

Nystagmus Awareness Day – 20 June 2020

Tuesday 2 June, 2020

It's national and international Nystagmus Awareness Day on Saturday 20 June 2020. We may all be staying at home this year, but we can still mark the day and raise awareness to ensure that the 1 in 1,000 adults and children living with nystagmus enjoys a greater understanding of their condition and a better quality of life as a result. Here are just some of the ways people can get involved.

How amazing are you?

In the lead up to the big day, the charity is running its 'how amazing are you?' campaign, sharing stories of adults and children who have achieved great things despite living with nystagmus, or maybe even because they do. These stories bring a great deal of hope and comfort to families where there is a new diagnosis of nystagmus. Anyone who has nystagmus can submit their story.

Our wobbly photography competition

We want to raise as much awareness of nystagmus as possible this year and make sure that everyone has a chance to take part, so we're running our wobbly photography competition: **The View From My Window**

We know that lots of people who have nystagmus are also keen photographers. Most notably, of course, is internationally acclaimed photographer, David Katz.

David revealed only in recent years, in his film "[Through my Lenses](#)" that he has ocular albinism and nystagmus and is actually registered blind. Nevertheless he has enjoyed a stellar career in photography and has created some of the [most iconic press images](#).

When the charity asked him to judge the competition, David said "I would be absolutely delighted and very honoured to judge the Nystagmus Network competition ... It has constantly amazed me since making my story public how many of us with VI are into photography."

Whether you have nystagmus or not, whether you have the latest camera or just a phone, and wherever you are in the world, you can take part.

Nystagmus is ...

The charity launches a brand new publication, **Nystagmus is ...**, inspired by 80 year old Roger, on Nystagmus Awareness Day 2020. The booklet is full of contributions from people, like Roger, who live with nystagmus, describing how they feel about it and how it affects their lives. For the first time people can read what it's really like to have nystagmus by the people who really know.

Nystagmus is ... will be available FREE from the charity's online shop from 20 June 2020.

Why do we need Nystagmus Awareness Day?

The Nystagmus Network raises awareness of the condition every single day of the year, because they believe that the more people who know about it the better. It means that adults and children who have nystagmus will get the help, support and services they need in education, employment, health, mobility and leisure to be able to lead a successful and independent life.

The charity's Information and Development Manager, Sue Ricketts says: "Holding a national and international **Nystagmus Awareness Day** serves as a reminder to everyone that the Nystagmus community is here and their voices need to be heard."

Every time someone takes part in **Nystagmus Awareness Day** or tells someone what they're doing and

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why, that's one more person who understands what nystagmus is.

Every pound raised or donated helps the Nystagmus Network support research teams across the UK to investigate this hugely complex condition, to find better diagnosis, treatments and continue to work towards prevention and cure.

Ends

Notes to editors

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Facebook: <https://www.facebook.com/NystagmusNetwork/>

Twitter: <https://twitter.com/NystagmusUK>

Images and logos available on request

Nystagmus is a serious, lifelong, incurable form of visual impairment where the eyes constantly move uncontrollably, affecting focus and depth perception. At least 1 in 1,000 babies are born with nystagmus. Many other people acquire nystagmus beyond infancy and into later life.

The **Nystagmus Network** is a registered charity in England and Wales, number 1180450. Our charitable objectives are to provide support and information, to raise awareness and to fund research.

Company Contact:

Contact Details Unavailable.

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Additional Assets: