**National Support Available**

**Contact-a-Family**

Provides useful information and support to families of children with disabilities and/or additional needs. A vast range of resource booklets and information leaflets available on a wide range of subjects relating to disability. Information is also available to parents and carers on request or to view online.

* Freephone helpline: 0808 808 3555

Textphone: 0808 808 3556

**www.cafamily.org.uk or**

[**www.makingcontact.org**](http://www.makingcontact.org/)

**The Children’s Society**

Provides an advocacy, consultation, participation and training services: Advocacy: commissioned to provide individual advocacy/spot purchasing, free health advocacy services and piloting visiting advocacy. Consultation: to develop resources, to develop services for bespoke pieces of work or commissioned services (participation worker).

• Tel: 0845 300 1128

**Email: supportercare@childrenssociety.org.uk**

[**www.childrenssociety.org.uk**](http://www.childrenssociety.org.uk)

**Council for Disabled Children**

The Council for Disabled Children is an independently elected council, established under the supervision of the National Children’s Bureau. The Council promotes collaborative work between voluntary and statutory organisations that provide services and support for children and young people with disabilities and special educational needs.

• Tel: 020 7843 1900

**Email: cdc@ncb.org.uk**

[**www.councilfordisabledchildren.org.uk**](http://www.councilfordisabledchildren.org.uk)

**S.W.A.N UK (Syndromes Without A Name)**

Supporting families of children with undiagnosed medical conditions.

• Tel: 020 7704 3141

**Email: sw****an@geneticalliance.org.uk**

[**www.undiagnosed.org.uk**](http://www.undiagnosed.org.uk)

**Genetic Alliance UK**

Information for those with genetic conditions and genetics diseases.

* [**www.geneticalliance.org.uk**](http://www.geneticalliance.org.uk/)

**Child Brain Injury Trust**

A UK-wide charity providing support, information and training about childhood acquired brain injury (ABI). It is not a medical organisation, the focus is on the social impact of childhood acquired brain injury, the way it affects the child and family in relation to their lives now and in the future. Support for both families and professionals.

• Helpline: 0303 303 2248

Email: helpline@cbituk.org

Tel: 01869 341075

**Email: info@cbituk.org**

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

**Treehouse**

Improving inclusion, information about inclusive education for children with Autism.

• Tel: 0208 815 5444

**Email: polic****y@treehouse.org.uk**

[**www.treehouse.org.uk**](http://www.treehouse.org.uk)

**Network 81**

A national network of parents working towards properly resourced inclusive education for children with special educational needs. Offers advice and support to parents on most issues relating to inclusion.

* **Email: netw****ork81@hotmail.co.uk**[**www.network81.org**](http://www.network81.org/)

**Genetic Alliance UK**

Working to benefit all people affected by genetic disorders. A national alliance of patient organisations with a membership of over 130 charities that support children, families and individuals affected by genetic disorders.

* Unit 4d, Leroy House, 436 Essex Road,

London, N1 3QP

Tel: 020 7704 3141

Fax: 020 7359 1447

**Email: mail@geneticalliance.org.uk**

[**www.geneticalliance.org.uk**](http://www.geneticalliance.org.uk)

**Rare Disease UK**

• Tel: 020 7704 3141

**Email info@raredisease.org.uk**

[**www.raredisease.org.uk**](http://www.raredisease.org.uk)

**Macmillan Cancer Support**

Provides information, general advice and support on how to ease financial burden of those affected by cancer.

* 89 Albert Embankment, London SE1 7UQ

Tel: 020 7840 7840

Fax: 020 7840 7841

[**www.macmillan.org.uk**](http://www.macmillan.org.uk)

Freephone no: 0808 808 0000

Helpline: 0800 500 800

**Turn2us**

Helping people to find out about the charitable grants and state benefits they may be entitled to by increasing awareness and improving access to the help available.

* + [**www.turn2us.org.uk**](http://www.turn2us.org.uk)

**Unique - the Rare Chromosome Disorder Support Group**

Supports families of children with a rare chromosome disorder. Information to families and comprehensive database.

* Unique, PO Box 2189, Caterham, Surrey, CR3 5GN Tel: 01883 330766

**Email: info@rarechromo.org**[**www.rarechromo.org**](http://www.rarechromo.org/)

**Oaasis**

Organisation providing information relevant to children on the Autistic Spectrum and Aspergers. Support provided for parents, carers, teachers and other professionals who care for children and young people with a range of learning disabilities.

