

# Working on shared goals

Eight in every 1000 babies are born with a heart defect, and other children acquire a heart problem as they grow up.

ECHDO works for CHD patients of all ages, gaining knowledge from parents of children with CHD and from adult patients to achieve common goals. As increasing numbers of heart children survive into adulthood, ECHDO members include both parent support groups, ACHD groups and associations in which both parents and adults are members.

Our members have a wealth of experience in overcoming the challenges facing new, growing and long-established support organisations, including raising funds, registering as a legal body, organising volunteers and staff, setting up events, lobbying and running campaigns.

Within the network, members have possibility to exchange resources to raise awareness and understanding of CHD and they collaborate for example on different kind of projects and events.



## Contact

Official address:  
Elzenlaan 20  
2390 Malle  
Belgium

info@echdo.eu  
board@echdo.eu  
**echdo.eu**



**ECHDO**  
European Congenital  
Heart Disease Organisation



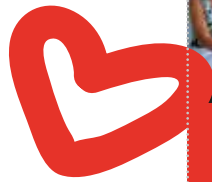
**ECHDO**  
European Congenital  
Heart Disease Organisation



Sharing information, knowledge and experiences in order to improve access to the best possible care and treatment for all the people affected by Congenital Heart Disease in Europe.

- Linking patient and parents groups
- Strengthening support networks
- Working on shared goals

# European Congenital Heart Disease Organisation



The European Congenital Heart Disease Organisation (ECHDO) is a non-governmental patient driven umbrella organization for patient organisations across the Europe which represents Congenital Heart Disease (CHD) patients of all ages.

Our vision is to share information, knowledge and experience in order to improve access to the best possible care and treatment for all the people affected by CHD in Europe.

## ECHDO works to:

- Increase understanding of CHD and support for patients of all ages: babies, children and adults with congenital heart disease (ACHD) in Europe
- Provide up-to-date information about CHD to patients and their families;
- Lobby for European standards on medical and psychosocial care of CHD patients, including access to safe medicines;
- Share information about research studies and patients' experiences within Europe;
- Stimulate the development of national CHD support networks;
- Increase its impact by liaising with other European networks.



## Linking patient and parent groups

ECHDO brings together people affected by congenital heart disease under a single umbrella to improve treatment and care across Europe.

## Strengthening support networks

ECHDO extends CHD support networks within and between countries, bringing positive change through the exchange of ideas and experience.

ECHDO arranges meetings and conferences where the representatives of the member organizations have the possibility to share knowledge, projects and best practices with each other. Attending the workshops and conferences enables delegates to keep up to date, giving them new ideas about how to tackle possible challenges.



## Members

ECHDO members include both parent support groups, ACHD groups and associations in which both parents and adults are members.

At the moment ECHDO is representing 42 CHD patient organisations in 29 countries across the Europe.

For more information about our member-organisations, visit our website [echdo.eu](http://echdo.eu).



ECHDO is also a full member of the Eurordis and the European Patient Forum (EPF)