

2018 TRUSTEES' ANNUAL REPORT

NYSTAGMUS NETWORK



MORE INFORMATION

For more information visit us
online at

www.nystagmusnetwork.org

or email us at

info@nystagmusnet.org



ABOUT US

The Nystagmus Network is the foremost charity in the United Kingdom providing support and information about nystagmus and its associated visual impairments.

The charity was established in 1984 and has been at the forefront in supporting people affected by the condition and funding research, whilst also promoting a better understanding of nystagmus.

Through the charity's close relationship with the medical and scientific community we are moving closer to finding effective treatments for the condition and preventing it from occurring.

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CHAIRMAN'S MESSAGE

Legally, this is the final Annual Review of the Nystagmus Network in its original guise. On 1 January 2019 we established a new Charitable Incorporated Organisation with a new Charity Commission registered number. The change has modernised the governance of our charity and its legal status, but our Members and service users will see no real change. Thank you to all those who voted for the change and well done to our Trustees who brought their skills and expertise to the

table, allowing us to convert to CIO at no cost.

In 2018 we increased our capacity with a job-share arrangement supporting Sue Ricketts, allowing us to increase our presence on social media, boost our membership, develop our contacts with hospitals and the research community, and improve our responsiveness to enquiries.

In a major shift, we moved international Nystagmus Awareness Day to a new fixed date – 20 June. A summer

A whole new era ...

date gives us more opportunities to raise awareness and funds. We were particularly pleased to have support from Marsha De Cordova MP and internationally-renowned photographer, David Katz. Both saw through their support by being our guest speakers at a highly successful Open Day in September.

The day before Open Day, we hosted a Research Workshop attended by many of the leading experts in eye movements generally and nystagmus specifically.

Our accounts show our continued commitment to engaging in research with a very healthy investment of over £37,000, thanks to the generous fundraising and donations of our members and supporters. We took the decisive action to reduce our reserves and invest in more research. Drawing on the advice of the experts attending our Research Workshop, we have committed to a funding partnership with Fight for Sight which will see around £250,000

going into post-doctorate level nystagmus research over the next 3 to 4 years.

In summary, 2018 has been an outstanding year of success for the Nystagmus Network, building more awareness, investing in more research, offering more support and guidance, boosting our membership and completing the transfer to a new legal entity. It looks as if we will do even more in 2019, given our new research partnership and our investment in training to give us more capacity to support parents through the education minefield for those affected by nystagmus.

We can only provide this practical support and research investment with the right level of financial income. That is why we value our Members and the impressive efforts of our fundraisers. Thank you so much for your support. It is a cliché, but still true, that every penny counts.

Richard Wilson

RICHARD WILSON OBE

Chairman

"It's great to feel part of a big nystagmus family."

- Parent



TRUSTEES SERVING IN 2018

Our trustees bring a wealth of third sector, commercial, legal, technological, educational and financial expertise to the table alongside firsthand experience of living with nystagmus or supporting a child with nystagmus.

Vivien Jones, President
Richard Wilson, Chairman
Vicky Pitman, Treasurer
Sam Jones, Secretary
Frances Lilley, Education Advocate
Tim Cuddeford
Peter Greenwood
Claire Brinn
James Ronson
Deborah McManamon
Mitch Pender
Mary Elliott
Marie Turnbull





WHAT IS NYSTAGMUS?

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

Nystagmus is caused by a range of ophthalmological and neurological causes. It is also a genetic condition. At least 1 in 1,000 babies in the UK are born with nystagmus and many other people develop nystagmus later on.

The most common form of the condition is congenital nystagmus. This simply means that it is present in the first few weeks or months of life. Sometimes it may not be noticed until later.

Congenital nystagmus is a life-long condition. The impact on vision varies greatly. A child's sight can continue to improve and they will learn to adapt and live with their nystagmus, but they may need support throughout their lives.

Most people have reduced distance vision and need to be very close to print or a screen. They may be registered sight impaired.

The different forms of 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 surgery and drug treatments are sometimes appropriate.

