

2019 TRUSTEES' ANNUAL REPORT

NYSTAGMUS NETWORK



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



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 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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Tim Cuddeford
Chairman of
the Nystagmus
Network

CHAIRMAN'S MESSAGE

2019 was another very busy and productive year for the Nystagmus Network.

Founded in 1984 as a self-help group, the Nystagmus Network became a registered charity in 1990. In 2019 we completed the next phase in our development through our transition to the status of a Charitable Incorporated Organisation, which was seamless to our members, thanks to the hard work of our support team and trustees.

After 9 outstanding years as chairman of the trustees, Richard Wilson decided to step down this year. Richard's contribution has been an inspiration to us all and we were pleased to celebrate his tenure at the 2019 Open Day. Richard remains an enthusiastic member and supporter of the charity and we wish him well in the future.

Investment in research

Through the efforts and energies of our fundraisers, plus donations and grants, we have been able to continue to provide serious investment in research (£28,000), provide a healthy level of support to our members and maintain a sensible financial reserve. Our thanks go to everyone who has contributed.

Open Day 2019

We held our Open Day in Cardiff in September. This was a well attended and excellent event with many inspiring guests. The previous day, at the Cardiff university campus, we hosted a meeting of nystagmus researchers from the UK universities.

Support for parents

Educational advocacy continued to be an important aspect of our help to parents.

In addition to support for individuals, we ran a number of Parent Power workshops in different parts of the country to share knowledge and empower parents to get the best start in education for their children with nystagmus.

Thanks again to all our members and fundraisers.

Tim Cuddeford

Tim Cuddeford Chairman

"Thank you so much for arranging our tickets for Open Day. We had a lovely day and we all left feeling very positive." Cardiff parent



TRUSTEES SERVING IN 2019

The Nystagmus Network is led by a committee of volunteer trustees. Each one brings his or her own expertise to the table, whether that be from the third sector, commerce, the law, technology, education or finance. They all share a firm commitment to the nystagmus cause.

Vivien Jones, President
Richard Wilson OBE, Chairman
Vicky Pitman, Treasurer
Sam Jones, Secretary
Frances Lilley, Education Advocate
Tim Cuddeford, Chairman elect
Peter Greenwood, Vice Chair elect
Claire Brinn, Education Advocate
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.

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 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.

"Thank you for the invitation to attend the research workshop and open day. It was wonderful to meet the Nystagmus Network team, other researchers and patients/families with nystagmus. It was organised to perfection, so hats off to the organising committee." Dr Mervyn Thomas, Leicester

SUPPORTING OUR COMMUNITY

The Nystagmus Network provides a wide range of support to the nystagmus community. 2019 was another very busy year.



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 up to date information available free of charge to all.

"Your organisation has been a godsend for our families to understand and help our little one. I truly believe some of the advice has enabled him to thrive - and without you that wouldn't have been possible." Parent



SUPPORT COMMITTEE

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INDIVIDUALS
REQUESTING
AND RECEIVING
SUPPORT
IN 2019

Sue Ricketts

SUE RICKETTS
on behalf of the
Support Committee

The Nystagmus Network provides support by phone and email as well as on Facebook. Every enquiry is answered individually and each person is afforded sympathy, understanding and respect. If we don't know the answer, we find someone who does. When the phone rings it could be the anxious parent of a newly diagnosed child wondering what the future may hold or a

mature person struggling with acquired nystagmus, simply needing to talk to someone who appreciates what they're going through.

Our online information documents on everything from supporting a child with nystagmus, to education, driving and benefits were as popular as ever with no fewer than 3,001 downloads.

Nystagmus Network

OPEN
DAY
2019



Just say *yes!*

5 K 5 F 9 B 9 G G
7 C A A = H H 9 9

£63,299

RAISED IN 2019 BY
OUR EXCEPTIONAL
FUNDRAISERS

Nystagmus Awareness Day

We ran our awareness day again on its new date of 20 June, but also encompassing the whole week (and most importantly a wobbly Wednesday).

The theme this year was "How amazing are you?" and was a celebration of good times, successes, and achievements. We also joined forces with parkrun UK on Saturday 22 June to help raise awareness of nystagmus and the charity.

