

# Other UK support groups and charities

## National heart charities



### Barth Syndrome Trust

The Barth Syndrome Trust was created in the United Kingdom in order to better serve the needs of affected families here in the UK and in the rest of Europe. An affected family in the UK may have certain specific needs that cannot always be fully met unless it is through a regional organisation that understands these issues. The Barth Syndrome Trust aims to increase awareness amongst physicians and the general public both to facilitate accurate diagnosis and to provide continuing support to affected families after diagnosis. They put families in touch with each other and share information and experiences, both regionally and internationally.

Website: [www.barthsyndrome.org.uk](http://www.barthsyndrome.org.uk)



### Cardiomyopathy Association

The Cardiomyopathy Association (CMA) is a registered charity that offers information and support to people and their families affected by the heart muscle disease cardiomyopathy. The charity has a freephone helpline (0800 0181 024), manned from 8.30am to 4.30pm on weekdays, support groups and a network of volunteers who offer support on the telephone. It holds information days around the country and produces a quarterly newsletter for its members.

Website: [www.cardiomyopathy.org](http://www.cardiomyopathy.org)



## CRY Cardiac Risk in the Young

CRY is a charity founded in May 1995 to raise awareness of Cardiac Risk in the Young – Sudden Cardiac Death (SCD), Sudden Death Syndrome (SDS, SADS).

CRY offers support to those who have suffered a loss through a network of affected families & counselling. They promote heart screening, ECG Testing Programmes & contribute to medical research. CRY has also donated medical equipment to doctors' surgeries and hospitals and they fund the CRY Centre for Sports Cardiology at the Olympic Medical Institute.

Website: [www.c-r-y.org.uk](http://www.c-r-y.org.uk)



## Lagan's Foundation

The UK's first and only National Charity to provide support and at home care to families with babies and children under the age of 5 diagnosed with Congenital Heart Defects and / or feeding difficulties. Supported by Alder Hey Children's NHS Foundation Trust – Cardiac and Gastroenterology Departments.

A Congenital heart defect is a problem with the structure of the heart that is present from birth. Congenital heart defects are the most common type of major birth defect, affecting 1 in every 100 newborn babies. This is a staggering 1 every 15 minutes of every day! A small number of babies are born with complex congenital heart defects that require special medical care soon after birth.

Associated with these cardiac conditions are feeding difficulties. The feeding difficulty can become the centre of attention for any baby or child and can cause failure to thrive. We know first hand how parents feel the strain of having a baby or child that cannot feed and from this we would like to offer other parents support in the form of respite care at home and at hand information.

### **Email**

General Enquiries – [info@lagans.org.uk](mailto:info@lagans.org.uk)

Fundraising – [fundraising@lagans.org.uk](mailto:fundraising@lagans.org.uk)

Accounts Team – [finance@lagans.org.uk](mailto:finance@lagans.org.uk)

### **Phone**

Mobile: 07879663304

Office: 01204 468300

### **Website**

[www.lagans.org.uk](http://www.lagans.org.uk)



Somerville Foundation (Formerly Grown Up  
Congenital Heart Patients Association)

The Somerville Foundation supports young people and adults who were born with a heart condition. Services include a free-phone helpline 0800 854759, conferences, workshops and weekends away. Free information and advice leaflets are provided covering areas such as transition (moving from paediatric to adult care) lifestyle issues (alcohol recreational drugs, sex and contraception etc). The organisation's quarterly newsletter GUCH News keeps patients up to date and is entirely free of charge. Small grants are available to support young people in education, through the Beverly Downey Fund. GUCH works in partnership with the NHS to help ensure that patients receive appropriate care from an expert from a recognised GUCH centre. The organisation also campaigns more widely for changes that will benefit patients. New members are always, always welcome!

Website: [www.thesf.org.uk](http://www.thesf.org.uk)



## Heartline

Heartline is a voluntary organisation set up to offer help and support to children with heart disorders and their families. Telephone: 01276 707636

Heartline provides:

- Information on congenital heart defects
- A book Heart Children – a practical handbook for parents covering all aspects of having a heart child.
- Contact between families by the maintenance of local support groups, social events and a regular newsletter.
- Support through a rota of hospital visitors and the staffing of information desks at cardiac outpatients clinics.

