



Contact information for support organisations


















Support (For families of deaf children and young people ages 0+)

Condition Website/Phone number/Email	National Organisation	Condition Website/Phone number/Email	National Organisation
CHED/Harboyan Syndrome www.ndcs.org.uk 0808 800 8880 helpline@ndcs.org.uk	 National Deaf Children's Society	Microtia www.microtiauk.org info@microtia.org	 Microtia UK
Charge Syndrome chargesyndrome.org.uk 020 8265 3604 si_howard@hotmail.com	 CHARGE Family Support Group	Pendred Syndrome www.ndcs.org.uk 0808 800 8880 helpline@ndcs.org.uk	 National Deaf Children's Society
Connexin 26/DFNB1 www.ndcs.org.uk 0808 800 8880 helpline@ndcs.org.uk	 National Deaf Children's Society	Retrocochlear www.cochlear.com/uk +44 (0) 1932 263 600 www.cochlear.com/uk/contact/contact-us	 Hear now. And always. Cochlear®
EAST Syndrome (SeSAME) www.ndcs.org.uk 0808 800 8880 helpline@ndcs.org.uk	 National Deaf Children's Society	Tinnitus www.tinnitus.org.uk 0800 018 0527 helpline@tinnitus.org.uk	 TINNITUS
Enlarged vestibular aqueducts syndrome www.ndcs.org.uk 0808 800 8880 helpline@ndcs.org.uk	 National Deaf Children's Society	Ushers syndrome www.usherkidsuk.com	 Usher Kids UK
Eustachian tube dysfunction www.ndcs.org.uk 0808 800 8880 helpline@ndcs.org.uk	 National Deaf Children's Society	Waardenburg www.mdjunction.com/waardenburg-syndrome	
		Wolfram's syndrome www.wolframsyndrome.co.uk 01903 211358 admin@wolframsyndrome.co.uk	 WOLFRAM SYNDROME UK Inform, Support, CURE

Support groups for families of children and young people with vision impairment ages 0+

Condition Website/Phone number/Email	National Organisation	Condition Website/Phone number/Email	National Organisation
Albinism www.albinism.org.uk 01282 771 900 support@albinism.org.uk	 albinism Fellowship	Bi-lateral pseudophakia www.rnib.org.uk / 0303 123 9999	 RNIB
Alstrom Syndrome www.alstrom.org.uk 07970 071675 info@alstrom.org.uk	 Alström Syndrome UK	Bi-lateral ptosis www.rnib.org.uk 0303 123 9999	 RNIB
ANOPHTHALMIA www.macs.org.uk 0800 169 8088 enquiries@macs.org.uk	 MACS	Bi-lateral subluxed lenses www.rnib.org.uk 0303 123 9999	 RNIB
Aniridia https://aniridia.org.uk 07792 867 949 info@aniridia.org.uk	 Aniridia Network UK	Cataracts www.childhoodcataracts.org.uk membership@childhoodcataracts.org.uk	
Bardet-Biedl Syndrome www.lmbbs.org.uk 01604 492916 info@bbsuk.org	 BBS UK Bardet-Biedl Syndrome UK	Coloboma www.macs.org.uk 0800 169 8088 enquiries@macs.org.uk	 MACS
Batten Disease www.bdfa-uk.org.uk 0800 046 9832 support@bdfa-uk.org.uk	 BDFUK	Cornelia de lange syndrome www.cdls.org.uk 01375 376439 info@cdls.org.uk	 www.cdls.org.uk

Regulars

Condition Website/Phone number/Email	National Organisation	Condition Website/Phone number/Email	National Organisation
CVI www.cvisociety.org.uk		Retinitis pigmentosa www.rpfightingblindness.org.uk 0845 123 2354 info@rpfightingblindness.org.uk	
Field Loss www.rnib.org.uk 0303 123 9999		Retinoblastoma www.rpfightingblindness.org.uk 0845 123 2354 info@rpfightingblindness.org.uk	
Glaucoma www.glaucoma-association.com 01233 648170 info@iga.org.uk	 The Charity for People with Glaucoma Established 1974	Rod-cone dystrophy www.rpfightingblindness.org.uk 0845 123 2354 info@rpfightingblindness.org.uk	
Haemanopia www.rnib.org.uk 0303 123 9999		ROP (retinopathy of prematurity) www.rnib.org.uk 0303 123 9999	
Marfan syndrome www.marfan-association.org.uk 01252 810 472 contactus@marfan-association.org.uk		Septo-optic dysplasia www.magicfoundation.org/Growth-Disorders/Septo-Optic-Dysplasia	
Microphthalmus www.macs.org.uk 0800 169 8088 enquiries@macs.org.uk		Stargardt's www.macularsociety.org 0300 3030 111 info@macularsociety.org	
Nystagmus www.nystagmusnet.org 0845 634 2630 info@nystagmusnet.org		Strabismus www.rnib.org.uk 0303 123 9999	
Ocular albinism www.albinism.org.uk 01282 771 900 support@albinism.org.uk		Sturge weber www.sturgeweber.org.uk 01392 464 675 support@sturgeweber.org.uk	
Optic atrophy www.rnib.org.uk 0303 123 9999		Ushers syndrome www.usherkidsuk.com	
Optic nerve hypoplasia www.rnib.org.uk/ 0303 123 9999		Visual processing difficulties www.rnib.org.uk 0303 123 9999	
Convergent squints www.rnib.org.uk 0303 123 9999		Wolfram's syndrome www.wolframsyndrome.co.uk 01903 211358 admin@wolframsyndrome.co.uk	
Reduced vision www.rnib.org.uk 0303 123 9999		Visual impairment or recognised eye condition (Devon) www.moovision.org 01752 892058 info@moovision.org	
Retinal dystrophy www.rnib.org.uk 0303 123 9999			

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Inspirational role models

The Ling-Madell-Hewitt
(LMH) Test Battery

My first memories of
being deaf

Working with and
learning from families

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