

EUROCYS NEWSLETTER No.3

Multidisciplinary **E**uropean multicenter
Registry of patient with **C**ystinuria

What is EUROCYS?

EUROCYS is a multidisciplinary, European, multicenter and prospective registry of patients with cystinuria.

It includes demographic, clinical, surgical, biological, genetic, radiological and therapeutic data.

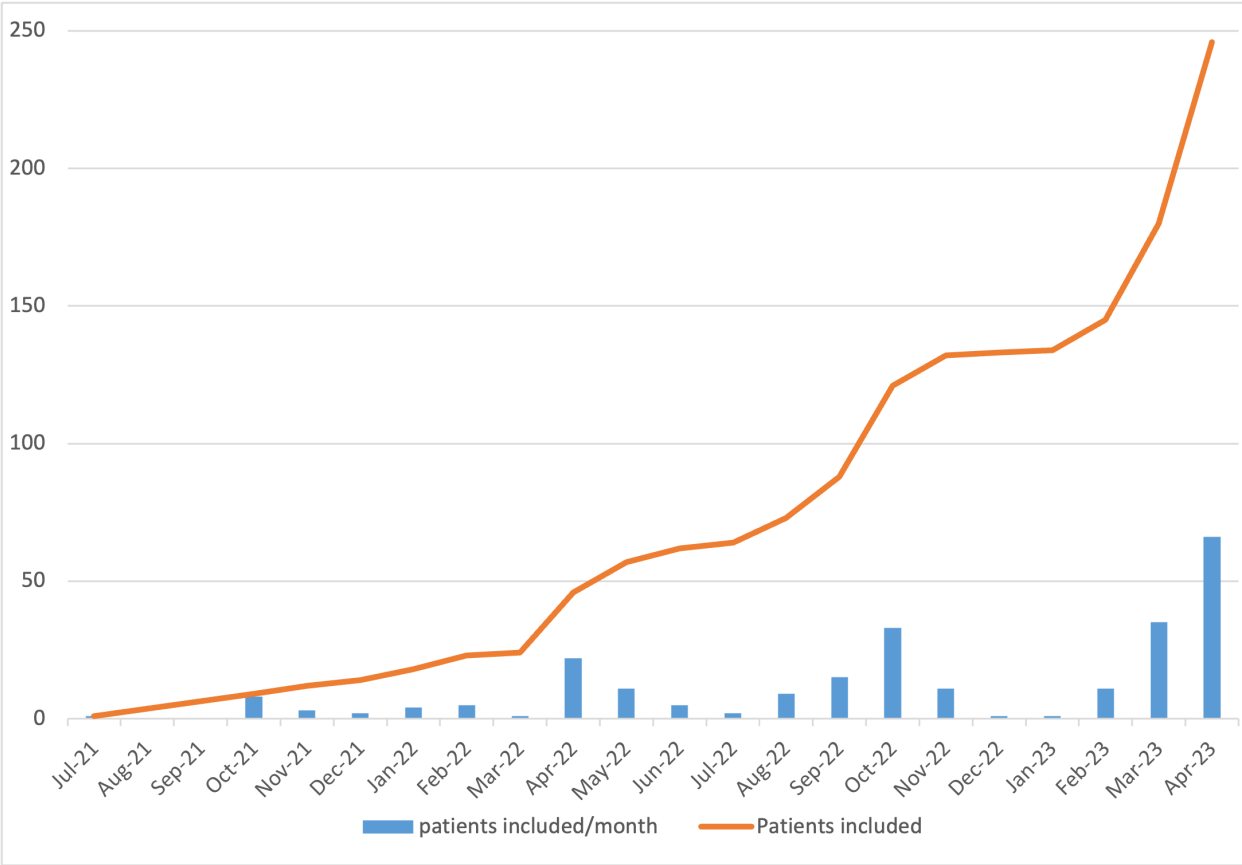
These data will be recorded via the ERKReg registry platform.

Inclusions have been opened since July 2021; all centers can include their patients that have cystinuria.

