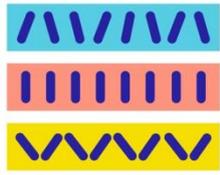


CELEBRATING 30 YEARS
30



**PCD
SUPPORT
UK**

MEDIA RELEASE



New look, new direction for PCD Support UK

6 October 2021

This PCD Awareness Month sees the launch of a vibrant new name and new look for respiratory charity PCD Support UK. The new name and visual identity celebrate the national charity's 30-year journey supporting those with Primary Ciliary Dyskinesia and the transformative impact its work has had on those affected by this rare genetic disease – patients and carers alike - along the way.

PCD or 'Primary Ciliary Dyskinesia' is a rare genetic condition affecting one in 15,000 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.'

The new name represents our vision to be an inclusive and accessible charity that supports both individuals and families affected by PCD, as well as working alongside healthcare professionals to further understanding and awareness of this disease. Thanks to the invaluable support of The National Lottery Community Fund, the new charity brand identity developed by design consultancy Gaggeroworks proudly projects PCD Support UK's warm,

Charity No. 104 9931

friendly and expert approach, whilst also representing the community it serves. The fresh look has also been incorporated into a fresh website for the organisation, designed by Polkadot Agency – www.pcdsupport.org.uk. Illustrations are by Alex Foster.

The charity's achievements across its 30-year history include the establishment of a national PCD paediatric service across England (in 2006), resulting in specialist centres across England, well-equipped with the resources to deliver effective in-house and outreach service to young patients. More recently, persistent lobbying of NHS commissioners over many years was finally rewarded with funding for a new adult service in 2019. This could not have come at a more crucial time, with the entire adult PCD community being considered 'Clinically Extremely Vulnerable' during the current Covid-19 pandemic.

Committee member and patient Myra Tipping reflected on the charity's achievements over the past 30 years:

"I'd like to thank Carol Polak for setting up this important charity in 1991 at a time when PCD was still a little-known rare disease. Next Chair Fiona Copeland was instrumental in raising awareness of PCD and securing the strong relationship between the patient and medical communities. Latterly, Lucy Dixon has really helped to modernise the charity – bringing its activities online, helping to engage young adults and teenagers and overseeing this fresh new look."



Talking about the charity's 30-year milestone, charity Chair Lucy Dixon said:

"We're thrilled to be celebrating 30 years of being there for the PCD community with the launch of a friendly, approachable and inclusive, fresh look for our charity. This together with a brand-new website will help us to reach and engage with even more people across the UK and enable us to champion even wider research to improve diagnosis, management and treatment of this rare disease."

The future of PCD is something to be excited about, with increasing developments in treatments, research and PCD management. But there is still more to do, and we will keep fighting for equal PCD care across all UK nations, bringing PCD to the attention of the medical community and making sure that patients and their families are supported throughout their PCD journeys”

----- ENDS -----

NOTES FOR EDITORS

For further information, please contact: comms@pcdsupport.org.uk

What is PCD (Primary Ciliary Dyskinesia)?

Primary Ciliary Dyskinesia (PCD) is a multisystem, inherited, 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 diverse 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 Support UK:

PCD Support UK (formerly 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 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 Support UK is a registered charity run by a committee of volunteer Trustees. It 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

LinkedIn: PCD Support UK

About The Coronavirus Community Support Fund and The National Lottery Community Fund

Funding from the Coronavirus Community Support Fund, distributed by The National Lottery Community Fund, has helped us to ensure PCD Support UK meets our community's needs throughout the pandemic and beyond. Thanks to the Government for making this possible.

- Twitter: [@TNLComFund](#) & [@DCMS](#)
- Facebook: [@TNLCommunityFund](#) & [@dcmsgovuk](#)



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