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# On This Day 76 Years Ago the British Polio Fellowship Was Formed

Wednesday 28 January, 2015

On 29 January 1939 The British Polio Fellowship was formed, meaning today the charity enters its 76th year helping and supporting those living with the late effects Polio and Post Polio Syndrome (PPS). Even after all of this time and with Polio now eradicated in the UK, the charity still provides a valuable service for those now living with the late effects of Polio and PPS, a debilitating neurological condition affecting approximately 120,000 people in the UK.

Initially the charity was formed as the Infantile Paralysis Fellowship by Patricia Carey and Frederic Morena for those disabled by Polio in the 1930s and living in a society far less accepting of disability than the modern world. As the Polio virus has moved through many stages in the UK - from the epidemic in the 1950s, to its successful eradication in the 90s - The British Polio Fellowship has remained the leading voice for those living in its shadow.

The charity continues to campaign for more to be done to get the PPS message heard by the NHS, the Government and members of the public so the needs of those living with this condition don't go unnoticed. Around 80% of Polio survivors will go on to develop PPS, which equates to approximately the same number of people that are impacted by other neurological conditions such as Parkinson's disease.

"The charity's role in society has changed with every stage that the Polio virus has gone through, however many people believe that Polio can now be forgotten about in Britain, this is simply not the case," said Ted Hill, MBE, CEO of The British Polio Fellowship. "As the leading voice for those affected by PPS the charity is going through one of its most important phases as we attempt to get the condition and its symptoms more recognition in the medical profession, so it can be properly managed."

Aside from many victims of Polio being paralysed as the initial result of the disease, those confronting the onset of PPS also face a fresh host of debilitating symptoms to cope with many years down the line.

People suffering from PPS will notice a steady decline in mobility which may eventually lead to being consigned to a wheelchair, whilst other problems include chronic fatigue and joint ache, reduction in stamina and a heightened sensitivity to cold.

The British Polio Fellowship, which has 49 local branches in the UK and a membership of over 7,000 members, offers information, available online or over the telephone, support through schemes such as Winter Warmth grants that provide a contribution towards gas and electricity bills, whilst it continues to provide a community of people that understand the struggles of late effects of Polio and PPS.

With many Polio and PPS survivors being limited by a disability, the charity is also a strong campaigner for improved accessibility in the UK.

Full details of how you can get involved are on the charity's website at<u>www.britishpolio.org.uk</u> which has a lot of helpful advice for those with late effects Polio or PPS or call us on Freephone 0800 018 0586.

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Notes to editor

#### About the British Polio Fellowship

The British Polio Fellowship is a charity dedicated to helping, supporting and empowering those in the UK living with the late effects of Polio and Post Polio Syndrome (PPS). It provides information, advocacy, welfare and support to enable its members to live full independent and integrated lives and works to develop worldwide alliances with other Polio and Post Polio groups for the mutual benefit of its members. Further information about the British Polio Fellowship and details on how to make a donation can be found at <u>www.britishpolio.org.uk</u> or by calling 0800 018 0586.

About Post Polio Syndrome (PPS)

Post Polio Syndrome (PPS) is a neurological condition which can occur in up to 80% of those who have had Polio. It is estimated that around 120,000 people in the UK are living with PPS today. After an

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interval of several years of stability, individuals can develop increasing weakness, fatigue and pain in previously affected or unaffected muscles, a general reduction in stamina, breathing, sleeping and/or swallowing problems and cold intolerance. PPS usually begins very slowly, although it can appear suddenly and often following triggers such as falls, surgery or immobility. There is no specific cure for PPS, but properly managed it may stabilise or only progress slowly and lessen the cost on the NHS whilst increasing the quality of life of those affected.

Much can be done to retain independence, including self-management strategies such as pacing and energy management, appropriate use of adaptive equipment, looking after your general health, and social and emotional support.

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