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Introducing the Nystagmus Network

The Nystagmus Network is the longest established 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 whilst also promoting a better understanding of nystagmus.

"2015 was the Nystagmus Network’s busiest year yet. This report highlights the range of work the charity undertakes in terms of client support, raising awareness and developing research. Do read it!"

Vivien Jones
President of the Nystagmus Network

Through the charity’s extensive involvement in research we are moving closer to finding effective treatments for the condition.
Richard Wilson, Chairman

I am clear as Chairman that the Nystagmus Network can be hugely proud of what we continue to do and our activities in 2015.

We delivered our first Clinical Training event for professionals, we invested the equivalent of £1,000 per week in various research projects, Wobbly Wednesday was just as much fun as its previous two events, and we invested in two outstanding videos about life with nystagmus, securing the services of the very famous Richard Osman into the bargain.

I am also clear that we can do much more to raise awareness, offer support generally and fund research. But to do that, we need to build capacity and capability. The Trustees were focused on that building job in 2015. In August we brought Sue Ricketts into the Team, and Sue has proved a great asset. Then we had the news that John Sanders was intending to take a well-earned retirement. We recognised that John was unique and it would take something special to replace him. We embarked on an exercise that resulted in Dan Lewi being recruited at the end of the year.

I must pay tribute to John Sanders (ably supported by Northwick Bear) for his outstanding service to the Nystagmus Network over so many years. To many people he is rightly known as “Mr Nystagmus” and we are sorry to lose him.

But we know that 2016 and beyond presents new opportunities with our new team, with a new logo and website. With the support of our membership and the wider nystagmus community, I am confident that we will continue to be the UK’s leading charity for nystagmus, raising awareness, fostering research and providing unparalleled support.

Richard Wilson
Chairman of the Nystagmus Network
Structure and governance

The Nystagmus Network has a board of trustees who manage the charity and are responsible for the direction which the charity takes.

“The Nystagmus Network has come a long way since it was established. We now have members from all over the world who need support.”

The Nystagmus Network became a charity in 1990 and is managed by a committee elected from the membership at the AGM.

The Nystagmus Network is run mainly by volunteers in their spare time plus three part-time employees. Our income comes mainly from subscriptions, fundraising and donations and these are activities which we actively promote.

Without the support of our members we would not be able to continue providing all of our services, which include support and leading the research into nystagmus.
The Nystagmus Network has three main objectives which it works towards through all of the activities which the charity undertakes. These objectives are listed below:

### Our charitable objectives

**Research**
Find a cure

Encourage research with a view to finding treatments and a cure for nystagmus.

**Support**
Our community

Be there for the 1 in 1,000 or more people estimated to have poor vision due to nystagmus.

**Fundraise**
Help our community

The charity undertakes fundraising activities to support our community.

**Awareness**
Challenge perceptions

Raise the awareness and the understanding of nystagmus in the wider community.
What is nystagmus?

Nystagmus is a complex eye condition that is characterised by involuntary movements of the eye 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 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 called congenital nystagmus. This simply means nystagmus that is noticed in very young children and is usually seen soon after they are born or sometimes in the first couple of years of their life.

Congenital nystagmus is a lifelong condition and the impact it can have on an individual’s vision varies greatly. A child’s sight can continue to improve and they will learn to adapt and live with their nystagmus. Most people will have reduced distance vision, but can see fine detail if they get close enough.

Nystagmus that develops later, generally in adults, is called acquired nystagmus. Often acquired nystagmus is a sign of another (underlying) condition such as stroke, multiple sclerosis, brain tumor, the effect of a drug or a head injury. Anything that damages the parts of the brain that control eye movements can result in nystagmus.

The main effect of acquired nystagmus is the sense that things are always moving (oscillopsia). Unlike in congenital nystagmus where the brain somehow adapts to the eye movement, giving a generally still image, this is not usually the case with acquired nystagmus. For this reason acquired nystagmus can sometimes be a more disorienting form of nystagmus than congenital nystagmus.