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

"I will never forget the first call I made to the Nystagmus Network. My baby daughter had just been diagnosed and I needed to talk to someone. Luckily the Nystagmus Network was there for me. I'm still a member today and always will be, because I need to know that this charity will still be there for parents like me."
- Parent

SUPPORTING OUR COMMUNITY

The Nystagmus Network provides the widest possible range of support to the nystagmus community. 2018 was our busiest year yet.



Online

We use social media and our website to provide clear information.



Open Day

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



Volunteers

We provide peer to peer support and an education advocacy service.



Free documents

We make regularly updated information accessible free of charge to all.



SUPPORT COMMITTEE

442

INDIVIDUALS
REQUESTING AND
RECEIVING
SUPPORT
IN 2018

Sue Ricketts

SUE RICKETTS

on behalf of
Support Committee

2018 saw another huge increase in the number of people seeking information and support from the charity. Among those, the biggest group remains parents, closely followed by the growing number of people affected by acquired nystagmus. Every single request was dealt with by our staff team, offering an empathetic ear,

signposting to our online resources on benefits or driving or services and information from other agencies, such as RNIB, initiating education advocacy or appealing for peer to peer advice through our social media. Our free to download digital publications continued to grow in popularity with 3,228 copies downloaded during the year.



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7 C A A = H H 9 9

£48,410

RAISED IN 2018 BY OUR
FABULOUS FUNDRAISERS

Nystagmus Awareness Day

In 2018, we took the decision to move our annual awareness day from Wobbly Wednesday in November to 20 June. This was driven by a number of factors including a summer date providing more daylight hours for activities and to avoid clashes with other appeals. We also extended our awareness activities to encompass the whole week around 20 June so there will always be a Wednesday for those who enjoy a wobble.

2018 was hugely successful with the 'nystagmus in the open' theme raising much needed awareness and funds. Our Trustees also pitched in, raising awareness and collecting on the London Underground.

Open Day

Birmingham was so good in 2017 we returned to host our annual Open Day there in 2018 with over 200 people attending, including our members, supporters, researchers and partner organisations. The day



included updates from our research centres, presentations from our partner organisations, invaluable education and benefits advice, stories of fundraising feats, musical performances and members approving the charity becoming a Charitable Incorporated Organisation (CIO).

If that wasn't enough, we were incredibly fortunate to have two inspirational speakers – Marsha De Cordova (MP for Battersea and Shadow Minister for Disabled People) and David Katz (internationally acclaimed photographer). Both have nystagmus and shared stories of their many achievements and how their visual impairments have not stopped them inspiring others. In the words of David, "there's no such word as can't."

All this was provided free of charge to members.

Fundraising

Where do we start on fundraising Firstly with a huge thank you to all our brilliant fundraisers who have raised an extraordinary amount for the charity in 2018. We've had runners, walkers, Christmas cards, online shopping, lotteries, T-shirts, mudders, abseilers, sky divers, cyclists, bakers, triathletes, tin rattlers, gift aiders and gardeners. We simply could not have delivered on our support and research commitments without your hard earned donations. Thank you.

Peter Greenwood

PETER GREENWOOD

Chair of Awareness Committee

#YouMadeItHappen



RESEARCH COMMITTEE

IMPROVING QUALITY OF LIFE THROUGH RESEARCH

In 2018 we invested some £37,000 in research. That we were able to do this is down to fundraising by and donations from our members and supporters. We are deeply grateful to them.



2018 saw our increasing collaboration with **Fight for Sight**, the UK's leading eye research charity, who provided matched funding for our 3 research projects.

Firstly, we funded Dr Matt Dunn from Cardiff University to research an improved diagnostic technique for nystagmus in children. Until now, the challenge for patients has been keeping their eyes

still while the test is being performed. Dr Dunn's project involves investigating a new technique that can be used while the eye is also moving – which could improve the earlier diagnosis of this condition in future.

Dr Mervyn Thomas from the University of Leicester is being funded to investigate how nystagmus affects the clarity of vision of children. The project



THE NYSTAGMUS NETWORK HOSTS THE UK NYSTAGMUS RESEARCH WORKSHOP 2018

will look at predicting future vision in infants and young children with nystagmus.

