Press Release – 31st December 2020

IMPORTANT NOTE – UNDER STRICT EMBARGO UNTIL 23:30 on Weds 30 December 2020

Queen's New Year's Honour for Bucks Charity Champion

Milton Keynes resident Fiona Copeland has been awarded a British Empire Medal (BEM) for her tireless work for respiratory charity Primary Ciliary Dyskinesia (PCD) Family Support Group in the Queen's New Year's Honours list.

Fiona Copeland

Fiona, of Wavendon Gate, Milton Keynes chaired the PCD Family Support Group on an entirely voluntary basis until June 2020 for nearly 17 years, transforming it into the professional and well-regarded organisation it is today. The charity offers a range of support to individuals and families affected by PCD, as well as information to medics and the clinical community. Fiona's tireless work has involved providing constant telephone and in-person support to individuals and families affected by PCD, providing them with information, reassurance and help when they need it. She has transformed the care of PCD patients across the UK and even globally, assisting international PCD charities with help and advice.

PCD or Primary Ciliary Dyskinesia is a rare genetic condition affecting one in 10,000 people in the UK. It is associated with the abnormality of cilia (microscopic hairs that beat in the airways, sweeping secretions out of the respiratory tract) and can affect the lungs, nose, sinuses, ears and fertility. If left untreated can lead to a form of lung damage known as a ‘bronchiectasis’.

Fiona’s sons Euan and Gregor were diagnosed with PCD when they were aged 6 and 4 after being wrongly diagnosed with asthma. Unfortunately, by the time they were diagnosed they both had irreversible lung damage. From this personal experience Fiona was keen to get more awareness of PCD to the wider medical community so that other families would be able to get the appropriate diagnosis and care as soon as possible. It was Fiona's drive and determination that brought the leading experts and practitioners from different medical fields (paediatric, adult care, physiotherapy, ENT etc.) together to discuss this rare genetic respiratory condition in a new forum, establishing a common agenda as to how to help tackle and alleviate the impacts of this condition.

Euan and Gregor Copeland in 2002 just after diagnosis

The ability to get key people around the table is one of Fiona’s strongest attributes, and she worked tirelessly to attain funding from the NHS commissioners for a national PCD paediatric service across England Wales (established in 2006). As a result, there are now specialist centres across England who are well-equipped with the specialist resources to deliver an effective in-house and outreach service to young patients.

Most recently, Fiona lobbied for the funding of an adult service for PCD. Even when the case looked bleak and funding looked unlikely, Fiona did not give up on applying pressure to the NHS commissioners to set up this vital service. On Monday 18th December 2017 the NHS granted funding for the new adult service, which is something that would certainly not have been awarded without Fiona's persistence and determination. This service could not have come at a more important time, with the entire adult PCD community being considered ‘Clinically Extremely Vulnerable’ during the current Covid-19 pandemic. Fiona quickly mobilised the medical professionals in March 2020, to ensure that patients with PCD were kept up to date with guidance about the developing crisis, thus providing them with the information and support they needed to keep safe.

Undoubtedly, Fiona has been the 'glue' between the PCD community and the medical world. Internationally, she has helped organisations in Portugal, France and Australia to develop their own patient support groups and she has had a profound impact across a vast array of networks relating to genetics and rare diseases. This national honour at the end of a very

difficult year is richly deserved and the PCD community are infinitely grateful to her for all of her dedicated service.

As she accepted her award, Fiona said: "*I am delighted to accept this award – I have really enjoyed volunteering for the PCD Family Support Group and being able to help improve the diagnosis and management of PCD patients in the UK. I am also very pleased that by receiving this award it can in some small way help raise even more awareness of this rare condition".*

For further information including interviews with Fiona, please contact:
comms@pcdsupport.org.uk / 07899 922540

NOTES FOR EDITORS

What is PCD (Primary Ciliary Dyskinesia)?

Primary Ciliary Dyskinesia (PCD) is a multisystem, inherited, relatively rare genetic condition associated with the abnormality of cilia (microscopic hairs that beat in the airways, sweeping secretions out of the respiratory tract). PCD may affect the lungs, nose, sinuses, ears and fertility.

The condition involves recurrent infections in the nose, ears, sinuses and lungs. If left untreated can lead to a form of lung damage known as a 'bronchiectasis'.

Up to 50% of patients with PCD also have dextrocardia (heart on the right side) and situs inversus (internal organs on opposite side to normal).

PCD has a high treatment burden and significant impact on quality of life, though it can affect patients in a variety of ways and to different levels of severity. The mainstay of treatment for people with PCD is regular chest physiotherapy to clear secretions from the lungs and targeted antibiotics to treat infections.

About PCD Family Support Group:

The PCD Family Support Group was formed in 1991 to:

- Provide support to patients and their carers who have, or are suspected of having, PCD
- Bring PCD to the attention of medics who may come across PCD and continue to provide an up-to-date information service for them and the general public
- To promote research to aid diagnosis and treatment of patients with PCD
- Support the NHS and other bodies to ensure patients have access to diagnostic services and on-going care
- Fundraise to support the above activities

PCD Family Support Group is a registered charity run by a committee of volunteer Trustees. The charity is supported by the PCD Medical Board,a group of clinicians/scientists with an interest in PCD. This group is led by Dr. Mary Carroll, Professor Claire Hogg, Dr. Michael Loebinger, Professor Jane Lucas, Professor Chris O'Callaghan, Dr. Daniel Peckham and Dr. Simon Range.

Web address: www.pcdsupport.org.uk

Twitter: @PCD_UK

Facebook: @PCDSupportUK

Instagram: @pcdsupport

Euan and Gregor a few weeks before diagnosis

Fiona and her boys, Gregor and Euan in 2008

Euan and Gregor now with their proud parents Fiona and Stuart Copeland - all suited and booted

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