

Nystagmus Information Pack



Part 6. Useful contacts, sources
of information and support

USEFUL CONTACTS AND SOURCES OF INFORMATION

Albinism	www.albinism.org.uk
American Nystagmus Network	www.nystagmus.org
British and Irish Orthoptic Society (BIOS)	https://www.orthoptics.org.uk/
British Blind Sport	www.britishblindsport.org.uk
British Society of Audiology (BSA) Balance Interest Group	<p>Audiology is the profession concerned with hearing and balance. Within the British Society of Audiology there is a Balance Interest Group</p> <p>http://www.thebsa.org.uk/bsa-groups/group-bi/</p>
<p>Education (SEN & EHC)</p> <p>Specific information relating to education and special educational needs</p>	<p>SEN area of the website https://www.gov.uk/topic/schools-colleges-childrens-services/special-educational-needs-disabilities</p> <p>Children with SEN area of the website https://www.gov.uk/children-with-special-educational-needs</p>



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Employment and access to work	Access to Work Team 0345 268 8489 https://www.gov.uk/access-to-work/overview
Guide Dogs	http://www.guidedogs.org.uk/
IN-Vision	www.in-vision.org.uk  @INvision_Buzz
Independent Parental Special Education Advice (IPSEA)	www.ipsea.org.uk Advice line on 0800 018 4016
Leber's congenital amaurosis (LCA)	facebook support group for parents and individuals with LCA  LebersCongenitalAmaurosis SupportGroup
LOOK	www.look-uk.org/ Helpline 01214507754 information@look-uk.org
Ménière's Society	A charity for people with dizziness and balance disorders of vestibular origin



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	www.menieres.org.uk
National Institute for Health and Care Excellence (NICE)	https://www.nice.org.uk/guidance guidance on 'tenotomy of horizontal eye muscles for nystagmus (with reattachment at their original insertions)' https://www.nice.org.uk/guidance/ig299/informationforpublic
Nystagmus Network (NN)	www.nystagmusnetwork.org  NystagmusNetwork/  @press_nystagmus
Royal College of Ophthalmologists	https://www.rcophth.ac.uk/patients/
Royal National Institute Of Blind People (RNIB)	www.rnib.org.uk Helpline 0303 123 999 Email helpline@rnib.org.uk
Sightline Directory	www.sightlinedirectory.org.uk
VICTA	http://www.victa.org.uk/



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	<p>Helpline 01908 240831</p> <p> VICTAChildren</p> <p> @VICTAchildren</p>
Visionary	www.visionary.org.uk
<p>Wobbly Wednesday</p> <p>Nystagmus awareness day led by Nystagmus Network</p>	http://nystagmusnetwork.org/fundraise/wobbly-wednesday/
<p>You Tube</p> <p>“The Way We See It” a video developed by Nystagmus Network.</p>	<p>It is presented by individuals with nystagmus discussing school, university, employment, driving, sport and being the parent of child with nystagmus. Available at www.youtube.com/watch?v=Ey-UD5Vzu_Q</p>

SUPPORT

Nystagmus Network (NN) – a charity that aims to provide support and fund research into nystagmus. NN provides support and information to individuals with nystagmus, their parents, families, friends and teachers. Their website contains useful booklets regarding nystagmus, adaptations and support for nystagmus and leaflets for teachers. Current events, updates, campaigns and peer



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support are available via their website, facebook page, twitter feed, telephone helpline or email support. They can help with issues such as education, employment, discrimination and benefits as well as providing an advocacy service to help ensure your rights are upheld and you receive the support you are entitled to live an independent lifestyle.

IN-Vision – a patient led charity aiming to find a cure for infantile nystagmus. “In Vision” provides lots of information regarding current research into nystagmus, its causes and treatments as well as an in depth resources guide for equipment, low vision aids and education guides. If you would like to participate in future research projects, IN-Vision is compiling a secure, private database where you can register your interest.

Royal National Institute Of Blind People (RNIB) – a charity that provides services and support for individuals and families/carers of individuals with impaired vision. Specialist services such as an eye health information service, advice service, and legal rights service, sight loss counselling team, talking books service and digital skills training can be accessed by contacting them via their helpline or by email. The “connect” service helps you to meet people with similar experiences to you, to share your experiences and find solutions to the difficulties you may be facing. Connect provides opportunities for telephone group chat or online chat to find out more about local activities and services in your area. The charity ‘Action for Blind People’ has merged with RNIB.

LOOK – a charity that provides help, support and services for visually impaired children and their families and carers. Their helpline provides practical advice, emotional support and information regarding different eye conditions. Their website has links to youth



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groups and parent groups across the UK. They run regular events as part of youth projects, such as confidence building weekends and dance events. OutLOOK audio magazine is written and produced by children and young people with visual impairment and looks at different aspects of growing up with a visual impairment.

VICTA - VICTA supports children and young people who are sight impaired or severely sight impaired and their families. Across the UK, they provide a range of activities to improve emotional, social and living skills. Throughout the year, they organise many different events to socialise, have fun and travel. Activities such as annual family weekends for parents with workshops and organised activities, early years weekends for families with children under 5 years, youth weekends for young people aged 18 to 29 with activities such as canoeing, surfing and indoor skydiving to build confidence are available. Family days and activities in a range of locations such as zoos, museums and theatres bring together families and their children.

Guide Dogs - This charity aims to deliver a guide dog service and other mobility services for people who are sight impaired or severely sight impaired. The charity 'Blind Children UK' has merged with Guide Dogs, to help expand the services available to children with sight impairment.

Sightline Directory – a very useful directory aimed at helping sight impaired or severely sight impaired people to find services in their local area.

Local charities and support groups - as well as national charities and support groups, there are also a wide range of local charities and groups available for people with sight impairment.



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British and Irish Orthoptic Society



Nystagmus Network

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Visionary – is a membership organisation for local sight loss charities and support groups. Helps you to get in contact with local societies and associations in your area for blind and partially sighted people.

Sensory impairment team – local councils provide a sensory impairment service that can advise and provide specialist equipment, group activities, emotional support and learning new skills.

Eye Clinic Liaison Officer (ECLO) – an ECLO is based in a hospital eye clinic and they support individuals with visual impairment to help them understand their diagnosis or eye condition. They offer help, support and advice on the emotional and practical aspects of life with a visual impairment, to both patients and their families. They help patients deal with their sight loss and maintain their independence.

Low vision support – depending on where you live, your low vision service may be provided within the hospital setting or in the community. Your eye care team will be able to advise you further and provide a referral when required.

A low vision assessment aims to provide advice, aids and strategies to help maximise vision. Equipment such as magnifiers, monoculars, lighting and technology are discussed; as are adaptations and strategies to help vision. Depending on your local low vision service, low vision aids may be loaned to you; along with advice and training in how to use them.



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