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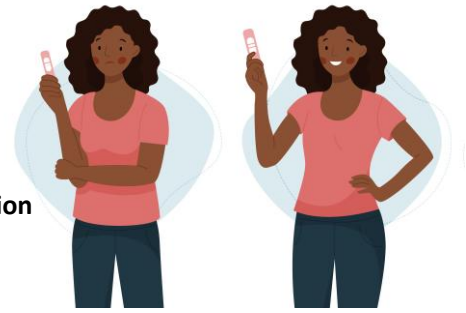

Fertility experiences of people with PCD

Written by **Leonie D Schreck**, **Myrofora Goutaki** and **Michele Manion**

Why did we do this research and why is it important?

Women and men with primary ciliary dyskinesia (PCD) often have problems having children. This can significantly impact their lives, yet little is known about their fertility experiences. Understanding these experiences is important to improve support, address concerns, and ensure people with PCD can make informed decisions about family planning.

How did we do this research?

We sent a questionnaire to all participants of the *Living with PCD* study. The questionnaire included open-ended questions about fertility. Participants, including adults and adolescents with PCD, and parents of children with PCD, shared their experiences, concerns, and challenges related to fertility.

What did we find out?

Many participants shared that they faced big challenges when it came to getting help with fertility. They often did not get enough information or support from their doctors and felt unsure about whether they could have children. They also worried about how PCD might affect a pregnancy, and whether their children might inherit the condition. Some found it hard to access fertility treatments, and dealing with infertility caused a lot of emotional stress. Parents of children with PCD often manage access to information on fertility in PCD, deciding when and how to talk to their children about these issues.

What does it mean?

Our findings show that more research is needed on fertility issues in PCD and that people with PCD and their families need better care and support when it comes to fertility. Healthcare professionals need to give clear and accurate information, talk about fertility as a regular part of their PCD care, and help them cope with the emotional stress of infertility. By creating clear guidelines and making sure healthcare providers understand these issues, we can help people with PCD get the support they need to make informed choices about having children.

Further information: pcd.ispm.ch

Full article reference: Schreck LD, Meyer S, Pedersen ESL, Lam YT, Silberschmidt H, Bellu S; Living with PCD patient advisory group; Zambrano SC, Kuehni CE, Goutaki M. 'Nobody Has Ever Spoken to Me About PCD and Fertility Issues': Fertility Experiences of People With Primary Ciliary Dyskinesia and Their Family Caregivers. Health Expect. 2025 Jun;28(3):e70316.
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You can find the full article in English **here**.

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