

# Support for Specific Conditions

Condition and Service	Description of service provider	Contact information
<p>ADD ADDISS</p> 	<p><b>ADDIS</b> is the National Attention Deficit Disorder Information and Support Service</p> <p>They provide people-friendly information and resources about Attention Deficit Hyperactivity Disorder to anyone who needs assistance - parents, sufferers, teachers or health professionals.</p>	<p><b>Telephone number:</b> 02089 521 515</p> <p><b>Postal address:</b> ADDISS, PO Box 340, Edgware, Middlesex, HA8 9HL</p> <p><b>Email address:</b> <a href="mailto:info@addis.co.uk">info@addis.co.uk</a></p> <p><b>Website:</b> <a href="http://www.addiss.co.uk/">http://www.addiss.co.uk/</a></p>
<p>ADD ADDUP</p> 	<p><b>ADDUP</b> stands for “Attention Deficit Disorders: Uniting Parents”.</p> <p>They are a registered charity, support and action group run by parents of children with ADHD. They are a friendly group of parents and children from all walks of life who share the common thread - they live with ADHD which is a disorder that effects the whole family framework and not just the individual with the diagnosis.</p>	<p><b>Telephone number:</b> 01708 454 040</p> <p><b>Postal address:</b> ADDUP, 59 Billet Lane, Hornchurch, RM11 1AX</p> <p><b>Email address:</b> Not available. See website.</p> <p><b>Website:</b> <a href="https://www.addup.co.uk/">https://www.addup.co.uk/</a></p>

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<p style="text-align: center;"><b>ADHD</b> ADHD Foundation</p> 	<p>ADHD Foundation offer information on ADHD by providing factsheets and support for you/your child with recent diagnosis of ADHD.</p>	<p><b>Telephone:</b> 01515 419 020</p> <p><b>Postal address:</b> 3rd Floor, 54 St James Street, Liverpool L1 0AB</p> <p><b>Email address:</b> <a href="mailto:info@adhdfoundation.org.uk">info@adhdfoundation.org.uk</a></p> <p><b>Website:</b> <a href="https://www.adhdfoundation.org.uk/">https://www.adhdfoundation.org.uk/</a></p>
<p style="text-align: center;"><b>Angleman Syndrome</b> Angelman UK</p> 	<p>Angelman UK are a volunteer-led registered charity based in the UK. They provide support, information and advice for families affected by Angelman syndrome.</p>	<p><b>Telephone:</b> 03009 990 102</p> <p><b>Postal address:</b> AngelmanUK, PO Box 4962, Nuneaton, CV11 9FD</p> <p><b>Email address:</b> <a href="mailto:support@angelmanuk.org">support@angelmanuk.org</a></p> <p><b>Website:</b> <a href="https://www.angelmanuk.org/">https://www.angelmanuk.org/</a></p>

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<p style="text-align: center;"><b>Autism</b> Autism Wales</p> 	<p><b>Autism Wales</b> (previously known as ASDInfoWales) belongs to and is operated by the National Autism Team.</p> <p>Autism Wales provides information and resources for individuals of all ages with autism, as well as information and resources for families, carers and professionals supporting people with autism.</p>	<p><b>Telephone:</b> 07469 485 643</p> <p><b>Postal address:</b> Not available. See website.</p> <p><b>Email address:</b> <a href="mailto:AutismWales@WLGa.gov.uk">AutismWales@WLGa.gov.uk</a></p> <p><b>Website:</b> <a href="https://autismwales.org/en/">https://autismwales.org/en/</a></p>
<p style="text-align: center;"><b>Bardet-Biedl Syndrome</b> Bardet-Biedl Syndrome UK</p> 	<p><b>Bardet-Biedl Syndrome UK</b> provides information, advice and support from diagnosis through to living with the condition to people with Bardet-Biedl Syndrome, their families, and carers.</p>	<p><b>Telephone:</b> Not available. See website.</p> <p><b>Postal address:</b> 43 Balton Way, Dovercourt, Harwich, Essex, CO12 4UP</p> <p><b>Email address:</b> <a href="mailto:admin@bbsuk.org.uk">admin@bbsuk.org.uk</a></p> <p><b>Website:</b> <a href="http://www.bbsuk.org.uk/">www.bbsuk.org.uk/</a></p>

