



# What we do and how we help

## Supporting patients and their parents and carers

### CHF Help & Advice Service

Patients, Parents and Carers can contact CHF for

- practical advice
- a listening ear
- emotional support

The service is staffed by both staff members and experienced volunteers who can be contacted by

- Telephone: 0300 561 0065
- Email: [info@chfed.org.uk](mailto:info@chfed.org.uk)

CHF have been a valuable resource for information in helping us to understand and manage our son's condition and provides a support network to families supporting children with these conditions. JH, 2019

### Publications

Our range of publications are written in a clear and accessible format. These include:

A series of **information sheets** that cover

- Conditions and treatments
- Lifestyle
- Education and social needs

15,236  
per month  
downloaded

**Heart2Heart** a fortnightly e-newsletter for all who are interested in congenital heart disease (CHD)

- Subscribers include CHF partners, parents, supporters and medical, healthcare and social care professionals.

8,938  
per month  
distributed

### Peer Support and Networking



We provide opportunities for families to meet together, share experiences and provide support to one another.

In November 2018 CHF and parkrun joined forces to encourage children with heart conditions to reap the benefits of exercise safely. Several heart families came together to participate in the inaugural run.

### Online Resources



We have developed a much respected web-site used by both parents and the professionals caring for their children.

We support an active **On-line Community** and have a number of online forums where we can connect with each other.

7,000  
people

### CHF Support Fund

We fund:

**Small grants** for families facing financial hardship as a direct result of their child's heart condition.

e.g: helping meet the additional travel costs to the specialist hospital.

**Necessary medical equipment** that improves a child's quality of life.

e.g: providing INR machines in order to enable a child to have their blood coagulation levels tested at home, saving them taking time off school.

*"Poverty amongst families that include someone with a long-term medical condition, or a disability is consistently underestimated."*

*New Policy Institute 2014*

### Resources for children

We provide resources for children and the professionals working with them.

These include:

- **Rosie goes red, Violet goes blue** a book introducing heart conditions to young children
- **Molly's Dollies** rag dolls with surgical scars that are customized to match the child's scars.



## Research

We participate and encourage research into:

- treatments and psycho-social support
- medicines for children
- care
- improving communication



Our current partners include:

- Düsseldorf University and LENA Consortium Members
- University College London
- Great Ormond Street Hospital

## Campaigning for support and services

### Collecting and Sharing Information

We believe that it is important for CHF to hear and learn from the wide and varied experiences of parents:

- from parents through direct contact, meetings and surveys
- from the range of parent support groups that are usually condition-specific or location-specific

We use this information to increase our knowledge and share this with:

- parents
- support groups
- service providers
- policy makers



### Sharing Knowledge

We share our knowledge by participating in:

- study days for clinicians
- parent support conferences
- medical conferences.

We are active members of pressure groups which include:

- Specialist Healthcare Alliance
- Health Conditions in Schools Alliance
- National Council for Child Health and Wellbeing
- The European Congenital Heart Disease Organisation
- Council for Disabled Children



And regularly participate in events designed to influence change.

### CHF Better Care Campaigns



#### ThinkHEART

The ThinkHEART campaign aims to aid early identification of possible heart problems in children.

#### Pulse Oximetry Campaign

We want Pulse Oximetry screening for all newborn babies in the UK. The test, which measures the oxygen level in the blood is effective in detecting most congenital heart conditions, often before the baby shows any symptoms.



#### INR Self-Monitoring Campaign

Warfarin is an anticoagulant (blood thinner), used to stop the blood from clotting too easily thereby reducing the risk of excessive bleeding or a stroke. INR machines monitor the clotting levels of the blood. In line with NICE Guidelines, we want all children, for whom self-testing or home testing is appropriate, to have their own monitor.



### Fundraising Campaigns

We receive no statutory funding, so we rely completely on voluntary income. We are very grateful to:

- the **grant making** trusts whose grants make much of our work possible
- the **companies** whose generous gifts help us greatly
- the **schools** whose fundraising activities enable us to help more children
- the **individuals** whose amazing efforts that include runs, parachute jumps, cake sales, balls
- and many more help us reach out to families that need our support.



**89p of each £1  
is spent on our  
charitable activities**



To everyone who has helped us,  
a huge **thank you**