MORE INFORMATION
For more information visit us online at
www.nystagmusnetwork.org or email us at
info@nystagmusnet.org
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 or preventing it from occurring.
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In our last Annual Review, I explained that 2016 had been a year of major transition as we modernised our communications channels, invested in our infrastructure and reflected on our approach to funding research, while continuing to support everyone affected by nystagmus. In 2017 we put our research strategy into practice and invested in three exciting projects. Our accounts show direct investment in research, coupled with the use of some residual funding we were holding from the Giles Warman Foundation, to whom we are very grateful for their generous support. This Annual Review explains the importance of our paid-up members and fundraisers. The more money that comes in, the more support and research we can fund.

We were sorry to see Dan Lewi leave us as our Executive Information and Development Manager half way through the year. Dan had an offer he could not refuse to return to
Building capacity ...

his financial background and we wish him and his family well. Sue Ricketts has taken on that role and our members and supporters will know that she arrived running and is doing a fantastic job for the charity. The Trustees recognised the need for additional support for Sue and recruitment was completed at the end of 2017.

Also at the end of 2017, I was humbled and honoured to be awarded the OBE in the Queen's 2018 New Year's Honours. That is in recognition of the amazing work that the Nystagmus Network has done and continues to do and I am proud to have led the charity as its Chairman since 2011. Looking ahead, 2018 promises to be an even more exciting year. We will be moving our Nystagmus Awareness Day to the summer, our Open Day will be bigger and better in terms of the speakers we already have booked, our investment in research will be increased, we will be making proposals to change the legal status of the charity to modernise its standing and our new staff will give us even greater capacity to match our ambition.

Richard Wilson
RICHARD WILSON OBE
Chairman

“When my son was diagnosed, our GP and health visitor didn’t know a lot about nystagmus so suggested I look on the internet. Thank goodness for the Nystagmus Network who have helped us so much!!!”
- Parent
TRUSTEES SERVING in 2017

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
Graham Dickson, Secretary
Frances Lilley, Education Advocate
James Taylor
Peter Greenwood
Tim Cuddeford
Fola Tayo
Claire Brinn
James Ronson
Deborah McManamon
Mitch Pender
Mary Elliott
Sam Jones
Marie Turnbull
Nystagmus is a complex eye condition characterised by involuntary movements of the eyes, where they appear to wobble or flicker.

Nystagmus is caused by abnormal functioning of the part of the brain which regulates eye movement and positioning. It has an incidence rate of at least 1 in 1,000 people in the UK and is regularly seen as a symptom of many other underlying conditions.

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 lifelong 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.
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.

“Without the help of you guys and Jay Self at Southampton I would still be rocking in a corner not knowing what to do.”

- Parent
OUR KEY PROJECTS

During 2017 the Nystagmus Network continued to make progress towards our stated goals: supporting the nystagmus community, raising awareness and funding research.

**Awareness**
Wobbly Wednesday awareness raising was complemented by a nationwide fundraising swimathon

**Communication**
Daily Facebook posts and a brand new Twitter account increased our weekly audience to 9,000+

**Research**
3 research grants were awarded to the University of Sheffield and the University of Cardiff

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

**Fundraising**
We actively recruited new fundraisers and supported our regular ones and celebrated their hard work

**Advocacy**
Our education advocate worked on a large caseload of support issues in schools and early years settings
With the new website up and running, 2017 saw a major increase in the number of parents, adults and professionals seeking information and support via our contact form. Every single request was dealt with by the staff team, whether that meant advice and guidance for the parent of a newly diagnosed infant, or an adult with acquired nystagmus, signposting to our online resources on benefits or driving, initiating support from our education advocate or appealing for peer to peer advice through our social media. Our newly available free to download digital publications continued to grow in popularity with 2,389 copies downloaded during the year.
Wobbly Wednesday
In 2017 the Nystagmus Network focused Nystagmus Awareness Day/Wobbly Wednesday activity on a national swimathon, encouraging individuals and clubs to take part in a sponsored swim to raise awareness of nystagmus and, in particular, to highlight a sport where a visual impairment is no barrier to participation. In total there were 19 swimathons. These events were supported by a social media campaign using the hashtag #nystagmusbigswim. For the non-swimmers there was a photography competition, judged by a professional photographer who also has nystagmus.

