

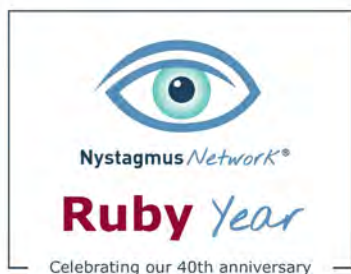
Our vision is a world which welcomes people living with nystagmus, affords them comprehensive support and the opportunity to reach their full potential.

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



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**



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

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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



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

of a group. The first meeting took place at the end of 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 Network 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.



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.

"I had forgotten how much I get out of these meet ups and how emotional they can be." - a meet up attendee

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,

"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

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!

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**

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

Nystagmus Network

International Nystagmus Symposium Friday 25 October 2024



Online
13.00 - 17.30
GMT/UTC+1

Register now!

Co-chairs

Jon Erichsen
Cardiff University

Jay Self
University of Southampton

"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

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

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

Our partnership with NUKE remains central to our mission

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



Are you a *member?*



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

"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

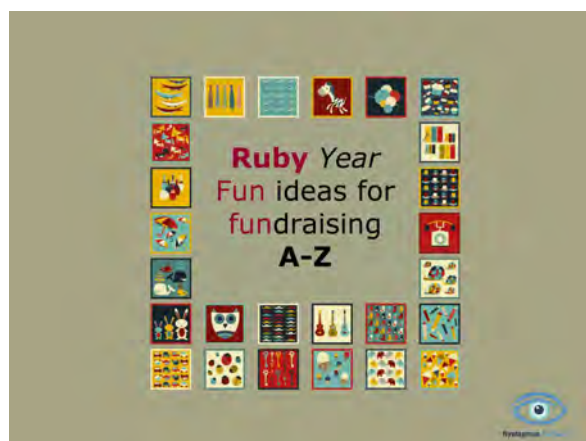
We ended the year with a £18,655 deficit, mainly as a result of spending restricted funds received prior year. Unrestricted funds remained stable with only a £1,955 deficit. Our reserves now stand at £101,632, with £61,517 in general funds, meeting our six-month reserves policy.

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
	<u>86,659</u>	<u>10,760</u>	<u>97,419</u>	<u>122,841</u>
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
	<u>88,614</u>	<u>27,460</u>	<u>116,074</u>	<u>68,632</u>
Net Surplus/(Deficit) for the year	<u>-1,955</u>	<u>-16,700</u>	<u>-18,655</u>	<u>54,209</u>
<i>Total Staff costs included above</i>			<i>£73,071</i>	<i>£52,944</i>
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	<u>61,517</u>	<u>40,115</u>	<u>101,632</u>	<u>120,287</u>
Statement of Assets and Liabilities				
Cash funds	<u>61,517</u>	<u>40,115</u>	<u>101,632</u>	<u>120,287</u>

Accounts Prepared by



Vicky Pitman FCA (Treasurer)

Accounts Examined by

 16/2/25
 Andrew Black ACA

Nystagmus Network[®]

Saturday

September

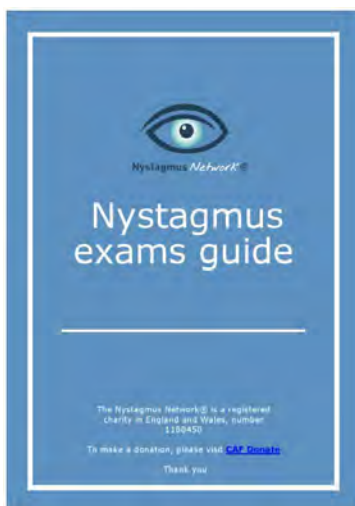
The big *nystagmus* meet up!

Charity objects

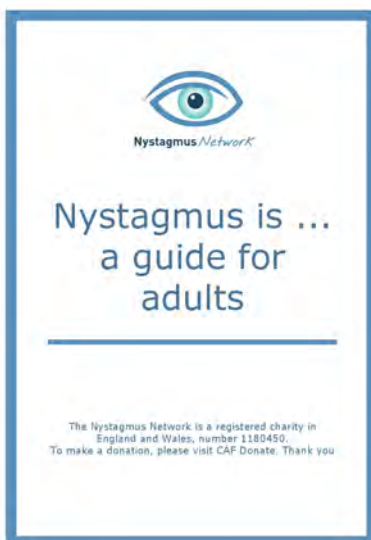
policy and to reflect lived experience of nystagmus. They are appointed after a thorough interview process. Induction includes immersion in the Charity Governance Code and charity policies and procedures. Introduction to the work of the charity is through peer to peer training via our sub-committees.

Trustees' responsibilities

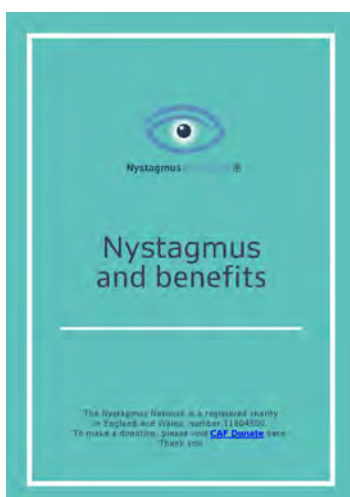
Trustees are responsible for the preparation of financial statements for each financial period which give a true and fair



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



MORE INFORMATION

For more information visit us online at
nystagmusnetwork.org

or email us at info@nystagmusnet.org.

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Accounts Prepared by


Vicky Pitman FCA (Treasurer)

Accounts Examined by

 16/2/25
Andrew Black ACA



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 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,
5 CHARTSWORTH GARDENS,
STREWSBURY, 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