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<p><b>Blindness</b> Royal Society for Blind Children</p> 	<p>The <b>Royal Society for Blind Children</b> offers a range of services including emotional support and practical advice for families, opportunities for children and young people to build confidence and skills through activities, and a specialist further education college.</p>	<p><b>Telephone:</b> 02031 980 225</p> <p><b>Postal address:</b> RSBC, Life Without Limits Centre (LWLC), 10 Lower Thames Street, London, EC3R 6EN</p> <p><b>Email address:</b> <a href="mailto:connections@rsbc.org.uk">connections@rsbc.org.uk</a></p> <p><b>Website:</b> <a href="https://www.rsbc.org.uk/">https://www.rsbc.org.uk/</a></p>
<p><b>Brain conditions</b> Cerebra</p> 	<p><b>Cerebra</b> support children with a brain condition by offering advice and support on:</p> <ul style="list-style-type: none"> <li>• Education and transport</li> <li>• DLA and accessing public services</li> <li>• Getting some sleep</li> <li>• Stress and emotional wellbeing</li> <li>• Toilet training and continence</li> <li>• Managing behaviour</li> </ul>	<p><b>Telephone number:</b> 01267 244 200</p> <p><b>Postal address:</b> Cerebra, The MacGregor Office, Jolly Tar Lane, Carmarthen, SA31 3LW</p> <p><b>Email address:</b> <a href="mailto:enquiries@cerebra.org.uk">enquiries@cerebra.org.uk</a></p> <p><b>Website:</b> <a href="http://www.cerebra.org.uk/">www.cerebra.org.uk/</a></p>

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<p><b>Brain injury</b> Headway</p> 	<p><b>Headway</b> is a UK wide charity that works to improve the life after brain injury by providing information, support and resources for anyone affected by brain injury or a brain condition.</p>	<p><b>Telephone number:</b> 01159 240 800</p> <p><b>Postal address:</b> Headway, Bradbury House, 190 Bagnall Road, Old Basford, Nottingham, NG6 8SF</p> <p><b>Email address:</b> <a href="mailto:enquiries@headway.org.uk">enquiries@headway.org.uk</a></p> <p><b>Website:</b> <a href="https://www.headway.org.uk/">https://www.headway.org.uk/</a></p>
<p><b>Cardiomyopathy</b> Cardiomyopathy UK</p> 	<p><b>Cardiomyopathy UK</b> are the specialist national charity for people affected by cardiomyopathy, a condition that affects the heart muscle. Their vision is that everyone affected by cardiomyopathy should live a long and fulfilling life.</p>	<p><b>Telephone:</b> 01494 791 224</p> <p><b>Postal address:</b> Cardiomyopathy UK, 75a Woodside Road, Amersham, Buckinghamshire, HP6 6AA</p> <p><b>Email address:</b> <a href="mailto:contact@cardiomyopathy.org">contact@cardiomyopathy.org</a></p> <p><b>Website:</b> <a href="https://www.cardiomyopathy.org/">https://www.cardiomyopathy.org/</a></p>

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<p><b>Cerebral Palsy</b> CerebralPalsy.org.uk</p> 	<p><b>CerebralPalsy.org.uk</b> offer information and network resource, as well as signposting to the latest research and provides information for individuals with Cerebral Palsy.</p>	<p><b>Telephone:</b> Not available. See website.</p> <p><b>Postal address:</b> Not available. See website.</p> <p><b>Email address:</b> <a href="mailto:info@cerebralpalsy.org.uk">info@cerebralpalsy.org.uk</a></p> <p><b>Website:</b> <a href="http://www.cerebralpalsy.org.uk/">http://www.cerebralpalsy.org.uk/</a></p>
<p><b>Congenital Disorders of Glycosylation</b> CDG UK</p> 	<p><b>CDG UK</b> is the national charity supporting those affected by Congenital Disorders of Glycosylation (CDG). Partnered with the UK Genetic Disordered Partnership Network, they support UK patients and families.</p>	<p><b>Telephone:</b> Not available. See website.</p> <p><b>Postal address:</b> Not available. See website.</p> <p><b>Email address:</b> Not available. See website.</p> <p><b>Website:</b> <a href="https://cdg-uk.org/">https://cdg-uk.org/</a></p>