Unfortunately, there is currently no effective cure or treatment for nystagmus. However, the Nystagmus Network supports the research into finding therapies that could one day potentially have a positive impact on managing the condition.
Our activities

The Nystagmus Network is committed to providing a wide range of services to its members. We believe that it is important to empower the nystagmus community so that they are able to find access to all the support services they need and realise their full potential.

The activities which the charity undertakes are varied, and our emphasis is on supporting the individual. We are working hard to lead the way into understanding nystagmus and our involvement with research plays a key role in this.

The Nystagmus Network provides:

- Encouragement and support to its members with nystagmus.
- Funding for research into the field of nystagmus.

- Telephone helpline and email support
- Information and advice on issues such as:
- Peer support through events
- Printed, electronic and audio publications
- A quarterly newsletter (print, PDF and audio)
- A website, forum, Facebook page and Twitter
- Training and talks for medical staff, teachers, charities and other professionals
- Funding for research
- Support for hospital and university grant applications
- Help finding research subjects
- Promoting nystagmus research
The Nystagmus Network supports both adults and children affected by all forms of nystagmus. We provide many different services to ensure that they have access to all the support they need.
How we help

The Nystagmus Network helps its members in a variety of ways. Our focus is on empowering our community so they have all the tools to cope with their condition.

The Nystagmus Network is dedicated to supporting the nystagmus community through its varied services.

Helpline

During 2015 we replied to more calls for support and information than in any previous year. And there is no sign of the level of need reducing. The scope of enquiries is becoming wider too, with one call from a matchmaker concerned that a client may marry someone with nystagmus. The most common issues raised by people contacting us remain discrimination, benefits such as DLA and PIP, driving, inheritance patterns, support in school, employment problems and the general lack of information about the daily impact of nystagmus. Analysis of
our helpline records shows that the Nystagmus Network members are far better informed than non-members. Members tend to ask for information about specific issues such as employment, while non-members come to us because they have been told so little at the point of diagnosis.

Sadly, the evidence suggests that many people still get little, no, or even misleading information from some professionals. For example, one mother wrote about her son: “He is in Reception at school and his teacher and teaching assistant have noticed he is struggling with reading and they also have to move him sometimes so he can see properly. He doesn’t wear glasses at the moment as his doctor said his eyes were ok, although he does tilt his head quite a lot.”

Several people with no vision at all contacted us angry that they had never been told they had nystagmus. Although their loss of vision is not due to nystagmus, they said they should have been told that their eyes wobble as this affects how others perceive them and their sense of identity.

We do, though, hear from people with positive experiences of hospitals. For instance, one parent wrote: “the doctor was very happy to hear we had already been in touch with you! I would just like to thank you for taking the time out to email me back and your words were very reassuring, you put things into perspective on this difficult matter and thank you for sending us the newsletter too!”

It’s also positive that more parents seem to be finding out about education support and DLA from hospital based staff, especially orthoptists and ophthalmologists. Encouragingly, the anecdotal evidence suggests that
more children are being given a CVI (Certificate of Vision Impairment) as well, although this varies a lot around the country.

Several employers (including the National Trust) contacted us to find out about nystagmus so that they in turn could help staff with the condition. But we continue to hear from adults who feel discriminated against because they have nystagmus. Once again the financial services sector and the NHS are among the main culprits.

We heard from more middle aged people that they are struggling at work because of declining vision. One 47 year old man said: “I have noticed in recent months that my vision is deteriorating - am having to squint a lot more to focus, and when I wake up, it can take a fair amount of rubbing for mistiness to go.”

It’s not clear exactly why this is, as received wisdom suggests that nystagmus does not worsen with age. One possibility is that normal age-related changes in vision have a greater impact on some people with nystagmus.

