# NYSTAGMUS NETWORK

England & Wales · Charity number 1180450

## Details

| | |
|---|---|
| **Status** | Registered |
| **Legal form** | CIO |
| **Registered** | 2018-10-29 |
| **Register** | View on the Charity Commission register |

## Contact

| | |
|---|---|
| **Address** | 6 Lancaster Gardens<br>Kingston Upon Thames<br>Surrey<br>KT2 5NL |
| **Phone** | 01427718093 |
| **Email** | info@nystagmusnet.org |
| **Website** | www.nystagmusnetwork.org |

## Activities

**Objects:** 1) TO ADVANCE 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.2) FOR THE RELIEF OF SICKNESS OF NYSTAGMUS SUFFERERS AND THEIR FAMILIES.

**Activities:** The Nystagmus Network provides information and support to people affected by nystagmus, raises awareness of this complex condition, and funds research.

## Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Disability
- **Who:** People With Disabilities

## Geography

- Throughout England And Wales

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## Finances

| Period end | Income | Expenditure | Assets | Employees |
|---|---|---|---|---|
| 2025-12-31 | £160,052 | £108,595 | - | - |
| 2024-12-31 | £97,419 | £116,074 | - | - |
| 2023-12-31 | £122,841 | £68,632 | - | - |
| 2022-12-31 | £94,707 | £95,927 | - | - |
| 2021-12-31 | £88,702 | £99,688 | - | - |

## Trustees

| Name | Role | Appointed |
|---|---|---|
| Andrew Charles McFarlane | | 2023-04-28 |
| Anthony Blackman | | 2025-12-13 |
| David John Parfett | | 2025-08-22 |
| Dr Harshal Kubavat | | 2021-11-19 |
| Dr John Symeon Vekinis | | 2021-06-09 |
| Hannah Donnelly | | 2024-08-01 |
| KATHRYN HEATHER SWANSTON | | 2020-11-25 |
| Karen Ann Chu | | 2020-11-25 |
| Mari McLellan | | 2026-02-17 |
| Nigel Antony Brice | | 2026-06-01 |
| Oliver James Coburn | | 2026-06-01 |
| PETER JAMES GREENWOOD | | 2018-10-29 |
| RICHARD GELLER | | 2026-02-17 |
| VICKY PITMAN | | 2018-10-29 |
| VIVIEN MARY JONES | | 2018-10-29 |

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**NYSTAGMUS NETWORK**

England & Wales - Charity number 1180450

# Accounts

**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.**

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**"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**











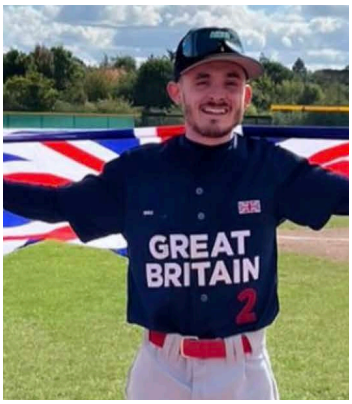











GREAT
BRITAIN
2



# 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




*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.**

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**

25 for '25

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

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**136**

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

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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

# R E S E A R C H, 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**



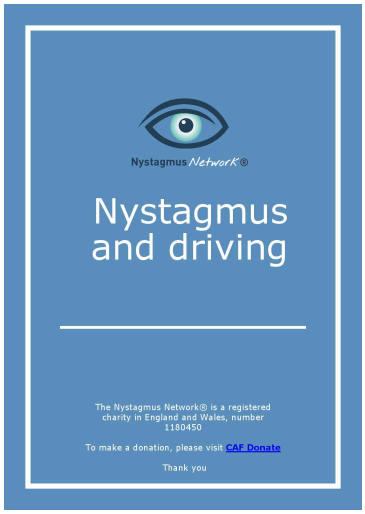

# LEGAL DETAILS

**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.

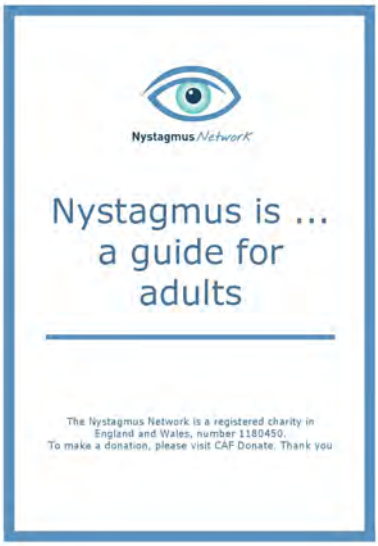
**Appointment of trustees**
Trustees are recruited in line with our equality and diversity policy and to reflect lived experience of nystagmus. They are appointed after a thorough interview process. Induction includes immersion in the Charity Governance Code and charity policies and procedures. Introduction 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

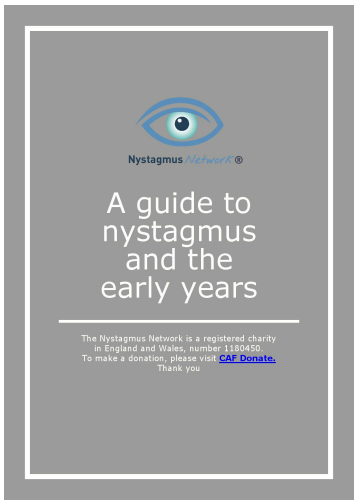
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Nystagmus and driving




Nystagmus is ... what it's really like




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.

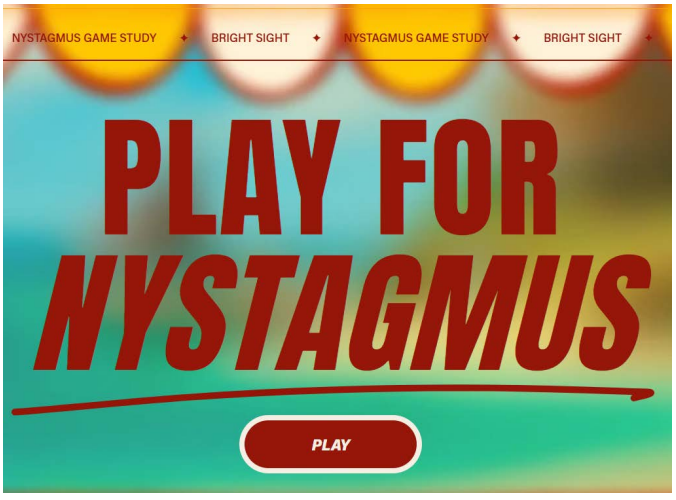






**Empowering families**
The charity helps parents and carers to access support for their children at school so that they thrive and reach their full potential.

**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.

**NYSTAGMUS NETWORK**

England & Wales - Charity number 1180450

# Accounts

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

# 2024 TRUSTEES' ANNUAL REPORT

**"We never dreamed that our little help group would grow into such a big and successful organisation! Hats off to all you enthusiastic, creative, techno-brilliant people!"**

**NYSTAGMUS NETWORK**

Nystagmus Network®
Ruby Year
Celebrating our 40th anniversary

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

**"It has been such a scary time for us and the Nystagmus Network has been such an amazing support and hub of valuable information whilst navigating this challenge."**
**- a parent**




A child in a Nystagmus Network T-shirt walks along a hospital corridor.

## 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.**

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**"Thank you for looking after us. It was a really lovely day. It was great to understand all the important work Nystagmus Network do." – an Orthoptist**



Vivien Jones MBE (right) Founder and Honorary President of the Nystagmus Network, with Lord Drayson (centre) our event sponsor, and Harshal Kubavat, trustee.

# A MESSAGE FROM VIVIEN

In 1984 there was no internet and so no email – but the price of a first class stamp was 17 pence. Today, we have the internet, email and other forms of electronic communication – and the price of a first class stamp is £1.70.

In 1984, Mrs Thatcher was prime minister, Ronald Reagan was president of the United States and, my husband tells me, David Gower was the England cricket captain. (He also tells me the price of a pint of beer was 72 pence, but that's enough nostalgia.)

So, what else happened in 1984? If you're reading this, you know the answer – it's when the Nystagmus Network was founded.

The charity came about as a result of a conversation between myself and one of the leading practitioners at the London Refraction Hospital – now the Institute of Optometry – Ron Mallett.

We had taken my son Sam, born in August 1983, to him after reading a short article in a national newspaper stating that the Hospital was conducting research into nystagmus. Sam had been diagnosed with nystagmus when he was three months old and we had struggled ever since to find out

## Face to face meetings had an important role to play in our work

information about the condition. Mr Mallett was an encouraging and kindly man and we fell to discussing the difficulty for patients and their families of obtaining information about nystagmus. I was desperate to meet others with the condition who could perhaps answer my questions. What could they see? What problems did they encounter in education or at work?

Mr Mallett and I agreed that setting up a group for people living with nystagmus was a good idea. With Mr Mallett's help – remember this pre-dates data protection! - I contacted other patients and most replied saying they would welcome the formation of a group. The first meeting took place at the end of 1984.



Vivien and her infant son, Sam on holiday in 1984.

So the Nystagmus Action Group was born. Subsequently we changed the name to the Nystagmus Network which seemed to better express what we were about. Largely through media coverage, we soon attracted attention from families who were as bewildered and distressed by the diagnosis and lack of support as I had been and from those with the condition who felt their needs had always been ignored. Answering their letters became the central focus.

There was a huge unmet need for support. So we started to produce leaflets. Our graphics were rudimentary – our first leaflet had stick men on the front! - but people lapped up the information.

We began to organise events, too. Nothing beats human contact. So we held Open Days once a year which were attended by large numbers of people. Just seeing the look on people's faces as they met others who had nystagmus – often for the first time – was enough to convince me that face-to-face meetings had an important role to play in our work.

Computers and the Internet changed everything, of course, allowing us to establish much more effective – and more attractive - communications!

contd.



Vivien's husband, Ian and their son, Sam at the Ruby Reception.

That said, talking to people going through diagnosis or wanting advice or just to talk about the condition is something we have always held dear. I am very glad we maintain our telephone advisory service today.

We became a registered charity in 1990 and appointed our first paid employee in 1997. New publications and a website followed. We also developed excellent relationships with researchers and clinicians. Social media has changed how we work – we are in touch with thousands of individuals and families as a result of it.

There's no question that the charity has moved on massively since those early days in the eighties. When I look at the website, and in particular our publications list, I am amazed at how much information is now available at the touch of a button. Covering topics such as driving, benefits and education – and many more – there is a vast amount of information ready to download free of charge. It isn't just the written material that has moved on, but our accessibility – regular Zoom meetings for people to join, and regional meetings to bring people together.

Our role in supporting research – once just an aspiration – has developed over the years. We support research projects and through our research committee we maintain close links with the university and clinical world. We would, of course, like to do more but we have to live within our budget. We are grateful to those who give to us but we are forever trying to raise more money for our activities and our research!

Huge thanks are due to all those who have supported us over the years. It is because of them that the Nystagmus Ntwork has become a thoroughly professional charity – but also one that believes in personal contact.

2024 marked the 40th anniversary of our charity and we

**"I just wanted to say thank you to you and the team for organising yesterday's event. It was lovely to meet people who have been - and largely remain - a part of the Nystagmus Network story over the last 40 years and see how well things are going now." - a guest**

decided we should celebrate it. Sue Ricketts, our wonderful Executive Information and Development Manager, led the way by managing to organise a reception for friends and supporters at the House of Lords last November. David Blunkett sponsored it. Alas, he was ill on the evening but Lord Drayson agreed to come in his stead and proved a charming – and interested - host. It was an evening to remember, with wonderful conversations going on everywhere. I even made a speech about the origins of the charity!

I still can't quite believe it is 40 years since the charity got started. Much has changed in that time: I am glad we are no longer communicating by post! Sam has grown into a splendid young man. In case you wonder, he has always worked since he left university and has a very good job.

Here's to the next 40 years!

Vivien Jones MBE

*Vivien Jones*

Founder



**Nystagmus Network trustees, staff, friends and members were delighted when Vivien received the MBE in His Majesty's New Year's Honours list 2025 "for services to the nystagmus community".**

Tim Cuddeford, Chair of the Nystagmus Network trustees.




# CHAIR'S MESSAGE

Our Ruby year was a fantastic experience. I was so pleased to be Chair during this significant milestone. It was great to hear Vivien's heartfelt speech at the House of Lords in November, our event kindly sponsored by Lord Drayson.

The charity continues to deliver excellent support, funding research and raising awareness.

Like all charities we faced financial headwinds, so I am pleased that fundraising could continue at a comparable level to previous years. Thanks to all our donors, grant givers and individual fundraisers with such varied efforts running, knitting, raffles, walking, bungee jumping, swimming, baking.

In 2024 we held very successful in-person events in Oxford, London and Sheffield and will continue this model moving forward with more regional events and support groups. If you hear of one near you, we would love to see you there. We will continue to use Zoom for larger events with a more dispersed audience eg our AGM and, of course, our very popular monthly get togethers.

It was so good to see many representatives of our research community at the House of Lords Ruby Reception, a delight to meet the recipient of the inaugural Richard Wilson Prize and an honour to have with us Marsha de Cordova MP, our newly appointed charity ambassador.

## Like all charities, we faced financial headwinds.

I would like to thank again all our members, supporters, fundraisers, trustees and staff for all their efforts ensuring success in 2024.

Tim Cuddeford

*Tim Cuddeford*

Chair of trustees

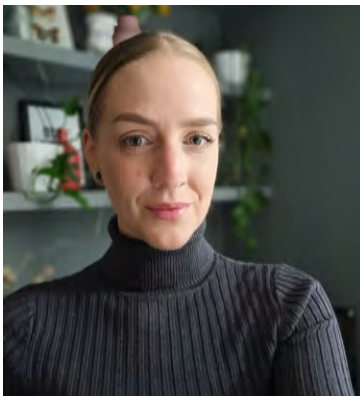
**"The best bit about a big nystagmus meet up in Oxford in 2024?**

**Meeting people with nystagmus like me for the first time in my life."**



Nystagmus Network trustees and staff at the Ruby Reception with Nystagmus Network ambassador, Marsha de Cordova MP (centre).

**"What a wonderful evening shared with inspiring people - from Vivien to researchers to past colleagues and chatting to everyone including yourself, who are making the magic happen every day for people affected by nystagmus. Truly life affirming, thank you so much."**
**- a Ruby Reception guest**














# TRUSTEES SERVING IN 2024

**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.**

**Tim Cuddeford**
**Chair of Trustees**
**Chair of Finance and Governance**



**Vivien Jones MBE**
**Founder and**
**Honorary President**



**From the top row, left to right:**

**Miriam Blackburn**
**Karen Chu, Chair of Funding**
**Sharon Clifford**
**Peter Greenwood, Vice Chair of Trustees, Chair of Awareness**
**Harshal Kubavat**
**Vicky Pitman, Treasurer**
**Andrew McFarlane, Chair of Support**
**David Singleton**
**Kathryn Swanston**
**John Vekinis**
**Paul Rose**
**Hannah Donnelly**



Nystagmus Network trustees, staff and Marsha de Cordova MP.

# 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.

**"Keep the good work up!" - a Newsletter subscriber**

**"I am sure everyone who contacts you appreciates everything that you do for us. It was my first glimmer of hope after 4 plus years of negativity from people I thought may be able to help me."**
**- a beneficiary**

# SUPPORTING THE NYSTAGMUS COMMUNITY

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



SUPPORT COMMITTEE

# 796

PEOPLE SUPPORTED

**"There's no substitute for talking to others who know something about the condition and/or have experienced it." – a get together attendee**

## Building Connections, Changing Lives

For 40 years, the Nystagmus Network has been bringing people together, creating a community where no one faces nystagmus alone. In 2024, we've expanded our reach and deepened our impact through innovative programmes, meaningful gatherings and our important support services.

## Community Connections

Our year began with the winter "nystagmus get together" on Zoom, featuring our popular 1984-themed quiz — by popular demand, now established as an annual tradition. Beyond our regular monthly online meetups, we hosted in-person "big nystagmus meet ups" in Oxford, London, and Sheffield. These gatherings provided valuable opportunities to hear from experts, connect with others living with nystagmus and share strategies for living well with the condition. There were also some very tasty lunches!

A highlight of our community-building efforts was a special weekend retreat in Shropshire, made possible through the Landmark Trust "50 for Free" project. This intimate gathering fostered deep connections and lasting friendships among participants.

## Youth Engagement

Thanks to our Get Set Progress intern George, partially funded by Thomas Pocklington Trust, we engaged our younger members through virtual Easter egg hunts and creative challenges, culminating in our Christmas card design competition. These activities brought joy and fun while strengthening bonds among our youngest community members.

