

Educational information and informed consent for children to participate in the registry study

Functional testing of variants of unclear significance in the *ALPL* gene as a cause of hypophosphatasia.

In addition to assessing this consent form, parents/guardians must read and sign the parental consent form to receive the full study information.

Dear patient!

You have recently had a blood test which showed that it is possible that you may have a rare disease called hypophosphatasia (HPP). Or it could be that your doctor has already diagnosed you with this HPP. This HPP softens the normally hard bones and causes sometimes more and sometimes less problems for the people who have it.

All over the world there are children and adults living with HPP. That's why many researchers and doctors are trying to improve the treatment of this disease, through so-called "clinical trials" like this one.

What should I do?



We would like to ask you if you would help us to conduct such a clinical study to better understand HPP.

We will also ask many other children and adults in Austria and around the world if they would also like to help us.

What will happen to me during the study?

We will ask you and your parents just **a few questions** during your visit to the clinic. You and your parents will answer questions about your medical history, such as "When did you lose your first baby tooth?", "Do you have pain in your legs?" or "Have you ever had a broken bone?". We will collect the answers and send them, along with the results of your blood test, to the team leading the study. Your name will not be shared, however, so no one but your doctor will know that this information is from you.





Complications (problems) during or after the study are not expected. If any problems occur after the study, feel free to contact us!

Can I change my mind?

If you decide to take part in this study, you must tell one of your parents. If you want to participate in the study, but change your mind later, it doesn't matter. **You can stop the study whenever you want.** The doctors will still take good care of you.

If you have questions about what will happen to you in the study, **you can ask your parents or the doctors.** They will answer all your questions.

Principal investigator:

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CONSENT FORM

- Have you read the information sheet?

Yes No

- Did you ask all the questions you wanted to ask?

Yes No

- Did the doctor answer all your questions?

Yes No

- Are you aware that you can stop the study if you want to?

Yes No

- Do you want to participate?

Yes No

Patient

- Name (block capitals):

- Date of birth: _____

- Signature: _____

- Date: _____

Parents / legal representative

- Name (block capitals):

- Date of birth: _____

- Signature: _____

- Date: _____

Informing physician

- Name (block capitals):

- Signature: _____

- Date: _____