Website: [www.heartline.org.uk](http://www.heartline.org.uk)



Little Hearts Matter

## Little Hearts Matter

Little Hearts Matter is the national voice for families where a single ventricle heart condition, such as Hypoplastic Left Heart Syndrome, Tricuspid Atresia, Double Inlet Ventricle or Pulmonary Atresia has been diagnosed. The charity works with medical and social care teams to offer a multi-disciplinary approach to the support and information needed by this group of people and their carers.

Little Hearts Matter:

- ♥ Offers support to families at the time of diagnosis, through treatment and into life at home.
  - ♥ Provides written information for parents and children.
  - ♥ Works with health and community professionals to raise awareness
- Promotes research into single ventricle heart conditions and their treatment

Website: [www.lhm.org.uk](http://www.lhm.org.uk)



## Max Appeal

Max Appeal supports families affected by DiGeorge syndrome, VCFS and 22q11.2 deletion. They are a registered charity set up in 1999 by parents of children with the condition.

Max Appeal offers:

- ♥ A wide range of information, including a comprehensive handbook covering the main, or more commonly noted, aspects of this very variable group of conditions.
- ♥ A freephone number manned by a parents who have been trained for telephone helpline services: 0800 389 1049
- ♥ Contact with other families and support to regional and local groups.
- ♥ A regular newsletter that has a circulation of 1,000 copies.

We are also developing international and research links.

Website: [www.maxappeal.org.uk](http://www.maxappeal.org.uk)



## The Scottish Association for Children with Heart Disorders

Formerly part of The Association for Children with Heart Disorders, The Scottish Association for Children with Heart Disorders was formed as a new charity in 2004. There are six local / area branches in Aberdeen, Banff & Buchan, Edinburgh, Glasgow, Dumfries and Tayside and a Young Adults Group.

They offer support and understanding in everyday care and welfare to parents and families of children with heart disorders and seek to improve facilities for children and young adults at heart units and in hospitals throughout Scotland.

Website: [www.youngheart.info](http://www.youngheart.info)



## Over The Wall

For the last 20 years Over The Wall have been running completely free-of-charge and inclusive residential activity camps for children with health challenges, aged 8-17 years, as well as for their siblings and the whole family. In response to the COVID-19 pandemic and having to cancel their camp events in 2020, the charity created Camp in the Cloud, a virtual, inclusive and engaging online activity programme, where campers and families can experience the magic of an Over The Wall residential camp without having to leave their home.

Visit website: <https://www.otw.org.uk/>

## Local support groups



### Brompton Fountain

The Brompton Fountain is a parent support charity for families whose children are being treated for cardiac and respiratory conditions at the Royal Brompton and Harefield NHS Trust.

The Brompton Fountain was born from a need and desire on the part of the hospital and families to improve parent involvement with patient care. A meeting in November 2003, organised by the hospital, brought together staff and parents to discuss how better to improve

the experience for paediatric patients and their families. As a result of this, a group of parents went on to form The Brompton Fountain.

Website: [www.thebromptonfountain.org.uk](http://www.thebromptonfountain.org.uk)



## Children's Heart Unit Fund

The Children's Heart Unit Fund is a registered charity that supports the Children's Heart Unit at the Freeman Hospital in Newcastle.

They help by funding equipment, personnel, research, or anything else that may be needed to help keep the unit at the forefront of children's cardiac care.

Website: [www.chuf.org.uk](http://www.chuf.org.uk)



## Heart Children Ireland

Heart Children Ireland was founded in 1990 by a group of parents who met in Our Lady's Hospital in Crumlin while their children were being treated for congenital heart defects. Their aim is to provide practicable support for members in any way that they can, this will include the setting up of local groups, the purchase of medical equipment, financial assistance to families, the funding of specialist posts and special events for the children and their families.

Website: [www.heartchildren.ie](http://www.heartchildren.ie)



## Heart Link

Heart Link was formed in 1981 to provide a vital role in parental support to parents of children with congenital heart conditions

Heart Link's main objectives

- Support for parents by parents
- Provide regular social events for members
- Help parents to communicate with each other
- Fund raising to provide better facilities for parents and children

Website: [www.heartlinkchildrenscharity.co.uk/org.uk](http://www.heartlinkchildrenscharity.co.uk/org.uk)



## Children's Heart Support Network (Formerly Wessex Children's Heart Circle)

The CHSN is a support group for the families of children with heart disorders, and its members can all relate to one another regarding the emotions, experiences and fears that occur when a hospital visit or surgery is required. Our work is centred with the children's Cardiac Units that our membership attends.