## Educational Innovation

The "nystagmus friendly learning materials" project, generously funded by **The Powell Family Foundation**, represents a significant step forward in our educational support. Working collaboratively with VIEW, SALT Projects Ltd and a dedicated team of parents, children,

**contd.**

**"A big thank you to you and all the staff at Nystagmus Network for putting on this brilliant event. The time and effort that goes into making these events work is enormous and all credit to you." - big meet up attendee**

# 2,803

DOCUMENT DOWNLOADS



Guests at the Ruby Reception.

**"Thanks for your support in a challenging life." – a beneficiary**

teachers and QTVIs, we're developing adaptable learning resources for Key Stage One children with nystagmus. This vital work will continue through to July 2025. With thanks to everyone who has contributed to this important work.

Expanding Support Networks

With NPC funding secured for the next three years, we're growing our peer-to-peer support through volunteer-led local groups. The "two Andys" have successfully established support groups in Oxfordshire and Manchester, with more locations planned.

The Inman Charity's support is enabling us to launch a telephone befriending service. We hope our first volunteer callers will soon be making connections with those who need it most.

THE POWELL FAMILY FOUNDATION

**Looking Forward**

Since 1984, the Nystagmus Network has stood as a beacon of support for the nystagmus community.

As we reflect on 2024's achievements, we remain committed to our founding mission: bringing people together to support each other and feel part of a community where everyone with nystagmus can thrive. Together, we're making connection happen.

Sue Ricketts

*Sue Ricketts*

Sue Ricketts (EIDM)
for the Support Committee

# A STORY of SUPPORT

## "The Nystagmus Network Zoom calls and meet-ups are one of the few places I can be the 'new me'. It's the best care plan I have."

After over forty years of trouble-free vision, out of the blue, the world I saw started to change; vertigo-like symptoms, blurred or double-vision, tinnitus, migraines etc. Sporadically at first, then over the years becoming more and more persistent and prevalent. Opticians and GPs couldn't identify a cause and my descriptions of seeing things 'moving' couldn't help. This is a very difficult condition, as a sufferer, to describe.

A long wait for a Neurology assessment resulted in (two years after symptoms started) my Acquired Nystagmus diagnosis, quickly followed by the words, "there's no cure". The shock of that! I'd never even heard of Nystagmus, now I have it and there's no cure? Many tests ensued (long waits for these too) and referrals to clinicians such as Ophthalmologists and Orthoptists (sorry, who)? One clinician told me, "something has flipped and we don't know what or why!" A refreshingly honest assessment, no assumption, no presumption or mis-diagnosis.

Fast-forward several years ... my symptoms, still with no hard evidence of cause, are permanent and fluctuate in severity throughout any day. Extra levels of stress, light levels, glare and illness etc. exacerbate everything, making this incredibly debilitating condition worse. By far the trickiest symptom for me is oscillopsia. I see everything as moving: horizontally (as if I have just stepped off a roundabout), vertically (like fast-moving credits at the end of a film) or sometimes both at once! Panic and nausea are frequent companions. My perception of what I see often massively hinders my ability to move around, focus on objects or people properly, read, write, balance and do the jobs and activities I could previously do. I had to leave my job after struggling for many years and not receiving the workplace support I needed to continue. I didn't have the energy to fight my own cause anymore. Imagine living like this...forever? There are videos of oscillopsia simulation on YouTube, which I would urge you to see, as

contd.

this could happen to anyone at any time (not to scare but to inform). I have a long list of aids which assist somewhat with the impacts, including trials on drugs which are non-specific to my condition - with varying levels of success versus side-effects.

One huge help is knowing there are others who are going through this and can connect with each other via the Nystagmus Network, who I was fortunate enough to be told about in a random conversation with a workmate (sadly not from any clinician I had encountered).

This has been a lifeline for me, knowing others who understand what this is actually like to live with; how it lowers your confidence, stops you from taking part in everyday activities you once enjoyed and can change your identity of yourself.

I don't feel like I fit into the life I had, so the work of the Nystagmus Network to support, connect and understand those who live with nystagmus is invaluable.

Many thanks to the well-informed and dedicated team for all your work. Our Zoom calls and meet-ups are one of the few places I can be the 'new me'. It's the best care plan I have! My symptoms quieten in the right environment and with the right people.

## More impactful than you can imagine

**Eyes bleary and frantic, world spins,**
**Unbalanced, nausea, fatigue,**
**'Wobbly' vision, 'drunken' gait,**
**Calm yourself…**
**Family member/friend is driver and helper,**
**Too much traffic, too little parking.**
**Busy corridors, harsh lighting,**
**Signs 'move', so can't be read.**
**Visual stress! Body and mind in perpetual flux.**
**Calm yourself…**
**A long, hot wait – my name is called,**
**A weary smile, head down, reading.**
**A knock at the door – more notes brought in. Not mine**
**Other people's lives intruding, impinging.**
**The clock ticks silently.**
**My 'mask of capability' hosts an unconscious tug of war**
**With my new, vulnerable self,**
**Kindness and patience will tease out the latter.**
**Cursory checks, sometimes more thorough.**
**Hopes deludedly high, expectations often low,**
**Since there's 'no cure.'**
**Symptoms worse; more cross-over drugs to try,**
**Side-effects are no joke and no lure.**
**This is 'your condition to manage.'**
**Heal yourself …**

## AWARENESS COMMITTEE

**14k**

FACEBOOK FOLLOWERS

**"As one recently aware that I have AN and not ever knowingly met anyone aware of the complaint it is very reassuring there are others out there experiencing the same or similar symptoms to me. Thank you." – a new member**

Raising awareness of nystagmus is one of the key pillars of the charity. We firmly believe that the more people who know about nystagmus, the better the quality of life will be for those who live with the condition. The Awareness Committee is tasked with raising awareness.

As we celebrated our 40th anniversary in 2024, our awareness events and campaigns had a distinct ruby theme to them! These are some of the highlights from 2024.

### Big Nystagmus Meet Ups

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

In April, we hosted a meet-up in Oxford at the Florence Park Community Centre with some great guest speakers including Ophthalmologists Jay Self and Helena Lee; Andy and Jamie from MyVision Oxfordshire provided advice on all aspects of living with nystagmus including local services and, most importantly of all, there was the chance for attendees to meet other parents and people living with nystagmus.

In July, we went to London and heard from Moorfields Consultant Ophthalmologist, Maria Theodorou; we got lots of advice from QTVI (Qualified Teacher of Children and Young People with Vision Impairment) Paul from Brent Sensory Services and premiered our Ruby Year video.

In September, we went to Sheffield where we were hosted by Sheffield Royal Society for the Blind. Attendees heard from Dr Gemma Arblaster, Orthoptist and Lecturer at the University of Sheffield and met some of her Orthoptics students; chatted with Tracy and Sharon, two very friendly ECLOs (Eye Care Liaison Officers) from Sheffield who told us about their services and met Chloe, a Family Support Services Officer with SRSB. We enjoyed a delicious lunch of pie and mash!

contd.

## Our Ruby stories for Nystagmus Awareness Day 2024



Vivien and Sam in 1984



Harshal in 1984



Peter in 1984

### BBC Radio 4 Charity Appeal

We were once again awarded a BBC Radio 4 Charity Appeal. Presented by Gerard McDermott (actor, singer, musician, children's author and charity super supporter), the appeal helped bring awareness to a national audience as well as raising significant funds for the charity.

### 2024 Nystagmus Awareness Day

Nystagmus Awareness Day serves as a reminder that we are here and our voices need to be heard. In our Ruby year, we asked people to share their stories, especially those old enough to have been around in 1984. We also went 'looking for Ruby', anyone celebrating a 40th birthday or anniversary. We received lots of incredible and inspiring stories which can be found on our website.

There was a ruby inspired A-Z of fundraising ideas, a children's colouring competition and we raised awareness of the many materials available to members and supporters.

### Great Get Togethers

Inspired by the Jo Cox Foundation, we held two 'great' get togethers with members from all our groups all together. The Winter Get Together included a highly competitive quiz (congratulations Team Congenital Nystagmus!). The Summer event included participants from as young as 2 to over 70 years. It felt good to share ideas and experiences on everything from driving to sports and even GCSEs.

### Our Zoom calls

We continue to host our regular calls for parents of children with nystagmus, adults with acquired nystagmus and adults with congenital nystagmus – an amazing opportunity to meet other people living with nystagmus or supporting someone who does and a valuable chance to share experiences.

Peter Greenwood

*Peter Greenwood*

Chair of Awareness Committee

## FUNDING COMMITTEE

## Thank you to everyone who gave to our BBC Radio 4 appeal

Our income target for 2024 was £100,000, 12% higher than in 2023 due to an anticipated rise in running costs and an ambition to continue to respond to the increase in demand for support and information whilst supporting our objectives in research.

We were just 3% under target at £97,000 for 2024, largely thanks to cash flow from prior-year grants, fundraising and donations.

2024 was a difficult year to secure grants with only one secured from Thomas Pocklington Trust for an internship. The grant success rate fell from 26% in 2023 to just 8% which was reflective of a more competitive funding environment.

Donations, subscriptions and fundraising totalled close to £63,000 and we are so grateful to all the groups, families, teams and individuals who supported us in 2024. Donations were a real highlight for the year, more than doubling the donations received in 2023, which was extra special as we were celebrating the charity's 40th Anniversary, our Ruby Year and that coincided with the BBC Radio 4 appeal. Thank you.

Just a few of the 2024 fundraising highlights, with thanks to everyone who sponsors, organises and pledges to fundraise.

- Our 17 runners who ran the Royal Parks Half marathon in October raised almost £12,000 between them. Thanks to Adam, Bill, Chloe, Hannah, Ian, Imogen, Jeremy, Joseph, Mari, Mark, Matt, Matthew, Philip, Richard, Stephen, Stuart and Tim
- We also had runners in the Nottingham Winter Warmer 10k, London Landmarks Half, Lisbon Marathon and the London Marathon, raising over £5,000 thanks to Bob, Jola, Peter, David and Rachel who bring inspiration to all the runners signed up for 2025.
- Music was in the air in December with the Richmond Light Orchestra kindly raising £350 from their concert.
- A mufti day was held for Nystagmus Awareness Day at a primary school, thanks to pupils Joseph and Grace, raising £200
- Barbara's guests donated

**"I am happy to donate to a charity that is making such a difference."**
**– a generous donor**

contd.

# 136

CALLS TO OUR SUPPORT LINE




Our radio appeal presenter, Gerard McDermott and Sue with our Ruby banner at the BBC on recording day.

over £140 from her special 80th birthday lunch in December. Happy Birthday, Barbara!

- Harry went bungee jumping and raised £412
- Keen swimmer, Jenna raised £230 taking part in the Great North Swim supported by her daughter
- Mary hosted her annual cake morning in January raising £285

Recognising the difficult funding challenges ahead, we continue to diversify our income streams, introducing a new CRM to build on funder relationships and support a new three-year fundraising strategy, exploring all possible ways to increase income in 2025 to sustain the charity and its important services.

Karen Chu

*Karen Chu*

Chair of Funding Committee

**In 2023, we received a legacy gift from the late Mrs Rhoda Clarke, who wished to benefit children like her great niece through research. In 2024 the charity launched the Legacy Grant Award for research into infantile nystagmus.**

# RESEARCH COMMITTEE

## IMPROVING QUALITY OF LIFE THROUGH RESEARCH

**The Nystagmus Network has invested in research since the 1990s. In 2024 we invested £27,287.**

**"I am thrilled to say that we have had loads of interest in this study and we are able to stop recruitment at this point, for which I genuinely can't thank you enough." – a researcher**

### Opening reflections

Research is one of the core priorities of the Nystagmus Network. As a charity dedicated to supporting everyone living with nystagmus, we recognise that investing in high-quality scientific research is essential to improving understanding, treatment and, ultimately, outcomes for people living with this complex condition.

Our Research Committee plays a vital role in guiding this work, ensuring that every grant we award has the potential to make a real and lasting difference. Thanks to the generosity of our supporters, we remain firmly committed to funding innovative research into nystagmus now and in the years to come.

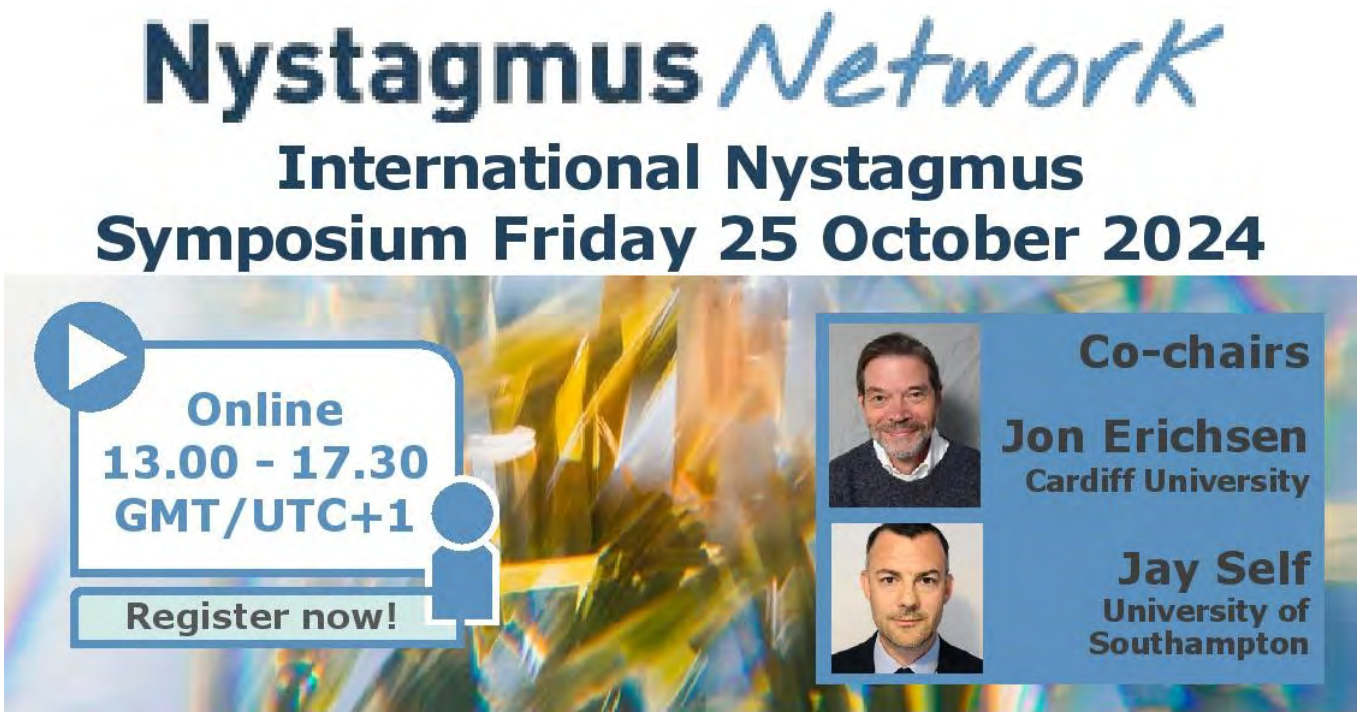
In 2024, the Nystagmus Network marked a significant transition as Vivien Jones MBE, the charity's founder and Honorary President, stepped down as Chair of the Research Committee, appointing fellow Trustee, Harshal Kubavat. Since establishing the charity in 1984, Vivien has been a driving force in the charity's growth and success and has been instrumental in advancing research and awareness, shaping this committee into what it is today, for which we are ever grateful. Vivien continues to serve as a trustee and Honorary President, providing invaluable support and guidance to the committee during this transition.

Harshal joined the charity as a trustee in November 2021 and is deeply committed to our mission, actively contributing to the research committee and initiatives like the Nystagmus UK Eye Research group (NUKE) and looks forward to continuing the momentum in the months and years ahead.

### Our inaugural essay prize

In 2024, the Nystagmus Network proudly launched the Richard Wilson Essay Prize, an exciting new initiative designed to raise

contd.




**"I wanted to applaud Nystagmus Network's recognition of the International Day of Women and Girls in Science." – PhD researcher**

awareness of nystagmus among early-career researchers and medical students within the UK. Named in memory of Richard Wilson OBE, Chair of Trustees (2010-2019) and a long-standing supporter of the charity, the prize aims to inspire the next generation of clinicians and scientists to take an interest in this under-researched condition. The inaugural winner this year was Justine Chan from the University of Cambridge, who impressed the judging panel with her insightful exploration of the genetic basis of nystagmus - research that has already influenced her decision to pursue a career as a clinical academic. By encouraging curiosity, promoting excellence, and showcasing promising new voices in the field, the Richard Wilson Essay Prize helps ensure that nystagmus remains a visible and compelling subject for future research. Initiatives like this are central to our goal of driving forward understanding, treatment and support for everyone living with nystagmus.

