Our vision is a world which welcomes people living with nystagmus, affords them comprehensive support and the opportunity to reach their full potential.

2025 TRUSTEES' ANNUAL REPORT

"This charity means a lot to us and with all the work they are doing the world is certainly a better place for our boy." – parent and fundraiser

NYSTAGMUS NETWORK

Nystagmus Network®
25 for '25

For more information visit us online at www.nystagmusnetwork.org or email us at info@nystagmusnet.org

"Thank you so much Nystagmus Network! My life would be lonelier and scarier without you." – person living with acquired nystagmus

A parent sitting in a garden with his child standing beside him on a bench.

ABOUT US

The Nystagmus Network is a registered charity in England and Wales providing support and information about nystagmus and its associated visual impairments.

The charity was established in 1984 and since then has been supporting people living with the condition and funding research, whilst also continuing to raise awareness of nystagmus.

Through the charity’s close relationship with the medical and scientific community we are driving more research, better patient care and signposting to sources of information and support.

TABLE OF CONTENTS

"I am very grateful for all the vital work the charity does and I am constantly guiding my patients to seek out and get in touch with you." – nystagmus clinician

Tim Cuddeford,
Chair of the
Nystagmus Network
trustees.

CHAIR'S MESSAGE

Sitting down to write my final report as chair of trustees I find there is much to reflect on. I first took up the baton from our former chair, the late Richard Wilson OBE in 2019.

Little did we know then what lay ahead of us: the Covid 19 pandemic, straightened financial times, increased global conflicts and inflation.

And yet we have rallied the storm. 2025 built on the success and celebration of our Ruby year and I am so pleased that, despite some financial headwinds in the charity sector, the Nystagmus Network has solid reserves and continues to deliver excellent support, fund research and raise awareness. Thanks to all our donors, grant givers and individual fundraisers with such varied efforts as running, knitting, raffles, walking, bungee jumping, swimming and, of course, baking. It's tremendous to see our investment in time and money into research continuing at pace. Over £36k in grants and nearly 200 people at the symposium is amazing.

As well as research, a key aspect of our work is to support members of our community. It's heartwarming to see that in 2025 we supported over 700 individuals through the helpline and emails and by way of nearly 3,000 downloads.

I would like to thank again all our members, supporters, fundraisers, trustees and staff for all their

It’s tremendous to see our investment in time and money into research continuing at pace.

hard work, ensuring success in 2025.

At the end of 2025 after 6 years as chair and 9 years as a trustee I will be standing down, knowing full well that I leave the charity in good hands. I wish all the best to every single member of our community for 2026 and beyond.

Tim Cuddeford

Tim Cuddeford
Chair of trustees 2019-2025

"We with nystagmus are better off due to your efforts; we are more informed and now more able to inform others." – adult with congenital nystagmus

Nystagmus Network trustees and staff hold up their charity banner.

"If it wasn’t for the Nystagmus Network we would still be clueless with limited support and feeling like the only family dealing with this condition." - a parent


GREAT
BRITAIN
2

TRUSTEES SERVING IN 2025

The Nystagmus Network is led by a committee of volunteer trustees. Each of them brings expertise to the table, whether from commerce, training, the law, employment, the charity sector, technology, medicine or finance. They all share a firm commitment to the nystagmus cause. Our recruitment process ensures equality, diversity and lived experience.

From the top row, left to right:

Vivien Jones MBE, Founder and Honorary President
Tim Cuddeford, Chair of Trustees, Chair of Finance and Governance
Peter Greenwood, Vice Chair of Trustees, Chair of Awareness
Vicky Pitman, Treasurer
Kathryn Swanston, Secretary
Harshal Kubavat, Chair of Research
Andrew McFarlane
Karen Chu, Chair of Funding
John Vekinis
Hannah Donnelly, Chair of Support
David Parfett
Anthony Blackman

The Nystagmus Network is celebrated as the ABDO* Eye Health Care Charity of the Month in January 2025

ABDO
14h ·

Eye Health Care Charity of the Month - Nystagmus Network

ABDO.ORG.UK
Eye Health Care Charity of the Month - ABDO
Nystagmus Network

*Association of British Dispensing Opticians

WHAT IS NYSTAGMUS?

Nystagmus is a complex eye condition characterised by involuntary movements of the eyes, where they appear to wobble or flicker.

Congenital nystagmus has a range of ophthalmological and neurological causes. It can also be a genetic condition. At least 1 in 1,000 babies in the UK are born with nystagmus.

