

TRUSTEES' ANNUAL REPORT 2016

NYSTAGMUS NETWORK



Nystagmus *Network*

MORE INFORMATION

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

ABOUT US

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.

Through the charity's extensive involvement in research we are moving closer to finding effective treatments for the condition.

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CHAIRMAN'S MESSAGE

In 2016 we saw a great deal of change in the Nystagmus Network. We modernised and refreshed our logo and made big improvements to our website and our documents. We have streamlined our operations by moving away from storing lots of printed material to making information even easier to access digitally; and we have put effort into making the information easier to understand too, providing

signposting for those who want to know a bit more.

Over the past five years or so, our brilliant members, fundraisers and supporters have allowed us to invest more than £140,000 in research projects associated with nystagmus. We have seen real advances in the medical world's understanding of genetics, underlying causes, diagnoses, as well as the

OUR NEW RESEARCH STRATEGY

impact and measurement of how sight is affected for those with nystagmus. This year we have developed a strategy to guide future investment in research projects that will have the biggest impact on the nystagmus community. We have adopted the broad guiding theme of "Quality of Life" against which to assess where our support should go.

At our Open Day in Reading in May 2016 we gave a commitment to making future Open Days free for those attending, with priority going to our members. We will deliver

on that commitment at our Open Day on 30 September 2017. It is a big investment, but it is the right thing to do.

Thank you to everyone involved with the Nystagmus Network. What we all do makes a difference – let's keep doing it!

Richard Wilson

RICHARD WILSON

Chairman

"This Report is dedicated to the memory of Steve McKay, trustee and friend who died in December 2016."

- Trustees of the Nystagmus Network



TRUSTEES SERVING in 2016



RICHARD WILSON
Chairman & trustee



VIVIEN JONES
President & trustee



FOLA TAYO
Treasurer & trustee



GRAHAM DICKSON
Secretary & trustee



JAMES TAYLOR
Trustee



PETER GREENWOOD
Trustee



DONNA MCNAUGHTON
Trustee



FRANCES LILLEY
Trustee and Education Advocate



NIGEL ALLEN
Trustee



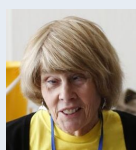
KATY FAULKNER
Trustee



STEVE MCKAY
Trustee



CLAIRE ENTWISTLE
Trustee



PAMELA JARMAIN
Trustee



WHAT IS NYSTAGMUS?

Nystagmus is a complex eye condition 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 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 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 life-long 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 IS A VARIABLE CONDITION

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 and although not as common, 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 research into finding therapies that could one day potentially have a positive impact on managing the condition.

"Can I just take this opportunity to say how grateful I am for the Nystagmus Network? It's been so informative and it's great to meet other people who have children with the condition."

- Parent

OUR KEY PROJECTS

During 2016 the Nystagmus Network underwent a lot of change which was reflected in the projects that were completed.



Re-branding

New look for the Nystagmus Network was launched in 2016



New website

A modern and interactive website was released



Research

A clear plan on the charity's research funding established



New staff

New staff in 2016 have led the charity's projects



Strategy

A strategic review was carried out for the charity



New documents

New documents to provide support to the community



A NEW LOOK FOR THE CHARITY

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NEW MEMBERS
IN 2016

2016 was an important year for the Nystagmus Network because this is the year in which the charity undertook a re-brand project. We wanted to modernise the look and feel of the charity whilst sticking to our core values of supporting and representing

the nystagmus community.

All of the trustees were delighted to release not only a new logo, but also a new website, support documents and digital newsletter to growing membership which have brought us into the digital age.



STRATEGIC REVIEW OF THE CHARITY

In 2016 the trustees of the Nystagmus Network undertook a strategic review to help define and clarify the longer term direction and aims of the charity. The objective of the strategic review was to assess the charity's underlying strategy to ensure there is a clear and transparent approach to achieving its objectives; ensure the charity is aligned with any Charity Commission

recommendations and best practices; draft an action plan to address any gaps and prioritise activities in the next twelve months. Through the development of this strategy the trustees defined their vision for the charity. This would be a world in which nystagmus is consistently and fully understood and supported in all environments (home, medical care, education and work).



With a clear mission of supporting people affected by nystagmus, raising awareness and leading the research to find a potential treatment, the strategic review enabled the trustees to set the following goals:

- Help and support the at least 1 in 1,000 people estimated to have poor vision due to nystagmus, and also those who are affected by it such as friends and family
- Encourage research with a view to finding treatments and a cure, and to improve the everyday lives of those with nystagmus
- Raise awareness and the understanding of nystagmus so those affected have access to all the services they require.



The trustees are confident that the Strategic Review will have a great benefit to the charity and our members. During the project the trustees set various ambitious goals which they would like the charity to achieve by 2018. Some of these are:



- Establish a volunteer support team
- Implement the Nystagmus Care Pathway
- Launch the Nystagmus Educational Route Map
- Create a Nystagmus Employment Handbook
- Increase membership and fundraising

OPEN DAY 2016

Bringing us all together

Over 170 people travelled to the Hilton Hotel, Reading on Saturday 7th May 2016 for the Nystagmus Network's annual Open Day.

Among them were parents, their children, adults with nystagmus, clinical and research experts, exhibitors and speakers, charity trustees and volunteers. Keynote speaker Kristina Venning sought to allay the



worst fears of parents with newly diagnosed children as she highlighted the successes of her career in the media. The well attended and ever popular breakout sessions covered such varying aspects as living with a family member who has nystagmus, building a positive relationship with your child's school, applying for benefits and the world of work.