Objective of EUROCYS

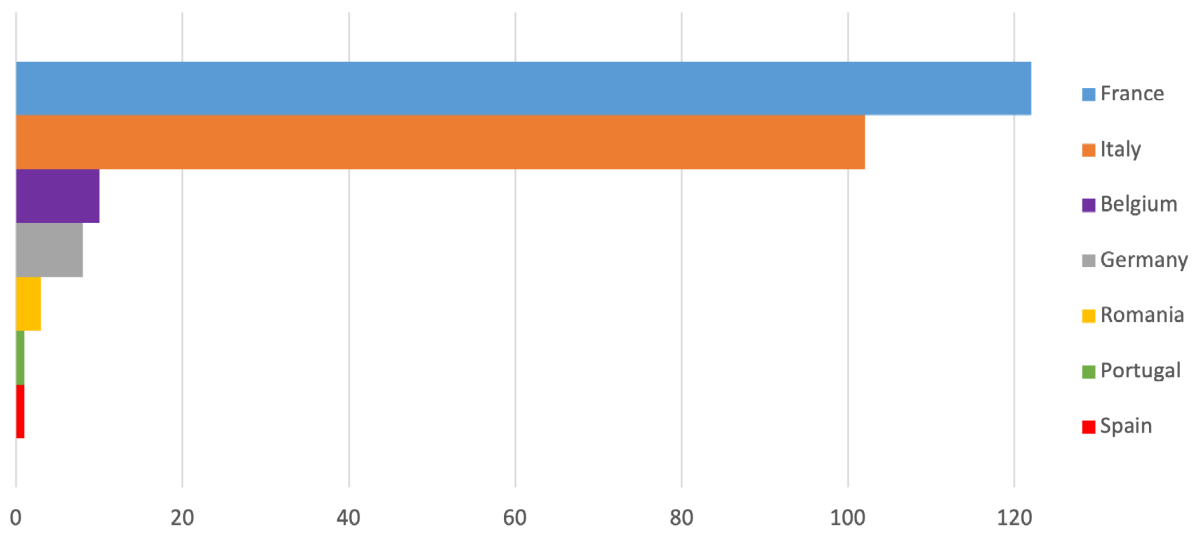
To collect consistent and comparative prospective clinical, biological, genetic and radiological data from patients (children and adults) with cystinuria followed in European centers.

