



## *children's heart* FEDERATION

The **Children's Heart Federation** is dedicated to helping children with congenital or acquired heart disease and their families in the UK and Ireland and represents the key organisations supporting families of children with heart conditions. It is an active member of **ECHDO**, the European congenital heart disease organisation for families affected by congenital heart disease with the aim of sharing information and experiences in order to improve the care and treatment for all people affected everywhere in Europe.

There is a lack of information concerning the long-term outlook for patients with congenital heart defects, so together we:

- Exchange information and experience lobby together.
- Liaise with other European networks.
- Provide up-to-date information about CHD to all European patients and their families.
- Lobby for European standards on medical and psychosocial care of CHD patients.
- Ensure safety of drugs for all European patients with CHD.
- Improve the circumstances of GUCH (Grown ups with congenital heart disease) in Europe.
- Provide information about research studies within Europe and share results and experiences

We are keen to work doctors scientists, parents and self-help associations to make policy-makers aware of the needs of children and young people living with congenital heart disease contribute to and promote scientific research and developments and to this end have participated in the development of the European –wide web-site **Corience**.

We seek your interest and support for the 5 million Europeans living with a congenital heart defect so that no longer does anyone born with a heart defect face a shorter lifespan.

**[www.chfed.org.uk](http://www.chfed.org.uk) | [www.corience.org](http://www.corience.org) | [www.echdo.org](http://www.echdo.org)**