## Increasing reach and visibility

Over the past year, the Nystagmus Network has continued to build and strengthen its collaborations with researchers, clinicians, and the wider vision science community - both in the UK and internationally. A key highlight was the International Nystagmus Symposium 2024, held online in October and attended by 89 delegates from 13 countries, including Australia, the USA, India, and the Netherlands.

# RESEARCH, continued



Richard Wilson Essay Prize 2024 winner Justine Chan (centre) with Jackie and Claire Wilson at the Ruby Reception.

With presentations from seven expert speakers - spanning patient experience, genetic research, clinical studies, and treatment pathways, the symposium showcased the breadth and depth of current nystagmus research. Of note, Chris Harris delivered a thought-provoking talk titled "Ocular Motor Reciprocal Innervation Holds the Clue for INS", offering fresh insights into the neural mechanisms behind infantile nystagmus and sparking valuable discussion among delegates. Additionally, Actor and charity ambassador Gerard McDermott (who supported us in the BBC Radio 4 Charity Appeal this year) provided a moving patient perspective and we were proud to introduce the inaugural Richard Wilson Essay Prize winner, Justine Chan, who shared how her research had inspired her to pursue a clinical academic career. Symposium recordings were made available to healthcare professionals and academic researchers on our YouTube channel for continued future training and outreach.

In addition to the symposium, the charity hosted its annual Research Workshop in November 2024, providing a space for in-depth discussion and reflection on their current UK-based studies and research priorities and the potential impact this may have on our community. This workshop also brought together our core group of experts to help shape future nystagmus research strategy and aimed to produce a short position statement on the state of nystagmus research in the UK, which we hope to publish in 2025. Both events underscore our commitment to fostering collaboration and knowledge exchange across borders and disciplines, ensuring that the voices of patients and families remain central to scientific progress.

## Partnerships

The Nystagmus Network continues to work in close collaboration with the Nystagmus UK Eye research

contd.

group (NUKE) - a partnership that remains central to our mission to advance understanding and improve care for people living with nystagmus. This year, NUKE has been instrumental in shaping the nystagmus UK research landscape, for example through projects such as the development of a more meaningful way to measure visual function in individuals with nystagmus - a challenge that has long perplexed clinicians and patients alike. Led by Dr. Helena Lee, with input from multiple NUKE centres, this ambitious project aims to go beyond standard visual acuity tests to better reflect real-world visual experience, and is currently seeking funding from research bodies. The group also continues to support innovation in diagnostics, with research like the RETeval project, exploring whether hand-held tools can reduce waiting times for diagnosis compared to traditional imaging. Members of NUKE regularly contribute to key Nystagmus Network initiatives, including co-chairing the International Symposium and advising on small grant schemes, while also supporting the development of resources such as the proposed patient leaflet to accompany the Royal College of Ophthalmologists' Practice Points. This enduring partnership ensures that clinical expertise, patient insight and academic rigour remain at the heart of all we do.

Our longstanding partnership with Fight for Sight also continues to play a vital role in our research efforts. As the UK's leading eye research charity, Fight for Sight shares our commitment to improving the lives of people affected by nystagmus through scientific discovery. This year, we were pleased to see the restart of the joint-funded PhD studentship with Dr Frank Proudlock at the University of Leicester, a project which had previously been delayed but is now making encouraging progress. In addition, our Small Grant Award scheme, run in partnership with Fight for Sight, received two strong applications that were both deemed fundable: an exciting milestone. The successful projects are based at Cardiff University, where Dr. Lee Mcilreavy is investigating the cortical organisation of visual acuity and eccentricity in infantile nystagmus, and at the University of Southampton, where Dr. Eloise Keeling is exploring the use of benzophenones as a potential treatment for Oculocutaneous Albinism Type 1 (OCA1), a condition often linked with nystagmus. These collaborations demonstrate the powerful impact we can achieve when working together, and we are proud to partner with Fight for Sight to fund high-quality, innovative research that moves us closer to better outcomes for everyone living with nystagmus.

# RESEARCH, continued

## Our partnership with NUKE remains central to our mission

In 2024, we began the process of identifying a suitable project to receive a special legacy-funded research grant, thanks to a generous bequest from the late Rhoda Clarke, affectionately known to us as "Aunt Rhoda." Her remarkable gift of £32,000 was ring-fenced for research into congenital or infantile nystagmus—a condition that affected her family. Throughout the year, the Research Committee has carefully considered how best to honour this legacy, ultimately deciding to invite direct applications from UK-based researchers for imaginative and forward-thinking proposals. With the application window running from September to December 2024, we look forward to commissioning a new research project in early 2025 that will continue Aunt Rhoda's wish to improve understanding and treatment of nystagmus for generations to come.

### From 2024 to 2025 and beyond

Looking back on 2024, it is clear that our research activities continue to go from strength to strength. This year has been marked by fresh ideas, renewed partnerships and the nurturing of a new generation of researchers. From the success of our first-ever Richard Wilson Essay Prize to the relaunch of our PhD studentship and the awarding of two promising small grants, our commitment to funding meaningful and innovative research is stronger than ever. We continue to place collaboration at the core of our work - whether through partnerships or by bringing together voices from across the globe at our International Symposium. Above all, we remain guided by the lived experiences of those with nystagmus and/or their families, ensuring that their voices are heard and their needs are reflected in the research we support. As we look ahead to 2025, with further strategic planning underway and through our advocacy and championing of new initiatives, we hope to make further connections within the research community networks, expanding beyond research centres and looking towards the intersection of industry and academia to ensure that our work translates into meaningful future interventions.

Harshal Kubavat

*Harshal Kubavat*

Chair of Research Committee

# 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 2024 we continued to work hard to fulfill our goals: supporting the nystagmus community, raising awareness, funding research.



## Awareness

**We celebrated Nystagmus Awareness Day and delivered 3 big meet ups**



## Communication

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



## Research

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



## Support

**We answered 796 enquiries from adults, parents, teachers, clinicians and eye care practitioners**



## Fundraising

**Our supporters found all sorts of ways to raise £33,419 and we secured £34,147 in grants.**



## Information

**2,803 people downloaded our digital guides to living well with nystagmus.**

# MEMBERSHIP






A long-standing member chats with Marsha and Vivien at the Ruby Reception.

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.

**"I just wanted to say a huge thank you for the time you took to give me the advice about where to look to get an assessment for my son who has nystagmus, going into his A levels. Our local visual impairment team were excellent and had done the assessment within a few days of me contacting them. This would not have happened without your guidance of where to start. Many, many thanks." – a parent**

contd.

**"Please keep up your much needed work. We could not manage without people putting in the effort like you do." – a beneficiary**

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 your subscription goes directly into research

We offer affordable membership to anyone living with nystagmus.

## PARTNERSHIPS

The Nystagmus Network is a member of NUKE, Visionary and the Alliance and works closely with QTVIs, ECLOs and Eye Care Practitioners and 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

**2024 has been a year of resilience and commitment. While financial challenges persisted, our incredible community of supporters, donors and volunteers continued to show their dedication, allowing us to push forward with our important work.**

## Income

We raised £97,419 this year - 20% lower than 2023's £122,841, but still a testament to our supporters' generosity. A standout success was the sharp rise in general donations, which more than doubled to £18,588. However, we did not receive any legacy donations this year (£32,115 in 2023). Fundraising efforts remained strong at £33,989, while grants totalled £28,260 and membership subscriptions remained stable at £10,271.

## Investing in our mission

Expenditure increased to £116,074 (from £68,632), largely due to a £27,287 investment in research, a crucial step forward in our commitment to advancing knowledge and treatment. Support services also expanded to £31,755, ensuring we continue to provide direct support to those who need it most. We also proudly welcomed a sight-impaired intern, co-funded by the Thomas Pocklington Trust, furthering our commitment to inclusion and opportunity.

## Financial position and looking ahead

We ended the year with a £18,655 deficit, mainly as a result of spending restricted funds received prior year. Unrestricted funds remained stable with only a £1,955 deficit. Our reserves now stand at £101,632, with £61,517 in general funds, meeting our six-month reserves policy.

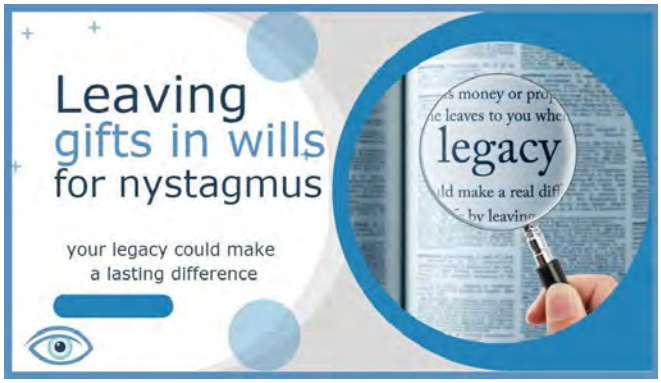
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The road ahead will require creativity and determination. We are actively seeking new grants, partnerships, and innovative fundraising initiatives. With continued support, we remain optimistic that we can navigate these challenges and continue to make a lasting impact.

Vicky Pitman FCA

*Vicky Pitman*

Treasurer









Vicky, treasurer, chats with a volunteer and one of our longstanding members and supporters at the Ruby Reception.

**"From the bottom of my heart, thank you. Thank you for holding the events and allowing people like myself to meet other people and hear their stories. It was the first time I met anyone else with nystagmus and to know that I'm not alone means more than you'll imagine."**

# FINANCIAL ACCOUNTS 2024

## Nystagmus Network - Financial Accounts 2024

| | 2024 | | | 2023 |
|---|---|---|---|---|
| | £ | £ | £ | £ |
| | Unrestricted Funds | Restricted Funds | Total Funds | Total Funds |
| **Receipts** | | | | |
| Fundraising | 33,989 | | 33,989 | 35,857 |
| Grants | 17,500 | 10,760 | 28,260 | 31,600 |
| Legacies | 0 | | 0 | 32,115 |
| General Donations | 18,588 | | 18,588 | 7,009 |
| Subscriptions | 10,271 | | 10,271 | 10,675 |
| Shop Sales | 2,486 | | 2,486 | 2,250 |
| Events | 1,207 | | 1,207 | 2,306 |
| Bank Interest | 2,617 | | 2,617 | 1,029 |
| | 86,659 | 10,760 | 97,419 | 122,841 |
| **Expenditure** | | | | |
| Income generation costs | 24,703 | | 24,703 | 24,901 |
| Support services | 4,295 | 27,460 | 31,755 | 21,610 |
| Office and Administration | 25,133 | | 25,133 | 17,972 |
| Research | 27,287 | | 27,287 | 0 |
| Trustee expenses | 60 | | 60 | 0 |
| Events | 7,136 | | 7,136 | 4,149 |
| | 88,614 | 27,460 | 116,074 | 68,632 |
| **Net Surplus/(Deficit) for the year** | -1,955 | -16,700 | -18,655 | 54,209 |
| *Total Staff costs included above* | | | *£73,071* | *£52,944* |
| Reserves b/f | 63,472 | 56,815 | 120,287 | 66,078 |
| Movement in year | - 1,955 | - 16,700 | - 18,655 | 54,209 |
| Reserves c/f | 61,517 | 40,115 | 101,632 | 120,287 |
| **Statement of Assets and Liabilities** | | | | |
| Cash funds | 61,517 | 40,115 | 101,632 | 120,287 |

Accounts Prepared by

Vicky Pitman FCA (Treasurer)

Accounts Examined by

AR Black 16/2/25

Andrew Black ACA




# LEGAL DETAILS

## Charity objects

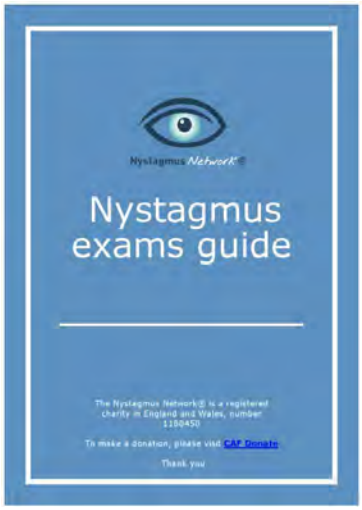
The charity's objects focus on the relief of nystagmus (visual impairment sufferers and their families. The objects also focus on advancing the education of the public in and to promote research into the condition known as nystagmus and to publish the useful results of any such research which the charity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

## Appointment of trustees

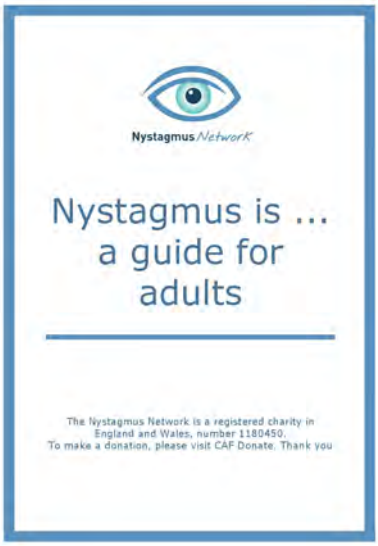
Trustees are recruited in line with our equality and diversity policy and to reflect lived experience of nystagmus. They are appointed after a thorough interview process. Induction includes immersion in the Charity Governance Code and charity policies and procedures. Introduction to the work of the charity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

## Trustees' responsibilities

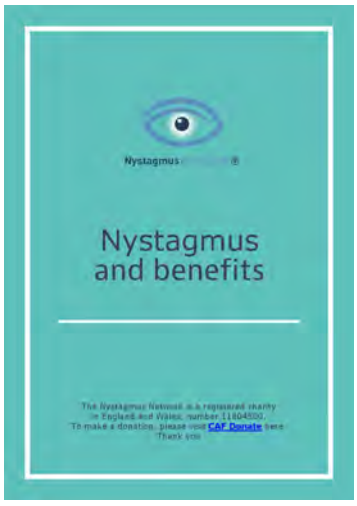
Trustees are responsible for the preparation of financial statements for each financial period which give a true and fair




Exams guide




Nystagmus is ... a guide for adults




Benefits 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

Celebrating our **Ruby** *Year*



Nystagmus *Network*®

1984 - 2024

**"A big thank you to you and all the staff at Nystagmus Network for putting on this brilliant event. The time and effort that goes into making these events work is enormous and all credit to you.**

**I met some lovely people and learned a lot.**

**The two researchers were excellent speakers.**

**I have been very appreciative all these years for your organisation. Thank you."**

**– a parent**

NYSTAGMUS NETWORK

Nystagmus *Network*

MORE INFORMATION

For more information visit us online at nystagmusnetwork.org

or email us at info@nystagmusnet.org.

# Nystagmus Network - Financial Accounts 2024

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|---|---|---|---|---|
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Accounts Prepared by

**Vicky Pitman FCA (Treasurer)**

Accounts Examined by

AR Black 16/2/25

**Andrew Black ACA**

CHARITY COMMISSION FOR ENGLAND AND WALES

# Independent examiner's report on the accounts

## Section A Independent Examiner's Report

**Report to the trustees**

Charity Name: NYSTAGMUS NETWORK

**On accounts for the year ended**: 31st DECEMBER 2024

**Charity no (if any)**: 1180450

**Set out on pages**: 1 (remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended DD / MM / YYYY.

**Responsibilities and basis of report**

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent examiner's statement**

[The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of [insert name of applicable listed body]]. *Delete* [ ] *if not applicable.*

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination (other than that disclosed below *) which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

**Signed:** A.R.Black **Date:** 16/2/2025

**Name:** ANDREW BLACK A.C.A.

**Relevant professional qualification(s) or body**: INSTITUTE OF CHARTERED ACCOUNTANTS OF ENGLAND & WALES

| | |
|---|---|
| **(if any):** | |
| **Address:** | ORCHARD HOUSE,<br>5 CHATSWORTH GARDENS,<br>SHREWSBURY, SY3 7BG |

## Section B Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

**Give here brief details of any items that the examiner wishes to disclose.**

NONE

**NYSTAGMUS NETWORK**

England & Wales - Charity number 1180450

# Accounts

**Our vision is for a world in which nystagmus is consistently and fully understood and supported in all environments.**

# 2023 TRUSTEES' ANNUAL REPORT

**"Many thanks for your email. I have shared it with my son who has found it useful and that someone actually understands! Thank you once again."**
**– a parent**

NYSTAGMUS NETWORK


Nystagmus Network

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

**"The Nystagmus Network gives us hope ... the joy of being part of a caring community which raises awareness and funding to enable everyone living with nystagmus to be happy and hope-full. You are inspirational."**
**- a grandparent**



# 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.**

A mother and daughter at a Nystagmus Network event in Southampton.