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<p><b>Cornelia de Lange Syndrome</b> CdLS Foundation UK &amp; Ireland</p>  <p><b>CdLS Foundation</b> UK &amp; Ireland</p>	<p><b>The CdLS Foundation UK &amp; Ireland</b> is a family support organisation which exists to ensure early and accurate diagnosis of CdLS throughout the world, promoting research, and enabling individuals, families, friends and professionals make informed decisions and plan for the affected person's present and future.</p>	<p><b>Telephone:</b> 01375 376 439</p> <p><b>Postal address:</b> CdLS Foundation UK &amp; Ireland, PO Box 8368, Ripley, Derbyshire, DE5 4DA</p> <p><b>Email address:</b> <a href="mailto:info@cdls.org.uk">info@cdls.org.uk</a></p> <p><b>Website:</b> <a href="http://www.cdls.org.uk/">http://www.cdls.org.uk/</a></p>
<p><b>Cri Du Chat</b> Cri Du Chat Support Group</p> 	<p><b>Cri Du Chat Support Group</b> provides information, grants and support from diagnosis, also run a link service via email for families to get support from each other as well as running family weekends.</p> <p>Registration is required in order to access their groups and information.</p>	<p><b>Telephone:</b> Not available. See website.</p> <p><b>Postal address:</b> Not available. See website.</p> <p><b>Email address:</b> <a href="mailto:office@criduchat.org.uk">office@criduchat.org.uk</a></p> <p><b>Website:</b> <a href="http://criduchat.org.uk/">http://criduchat.org.uk/</a></p>

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<p><b>Cystic Fibrosis</b> Cystic Fibrosis Care</p> 	<p><b>Cystic Fibrosis Care</b> supports people with Cystic Fibrosis, their families and specialist Cystic Fibrosis centres.</p> <p>They provide hardship and welfare grants, emotional support, essential medical and physio equipment, and fund the training of Cystic Fibrosis nurses.</p>	<p><b>Telephone:</b> Not available. See website.</p> <p><b>Postal address:</b> Cystic Fibrosis Care, Head Office, Westgarth, Snape, Bedale, North Yorkshire DL8 2TJ</p> <p><b>Email address:</b> <a href="mailto:contactus@cysticfibrosiscare.org.uk">contactus@cysticfibrosiscare.org.uk</a></p> <p><b>Website:</b> <a href="http://www.cysticfibrosiscare.org.uk/">www.cysticfibrosiscare.org.uk/</a></p>
<p><b>DeafBlind</b> DeafBlind UK</p> 	<p><b>DeafBlind UK</b> provide practical help, emotional support, help with technology, information, advice and even holidays to anyone who needs it for people living with sight and hearing loss.</p>	<p><b>Telephone number:</b> 0800 132 320</p> <p><b>Postal address:</b> Deafblind UK, 19 Paston Ridings, Peterborough, Cambridgeshire, PE4 7UP</p> <p><b>Email address:</b> <a href="mailto:info@deafblind.org.uk">info@deafblind.org.uk</a></p> <p><b>Website</b> <a href="https://deafblind.org.uk/">https://deafblind.org.uk/</a></p>