Congenital, or infantile, nystagmus simply means that the condition is present in early infancy. An early diagnosis will ensure the family receives support.

Congenital nystagmus is a lifelong condition. The impact on vision varies greatly. Most people have reduced distance vision, need to be very close to print or a screen, their 3D vision may be compromised and they may struggle to recognise people. They may be registered sight impaired.

A child will learn to adapt and live with their nystagmus, but they may need support throughout their life.

Acquired nystagmus

Nystagmus which develops later in life is called acquired nystagmus. It is often associated with another health condition such as a stroke, multiple sclerosis, brain tumour, the effect of a drug or head injury.

Anything that damages the parts of the brain that control eye movements can result in acquired nystagmus.

Whereas in congenital nystagmus the brain seems to adapt to the eye movements, giving a generally still image, this is not usually the case with acquired nystagmus.

In cases of acquired nystagmus oscillopsia can occur, giving the impression that everything is moving. For this reason, the acquired form can sometimes be more disorienting and debilitating than congenital nystagmus.

Unfortunately, there is currently no effective cure or treatment for nystagmus of either kind, though optical, medical and surgical interventions are sometimes appropriate.

The Nystagmus Network funds research into diagnostics and therapies which could have a positive impact on quality of life as well as exploring prevention and, ultimately, cure.

"Many thanks for all your incredible advice as always." – a parent

"Thank you for your time and for providing so much helpful information."
– parent of adult with acquired nystagmus

SUPPORTING THE NYSTAGMUS COMMUNITY

The Nystagmus Network provides a wide range of support by phone, email, in person and online.

Online

We provide a safe space for a thriving virtual nystagmus community.

Events

We are proud to host big meet up events around the country.

Volunteers

We offer peer to peer support and a benefits advice service.

Documents

We provide free accessible guides to all aspects of life with nystagmus.

> **"It's so nice you have created this community. I feel so blessed to have found you. – attendee of our online get togethers**

SUPPORT COMMITTEE

709

PEOPLE SUPPORTED

> "My son got diagnosed with congenital nystagmus at 3 months old. It was a huge shock. Finding this network has helped me cope with his condition." – a parent overseas

Meeting the need

Throughout 2025 we continued to provide information and support in a wide range of ways and formats to our members and the wider nystagmus community.

Through emails and our telephone line, offering support to individuals and families continues to be very much at the heart of what we do and we have made investments into our resources to ensure we are able to meet demand and expand this offer.

Building our resources

Our website remains a vital resource of information and is packed with a variety of current advice and relevant information across a range of topics which continues to be used by the community and our members.

As we look to 2026, we are continuing to build on these resources and expand the selection of information available, ensuring everything is up to date and accurate for those accessing them. For example, we have spent the latter part of 2025 (with work continuing into 2026) on developing a parent friendly version of the Nystagmus Care Pathway, which will create a digestible document on what to expect when your child is going through a diagnosis of nystagmus. This project is kindly funded by a grant from **Jeans for Genes**.

Education matters

Sue once again attended the VIEW conference in Birmingham in March. This is the key annual conference for QTVIs (Qualified Teachers of Visually Impaired children and young people) and other professionals in this field. Here, Sue sought engagement with and feedback on a major project which the Nystagmus Network has worked on for a large part of 2025, the delivery of a nystagmus friendly educational resource aimed at Key Stage 1 pupils. The resulting pack is now available on our website. It aims to create a model resource to exemplify to teachers/practitioners how to create an accessible document

contd.

"Your information was extremely helpful." – an email enquiry

2,942

DOWNLOADS OF OUR
GUIDES TO LIVING WELL
WITH NYSTAGMUS

People chatting at a Nystagmus Network event.

THE POWELL FAMILY
FOUNDATION

for all children's educational needs. This project came about through a successful funding application to **The Powell Family Foundation** and saw many months of engagement with parents, professionals and others to build a vital resource which can be used to support children with nystagmus as they start school.

Our community

We continued to have regular online meet ups for our various groups, those with acquired and congenital nystagmus and for the parents and carers of children with nystagmus. This included our annual winter get together where we hosted a quiz for all the groups to come together and network. This year's quiz was a tricky one - so well done to all those who took part.

Welfare rights and benefits

We have recently welcomed new volunteer Sabine as our benefits adviser. This is following the retirement of Mike, who has been volunteering in this role for many years. A huge thank you to Mike for his longstanding support to the Nystagmus Network.

A big thank you to everyone who has engaged with us this year through our website, contacting us directly or joining our events and get togethers, whether in person or online. Your engagement and support for one another is what keeps the Nystagmus Network strong.