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**"Thanks so much for all your help with the form Mike - I got my PIP!"**
**- a member of the Nystagmus Network**



Tim Cuddeford
Chair of the
Nystagmus Network
trustees

# CHAIR'S MESSAGE

Through 2023 the charity has gone from strength to strength in delivering excellent support, funding research, and raising awareness.

Fundraising by our members and supporters continues unabated, without which the team could not deliver all the fantastic support our beneficiaries rely on.

Building on our 2020-22 experiences, in 2023 we have held very successful in person regional events in Banbury, Southampton and Manchester and will continue this model moving forwards with more regional events and support groups. This reduces onerous travel and provides a more personable experience. We will continue to use Zoom for larger events with a more dispersed audience e.g. our AGM.

Online events with researchers, #Symposium2023, the UK Research workshop and NUKE (Nystagmus UK Eye research group) meetings, were very well attended.

We continued to support children with nystagmus and their parents to get the best educational outcomes from their local educational authority. This included 1-2-1 support,

## Through 2023 the charity has gone from strength to strength in delivering excellent support, funding research, and raising awareness.

published guidance and IPSEA workshops. Demand for support for adults is increasing both for in the workplace and in general living, in particular, for people with acquired nystagmus.

As we enter our Ruby anniversary year I would like to thank again all our members, supporters, fundraisers, trustees and staff for all their efforts ensuring success in 2023 and a great basis for a positive 2024.

Tim Cuddeford

*Tim Cuddeford*

Chair of trustees



The big nystagmus meet up - Manchester

**"I only found you guys today ...
Reading other people's experiences
has made me so happy today.
We are not alone.
Thank you.
– a parent**













**"Your group has been so kind and informative for me with lots of support." – an adult with Acquired Nystagmus**

# TRUSTEES SERVING IN 2023

**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.**

**Tim Cuddeford**
**Chair of Trustees**
**Chair of Finance**



**Vivien Jones**
**Founder and Honorary President**
**Chair of Research**



**From the top row, left to right:**

**Miriam Blackburn**
**Karen Chu, Chair of Funding**
**Sharon Clifford**
**Peter Greenwood, Vice Chair of Trustees, Chair of Awareness**
**Harshal Kubavat**
**Vicky Pitman, Treasurer**
**Andrew McFarlane**
**David Singleton**
**James Singleton**
**Kathryn Swanston, acting Chair of Support**
**John Vekinis**




The team at the big nystagmus meet up in Southampton, April 2023

# 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.

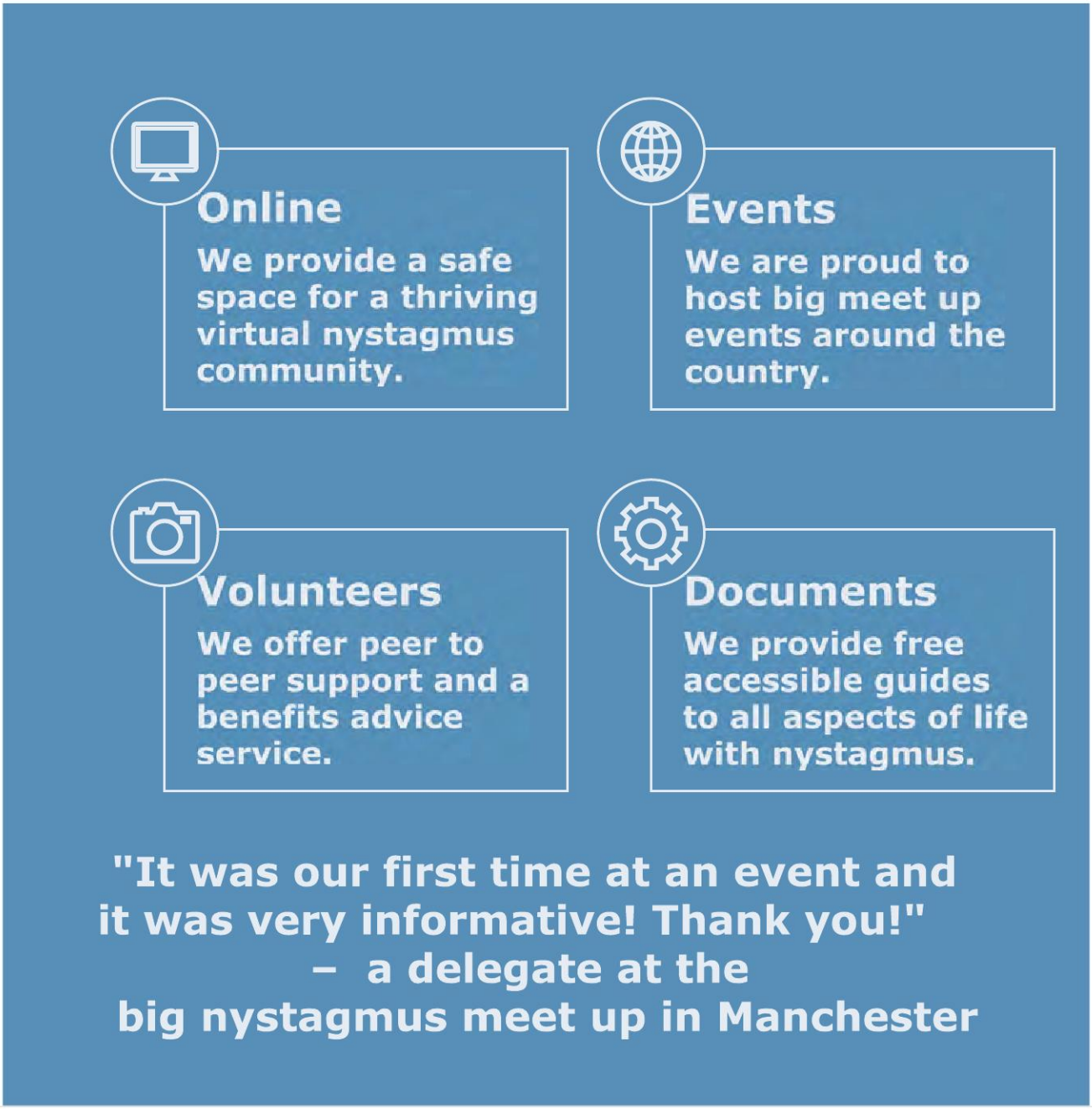
The Nystagmus Network funds research into diagnostics and therapies which could have a positive impact on quality of life as well as exploring prevention and, ultimately, cure.

**"I really appreciate your guidance. The service you offer is really wonderful." – a parent**

**"I really appreciate your effort. For me, you listening to my explanation and what I and my daughter are facing in the current situation is something I am really grateful for." – a parent**

# SUPPORTING THE NYSTAGMUS COMMUNITY

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



## SUPPORT COMMITTEE

# 781

PEOPLE SUPPORTED

**"It has been amazing having this charity in our corner." - a parent**

We have had another busy and active year providing information and support in a wide range of different ways and formats. Offering front-line support to individuals and families by email and telephone continues to be very much at the heart of this.

Three monthly online forums, including one for parents, continue to meet and this year these were rebranded as get togethers with a variety of guest speakers and specific themes being introduced. In January 2023, inspired by the Jo Cox Foundation's Great Get Together initiative, we hosted a special joint acquired and congenital nystagmus 'Great Winter Warmer Get Together' at which we welcomed guest speaker, Gerard McDermott, an actor who has nystagmus. This enjoyable online event also included time to chat and to enjoy a great quiz.

To complement our online get togethers and larger regional meet ups, we have also established some new local in-person support groups. Our very first regional get together, hosted by newly recruited volunteer, Andy was held in Banbury in March 2023. Another new local Manchester group led by anther volunteer called Andy began to meet up regularly. We plan to widen this offering into other locations in the future.

We have an extensive library of up-to-date guides to nystagmus on our website, free to download, providing support and guidance in a wide range of areas. In November 2023 a new publication, 'A Guide to Nystagmus in the Early Years' was launched. Offering support for the 0-5 year age group, this guide was downloaded more than 100 times in the first week. Written for parents, carers, families and education staff, the guide includes practical advice from a parent in the form of a case study. With cost-of-living challenges continuing, our guide to benefits has remained a resource that many people have been signposted to during the year.

This year we have also provided information and guidance on

contd.

**"Thank you so much for organising such a wonderful event last weekend. It was a very stimulating event. Our daughter's highlight was meeting other children of her age who have nystagmus." - big meet up attendee**

# 3,182

DOCUMENT DOWNLOADS

nystagmus in a growing number of external professional settings which has resulted in new contacts being made and existing networks developed.

Hanni from the staff team joined the Royal National Institute of Blind People (RNIB) panel of education experts and spoke about the particular support needed for children with nystagmus.

Sue attended the first in person conference of VIEW in Birmingham in March 2023. This is the key annual conference for QTVI's (Qualified Teacher of Children and Young People with Vision Impairment) and other professionals in this field.

Sue delivered nystagmus awareness raising training to 4 London Boroughs, Lancashire QTVIs, national QTVIs and



national and Southwest ECLOs (Eye Care Liaison Officer) teams. She was also invited to deliver training for a fostering agency supporting carers fostering children with nystagmus and presented and exhibited at the Albinism Fellowship UK conference in November 2023.

Thank you to everyone who has joined an event or get together during the last year, in person or online, as it is through this mutual encouragement and support of one another that Nystagmus Network draws its strength.

Kathryn Swanston

*Kathryn Swanston*

Chair, Support Committee

## AWARENESS COMMITTEE

**13k**

FACEBOOK FOLLOWERS

**"My daughter was diagnosed with nystagmus earlier this year and I have found your social media pages and information leaflets a huge help for us all." - a parent and fundraiser**

One of the key objectives of the charity is to raise awareness of nystagmus. Every time you take part in an event or tell someone what you're doing and why, that's one more person who understands what nystagmus is. We believe that the more people who know about nystagmus, the better the condition is understood.

The Awareness Committee is tasked with raising awareness every single day, these are the highlights from 2023.

**Big Nystagmus Meet-up in Southampton (April)**
Following the pandemic, we were keen to re-establish our 'meet in person' events with an emphasis on local meet-ups with the objective of encouraging local support groups to be formed. Hosted by the amazing Jackie Powers at Southampton Sight, we had over 50 members and supporters who got to:

- hear inspiring guest speakers;
- get advice and find out about local services;
- help us celebrate the achievements of nystagmus heroes;
- ask researchers Jay Self and Helena Lee anything they liked;
- meet Nystagmus Network staff and trustees;
- chat with other parents and carers and people living with nystagmus

If that wasn't enough, there were some fantastic raffle prizes available to win and help raise money for the charity.

**Big Nystagmus Meet-up in Manchester (September)**
Later in the year we hosted another meet-up in Manchester with over 50 members and supporters attending at the Limelight community hub in Trafford.

Attendees got to hear some great guest speakers, information and advice on all aspects of living with nystagmus including local services, a Q+A session with clinicians, and, most importantly of all, the chance to meet other parents and people living with nystagmus.

contd.

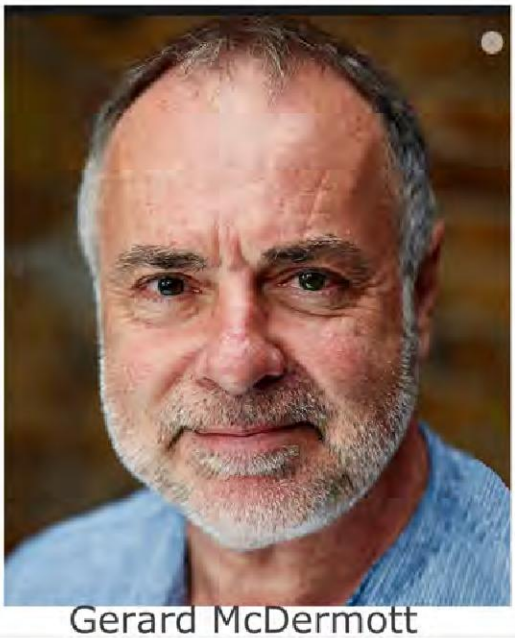
## NYSTAGMUS AWARENESS DAY STORIES



Marsha de Cordova MP



Mason



Gerard McDermott

**Local Nystagmus Get Together in Banbury (March)**
Our volunteer, Andy hosted a coffee and chat in Banbury. Look out for a 'big meet-up' planned in Oxford for 2024.

**Nystagmus Awareness Day (20 June)**
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.
We invited you to share your story and received lots of incredible and inspiring stories. Thank you to Marsha, Mason, Savannah, Isabelle, Jude and all the others who shared their stories. A special call-out to Peter who shared his story in the form of a poem and Gerard who sang the Nystagmus Blues! Check out our website to read these amazing stories.

Other events helping to raise awareness included:
**Great Winter Get Together (January)**
Special guest Gerard McDermott (actor, songwriter and children's author) joined us to talk about his new musical Painting the Town and share his experience of nystagmus.

We have continued to host our regular virtual get togethers for parents of children with nystagmus, adults with acquired and congenital nystagmus, a chance to share experiences.
Look out for more events in 2024 including big meet-ups in Oxford, London and Sheffield and celebrating our 40th anniversary, our Ruby Year.

Peter Greenwood

*Peter Greenwood*

Chair of Awareness Committee

# FUNDING COMMITTEE

Our target for 2023 was £88,000, 10% more than our actual income for 2022, to enable us to respond to the increase in demand for support and information whilst supporting our ambition in areas of research.

We didn't quite reach the target, but we were pleased to have again secured grants for multi-year core service and project delivery, which therefore means we have future year income already secured and ring-fenced for specific projects. We are grateful to the **Pears Foundation, Thomas Pocklington Trust**, **The Inman Charity** and **Magic Little Grants**. At the very end of 2023 we were delighted to be awarded a grant from T**he Powell Family Foundation** to deliver our most ambitious project yet, an exemplary set of adaptable, nystagmus-friendly learning materials. We will report on our progress in 2024.

Grant applications in 2023 continued with a 35% success rate, the total value of grant applications increasing from 2022. We are very pleased that

**In a difficult economic climate there were significant challenges for fundraising**

the staff team managed to secure £31,600 worth of grant funding, of which we will be able to utilise £29,260 in 2024. We hope that 2024 will continue to see successes in this area.

Fundraising finished the year just under target by 8%. We are grateful to the groups and individuals who supported us. We hope that 2024, our Ruby Year will see additional fundraising to celebrate the impact of the charity on so many people over its 40-year history. Here are just a few of the 2023 fundraising highlights.

- The Jersey Golf Day raised over £4,500. Thanks to James for organising this popular annual fixture.
- Dom raised £500 from many supporters to cut his lockdown hair.
- Edward hosted a concert in Burton on Trent raising £720.
- Rapha donated over £2,500 from his Barmitzvah in October.

**"Thanks so much. This will really help in pushing for registration for those patients who have good visual acuity but poor functional vision." – an ECLO**

contd.

# 147

CALLS TO OUR SUPPORT LINE




A charity concert for the Nystagmus Network

- Kirsty and Vicky took on the challenge of press ups raising over £400.
- We had runners for the Mud Run, Bournemouth Half and the London Marathon along with obstacle races and other runs and walks, raising over £7,500. Thanks to Olly, Mike, Yvette, Ann, Mike, Joanna and Kylie.
- The Regatta Right Move team raised over £1,500.
- Keen swimmer, Jenna raised £170 taking part in the Great North Swim supported by her daughter.
- Mary hosted her annual coffee morning in March raising £400.
- Issac and Everlyn raised over £470 for their baby brother Jude by walking 5km a day for a week over the summer, with wonderful photos of them pushing Jude even in the rain.

We thank everyone who sponsored, organised and pledged to fundraise.

Karen Chu

*Karen Chu*

Chair of Funding Committee

**In 2023, we received a legacy gift from the late Mrs Rhoda Clarke, in the name of her great niece, Florence who has albinism and nystagmus. Aunt Rhoda wished to benefit Florence and other children like her through continued research and support from the Nystagmus Network.**

# RESEARCH COMMITTEE

**IMPROVING QUALITY OF LIFE THROUGH RESEARCH**

## The Nystagmus Network has been investing in research since the 1990s

### "The Nystagmus Network is unique in its support of research in the UK." - a nystagmus researcher

A highlight of the year was the publication of the **Nystagmus Care Pathway** to which the Nystagmus Network made a significant contribution. The guidance on the management of nystagmus in children – called the Clinical Practice Point - was published on the Royal College of Ophthalmologists' website. The purpose of the Practice Point is to provide a single point of reference for busy clinicians when managing patients with this complex eye condition. The charity contributed to the development of the Practice Point through its membership of **NUKE**, the UK nystagmus eye research group. Members of NUKE worked together to develop guidelines on diagnosis and care for patients with nystagmus – the first time such guidelines have been created for this condition.