They also produce publications on a wide range of other learning disabilities.

• Tel: 0800 197 3907

Fax: 01590 622 687

**Email: oaasis@cambiangroup.com**

[**www.oaasis.co.uk**](http://www.oaasis.co.uk)

**Downs Syndrome Association**

The Down’s Syndrome Association is a national charity dedicated solely to every aspect of living with Down’s Syndrome. All age ranges supported.

• Langdon Down Centre,

2A Langdon Park,

Teddington,

Middlesex TW11 9PS

Tel: 0333 121 2300

**Email: info@downs-syndrome.org.uk**

[**www.downs-syndrome.org.uk**](http://www.downs-syndrome.org.uk)

**Elyons Heart Foundation**

Offers emotional and practical support to children with a heart condition and their families. The criteria for assistance can be provided to children, ranging from a one-off operation, to one needing a lifetime of medication and multiple surgery. Services offered include: support groups; information on heart conditions and medical terminology; guides to grants and benefits; assistance and transportation to medical appointments and assistance in organising parental accommodation during the child’s hospital stays.

• Tel: 07944 582 080

**Email: enquires@ehfuk.org**

[**www.ehfyk.org**](http://www.ehfyk.org)

**National Autistic Society**

Leading UK charity for people with autism (including Asperger Syndrome) and their families. They provide information, support and pioneering services and campaign for a better world for people with autism.

• Helpline: 0808 800 4104
[**www.nas.org.uk**](http://www.nas.org.uk)

**Down’s Heart Group**

Offers support and information to families who have a family member with Down’s syndrome and congenital heart defects.

• PO Box 4260, Dunstable, LU6 2ZT
 Tel: 0844 288 4800

**Email: info@dhg.org.uk** **Email: penny@dhg.org.uk**

[**www.dhg.org.uk**](http://www.dhg.org.uk)

**RNID (Royal National Institute for Deaf People)**

• Tel: 020 7296 8000

Fax: 020 7296 8199

Minicom: 0808 808 9000

Helpline: 0808 808 0123

**Email: informationline@rnid.org.uk**

[**www.rnid.org.uk**](http://www.rnid.org.uk)

**RNIB (Royal Institute for Blind People)**

• Tel: 020 7388 1266

Fax: 020 7388 2034

Helpline: 0303 123 9999

**Email: helpline@rnib.org.uk**

[**www.rnib.org.uk**](http://www.rnib.org.uk)

**Action for Blind People**

• Tel: 020 7635 4800

**Email: helpline@mib.org.uk**

[**www.actionforblindpeople.org.uk**](http://www.actionforblindpeople.org.uk)

**Visual Impairment News**

* **Email: info@partially-sighted.com**

[**www.partially-sighted.com**](http://www.partially-sighted.com/)

**Ann Craft Trust**

National association for the protection from sexual abuse of adults and children with learning disabilities

• Tel: 0115 9515400

Fax: 0115 9515232

**Email: ann-cr****aft-trust@nottingham.ac.uk**

[**www.anncrafttrust.org**](http://www.anncrafttrust.org)

**The Centre for Child Mental Health**

• Tel: 020 7354 2913

**Email: info@childmentalhealthcentre.org**

[**www.childmentalhealthcentre.org**](http://www.childmentalhealthcentre.org)

**Genetic Disorders UK**

Advice and support for individuals and families affected by genetic disorders

• Tel: 0800 987 8987

[**www.geneticdisordersuk.org**](http://www.geneticdisordersuk.org)

**KIDS**

Information, support and advice for disabled children, young people and their families around the development of inclusion

• Tel: 020 7520 0405

[**www.kids.org.uk**](http://www.kids.org.uk)

**Institute of Well Being**

Organisation promoting well-being and healthy living, through a range of personal development programmes, private therapies, multimedia and creative arts for all people at all stages in life.

• Tel: 0700 2222 700

Fax: 020 8659 6659

Mob: 07973 383 042

[**www.theinstituteofwellbeing.com**](http://www.theinstituteofwellbeing.com)

**The Rix Centre**

The Rix Centre delivers a rolling programme of research and development projects as well as providing teaching and learning in Multimedia Advocacy and implementing wider Multimedia Advocacy based initiatives across the fields of health, social care and education.

