Society members, GPs and company representatives who came to the Society's conference that sought to

bring together scientists, doctors and patients to highlight the innovations and examples of best practice for the treatment and diagnosis of Pernicious Anaemia.

The packed programme included intriguing lectures from three distinguished doctors, insights into the geo-demographic trends of Pernicious Anaemia sufferers, an oral presentation from a clinical negligence solicitor, and group sessions that allowed members to share experiences on their treatment and diagnosis of Pernicious Anaemia. One member commented, "The event has given me far more information on Pernicious Anaemia than I have had in the eight years since being diagnosed. It was good to share experiences with the other participants".

The conference opened with a very touching Welcoming Address by Madeleine Moon M.P., who has been extremely helpful in supporting the key political activity generated by The Pernicious Anaemia Society. She then went on to introduce the first of the speakers, Martyn Hooper, founder and Chairman of The Pernicious Anaemia Society.

Martyn's presentation depicted "a Geo-demographic Analysis of The Pernicious Anaemia Society's membership".

Martyn discovered that "there are areas of the UK where there are high concentrations of members even when population density is taken into account". Martyn established that "these concentrations are centred on the South East of the UK".

Martyn Hooper then introduced the next speaker, Dr. Joseph Chandy from the Shinwell Medical Group. Dr. Chandy has been investigating the problems and possible answers to the treatment and diagnosis of Pernicious Anaemia. The problems that Dr. Chandy

raised included “the non-blood symptoms being ignored today” and “the fear factor associated with making a diagnosis”. Dr. Chandy explained that Pernicious Anaemia has become “a forgotten illness” due to the latest textbooks having “sparse and irrelevant information on B₁₂”.



Dr. Chandy and Dr. Hugo Minney, Business Development Manager for the Shinwell Medical Group, then went through the responses presented by Ann Keen MP to the recent Early Day Motion. This provided an opportunity for discussion between patients with the aim of formulating a response to the official answer given by the UK Government to the Adjournment Debate. Dr. Minney suggested that by taking this approach the response would be more credible as it will be coming directly from the people who are being affected by PA. The points that were raised in these group discussions would then be brought forward to the Secretary of State with a view to updating the treatment and diagnosis of PA.



Next to speak was Dr. Edward Valente, Marketing Manager from Axis-Shield Diagnostics, on the subject of the new Active B₁₂ test. Dr. Valente’s presentation explored the circulation of B₁₂ and the stages of B₁₂ deficiency. Dr. Valente summarised that “Active B₁₂ has been shown to change early in the developing deficiency state”. He stated that “around 7% of the routine B₁₂ test population will have a normal B₁₂ level but a

low Active B₁₂ level (or, around only half of patients with low B₁₂ status will be detected using the total B₁₂ assay)”. Dr. Valente’s hope is that “the new Active B₁₂ test should eventually replace total B₁₂ testing”. Dr. Valente’s research into Active B₁₂ and Inactive B₁₂ is available to view in the ‘Download’ section on the PAS website as a PowerPoint presentation. Additionally, if you would like to request literature on the new Active B₁₂ test then please contact the office on 01656 724163 or email kim@pasoc.org.uk.

The fourth presentation was by Dr. Siddharth Banka from the Department of Medical Genetics at Manchester University, and was entitled “The Genetics of Pernicious Anaemia”. Dr. Banka pointed out “the key areas of research in PA” and referred to his current research project that studies the genetics of PA. Dr. Banka showed that “20%-30% of patients with Pernicious Anaemia have at least one close relative that also suffers with PA” and the aim of his research project is to “determine changes in which genes increase susceptibility to PA”. Dr. Banka suggested that “if we are able to determine that gene then we can then determine how changes in that gene lead to PA”. The research project is still on-going for both the individual and family studies. If you would

like to participate in this research please ask for an information leaflet or contact Dr. Siddharth Banka on 01612 766506 or email siddharth.banka@manchester.ac.uk.

Solicitor Andrew Thomas provided the audience with definitions and tips on “Medical Negligence and Pernicious Anaemia”. Andrew’s presentation fully engaged with the conference attendees through question and answer opportunities. Patients were able to receive professional advice from Andrew on the clinical experiences of their treatment and diagnosis of PA. If you would like to contact Andrews Solicitors for further information or advice on your own medical experiences please telephone 0870 112 7330 or email enquires@andrewssolicitors.co.uk. Alternatively you can visit the website at www.andrewssolicitors.co.uk.



Dr Hugo Minney

The final presentation was offered by Hugo Minney who read Kevin Byrne’s paper on ‘The Enterohepatic Circulation of Vitamin B₁₂’. In his paper Kevin lays out his theory as to “why low B₁₂ in the diet affects us in different ways”. The paper was made available to all conference attendees and was available in both a professional and simplified version.



Mary Southcott & Hugo Minney

We hope that all conference attendees went away with a better understanding of the future developments in the diagnosis and treatment of PA. Many members commented on this “fantastic conference” that offered an “excellent opportunity for networking”. However, the conference could not have been the success that it undoubtedly was without the dedication of the conference speakers who took the time to attend the event and provide such interesting discussions between doctors and patients. One attendee commented on “going home much more knowledgeable” due to the “very professional speakers (thank God for them)”. The Society would also like to offer a special thank you to everyone who attended the conference and provided The Pernicious Anaemia Society with such generous donations.

The conference was filmed and the footage is currently being edited. It will be made known to all members when the recording of the conference will be available for members to request a copy.