The Acquired Nystagmus cases are usually the most challenging. One woman with AN emailed: “I have drawn myself into the black hole, thinking I will be useless and no good use.” Fortunately, we can help people with AN – and so can medics, although not necessarily in conventional medical terms with drug, etc. What often helps people with AN is simply being listened to, having the condition explained to them and being reassured that they are neither “bonkers” (a word several used in phone conversation during the year) nor alone. Yet many tell us they feel abandoned by the medical profession.

Open Day

Around 160 people attended our annual Open Day in May in Newcastle and the feedback was overwhelmingly positive. Actor and key-note speaker Gerard McDermott set the tone with a funny, positive, yet also sometimes sad account of his experiences of
nystagmus.

One orthoptist said: “I really wish I had had the opportunity to attend a meeting as a student Orthoptist before I qualified. Over the past 16 years of being an Orthoptist I have learned for myself many of the non clinical things that bother patients and parents, and given advice, but to hear the info from ‘the horse’s mouth’ so early on in my career would have been fantastic. May be something to push for in future meetings?!”

A parent emailed: “I’ve not had a chance to thank you for the open day in Newcastle. There were many highlights, one of the most valuable was the new found friendship between my 8 yr old son and a lovely boy called H. Since the event they have chatted on face time, exchanged jokes and anecdotes about previous spelling tests at school!”

We are very grateful to local volunteers Claire Moss and Sue Robson for organising a party the night before. This extended opportunities for people to meet informally, a vital aspect for many, especially those who have never knowingly met anyone else with nystagmus before.

This year was also probably the most international Open Day we’ve ever held, with delegates travelling from Belgium, France, Germany and Sweden.

**Education and training**

In January we held our first ever Nystagmus Clinical Training Day. The aim was to share the latest
research and best practice with ophthalmologists, orthoptists, QTVIs (Qualified Teachers of the Visually Impaired) and other professionals. Judging by the feedback, we did just that. Among the comments from the 60 delegates were: 53% “It was extremely informative and will change my practice. ... I will offer more information.”

And: “(I will) improve quality of care to nystagmus patients, taking on board help that can be provided by multi-disciplinary team & including non-clinical services. Will reassure patients & families, more inclusive care. Signpost more to VI services & other services to improve patients’ quality of life.”

In March, the Nystagmus Network development manager John Sanders ran two workshops at the VIEW conference for QTVIs in Birmingham. Again the aim was to increase understanding and awareness of nystagmus and its impact on everyday life. Feedback from teachers included:

“I didn’t understand the impact of nystagmus before now. We treat it as a secondary condition. It’s often a case of ‘oh, this child also has nystagmus.’”

And: “A lot of mainstream teachers still don’t understand the null point. We often hear of them telling children with nystagmus to stop staring out of the window and pay attention.”

John also gave talks to orthoptists in Middlesbrough, Educational Psychologists in London and teachers in Gwent and Derbyshire. He attended the first conference of the newly formed CVI (Cerebral Visual Impairment) Society and has been invited to speak at their second conference in 2016.

Newly recruited development officer Sue Ricketts represented the Nystagmus Network at the Albinism Fellowship conference in Derbyshire with a stand and an evening workshop. Among other
outcomes Sue was able to provide an ad hoc counselling session for a family whose daughter had disclosed to her parents during the weekend that she was being bullied at school. Sue also represented the Nystagmus Network at the Aniridia Network conference in Newcastle.

Our volunteer publicity officer Steve McKay gave a presentation about living with nystagmus at a south-west regional meeting of orthoptists. Steve also represented the Nystagmus Network at a fundraising ball in Lancashire in addition to issuing regular news releases and maintaining our Facebook presence.

Our new volunteer educational advocate Frances Lilley took on (and won) her first case in March and has been helping families ever since. Like trustee and former educational advocate Sam Jones, Frances has been trained to do this work by the charity IPSEA.

**Campaigning, networking and lobbying**

Our campaigning work had an impact on education too by ensuring that nystagmus was mentioned in an updated version of the NatSIP eligibility criteria. These are the criteria used by Local Authorities and teachers to
decide whether a child with a visual impairment should get help in school. As comments above from the VIEW conference show, even specialist teachers of the visually impaired acknowledge that their understanding of nystagmus could be better.

