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Nystagmus network

Organisation details

Description of activity

The Nystagmus Network is a registered charity in England and Wales supporting people living with nystagmus. Nystagmus is a complex eye condition, characterised by involuntary movements of the eye. The eyes appear to wobble or flicker from side to side, up and down or round and round. Nystagmus causes impaired vision, affecting the ability to focus, speed and depth perception and facial recognition. At least 1 in 1,000 people are born with nystagmus and many more acquire the condition later in life.

The charity was founded in 1984 by Vivien Jones after her son was diagnosed with nystagmus when he was three months old. It has grown exponentially from very humble beginnings to the hi-tech digital online presence of today. The Nystagmus Network provides support and information, promotes a better understanding of nystagmus through an annual Nystagmus Awareness Day on 20 June and throughout the year and funds research to find effective treatments. Through its support services, the Nystagmus Network ensures that, following diagnosis, there is somewhere for a family to turn to.

Contact

Website: www.nystagmusnetwork.org

Email: info@nystagmusnet.org

Tel: 01427 718093

Address: 70 Hyde Vale London SE10 8HP

Social media

Linkedin: [Linkedin.com/nystagmusnetwork](https://www.linkedin.com/company/nystagmusnetwork)

Twitter: [Twitter.com/NystagmusUK](https://twitter.com/NystagmusUK)

Facebook: [Facebook.com/NystagmusNetwork](https://www.facebook.com/NystagmusNetwork)

Instagram: [Instagram/NystagmusNetwork](https://www.instagram.com/NystagmusNetwork)

Nystagmus Awareness Day - 20 June

Thanks

Contact details

Contact name

Sue Ricketts

Telephone

01427718093

Email address

info@nystagmusnet.org

Website

<http://www.nystagmusnetwork.org>

Address details

Building name

Nystagmus Network

Address 1

70

Address 2

Hyde Vale

Town

London

County

London

Postcode

SE10 8HP

Accessibility**Accessible building**

N/A

Accessible toilets

N/A

Parking facilities

N/A

Dietary needs catered for

N/A

Staff have specialist training

Yes

Please enter any further details about your accessibility / specialist support

We operate a virtual service and have no physical premises however we have website support and information service and telephone helpline available,

Availability details**Days and times of activity / opening**

| | | | |
|------------------|-----------|---------|--------------------|
| Monday | from 0900 | to 1700 | telephone helpline |
| Tuesday | from 0900 | to 1700 | ditto |
| Wednesday | from 0900 | to 1700 | ditto |
| Thursday | from 0900 | to 1700 | ditto |
| Friday | from 0900 | to 1700 | ditto |

When is the activity or service available

All Year Round

How to access the service/activity

Drop-in / Turn-up |

Description of eligibility or referral criteria and pathways (if applicable)

We support all age groups free of charge. Self referral via telephone or email 24/7 support and advice on website 9-5 telephone support service

Does a parent / carer need to stay on premises during activity

No

Is there a cost for this service or activity

No

Taking part if you are a child or young person with additional needs or a disability.**How can a child or young person with SEND take part in this activity**

We provide support and assistance to children and young people, their carers and parents with Nystagmus. in addition, we offer an advocacy service and free 24/7 support on our website. telephone helpline and e mail facility is also available free of charge

Who to contact for more information about inclusion and accessibility**Name**

Sue Ricketts

Email address

info@nystagmusnet.org

Phone

01427718093

Age range

Age of users

From 0 years to 100 years

Additional useful information to download

File attachments

- Nystagmus Logo (Microsoft Office - OOXML - Word Document , 16.3 KB)

Location Map