

What is a patient registry?

A patient registry is a database containing a systematic collection of data on individuals affected by a specific disease or group of diseases. It is used to collect, analyze, and utilize health information in order to improve research, diagnosis, therapy development, and care, as well as to promote understanding of the disease.

Why should I take part?

- The data from the PATRAS patient registry is used directly by the EURAS research consortium for research on therapies
- A cross-border patient registry enables meaningful results
- Every single data record is important in rare diseases
- Help improve diagnosis, care, and therapy development
- Preparation for and easier access to clinical trials
- The project is supported by your national patient organization



Costello Kids UK



CFC International
Cardio-Facio-Cutaneous Syndrome



RASOPATHIES NETWORK
connect • collaborate • accelerate



Funded by
the European Union

Grant No. 101080580

About us

The study is coordinated by:

Prof. Dr. Martin Zenker

 martin.zenker@med.ovgu.de



Investigating physician:

Lorenz Kiwull

 lorenz.kiwull@med.ovgu.de



**Otto von Guericke University Magdeburg
Institute of Human Genetics**

Leipziger Str. 44
39106 Magdeburg

Tel.: +49391/67-15062

Contact us

Patient recruitment is led by the EURAS Patient Board Officer, Verena Schmeder, and is supported by members of the EURAS Patient Board and patient organizations for RASopathies.

Contact person:

Verena Schmeder

 verena@patre.info



PATRAS

PATient registry for RASopathies



**Patient Research Partnership
- Towards New Treatments
for Neurodevelopmental RASopathies**

euras-project.eu

What is a RASopathy?

RASopathies are a group of genetic disorders that can affect physical, neurological, and psychological development to different degrees. They include Noonan syndrome, CFC syndrome, and Costello syndrome. The various genetic mutations have a major influence on the severity of the clinical picture. The exact biological mechanisms underlying the symptoms of the disease are still poorly understood, and there are currently few targeted treatment approaches. This is particularly true for neurological and psychological developmental disorders.

Who can take part in the registry study?

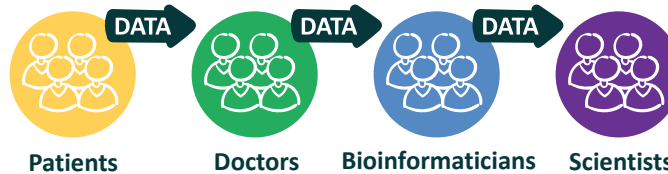
All affected individuals or parents or legal guardians of affected individuals can register individuals with CFC, Costello, or Noonan syndrome in PATRAS.

Have you received a genetic or clinical diagnosis for one of these syndromes?
If so, we invite you to participate in our patient registry for RASopathies.

How will my data be used?

The data from the PATRAS patient registry are used directly by the EURAS research consortium. This EU-funded project aims to gain a better understanding of the diseases and find new treatment options to improve the quality of life of patients and their families.

The patient data collected is anonymized, evaluated, and made available to researchers. Anonymized data may also be used for other research projects.



How are my data protected?

Your data is collected via a secure digital app (myCap) and stored on a secure server within the EU. Personal data is stored separately from your medical data. The handling and protection of your data has been reviewed and approved by an ethics committee and the data protection officer.

How do I take part in the study?



Register online

Visit the website www.rasopathies.eu or scan the **QR code**. After completing the registration form, you will receive consent and data protection documents to sign and a link for uploading.



Your personal invitation

After receiving your consent, we will send you your personal invitation with a link and a QR code for the myCap app.



Using the myCap app

The myCap app makes it very easy to participate in our registry. At various intervals, you will receive short tasks/questionnaires that you can answer on your smartphone while enjoying a cup of coffee or tea.