Until now the NatSIP criteria have made almost no mention of nystagmus. This deficit has contributed to some children with nystagmus being denied access to support in school. Thanks to input from the Nystagmus Network, the new criteria make frequent mention of nystagmus, so should make it easier for children to get appropriate support in school.

The Nystagmus Network was also invited to comment on draft guidelines for revising the Certificate of Vision Impairment (CVI) in Wales. Although many people with nystagmus have a CVI (which opens the door to other support and services), not all do. Some people with nystagmus are told that they cannot see well enough to drive, but at the same time are denied the opportunity to register as sight impaired.

In a strategy aimed at moving towards a uniform approach to nystagmus in the health service, the Nystagmus Network published a draft Nystagmus Clinical Pathway (NCP) in October. This discussion document covers diagnosis, management, treatment and patient information. It was written with the Nystagmus Network scientific adviser Professor Chris Harris and orthoptist Julie Owen, both of the Royal Eye Infirmary, Plymouth.

**Raising awareness**

The release of our two videos on YouTube on Wobbly Wednesday (our
international awareness raising day on November 4th) was the publicity highlight of the year. Within a month “The way I see it” had been viewed 20,000 times and “Professional perspectives” more than 2,200 times. In addition to these online viewing figures, professionals are downloading the videos to use for training purposes.

The videos are having a very positive impact at a personal level. After watching the video, one seven year old told his mum “it’s good to know I’m not alone.” A father emailed: “I copied and pasted the video to my family -- my brothers and sisters. They all thought until now that he’d have been OK. Their reaction was quite astonishing. They hadn’t understood nystagmus before. They get it now. For us (his parents) it’s woken us up a bit too.”

In addition to the launch of the videos, our third Wobbly Wednesday gave people an opportunity to talk about nystagmus. Once again dozens of schools and hospitals helped to spread the word about wobbly eyes. One school in Wales held a wobbly duck race. Throwing jelly at your favourite teachers was a hit in Scunthorpe. And a Minions themed day attracted a lot of attention at a school in Northampton.

Among hospitals Leicester Royal Infirmary organised a sports day, while in Wigan they had a colouring competition. Southampton Eye Hospital used the day as a nystagmus training event, ably assisted by one orthoptist dressed as Northwick, the bear with nystagmus. And for the second year in a row the day finished with quizzes, parties and Blackpool Tower being lit up for nystagmus.

One unexpected consequence from Wobbly Wednesday was a chance meeting which sparked interest in a new research venture in Sheffield University. Two medical physics researchers happened to see a stand about nystagmus set up by the University’s orthoptists. Within months the two departments were collaborating on projects to help people with acquired
Apart from Wobbly Wednesday and the videos, our online presence remains a focus for getting people talking about nystagmus. New visitors to our website accounted for 71% (72% in 2014) of traffic. Only 28% or 29% are returning visitors. This suggests there’s huge potential for growth in activity, income and our membership / supporter base.

Publications & information

One of the most consistent complaints from people contacting us is how hard it is to get straightforward, accurate information about nystagmus. Parents in particular struggle to find answers to three basic questions; why does my child have nystagmus? How will it affect him/her in everyday life? What can we do to help him/her?

We try to fill this yawning information gap in print, online and through face to face education. The four issues of our Focus newsletter published during the year unveiled the prospect of a new diagnostic test and an end to the unhelpful diagnosis of “idiopathic nystagmus”. Our regular e-newsletters updated professionals on developments in research and our programme of research grants.

We updated our information pack for teachers which is available free – simply contact the the Nystagmus Network team – and is widely used in the USA and other countries as well as the UK. Thanks to volunteer Mike Hughes, we also updated our information on DLA and PIP benefits.
Articles we wrote for our Facebook page provoked a lot of feedback on issues as wide-ranging as being a teenager with nystagmus, employment discrimination, the null point, personal space and nystagmus in middle age.

