

## PCD Family Support Group UK



### Overview

**Reference:** 06

**Location:** UK

**Target Group:**

Individuals and families with Primary Ciliary Dyskinesia

**Initiative type:** Social media support

### Contact

**Email:**

[comms@pcdsupport.org.uk](mailto:comms@pcdsupport.org.uk)

**Website:**

<https://pcdsupport.org.uk>

**Twitter:**

@PCD\_UK

### Top Tip

*Make information easy to understand and disseminate it on as many channels as possible.*

### Why is this important to us?

We are a community of people affected by Primary Ciliary Dyskinesia (PCD), A rare genetic condition that affects the lungs, sinuses, hearing, internal organ placement and fertility. Many people who have contacted us with their vaccine concerns have asked: 'is the vaccine going to affect my fertility?' or 'will it make my lungs worse'. Our community were also concerned about leaving their home to get the vaccine, many had not been outside their homes for the last year. They wanted to know whether the GP or vaccination centre would be clean and safe and whether people were wearing masks. PCD disproportionately affects some ethnic groups, who have also been disproportionately impacted by COVID-19, so we were aware we had a lot to do in terms of engaging all members of our community.

### What are we doing?

The Vaccine Stories initiative on Twitter had a number of purposes: to normalise getting the vaccine for people with rare diseases; to share good news stories within the PCD community; and to connect with people who might have concerns about the vaccination process. We got a lot of conversations started on social media and we were able to provide information.

### Who is involved?

This initiative is a PCD community effort. It started with posts from our own committee members, and led to other patients who had received the vaccine coming forward on social media, wanting to show others how easy it was. It encouraged collaboration in the PCD community.

### What works for us?

Infection control is naturally in our daily conversation because of our heightened risk of respiratory tract infections. For our community, the concepts of social distancing, hygiene are not new, we've been doing this for years. **The initiative has brought the community together and reinforced our sense of togetherness in a time where we've never been so isolated.** By making people feel more comfortable to ask questions often we can then support them in ways that they may not realise that we can. One thing that we hope is that people can understand the needs of the PCD community more after this period.