

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

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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.



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).

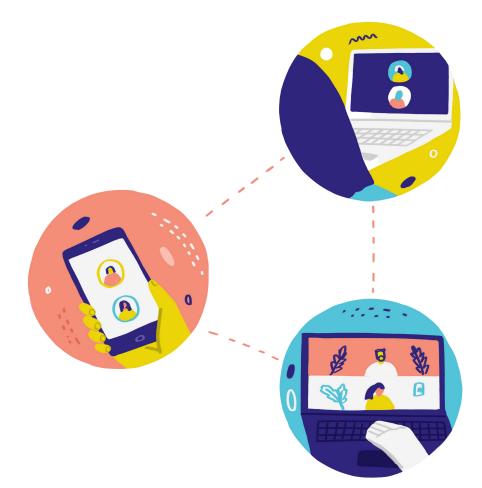
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Moving events online



1. Annual General Meeting (AGM)

- Our AGM (includeing 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. Find us on YouTube!

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

PCD SUPPORT UK

- 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



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.

it PCD - Who We Are - Get Involved - Community

Hello! We are **PCD** Support UK



www.pcdsupport.org.uk



- 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!



ELF Patient Organisation Networking Day 2021