The adoption of the Nystagmus Care Pathway means that clinicians can now refer to them when treating patients with nystagmus – something the Nystagmus Network hopes will lead to continuing improvements in developing standardisation of medical diagnosis and care.

Another high point was the **International Symposium** in September. The conference was attended by clinicians, researchers and students and ably chaired by Jon Erichsen (Cardiff University) and Jay Self (University of Southampton). There were presentations on all aspects of nystagmus with lively discussions particularly on genetic testing and training on nystagmus for clinical practitioners, as well as some exciting insights into testing potential new therapies for albinism and nystagmus. Marsha de Cordova MP, who has nystagmus, gave a keynote address with a personal contribution recorded specifically for us.

contd.

## We have invested on average £18k per annum in nystagmus research over the past decade

NUKE
NYSTAGMUS UK EYE RESEARCH GROUP




Nystagmus Symposium 2023

## "Thanks for organising this cool event!" a Symposium delegate

We plan to continue to deliver the symposium annually, to extend the visibility and impact of nystagmus-related research both in the UK and through collaborations across the globe.

Increasing the pool of academic and scientific research continues to be of importance to us, as we seek further investment and involvement in this field. To support this priority, we spent time in 2023 preparing '**The Richard Wilson Essay Prize**', in remembrance of our former chair (2010-19). We hope this encourages students and early career researchers to consider future work in the nystagmus space.

Research supported by the partnership between the Nystagmus Network and the charity Fight for Sight continues. At the University of Plymouth, Dr Mahesh Joshi and Asma Zahidi are investigating whether vision therapy using a moving target leads to better control of eye movements. The charity is supporting participant recruitment. The project is expected to finish in April 2025.

At the University of Leicester, Mervyn Thomas is exploring novel animal models for infantile nystagmus. This project is expected to end in June 2024.

The Nystagmus Network PhD studentship project – looking at nystagmus and glare – suspended in February 2023 due to illness - has now resumed. Mohammed Bakhit took up the baton in November 2023 and is now scheduled to complete his

**contd.**

# RESEARCH, continued

**The Nystagmus Network received a legacy gift in 2023 to be invested in nystagmus research**

**£32,115**



Florence presents Aunt Rhoda's gift

research in October 2026.

Disappointingly, no new applications were received in 2023 for the 2023 Nystagmus Network-Fight for Sight small grant awards. We are investigating with Fight for Sight whether the amount of the awards – currently £15,000 with each charity contributing half - needs to be increased but we are continuing with the scheme in 2024.

Although 2023 was a setback in terms of the joint awards, the Nystagmus Network is proud of its history in terms of supporting research financially. Between 2014-2023, thanks to our supporters and fundraisers, the charity has invested an average £18,000 per year in research. The total over the decade is £180,239 – not bad for a small charity, although we would of course wish it could be more.

We have established ourselves as a valuable patient resource for the research community with our participation and engagement.

Good news came through to the charity in 2023 in the form of a £32,000 legacy to be used for research. We are determined to find the best possible home for this generous gift.

Vivien Jones

*Vivien Jones*

Chair of Research Committee and **Harshal Kubavat, trustee**

**"It would be amazing if you could come and speak. I have seen you at a conference before and your presentation was excellent."**
**- a university training organiser**

# OUR KEY PROJECTS

In 2023 the Nystagmus Network continued to fulfill our stated goals: supporting the nystagmus community, raising awareness and funding research.



## Awareness

**We celebrated Nystagmus Awareness Day and delivered 2 big meet ups**



## Communication

**Daily Facebook posts and Tweets helped us reach an audience of 14,300 people**



## Research

**We held a UK research workshop and an international symposium**



## Support

**We answered 781 enquiries from adults, parents, teachers, clinicians and eye care practitioners**



## Fundraising

**Our supporters found all sorts of ways to raise £35,857 and we secured £31,600 in grants.**



## Information

**We revised and updated our digital information and published a new guide to nystagmus and the early years.**

# MEMBERSHIP

**Are you a *member?***



Our volunteer, Karen who knits our nystagmus mascots

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.

**"This is such a lovely idea!
I'm trying to collect different representations of conditions for my class of primary aged children with complex needs. We've just adopted a dinosaur with a gastro tube! I would LOVE some dolls with nystagmus and will be taking a look at your shop."
- a Facebook follower**

## "My 2 year old has nystagmus and would love to help fundraise to pay back the amazing work and information your charity produces!" - a parent

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 your subscription will go directly into research

We offer affordable membership to anyone living with nystagmus.

### PARTNERSHIPS

The Nystagmus Network is a member of NUKE, Visionary and the Alliance and works closely with QTVIs, ECLOs and Eye Care Practitioners and 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

## It's important to acknowledge that the charity relies entirely on voluntary contributions. Fundraising has been exceptionally challenging this year.

We extend our heartfelt thanks to our members, fundraisers and donors whose generosity enabled us to raise a total income of £122k for the year, a 30% increase on prior year. This ensures the Nystagmus Network maintains its position as the foremost charity supporting people living with nystagmus in the UK.

A significant share of the annual income was from a generous £32k legacy, which is held in restricted funds to be spent exclusively on research in the near future. Other significant income streams were £32k from grants received and £36k from fundraising, similar levels to prior year. The charity saw a 24% decrease in donations to £[illegible] and a 10% decrease in membership income to £10k. Fundraising continues to be challenging due to the ongoing cost of living crisis, but the charity has shown resilience over the past few years thanks to the continued dedication of our supporters and staff.

Continued cost management of our resources, meant that total expenditure for the year was limited to £69k, giving a surplus for the year of £54k.

The year ended with cash reserves of £120k, of which £57k was restricted funds, in line with our reserves policy of putting aside free cash reserves of 6 months' cover for annual expenses. The charity organised the annual research symposium but did not spend any funds

contd.

specifically on research in the year, instead carrying forward the £32k legacy to next year with the intent of funding a significant research project.

As we embark on our ruby anniversary year, the small and dedicated staff team continue to work hard to provide support through the helpline, raise awareness, and drive fundraising efforts.

Together we are making a tangible difference to the lives of those living with nystagmus, fostering a community where everyone feels supported on their journey.

*Vicky Pitman FCA*

*Vicky Pitman*

Treasurer



A young child tries out a new app for children with impaired vision at a Nystagmus Network event.

**"I wanted to do this because two of my children, now adults, have nystagmus and the group has been very helpful."**
**- a volunteer**

# FINANCIAL ACCOUNTS 2023

## Nystagmus Network - 2023 Accounts

| | 2023 | | | 2022 |
|---|---|---|---|---|
| | £ | £ | £ | £ |
| | Unrestricted Funds | Restricted Funds | Total Funds | Total Funds |
| **Receipts** | | | | |
| Fundraising | 35,857 | | 35,857 | 36,955 |
| Grants | - | 31,600 | 31,600 | 32,520 |
| Wills | - | 32,115 | 32,115 | 100 |
| General Donations | 7,009 | - | 7,009 | 9,236 |
| Subscriptions | 10,675 | - | 10,675 | 11,845 |
| Shop Sales | 2,250 | - | 2,250 | 2,944 |
| Events | 2,306 | - | 2,306 | 891 |
| Bank Interest | 1,029 | - | 1,029 | 216 |
| | 59,126 | 63,715 | 122,841 | 94,707 |
| **Payments** | | | | |
| Fundraising Costs | 24,901 | - | 24,901 | 31,253 |
| Support services | 7,060 | 14,550 | 21,610 | 25,977 |
| Office and Administration | 17,972 | - | 17,972 | 19,632 |
| Research | - | - | - | 18,854 |
| Trustee expenses | - | - | - | 92 |
| Events | 4,149 | - | 4,149 | 119 |
| | 54,082 | 14,550 | 68,632 | 95,926 |
| **Net Receipts/(Payments)** | 5,044 | 49,165 | 54,209 | - 1,219 |
| *Total Staff costs included above* | *38,394* | *14,550* | *52,944* | *64,857* |
| Reserves b/f | 58,428 | 7,650 | 66,078 | 58,428 |
| Movement in year | 5,044 | 49,165 | 54,209 | 7,650 |
| Reserves c/f | 63,472 | 56,815 | 120,287 | 66,078 |
| **Statement of Assets and Liabilities** | | | | |
| Cash funds | 63,472 | 56,815 | 120,287 | 66,078 |

Accounts Prepared by

Vicky Pitman FCA (Treasurer)

Accounts Examined by

ARBlack

Andrew Black ACA



A Dad and his daughter at a 2023 Nystagmus Network event

# LEGAL DETAILS

## Charity objects

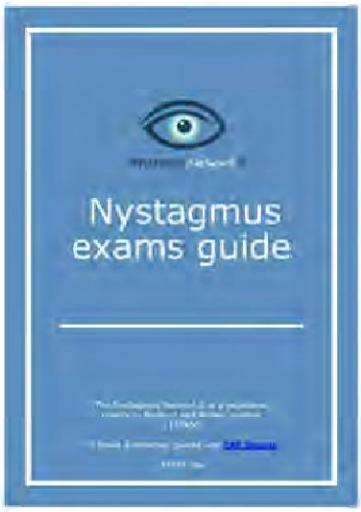
The charity's objects focus on the relief of nystagmus (visual impairment) sufferers and their families. The objects also focus on advancing the education of the public in and to promote research into the condition known as nystagmus and to publish the useful results of any such research which the charity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

## Appointment of trustees

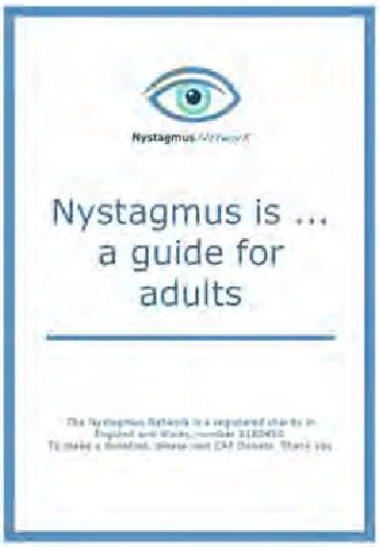
Trustees are recruited in line with our equality and diversity policy and to reflect lived experience of nystagmus. They are appointed after a thorough interview process. Induction includes immersion in the Charity Governance Code and charity policies and procedures. Introduction to the work of the charity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

## Trustees' responsibilities

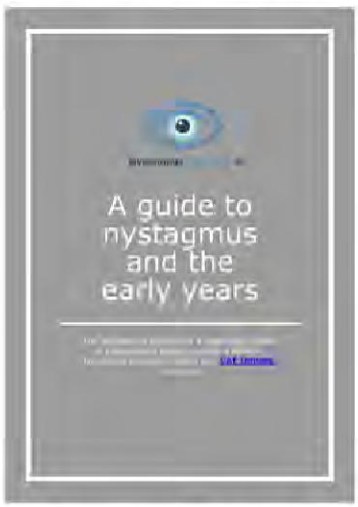
Trustees are responsible for the preparation of financial statements for each financial period which give a true and fair




Exams guide




Nystagmus is ...
a guide for adults




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

**"I really loved the friendly atmosphere at your event in Manchester. We loved the messy table!!! We learned such a lot of helpful stuff too." - a grandparent**

NYSTAGMUS NETWORK

Nystagmus Network

MORE INFORMATION

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

**NYSTAGMUS NETWORK**

England & Wales - Charity number 1180450

# Accounts

**Our vision is for a world in which nystagmus is consistently and fully understood and supported in all environments.**

# 2022 TRUSTEES' ANNUAL REPORT

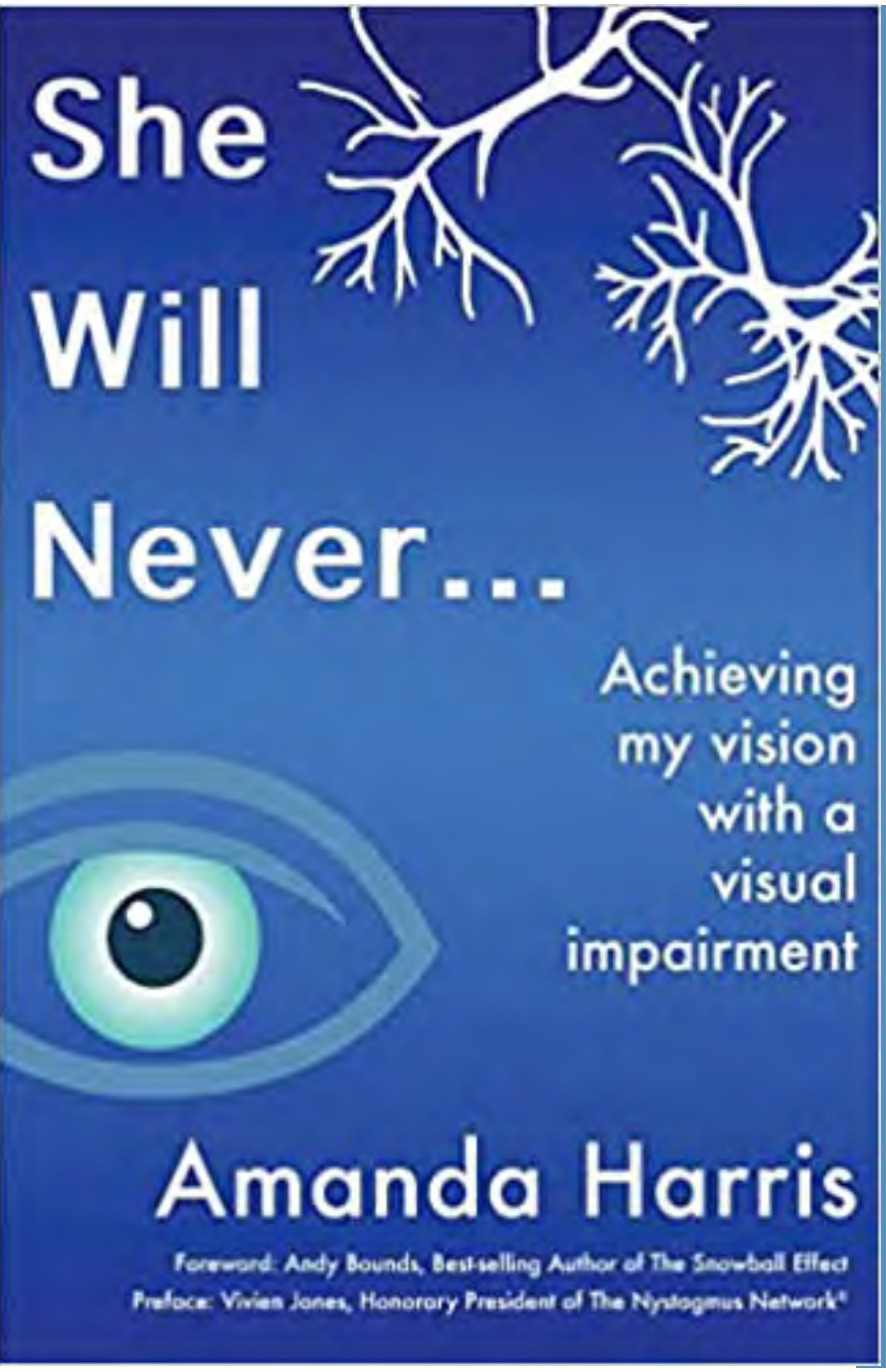
**"I've had nystagmus for over 12 years and it was by chance I came across your charity on the web. It's good to know there is support available for people with this debilitating condition."**

**- a Facebook follower**

NYSTAGMUS NETWORK


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

**"Thanks so much for all you do." – a Facebook follower**




She Will Never ... a book by Amanda Harris giving her account of living with nystagmus

## 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.**

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**"Thank you for the excellent work by the Nystagmus Network. Through it, I've learned more about how to live well with my condition in the last few years than I ever thought possible!" - a Facebook follower**




Tim Cuddeford
Chair of the
Nystagmus Network
trustees

# CHAIR'S MESSAGE

Through 2022 I am pleased to report that we continued to provide a wide range of support for members of the nystagmus community, to fund research and raise awareness.

