

Lung exacerbations in PCD

Written by **Leonie D Schreck**, **Myrofora Goutaki** and **Fiona Copeland**



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

Lung exacerbations, i.e. flare-ups of lung symptoms, are common among people with primary ciliary dyskinesia (PCD) and often due to infections. Frequent exacerbations can damage the lungs over time and reduce quality of life. However, it is unclear how often people with PCD have an exacerbation. We also do not know who is at higher risk of frequent exacerbations. This knowledge could lead to earlier and more targeted treatments when needed, improving the care and health outcomes of people with PCD.

How did we do this research?

In the *Living with PCD* study, we collected information from 660 people with PCD worldwide, including 408 adults, 57 adolescents, and 195 children. Over two years, participants filled out 17,854 online questionnaires, regularly reporting their symptoms and any changes in their health. These data allowed us to identify when they experienced lung exacerbations.

What did we find out?

We found that people with PCD had about three lung exacerbations each year on average. The frequency was similar for both adults and children. However, adult women and people with the bacterium *Pseudomonas aeruginosa* found in their sputum had more exacerbations. Half of the participants managed their exacerbations at home without contacting a health

professional. They adjusted their treatments, such as starting antibiotics or doing more physiotherapy.

What does it mean?

These findings highlight how much lung exacerbations can impact the lives of people with PCD. Adult women and those with *Pseudomonas aeruginosa* infections may benefit from targeted management strategies, such as eradicating *Pseudomonas aeruginosa* or taking preventive antibiotics. More research is needed to understand why certain people have more exacerbations than others. By working together, patients, families, researchers, and healthcare teams can reduce the burden of exacerbations and improve long-term outcomes for people with PCD.

Further information: pcd.ispm.ch

Full article reference: Schreck LD, Goutaki M, Pedersen ESL, Copeland F, Fernández TL, Living with PCD patient advisory group, Lucas JS, Kuehni CE. Incidence and predictors of lung exacerbations in primary ciliary dyskinesia: an international prospective cohort study.

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You can find the full article in English [here](#).

Contact:

Dr. med. Leonie D Schreck
(leonie.schreck@unibe.ch) and

Prof. Claudia E Kuehni
(claudia.kuehni@unibe.ch)

