



4 February 2009

Widespread failure of GPs to diagnose Post Polio Syndrome affects thousands

A recent survey carried out on behalf of the British Polio Fellowship revealed that 55% of GPs are unable to diagnose the debilitating effects of Post Polio Syndrome (PPS) which affects up to an estimated 100,000 people in the UK.

Up to 120,000 people in the UK today were diagnosed with polio – now eradicated in this country. Up to 80% of these will develop PPS, a neurological condition which can be as debilitating as polio itself. PPS can arise 15 – 40 years after the initial disease; symptoms include: muscle wastage, muscle and joint pain, and mental and physical fatigue, as well as impaired circulation and breathing.

However, proper diagnosis and treatment can stabilise and reduce the progress of PPS and dramatically improve lives. Without treatment symptoms will deteriorate, affecting not only the lives of the individuals concerned and their families, but having a knock on economic impact through withdrawal from working life, dependence on benefits and increased use of NHS services.

Graham Ball, Chief Executive of the British Polio Fellowship said:

“We are obviously very concerned by these findings. PPS is a major problem for many thousands of people and for those who aren’t diagnosed their symptoms will deteriorate. There is clearly an urgent requirement for GPs to be trained in the diagnosis of PPS.”

It took Neill Jupp, 59, seven years to get a proper diagnosis for his PPS. Neill, from Cumbria, was in his late 40s when he started to experience unusual pains in his legs, arms, hips and ankles. Neill said: “I didn’t really pay any attention to the pain at first – I tried to just work through it. But I soon learnt that that doesn’t work. I was constantly tired and always falling asleep and then waking up feeling twice as bad. It was horrible, I felt like I was being drugged. I was also in constant pain and I wasn’t sleeping properly either. I had no idea what was going on – and neither did my GP, he just kept prescribing painkillers.”

Neill found out about Post Polio Syndrome from the British Polio Fellowship and provided his GP with information about the condition, but says his GP refused to listen. Finally, after seven years, Neill changed GP and got a referral to a specialist who confirmed the diagnosis.



Neill continued: "It was a huge relief to get a proper diagnosis; I'm now getting the care I need. But had I been diagnosed when this all started I'd have had seven years of much less pain, of sleeping properly and leading a relatively normal life. Waiting that long for a diagnosis has caused me to deteriorate. I was lucky to have found out myself and been able to ask for that referral – there are a lot of people out there who are just deteriorating but don't know why and that's frightening."

The survey's findings are supported by a further British Polio Fellowship survey carried out amongst the organisation's 8,500 members. This revealed that it takes a shocking average of six years to get a diagnosis for PPS.

Dr Steve Sturman, Consultant Neurologist at City Hospital, Birmingham said:

"PPS is a serious condition but early diagnosis can alleviate symptoms and delay deterioration. Many medical personnel could be unknowingly working with someone with undiagnosed PPS – from physiotherapists, to nurses and GPs. We urgently need to raise the profile of this disease and ensure that everyone with PPS is getting the treatment they need."

The GP Net survey also showed that only 18% of GPs know how to treat PPS once diagnosed.

Notes to Editor

For more information on this press release contact **Kat Huxtable** on **07958 701405** or **kat@cantadora.co.uk**.

For more information on the British Polio Fellowship and polio and PPS visit www.britishpolio.org.uk

Case studies are available.

The British Polio Fellowship is calling for:

- A Read Code to be created for Post Polio Syndrome and all cases of polio to be registered by each GP surgery in order to facilitate faster recognition of PPS.
- Government support for the development and implementation of training modules in PPS across the primary care field.
- PPS to be a topic reviewed by NICE, leading to accepted national guidelines on diagnosis, treatment and management of PPS.
- All non-members with polio to contact them to learn about the help they can be given.

The survey was carried out on behalf of the British Polio Fellowship with a sample 200 GPs nationally.

Polio was epidemic in the 1940s and 1950s but with the introduction of widescale vaccination, was largely wiped out by the 1970s in the UK.

The British Polio Fellowship is the largest charity for people with polio and PPS in the UK, providing information and support to people with polio and PPS, their families and healthcare professionals.