Patient information pour adolescent patients aged 12 to 18 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 Dijon hospital in France are currently taking part in a study of your disease. The aim is to combine your hospital follow-up data (medial examination, X-rays, blood tests) with those of the few patients in the world with the same type of disease. This should enable us to better understand the disease, and to find out whether the drugs that are currently prescribed for it, tyrosine kinase inhibitors (TKIs), are effective.

Other patients with this disease, both children and adults from France and around the world, will also take part in this research.

As part of your medical care, you are already seeing several doctors and specialists**.**

The doctor examines you and asks questions to find out if you're having any complaints, and to understand how you're feeling. He or she may also carry out tests, such as making you walk or measuring your muscle strength. With your parents' agreement, he or she may also prescribe a drug treatment, such as TKIs. Sometimes blood is drawn for biological tests, and you may have to do imaging exams, such as X-rays, ultrasounds or MRIs.

What does my participation involve?

Your participation will consist of saying whether or not you agree to your medical data being collected in a database for research purposes. If you agree, your medical data will be combined in a single computer database with those of other patients worldwide with the same medical condition. From this database, studies could be carried out to make progress in the management of your disease.

Do I have to participate?

No. The decision is yours and you can change your mind at any time.

If you don't want to take part, this will have no effect on your care or your relationship with your doctor.

Thank you for reading this document. Do you have any questions?

If you agree to take part in the study, we would like to collect the data from your visits to the hospital. Thanks to the data from all these examinations, we will be able to find out more about your medical condition, and in future we may be able to help other people who have this disease.

Date: ……/……/ 20…….

I undersigned, Dr/Pr .....

attest to having informed the adolescent patient (First name, Last name; written by the patient) .....

born (day/month/year) ……./……./ 20…….

☐ I agree to participate

☐ I do not agree to participate

Doctor's signature and stamp:

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