LifeArc pioneering new patient-led approach to rare lung diseases

People power is breathing new life into rare respiratory disease research, as patients join forces with scientists and clinicians in a groundbreaking collaboration in Nottingham on March 4.

It is part of a £9.4m project by LifeArc Rare Respiratory Diseases (RRD) Centre, a not-for-profit medical research charity supporting this new UK-wide programme that aims to speed up the development of new treatments and tests for rare lung diseases.

The centre connects adults, children and families with clinical experts, researchers, investors, and industry leaders to work together to drive progress in research and influence policy direction.

“I’m incredibly excited about our first patient group meeting,” said Professor Kev Dhaliwal, who co-leads the RRD Centre supported by LifeArc, at the Baillie Gifford Pandemic Science Hub University of Edinburgh.

"It’s a pivotal moment, uniting patients, researchers, and clinicians to collaborate in new ways and accelerate better diagnosis, treatment, and potential cures never done before.

"We believe this groundbreaking, community-driven approach will transform the treatment of rare respiratory diseases by creating a strong, patient-led research network.

“The collaboration will be crucial in advancing our understanding and treatment of these conditions, and we are excited to take this important step forward together.”

The patient groups– Action for Pulmonary Fibrosis, Childhood Interstitial Lung Disease, LAM Action, PCD Research, PCD Support UK and Myrovlytis Trust / Birt-Hogg Dube foundation – will network with scientists, delegates from six UK universities, and representatives from across the NHS and funders.

Work with patients has already begun.

Former BBC TV News presenter Philippa Thomas was diagnosed with lymphangioleiomyomatosis (known as LAM) a rare lung disease that causes abnormal muscle-like cells to grow in the lungs, while working for the BBC as a Washington-based White House correspondent.

She suffered a collapsing kidney tumour, followed by a lung collapse five years later; it wasn’t until a hospital doctor in the UK, who had seen a rare disease in a single patient 17 years earlier, considered whether there might be a link.

“It has been hugely encouraging to be involved in this collaboration right from the start, from helping to draft the application for LifeArc funding, to having a voice at every stage of planning this exciting new research centre,” said Philippa.

Professor Simon Johnson, who also co-leads the LifeArc Centre and is director of the UK centres for lymphangioleiomyomatosis and Rare Cystic Lung Diseases, based at the University of Nottingham, says rare diseases are often poorly recognised by doctors and difficult for researchers to study.

"This new approach for rare respiratory diseases offers a single front door, initially for the UK and eventually expanding to Europe and the rest of the world," said Prof Johnson.

"The philosophy is to champion a patient-led approach, integrating patient perspectives into every phase of our work, from pre-clinical research onward.

"We are bringing children and adults who know best, together with experts who know the condition best to collaborate to co-create solutions.

"We want to engage patients in the science and policy workshops and make them feel part of the same team. That is the challenge."

Prof Johnson says living with a rare respiratory disease can be tough, with often limited treatment options, delayed diagnoses, and lack of understanding, leaving patients feeling isolated.

"Many of these conditions present with similar symptoms – such as breathlessness and a chronic cough – yet diagnoses can take years," he added.

"Training clinicians to recognise rare respiratory diseases earlier could reduce diagnostic delays and spare patients unnecessary suffering and uncertainty," added Prof Johnson.

"Bringing everyone together like this will also make it easier to recruit people for medical research by building trust, raising awareness, and amplifying our voices."

Philippa Thomas says she's "honoured" to be a part of that effort.

"I've had it easy compared with so many of my fellow patients," she added. "Now we have the chance to contribute our own experiences to the brilliant work that LifeArc is empowering from our medical and scientific colleagues. This initiative will be life-changing".

Currently, around 350 women in the UK have a diagnosis of LAM. For further information visit: www.lamaction.org

ENDS

Issued by Empica Ltd on behalf of LAM Action for further information contact Judith May on 01275 394400.

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About LifeArc

LifeArc is a self-funded medical research charity. We take science ideas out of the lab and help turn them into medical breakthroughs that can be life-changing for patients. We have been doing this for more than 25 years and our work has resulted in five licensed medicines, including cancer drug pembrolizumab (Keytruda®), lecanemab for Alzheimer's (Leqembi), and a diagnostic for antibiotic resistance.

Our teams are experts in drug and diagnostics discovery, technology transfer, and intellectual property. Our work is in translational science – bridging the gap between academic research and clinical development, providing funding, research and expert knowledge, all with a clear and unwavering commitment to having a positive impact on patient lives.

LifeArc is a company limited by guarantee (registered in England and Wales under no. 2698321) and a charity (registered in England and Wales under no. 1015243 and in Scotland under no. SC037861).

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