

Patient information leaflet

Subject : EUROCYCYS : European registry of children and adults with cystinuria.

Introduction

Dear sir or madam,

We would like to propose you to be part of the EUROCYCYS registry as you have cystinuria.

Please read this information note carefully and do not hesitate to ask any question to one of the principal investigators of this study (Aude.servais@aphp.fr or Marie.courbebaisse@aphp.fr) or to contact the physician who is in charge of your care.

1. General informations :

The European registry of children and adults with cystinuria is carried by ERKnet (European rare kidney disease reference network) and eUROGEN. It is owned by the ERKreg (ERKnet registry) data platform. The EUROCYCYS registry will provide access to consistent and comparable data between centers with long term follow-up for this rare disease. This European collaborative project is led by experts in cystinuria : nephrologists, urologists, pediatricians, biochemists and geneticists. The registry data can be used for research studies on the natural history of the disease, genotype/phenotype correlations, evaluation of dietary, surgical and medical treatment and assessment of quality of life.

2. What does your participation involves?

Your participation means that we will use your medical data to implement the EUROCYCYS registry. This will include demographic, clinical, biological, genetic, radiological and therapeutic data. We will not collect other information or perform any additional medical or blood tests. So, you will not have to do anything else for this research.

3. Benefits and risks

As it is a collection of data that already exist, there is no benefit or risk to expect from this research. However your participation can contribute to improve the knowledge on cystinuria and patients' care.

4. Research opt-out :

If you do not wish to participate in this research, you can indicate this to the physician in charge of your care or send an email to one of the principal investigators: aude.servais@aphp.fr / marie.courbebaisse@aphp.fr. You do not need to justify your decision. Your participation in this research (or your decision to not participate) will not affect the way you are treated.

5. Use of your data

For this research, your data will be collected, used and stored according to the same rules as those used for any other patient data. The collection, use and storage of your data is required to answer the issues raised by the research and to publish the results.

Your data will be recorded anonymously by using a unique participant code in EUROCYS database that is hosted by the ERKNet data platform. No identifying data will be recorded in the registry. Other participating centers will also add their patients' data to this database.

Your encoded data can only be viewed by your physician and the principal investigator and it will not be possible to trace your data back to you through reports and publications resulted from the research.

Your data will be treated and processed according to the General data protection regulation n°2016/679

6. Any questions ?

If you have any questions or concerns about this research, you can contact the doctor in charge of your care:

Name : _____

Phone : _____

Email : _____