

2021 TRUSTEES' ANNUAL REPORT

**"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..

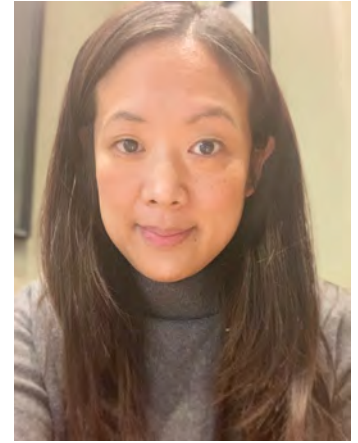
Thanks again to all our members, supporters and fundraisers. We look forward to a positive 2022.

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 adaptations 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.

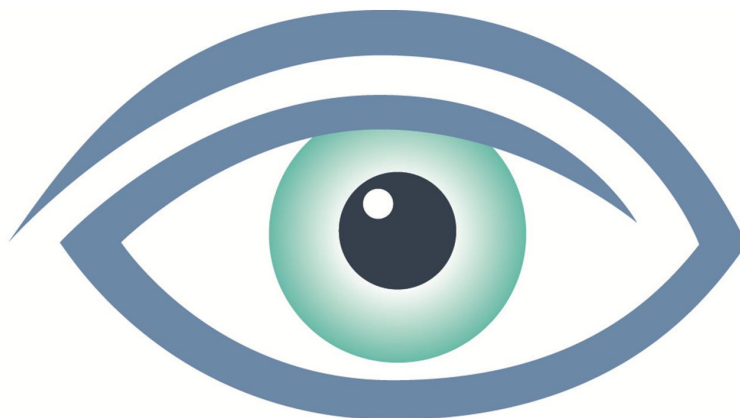
Education Support

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

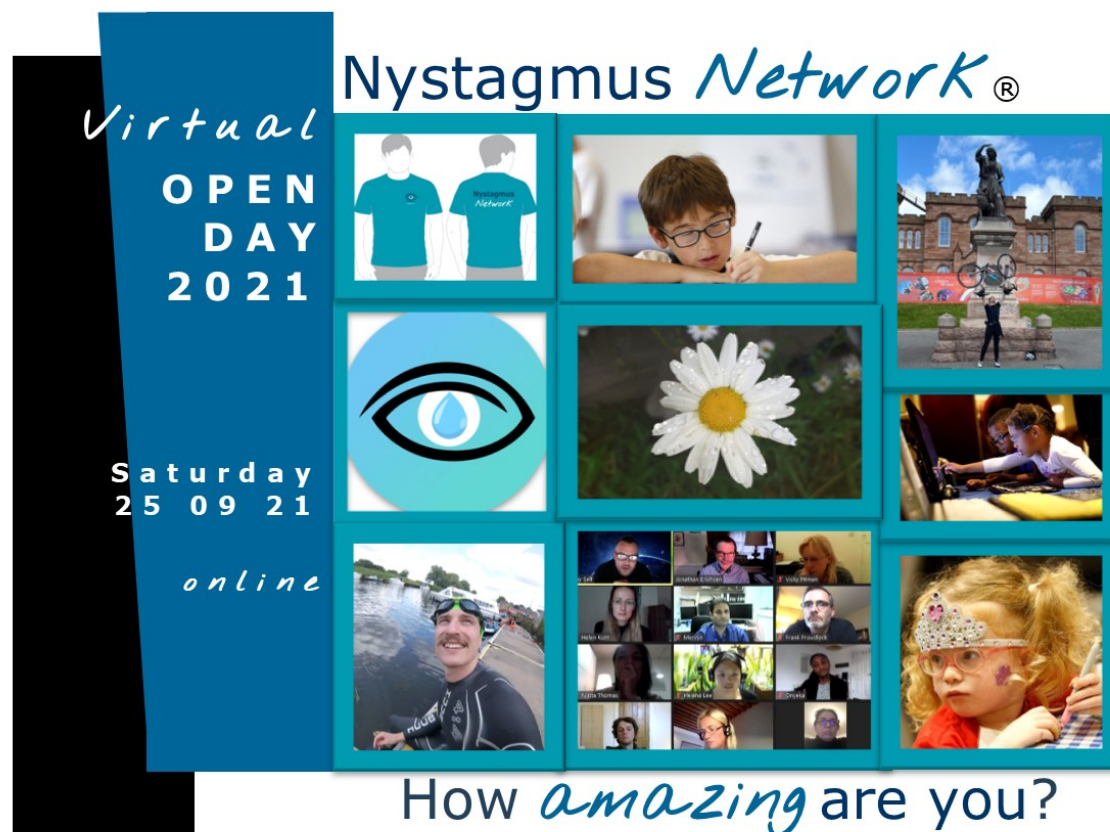
Fundraising

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 virtual Open Day and our thanks to all our fundraisers.