We also sent leaflets and newsletters to 50 hospitals in Scotland and northern England to coincide with our Newcastle Open Day in May. This was a targeted mail shot in addition to the information we regularly send out in response to requests from hospitals.

**Research grants**

At more than £1,000 a week we invested a record amount in research during 2015. This was thanks largely to generous donations from the Giles Warman Foundation (GWF) and the EBM Charitable Trust.

The GWF funded a £43,000 genetic research project in Southampton University which will lead to much faster and more accurate post-natal diagnosis of nystagmus. The EBM grant of £10,000 went to Sheffield University and is part of a £30,000 project to establish an eye movement training and research laboratory for orthoptists.

This is the first time we have awarded a grant to the Orthoptics Department of Sheffield University. It is a promising development for several reasons. Sheffield is one of only two universities in the UK training orthoptists, so around half of future graduates will have a better understanding of nystagmus than was previously the case. The grant creates a new research centre for nystagmus. And it shows our ability to work with others and leverage our investment.

One unexpected spin-off of developments in Sheffield is a possible project to help people with Acquired Nystagmus as well as Congenital Nystagmus. We are also supporting (albeit not financially) the
experimental use of medical magnets by UCL and Moorfields, which is aimed at helping people with Acquired Nystagmus.

Together with the charity Fight for Sight we once again funded a joint nystagmus research project. The beneficiary this year was Moorfields Eye Hospital in London which is investigating whether there is an optimum age for null point surgery among other questions.

Under our small grants scheme we gave £1,000 to Sheffield to develop patient information for families affected by nystagmus. And we gave a £550 equipment grant to help set up a new nystagmus clinic at Moorfields.

Research developments

During the summer the Nystagmus Network became a non-commercial partner of the NIHR (National Institute of Health Research). This is a very significant development as it once again leverages many of the research grants we make. For instance, most of our clinical research partners will now be eligible to receive additional funding and support from the NIHR, possibly even exceeding the size of our initial grant.
During the summer we attended the 4th international nystagmus research workshop. We organised the first three research workshops in the UK. This 4th workshop in New Orleans was the first in the series organised by the American Nystagmus Network (ANN).

One emerging theme at the workshop was how eye muscle structure appears to develop differently in those with nystagmus. This is early phase research which may one day shed light on why and how nystagmus develops.

The researchers gathered in New Orleans were more confident than ever that they can do more to help people with nystagmus. However, they emphasised that they (and we) need to educate their clinical colleagues about the latest developments.

Collaboration between research centres in the UK and abroad continues to grow. Cardiff, Moorfields, Plymouth and Southampton are all working together. The newcomers in Sheffield are developing links with our existing research partners too.

In addition to providing grants, the Nystagmus Network plays an important role in recruiting subjects to take part in research. During the year we helped recruit volunteers for Cardiff, Leicester and Southampton. We also supported funding applications by researchers to grant givers, including a successful application by a research group in the Netherlands.

Another important non-financial contribution the Nystagmus Network makes is in helping to set the research agenda. During the year we expanded the list of unanswered questions we would like researchers to
consider.

Finally on research, more clinicians are becoming aware of the value of OCT (Optical Coherence Tomography) scanners in diagnosing and understanding nystagmus. Although awareness of the value of OCT for nystagmus is in its early stages, it is growing thanks largely to the pioneering work done by Leicester University.

**International**

The Nystagmus Network remains the largest and most active research and support group for people with nystagmus in the world. We continue to use this position and share our expertise with others in the belief that an international network of support groups will be able to achieve even more.

During the year we were particularly pleased to see the establishment of a charity in France – Association Mouvement Nystagmus. Several of the founders attended our Open Day in Newcastle.

We are encouraging the establishment and development of nystagmus Facebook groups in several countries. One of the most active is in India. We support individuals who have set up nystagmus websites in Germany and the Netherlands in the hope that these will eventually form the nucleus for larger support groups.