Cost of living pressures and crises abroad impacted fund raising in the early part of 2022. Thankfully though excellent fund raising by our supporters and successful grant applications resulted in us finishing the year on plan in terms of income, expenditure and reserves. I would like to thank all of you, our members and supporters, and of course the staff team, who made this possible.

Although 2022 in Covid terms was a more normal year, we continued with mainly online events.

We had planned for Open Day this year to be an in person occasion at the end of September, but, sadly, this time the national train strikes were the cause of us moving back to a virtual event at short notice. This meant that more people were able to attend.

Two key online events with researchers, namely #Symposium2022, a hybrid event with a truly international audience, and the UK research

**Excellent fundraising by our supporters and successful grant applications resulted in us finishing the year on plan.**

workshop, were well attended, productive, collaborative and extremely well received by delegates.

We began to build our volunteer network this year and in 2023, with volunteer support, you should see more regional face to face events, that involve less travelling, in combination with our continued online get togethers where appropriate.

With education at the front of many families' minds, particularly following extended periods of home-schooling, we continued to support children with nystagmus and their parents to access appropriate support from their local educational authority to achieve their best educational outcomes. This included one-to-one educational advice and guidance, our digital information and IPSEA workshops as well as our online parent forums, where lots of advice and experience was shared.

Demand for support for adults particularly around benefits and the workplace continued to grow, with a notable increase in enquiries from people with acquired nystagmus.

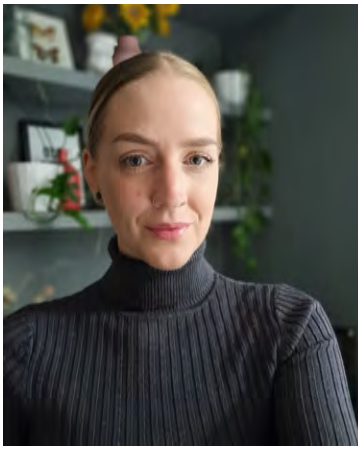
I would like to thank again our members, supporters, fundraisers, trustees and staff for all their hard work and enthusiasm ensuring success in 2022 and helping us build a great base for a positive 2023.

Tim Cuddeford




Chair of trustees

**"I have always found Nystagmus Network to be really positive and informative - with no personal bias attached to the information, which is a real relief when navigating a new diagnosis." - a documentary maker**














# TRUSTEES SERVING IN 2022

**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, technology, medicine or finance. They all share a firm commitment to the nystagmus cause. Our recruitment process ensures equality, diversity and lived experience are fully represented.**

**Tim Cuddeford**
**Chair of Trustees**
**Chair of Finance**



**Vivien Jones**
**Founder and Honorary President**
**Chair of Research**



**From the top row, left to right:**

**Miriam Blackburn**
**Richard Blackmore**
**Claire Brinn, Education Advocate**
**Karen Chu, Chair of Funding**
**Peter Greenwood, Vice Chair of Trustees, Chair of Awareness**
**Harshal Kubavat**
**Vicky Pitman, Treasurer**
**David Singleton**
**James Singleton**
**Kathryn Swanston, acting Chair of Support**
**John Vekinis**
**Daniel Williams**




Trustees at their May 2022 committee meeting

# 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.

**Thank you so much! Really grateful for your kindness and valuable time given – an adult with AN**

**"We're quite early on in learning about our son's nystagmus and how it affects him and the Nystagmus Network has been so helpful so far. The resources available have explained so much."**
**– a parent**

# 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.



## Open Day

We are proud to host the biggest annual UK nystagmus event.



## Volunteers

We offer peer to peer support and an education support service.



## Documents

We make up to date information available free of charge to all.

**"Thank you for all the great work you do, so helpful and informative, makes us not feel alone." – a member of our AN forum**

SUPPORT COMMITTEE

**745**

PEOPLE SUPPORTED

**"You have been very helpful! I feel much better after speaking with you and getting access to the support that is available." - a parent**

It was another very busy year for our information and support line and for email enquiries. Questions covered the broadest possible range of topics, from the early years, to driving, to medical interventions, research, benefits and registration as sight impaired. The majority of queries came from parents, though there continued to be a steady increase in the number of adults with acquired nystagmus finding their way to us for support.

**Peer to peer support**

As we finally emerged from the pandemic, we tentatively planned face to face events and networking opportunities for the nystagmus community. With generous support from the Pears Foundation, we began recruiting a small team of volunteers to host local and regional get togethers. Although at least 1 in 1,000 people have nystagmus you can go a lifetime without meeting anyone else who has it, so giving people the opportunity of getting together is vital for their social and emotional wellbeing in particular.

Meanwhile, the monthly online sessions we started hosting in early 2020 remain as popular as ever, with people joining from across the UK and also occasionally from Europe, the US and New Zealand.

**50 for Free**

In March a party of people living with acquired nystagmus, their partners and Sue from the Nystagmus Network were lucky enough to enjoy a weekend together in Georgian splendour at a Land Mark Trust property in Bath as part of the Trust's 50 for Free initiative. It was the first time the group had come together in person following our monthly zoom calls throughout the pandemic and it felt like meeting up with old friends. With enormous thanks to the Landmark Trust.

**School and education**

As we hosted the final in our current series of IPSEA workshops for parents and carers on SEND law, the question of support for children and young people in the exam

**contd.**

**"It was so lovely to meet everyone in Bath last weekend. We had a great connection and got on so well despite the very troublesome nystagmus. I can't thank you enough for all the work you put in to arranging this." - 50 for Free participant.**

# 2,722

DOCUMENT DOWNLOADS




Our 50 for free weekend in Bath in March 2022

room emerged as a challenge for many. In response, we wrote and published our new guide to nystagmus and exams, setting out the adaptations and concessions available and how and when to secure these.

**The cost of living crisis**
Alongside the annual review and updating of our range of free to download digital documents, we introduced a new guide to benefits, in response to the cost of living crisis, thanks to the support of our volunteer benefits adviser, Mike Hughes. Mike was especially busy this year, supporting no fewer than 13 people we referred to him for help with their PIP and DLA applications, appeals and tribunals. There were some notable successes for which our beneficiaries were especially grateful.

**Social prescribing**
The charity began exploring opportunities to reach and support more people living with nystagmus through the National Academy of Social Prescribing and the regional voluntary sector. We hope to raise awareness of our support and information services at local community level.

Sue Ricketts

*Sue Ricketts*

Executive Information and Development Manager

## AWARENESS COMMITTEE

**13k**

FACEBOOK FOLLOWERS

**"We never dreamed that our little help group would grow into such a big and successful organisation! Hats off to all you enthusiastic, creative, techno-brilliant people!" a long-standing member**

Here at the Nystagmus Network, we raise awareness of the condition every single day of the year because we believe that the more people who know about it, the better. There were two key events in the Awareness calendar for 2022:

**Nystagmus Awareness Day**
Holding a national and international Nystagmus Awareness Day on 20 June serves as a reminder to everyone that we are here and our voices need to be heard. Every time you take part in an event or tell someone what you're doing and why, that's one more person who understands what nystagmus is.

This year's Nystagmus Awareness Day we asked our members and supporters to 'Step Up for Nystagmus'. It not only helped raised awareness of nystagmus but also highlighted that steps can be tricky for people with the condition. We asked you to 'show us your steps' whether that was taking the stairs, counting your steps or helping us with our challenge to walk 500 miles.

Thank you to everyone who took part. Even Marsha de Cordova MP joined in, sharing images of herself using nystagmus friendly steps in her constituency. Thank you, Marsha.

Assistant Manager at Specsavers Leicester, Khalil, who has nystagmus himself, encouraged the whole staff team to wear Nystagmus Network T-shirts and wristbands for the day. Everyone posed outside the shop and even got their picture and story in the local press. We also heard the heart-warming story of the amazing Charlie and Luke who raised money to buy Charlie's U7s team some new football kit (complete with our charity logo). Both Khalil and Charlie were named Nystagmus Champions of 2022.

**Open Day**
We were initially very excited to be holding our first 'meet in person' event since the pandemic but unfortunately were defeated at the eleventh hour by a national train strike.

**contd.**

## NYSTAGMUS AWARENESS DAY




Khalil and Specsavers



Charlie and his team mates



Marsha de Cordova MP

Not to be thwarted, Sue and her amazing team reverted last-minute to a virtual format so we could still meet virtually and hear from our members and supporters including:

- Joanne Roughton-Arnold - our keynote speaker and Nystagmus Network member, Joanne is a violinist, soprano singer and founder of FormidAbility. A prominent advocate of fully accessible music and theatre, Joanne talked about her childhood in Australia, going to school with nystagmus, arriving in the UK as a young violinist and, more recently, her work with the Paraorchestra.
- Amanda Harris - first time author, Amanda joined us to talk about her newly published book, 'She will never ...', an autobiographical account of her life with nystagmus. Amanda is an accomplished, engaging and entertaining public speaker and was happy to answer our questions and take dedications for specially signed copies of her book.
- Open Day wouldn't be complete without our super-talented Research teams from Cardiff University, Moorfields, the University of Sheffield and the University of Leicester who all provided updates on their current research projects.

And finally, we announced our Nystagmus Champions of 2022. Congratulations to Lucy, Khalil, Tracy and Charlie – all nominated for their tremendous support of the nystagmus community and for helping make living with nystagmus just that little bit better.

Peter Greenwood

*Peter Greenwood*

Chair of Awareness Committee

## FUNDING COMMITTEE

We began 2022 with an ambitious target of £113,000 to respond to the increase in demand to provide support and information and an increasing need to contribute to research. We didn't quite reach the target this year and fell short by just over £18,000, although we did increase our funding income overall compared to last year by £6,000.

Fundraising finished the year at £36,955, lower than 2021 by £9,637, but we are grateful to the groups and individuals who supported us. Some key highlights included:

- At Easter Will took part in a 50km Easter challenge and raised over £1,300
- The annual Jersey Golf Day raised over £6,000 and received news coverage in a Jersey newspaper. Thanks to our trustee, James for organising this and for making it a regular fixture.
- James and friends found the time again over the summer to do a fundraising abseil for us, raising over £2,000, and lots of awareness fully kitted out in their Nystagmus Network T-shirts.

**2,064**

TWITTER FOLLOWERS

- Lucy took on a 12-hour bake-athon, making everything from lemon drizzle cake to chocolate brownies. She was nominated as a Nystagmus Champion for her baking skills and for raising a lot of awareness and a phenomenal £2,000.
- New author, Amanda Harris was one of our guest speakers at Open Day. Amanda is generously offering us £4.50 profit from the sale of every copy of her newly published book, She will never. She also donated some of her speaker fees and proceeds from a raffle at her book launch.
- Tracey took part in a full Iron Man event and raised over £1,500 for the Nystagmus Network.
- In October Adam ran his much-postponed London Marathon and raised £2,100.
- The same month Susannah and Mike raised £1,155 running the Royal Parks Half Marathon.

contd.

**"I just wanted to say how great your downloadable teacher resource is for supporting nystagmus in schools." - a QTVI**

# 147

CALLS TO OUR SUPPORT LINE




Our fundraising A-Z guide

Our applications for grant funding were more successful in 2022, improving by just over 141% compared to 2021, totalling £32,520. Our staff team worked very hard over the year applying for numerous grants and we hope that the coming year will continue to see successes.

General donations, shop sales and gifts in wills came to £12,280, which was slightly lower than last year.

Recognising a difficult economic climate resulting in challenges for fundraising, we are continuing to develop our focus on grant funding and develop our approach to corporate sponsorship in 2023.

Karen Chu

*Karen Chu*

Chair of Funding Committee

**"Just wanted to say thank you. I'm 26 and have congenital nystagmus. About 10 years ago I was told I was probably never going to drive. Thanks to your booklet on nystagmus and driving, I've just received my provisional licence! There's still a way to go, but this may have a big impact and I thought it was only right to give you credit."**

# RESEARCH COMMITTEE

**IMPROVING QUALITY OF LIFE THROUGH RESEARCH**

## The Nystagmus Network has been investing in research since the 1990s

**"I just made my first donation for research! I have AN. Fortunately, 12 weeks of neuro rehab has helped me to walk and jog on the beach again. Each mile accomplished is taken with gratitude for the work and support that Nystagmus Network brings. Thank you for all you do!" - a Facebook follower**

2022 was a busy year for the Research Committee of the Nystagmus Network, with some exciting new developments.

**#Symposium2022**

A first new initiative during the year was the decision to hold an international symposium which was held on 24 June. Nearly 100 researchers, academics, clinicians and students working in the field of nystagmus attended. An amazingly high percentage – 97 per cent – said they would recommend it to their peers. All the presentations went well, but we were particularly grateful to Professor Michele Rucci whose keynote speech on Seeing with Unsteady Eyes – the Visual Consequence of Eye Movements attracted a lot of interest. Thanks are due to Trustee Harshal Kubavat and Nystagmus Network staff team member Sue Ricketts for their hard work in organising the event. We were delighted with the universally positive feedback the symposium received and plans are already advanced for another international event in September 2023.

**UK nystagmus research workshop**

On 30 September 2022 we held our annual UK workshop, an event at which representatives from the six UK research centres updated each other on progress with their research in a highly collaborative session. The teams brought along their early career researchers to ensure they were

contd.

## In 2021 we invested £17,320 in research

NUKE
NYSTAGMUS UK EYE RESEARCH GROUP




Our Symposium22 highlights video

## "Thank you for all your hard work and keeping us all focused."– a NUKE member

updated and engaged with current thinking and practice.

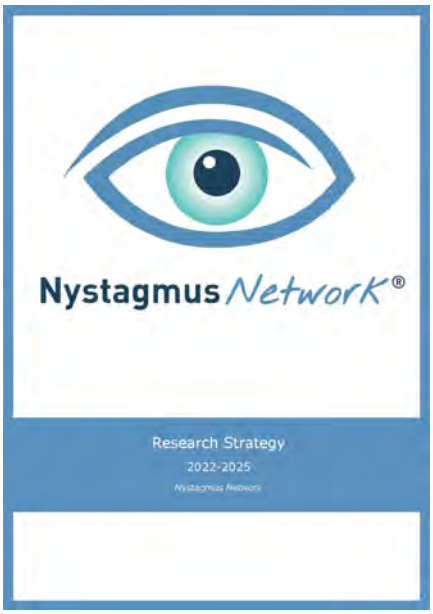
**The Nystagmus Care Pathway**
Through our membership of NUKE, the national nystagmus research body, we worked hard on the development of a National Care Pathway (NCP) which sets guidelines on diagnosis and care for patients with nystagmus – the first time such guidelines have been created. Work on the NCP has been in training for some time, but it reached its final stages in 2022 and the end of the year saw the finishing touches being put to the draft guidelines. It is pleasing to report that, in early 2023, the guidelines were approved with only small amendments by the Royal College of Ophthalmology. The adoption of these guidelines means that Ophthalmologists can now follow them when treating patients with nystagmus – something that we hope will lead to an improvement in standardisation of medical diagnosis and care.

**Two small grant awards**
Awards were made for two research projects in partnership with the charity, Fight for Sight (we joint fund the awards). At Plymouth, Dr Mahesh Joshi and Asma Zahidi are investigating training the eyes to fix on a moving target to see if they can gain better control of their eye movements. At Leicester, Mervyn Thomas won funding for a project to develop genetically modified zebra fish which can be used to test treatments for infantile nystagmus.

**contd.**

# RESEARCH, continued

Research strategy document




**The Nystagmus Network Research Committee continued to award grants in 2022 in the amount of**

# £14,976

There has been a setback in our sponsored PhD research studentship, another jointly funded project with Fight for Sight. In January 2022, we were delighted that the project, supervised by Frank Proudlock at the University of Leicester, successfully recruited a PhD student to conduct the research into the impact of glare in nystagmus. The project has currently been paused, however, due to the student's ill-health.

**Our investment in research**
In terms of funding in 2022, we spent a total of £18,854 on research, of which £14,976 was spent on grants awarded through our partnership with Fight for Sight; £3,328 on the international symposium; and £550 on equipment for the University of Sheffield to enable them to measure abnormal head posture in patients with nystagmus.

Vivien Jones

*Vivien Jones*

Chair of Research Committee

**"Thank you so much for joining us and sharing your lived experience with us! You are an amazing speaker and I really hope to have you at our future events, too. – a research event organiser**

# OUR KEY PROJECTS

In 2022 the Nystagmus Network continued to fulfill our stated goals: supporting the nystagmus community, raising awareness and funding research.



