"I'm Not Making This Up!" a new awareness campaign shines a light on nystagmus

Monday 1 June, 2026

"I'm Not Making This Up!" a new awareness campaign shines a light on nystagmus

The Nystagmus Network today launches its nystagmus Awareness Day 2026 campaign under the theme *"I'm Not Making This Up!"* The slogan is a rallying call for greater understanding of a relatively rare, complex and often invisible visual condition that affects around 2.4 in 1,000 adults and children.

Nystagmus is a little-understood condition that cannot be corrected with glasses or contact lenses. Yet one of the most common and painful experiences reported by people living with it is being disbelieved. People are told to "just get their eyes tested", accused of exaggerating or dismissed by professionals who have never encountered the condition before.

Why "I'm Not Making This Up!"?

The theme was chosen to give a direct voice to the nystagmus community. The staff team at the Nystagmus Network hear time and again from the people they support stories of them not being believed. Because the condition is not always visible to others and people who have it look pretty much the same as everyone else, many people spend years, sometimes even decades, trying to be believed and properly supported.

Sue Ricketts, Executive Information and Development Manager at the Nystagmus Network, said:

"People living with nystagmus are some of the most resilient people you will ever meet. They navigate a world that wasn't designed with their vision in mind and they do it every day. What they shouldn't have to do is fight to be believed on top of dealing with their impaired vision. That is what this campaign is about. We want to make sure this doesn't keep happening."

What is nystagmus?

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

Campaign Activities

Throughout Awareness Day, the Nystagmus Network will be running:

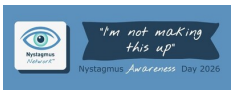
- A social media challenge inviting people to share their own "I'm not making this up!" moment using #ImNotMakingThisUp
- Training sessions for healthcare professionals, educators and employers
- A fundraising appeal to support the organisation's vital work across support, awareness and research

How to Get Involved

Visit https://nystagmusnetwork.org/awareness/ to read stories, take part in the campaign, and make a donation. Follow us using #ImNotMakingThisUp.

ENDS

Media:



Related Sectors:

Charities & non-profits :: Children & Teenagers :: Education & Human Resources :: Health ::

Related Keywords:

Nystagmus :: Vision :: Awareness :: Campaign :: Education :: Training :: Charity :: Support :: Condition :: Impairment :: Stories :: Congenital :: Acquired ::

Scan Me:

Company Contact:

Nystagmus Network

T. 01427718093
E. info@nystagmusnet.org
W. https://nystagmusnetwork.org/

View Online

Additional Assets:
https://nystagmusnetwork.org/awareness/

Newsroom: Visit our Newsroom for all the latest stories:
https://www.nystagmus-network.pressat.co.uk