

COVID-19 disease in people with Primary Ciliary Dyskinesia (PCD)

Study for children

Dear child with PCD

This study wants to find out what happens to children and adults with PCD during the Coronavirus outbreak. PCD is a disease, where the cilia do not work properly. Cilia are small hairs that can move and transport the mucus out of our lungs and our nose. When these cilia don't work properly, people cough a lot, have many colds and a runny nose. It is possible that people with PCD have more problems if they catch a Coronavirus infection than other people, but we don't really know. Patient support groups from all over the world asked us to organise the study.

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

We are a group of doctors who do research in PCD. We want to understand if people with PCD have a similar disease to others when they catch COVID-19, or if anything is different. We also want to find out how treatments can best be done during this time, and what are the challenges children with PCD face, and their wishes.

Who can take part?

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

What happens if you take part?

If you take part, your parents will receive questionnaires about your health. They must first give us an e-mail address. Then they will receive regular e-mails with links to online questionnaires. The first questionnaires will be long, so that you can describe all the details of your disease, because PCD can be very different from one person to another. We will also ask questions like how you spend your day, if you do a lot of sports, and who is part of your family. After that you will receive a short questionnaire every week, where we ask how you get on, if you have caught the Coronavirus infection or not, and how it was. You can also suggest questions that we can include in one of the next questionnaires. This allows you to help us ask questions that are important for people with PCD.

Does it hurt me if I take part in the study?

Those who take part should fill in the questionnaires, ideally every week. This can be a bit boring for your parents. But if they forget to fill it in once or twice this is not a big problem. All information is collected in a way that nobody can find out who you are.

Does it help me if I take part?

If you take part, you can help us to better understand your disease. That knowledge will help us in the future to better advise and inform people with PCD from the Coronavirus or other infections. In the internet, you will always see the latest results of the study: how many people take part, how they get along, and what are their wishes and problems.

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

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

Do you have any questions?

If you have questions, you or your parents can phone us (+41 78 912 75 74) or write us an e-mail (to pcd@ispm.unibe.ch). You can also ask questions to the leaders of the patient support organisation of your country.

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