## Awareness

**We celebrated Nystagmus Awareness Day and delivered a virtual Open Day**



## Communication

**Daily Facebook posts and Tweets helped us reach an audience of 13,700 people**



## Research

**We invested £18,854 in research and hosted an international symposium**



## Support

**745 enquiries were answered from adults with CN and AN, parents, teachers, clinicians and eye care practitioners**



## Fundraising

**Our amazing supporters managed to find imaginative ways to raise £36,955 and we secured £32,520 in grants.**



## Information

**Our digital information guides were revised and updated and we published a new guide to nystagmus and exams.**

# MEMBERSHIP




**The Nystagmus Network has been a membership organisation since 1984**

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.

**"I just followed you on Twitter and saw these lovely, knitted mascots. I was born with nystagmus and visual impairment as a result. Now I'm 22 and studying medicine at the University of Oxford: something I never thought could happen! It's so lovely that people can have something like this that represents them. Keep up the great work!" – a young person on Twitter**

**"Thank you for all your advice in the last few years ... you do a great job getting it out there and I will continue to support you. "**
**- a member**

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
- Access to our education advocacy service
- Referral to bespoke advice and guidance on benefits
- A proportion of your subscription will go directly into research

We offer affordable membership to anyone living with nystagmus.

## PARTNERSHIPS

The Nystagmus Network is a member of NUKE, Visionary and the Alliance and works closely with QTVIs, ECLOs and Eye Care Practitioners and 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

## It's important to acknowledge that the charity relies entirely on voluntary contributions. Fundraising has been exceptionally challenging this year.

The Nystagmus Network continues to work hard to achieve its charitable objects, in support of those living with nystagmus in the UK and we are proud to report that our efforts have paid off. We are immensely grateful to our members, fundraisers and donors for their continued support, which has helped us raise a total of £95k during the year ended 31st December 2022, a 7% increase on the prior year.

We are pleased to report that we raised £33k from grant income, a substantial 141% increase compared to the prior year. This cushioned the decline in fundraising income by 21% to £37k and in donations by 30% to £9k. Membership income remained stable at £12k.

It's important to acknowledge that the charity relies entirely on voluntary contributions and fundraising has been exceptionally challenging this year due to the ongoing cost of living crisis. Our supporters have been facing increased financial pressures, which has made it difficult for them to contribute to our cause.

Nevertheless, we remain grateful for the support we have received and are committed to finding new ways of raising funds in the face of these challenges. We believe that, with the continued dedication of our supporters and staff, we can overcome these obstacles and continue to make a positive impact in the lives of those living with nystagmus.

contd.

We take great care in how we allocate funds and this year was no exception. We invested £19k in research. Our staff team has been working hard to provide support through the helpline, raise awareness and direct fundraising efforts. We are proud of their dedication and are grateful for their continued efforts. Total expenses for the year amounted to £96k, a 4% reduction on prior year, resulting in a small deficit for the year of £1k.

The year ended with total cash reserves of £66k, in line with our reserves policy of putting aside free cash reserves of 6 months' cover for annual expenses. Continued cost management ensures that the charity is in a strong position to continue navigating the uncertainties and challenges of the year ahead.

*Vicky Pitman FCA*

*Vicky Pitman*

Treasurer



A young child undergoes an eye exam

**"The information I've received from the Nystagmus Network has been invaluable to my sanity." – an adult with AN**

# FINANCIAL ACCOUNTS 2022

## Nystagmus Network - Financial Accounts 2022

| | 2022 | | 2021 | |
|---|---|---|---|---|
| | £ | £ | £ | £ |
| **Income** | | | | |
| Fundraising | 36,955 | | 46,592 | |
| Grants | 32,520 | | 13,520 | |
| Wills | 100 | | 0 | |
| General Donations | 9,236 | | 13,261 | |
| Subscriptions | 11,845 | | 11,640 | |
| Shop Sales | 2,944 | | 3,005 | |
| Open Day | 891 | | 678 | |
| Bank Interest | 216 | | 6 | |
| | | 94,707 | | 88,702 |
| **Expenditure** | | | | |
| Fundraising Costs | 31,253 | | 27,921 | |
| Support services | 25,977 | | 34,006 | |
| Office and Administration | 19,632 | | 19,779 | |
| *Research* | 18,854 | | 17,320 | |
| Trustee expenses | 92 | | 0 | |
| Open Day | 119 | | 662 | |
| | | 95,927 | | 99,688 |
| **Net Surplus/(Deficit) for the year** | | -1,220 | | -10,986 |
| *Total Staff costs included above* | *£64,857* | | *£61,167* | |
| General reserves at 31st December | | £58,428 | | £62,447 |
| Restricted reserves at 31st December | | £7,650 | | £4,850 |
| **Cash at the Bank 31st December** | | £66,078 | | £67,297 |

Accounts Prepared by

Vicky Pitman FCA (Treasurer)

Accounts Examined by

ARBlack

Andrew Black ACA



Delegates at a Nystagmus Network event

# LEGAL DETAILS

## Charity objects

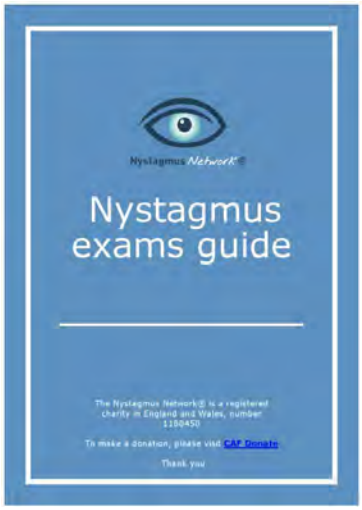
The charity's objects focus on the relief of nystagmus (visual impairment) sufferers and their families. The objects also focus on advancing the education of the public in and to promote research into the condition known as nystagmus and to publish the useful results of any such research which the charity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

## Appointment of trustees

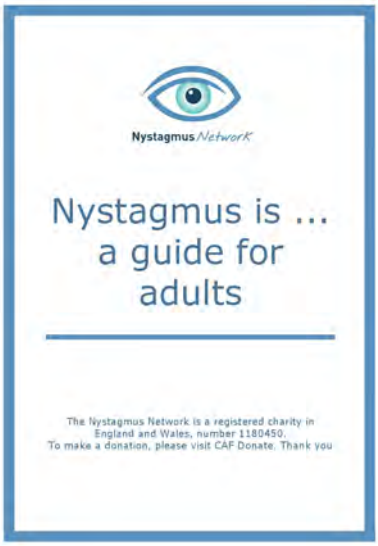
Trustees are recruited in line with our equality and diversity policy and to reflect lived experience of nystagmus. They are appointed after a thorough interview process. Induction includes immersion in the Charity Governance Code and charity policies and procedures. Introduction to the work of the charity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

## Trustees' responsibilities

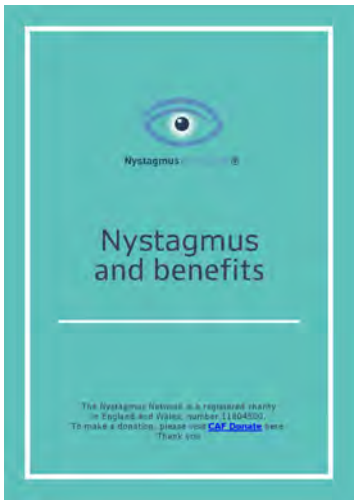
Trustees are responsible for the preparation of financial statements for each financial period which give a true and fair




Exams guide




Nystagmus is ...
a guide for adults




Benefits 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 does an amazing job. Keep up the good work!"**
**- a trainee teacher**

NYSTAGMUS NETWORK




MORE INFORMATION

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

**NYSTAGMUS NETWORK**

England & Wales - Charity number 1180450

# Accounts

# 2021 TRUSTEES' ANNUAL REPOR T

**"Thank you for building this online community and thank you for all you do."**

**A Facebook follower**

NYSTAGMUS NETWORK


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

"Thank you for your advice. You have been incredibly helpful and supportive." A parent



# ABOUT US

The Nystagmus Network is a registered charity in the United Kingdom 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.

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**"The programme looks excellent as usual. Thanks as ever for doing us all proud and doing so much for those with nystagmus and their families." An Open Day delegate**




Tim Cuddeford
Chairman of
the Nystagmus
Network

# CHAIRMAN'S MESSAGE

Building on the success of riding out the pandemic in the previous year, 2021 has seen a strengthening of the charity and, while there are still challenges from Covid, we are supporting more people than ever before.

I would like to commend the efforts of our team, volunteers, trustees and members in maintaining the aims and mandate of the charity in terms of providing support to our members, funding research and raising awareness.

In 2021 most of our regular support activity continued online, nevertheless fundraising in many diverse forms has continued. You will be able to read elsewhere in this report some of our supporters' fundraising highlights.

Thanks to all our fundraisers. Your support is invaluable to us. Your fundraising together with grants and careful cost management means we finish the year on plan in terms of income, expenditure and reserves.

We enjoyed a second virtual Open Day by Zoom. Whilst the format is great, we can't wait to be back together in person in Sheffield on 1 October 2022.

## As we began to emerge from the pandemic we redoubled our commitments to supporting the nystagmus community

Raindrops was the theme of Awareness Day in June. It was great to see your pictures and so many young writers get involved. Let's hope for a bit more sunshine in 2022.

We maintained our commitment to funding research into nystagmus and once again held a very productive research workshop. We have funded a PhD at the University of Leicester and also the purchase of useful research and clinical equipment at Southampton to the tune of £17,000.

We continued to support children with nystagmus and their parents to get the best educational outcomes from their local educational authority with a new series of parent power workshops.

We will continue these in 2022, as funding permits, along with adult support, particularly in the areas of employment and benefits.

As we move into 2022, learning from the past two years, we will continue both virtual and physical events and to develop our services in any way we can to support the nystagmus community..

Thanks again to all our members, supporters and fundraisers. We look forward to a positive 2022.

Tim Cuddeford

*Tim Cuddeford*

Chairman

**"I think it's great that people are now being more aware of this eye condition and its effects on people's lives! Though, as a 73-year-old, future developments may come too late for me, I feel that if younger people can receive meaningful help and don't have to suffer the stigma and suffering and embarrassment that I went through it would be great!" An adult with nystagmus**














# TRUSTEES SERVING IN 2021

**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, technology, medicine or finance. They all share a firm commitment to the nystagmus cause.**

**From the top row, left to right:**

**Richard Blackmore, Trustee**
**Claire Brinn, Trustee, Education Advocate**
**Karen Chu, Chair of Funding committee**
**Tim Cuddeford, Chair of Trustees, Chair of Finance committee**
**Peter Greenwood, Vice Chair of Trustees, Chair of Awareness and Support committee**
**Sam Jones, Secretary**
**Vivien Jones, Founder, Honorary President, Chair of Research committee**
**Harshal Kubavat, Trustee**
**Vicky Pitman, Treasurer**
**Kathryn Swanston, Trustee**
**John Vekinis, Trustee**
**Daniel Williams, Trustee**



# 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 lives.

# Acquired nystagmus

Nystagmus which develops later in life is called acquired nystagmus. It is often associated with another health condition such as 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.

**"Thank you for being there. It helped me come to terms with my nystagmus, following a stroke."**

**"It was invaluable to be able to speak to someone who truly understood the condition, its effects and the adaptions needed. Thank you again. I felt a huge weight being lifted off my shoulders after speaking to you." A parent**

# SUPPORTING THE NYSTAGMUS COMMUNITY

The Nystagmus Network provides a wide range of support. During the pandemic, people's need for support and information was even greater.



## Online

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



## Open Day

**We are proud to host the biggest annual UK nystagmus event.**



## Volunteers

**We offer peer to peer support and an education support service.**



## Documents

**We make up to date information available free of charge to all.**

**"The Nystagmus Network has helped me through some real tough times, so I just wanted to say thanks." A Facebook follower**

# AWARENESS AND SUPPORT COMMITTEE

**591**

PEOPLE RECEIVING SUPPORT

**"It was a real pleasure to meet the other parents: I found it all so enjoyable and informative. A lovely group!" A member of the parents' forum**

In 2021, we continued to face the challenges presented by the Covid-19 pandemic and to extend our services to support members of the nystagmus community in several key areas including social isolation and postponed/cancelled medical appointments.

As we found in 2020, people's need for support and information during the pandemic remained significant. We continued to develop our services with a series of recorded messages, live webinars and Q+A sessions by nystagmus experts, Paediatric Ophthalmologists, Orthoptists, researchers, and senior university lecturers.

## CET Webinars

Building on our CET webinars in 2020, we hosted a new set of CET accredited interactive webinars as part of our professional training programme for eye care practitioners. Topics covered included: Investigating and managing nystagmus in the orthoptic clinic, delivered by Gemma Arblaster, Lecturer in Orthoptics, University of Sheffield; Solutions for patients with nystagmus, delivered by Jayshree Vasani, Dispensing Optician; and 1 in 1,000 things you never knew about nystagmus, delivered by Sue Ricketts from the charity.

## Education Support

Thanks to a grant from the Thomas Pocklington Trust, we were able to offer parents of children and young people with nystagmus the opportunity to attend one of a brand-new series of Parent Power webinars.

Each webinar introduced parents to the special educational needs support available in schools and early years settings, empowered them to access it for their child and introduced them to EHC plans.

Each session was delivered by a qualified and experienced trainer from IPSEA (the Independent Provider of Special Education Advice), supported by Sue from the charity staff team and our volunteer education advocate, Claire.

**contd.**

# Nystagmus Aware

## 2021 Nystagmus Awareness Day - 20 June

Our annual awareness day was similarly a virtual experience. This encompassed:

- Raindrops story writing and drawing competition for children and photography competition for adults – some fabulous prizes were on offer
- Welly Walking – over 2 days some of our wonderful supporters (2 and 4 legs!) went for a walk in their wellies and raised a phenomenal £2,500!
- Trustee, Sam Jones successfully completed the North Coast 500 cycling challenge, cycling 500+ miles in just 8 days and raising over £3,000 for the charity founded by his Mum, Vivien. Supported part of the way with the navigation by his cycling buddy, Bill and his parents, Vivien and Ian, with Nystagmus Network Chair of Trustees, Tim driving the support vehicle, Sam managed to avoid the potholes and other road hazards, climb several steep hills and break through the 'legs of lead' stage, sustaining himself each evening with burgers and beer.
- More amazing stories from our supporters to help raise awareness– thank you Rory, Edwin, Wyatt, Doug, Poppy, Tim, Grayson and Katrina.

**"Love the work you and the team are doing, please, please, please keep going. It gives people such hope for the future."**
**An adult with nystagmus**

# £46,592

FUNDRAISING

Raindrops

Nystagmus Awareness Day



Fundraising

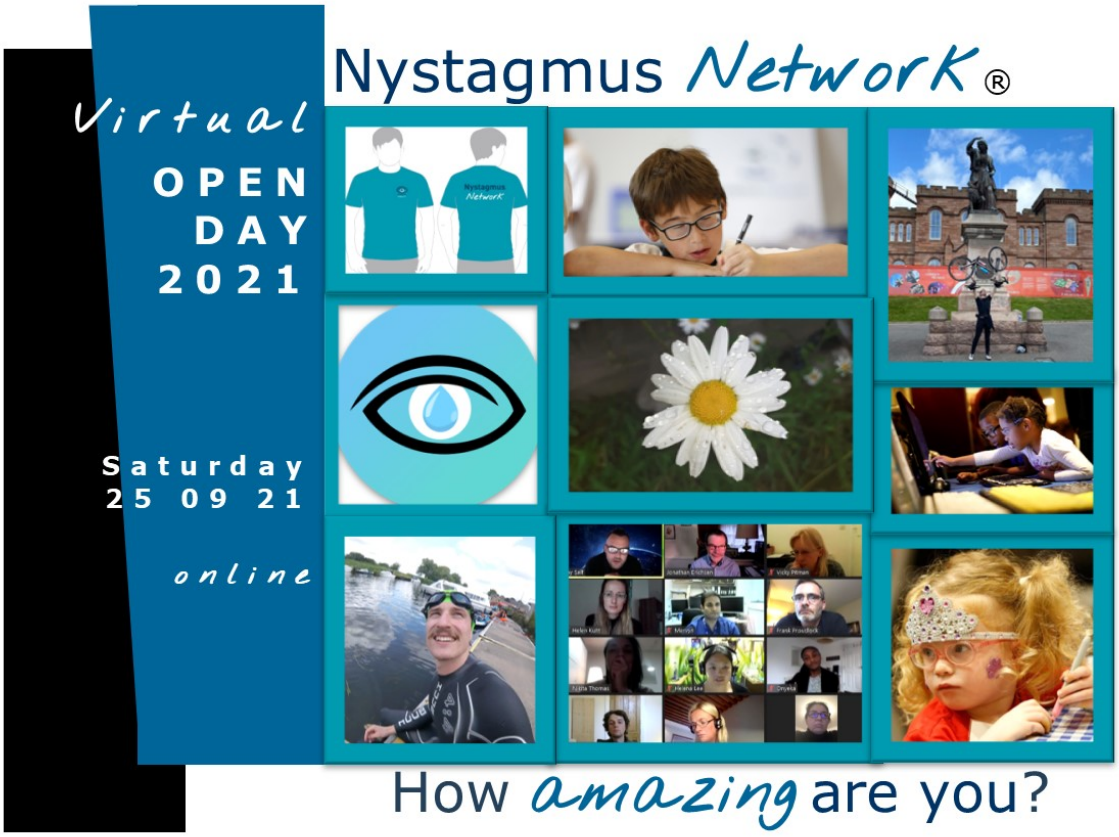
## Fundraising

As we began to emerge from the pandemic our fundraisers were out in force once again. A few highlights included:

- The 19-21 challenge meant our supporters started the new year with a personal fitness goal to walk, run or cycle their way to health. They did, raising over £5,600 into the bargain. Special mention goes to James and Cara.
- In April, our supporters took part in the Captain Tom 100 campaign. Thanks, in particular, to Leon, who ran 100km in 3 days and to Georgie who baked and sold 100 cupcakes.
- Our welly walkers did us proud in June, raising lots of funds, but awareness of nystagmus, too. Thank you, Tyler, for manning the stall!
- Also in June trustee, Sam Jones cycled 500 miles round the NC500 in northern Scotland, raising over £3,000.
- Sarah ran the three peaks challenge in July and held a big prize raffle with prizes donated by local businesses.
- James held a charity golf day in September. The total raised topped £5,000 and a good day of golf was enjoyed by all. Meanwhile Josh raised £800 with his very first half marathon.
- In the autumn, Kieran and his team smashed the Liverpool Rock 'n' Roll Marathon and Stephen did us proud in the Royal Parks Half Marathon.