When funds allow, the CHSN provides small, relevant pieces of medical equipment for home use where finance is unavailable from the Health Trust or other statutory authorities. As funds allow, we also supply some of the niceties to make the children's stay at cardiac units more comfortable, e.g., Nursery Bedding, Playroom equipment, audio/visual equipment.

Welfare Payments, as funds allow, are also available through a grant making application and help those families who are experiencing financial difficulties due to being in hospitals, and to those families who have extended stay.

We support families by putting them in touch with others, often local to themselves, who have experienced the traumas, fears and stresses that occur with having a heart child. We also help with emotional support before, during and after hospitalisation. Sadly, this can, on occasions, extend to bereavement support.

If you would like further information about the Children's Heart Support Network or if you would like to help please email: [chsn@live.co.uk](mailto:chsn@live.co.uk)



Young at Heart is the support Group for families of children treated at the Cardiac Unit, Birmingham Children's Hospital. YAH support babies & children with a cardiac condition and their families, whilst offering advice and information. YAH provide a forum for families to meet socially for trips, parties and other social events. They also provide a network of support via the telephone helpline and offer Ward visits for families & financial grants.

Young at Heart fundraises for the benefit of the Cardiac Unit, Birmingham Children's Hospital.

Website: [www.youngatheart.org.uk](http://www.youngatheart.org.uk)



## Children's Heartbeat Trust

The Children's Heartbeat Trust delivers emotional and practical support to children and young people with heart disease in Northern Ireland, and their families. The charity provides financial support, accommodation at RBHSC, family support groups and services, as well as campaigning and funding research.

[www.childrensheartbeattrust.org](http://www.childrensheartbeattrust.org)

## Others/General



### Contact a family

Contact a Family is the only UK-wide charity providing advice, information and support to the parents of all disabled children – no matter what their disability or health condition. We also enable parents to get in contact with other families, both on a local and national basis. Each year we reach at least 275,000 families.

Contact a Family, 209-211 City Road, London EC1V 1JN

Tel: 020 7608 8700

Fax: 020 7608 8701

Helpline 0808 808 3555 or Textphone 0808 808 3556

Freephone for parents and families (Mon-Fri, 10am-4pm & Mon, 5.30-7.30pm)

Email: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

# Sibs

## Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. Siblings have a lifelong need for information, they often experience social and emotional isolation, and have to cope with difficult situations. They also want to have positive relationships with their disabled brothers and sisters and to be able to choose the role they play in future care.

We support siblings of all ages who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition. We work with Adult Siblings, Young Siblings, Parents of Siblings and Service Providers.

[www.sibs.org.uk](http://www.sibs.org.uk)



## Working Families

Working Families is the UK's leading work-life balance organisation. The charity helps working parents and carers and their employers find a better balance between responsibilities at home and work.

Our free Legal Helpline gives parents and carers advice on employment rights such as maternity and paternity leave, rights to time off in an emergency, and parental leave, as well as helping them to negotiate the flexible hours they want. We can also give basic advice on the benefits and tax credits that working parents can claim. We also give advice on maternity discrimination and pregnancy discrimination. Our ground breaking research and campaigns seek to change the way we live and work. To that end, we also work with employers to support them in creating workplaces which encourage work-life balance for everyone.

By operating in the real world of pragmatic advice and practical solutions, we are making our vision a reality

[www.workingfamilies.org.uk](http://www.workingfamilies.org.uk)



## Council for Disabled Children

“The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to other UK nations. We are the only national body that brings together the diverse range of organisations that work with and for disabled children to support the development and implementation of policy and practice. Our work impacts on over 800,000 disabled children and their families. CDC does not provide an advice or support service directly to families with disabled children or children with SEN, however there are a number of organisations that may be able to help you.”

Their website contains useful links for many other organisations who give support, advice and assistance to families who have a disabled child. Visit

: <http://www.councilfordisabledchildren.org>



## Family Fund

We are the UK's largest provider of grants to low-income families raising disabled and seriously ill children and young people. We help ease the additional pressures families face. We can help with essential items such as washing machines, fridges and clothing but can also consider grants for sensory toys, computers and much needed family breaks together.

For more information, visit our website: [www.familyfund.org.uk](http://www.familyfund.org.uk)



Corience is a European initiative, bringing together support groups from all over Europe, such as Sweden, Norway, Germany, Spain, and of course the UK. It is an independent platform on congenital heart defects for patients, parents, doctors and scientists. It contains lots of very good information, not only from the UK but all over Europe.

[www.corience.org](http://www.corience.org)