

## Study: Patients' research priorities for primary ciliary dyskinesia

Tell us what **YOU** think research in primary ciliary dyskinesia (PCD) should focus next!

### What is this study about?

We invite all people with PCD and parents/carers of children with PCD across the world to participate in this study to identify which PCD research areas are important to them and should be prioritised.

There are still many unanswered questions related to PCD, researchers try to answer. Usually, priorities for research and decisions about disease management are directed by experts in the field. This study helps to understand the wishes for future studies in PCD from the perspective of people with PCD. Your opinion could play an important role in developing future research projects and informing management decisions for PCD. Ultimately the study aims to help improving the health and quality of life of people with PCD.

This study was developed in the framework of BEAT-PCD, a large network of clinicians and researchers interested in PCD (<https://beat-pcd.squarespace.com/>) and in close collaboration with representatives of PCD support groups.

### Are there any benefits or risks involved?

There are no direct benefits for you if you decide to part in this study. However, this study will help enhancing research in PCD and inform the next steps of the BEAT-PCD network. There are no risks; the survey is completely anonymous, and we do not collect any traceable information.

### Where can I get more information?

If you have any questions or concerns about this study, please contact **Dr Myrofora Goutaki** [myrofora.goutaki@unibe.ch](mailto:myrofora.goutaki@unibe.ch) or **Yin Ting Lam MD** [yin.lam@unibe.ch](mailto:yin.lam@unibe.ch) (Phone 0041 31 684 5973).

The survey will take around 10 minutes. **To participate please choose from available languages:**

English	<a href="https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=en">https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=en</a>
French	<a href="https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=fr">https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=fr</a>
German	<a href="https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=de">https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=de</a>
Greek	<a href="https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=el">https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=el</a>
Italian	<a href="https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=it">https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=it</a>
Norwegian	<a href="https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=no">https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=no</a>
Spanish	<a href="https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=es">https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=es</a>
Turkish	<a href="https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=tr">https://redcap.ctu.unibe.ch/surveys/?s=3PHAFDXEMEMXA3KM&amp;language=tr</a>

**Thank you very much for participating!**