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<p style="text-align: center;"><b>Deafblind Sense</b></p> 	<p><b>Sense</b> helps people communicate and experience the world, no matter how complex their disabilities by offering advice, short breaks and information.</p>	<p><b>Telephone number:</b> 03003 309 280</p> <p><b>Postal address:</b> SENSE, Caerphilly Business Park, Van Road, Caerphilly, CF83 3ED</p> <p><b>Email address:</b> <a href="mailto:info@sense.org.uk">info@sense.org.uk</a></p> <p><b>Website</b> <a href="https://www.sense.org.uk/places/sense-cymru-wales/">https://www.sense.org.uk/places/sense-cymru-wales/</a></p>
<p style="text-align: center;"><b>Deafness National Deaf Children's Society</b></p> 	<p><b>National Deaf Children's Society</b> offer up to date information, family support and workshops, events and campaigning for the rights of deaf children.</p>	<p><b>Telephone:</b> 02074 908 656</p> <p><b>Postal address:</b> National Deaf Children's Society, 2 South, Ty- Nant Court, Morganstown, Cardiff CF15 8LW</p> <p><b>Email address:</b> <a href="mailto:ndcswales@ndcs.org.uk">ndcswales@ndcs.org.uk</a></p> <p><b>Website:</b> <a href="https://www.ndcs.org.uk/">https://www.ndcs.org.uk/</a></p>

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<p>DiGeorge Syndrome Max Appeal</p> 	<p><b>Max Appeal</b> provides support, events, resources and information for families affected by DiGeorge Syndrome (22q11.2 deletion). They also conduct research to expand knowledge of the condition.</p>	<p><b>Telephone:</b> 03009 992 211</p> <p><b>Postal address:</b> 15 Meriden Avenue, Stourbridge, West Midlands, DY8 4QN</p> <p><b>Email address:</b> <a href="mailto:info@maxappeal.org.uk">info@maxappeal.org.uk</a></p> <p><b>Website:</b> <a href="https://www.maxappeal.org.uk/">https://www.maxappeal.org.uk/</a></p>
<p>Down's Syndrome Down's Syndrome Association</p> 	<p><b>Down's Syndrome Association</b> provides information, support, advice, and advocacy for people and families with Down Syndrome. Also run local groups across UK.</p>	<p><b>Telephone:</b> 03331 212 300</p> <p><b>Postal address:</b> Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex, TW11 9PS</p> <p><b>Email address:</b> <a href="mailto:info@downs-syndrome.org.uk">info@downs-syndrome.org.uk</a></p> <p><b>Website:</b> <a href="https://www.downs-syndrome.org.uk/">https://www.downs-syndrome.org.uk/</a></p>

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<p><b>Dravet Syndrome</b> Dravet Syndrome UK</p> 	<p><b>Dravet Syndrome UK</b> are dedicated to improving the lives of those affected by Dravet Syndrome through support, education and medical research.</p>	<p><b>Telephone number:</b> 01246 912 421</p> <p><b>Postal address:</b> Dravet Syndrome UK, PO Box 756, Chesterfield, S43 9EB</p> <p><b>Email address:</b> <a href="mailto:info@dravet.org.uk">info@dravet.org.uk</a></p> <p><b>Website:</b> <a href="https://www.dravet.org.uk/">https://www.dravet.org.uk/</a></p>
<p><b>Duchenne muscular dystrophy</b> Duchenne UK</p> 	<p><b>Duchenne UK</b> are the UK's leading Duchenne muscular dystrophy (DMD) charity. They're connecting scientists, industry, the NHS and families to accelerate research and bring the best care and treatments to everyone affected by DMD.</p>	<p><b>Telephone:</b> Not available. See website.</p> <p><b>Postal address:</b> Duchenne UK, Unit G20, Shepherd's Building Charecroft Way, Hammersmith, W14 0EE</p> <p><b>Email address:</b> Not available. See website.</p> <p><b>Website:</b> <a href="https://www.duchenneuk.org/">https://www.duchenneuk.org/</a></p>