Hannah Donnelly

Hannah Donnelly
Chair of the Support Committee

AWARENESS COMMITTEE

15k

FACEBOOK FOLLOWERS

> **"I live with nystagmus or moving eyes. Today is nystagmus awareness day - so everybody keep your chin up!" - an adult with congenital nystagmus**

Raising awareness of nystagmus is one of the core pillars of the charity. By raising awareness and increasing the number of people who know about nystagmus, the condition is better understood.

These are some of the highlights from raising awareness in 2025.

25 for '25

Our awareness challenge for 2025 was '25 for '25' – what 25 things could our supporters and members do to help raise awareness whilst also helping to fundraise for the charity? Each month we highlighted one of our '25ers' and the amazing things they did to help raise awareness. We had runners, walkers, knitters and people completing 25 tasks they've never done before!

Big Meet Up in Birmingham

We continued our successful 'meet in person' events focusing on smaller regional events to help raise awareness and encourage local support groups to be formed.

In June, we hosted a meet up in central Birmingham where members and supporters could find out more about education support, help at work, benefits, registration, the latest research and lots more, as well as meeting other people living with nystagmus.

Birmingham included some amazing guest speakers: Onyeka Amiebenomo from the University of the West of England spoke to us about work she's doing with nystagmus; Donna McNaughton from the Staffordshire education team talked about support in schools; Joerg Fliege from the University of Southampton provided an overview of the NystagME games they are developing and we met two local ECLOs (Eye Care Liaison Officers) Bhavini Mistry and Geraldine Carragher.

Nystagmus Awareness Day

Holding a national and international Nystagmus Awareness Day serves as a reminder to everyone that we are here and our voices need to be heard.

This year there was a spotlight on Acquired Nystagmus. We also

contd.

"I feel such gratitude for all you do." – acquired nystagmus group member

introduced key people at the Nystagmus Network, celebrated the amazing achievements of all our 25 for '25ers and held a children's colouring competition. Our Birmingham Big Meet Up was planned to coincide with Awareness Day and, of course, it wouldn't be Nystagmus Awareness Day without your stories.

Nystagmus interviews
In April, we launched the first of our new video interviews featuring the inspiring Dr Gemma Arblaster, an Orthoptist and lecturer at the University of Sheffield. In the video, Gemma deep dived into the fascinating world of Orthoptics and explored the complexities of nystagmus, providing a comprehensive overview of what an Orthoptist does. She also explained the critical role Orthoptists play in diagnosing and managing conditions like nystagmus and how they collaborate with Optometrists and Ophthalmologists to provide the best care for patients.

Updated website
We also launched a project to update our website to make it easier to use. Our two amazing new volunteers, Rose and Harry, who both have nystagmus, have worked very hard behind the scenes to develop a Nystagmus Network website which is simpler to navigate and easier to see. All the same great content will still be there, but we hope you'll be able to find what you need much more quickly. Look out for its launch in 2026!

Great get togethers
We continued to hold our popular 'great' get togethers where we had members from all our focus groups join. Not only are these opportunities to catch-up with some familiar and new faces, it was also a chance to have some fun and host our fiercely competitive quizzes!

The hugely successful focus groups also continued through the year when we hosted virtual calls for three groups: parents of children with nystagmus; adults with acquired nystagmus and adults with congenital nystagmus. Always an amazing opportunity to meet other people living with nystagmus or supporting someone who has it and a chance to share experiences.

As well as all these events, we continued to raise awareness of our amazing fundraisers and highlighted opportunities to support the charity.

Peter Greenwood

Peter Greenwood
Chair of Awareness Committee

FUNDING COMMITTEE

"We really enjoyed all of the challenges he has completed and we are only two away from completing all 25 which we will have done by the end of the year! It's not only been fantastic to raise awareness and vital funds to support Nystagmus Network's ongoing work but we've had such a great time!" - a 25 for '25er

The Nystagmus Network entered 2025 with a total funding target of £100,072, including £31,972 to be raised through grant awards and £32,800 from fundraising activities, with ambitions to explore corporate sponsorship and merchandise sales.

A total of 33 grant applications were completed during the year, achieving a 21% success rate, with a further 24% of applications still pending at the time of reporting. Through the hard work and commitment of a very small charity core team, grant income exceeded the annual target by over 38%, achieving a total of £44,172. This represents a significant improvement compared to 2024, when the grant success rate was 8%.

The Nystagmus Network is extremely grateful to the many grant-making organisations that supported our work during the year. We recognise the highly competitive nature of grant funding and deeply appreciate the confidence shown in our small, focused charity delivering impactful research, support and awareness on behalf of our beneficiaries.