• University of East London, Docklands Campus 4-6,

University Way, London E16 2RD

Tel: 020 8223 7561

**Email: rixadmin@uel.ac.uk**

[**www.rixcentre.org**](http://www.rixcentre.org)

**Action for Kids**

Providing advice, training and learning support and the provision of mobility equipment for young people with disabilities.

• Ability House, 15a Tottenham Lane, Hornsey

London, N8 9DJ

Tel: 020 8347 8111

**Email: info@actionforkids.org**

**w**[**ww.actionforkids.org**](http://www.actionforkids.org/)

**Reconstruct (Child/YP advocacy)**

Promotes advocacy for children and young people with disabilities and/or additional needs. Self-referral or through a social worker. Age range 5 - 18.

• Tel: 020 8540 0020

Fax: 020 8417 0883

Young People Freephone: 0800 389 1571

**Email: yourv****oice@reconstruct.co.uk**

[**www.reconstruct.co.uk**](http://www.reconstruct.co.uk)

**Epilepsy Action**

Provides information on epilepsy.

* Tel: freephone helpline: 0808 800 5050

Fax: 0808 800 5555

FREEPOST LS0995, Leeds, LS19 7YY

**Email: helpline@epilepsy.org.uk**

[**www.epilepsy.org.uk**](http://www.epilepsy.org.uk)

**Voice - (advocacy service)**

For young people that need advocacy support, freephone helpline.

• Tel: 0808 800 5050

**Email: helpline@epilepsy.org.uk**

Text msg: 07797 805 390

**GINGERBREAD Single Parent Helpline**

The Helpline provides independent, confidential information and advice. Can advise on benefits, childcare, CSA (Child Support Agency), contact, divorce, employment, housing, maternity rights and lone parenthood.

• Tel: 0808 802 0925

[**www.gingerbread.org.uk**](http://www.gingerbread.org.uk)

**The National Society for Epilepsy**

Provides information and support to people with epilepsy. Also care for people with epilepsy through medical and residential services, including long term residential care, respite care and rehabilitation services for older people with epilepsy.

• Contact for further details.

Tel: 01494 601300

Fax: 01494 871 927

National epilepsy helpline: 01494 601 400

[**www.epilepsysociety.org.uk**](http://www.epilepsysociety.org.uk)

**The National Centre for Young People with Epilepsy**

Includes the Childhood Epilepsy Enquiry Service.

Provides an information service for young people, parents, families and professionals about childhood epilepsy. Signposting to other agencies and further sources of support. They also provide an education service (special study days) including young people and others involved and interested in information regarding epilepsy.

• Tel: 01342 832243

Fax: 01342 834639

**Email: info@ncype.org.uk**

[**www.ncype.org.uk**](http://www.ncype.org.uk)

**National Children’s Bureau**

NCB is a leading national charity which supports children, young people and families and those who work with them. They work with organisations from across the voluntary, statutory and private sectors through their membership scheme, and through the sector-led specialist networks and partnership programmes that operate under their charitable status. The Bureau also produces a range of information and free seminars for parents of children with disabilities.

• Tel: 020 7843 6000

**Email: enquiries@ncb.org.uk**

[**www.ncb.org.uk/cdc**](http://www.ncb.org.uk/cdc)

**Parents for Inclusion**

Run by parents for parents of disabled children and those said to have special educational needs. Provides an inclusion helpline, works closely with disabled adult trainers to provide ‘Planning Positive Futures’ training for parents and helps parents set up self help groups in schools.

• Tel: 0800 652 3145

**Email: info@parentsforinclusion.org**

[**www.parentsforinclusion.org**](http://www.parentsforinclusion.org)

**Disabled Living Foundation**

The Disabled Living Foundation (DLF) gives insight into issues surrounding disability, particularly focusing on the ways in which disability in society today continues to be a barrier to achievement and equality.

* 380-384 Harrow Road, London, W9 2HU Tel: 020 7289 6111

Fax: 020 7266 2922

Helpline: 0845 130 9177 - 10am to 4pm

Textphone: 020 7432 8009

[**www.dlf.org.uk**](http://www.dlf.org.uk)

**Email: ad****vice@dlf.org.uk**

**www.livingmadeeasy.org.uk - leisure specialist/swimming aids**

**Foundation for People with Learning Disabilities**

The Foundation produces an informative booklet entitled ‘First Impressions’ for families of young children with a learning disability.