Peter Greenwood

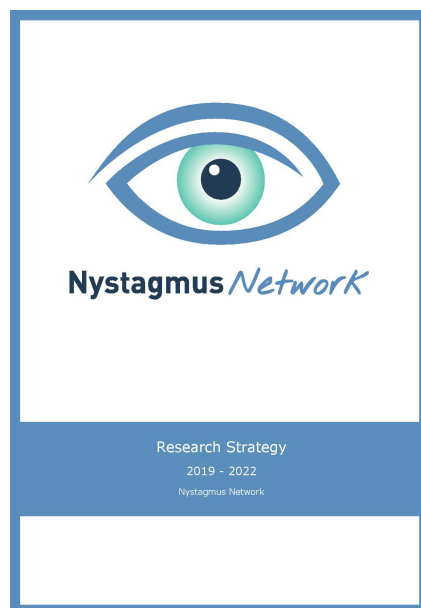
Peter Greenwood

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



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 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.

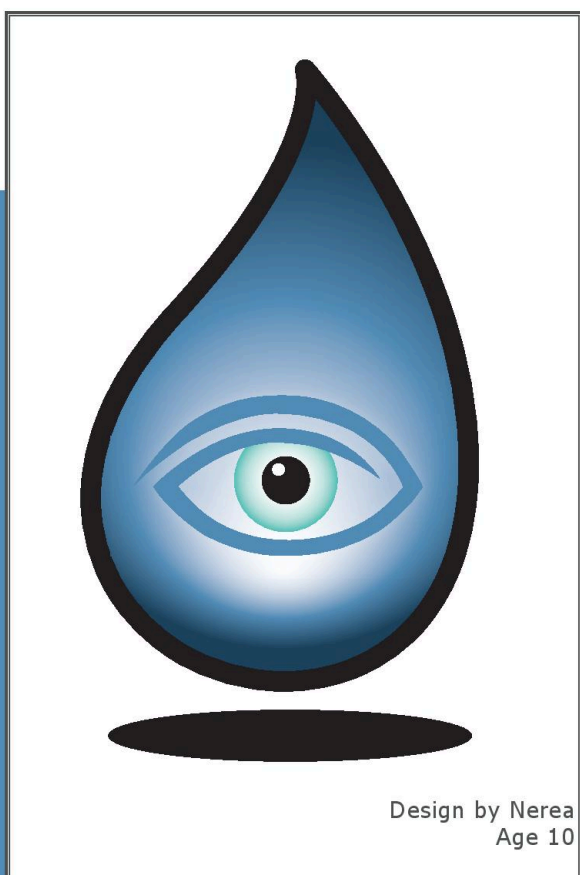
The resulting deficit for the year of £10,986 meant the charity ended the year with total cash reserves of £67,297. This is in line with the reserves policy of putting aside free cash reserves of 6 months' cover for annual expenses.

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



***Nystagmus
Awareness Day***

Children's Story Writing
and Drawing Competition

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
<i>Total Staff costs included above</i>	<i>£61,167</i>		<i>£44,724</i>	
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

 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

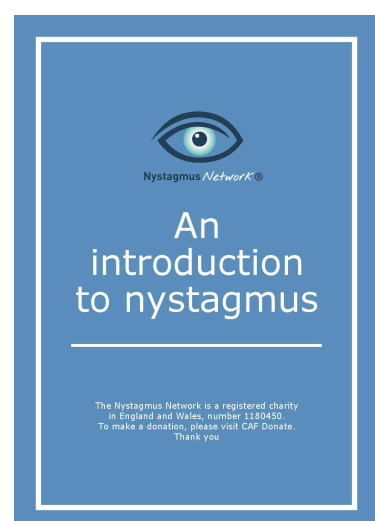
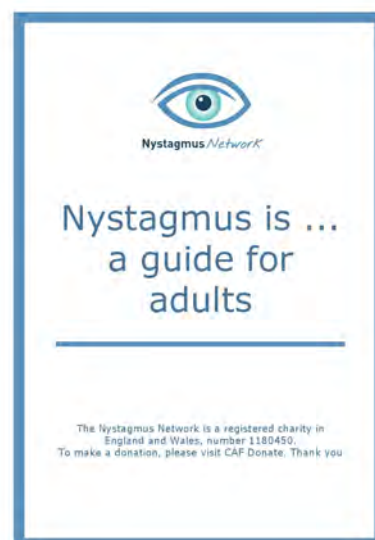
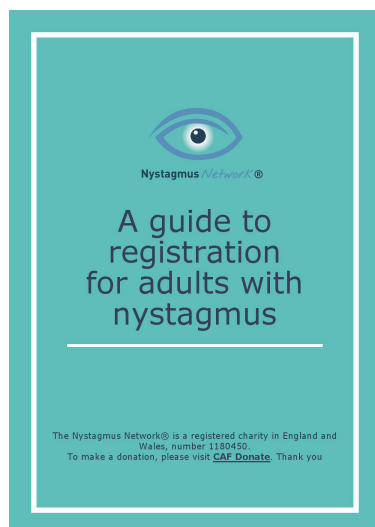
The charity's objects focus on the relief of nystagmus (visual impairment) sufferers and their families. The objects also focus on advancing the education of the public in and to promote research into the condition known as nystagmus and to publish the useful results of any such research which the charity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



MORE INFORMATION

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or email us at info@nystagmusnet.org.