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<p>Dwarfism Little People UK</p> 	<p><b>Little People UK</b> website aims to be an invaluable resource to the dwarfism community, their friends and families. You can find out about the LPUK committee, along with all of their policies via the About Us pages.</p>	<p><b>Telephone:</b> 07925 893 398</p> <p><b>Postal address:</b> Little People UK, P.O Box 1292, Peterborough, PE2 2NT</p> <p><b>Email address:</b> <a href="mailto:info@littlepeopleuk.org">info@littlepeopleuk.org</a></p> <p><b>Website:</b> <a href="https://littlepeopleuk.org/">https://littlepeopleuk.org/</a></p>
<p>Dyslexia British Dyslexia Association</p> 	<p><b>British Dyslexia Association</b> provide impartial and objective advice and support to dyslexic people and those with whom they come into contact. They do this by raising awareness, promoting understanding and empowering people.</p>	<p><b>Telephone:</b> 0333 4054 555</p> <p><b>Postal address:</b> The British Dyslexia Association, Office 205 Access Business Centre, Willoughby Road, Bracknell, RG12 8FB</p> <p><b>Email address:</b> Not available. See website.</p> <p><b>Website:</b> <a href="https://www.bdadyslexia.org.uk/">https://www.bdadyslexia.org.uk/</a></p>

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<p><b>Ehlers-Danlos Syndromes &amp; Hypermobility Spectrum Disorders</b> The Ehlers-Danlos Society</p> 	<p>The <b>Ehlers-Danlos Society</b> is a global organization dedicated to advancing and accelerating research and education in Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD).</p> <p>They support the development of effective and equitable EDS and HSD therapies and work collaboratively to improve the lives of individuals affected by EDS and HSD.</p>	<p><b>Telephone:</b> 02038 876 132</p> <p><b>Postal address:</b> The Ehlers-Danlos Society, Office 7, 35-37 Ludgate Hill, London, EC4M 7JN</p> <p><b>Email address:</b> Not available. See website.</p> <p><b>Website:</b> <a href="https://www.ehlers-danlos.com/">https://www.ehlers-danlos.com/</a></p>
<p><b>Epilepsy</b> Epilepsy Action Cymru</p> 	<p><b>Epilepsy Action Cymru</b> support individuals with epilepsy by providing support and information, events and awareness training. They also advocate for people with epilepsy by lobbying and campaigning.</p>	<p><b>Telephone:</b> 01132 108 800</p> <p><b>Postal address:</b> New Anstey House, Gate Way Drive, Yeadon, Leeds, LS19 7XY</p> <p><b>Email address:</b> <a href="mailto:epilepsy@epilepsy.org.uk">epilepsy@epilepsy.org.uk</a></p> <p><b>Website:</b> <a href="https://www.epilepsy.org.uk/support-for-you/epilepsy-action-cymru-wales">https://www.epilepsy.org.uk/support-for-you/epilepsy-action-cymru-wales</a></p>

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<p><b>Foetal Alcohol Syndrome</b> National Organisation for FASD</p> 	<p><b>National Organisation for FASD</b> is dedicated to supporting people affected by Foetal Alcohol Spectrum Disorders (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy. The organisation is a source for information on FASD to the general public, press and to medical and educational professionals.</p>	<p><b>Telephone:</b> 02084 585 951</p> <p><b>Postal address:</b> The Priory, High Street, Ware, Hertfordshire, SG12 9AL</p> <p><b>Email address:</b> <a href="mailto:info@nationalfasd.org.uk">info@nationalfasd.org.uk</a></p> <p><b>Website:</b> <a href="https://nationalfasd.org.uk/">https://nationalfasd.org.uk/</a></p>
<p><b>Fragile X</b> The Fragile X Society</p> 	<p><b>The Fragile X Society</b> aims to improve the lives of those affected by Fragile X and associated conditions by providing information and continued support to families and professionals they work with.</p> <p>Working together with those affected, the Society supports an inclusive community of people who understand the specific needs of Fragile X.</p>	<p><b>Telephone:</b> 01371 875 100</p> <p><b>Postal address:</b> The Fragile X Society, The Chestnuts, 4 Stortford Road, Great Dunmow, Essex, CM6 1DA</p> <p><b>Email address:</b> <a href="mailto:info@fragilex.org.uk">info@fragilex.org.uk</a></p> <p><b>Website:</b> <a href="https://www.fragilex.org.uk/">https://www.fragilex.org.uk/</a></p>