We would like to thank the following organisations:

Thomas Pocklington Trust; Matthew Good Foundation; Keele University; Jeans for Genes UK; Gene People (Volunteer Award 2026); The Chaldean Charitable Trust; The Charity Governance Award; The Vision Foundation; New Philanthropic Capital and The Powell Family Foundation.

Corporate sponsorship targets were not achieved during 2025; however, engaging with the corporate sector remains an important ambition as we seek to raise greater awareness of nystagmus and secure additional funding to support our expanding programme of initiatives for individuals and families living with nystagmus.

During 2025, fundraising activities raised a total of £30,358 and we

contd.

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CALLS TO OUR SUPPORT LINE

Karen with her Nystagmus Network T-shirt

only missed the target by 10%. We extend our sincere thanks to everyone who sponsored, organised or participated in fundraising events, including:

Half-marathon runners raising over £7,321 collectively: Sarah, Liam, Craig, Chloe, Barry, Thomas, Liam, Carly, Ian, Tim, Hannah, Lauren and Stephen - an inspiration as we look ahead to 2026.

David and James, who raised £1,285 by running the London and Valencia Marathons.

The 25 for '25 campaign, inspired by trustee, Hannah and supported by trustees Peter and Kathryn, alongside supporter Katie and staff team member, Sue, which raised £1,728.

Participants in events including the London South Tough Mudder, Great Manchester Run, London Winter Run, and Jurassic Coast Challenge. Thank you to Lauren, Sophie, Julian, Chris, Stuart, Bethany and Karen.

Boxing and MMA fundraising, with Samuel, Lennie and Nathan raising £825.

A special mention to the fundraising support from Daniel, Magdalena, Jeanette, Jeanne and Winifred, raising £835.

Recognising the increasingly challenging funding environment, the charity continues to focus on diversifying income streams to support members of the nystagmus community and fund important research. In 2026 we will continue to explore all opportunities to grow sustainable income, a key focus will be on corporate sponsorship and sponsorship for our valuable research symposiums. If you are able to help in any way please get in touch - Thank you.

Karen Chu

Karen Chu
Chair of Funding Committee

RESEARCH COMMITTEE

IMPROVING QUALITY OF LIFE THROUGH RESEARCH

The Nystagmus Network has invested in research since the 1990s. In 2025 we invested £36,124.

Opening reflections

2025 was a positive and purposeful year for research at the Nystagmus Network. Throughout the year, the Research Committee remained firmly focused on our core purpose: supporting high-quality research that is relevant, impactful, and meaningful for people living with nystagmus, as well as their families and carers. I am pleased to report that we continued to invest directly in research, with a significant increase in total research spend compared with previous years. This progress has been made possible through the generosity and commitment of our members, fundraisers and donors to whom we are deeply grateful for helping us advance our mission.

I am particularly proud of how the year came together. By working thoughtfully and prioritising what mattered most, the committee strengthened partnerships and delivered moments of genuine impact throughout the year. The highlight of the year was undoubtedly our International Nystagmus Symposium, which brought together researchers, clinicians and the nystagmus community in a way that reflected both the maturity and ambition of our research programme.

Equally encouraging was the significant donation received during the year, which provides confidence and stability as we look ahead. This support allows us to think beyond short-term delivery and towards how we can sustain and grow our contribution to nystagmus research in the years to come.

I would like to thank my fellow Research Committee members, our clinical and research collaborators and everyone who supports the Nystagmus Network's research mission. The progress outlined in our Committee's report is very much a collective achievement.

Research Committee Overview

The Research Committee exists to guide, oversee and support the Nystagmus Network's research activity. Our work spans funding decisions, partnership development, research events and engagement with the wider

contd.

Nystagmus Symposium 2025

research and clinical community. Throughout 2025, the committee met regularly to review progress, assess opportunities and ensure that research activity remained aligned with the charity’s strategic aims and lived experience priorities. Our breadth of expertise, combined with strong trustee commitment, places the committee in a positive position as we look ahead, equipped to build on current momentum and to support research activity that is collaborative, credible and increasingly impactful.

Research Activity and Achievements in 2025

The International Nystagmus Symposium

The International Nystagmus Symposium, held online in November 2025, was the standout nystagmus research event of the year and marked a significant step forward in both scale and international reach. Co-chaired by Frank Proudlock and Mervyn Thomas (University of Leicester), the symposium brought together a fantastic global research community focused exclusively on nystagmus.

