

# Living with PCD: By and for people with PCD

Updates and plans

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### Living with PCD

Together with Primary Ciliary Dyskinesia (PCD) support groups from all over the world we set up the Living with PCD (previously COVID-PCD) study in 2020.

The Living with PCD study collects data through online anonymous questionnaires. So far, we studied COVID-19 in people with PCD, vaccinations against COVID-19, PCD diagnostic tests, fertility, fertility care, and physical activity in people with PCD. Participants receive a detailed questionnaire when they start the study and extra questionnaires on special topics from time to time.

**Join Living with PCD: Anyone with PCD from anywhere in the world who did not yet participate can join the study via [covid19pcd.ispm.ch](https://www.covid19pcd.ispm.ch)**

### Partners

University of Bern, Switzerland; University of Southampton, UK; Selbsthilfegruppe Kartagener Syndrom und Primäre Ciliäre Dyskinesie, Switzerland; PCD Support UK; Verein Kartagener Syndrom und PCD, Germany; PCD Australia; PCD Foundation, USA; Asociación Española de Pacientes con Discinesia Ciliar Primaria, Spain; Associazione A.I.D. Kartagener Onlus, Italy; and Association ADCP, France.

### Study Funding from

- Swiss National Science Foundation (320030B\_192804/1)
- Swiss Lung Association
- PCD Foundation, USA
- Verein Kartagener Syndrom und Primäre Ciliäre Dyskinesie, Germany
- PCD Support UK
- PCD Australia

### COVID-PCD becomes Living with PCD: evolving into a new era

Thank you for taking part in this study. We truly appreciate the time you have given and continue to give in completing the questionnaires, and we hope you will continue to participate.

With your help, we changed the name of the study from COVID-PCD to **Living with PCD**. We did this to reflect that the study no longer focuses on COVID-19 in people with PCD but focuses on any research question relevant for people with PCD. The name, **Living with PCD**, was chosen based on a poll sent to study participants in October 2023 - find out more about this poll on page 4. We are currently in the process of updating the study website and changing the email to reflect the new study name.

In this newsletter, you can read about the research questions we investigated last year and latest study results (pages 2-3), about the future plans for Living with PCD (pages 4-5) and about publications and communication (page 5).

You are very welcome to contact us if you have questions or suggestions about the study or you have an idea for a questionnaire. Please send us an email: [covid19pcd.ispm@unibe.ch](mailto:covid19pcd.ispm@unibe.ch). We look forward to your suggestions and input!

With thanks,



The PCD study team from the Institute of Social and Preventive Medicine at the University of Bern in Switzerland: (from left) **Eva Pedersen** (postdoc researcher), **Claudia Kuehni** (group leader, professor), **Leonie Schreck** (PhD student), **Myrofora Goutaki** (senior researcher).

### What research questions did we address during the past year?

Last year, we focused on fertility and physical activity. We asked the following questions:

- How many people with PCD have received information on fertility from their doctors, and how satisfied are they with it?
- How many people with PCD have fertility problems, how many use fertility treatments, and how many have conceived a child?
- How physically active are people with PCD and how often do they reach recommended duration and frequency of activity?

#### How many people with PCD have received information on fertility from their doctors, and how satisfied are they with it?

People with PCD can face problems having children. It is important that they are informed about these problems before trying to conceive and that they receive information about family planning options if needed. We therefore wanted to know how many people with PCD had ever visited a doctor who specializes in fertility, and at which point in their life. We also

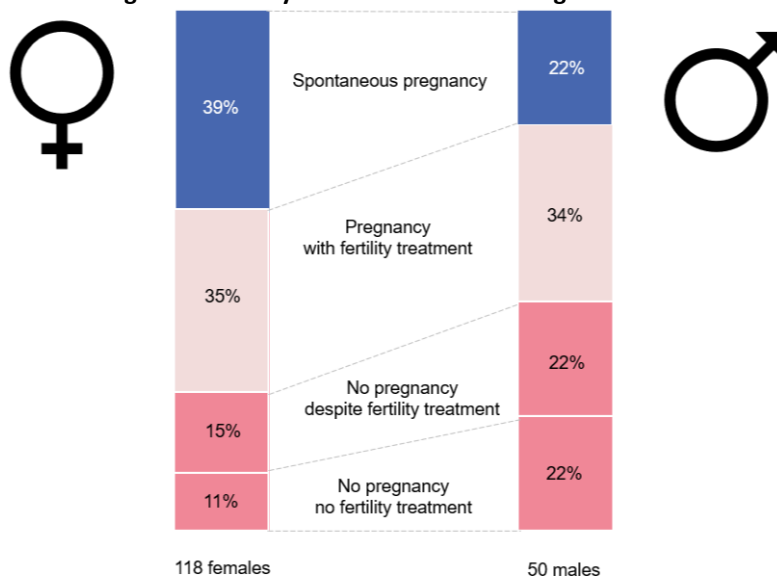
wanted to know if they were satisfied with the received information about fertility.

