

Charity welcomes £9.4 million research centre for rare respiratory diseases.

A national charity that supports women with a rare lung disease has welcomed the announcement of a new £9.4 million [research centre](#) involving researchers from the [University of Nottingham](#).

For the first time ever, there will be a hub connecting people affected by rare respiratory diseases with a network of clinical experts, researchers, investors, and industry leaders across the UK.

[LAM Action](#) is a UK charity that supports people with lymphangioleiomyomatosis (LAM), which almost exclusively affects women, and funds research into the disease. LAM is a progressive disease that leads to the development of cysts in the lungs and can involve lung collapse, benign kidney tumours and other complications.

Professor Simon Johnson, director of the UK centres for LAM and Rare Cystic Lung Diseases in Nottingham, will co-lead the centre, which is being funded by the not-for-profit medical research charity [LifeArc](#).

“Rare diseases are often poorly recognised by doctors and difficult for researchers to study,” said Professor Johnson who has played a pioneering role into research into LAM and leads the National Centre for LAM clinical care in Nottingham.

“This funding from LifeArc is a major boost for UK rare lung disease research that will raise the profile of rare diseases, reduce diagnostic errors and enable the development of treatments for these currently incurable conditions.”

There are around 350 women diagnosed with LAM in the UK. Studies investigating the underlying cause of the disease have led to a treatment which, while not a cure, slows the progression of LAM in most women.

Former BBC News journalist and presenter, Philippa Thomas, was diagnosed with LAM after falling ill while covering the US election night in Ohio in 2004.

“My first consultant said, ‘I give your lungs ten years, give or take three or four’. I was a BBC foreign news correspondent and a very busy mum. And now I had an incurable chronic condition that only strikes women of child-bearing age and that my GP had never heard of.

“Thankfully he was wrong, and I am one of the lucky patients not to be relying on bottles of supplementary oxygen or surviving with a lung transplant.

“Many of my fellow patients have been denied motherhood, a career, even life, by this rare disease that can literally shred your lungs. I see the new LifeArc centre as a potential lifeline for thousands of us who’ve been living in the dark.

“I found a supportive community in the LAM Action patient group. I also found some of the rare LAM experts in the world and I stabilised – I got lucky.

“There is so little research funding for rare respiratory diseases, that getting treatment – let alone an accurate diagnosis – really does feel like a lottery.

“The new LifeArc centre represents new and significant hope for all rare lung disease patients and their families –hope that we can speed up and bring together the provision of essential information, access to specialised care, new clinical trials, and above all a future with a cure.”

Thirty years ago, virtually nothing was known about LAM, but since then, clinical research has provided a great deal of information on how LAM affects women and the best ways to manage the condition.

With a budget of £9.4 million, the new LifeArc centre will establish a nationwide biobank housing patient samples and disease models that will allow researchers to advance pioneering therapies and engage with industry and regulatory partners to develop innovative human clinical studies.

The new centre will also significantly boost public awareness of the realities of living with rare respiratory diseases and patient awareness of resources that can improve their quality of life.

The centre is a partnership between Universities and NHS Trusts, co-led by Edinburgh with partners in Nottingham, Dundee, Cambridge, Southampton and at University College London. It is supported by six other clinical partners in Belfast, Cardiff, Leeds, Leicester, Manchester and at Royal Brompton.

ENDS

Issued by Empica Ltd on behalf of LAM Action. For further information contact Judith Skorupski on 020 8983 0779 or Martin Powell on 01275 394400.

29 April 2024