Open Day

Our latest Open Day held outside England – welcome to Wales and the amazing Principality Stadium in Cardiff. Over 200 people attended and were motivated, informed and moved by some truly inspirational speakers and presenters:

- Our ever-popular Research Hub with lead researchers from Cardiff, Leicester, London, Plymouth Sheffield and Southampton provided insight into current research initiatives;



Open Day



Nystagmus Awareness Day



Eye to Eye

Open Day contd

- The motivational Daniel Williams (founder of Visualise Training and Consultancy) was our keynote speaker;
- Rubina Ahmed from Fight for Sight and Joanne Green from Moorfields Eye Charity spoke about our joint fundraising and research projects;
- For the children there was a drama workshop by UCAN Productions, rugby ace, Wil Maudsley and surprise guest Adam Hills;
- Frances and Claire provided parents with education advice and support;
- Nadine Neckles spoke about her book "Can I tell you about Nystagmus?";
- Hannah Ricketts ran a workshop on nystagmus in the workplace;
- Young Oliver Mitchell sang "Danny Boy" and singer/songwriter, Ben Haynes closed the day with some of his own music and an insight into his nystagmus journey.

Fundraising

It was a record-breaking year with our fundraisers setting themselves all sorts of challenges, big or small. Most notable was Shirley's auction of promises which raised almost £17,000. Thank you also to our online shoppers, raising money through Easyfundraising, to those who play our Weather Lottery and to everyone who made donations. We simply cannot deliver our support and research commitments without all the amazing fundraising and donations. Thank you from everyone at the charity.

Peter Greenwood

PETER GREENWOOD

Chair of Awareness Committee

RESEARCH COMMITTEE

**IMPROVING
QUALITY OF LIFE
THROUGH
RESEARCH**

In 2019 we invested some £28,000 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.



It has in truth been a somewhat frustrating year. We started the year with such high hopes – we negotiated our biggest ever fundraising partnership with the charity Fight for Sight and announced the news in April 2019. The partnership was to fund a post-doctorate position for around three years. Applications for the post opened in early May, with abstract applications due by the end of July and full

applications by the end of November. These things take a long time, but we were happy to wait, given the importance of the position we would be funding. The Nystagmus Network's contribution to this £68,000 multi year initiative - our biggest ever investment in research - was £28k in 2019. The overall value of the grant was £250,000, with Fight for Sight generously paying the difference. Alas, when it came to awarding

Research HUB HWB Ymchwil



Nystagmus *Network*

The research HUB at Open Day 2019 in Cardiff was popular with delegates and exhibitors alike

the project grant after a rigorous selection process, Fight for Sight's expert Grant Assessment Panel found that no application met the stringent success criteria required in this very competitive research arena. A post doctoral award is highly prestigious and offered only on a fully peer reviewed basis. For the charity, this was initially seen as a setback – but frustrating as it undoubtedly was, it also served to highlight our faith in Fight for Sight to carry out due diligence on our behalf and the importance of wise investment in robust

research projects which are most likely to yield tangible benefits for those living with nystagmus.

In consultation with our funding partners, Fight for Sight, the Nystagmus Network has now decided to re-direct the lion's share of the hard won funds already committed to the post doctoral project into funding one post-graduate researcher to address visual impairment associated with nystagmus (a new PhD studentship). In addition, the Nystagmus Network and Fight for Sight will provide a further

contd.

RESEARCH, continued

grant award of up to £15,000 (funded jointly by both charities) focusing on quality of life and one or more of the following: cause (including genetics), diagnostic testing/analysis and treatments. Following the application process, again overseen by the experts at Fight for Sight, we expect to award our PhD nystagmus studentship in March 2021. The additional small grant will be awarded in September/October 2020 or March 2021.

THE NYSTAGMUS NETWORK HOSTS THE UK NYSTAGMUS RESEARCH WORKSHOP 2019

In line with our commitment to improving collaboration between the UK research centres, we were delighted to host a research workshop the day before our annual Open Day in September. Held at the University of Cardiff, this event – at which all the UK research centres were represented – underlined that collaboration between the centres is indeed growing and we are grateful to Cardiff's Professor Jonathan Erichsen for anchoring the event.

Vivien Jones

VIVIEN JONES

Chair of Research Committee

The
Optometry
Building,
University
of Cardiff



OUR KEY PROJECTS

In 2019 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 with parkruns on 20 June



Communication

Daily Facebook posts and Tweets helped us reach an audience of 11,500 people



Research

We invested £27,775 in nystagmus research



Support

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



Fundraising

We actively supported nearly 100 fundraisers, celebrated publicly their hard work and thanked them with postcards



Advocacy

Our education advocates supported 22 families with issues in schools and early years settings

EDUCATION ADVOCACY



**Frances
Lilley**

2019 was the busiest year yet for the Nystagmus Network education advocacy team, both in terms of growth in the number of individual education support cases and in the range of education advocacy services offered.

