

Service de Chirurgie Pédiatrique

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Information Form

Swiss National Cleft Lip and Palate Registry (v. 1.1 – 8.11.2013)

Dear Sir, Dear Madam,

Your child has a cleft lip, a cleft of the lip and the palate or a cleft palate.

To improve our understanding of this problem, we have created a register for Swiss patients, with the approval and participation of all national centers involved in the care of these patients. We therefore request your permission to include your child in the register.

Presentation

National registries exist already for several congenital conditions. In most neighboring countries there are registries for cleft lip and palate, and we have recently established one in Switzerland to investigate this condition.

Purpose of register

To improve the epidemiological knowledge about cleft lip and palate, thereby improving the level of care that we offer to these children.

Who should participate?

All patients with a cleft lip and palate born in Switzerland since 2011.

What should you do?

You will have to meet with the doctor looking after your child to answer a short questionnaire about your child, the type of the cleft, the course of the pregnancy and your personal and family history.

These data are then transmitted to the Geneva Children's Hospital Research Platform and stored in a secure computer file.

These data are strictly confidential. In accordance with the law, you have the right to see the data collected for your child if you wish.

What should you know?

1. Your child and yourself will not need to undergo any further examination. Most information is already available in your child's medical record and are well known to you.
2. The participation in this study is on a volunteer basis and has no cost (free) to you.
3. The creation of this registry was approved by the Research Ethics Board of the Department of Children and Adolescents of Geneva University Hospitals and by the Swiss Cleft Lip and Palate Association.
4. The results of data analysis may be used for scientific publications, in this case data is anonymized, that is to say that your child can not be identified.
5. You can contact the investigator in charge of the study at any time to obtain more information.

We thank you for your help, which we hope will help improve the outcome for these children.

Dr. Emmanuelle Dorie
Co-Investigator

Dr. Giorgio La Scala
Principal investigator

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Consent Form

Swiss National Cleft Lip and Palate Registry (v. 1.1 - 8.11.2013)

Principal investigator: Dr. Giorgio La Scala

Co-Investigator: Dr. Emmanuelle Dorie

I have read and understood the information document about the purpose of the above project, and I can keep this information. I can also keep a copy of this consent form.

I had sufficient time to think before making my decision.

I had the possibility to ask all the questions concerning the participation of my child in this study, and I will be able ask more questions at any time should I feel the need.

I am aware that the information about my child will remain confidential.

I can withdraw my child from this study at any time without having to give a reason and without any consequences on my child's medical care.

I agree that the responsible investigators and the members of the Ethics Board have the right to verify the original data. However this information remains confidential.

I give my consent for my child to participate in this study, while maintaining the right to withdraw him/her from the study without the need to give a reason.

Place and date:

Last name and name of the child:

Date of Birth:

Signature of legal representative:

Place and date:

Physician Signature:

Please send copy of this consent form by fax to 022.372.50.85 or by mail to the following address:

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