

**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."**

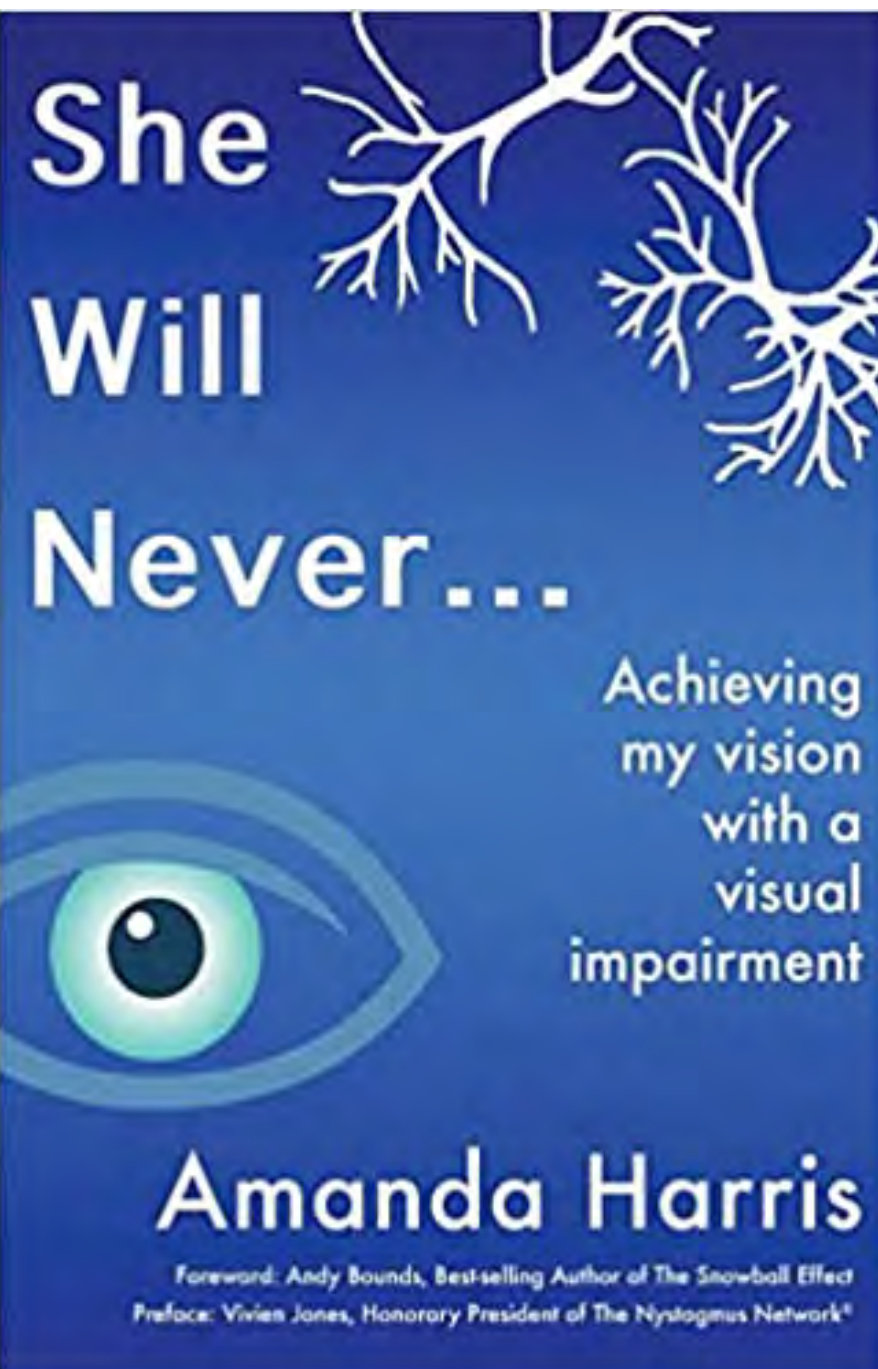
- a Facebook follower

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**



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.