A total of 194 delegates registered, more than doubling attendance on the day, compared with the previous year. Delegates joined from across the UK and over 25 countries worldwide, spanning Europe, North America, Asia, Australasia and the Middle East, underlining the symposium’s growing international profile.

The programme featured 10 speakers, including clinicians and researchers from the UK, Europe, the United States, China and Australia, alongside a dedicated patient voice contribution, which we hope both reminds and inspires the research community in the impact their work has for us and our members. Presentations from the speakers covered a wide range of topics, from surgical and clinical

Richard Wilson Essay Prize 2025 winner, Yasaman Salari (left) with trustees Anthony Blackman (centre) and Harshal Kubavat.

management, diagnostics and testing methodologies, to early-stage academic research and patient-centred perspectives. Early career researchers were strongly represented, including contributions from the Richard Wilson Essay Prize winner and runner-up, reflecting the committee’s commitment to nurturing future research leaders.

Feedback from delegates was overwhelmingly positive. Attendees highlighted the quality and enthusiasm of the speakers, the breadth of topics covered and the value of having a dedicated forum focused solely on nystagmus. Ninety-two per cent of respondents said they would recommend the symposium to colleagues. Accessibility of the online format was rated particularly highly. Speakers also reported valuing the opportunity for discussion, exchange of ideas and the sense of momentum within the field.

The symposium successfully raised the profile of both nystagmus research and the Nystagmus Network on the international stage. It reinforced the charity’s role as a trusted convener and collaborator, while laying strong foundations for future research dialogue, shared learning and collaboration moving into 2026 and beyond.

Research Partnerships and Funding

During 2025, the Nystagmus Network continued to work in partnership with established research funders and organisations. This included meeting our financial commitments to joint funding initiatives, such as contributions towards a PhD studentship and a jointly funded small grants programme via Fight for Sight.

A particularly positive development was the receipt of a significant donation, for which we are truly grateful, earmarked to support research activity in 2026 and beyond. This contribution provides a stronger foundation for future planning and offers

contd.

RESEARCH, continued

reassurance that the charity can continue to play a meaningful future role in the research ecosystem.

In March 2025, the Nystagmus Network was proud to award a Legacy Grant to Dr Gemma Arblaster and Dr Sonia Toor, lecturers and researchers in Orthoptics at Sheffield Teaching Hospitals, to support a pioneering study on accommodation and focusing ability in people with nystagmus. This innovative project, enabled by a generous legacy gift from Mrs Rhoda Clarke that was announced in 2024, will investigate how individuals with nystagmus and those with albinism and nystagmus focus at varying distances: an area that has been under-studied to date. By comparing results with a control group without nystagmus and identifying the most effective clinical measurement techniques, the research promises new insights that could inform clinical practice and future studies. We wish the group all the best in their research endeavours and look forward to seeing what their study uncovers.

In 2025, we announced support in collaboration with Fight for Sight, co-finding a small grant project for an important piece of early-stage research led by Lee Evans, a PhD researcher at the University of Portsmouth, investigating visual acuity development in infantile nystagmus. By facilitating connections with potential participants and clinicians, we are further helping to ensure that the study reflects lived experience and clinical relevance from the outset. The research aims to deepen understanding of how visual acuity changes over time in infants with nystagmus, filling a critical evidence gap that could inform future clinical assessment and care pathways.

In 2025, we also continued our longer-term commitments, by joint-funding a PhD studentship with Fight for Sight, with Mervyn Thomas’s team at the University of Leicester. The research addresses a critical gap in the field: while common genetic causes of infantile nystagmus, including mutations in the TYR gene (associated with albinism) and FRMD7 gene (linked to idiopathic nystagmus), are well recognised, there are currently no effective therapies that target the underlying biological mechanisms. A major barrier has been the lack of suitable models for testing potential treatments. This project uses novel models, which share key similarities in eye structure and visual

RESEARCH, continued

development with humans, to identify potential future treatments that can improve eye movements. By screening and testing potential therapies in this model, the research aims to lay the groundwork for treatments that could in the future, ultimately improve visual acuity, eye movement control and everyday functioning, with the long-term goal of enhancing quality of life for people living with nystagmus.

Across the year, the committee also reviewed potential collaborations that did not proceed, ensuring that funding decisions remained focused on projects with a clear nystagmus-specific benefit. While not all opportunities could be taken forward, which is of course disappointing, these discussions helped sharpen our strategic approach to partnership working and ensure that we provide ourselves the ability to commit towards a sustainable pipeline of future projects.

