

How did COVID-19 change communications at PCD Support UK?

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Hello! We are PCD Support UK

We are the UK's dedicated charity supporting those affected by **Primary Ciliary Dyskinesia (PCD)**, championing vital research into this rare disease since we began over 30 years ago. In the UK, all adults and some children with PCD are considered **clinically extremely vulnerable** to COVID-19, and were advised to shield (isolate) throughout much of 2020 and 2021.

Supporting our community

Due to **shielding**, many of our community were isolating at home. We increased our social media communications, hosted live online Q&As with clinical experts, and created informative posts about important topics, such as mental health and vaccines.

We ran **competitions** encouraging exercise among our members (important for PCD lung health) and held a **PCD Awareness Month** throughout October 2020. Our work was highlighted by the NHS Strategy Unit (2021).



@PCD_UK



pcdsupportuk



facebook.com/PCDSupportUK



Moving events online

1. Annual General Meeting (AGM)

- Our AGM (including a Q&A with clinicians) was hosted online for the first time in 2020, and again in 2021.
- Both were attended by more members and medical professionals than any previous in-person events!
- Many attendees said they preferred the virtual meeting from an infection-control point of view and for accessibility reasons, but some felt that children missed out on connecting with others.

2. PCD Live!

- We started PCD talks for patients and their families, with speakers from across the globe.
- Attendees listen to a speaker for 20 minutes and then take part in a 20 minute Q&A.
- Topics covered so far: mental health, fertility, genetics, diagnostics and microbiology.
- All are recorded and available to watch online. Scan the QR code!

3. For people with PCD, by people with PCD

- We encourage our members to be active participants in building our community.
- We recorded a conversation between adults with PCD on 'all the questions you never asked about PCD'
- We set up a patient-led private Facebook group for people to connect, share their experiences and make new friends

Find us on YouTube!



Big changes!

We officially became **PCD Support UK** in 2021. Before this we were called 'PCD Family Support Group UK.'

Thanks to a grant from the National Lottery Community Fund, we **rebranded** and built a **new website**, which is a hub of information for **patients, clinicians** and **researchers** alike.



www.pcdsupport.org.uk

What's next?

- We're holding a **virtual kids camp** to help connect our younger members in March 2022.
- We are developing a '**research-zone**' with lay summaries of current PCD research.
- We will continue building our **visual content**, with new 'PCD Live!' videos and many more patient opportunities to come!