Data inclusion until May 2023

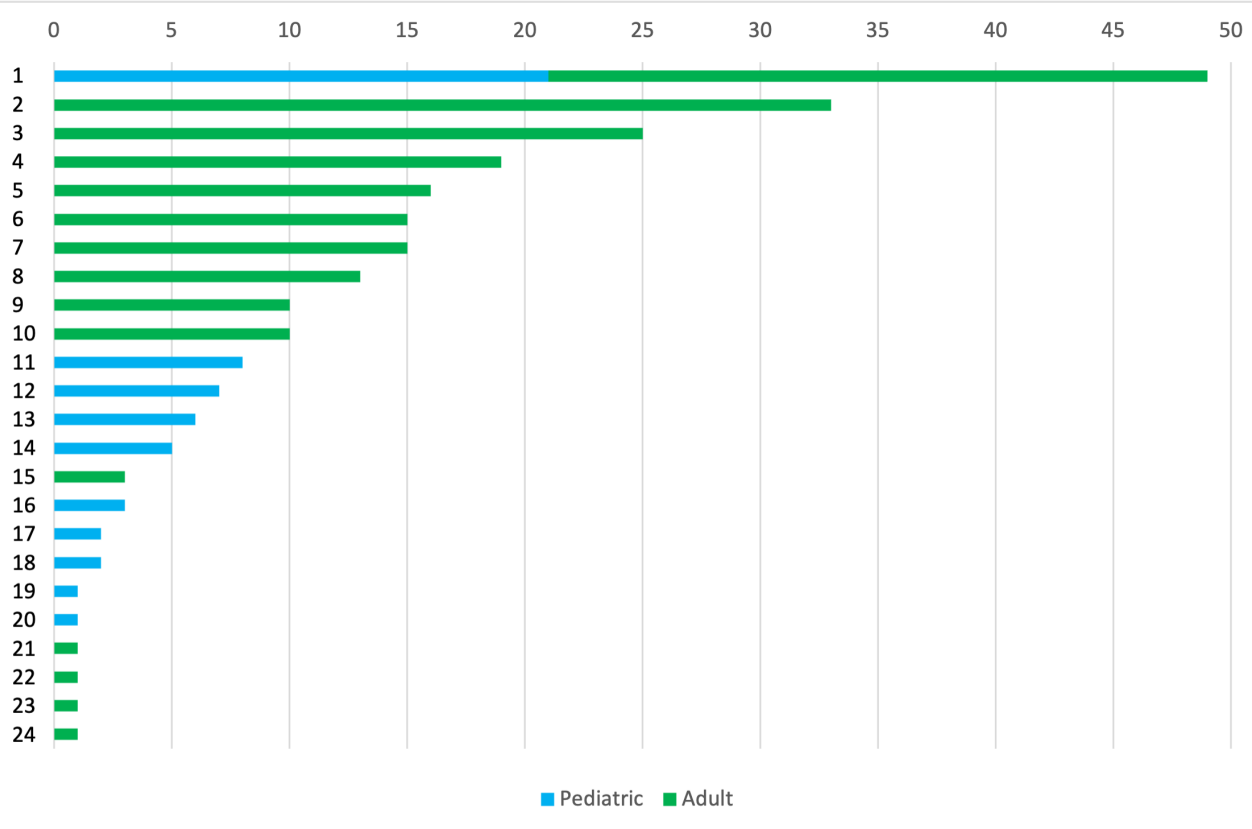


Since the previous newsletter, more than 180 patients have been included in the EUROCYC sub-registry. Data entry has been performed by 24 healthcare centers, mainly in France and Italy. A large proportion of the patients included since the beginning of the year are patients who were originally included in ERKReg and have been transferred to EUROCYC registry.

Cystinura patients enrolled/country



Cystinura patients enrolled by centre



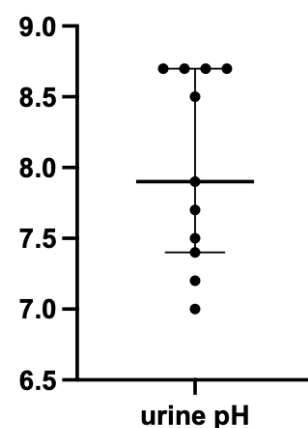
Some data about first patients included

Mean age :

At inclusion 31,9 yrs (0,3 ; 86,8 yrs) – at diagnosis 15,6 yrs (0 ; 78,4 yrs)
eGFR 97 ml/min1,73m² (12 ; 127)

Treatment	N = 134
Potassium citrate	106 (79,1%)
Potassium bicarbonate	27 (20,1%)
Sodium bicarbonate	27 (20,1%)
Tiopronin	18 (13,4%)
D Penicillamine	11 (8,2%)

urine pH at last visit



Using the potential of the ERKReg registry

Many patients with cystinuria are already enrolled in the ERKReg registry. We strongly encourage investigators to also include their patients in the EUROCYC sub-registry. This can be done easily in the patient data entry menu. By approving participation in the sub-registry, the extended questionnaire will be displayed.

The goal is to collect accurate data on the outcome of patients with cystinuria in order to improve knowledge and clinical practice. Investigators will be

involved in future publications.

How to participate in the EUROCYs registry?

- ERKNet centres but also other interested nephrology sites can enter their cystinuria patients. Don't hesitate to mention the EUROCYs registry to your nephrologist or urologist colleagues from other hospitals or clinics. Please forward the contact details below.
- Have the ERKReg patient informed consent form signed by the patient and by the nephrologist/urologist in charge.
- Provide the patient-specific note of the EUROCYs registry.

Visit the EUROCYs
website

See the EUROCYs user
manual

See the specific
EUROCYs patient note

Contact

If you are interested in participating to the Eurocys registry, please don't hesitate to contact:

EUROCYs
informations/Ethics
documents

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ERKReg/EUROCYs registry
access and informed
consent forms

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