

Patient information for children aged 6 to 12 years

IKKoPeS

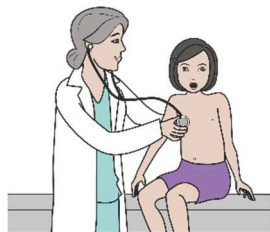
Improving knowledge of the natural history of patients with Kosaki/Penttinen syndrome and the impact of treatment with tyrosine kinase inhibitors

2 copies: one to be given to the participant, the other to be kept by the investigator

Your doctor and the doctors at the hospital of Dijon, France, are interested in learning more about your medical condition.

You are currently under an ongoing care by one or more doctors because you have an uncommon disease. For this reason, you come to the hospital regularly so that the doctor can monitor the progress of your disease. Your doctor may also have prescribed a drug to treat the disease.

As part of your medical care at the hospital, your doctor examines you; they ask you questions, may ask you to have blood tests or X-rays, or to take medication. Sometimes, you may see doctors who examine certain parts of your body in particular (your ears or eyes, for example).



A nurse will sometimes take a blood sample. Images of your body (e.g. X-rays) can be taken with various machines.



Doctors are interested in learning more about your disease and they want to help you feel better. To do this, they would like to be able to use the information in your medical file to do research and learn more about your disease.

If you agree to take part, we can use the data from your medical visits to help doctors learn more about your disease and perhaps help other people who have the same medical condition as you..

Date (Day/Month/Year):/...../ 20.....

I undersigned, Dr/Pr

certify that I have informed the child (Fist name, Last name; written by the child)

born (Day/Month/Year)/...../ 20.....

Doctor's signature and stamp:

Would you like to participate?



I would like to participate



I would not like to participate

**This project has been approved by Inserm's Ethical Evaluation Committee
(IRB0000388) dated 14/11/2023**