We sent a fertility questionnaire to 723 study participants, and 384 completed it. Of those who responded, 266 were adults, 16 were adolescents, and 102 were parents of children with PCD. Only half of the adult participants had ever visited a doctor who specializes in fertility. The visit typically took place 10 years after their PCD diagnosis (or age 18 for people diagnosed during childhood). Females had seen fertility doctors less often than males. Only 56% of participants were satisfied with information about fertility they received from their PCD care team.

#### How many people with PCD have fertility problems, how many use fertility treatments, and how many have conceived a child?

Among 168 adults who tried having children, 39% of females and 22% of males were successful without any fertility treatments. 50% of females, and 56% of males used fertility treatments, and of those, two-thirds were able to have a child (Figure 1). Overall, 63% (74% of females, 56% of males) who tried were able to have a child.

Figure 1: Fertility status of adults in Living with PCD



**How physically active are people with PCD and how often do they reach recommended duration and frequency of activity?**

Physical activity is important for health. Many research projects have studied physical activity in the general population, but few have focused on people with PCD. We therefore wanted to know how active people with PCD are and how often they reach the World Health Organization (WHO) recommendations for physical activity.

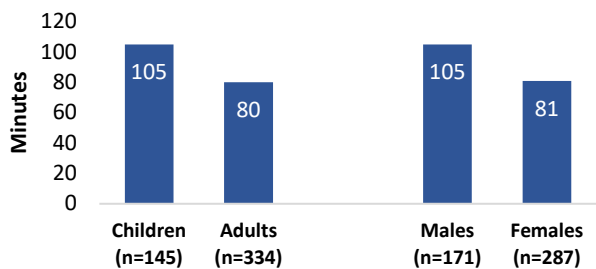


To study this, we used data from the short weekly questionnaire, sent to participants between May 2020 and January 2022. We asked if they were physically active the day before completing the questionnaire and how much time they spent on:

- **Light intensity activity**, e.g., walking, light housework.
- **Moderate intensity activity**, e.g., vacuum cleaning, tennis, brisk walking, slow cycling.
- **High intensity activity**, e.g., Zumba, running, football, fast cycling.

We analysed data from 145 children (5-17 years) and 334 adults. Participants completed between 5 and 79 questionnaires during the follow-up period, and they reported being physically active the day before completing the questionnaire during 65% of the weeks. On average, study participants spent 1.5 hours on

**Figure 2: Average minutes spent being active the day before completing the questionnaire including light, moderate, and high intensity**



physical activity the day before completing the questionnaire. Children were more active than adults, and males more than females (see Figure 2). Participants were more active during weekends compared to weekdays, and during summer versus winter.

**WHO recommendations**

The WHO recommends that children spend at least 60 minutes on moderate or high intensity activity per day. For adults, WHO recommends 150 minutes of moderate or 75 minutes of high intensity activity per week. We only have data from one day per week, and therefore only studied how often during the follow-up period children reached the WHO recommendations. Children in the study reached the WHO recommendations on 25% of the weeks.

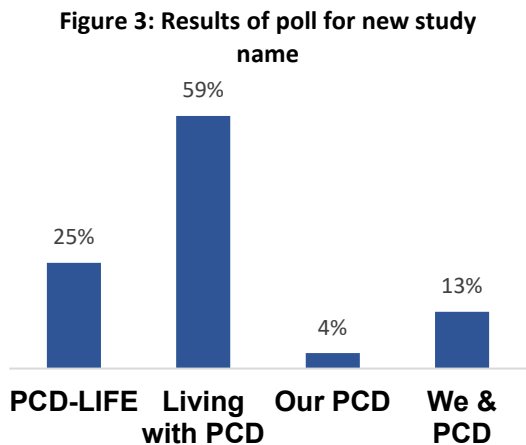


According to a report by the WHO from 2022\*, only 19% of children worldwide are active 60 min or more per day. Comparing with other studies, children with PCD are as active as children from the general population.