Frances Lilley and Claire Brinn, our two volunteer IPSEA-trained SEN advisers, ran several Nystagmus Network “Parent Power” events funded by the **National Lottery Community Fund**. The events provide parents with legally-based and practical advice to help secure support for children and young people with nystagmus across all stages of education in England. The legislation covered includes the Children and Families Act 2014,

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**FAMILIES
SUPPORTED**

the SEND Code of Practice and some aspects of the Equality Act. Frances and Claire also provide specific information on how to build a case for support for children and young people with nystagmus. In addition Frances delivered education support to parents and carers at a regional Nystagmus Network event in Manchester run by Marie Turnbull, a trustee of the Nystagmus Network.

Throughout 2019, Frances and Claire continued to manage individual cases, providing one-to-one legally-based advice and



support for parents and carers navigating the SEND education process in England.

Our Nystagmus Network Parents' Facebook group enables parents of children and young people with nystagmus to share education support issues and is a source of information on SEND legislation, legal updates, education resources and training opportunities.

In addition, the Education Resource Hub, which can be found on the Nystagmus Network website, continues to offer parents, carers and young people practical information

Claire Brinn



and resources related to education. The material is a compilation of the many years of experience Frances has as a parent to a child with nystagmus, and provides links to many useful external sources.

Frances Lilley

Frances Lilley
Volunteer education advocate

"Amazing volunteers! Our sincere thanks for sharing such valuable information."
PP delegate

**Parent Power
Southampton**



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

"You've been helping our family since the 1980's and now our son is running 10k to help you help others. Thank you."



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 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 regional groups and events
- 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 work with the national Eye Clinic Liaison (ECLO) team so that our information is available to all patients visiting eye clinics. 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 living with the condition.

TREASURER'S REPORT

In 2019 the Nystagmus Network allocated £28,000 to research.

We are delighted to report that the charity raised over £100k in income during the year ended 31 December 2019, a 30% increase on the previous year.

The main sources of income were £63,000 from fundraising, £13,000 from donations, £11,000 from membership subscriptions and £10,000 from grant income. We are very grateful to all our members, fundraisers and donors for their continued support, which enables us to work towards achieving the charity's objectives of raising awareness, offering support and investing in research.

We ended the year with

cash reserves of £78,000 and continue to adopt a policy of putting aside free cash reserves of 9 months' cover for annual expenses.

As a result, total spending for the year was £97,000 leaving a small surplus for the year of £4,000.

Our partnerships with Fight for Sight and Moorfields Eye Charity continue to strengthen and in 2019 Nystagmus Network allocated £28,000 towards research expenditure.

The charity continues to look at new ways of raising funds and creating partnerships in order to maintain our position as

a significant funder of
nystagmus research in
the UK.

Vicky Pitman

VICKY PITMAN FCA
Treasurer

**Nystagmus Network
treasurer, Vicky
Pitman, presents the
annual accounts to
members at Open Day**



FINANCIAL ACCOUNTS 2019


Nystagmus Network - Financial Accounts 2019

	2019		2018	
	£	£	£	£
Income				
Fundraising	63,299		48,410	
Grants	9,790		0	
General Donations	13,483		16,162	
Subscriptions	10,667		10,382	
Shop Sales	3,140		1,011	
Bank Interest	116		36	
Open Day	446		1,769	
		100,941		77,770
Expenditure				
Office and Administration	14,249		14,551	
Trustee expenses	303		820	
Communications	17,708		19,534	
Research	27,775		37,798	
Support services	1,457		1,237	
Fundraising Costs	22,431		23,507	
Open Day	13,349		11,474	
Other	0		240	
		97,272		109,161
Net Surplus/(Deficit) for the year		<u>3,669</u>		<u>-31,391</u>
<i>Total Staff costs included above</i>	<i>£44,269</i>		<i>£48,835</i>	
General reserves at 31st December	£71,033		£74,525	
Restricted reserves at 31st December	£7,161		£0	
Cash at the Bank 31st December	<u>£78,194</u>		<u>£74,525</u>	

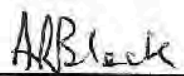
2018 figures are included for comparison purposes and relate to Nystagmus Network charity number 803440.

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

 13/3/2020
Vicky Pitman FCA (Treasurer)

Accounts Examined by

 13/3/2020
Andrew Black ACA

Nystagmus Network staff member, Sara,
with her son, Charlie



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 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 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.

Tim Cuddeford

Tim Cuddeford

Chairman

NYSTAGMUS NETWORK



MORE INFORMATION

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