UK Research Engagement and Wider Influence

The committee also maintained active engagement with wider research forums and networks, including rare disease and vision research groups, helping to ensure that nystagmus remains visible within broader scientific and policy conversations. We continue to support the Nystagmus UK Eye research group (NUKE), a UK-wide collaborative network of clinicians, researchers and academics with a shared interest in advancing understanding of nystagmus. Working closely with the Nystagmus Network, NUKE provides an important forum for knowledge exchange, discussion of emerging research and the development of research-informed approaches to care. During 2025, the Research Committee continued to engage with NUKE members, helping to strengthen links between research, clinical practice and lived experience. This partnership supports the Network’s ambition to act as a bridge between the research community and people living with nystagmus, while fostering collaboration and future research opportunities within the UK and beyond.

Looking Ahead

Research impact is not always immediate, but throughout 2025 there were clear indicators of our growing reach. Attendance at research events, continued engagement with funding partners and increasing international connections all point to a strengthening research profile.

Looking forward, the Research

contd.

RESEARCH, continued

Committee enters 2026 with renewed confidence. The momentum generated by the 2025 symposium, combined with the additional funding secured and our investment in nystagmus research, provides a strong platform for future activity. Priorities for the coming year include building on established partnerships, delivering planned research events and meetings and continuing to support research that is firmly grounded in the needs of our nystagmus community.

Thanks and Acknowledgements

The Research Committee would like to thank all researchers, clinicians, funders, donors and members of the nystagmus community who have contributed to and supported our work during 2025. Their engagement and trust make it possible for the Nystagmus Network to continue championing research that matters.

Harshal Kubavat

Harshal Kubavat

Chair of Research Committee

Dr Gemma Arblaster (left) and Dr Sonia Toor

OUR IMPACT

The Nystagmus Network is run by trustees, staff and volunteers with lived experience to ensure we represent the voice of the nystagmus community

In 2025 we continued to work hard to fulfill our goals: supporting the nystagmus community, raising awareness, funding research.

Awareness

We marked Nystagmus Awareness Day and delivered in person and online events

Communication

Daily Facebook and regular Instagram posts helped us reach an online audience of 15,000 people

Research

We held an international symposium and invested £27,287 in research projects

Support

We answered 709 enquiries from adults, parents, teachers, clinicians and eye care practitioners

Fundraising

Our supporters found all sorts of ways to raise £30,358 and we secured £44,172 in grants

Information

2,942 people downloaded our digital guides to living well with nystagmus.

MEMBERSHIP

Parents and their children enjoy the craft table at a Nystagmus Network event.

Nystagmus Network trustees have chosen to run the charity on a membership model, as this brings sustainability, enables sound financial planning and empowers us to grow.

As the representative body of a community of people living with the condition we can make sure that our voice is heard in education, research and funding.

"Thank you so much for all the support your team provides, it really makes a difference for families like ours." – a parent

"I'm super grateful to connect with others who also have congenital nystagmus!" – a new member of our get togethers

Isn't it great, feeling you belong, that you're part of a wider community, all working towards the same goals?

That's why the Nystagmus Network is a membership organisation. The more people we represent, the stronger the charity's influence and the louder our voice.

Together we can make real difference

Membership benefits include:

- Priority booking at all events
- Referral to bespoke advice and guidance on benefits
- One-to-one education support
- A proportion of every subscription goes directly into research

We offer affordable membership to anyone living with nystagmus.

PARTNERSHIPS

The Nystagmus Network is a member of NUKE (Nystagmus UK Eye research group), Visionary, the Alliance, the Genetic Alliance, the Neurological Alliance and the VI Research Network. We also work closely with QTVIs (Qualified Teachers of Visually Impaired children), ECLOs (Eye Care Liaison Officers) and Eye Care Practitioners as well as alongside other sight support charities, to ensure everyone living with nystagmus receives the help they need.

ACHIEVEMENT

The Nystagmus Network shares and celebrates every success members of the nystagmus community achieve.

CAMPAIGNS

The Nystagmus Network is committed to raising awareness of nystagmus to improve the quality of life of everyone living with the condition.

TREASURER'S REPORT

2025 was a strong and encouraging financial year.
We end the year in a solid position, but there is still more to do.

2025 was a strong and encouraging financial year for the charity, enabling us to invest in research, support services and awareness while also safeguarding our reserves. Income included some significant one-off items, which improved the overall result. At the same time, trustees remain focused on the need to broaden income sources and grow dependable, recurring funding to support the charity's long-term future.