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<p><b>Genetic Disorders</b> Gene People</p> 	<p>Offers a counsellor lead helpline, and advice and support throughout the life of a young person with a genetic disorder. Offering advice on grants, understanding genetics, benefits.</p>	<p><b>Telephone:</b> 08009 878 987</p> <p><b>Postal address:</b> Gene People, Nightingale House, 46-48 East, Street, Epsom, Surrey, KT17 1HQ</p> <p><b>Email address:</b> <a href="mailto:hello@genepeople.org.uk">hello@genepeople.org.uk</a></p> <p><b>Website:</b> <a href="https://genepeople.org.uk/">https://genepeople.org.uk/</a></p>
<p><b>Kabuki Syndrome</b> Kabuki UK</p> 	<p><b>Kabuki UK</b> aim to raise awareness of this rare syndrome, provide advice and help to newly-diagnosed families and organise events that enable families all over the UK to share stories and have fun!</p>	<p><b>Telephone:</b> Not available. See website.</p> <p><b>Postal address:</b> Not available. See website.</p> <p><b>Email address:</b> Not available. See website.</p> <p><b>Website:</b> <a href="https://www.kabukiuk.org.uk/">https://www.kabukiuk.org.uk/</a></p>

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<p><b>Learning Disabilities</b> Mencap Cymru</p>  <p><b>mencap cymru</b> Llais anabledd dysgu The voice of learning disability</p>	<p><b>Mencap Cymru</b> are the Welsh branch of <b>Mencap</b>.</p> <p>Mencap provide information and support for people with learning disabilities and their families, ranging from health to housing, to education support and more.</p>	<p><b>Telephone:</b> 02920 747 588</p> <p><b>Postal address:</b> Ground Floor, Unit 4, Ty Pennant Mill Street, Pontypridd, Rhondda Cynon Taff, CF37 2SW</p> <p><b>Email address:</b> Not available. See website.</p> <p><b>Website:</b> <a href="https://wales.mencap.org.uk/">https://wales.mencap.org.uk/</a></p>
<p><b>Macular Disease</b> Macular Society</p>  <p><b>Macular Society</b> Beating Macular Disease</p>	<p><b>Macular Society's</b> vision is to beat macular disease through funding research, building scientific capacity, facilitating collaboration and communication and involving patients.</p> <p>They offer a helpline and information to support people diagnosed with macular disease, as well as those supporting them.</p>	<p><b>Telephone:</b> 03003 030 111</p> <p><b>Postal address:</b> Macular Society, PO Box 1870, Andover SP10 2BN</p> <p><b>Email address:</b> <a href="mailto:help@macularsociety.org">help@macularsociety.org</a></p> <p><b>Website:</b> <a href="https://www.macularsociety.org/">https://www.macularsociety.org/</a></p>

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<p>Mitochondrial Disease Charlie Gard Foundation</p> 	<p>The <b>Charlie Gard Foundation</b> aims to be the leading UK charity supporting children, adults and their families that have been affected by mitochondrial disease. They invest in pioneering research into viable treatments for mitochondrial diseases, and collaborate with professionals and experts from around the world to ensure we have every chance of finding that all elusive cure.</p>	<p><b>Telephone:</b></p> <p><b>Postal address:</b> The Charlie Gard Foundation, Commerce House, 1 Exchange Square, Middlesbrough, TS1 1DE</p> <p><b>Email address:</b> <a href="mailto:connie@thecharliegardenfoundation.org">connie@thecharliegardenfoundation.org</a></p> <p><b>Website:</b> <a href="https://thecharliegardenfoundation.org/">https://thecharliegardenfoundation.org/</a></p>
<p>Neurological conditions The Brain Charity</p> 	<p><b>The Brain Charity</b> provide information, advice and emotional support, to anyone with a neurological condition and their family, friends and carers.</p>	<p><b>Telephone number:</b> 01512 982 999</p> <p><b>Postal address:</b> The Brain Charity, Norton Street, Liverpool, L3 8LR</p> <p><b>Email address:</b> <a href="mailto:info@thebraincharity.org.uk">info@thebraincharity.org.uk</a></p> <p><b>Website</b> <a href="http://www.thebraincharity.org.uk/">www.thebraincharity.org.uk/</a></p>