Jay Self at the University of Southampton will be funded to develop a new clinical test using an iPad app to measure a patient's ability to identify faces in a crowd, one of the challenges of nystagmus. The aim is for the app accurately and effectively to diagnose patients and ensure they are offered the most appropriate support for their nystagmus. The app can also be used in clinical trials of various therapies.

We were very pleased in 2018 to be able to host a research workshop for UK research centres the day before our Open Day in Birmingham on Friday 28th September. Participants included representatives from Cardiff, Southampton, Sheffield, London and Plymouth. The workshop focused on sharing research information and it was most encouraging to note the increasing emphasis on collaboration between the centres.

continued overleaf

RESEARCH, continued

OUR PARTNERSHIP WITH FIGHT FOR SIGHT BRINGS A NEW NYSTAGMUS EXPERT TO THE TABLE

Towards the end of the year, we entered into detailed discussions with Fight for Sight about working together on a 3 to 4 year project to fund a joint research doctorate – something which our research community has told us they would like us to do. These discussions bore fruit with the signing of a Memorandum of Understanding just before year-end. The doctorate will cost around £250,000 of which we will fund a significant proportion. It is our biggest ever research investment and ended the year on a very positive note.

Vivien Jones

VIVIEN JONES

Chair of Research Committee



OUR KEY PROJECTS

In 2018 the Nystagmus Network continued to strive towards our stated goals: supporting the nystagmus community, raising awareness and funding research.



Awareness

We celebrated Nystagmus Awareness Day 'out in the open' on our new annual date - 20 June



Communication

Daily Facebook posts and Tweets helped us reach a weekly audience of 11,000 people



Research

We awarded 3 research grants to Cardiff, Leicester and Southampton



Support

100s of enquiries were dealt with, from adults with CN and AN, parents, teachers and ECLOs



Fundraising

We actively supported over 80 fundraisers, celebrated publicly their hard work and thanked them with postcards



Advocacy

Our education advocate supported 75 families with issues in schools and early years settings

EDUCATION ADVOCACY

Frances Lilley

2018 saw a significant increase in demand for our education advocacy service. As a result Claire Brinn, a trustee of Nystagmus Network, has recently completed IPSEA training on SEND law in England and will be advising members of Nystagmus Network on education issues, alongside Frances Lilley who has held this role since 2015.

Frances and Claire give parents and carers one to one legally-based advice and support on how to negotiate the SEND system in England, so that children and young people with nystagmus can access support across all stages of education.

Education advocacy services include legally-based input and guidance on the Children and Families Act 2014, the SEND Code of Practice and some aspects of the Equality Act.

In addition, Frances has compiled an Education Resource Hub which can be found on the Nystagmus Network website. Parents, carers and young people can find practical information and resources related to education as it affects vision impaired children and



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**FAMILIES
SUPPORTED**

young people. The material is a compilation of the years of experience Frances has as a parent to a child with nystagmus and also provides links to many useful external sources.

As a representative of Nystagmus Network and as a parent, Frances is also a member of The Young Vision Alliance (YVA), a newly formed group of the main sight loss charities, parents of vision impaired children and the children and young people themselves.

“The support I’ve received from the Nystagmus Network has been a real lifeline. Membership means such a lot.” - Parent



The YVA came together as a result of increasing concern about the provision of SEND support for vision impaired children and young people. In November 2018, the YVA published a report called “Our Futures Matter” in Parliament and the Alliance seeks to secure government support for the issues highlighted in the report.



MEMBERSHIP



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 affected by the condition we can make sure that our voice is heard in education, research and funding.

"The challenges of nystagmus affect every age and stage, so we've joined the Nystagmus Network for life!" a member

Apart from our support, here are just some of the other benefits for you as a member:

- Priority booking and a FREE place at Open Day
- Access to our education advocacy service
- Referral for bespoke advice and guidance on benefits
- Automatic subscription to our fortnightly e-newsletter, Focus
- Support and information from a named staff member or volunteer
- Contact from us by email or post about charity developments
- Regular updates on research and trial participation opportunities
- News of fundraising events, including FREE run places
- Invitations to participate in local and regional groups
- Early notification of our annual Nystagmus Awareness Day campaigns
- Networking opportunities with others affected by Nystagmus
- A proportion of your subscription goes directly into research

PARTNERSHIPS

The Nystagmus Network works closely with the teaching profession to ensure that children with nystagmus have equal access to learning. We also work alongside other vision impairment charities to ensure maximum support.

