

## Fertility and PCD

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

People with primary ciliary dyskinesia (PCD) can have issues conceiving. It is unclear how many with PCD struggle to have children, and how many are able to have children with help. We also do not know if women with PCD tend to have more ectopic pregnancies (pregnancies outside of the uterus) than the general population. We wanted to know the answers to these questions.

### How did we do this research?

We sent a questionnaire about fertility to all participants in the Living with PCD study. The Living with PCD study is an online study. It collects information directly from people with PCD from all over the world. 265 adults completed this fertility questionnaire.

### What did we find out?

*How many people with PCD struggled to have children?* Eight out of ten men and six out of ten women experienced problems conceiving.

*How many were successful with help?* Among those who struggled, two out of three were able to have a child with the help of fertility treatments.

*Did women with PCD have more ectopic pregnancies?* In our questionnaire, women with PCD had more ectopic pregnancies than the general population. We found seven out of 100 pregnancies in PCD were ectopic, compared to

only two in 100 pregnancies in the general population.

### What does it mean?

We believe that people with fertility problems were more likely to complete our questionnaire. This means there may be many more people with PCD who have managed to conceive without any problems. We think that true risk of ectopic pregnancy in PCD may be lower than we found in our study.

However, we also believe that women with PCD should see their gynaecologist early in their pregnancy to confirm that the pregnancy is inside the uterus. The authors also suggest addressing fertility problems in routine PCD care, with the help of fertility specialists with an interest in PCD.

**Further information:** [pcd.ispm.ch](https://pcd.ispm.ch)

**Full article reference:** Schreck LD, Pedersen ESL, Dexter K, Manion M, Living with PCD study advisory group, Massin N, Maitre B, Goutaki M, Kuehni CE. Infertility and pregnancy outcomes among adults with primary ciliary dyskinesia. *Human Reproduction Open*, Volume 2024, Issue 3, 2024, hoae039, <https://doi.org/10.1093/hropen/hoae039>  
You can find the full article in English [here](#).

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