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<p>PITT Hopkins PITT Hopkins UK</p>  <p>Pitt Hopkins UK</p>	<p><b>Pitt Hopkins UK</b> is dedicated to supporting the Pitt Hopkins community by raising awareness of the condition amongst health professionals, to support and advocate for families, encourage research into the condition and to connect with families via social media.</p>	<p><b>Telephone:</b> 02032 392 123</p> <p><b>Postal address:</b> Not available. See website.</p> <p><b>Email address:</b> <a href="mailto:sue@pitthopkins.org.uk">sue@pitthopkins.org.uk</a></p> <p><b>Website:</b> <a href="https://pitthopkins.org.uk/">https://pitthopkins.org.uk/</a></p>
<p>Prada Willi Syndrome PWSA UK</p>  <p>PWSA UK PRADER-WILLI SYNDROME ASSOCIATION UK</p>	<p><b>Prada Willi Syndrome Association UK</b> offer a wide range of information and support to help families and professionals manage the complexities of Prader-Willi syndrome</p>	<p><b>Telephone:</b> 01332 365 676</p> <p><b>Postal address:</b> C/O Metcalf's Commercial Decorators, 3 Deer Park Road, Moulton Park, Northampton, NN3 6RX</p> <p><b>Email address:</b> <a href="mailto:admin@pwsa.co.uk">admin@pwsa.co.uk</a></p> <p><b>Website:</b> <a href="https://www.pwsa.co.uk/">https://www.pwsa.co.uk/</a></p>

Condition and Service	Description of service provider	Contact information
<p><b>Rett Syndrome</b> Rett UK</p> 	<p><b>Rett UK</b> is the only UK charity that provides professional support to people living with Rett syndrome across the UK. They provide support by offering family support services, activities and events – As well as educate health, social care and education professionals about the condition.</p>	<p><b>Telephone:</b> 01582 798 910</p> <p><b>Postal address:</b> Rett UK, Victory House, Chobham Street, Luton, LU1 3BS</p> <p><b>Email address:</b> <a href="mailto:info@rettuk.org">info@rettuk.org</a></p> <p><b>Website:</b> <a href="https://www.rettuk.org/">https://www.rettuk.org/</a></p>
<p><b>Scoliosis</b> Scoliosis Association</p> 	<p><b>Scoliosis Association UK</b> is the only UK wide patient support organisation for people with scoliosis and their families.</p> <p>Their aim is to provide advice, support, and information to people affected by scoliosis and their families and raise awareness of scoliosis among health professionals and the general public.</p>	<p><b>Telephone:</b> 02089 641 166</p> <p><b>Postal address:</b> The Scoliosis Association UK, 4 Ivebury Court, 325 Latimer Road, London, W10 6RA</p> <p><b>Email address:</b> <a href="mailto:info@sauk.org.uk">info@sauk.org.uk</a></p> <p><b>Website:</b> <a href="https://sauk.org.uk/">https://sauk.org.uk/</a></p>

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<p><b>Sight loss</b> RNIB Cymru</p> 	<p><b>RNIB (Royal National Institute of Blind People) Cymru</b> is the UK's leading sight loss charity. They offer practical and emotional support to blind and partially sighted people, their families and carers.</p>	<p><b>Telephone:</b> 03031 239 999</p> <p><b>Postal address:</b> RNIB, The Grimaldi Building, 154a Pentonville Road, London, N1 9JE</p> <p><b>Email address:</b> <a href="mailto:helpline@rnib.org.uk">helpline@rnib.org.uk</a></p> <p><b>Website:</b> <a href="https://www.rnib.org.uk/nations/walescymru/">https://www.rnib.org.uk/nations/walescymru/</a></p>
<p><b>Spina Bifida &amp; Hydrocephalus</b> Shine</p> 	<p><b>Shine</b> provides specialist support from before birth and throughout the life of anyone living with spina bifida and/or hydrocephalus, as well as to parents, families, carers and professional care staff.</p>	<p><b>Telephone:</b> 01733 555 988</p> <p><b>Postal address:</b> Unit 4 - The Forum, Minerva Business Park, Peterborough, PE2 6FT</p> <p><b>Email address:</b> <a href="mailto:firstcontact@shinecharity.org.uk">firstcontact@shinecharity.org.uk</a></p> <p><b>Website:</b> <a href="https://www.shinecharity.org.uk/">https://www.shinecharity.org.uk/</a></p>

