

1 Invitation for children 11 to 13 years old to participate in the study

2 **Living with Primary Ciliary Dyskinesia (PCD)**

3 **Dear child with PCD**

4 Thank you for considering taking part in this only study about PCD. It is totally voluntary and safe to
5 participate.

6 Doctor Claudia Kuehni is the main investigator of this project.

7 **What is the study about and why do we do it?**

8 This study wants to study health of children and adults with primary ciliary dyskinesia (PCD). PCD is a
9 disease, where the cilia do not work properly. Cilia are small hairs that can move and transport the
10 mucus out of our lungs and our nose. When these cilia don't work properly, people cough a lot, have
11 many colds and a runny nose. The study wants to help us understand more about PCD so that we can
12 make life better for people with PCD. The study started in 2020 when PCD patient support groups asked
13 for help to find out how people with PCD were doing during the COVID-19 pandemic.

14 **Who are we and what do we want to find out?**

15 We are a group of doctors who do research in PCD. By asking people with PCD from around the world
16 to fill out surveys, we learned more about how the coronavirus affected them. Now we want to keep
17 learning about other important topics for people with PCD such as how PCD affects their feelings, or it
18 makes things at school or work more difficult than other people without PCD.

19 **Who can take part?**

20 All children, youths, and adults with PCD can take part. We have participants from many different
21 countries.

22 **Does it help me if I take part? Is there anything that might bother me?**

23 If you take part, you can help us to better understand your disease. On the internet, you will always see
24 the latest results of the study: how many people take part, how they get along, and what are their wishes
25 and problems.

26 The questions might take a little while to answer, it won't bother you, although it might be a bit boring
27 for your parents.

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29 **Goal and more information**

30 Living with PCD is an international online study. We want to know more about PCD to improve daily life
31 of people with the disease. We would like to know more about the experience with PCD, so we plan to
32 ask about different topics such as how PCD affects feelings or if it makes thing at school or work more
33 difficult.

34 **What happens if you take part?**

35 If you take part, your parents will receive online questionnaires about your health. They must first give
36 us an email address. The first questionnaire will be long, so that you can describe all the details of your
37 disease, because PCD can be very different from one person to another. We will also ask questions
38 like how you spend your day, if you do a lot of sports, and who is part of your family.

39 After that, your parents will receive follow-up questionnaires, which ask about how you are doing
40 (probably about 1x per year). Sometimes, your parents will get a questionnaire about a special topic,
41 like the treatments you do for PCD. You can also suggest questions that we can include in one of the
42 next questionnaires. This allows you to help us ask questions that are important for people with PCD.

43 If you would like to skip some questions, you can do it.

44 **What happens if I take part in the study?**

45 Those who take part should fill in the questionnaires they receive. All information is collected in a way
46 that nobody can find out who you are.

47 **Will it help me? Is anything tricky?**

48 There are no tests or anything that will hurt or bother you in this study. Some questions might take a
49 little time to answer, but your parents will do the hard work.

50 You might not get anything just for you from taking part, but by helping with this study, you can help
51 doctors learn more about PCD. This could help other kids with PCD in the future.

52 **What happens if you don't want to take part any longer?**

53 Your participation is not compulsory. You can step out of the study anytime, without telling us why.
54 Nobody will be angry with you. You can also skip some questionnaires and later participate again.

55 **Do you have any questions?**

56 If you have questions, you or your parents can phone us (+41 31 684 68 55) or write us an email (to
57 pcd.ispm@unibe.ch). You can also ask questions to the leaders of the patient support groups of your
58 country.

59 You can also watch a video with the study information available on the study website.

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