

## **The Albinism Fellowship**

The Albinism Fellowship offers support to people with Albinism. Their website includes links to other organisations and more information about the condition.

- Discussion forum
- Facebook page
- Magazine (Albinism Life)
- Events

Website: <http://www.albinism.org.uk>

Tel: 01282 771900

## **Alstrom Syndrome UK**

Support group for families affected by alstrom syndrome.

- Family support
- Annual family conference
- Information

Website: <http://www.alstrom.org.uk/>

Email: [info@alstrom.org.uk](mailto:info@alstrom.org.uk)

Tel: 07970 071675 or 01709 210151

## **The Aniridia Network UK**

The Aniridia Network supports families and people affected by Aniridia through:

- Email news and updates
- Email discussion group
- Facebook page
- Support for people with aniridia and their families.
- Information on aniridia and its associated conditions.
- An annual meeting

Website: <http://www.aniridia.org.uk/>

Email: [info@aniridia.org.uk](mailto:info@aniridia.org.uk)

Tel: 07792 867 949

## **The Brain Tumour Charity**

Support for those affected by brain tumours through:

- Telephone helpline
- Facebook page
- Information
- Regional support groups

Website:

<http://www.thebraintumourcharity.org/>

Email: [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

Tel: 0808 800 0004

## **The Cerebral Visual Impairment Society**

Providing a wealth of information and news on cerebral visual impairment (also known as cortical visual impairment or CVI).

Website: <http://www.cvisociety.org.uk/>

## **Little Bear Sees**

Website offering information and support for families with children affected by Cortical Visual Impairment (CVI).

Website: <http://www.littlebearses.org/>

## **The CHARGE Family Support Group**

Offering support to all those affected by CHARGE syndrome:

- Newsletters
- Social opportunities for families
- Discussion forums

Website: [www.chargesyndrome.org.uk](http://www.chargesyndrome.org.uk)

Email: [si\\_howard@hotmail.com](mailto:si_howard@hotmail.com)

Tel: 020 8265 3604

## **Childhood Cataract Network**

Providing information and support for parents of children with cataracts and young people with cataracts themselves through:

- Email support group
- Personal stories
- Medical information
- Regional parent-led support groups

Website:

<http://www.childhoodcataracts.org.uk/>

Email:

[membership@childhoodcataracts.org.uk](mailto:membership@childhoodcataracts.org.uk)

## **The Colour Blind Awareness Organisation**

Provides support for people living with colour blindness. Information is provided on the everyday problems experienced by colour blind people and advice is offered to parents and carers.

Website:

<http://www.colourblindawareness.org/>

Email: [info@colourblindawareness.org](mailto:info@colourblindawareness.org)



## **Deafblind International**

An international association which promotes the awareness and knowledge of deafblindness. Support provided to professionals, families and individuals with the aim of providing a good quality of life for children and adults of all ages who are deafblind.

Website:

<https://www.deafblindinternational.org/>

## **SENSE**

Open to deafblind people, their families and professionals working with deafblind people. Support includes:

- Information and advice
- Children's specialist services
- Family events
- Holidays
- Siblings network

Website: <http://www.sense.org.uk>

Email: [info@sense.org.uk](mailto:info@sense.org.uk)

Tel: 0300 330 9256

## **International Children's Anophthalmia and Microphthalmia Network (ICAN)**

Includes a parents' forum for discussion and shared stories as well as an email information list.

Website: [www.anophthalmia.org](http://www.anophthalmia.org)

Email: [info@anophthalmia.org](mailto:info@anophthalmia.org)

## **MACS (Microphthalmia, Anophthalmia Childrens Society)**

MACS offer support and information to families and professionals affected by micro or anophthalmia. Macs provides a regular newsletter, can help to put families in touch with one another and organises family weekends.

Website: <http://www.macs.org.uk/>

Email: [enquiries@macs.org.uk](mailto:enquiries@macs.org.uk)

Tel: 0800 169 8088

## **International Glaucoma Association**

Providing information and support through

- Information leaflets
- Newsletters
- Discussion forum
- Information on regional support groups

Website: <https://glaucoma.uk/>

Email: [sightline@iga.org.uk](mailto:sightline@iga.org.uk)

Tel: 01233 648170

## **Keratoconus Self Help and Support Association**

Support includes:

- Information
- Newsletters
- Discussion forum for those with keratoconus and their families

Website: <http://www.keratoconus-group.org.uk/>

Email: [anne@keratoconus-group.org.uk](mailto:anne@keratoconus-group.org.uk)

Tel: 020 8993 4759

**Laurence-Moon-Bardet-Biedl Society  
(LMBBS)/Bardet-Biedl Society (BBS)  
UK**

Support for people with LMBB, their  
families, friends and carers:

Website: <http://www.lmbbs.org.uk/>

Email: [info@bbsuk.org.uk](mailto:info@bbsuk.org.uk)

Tel: 01604 492916

## **Macular Disease Society**

Supporting individuals, and their families, who suffer from any condition which is encompassed by the phrase 'macular disease'. Support includes:

- Telephone counselling service
- Helpline
- Discussion forum
- Regional groups

Website:

<https://www.macularsociety.org/contact>

Email: [help@macularsociety.org](mailto:help@macularsociety.org)

Tel: 0300 3030 111

## **The Neuro Foundation:**

Providing help for those affected by Neurofibromatosis including:

- information leaflets
- case studies
- specialist advisors
- telephone helpline
- regional groups

Website: <https://nervetumours.org.uk/>

Tel: 07939 046030

## **Nystagmus Network**

Supporting those affected by Nystagmus through:

- Telephone helpline
- Meetings and events
- Newsletters
- Discussion forum

Website:

<http://www.nystagmusnetwork.org>

Email: [info@nystagmusnet.org](mailto:info@nystagmusnet.org)

Tel: 01427 718093



## **Retina UK (previously RP Fighting Blindness)**

Support and information available via:

- Helpline
- Local branches
- Facebook pages
- Youth RP website

Website:

<https://retinauk.org.uk/information-support/retina-uk-helpline/>

Email: [helpline@retinauk.org.uk](mailto:helpline@retinauk.org.uk)

Tel: 0300 111 4000 (Helpline)