• Tel: 020 7803 1100

[**www.learningdisabilities.org.uk**](http://www.learningdisabilities.org.uk)

**Email: fpld@fpld.org.uk**

Useful resources: My Kind of Future - ‘work book to help young people with learning disabilities prepare for the future.’

**Instream Partnership**

Help and advice exploring the practical and operational issues for people with disabilities employing their own support workers through Direct Payments. A step by step guide to organising your own support and covers essential information, such as funding, recruitment and interview strategies, as well as information on employment law.

• Tel: 01706 642196

Mob: 07950 107 307

**Email: gary@instream.org.uk**

[**www.Instream.org.uk**](http://www.Instream.org.uk)

• Online database for Personal Assistants: [www.Pamatch.co.uk](http://www.Pamatch.co.uk/)

**SCOPE**

Information and support regarding Cerebral Palsy, welfare benefits, schooling, equipment and anything else to do with disability.

• PO Box, 833 Milton Keynes, MK12 5NY

Tel: 0808 800 3333

**Email: response@scope.org.uk**

[**www.scope.org.uk**](http://www.scope.org.uk)

**SIBS**

Sibs are a UK organisation for people who grow up with a brother or sister with a disability or chronic illness. It provides information and support to siblings and their families through their helpline, website and workshops. Sibs also influences service providers to develop services for siblings and trains professionals to run sibling groups.

• Tel: 01535 645 453

**Email: info@sibs.org.uk**

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

**Kidz Aware (previously known as Special Abilities)**

An organisation working to promote equality of opportunities, choices and independence for all disabled children and adults across services.

They produce comprehensive manuals covering issues, such as, Special Educational Needs and services available nationally to parents.

• Tel: 01924 385977

**Email: kidzaw****are@hotmail.com**

[**www.specialabilities.co.uk**](http://www.specialabilities.co.uk)

**Changing Faces**

A national charity that supports and represents people who have disfigurements of the face or body, from any cause. The charity aims to enable people who have disfigurements to develop high self-esteem and self- confidence.

• Tel: 0845 4500 275 or 020 7391 9270

**Email: info@changingfaces.org.uk**

[**www.changingfaces.org.uk**](http://www.changingfaces.org.uk)

**Breathe on UK**

Supports children on long term ventilation (LTV) and their families. Helps families come to terms with this difficult condition by providing an ever-growing support network and essential information on obtaining assistance. LTV is defined as any child who has been on a ventilator for over three months. Any medical questions are handled by Professor Peter Fleming, the charity’s chief medical advisor.

* Tel: 01258 820 274 (fax available)
[**www.breatheon.org.uk**](http://www.breatheon.org.uk)

**Cystic Fibrosis Trust**

Information, advice and support for people with cystic fibrosis, their families, friends and professionals.

• Tel: 020 8464 7211

**Email: enquiries@cftrust.org.uk**

[**www.cftrust.org.uk**](http://www.cftrust.org.uk)

**The Challenging Behaviour Foundation**

Provides information and support to parents/carers and professionals caring for individuals with severe learning disabilities and challenging behaviour. Links to useful resources.

• Tel: 01634 838 739

General Enquiries Family support Line:

Tel: 0845 602 7885

**Email: info@thecbf.org.uk**

[**www.challengingbehaviour.org.uk**](http://www.challengingbehaviour.org.uk)

**Disability Rights UK**

Specialises in information on disability-related income issues, such as, social security benefits.

• Tel: 020 7250 3222

Fax: 020 7247 8765

Helplines: Disabled Students: 0800 328 5050

 Independent Living: 0300 555 1525

**Email: enquiries@disabilityrightsuk.org**

[**www.disabilityrightsuk.org**](http://www.disabilityrightsuk.org)

**RADAR (Royal Association for Disability and Rehabilitation)**

National campaigning organisation and resource for Radar Key for accessibility to disabled toilets and changing places facilities.

• Tel: 020 7250 3222

Textphone: 020 7250 4119

**Email: enquiries@disabilityrightsuk.org**

[**www.radar-shop.org.uk**](http://www.radar-shop.org.uk/)