

# New website to unite cystic fibrosis patients and researchers

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People with cystic fibrosis (CF) will be able to access the latest research findings about their condition, volunteer for clinical trials and influence the direction of future scientific studies through a new website being launched later this week.

[CF Unite.org](http://CFUnite.org) is the brainchild of academics at The University of Nottingham who wanted to find a way of bringing patients together to discuss scientific and [medical breakthroughs](#) without risking the spread of infections that can be dangerous to those living with the condition.

Dr Matthew Hurley, leading the CF Unite project in the University's School of [Clinical Sciences](#), said: "There are a number of charities and groups that support [CF patients](#) with their condition but until now there has been nowhere that they can go to directly engage with the scientists and researchers who are studying the disease.

"Equally, patients with CF have a wealth of untapped experience

because they live with the condition every day. This unique knowledge could be extremely useful in designing new clinical trials and in guiding experts on the type of research that is going to have the greatest impact."

## Life-threatening disease

CF is the one of the UK's commonest life-threatening inherited diseases. It is caused by a [faulty gene](#) that controls the movement of salt and water in and out of the cells in the body, which leads to the [internal organs](#), especially the lungs and [digestive system](#), becoming clogged with thick sticky mucus.

People with CF are affected by bacteria which grow in the lungs. These are harmless to healthy people but could be potentially dangerous to other people with CF. These infections can usually be eradicated or kept at bay with early [antibiotic treatment](#) but bugs often eventually become established or become antibiotic-resistant, leading to patients' lungs becoming colonised.

The risk of cross-infection from such bacteria means that people with CF often have to avoid contact with others, which can lead to them becoming isolated.

The new website is a public engagement with science project which has been supported by a Wellcome Trust People Award. The site has been designed to work as a virtual 'conference,' where patients and their families will be able to access live webcasts of experts discussing the latest research findings and explaining the impact they could potentially have for people with CF. Patients will have the opportunity to ask the experts questions in real time.

## Publicise and communicate

As the disease affects just 9,000 people in the UK researchers can often find it difficult to recruit enough patients on to clinical trials.

CFUnite.org will offer academics and clinicians a shop window to publicise their future studies and to communicate with patients about how they can get involved.

The first virtual conference is set to take place on Saturday January 12 and the programme will include a discussion led by Dr David Sheppard from The University of Bristol on the new 'wonder drug' Ivacaftor, which is one of the most significant new treatments for some patients with CF in recent years.

The event will also include presentations on the results of [clinical trials](#) of Ivacaftor for two different types of CF mutations as well as a talk on the patient dimension by Ed Owen, CEO of the [Cystic Fibrosis Trust](#).

CF patients and their families can access the site at [www.cfunite.org](http://www.cfunite.org), can follow on social media via Twitter via @CFUnite and Facebook/CFUnite.

Provided by University of Nottingham

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