

Support Groups for conditions & syndromes affecting the baby

Contact-a-Family

www.cafamily.org.uk

A UK charity which provides support and advice to parents of children with a disability or special need. Can put families in touch with each other.

BLISS - the Premature Baby Charity

www.bliss.org.uk

Bliss is a support group for parents who have a baby requiring special care. It also campaigns for improvements in neonatal care and promotes new developments and innovations in care.

British Heart Foundation - BHF

www.bhf.org.uk

Is the leading national charity fighting heart and circulatory disease. The BHF funds research, education, life-saving equipment and helps heart patients return to a full and active way of life. Its heart conditions section has specific information on children with heart conditions.

Children's Heart Federation

<http://www.chfed.org.uk/>

Provides a range of information about all aspects of bringing up heart children. Runs a national helpline for both families and professionals involved with heart children. Can put parents in touch with appropriate federated groups around the UK.

CLAPA- Cleft Lip and Palate Association

www.clapa.com

CLAPA aims to organise local parent-to-parent support through its nation-wide network of branches. It runs a specialist service for parents and health professionals seeking help feeding babies with clefts. Offers support for children and adolescents affected by clefts, encourages research, public awareness and education. It also supports projects in countries where cleft treatment is limited or unavailable.

Down's Heart Group

www.dhg.org.uk

A UK charity which offers support and information to families who have a member with Down's syndrome and congenital heart defects. On this site you will find information about heart defects, tests and procedures and other useful websites and sources of information.

Down's Syndrome Association

www.downs-syndrome.org.uk

The organisation focuses solely on all aspects of living successfully with Down's syndrome. The site has information, a section for new parents and a magazine, Down 2 Earth, which is produced by people with Down's syndrome for people with Down's syndrome.

ECHO- Evelina Children's Heart Organisation

www.echo-evelina.org.uk

Is a support group for the families of children born with heart conditions. It is a voluntary organisation and a registered charity. ECHO is run by parents of heart-children who all appreciate the benefits that can be gained through contact with other parents in a similar

situation. The site also has a message board and newsletter.

Genetic Alliance

<http://www.geneticalliance.org.uk/>

Is a national alliance of patient organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders.

healthtalk.org

www.healthtalk.org

This section of our website contains video, audio and written clips from interviews with parents of children with congenital heart disease.

Little Hearts Matter (previously Left Heart Matters)

www.lhm.org.uk

A charity based in Birmingham which offers support and information to families of children with hypoplastic left heart syndrome. Their web site provides details of parents around the world with hypoplastic left heart syndrome children.

National Portage Association

www.portage.org.uk

Portage is a home-visiting educational service for pre-school children with additional support needs. They aim to support the development of young children's play, communication and relationships and to encourage full participation in day to day life within the family and beyond the home. Portage services are committed to securing inclusion in the wider community for all children and families in their own right.

Sense

www.sense.org.uk

Offers a wide range of support and services across the UK to help sensory impaired people of all ages to reach their full potential despite the many challenges facing them. They have regional advice centres a number of publications and local support groups.

Shine

www.shinecharity.org.uk

Works with people with spina bifida and/or hydrocephalus (SB/H), their families and carers to promote individual choice, control and quality of life. The site has a number of information sheets, lists of local associations, links to other organisations and the Link magazine.

SOFT -Trisomies Support Group

www.soft.org.uk

Provides support for families affected by Patau's syndrome (trisomy 13), Edwards' Syndrome (trisomy 18), partial trisomy, mosaicism, rings, translocation, deletion and related disorders.

SWAN -Syndromes without a name

www.undiagnosed.org.uk

Aims to preserve and protect the health and promote the welfare of children who suffer from undiagnosed conditions.

The Cystic Fibrosis Trust

www.cysticfibrosis.org.uk

The Trust is working to improve the lives of people with CF, raise the profile of CF and fund research into a cure. The site has information on the condition and how to live with it, leaflets, booklets, factsheets and links to other organisations.

The UK Thalassaemia Society

www.ukts.org

The society aims to promote and co-ordinate research, educate people on the problems of Thalassaemia and to offer counselling to sufferers and carriers. To bring together patients, families and well-wishers to exchange ideas and information.

TSS - Turner Syndrome Support Society

www.tss.org.uk

Aims to offer support & information to girls & adult women with Turner syndrome, their families and friends. The site has information on Turner syndrome, local support groups, other organisations and a newsletter.

Unique - Rare Chromosome Disorder Support Group

www.rarechromo.org

Unique -the rare chromosome disorder support group exists to inform and support families and parents about other rare chromosome disorders including deletions, trisomy, balanced translocations, unbalanced translocations, rings, inversions, duplications, tetrasomy, monosomy, triploidy, isodicentric, marker, mosaic, sex chromosome or aneuploidy.