

Support Groups for conditions & syndromes affecting the baby

Contact - Contact-a-Family

www.contact.org.uk

Tel: 0808 808 3555 9.30am-5pm Mon-Friday

A UK charity for parents and carers in any part of the UK with a disabled child aged from birth to 25.

ARC - Antenatal Results & Choices

www.arc-uk.org

Tel: 0207 77137486

ARC offers information and support to parents who are: making decisions during the antenatal testing process, told that their unborn baby has an abnormality, having to make difficult decisions about continuing the pregnancy, having to make difficult decisions about ending the pregnancy.

Shine - Association for Spina Bifida and Hydrocephalus

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.

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

Tel: 0300 330 3322 Mon-Fri 9am-5pm

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

www.chfed.org.uk

Tel: 03005610065 9.00am – 5.00pm Monday-Friday

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.

CLAPA- Cleft Lip and Palate Association

www.clapa.com

Tel: 020 7833 4883

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.

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.

Down's Syndrome Association

www.downs-syndrome.org.uk

Tel: 03331212300 10am-4pm

The organisation focuses solely on all aspects of living successfully with Down's syndrome.

ECHO- Evelina Children's Heart Organisation

www.echo-uk.org

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.

Genetic Alliance UK

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.

Hexi - Congenital Heart Disease

www.hexi.ox.ac.uk/parents-children-congenital-heart-disease/

The site contains video, audio and written clips from interviews with parents of children with congenital heart disease.

Klinefelter Organisation

www.klinefelter.org.uk

Provides general information about Klinefelter's Syndrome, medical links and contact for support and other interesting information about the condition.

Little Hearts Matter

www.lhm.org.uk

Tel: 0121 455 8982

A charity which offers support and information to families of children with hypoplastic left heart syndrome.

Mencap

www.mencap.org.uk

Tel: 0808 808 1111

Mencap is the UK's (for Scotland see Enable) leading learning disability charity working with people with a learning disability and their families and carers. Further contact details for Wales and Northern Ireland are available on the site.

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.

Perinatal hospice and Palliative Care

www.perinatalhospice.org

An American site that offers support for parents who are considering continuing a pregnancy after a prenatal diagnosis that indicates that the baby is likely to die before or after birth.

Rare Chromosome Disorder Support Group

www.rarechromo.org

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.

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.

Sickle Cell Society

www.sicklecellsociety.org

Tel: 020 8961 7795

The site has sections on information, research, education and a forum.

SOFT -Trisomies Support Group

www.soft.org.uk

Tel: 0300 102 7638

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 (on Genetic Alliance website)

www.geneticalliance.org.uk/support-and-information/swan-uk-syndromes-without-a-name/

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

Terence Higgins Trust

www.tht.org.uk

Tel: 0808 802 1221

Provides support for people and families living with HIV and AIDS.

The Cystic Fibrosis Trust

www.cysticfibrosis.org.uk

Tel: 0300 373 1000

The Trust is working to improve the lives of people with CF, raise the profile of CF and fund research into a cure.

The UK Thalassaemia Society

www.ukts.org

Tel: 020 8882 0011

The society aims to promote and co-ordinate research, educate people on the problems of Thalassaemia and to offer counselling to sufferers and carriers.

TssS - 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.

Bereavement Support**SANDS -Stillbirth and Neonatal Death Society**

www.sands.org.uk

Tel:0808 164 3332

Support for parents and families whose baby is stillborn or dies soon after birth.

Child Bereavement Trust

www.childbereavementuk.org

Tel: 0800 02888 40

A UK charity which provides support, information and resources for bereaved families.

The Compassionate Friends

www.tcf.org.uk

Tel: 03451232304

A national self-help group of bereaved parents offering support and friendship to those similarly bereaved. The Helpline is always answered by a bereaved parent who is there to listen when you need someone to talk to.