

Our Members:

Cystinosis Foundation Ireland
Cystinosis Foundation UK
Dutch Cystinosis Group
AIRG France
Cystinose France
AIRG-España
Asociación Cistinosis España
Cystinosis Group Belgium
Associazione Cistinosi, Italy
Cystinose-Selbsthilfe e.V., Germany
and more to come ...

Our Partners:

Patients all over Europe living in countries not having a national cystinosis support group yet

EURORDIS – Rare diseases Europe
FEDERG – Fed. of Europ. Associations of patients affected by renal genetic diseases

European reference centers and competence centers for cystinosis
Health care providers and researchers in Europe and all over the world

How to contact us:

All our members can be found easily on the WWW having their own websites.

Find more information about our network and a link to all members and partners on www.cystinosis-europe.eu



Please don't hesitate to use the postal and email address below. English, French, Spanish, German, Dutch mails will be answered soon, all others will take a little longer.

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Cystinosis Network Europe

connecting ...

supporting ...

strengthening ...

**Cystinosis support
groups in Europe**



What is cystinosis?

Cystinosis is a rare, genetic disease, which is mostly diagnosed early in childhood, usually before the age of two. It is autosomal recessive, which means that it is inherited when a child receives two copies of an abnormal gene, one copy from each parent. Because the parents each have only one abnormal gene, they are not affected.

It is estimated that cystinosis occurs in somewhere between 1 in 100,000 to 1 in 200,000 live births. There are 10 to 15 new cases of cystinosis diagnosed each year in Europe.

The problem in cystinosis is an increase in many parts of the body an amino acid called cystine. This build up causes cystine crystals to form in many organs of the body. These crystals form firstly in the kidneys and the eyes, late complications can occur in muscles, pancreas, thyroid gland and in other parts of the body.

There is a specific treatment for Cystinosis, but there is no cure. Children with cystinosis are experiencing much better outcomes and many young adults are living happy and active lives. But we still have a long way to go.

The Networks' challenges

Connecting

- We are an all volunteer, non-profit organisation
- We meet on a regular base to exchange and discuss achievements and unsolved problems not only in our own countries
- We encourage new research projects
- We connect patient groups and researchers networks

Supporting

- We help families all over Europe to get contact with other families and clinics.
- We inform patients and parents properly and continuously about their condition and what is going on in the "world of Cystinosis".
- We support patients' and researchers' projects (e.g. the development of international guidelines for treating cystinosis.
- We are an active part in the search for one or more good forms of transition for teens and young adults.

Cystinosis is a rare disease, but we can make our voice heard and help our families to a better life.



**Go for it –
Contact us soon
and become a partner
of our network!**