In conclusion, many adults with PCD report being physically active in the previous day, however we do not know from this study whether they are regularly meeting the weekly activity targets set by the WHO. Children with PCD (as well as children without PCD!) are recommended to increase their activity level to reach the WHO guidelines.

### Why did we rename the study and how did we choose the new name?

More than 3 years have passed, and fortunately we know much more about COVID-19 in people with PCD. For some time, we have been researching questions unrelated to COVID-19, such as diagnostic testing around the world, fertility care, and physical activity in people with PCD. To reflect this and to emphasize that the study is not just about COVID-19, we have renamed the study with your help. In October 2023, we sent a poll to the study participants to choose their favourite new name. 167 people completed the poll for a new study name and 59% voted for Living with PCD (Figure 3).



#### Plans:

#### Which research projects are planned for next year?

Next year, we will study symptoms experienced by people with PCD and how they change over time.

#### **Project: How do PCD symptoms change over time?**

We would like to find out how symptoms change over time. We already sent out a special questionnaire in January 2023 which repeated questions about symptoms that were asked in the baseline questionnaire. We will analyse this data in the coming year.

The weekly follow-up questionnaires, which were sent to study participants between May 2020 and January 2022, also included questions on symptoms. We asked about cough, sputum, shortness of breath, and fever in the last week. With this data, we want to understand how symptoms change over a short period of time.

#### What will the Living with PCD study do in the future?

There are many questions about PCD that are best answered with data contributed directly by people who have PCD (rather than their doctor). We therefore continue the “Living with PCD” study.

#### Next questionnaires

We plan to send you special questionnaires that cover a specific subject or topic. We already received many ideas from you for future questionnaires such as: quality of life, school/work and PCD, pregnancy and PCD, and mental health. You are welcome to suggest additional topics for questionnaires.

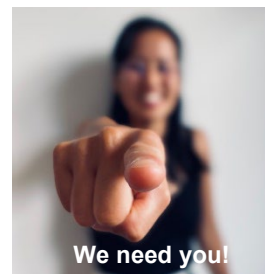
#### Study website and email address

We will change our website and email address to reflect the new study name. We will communicate these changes by email as soon as they are ready.

#### Participation:

#### How can you be involved in the Living with PCD study?

We appreciate your participation in the Living with PCD study, and we hope you want to continue. If you would like to influence and shape the “Living with PCD” study, this is possible in several ways:



- Send us your feedback about how it is to participate in the study.
- Send any suggestions you have for new questionnaires.
- Suggest topics that could be studied with the data already collected.
- Tell us if you want to participate in an advisory group that meets every few months to discuss new ideas.

You are also welcome to ask any question you may have about the study. Our email address is: [covid19pcd.ispm@unibe.ch](mailto:covid19pcd.ispm@unibe.ch).

We look forward to hearing from you!

### Publications and communication:

#### Publications

We already published 7 articles from the "Living with PCD" study. You can read short summaries of the articles by pushing the links:

[Fertility care among people with primary ciliary dyskinesia](#)

[Diagnostic testing in people with primary ciliary dyskinesia: an international study](#)

[Incidence and severity of SARS-CoV-2 infections in people with primary ciliary dyskinesia](#)

[COVID-19 vaccinations in people with primary ciliary dyskinesia](#)

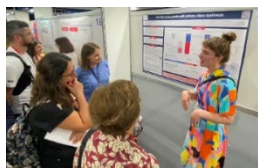
[Facemask usage during the COVID-19 pandemic among people with primary ciliary dyskinesia](#)

[SARS-CoV-2 in people with primary ciliary dyskinesia](#)

[COVID-PCD: a participatory research study to follow people with PCD during the COVID-19 pandemic](#)

#### Communication

During the past year, we presented results from the study at several congresses including the European Respiratory Society congress, the Swiss Pulmonology Conference, the BEAT-PCD annual meeting,



and the German PCD patient congress in Frankfurt.

#### Partners:

### Who are the partner institutions and groups for the "Living with PCD" study?

France: [Association ADCP](#)

Italy: [Associazione A.I.D Kartagener Onlus](#)



Spain: [Asociación Española de Pacientes con Discinesia Ciliar Primaria](#)

Australia: [PCD Australia](#)



United Kingdom: [PCD Support UK](#)

USA: [PCD Foundation](#)



Switzerland: [University of Bern](#)

United Kingdom: [University of Southampton](#)



Germany: [Verein Kartagener Syndrom und PCD](#)

Switzerland: [Selbsthilfegruppe Kartagener Syndrom und PCD](#)