Open Day
170 adults, children and parents attended our annual Open Day in Birmingham. With presentations from all 6 UK centres of nystagmus research excellence,
workshops for parents on education and for adults on building social networks and an art activity for the children, the day proved popular with all delegates.

In the afternoon there was a moving tribute to the late Steve McKay (former trustee) and an equally emotional joint presentation from father and son team, Jamie and Joshua Fuller. Jamie established a VI ski team when his son was adjudged insufficiently visually impaired to take part in regular disability skiing.

One of the highlights of the day was the world premiere of a brand new short film, Through my Lenses, the biopic of internationally acclaimed 'blind' photographer, David Katz, who reveals in the film that he has nystagmus and has been registered blind since childhood.

**Fundraising**

2017 was an extraordinarily successful year in terms of income from sponsorship of individuals undertaking personal challenges on behalf of the charity. We had an exceptional 5 runners in the London Marathon, several 10ks, half marathons, sponsored walks, our first ever sky dive and a rickshaw race across India, alongside numerous garden parties and coffee mornings. We were fortunate that two golf club captains, both with family members who have nystagmus, each named the Nystagmus Network as their captain’s charity of the year.
The charity invested judiciously in no fewer than three research projects in 2017, thanks to the generosity of our supporters and a funding partnership with Fight for Sight.

In August 2017 the research committee approved an application from Matt Dunn, Jonathan Erichsen and Nikita Thomas at Cardiff. Their project seeks through better diagnostic techniques to find an underlying cause for infantile nystagmus. A better understanding of how infantile nystagmus develops may help to interpret the main cause and the likely benefits of treatment in infancy, including the timing and methods of intervention. The project involves collaboration with Jay Self’s team in Southampton.

In 2017 we also approved two grants in partnership with Fight for Sight. Dr Lee Mcilreavy from Cardiff University is using the joint funding to determine whether a novel eye tracking
The Nystagmus Network is proud to work alongside the UK nystagmus research centres of excellence.
approach can correctly identify the patterns of eye movement in infantile nystagmus. This study could lead to a simple, child-friendly eye tracking test that does not rely on expensive technology. This has the potential to detect the condition earlier and allow earlier diagnosis.

Dr Helen Griffiths at the University of Sheffield was also successful in her bid for joint Fight for Sight / Nystagmus Network funding for her project to develop an image stabilisation technology in virtual reality to treat oscillopsia, a condition affecting those with acquired nystagmus where the individual perceives the world in constant motion.

We are delighted that we were able to fund all three projects, in line with our research investment strategy, thanks entirely to the generosity of our members, supporters and fundraisers.
SUPPORTING OUR COMMUNITY

At the Nystagmus Network we provide a whole range of support to the nystagmus community. 2017 was our busiest year yet.

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

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

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

Free documents
We make regularly updated information accessible free of charge to all.
Frances Lilley is our volunteer Education Advocate. Trained by IPSEA, Frances provides parents and carers who are members of the charity with one to one legally-based advice and support on how to negotiate the education system in England, so that children and young people with nystagmus can access support across all stages of education. Her caseload now numbers over 75 families.

Alongside her support work, Frances has been compiling resources for a Nystagmus Network Education Resource Hub which the charity plans to launch in 2018. The Hub will provide parents, carers and young people themselves with access to vital information and resources related to education support. The Hub will be available to both members of the Nystagmus Network and to everyone supporting a child with nystagmus.
In 2017 the Nystagmus Network was delighted to receive a sizeable anonymous donation in recognition of the work Frances has done in supporting families.

You seem like the only light at the end of a very long tunnel!! Thanks so much for your tireless, ongoing support.
- Parent

Thanks for all your support – honestly I can’t tell you how much it has meant to have someone share their journey and to encourage me with the process.
- Parent

Frances, you’re amazing! Thank you so very much. Thank you. Thank you. Thank you. Thank you.
- Parent
MEMBERSHIP

The Nystagmus Network is a membership organisation. 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 benefits of membership include:

- Priority booking for all events and a FREE place at Open Day
- Access to our education advocacy service
- Automatic subscription to our fortnightly e-newsletter, Focus
- Support and information from a named staff member or volunteer
- Updates on research and trial participation opportunities
- News of fundraising events, including FREE run places
- Invitations to participate in Nystagmus Awareness Day events and campaigns
- Networking opportunities with others affected by nystagmus
- A proportion of your subscription will go directly into funding 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.