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

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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

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

"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 "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

FACEBOOK
FOLLOWERS

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.

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.

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

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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

In 2021 we invested £17,320 in research



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

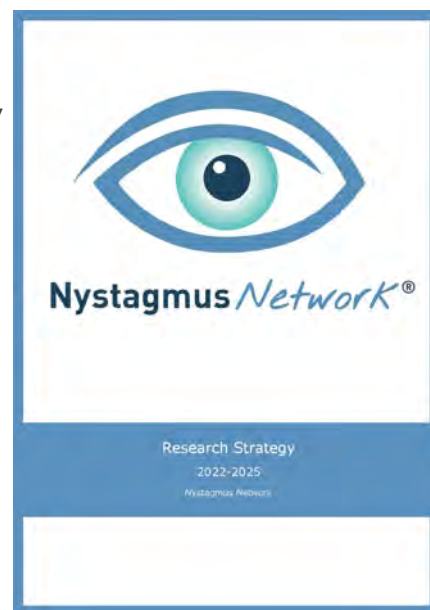
Awards were made for two research projects in partnership with the charity, Fight for Sight (we joint fund the awards). At Plymouth, Dr Mahesh Joshi and Asma Zahidi are investigating training the eyes to fix on a moving target to see if they can gain better control of their eye movements. At Leicester, 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



Are you a *member?*

**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
<i>Total Staff costs included above</i>	<i>£64,857</i>		<i>£61,167</i>	
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


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.

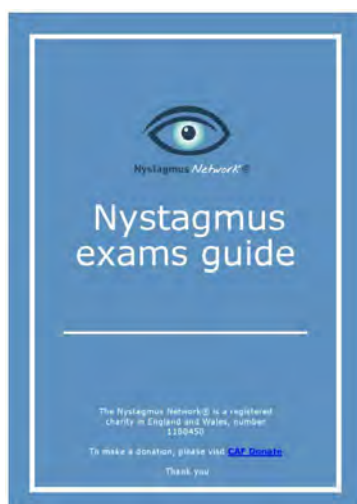
Appointment of trustees

Trustees are recruited in line with our equality and diversity

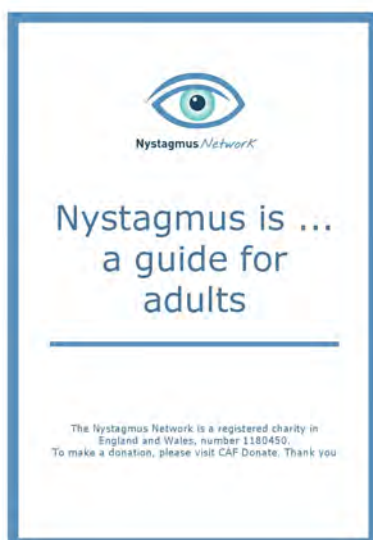
policy and to reflect lived experience of nystagmus. They are appointed after a thorough interview process. Induction includes immersion in the Charity Governance Code and charity policies and procedures. Introduction to the work of the charity is through peer to peer training via our sub-committees.

Trustees' responsibilities

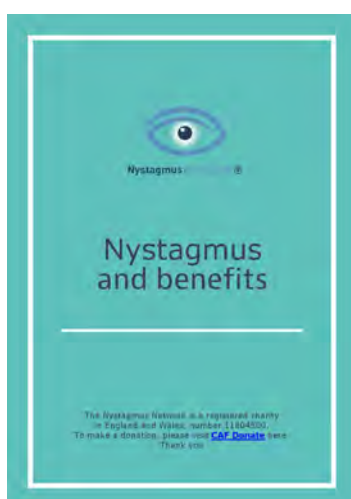
Trustees are responsible for the preparation of financial statements for each financial period which give a true and fair



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.