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 with nystagmus.

**"I can't run a marathon, but I can pay my subs to support this great charity."
a member**

TREASURER'S REPORT

We are proud to report significant spending on research thanks to our partnerships with Fight for Sight (who match fund our contributions) and Moorfields Eye Charity

Continued fundraising effort, good housekeeping and a change in financial policy enabled the charity to raise income in the year 2018 of £77,770 (a 2% increase on prior year), invest £37,798 in research expenditure and finish the year with a bank balance of £74,525.

The trustees decided in 2018 to reduce the charity's reserves to a more appropriate level. Putting aside free cash reserves of 9 months' cover for annual expenses meant that total spending for the year increased to £109,161 compared with prior year of £73,704, resulting in a planned deficit for the year of £31,391.

The major areas of income were £48,410 from fundraising, £16,162 from donations and £10,382 from membership subscriptions. We are very grateful to all our Members, fundraisers and donors for their continued support, which enables us to continue working towards the charity's objectives of raising awareness, offering support and investing in research.

We are proud to report significant spending on research, thanks to our partnerships with Fight for Sight (who match fund our contributions) and Moorfields Eye Charity.

In 2018, the Nystagmus

Network raised funds for Moorfields Eye Charity of £7,798, which has been ring-fenced for nystagmus research, from a charity abseil event.

We spent £15,000 on 3 small research grant awards with Fight for Sight.

We also committed £15,000 in 2018 towards

a 3 year post doctorate research project into nystagmus, a jointly funded project with Fight for Sight which in total is likely to cost in the region of £250,000.

Vicky Pitman

VICKY PITMAN A.C.A.
Treasurer

**Nystagmus
Network
treasurer,
Vicky Pitman,
completes her
fundraising
abseil**




MANAGEMENT ACCOUNTS 2018

Nystagmus Network - Financial Accounts 2018


	2018		2017	
	£	£	£	£
Income				
Fundraising	48,410		51,486	
Grants	0		0	
General Donations	16,162		17,826	
Subscriptions	10,382		6,145	
Shop Sales	1,011		305	
Bank Interest	36		90	
Open Day	1,769		196	
Other	0		0	
	<u>77,770</u>		<u>76,048</u>	
Expenditure				
Office and Administration	14,551		12,286	
Committee	820		832	
Communications & Events	19,534		15,836	
Research	37,798		7,665	
Giles Warman Foundation Funded Research	0		4,250	
Support services	1,237		0	
Shop Expenditure	0		0	
Fundraising Costs	23,507		20,793	
Open Day	11,474		12,042	
Other	240		0	
	<u>109,161</u>		<u>73,704</u>	
Net Surplus/(Deficit) for the year		<u><u>-31,391</u></u>		<u><u>2,344</u></u>
<i>Total Staff costs included above</i>	£48,835		£39,591	
Cash at the Bank 31st December				
General Fund		£74,525		£105,914
Giles Warman Fund		£0		£0
Total Funds		<u><u>£74,525</u></u>		<u><u>£105,914</u></u>

It is the policy of the Trustees to keep Free Cash reserves of 9 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 only be funded when cash reserves allow and/or grants are obtained to support this without compromising the expense cover policy as outlined.

Accounts Prepared by

 4/2/19
Vicky Pitman ACA (Treasurer)

Accounts Examined by

 4/2/19
Andrew Black ACA

Nystagmus Network Founder and Honorary President, Vivien Jones, with Marsha De Cordova MP at Open Day 2018



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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 judgments 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.

Richard Wilson

RICHARD WILSON OBE

Chairman



NYSTAGMUS NETWORK



MORE INFORMATION

For more information visit us online at

nystagmusnetwork.org

or email us at info@nystagmusnet.org.