CAMPAIGNS
The Nystagmus Network is committed to raising awareness of nystagmus to improve the quality of life of everyone with nystagmus.

ACHIEVEMENT
The Nystagmus Network shares and celebrates every success members of the nystagmus community achieve.
The year ended with the charity showing a small surplus of £2,344.
'Due to additional income raised during the year and good cost management we have committed a further £30,000 to be spent on research in 2018.'

As a small charity we have relied solely on income from membership subscriptions and generous support from donors and fundraisers during the year, for which we are immensely grateful. This has enabled us to continue supporting the charity’s objectives of raising awareness, offering support and investing in research.

Income for the year 2017 was £76,048, 7% higher than the previous year. Fundraising efforts were particularly successful with £51,486 generated, a 21% increase on the prior year. This includes income raised from Wobbly Wednesday, fun-run places, golf club charity nominations and a host of other fundraising activities. A fall in membership subscriptions of 17% has been addressed in 2018 and, with an overhaul of our membership database and communication with our members, we expect to see an increase in membership numbers in 2018.

The successful annual open day held in September was held free of charge for the first time to attendees. We were disappointed that some ticket holders for the event did not then attend, which has a financial impact on the charity. We will tweak the ticketing arrangements for 2018.

Expenditure for the year was well managed and totalled £73,704, an 11% reduction compared with the prior year. A change in staff structure saw a 23% reduction in office and administration costs and, despite an increase in fundraising income, the costs of raising that income fell by 57% because we relied on free to download fundraising packs rather than investing in merchandise and run places. Newsletter costs were eradicated by providing it electronically instead of printing. In 2017 we were able to spend an additional £7,665 on research as well as the £4,520 remaining from the Giles Warman Fund. We awarded a total of 3 research grants. Due to additional income raised during the year and good cost management we have committed a further £30,000 to be spent on research in 2018.

Vicky Pitman
VICKY PITMAN A.C.A.
Treasurer
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. The Trustees are therefore budgeting to be able to commit £30,000 to research projects in 2018, of which there are already specific plans for £15,000.
# MANAGEMENT ACCOUNTS 2017

<table>
<thead>
<tr>
<th>Income</th>
<th>2016 £</th>
<th>2017 £</th>
<th>2016 £</th>
<th>2017 £</th>
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<tbody>
<tr>
<td>Fundraising</td>
<td>42,684</td>
<td>51,486</td>
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<tr>
<td>Grants</td>
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<tr>
<td>General Donations</td>
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<td>17,826</td>
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<td>Subscriptions</td>
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<tr>
<td>Shop Sales</td>
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<tr>
<td>Bank Interest</td>
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<td>90</td>
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<tr>
<td>Open Day</td>
<td>3,021</td>
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<tr>
<td>Other</td>
<td>139</td>
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<td><strong>Total Income</strong></td>
<td><strong>70,888</strong></td>
<td><strong>76,048</strong></td>
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</table>

<table>
<thead>
<tr>
<th>Expenditure</th>
<th>2016 £</th>
<th>2017 £</th>
<th>2016 £</th>
<th>2017 £</th>
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</thead>
<tbody>
<tr>
<td>Office and Administration</td>
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<td>Committee</td>
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<td>Communications</td>
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<td>Research</td>
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<td>Giles Warman Foundation Funded Research</td>
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<td>Shop Expenditure</td>
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<td>Fundraising Costs</td>
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<td>Open Day</td>
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<tr>
<td>Other</td>
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<tr>
<td><strong>Total Expenditure</strong></td>
<td><strong>82,844</strong></td>
<td><strong>73,704</strong></td>
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<table>
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<tr>
<th>Net Surplus/(Deficit) for the year</th>
<th>2016 £</th>
<th>2017 £</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-11,956</td>
<td>2,344</td>
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</tbody>
</table>

Total Staff costs included above  

| £48,921                          | £39,591 |

Cash at the Bank 31st December  

| General Fund | £99,050       | £105,914 |
| Giles Warman Fund | £4,520 | £0       |
| **Total Funds** | **£103,570** | **£105,914** |

Accounts Prepared by  

Vicky Pitman A.C.A. (Treasurer)  

Accounts Examined by  

Andrew Black A.C.A.  

29.8.2018
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