Condition and Service	Description of service provider	Contact information
<p>Tourette's syndrome Tourette's Action</p> 	<p><b>Tourette's Action</b> works in England, Wales and Northern Ireland and is the leading support and research charity for people with Tourette Syndrome and their families.</p> <p>Their mission is for people with Tourette's syndrome to receive the practical support and social acceptance they need to help them live their lives to the full.</p>	<p><b>Telephone:</b> Not available. See website.</p> <p><b>Postal address:</b> Tourette Syndrome Association, The Meads Business Centre, 19 Kingsmead, Farnborough, Hampshire, GU14 7SR</p> <p><b>Email address:</b> <a href="mailto:help@tourettes-action.org.uk">help@tourettes-action.org.uk</a></p> <p><b>Website:</b> <a href="https://www.tourettes-action.org.uk/">https://www.tourettes-action.org.uk/</a></p>
<p>Turners Syndrome Turners Syndrome Support Society</p> 	<p>The <b>Turners Syndrome Support Society (TSSS)</b> provides up-to-date information on Turner Syndrome and the many aspects of living with the condition on a daily basis.</p>	<p><b>Telephone number:</b> 01419 528 006</p> <p><b>Postal address:</b> 12 Simpson Court, 11 South Avenue, Clydebank Business Park, Clydebank, G81 2NR</p> <p><b>Email address:</b> <a href="mailto:turner.syndrome@tss.org.uk">turner.syndrome@tss.org.uk</a></p> <p><b>Website:</b> <a href="https://tss.org.uk/">https://tss.org.uk/</a></p>

Condition and Service	Description of service provider	Contact information
<p>Undiagnosed syndromes SWAN UK</p> 	<p><b>SWAN UK (syndromes without a name)</b> is the only dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK. It is run by the charity Genetic Alliance UK</p>	<p><b>Telephone:</b> 03001 240 441</p> <p><b>Postal address:</b> SWAN UK, Creative Works, 7 Blackhorse Lane, London, E17 6DS</p> <p><b>Email address:</b> <a href="mailto:info@undiagnosed.org.uk">info@undiagnosed.org.uk</a></p> <p><b>Website:</b> <a href="http://www.undiagnosed.org.uk">www.undiagnosed.org.uk</a></p>
<p>Vascular Ehlers-Danlos Syndrome Annabelle's Challenge</p> 	<p><b>Annabelle's Challenge</b> is the leading charity for Vascular Ehlers-Danlos syndrome (vascular EDS) in the UK.</p> <p>They offer support groups and information for individuals and families affected by Vascular EDS.</p>	<p><b>Telephone:</b> 01617 974 746</p> <p><b>Postal address:</b> Annabelle's Challenge, Walshaw Park House, Walshaw Road, Bury, BL8 1PY</p> <p><b>Email address:</b> <a href="mailto:info@annabelleschallenge.org">info@annabelleschallenge.org</a></p> <p><b>Website:</b> <a href="https://www.annabelleschallenge.org/">https://www.annabelleschallenge.org/</a></p>

Condition and Service	Description of service provider	Contact information
<p><b>Williams Syndrome</b> The Williams Syndrome Foundation</p> 	<p><b>The Williams Syndrome Foundation</b> offer support, information and advisory services, as well as organise regular online and national and local gatherings for families.</p>	<p><b>Telephone:</b> 02085 671 374</p> <p><b>Postal address:</b> Williams Syndrome Foundation, Box 103, Charter House, Lord Montgomery Way, Portsmouth, PO1 2SN</p> <p><b>Email address:</b> <a href="mailto:enquiries@williams-syndrome.org.uk">enquiries@williams-syndrome.org.uk</a></p> <p><b>Website:</b> <a href="https://williams-syndrome.org.uk/">https://williams-syndrome.org.uk/</a></p>