

Charity's Founder & Chair recognised in New Year's Honours

Martyn Hooper, who established the Pernicious Anaemia Society, has been made a Member of the Order of the British Empire in recognition of his "services to people with Pernicious Anaemia" in the New Year's Honours List.

"I am privileged to be made a member of this distinguished order" says the 57-year-old from Bridgend, "and I accept it graciously on behalf of all those who help the PA Society do what it does. The honour shows that the society that I started twelve years ago is now an established and respected patient group that is able to raise awareness of the issues faced by patients with Pernicious Anaemia and their families and friends".

Martyn started the society, which is based in Bridgend, South Wales, in 2004 after being forced to take early retirement from a career teaching in further and higher education. His late diagnosis meant that he developed irreversible nerve damage that has left him permanently disabled.

The original remit of the society was to provide newly diagnosed patients with a plain English explanation of their condition. From the volume of people visiting the simple website he set up Martin quickly realised that he was not alone in struggling to understand and manage the diseases and now the Pernicious Anaemia Society supports over 7,000 members, and their families, around the world.

"It became apparent from very early on that there were serious problems with the way in which the disease is diagnosed and remedied and we soon became a campaigning body to get the medical profession to undertake a thorough review into identifying and treating the disease," says Martyn.

Pernicious Anaemia, or more accurately, Autoimmune Metaplastic Atrophic Gastritis, occurs when the patient is unable to absorb vitamin B₁₂ from food (any animal products). Vitamin B₁₂ is essential in forming healthy red blood cells.

The Pernicious Anaemia Society has already had some success in achieving its aim. Following a successful lobbying campaign aimed at politicians and officials at the Department of Health, the British Committee for Standards in Haematology issued new Guidelines in 2014 that acknowledges the failings in the current tests to determine the vitamin B₁₂ status of patients and whether any deficiency is caused by Pernicious Anaemia, and are advised to ignore the tests if there is a discordance between the results and the patient's symptoms and start treatment to prevent any neurological damage from developing.

Symptoms of B₁₂ deficiency are many and varied but include extreme tiredness, sudden mood swings, irritability, memory problems, irrational behaviour, balance problems and breathing difficulties. Left untreated it can and does lead to psychosis and irreversible nerve damage. It can affect all ages.

The society is now involved in eight research projects that are looking at better ways of treating the disease – there is no cure as such but replacement therapy injections of B₁₂ are used to keep the patient alive. Before 1925 patients died from the disease. Early treatment was eating raw or very lightly cooked liver.

“There is great variation in how the disease is treated” says Martyn, “not only in the UK but throughout the world; and we now know that the current one-size-fits-all treatment is not suitable for all patients and this is what we are now trying to change”.

A survey of members that was published in 2014 showed that 33% waited 5 years or more for a diagnosis, 44% were initially misdiagnosed and 64% were unhappy with their treatment.

The society is the only charity in the world that provides information, advice and treatment for patients with Pernicious Anaemia and their families and friends. It has over 7,000 members throughout the world and is run entirely by volunteers.

Martyn Hooper has written three books about the disease. They are published by Hammersmith Health Books.

“When I started the society I never imagined that there would be so much that needed doing and I am pleased that the efforts of myself and all the other volunteers in the society have been recognised by being made a member of this prestigious order. We've accomplished a great deal

but there is still a long way to go before this condition is properly understood, diagnosed and treated and we can go back to doing what we originally intended to do,” says Martyn.

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