Income

We raised £160,052 in 2025, a 64% increase on last year, boosted by grant income of £44,172 and a £50,000 major gift restricted for research. Fundraising activity and donations generated £50,795, a slight fall of 3% compared with last year, while membership subscriptions remained steady at £10,233, providing a dependable base of support.

While this year's total is very encouraging, legacy and major gift income can vary significantly year to year, so growing more predictable and recurring income remains a key priority.

Investing in our mission

Total expenditure was £108,595, 6% lower than last year, with continued focus on delivering impact. Research spend increased to £36,124, reflecting our commitment to advancing knowledge and treatment. Support and awareness activity totalled £28,541, enabling us to continue providing vital services and and support. Income generation costs were

£26,334, supporting our fundraising programme and office and administration costs were £14,881. Overall, spending remained aligned with our charitable objectives and strategic priorities.

Financial position and looking ahead

We recorded a surplus of £51,457 for the year, strengthening our financial position. Total reserves at year end were £153,089, including £55,748 in unrestricted funds, in line with our six-month reserves policy. During the year trustees designated £33,630 of reserves to support future research commitments. We end the year in a solid position, but there is still more to do to diversify income and build reliable, recurring funding streams. The coming year will focus on expanding regular giving, developing partnerships and securing ongoing grant support to ensure long-term sustainability and continued impact.

Vicky Pitman

Vicky Pitman FCA

Treasurer

Trustees celebrate their UK Charity Governance Award for improving impact in small charities.

"It’s a pleasure to be able to run for Nystagmus Network!" – a fundraiser and nystagmus parent

FINANCIAL ACCOUNTS 2025

Nystagmus Network - Financial Accounts

	2025				2024
£ Unrestricted Funds	£ Unrestricted Funds	£ Designated Funds	£ Restricted Funds	£ Total Funds	£ Total Funds
Receipts					
Fundraising	30,358	-	-	30,358	33,989
Grants	17,500	-	26,672	44,172	28,260
Legacies & Major gifts	-	-	50,000	50,000	-
General Donations	20,437	-	-	20,437	18,588
Subscriptions	10,233	-	-	10,233	10,271
Shop Sales	1,871	-	-	1,871	2,486
Events	365	-	-	365	1,207
Bank Interest	2,616	-	-	2,616	2,617
	83,380	-	76,672	160,052	97,419
Expenditure					
Income generation costs	26,334	-	-	26,334	24,703
Support & Awareness	6,806	-	21,736	28,541	31,755
Office & Administration	7,824	-	7,057	14,881	25,133
Research	11,840	-	24,284	36,124	27,287
Trustee expenses	82	-	-	82	60
Events	2,634	-	-	2,634	7,136
	55,519	-	53,076	108,595	116,074
Net Surplus/(Deficit) for the year	27,861	-	23,596	51,457	(18,655)
Total Staff costs included above				£68,614	£73,071
Statement of Assets and Liabilities					
Cash funds	55,748	33,630	63,711	153,089	101,632
Represented by:					
Funds brought forward	61,517	-	40,115	101,632	120,287
Movement in year	27,861	-	23,596	51,457	(18,655)
Funds transfer	(33,630)	33,630	-	-	-
Funds carried forward	55,748	33,630	63,711	153,089	101,632

Accounts Prepared by **Vicky Pitman FCA (Treasurer)**

Accounts Examined by **Andrew Black ACA 13/2/26**

LEGAL DETAILS

Charity objects
The charity's objects focus on the relief of nystagmus / visual impairment sufferers and their families. The objects also focus on advancing the education of the public in and to promote research into the condition known as nystagmus and to publish the useful results of any such research which the charity has funded.

Appointment of trustees
Trustees are recruited in line with our equality and diversity policy and to reflect lived experience of nystagmus. They are appointed after a thorough interview process. Induction includes immersion in the Charity Governance Code and charity policies and procedures. Introduction to the work of the charity is through peer to peer training via our sub-committees.