**"The information you have provided [on benefits] has been priceless."**
**An adult with nystagmus**

**contd.**




## 2021 Open Day

Trustees took the decision again to run our annual Open Day as a virtual event . The online sessions proved highly successful and enabled us to reach a much wider audience (602 people) than we would have been able to accommodate in person.

In the run up, we held our regular forums for parents, adults with acquired nystagmus and adults with congenital nystagmus.

On the day, events included:

- Nystagmus in the workplace (Zoom doom or accessibility dream) – hosted by Member, Hannah Ricketts and Trustee, Richard Blackmore.
- Nystagmus and employment law – Mike Cain, discussed aspects of employment law in relation to nystagmus.
- Our clinical advisers, Jay Self and Helena Lee from Southampton University, answered questions about how to prepare for video appointments, what you can do to support your vision and when things will (hopefully!) start to get back to normal.
- Ask an Expert – an interactive session with a panel

**"I can't tell you how helpful the webinar was. There was a sense of relief, enlightenment and every emotion in between. What an hour that was!" A virtual Open Day delegate**

**2,484**

DOCUMENT DOWNLOADS



Tim Hands

of eye care practitioners and researchers who answered your questions about nystagmus testing, treatments and therapies, supporting your child, quality of life and the future for research.

- Raindrops winners – we also announced the winners of our Raindrops story writing and illustration competitions for children and the Raindrops photography competition for adults.
- Research updates – the teams from the UK nystagmus research centres provided updates on their work, including the University of Sheffield, Cardiff University, Moorfields Eye Hospital (London) and the University of Leicester.
- There was also a chance to ask our super talented Trustees any questions as an introduction to the AGM.

The 2021 Open Day was brought to a close with a virtual quiz hosted by Interrupt the Routine and our inspirational guest speaker, Tim Hands who has forged an award-winning career in post-production sound for film and television. As Tim says, "I ain't done bad for a lad that can't see too well!"

And finally (but certainly not least), we continued to run our regular forums; answer queries via our support line, email and Facebook; our support documents continued to prove popular with nearly 2,500 downloads during the year; the number of hits to our social media accounts all increased; and we launched a membership campaign to encourage new members to join us.

Thank you to everyone who participated and supported Nystagmus Awareness Day, who attended virutal Open Day and our thanks to all our fundraisers.

Peter Greenwood

*Peter Greenwood*

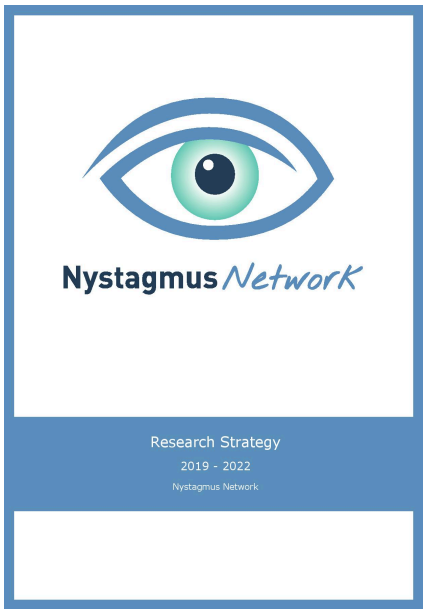
Chair of Awareness and Support Committee

# RESEARCH COMMITTEE

## IMPROVING QUALITY OF LIFE THROUGH RESEARCH

## The Nystagmus Network has been investing in research since the 1990s




Despite the problems associated with Covid, which caused research everywhere to slow down, 2021 was a busy year for the Nystagmus Network's Research Committee.

The year began with discussion about the joint PhD project with our charity partner, Fight for Sight. An assessment panel to discuss the merits of two shortlisted applications was held in February, as a result of which the winner of the award was declared to be Frank Proudlock, based at Leicester.

Dr Proudlock proposed a research study to explore strategies to alleviate glare in infantile nystagmus.

The formal announcement of Dr Proudlock's success came later in the year – on Nystagmus Awareness Day on 20 June. Hopes were high that the PhD student to take forward the project would be appointed in time for the new academic year, but unfortunately no suitable candidate was identified to take on the role. We are delighted to announce, however, that a

# In 2021 we invested £17,320 in research










## "Bless all those working towards enlightenment and treatment of this life changing condition." An adult with nystagmus

candidate has been appointed in early 2022 – Nick Dash, who brings with him long experience – and work has begun on the project. We will be keeping our members and supporters updated about progress.

The year was notable for the progress made on the Nystagmus Care Pathway, which aims to set national standards for the treatment and care of patients with nystagmus. The work on this has been undertaken by NUKE – the UK Eye Research Group whose members include the Nystagmus Network. The draft document – being prepared as Practice Points for the Royal College of Ophthalmology – was virtually complete by the end of the year, and it is hoped it can be launched in 2022.

We held the annual Nystagmus Network Research Workshop for UK researchers on Friday 24 September, the day before Open Day. This was a highly collaborative event, with an interesting discussion about the possibility of widening the scope of the event to an international audience.

The support for this led the Committee to conclude that it would make sense to hold two events – the UK event to continue to be held the day before Open Day and an international event to be held in nystagmus national awareness week in June. The proposal has been supported by Trustees and is being taken forward in 2022.

**contd.**

# RESEARCH, continued

## The Nystagmus Network Research Committee continued to award grants in 2021

The Research Committee continued to make grants in 2021. A small grant award of £15k – jointly funded by NN and Fight for Sight – was made to Dr Matteo Rizzi from UCL for an exciting project to pioneer gene therapy to treat nystagmus. We await the results with great interest. At the end of the year, the Research Committee offered the opportunity to research centres to bid for money for equipment.

Two centres won the opportunity. Southampton were awarded £17,000 to purchase four CROM machines which measure the position of the null point and to buy a Reteval device which helps with the evaluation of the retina. Sheffield were awarded £550 to buy slightly different CROM devices to aid in the measurement of abnormal head posture. (Sheffield's grant was actually made in early 2022.)

All in all we hope that plans laid in 2021 will come to fruition in 2022 and we look forward to a productive year.

*Vivien Jones*

VIVIEN JONES
Chair of Research Committee

**The Nystagmus Care Pathway will ensure the standardised care, support and information patients and their families need at diagnosis.**

**"Thank you for all the fantastic work you do. Children are so fortunate having an organisation such as yours backing them."**
**A parent**

# OUR KEY PROJECTS

In 2021 the Nystagmus Network continued to strive towards our stated goals: supporting the nystagmus community, raising awareness and funding research as the country began to emerge from the grip of the global pandemic.



## Awareness

**We celebrated Nystagmus Awareness Day on 20 June and delivered training**



## Communication

**Daily Facebook posts and Tweets helped us reach an audience of 13,000 people**



## Research

**We invested £17,320 in research and hosted a UK research workshop**



## Support

**591 enquiries were dealt with, from adults with CN and AN, parents, teachers, clinicians and eye care practitioners**



## Fundraising

**With many mass participation events still canceled, our amazing supporters still managed to find imaginative ways to raise £35,163**



## Information

**Our digital information guides were revised and updated and we published a new document on registration.**

# MEMBERSHIP




**The Nystagmus Network has been a membership organisation since 1984**

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.

**"I just wanted to say that I'm so glad I discovered your page! Knowing that there's all these other people out there that face similar challenges to me and know what I go through just makes me feel so much better. Sometimes it feels like I'm the only one. Now that I've found your page I don't feel so alone anymore, so thank you." A Facebook follower**

**"When I joined the Nystagmus Network I discovered a world of people just like me. Until that moment I thought I was the only one."**
**A new member**

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 events and a FREE place at Open Day
- Access to our education advocacy service
- Referral to bespoke advice and guidance on benefits
- A proportion of your subscription will go directly into research

We offer affordable membership to anyone living with nystagmus.

## PARTNERSHIPS

The Nystagmus Network is a member of NUKE, Visionary and the Alliance and works closely with QTVIs, ECLOs and Eye Care Practitioners and 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

## Continued cost management ensures the charity is in a strong position to continue navigating the uncertainties and challenges of the year ahead.

The Nystagmus Network continues to find ways of securing sufficient income to maintain our position as the foremost charity supporting people living with nystagmus in the UK. We are very grateful to all our members, fundraisers and donors for their continued support and for helping us raise income totalling £88,702 during the year ended 31 December 2021.

The main source of income is traditionally from fundraising events and, due to the return of physical fundraising events post lock down, we are pleased to report a 33% increase in fundraising income on prior year to give a total raised in 2021 of £46,592. Membership income remained stable at £11,640, whilst we saw a 24% reduction in donations compared with prior year (total £13,261) and a 52% reduction in grant income (total £13,520). Prior year total income of £100,592 included staffing and Covid-related grants of £23,447.

Total spending for the year was £99,688, roughly the same as prior year. Notable expenditure included an allocation of £17,320 towards research, £5,625 on Parent Power workshops and £3,363 on professional engagement webinars. The charity operates with a lean staff team to provide support, including through the helpline, raise awareness and direct fundraising endeavours.

The resulting deficit for the year of £10,986 meant the charity ended the year with total cash reserves of £67,297. This is in line with the reserves policy of putting aside free cash reserves of 6 months' cover for annual expenses.

Continued cost management ensures that the charity is in a strong position to continue navigating the uncertainties and challenges of the year ahead.

*Vicky Pitman*

VICKY PITMAN FCA
Treasurer

## The stories and drawings on the theme of raindrops will be published in a book in 2022



# FINANCIAL ACCOUNTS 2021

## Nystagmus Network - Financial Accounts 2021

| | 2021 | | 2020 | |
|---|---|---|---|---|
| | £ | £ | £ | £ |
| **Income** | | | | |
| Fundraising | 46,592 | | 35,163 | |
| Grants | 13,520 | | 28,447 | |
| Wills | 0 | | 4,593 | |
| General Donations | 13,261 | | 17,387 | |
| Subscriptions | 11,640 | | 11,490 | |
| Shop Sales | 3,005 | | 2,012 | |
| Open Day | 678 | | 1,453 | |
| Bank Interest | 6 | | 48 | |
| | | 88,702 | | 100,592 |
| **Expenditure** | | | | |
| Office and Administration | 19,779 | | 20,444 | |
| Trustee expenses | 0 | | 1,140 | |
| Communications | 24,926 | | 21,060 | |
| Research | 17,320 | | 26,500 | |
| Support services | 9,080 | | 1,810 | |
| Fundraising Costs | 27,921 | | 27,168 | |
| Open Day | 662 | | 2,382 | |
| | | 99,688 | | 100,504 |
| **Net Surplus/(Deficit) for the year** | | -10,986 | | 88 |
| *Total Staff costs included above* | *£61,167* | | *£44,724* | |
| General reserves at 31st December | | £62,447 | | £61,053 |
| Restricted reserves at 31st December | | £4,850 | | £17,230 |
| **Cash at the Bank 31st December** | | £67,297 | | £78,283 |

Accounts Prepared by

02.02.2022

Vicky Pitman FCA (Treasurer)

Accounts Examined by

ARBlack 2/2/2022

Andrew Black ACA

**Thanks to our close relationship with clinicians we can provide professional, accredited training for optometrists and opticians.**




**"Thank you for such an interesting and informative set of lectures. I felt they were a cut above a lot of CET. Well done!"**
**An eye care practitioner**

**It is the policy of the Trustees to keep Free Cash reserves of 6 months cover, for annual expenses, to ensure that, should income streams be compromised for any period of time, the charity can continue its essential and primary aim of supporting and communicating with its members. Investment in research will be funded when cash reserves allow and/or grants are obtained to support this without compromising the expense cover policy as outlined.**



# LEGAL DETAILS

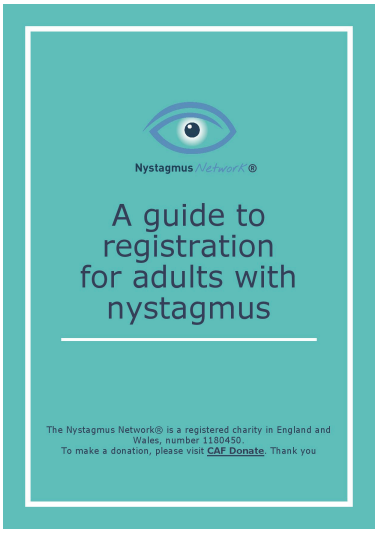
## Charity objects

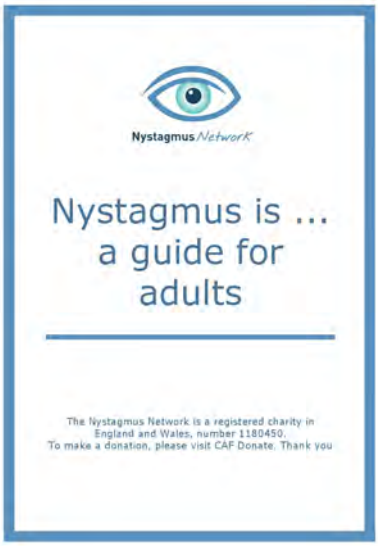
The charity's objects focus on the relief of nystagmus (visual impairment) sufferers and their families. The objects also focus on advancing the education of the public in and to promote research into the condition known as nystagmus and to publish the useful results of any such research which the charity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

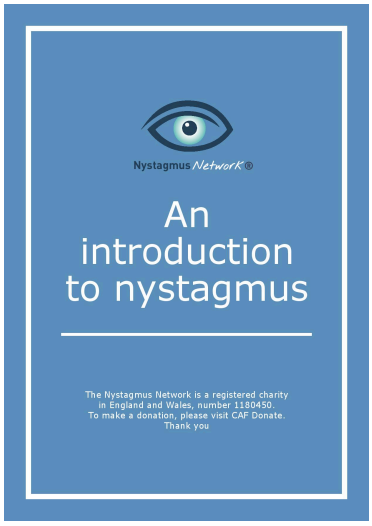
## Appointment of new trustees

Trustees are appointed from a pool of candidates, usually found amongst people known to the existing trustees. New trustees will be directed towards the advice available from the Charity Commission and additional training will be given where it is considered necessary by the existing Nystagmus Network trustees.

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




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 have considered all risks and procedures are put in place to mitigate these risks.

## 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*

Chairman

**"During our course we had a lecture on nystagmus, a condition most of us had never heard of before. I started teaching a student who had obvious signs of nystagmus, but who hadn't been getting help for it. I reached out to the SENCO as well as parents and got a plan in place. She is now in a much happier place in school, with teachers who know what she needs. The school have made me the "nystagmus expert", all because of the lecture in the middle of the course. I just wanted to say thanks. It's made a massive difference to this student." A trainee teacher**

## NYSTAGMUS NETWORK

Nystagmus Network

### MORE INFORMATION

For more information visit us online at nystagmusnetwork.org

or email us at info@nystagmusnet.org.