We attended the biennial American Nystagmus Network (ANN) conference in New Orleans to maintain and strengthen links with the second biggest nystagmus group in the world. Black Eyed Peas band member apl.de.ap (who has nystagmus) was the star guest.

As ever, in addition to replying to hundreds of enquiries from the UK, during the year we also helped people in the following countries: Argentina, Australia, Belgium, Brazil, Burma, Canada, the Czech Republic, Germany, France, India, Iran, Ireland, Italy, New Zealand, the Netherlands, Nigeria, Pakistan, Peru, Philippines, Portugal, Spain, Turkey and the USA.
Volunteers

In addition to the free time given by trustees, the Nystagmus Network benefits from many dedicated volunteers. In 2015 these included Jennifer Davies who proof-reads our Focus newsletter and Derry Dinkin who records an audio version. In Newcastle Sue Robson and Claire Moss helped organise our Open Day and a social event the evening before.

In Leicester, Sara Riggs took over distribution of Focus and along with several other “Leicester Mums” (including Nikki Espiner, Rachel Stephens and Julie Stewart) organised events in the city. In Essex Sue McPherson knitted more Northwick bears and came up with new ideas including glove puppets.

Accountant Andrew Black provided his services and advice free, including a seminar on budgeting for trustees and staff. Mike Hughes shared his professional expertise on benefits advice. Frances Lilley trained as a volunteer educational advocate and is now advising parents.

We would also like to thank those in the research community who gave up Saturdays and Sundays to support our events and help people with nystagmus. It is impossible to exaggerate their dedication and we do not take it for granted. Many others helped the Nystagmus Network in 2015 too and we are very grateful to all of you.
Financial Summary 2015
Treasurer’s report

Income at the end of December 2015 was £101,146, compared with £160,307 at the end of 2014. In 2014 the charity’s income was considerably increased due to the receipt of a sizable grant of £53,000 from the Giles Warman Foundation. Without this grant, the income from 2014 to 2015 remained fairly static.

The grant was given for the specific purposes of research and raising awareness, and in January a research grant of £43,000 was awarded to Southampton University. A portion of the remaining £10,000 was used to produce two awareness raising videos.

Due to the research grant awarded to Southampton University in 2015, the charity’s expenditure was £161,534, compared to £99,173 in 2014. As has been the trend in previous years; in order to keep the charity running and continue to hold an open day, most of our operational costs have increased. As a result, setting the grant aside, the charity’s expenditure still showed an increase on 2014, to £108,534. The year ended with the charity showing a deficit of £60,388.

To end on a positive note; we’ve continued to receive donations from our members and friends. We filled all marathon places we purchased for last year and people continue to engage with Wobbly Wednesday. Both of these provide us with valuable income which the charity depends on to survive. We are immensely grateful to all who continue to find ways to fundraise and support us financially. One particular other donation which comes to mind was from the gentleman who asked his colleagues not to buy him a retirement gift, but rather to donate any contribution to a fund which he planned to donate to the Nystagmus Network.

Fola Tayo

Fola Tayo
Treasurer of the Nystagmus Network
## Management accounts 2015

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<td><strong>Total</strong></td>
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**Accounts prepared by:** Fola Tayo (Treasurer)

**Accounts examined by:** Andrew Black A.C.A.
Legal Details


The Nystagmus Network key details:

Charity number - 803440 in England and Wales
Trustees - Vivien Jones, Richard Wilson, Carol Bashford, Graham Dickson, Claire Entwistle, Katy Faulkner, Terry Hayden (until January 2015), Pam Jarmain, Sam Jones, Steve McKay, James Taylor and Fola Tayo.
Registered office - 25 Eden Way, Beckenham, BR3 3DN.
Independent examiner - Andrew Black A.C.A

Charity objects - The charity’s objects focus on the relief of sickness of nystagmus 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.

Appointment of new trustees - Trustees are appointed and candidates are 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.

Statement of 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.

Fola Tayo
Treasurer of the Nystagmus Network