Trustees' responsibilities
Trustees are responsible for the preparation of financial statements for each financial period which give a true and fair

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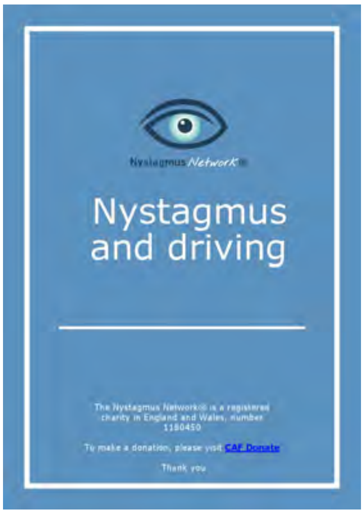


Nystagmus Network

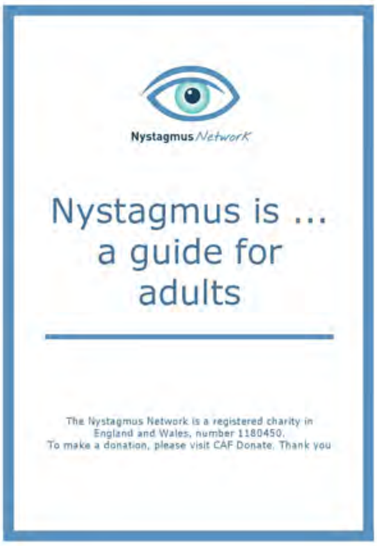
Nystagmus and driving

The Nystagmus Network® is a registered charity in England and Wales, number 1180450

To make a donation, please visit CAF Donate

Thank you

Nystagmus and driving

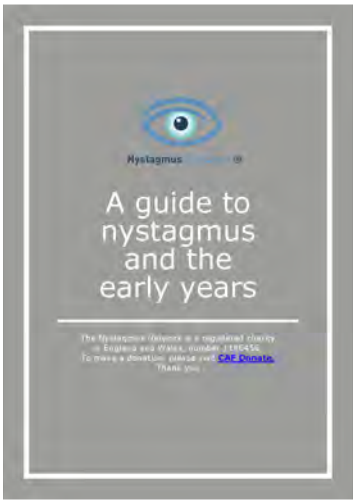


Nystagmus Network

Nystagmus is ... a guide for adults

The Nystagmus Network is a registered charity in England and Wales, number 1180450. To make a donation, please visit CAF Donate. Thank you

Nystagmus is ...
what it's really like



Nystagmus

A guide to nystagmus and the early years

Early years guide

view of the charity's incoming resources and application of resources during the year and of its state of affairs at the period end. In preparing these financial statements the trustees are required to do the following:

- Select suitable accounting policies and then apply them consistently;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

Risk
The trustees take risk management seriously and have a live risk register in place which is regularly reviewed and updated.

Signing of the Trustees' report
On completion of this report one of our trustees is required to sign that the information contained within it is both accurate and a true reflection of our work.

Tim Cuddeford

Tim Cuddeford

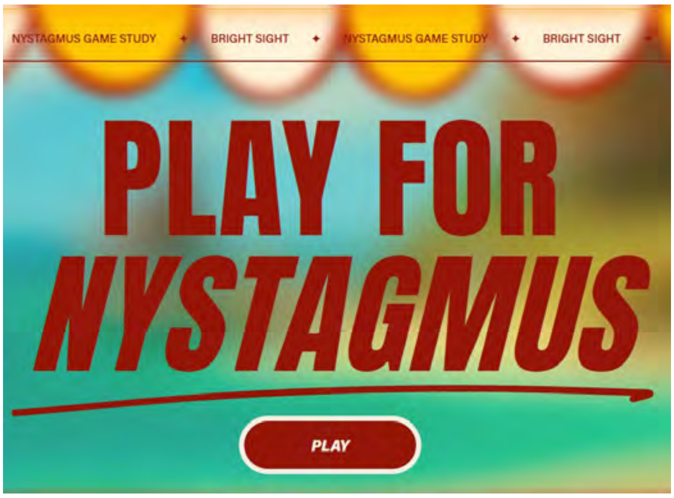
Chair of Trustees

The Nystagmus Network provides support for people living with the incurable eye condition nystagmus and their families. It raises awareness of the condition through training and an annual Nystagmus Awareness Day and champions and funds research.

Connecting people
Regular network events make it easier for people living with nystagmus to get together, learn about their condition and support each other.

Empowering families
The charity helps parents and carers to access support for their children at school so that they thrive and reach their full potential.

Finding solutions
The team brings patients, clinicians and researchers together to work towards a better understanding of the condition, which in turn helps improve quality of life for people with the condition.



"Thank you. Seeing the different stories has brought me strength and relief." – a parent

"I couldn't attend the last meeting and it was so helpful to read the notes. Thank you so very much for sending them out and for all that you are doing." - CN group member

"I feel such gratitude for all you do."
– AN group member

"Your information was extremely helpful." –
an enquiry by email

NYSTAGMUS NETWORK

Nystagmus Network

MORE INFORMATION

For more information visit us online at
nystagmusnetwork.org
or email us at info@nystagmusnet.org.