We also seized the opportunity to launch the charity's brand new look, with a new website and logo. Both were received to great acclaim and clearly signaled a new direction and a more positive outlook on the future for people with nystagmus everywhere



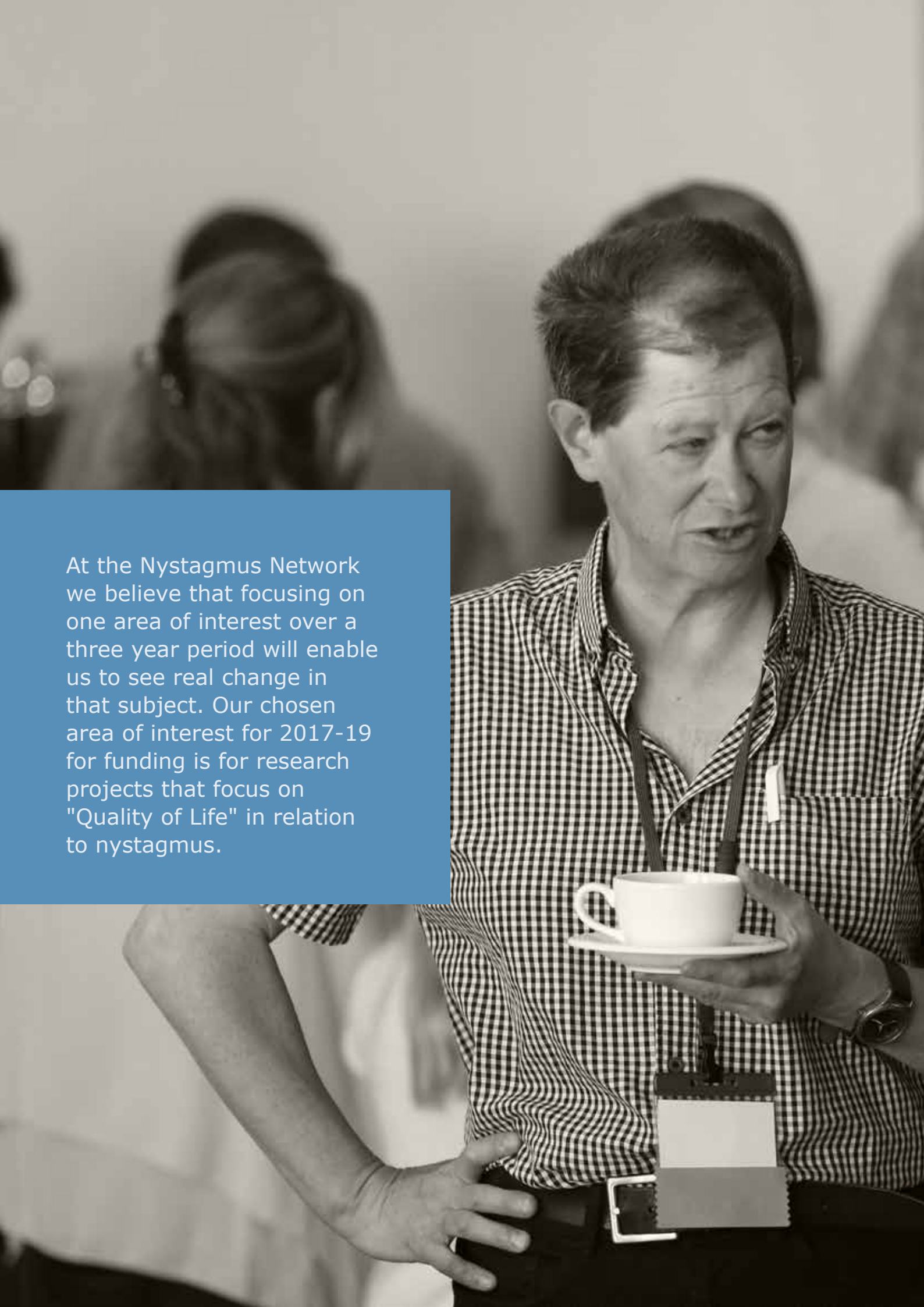
RESEARCH STRATEGY

The Nystagmus Network developed a research strategy in 2016 to streamline how it supports the research community.



In 2016 the trustees at the Nystagmus Network undertook a review of the charity's involvement in research projects focusing on nystagmus. After this review, the Research Committee reached out to the charity's research

partners and asked them to complete a short survey to help us build a research strategy which we could implement. The development of this strategy formed part of the charity's wider strategic review of its services.

A black and white photograph of a middle-aged man with short, dark hair, wearing a checkered button-down shirt. He is holding a white cup of coffee on a saucer with his left hand. He has a lanyard with a badge around his neck and a watch on his left wrist. The background is blurred, showing other people. A blue rectangular text box is overlaid on the left side of the image.

At the Nystagmus Network we believe that focusing on one area of interest over a three year period will enable us to see real change in that subject. Our chosen area of interest for 2017-19 for funding is for research projects that focus on "Quality of Life" in relation to nystagmus.

SUPPORTING OUR COMMUNITY

At the Nystagmus Network we provide various forms of support to the Nystagmus community to help them.



Online

We utilise social media as a tool to provide quick and clear communication.



Open Day

Our Open Day in 2016 was the best attended event we have ever held.



Peer-to-peer

We encourage a support model involving members supporting each other.



Free documents

All our documents can be downloaded for free by the nystagmus community.

A big change was establishing a new online shop which has made it quicker and easier for our members to download our support documents. These documents provide our members with all the information they may need in managing their nystagmus and sign posts them to various support services. Frances Lilley continues to work as a volunteer Education Advocate. Trained by Independent Parental Special Educational Advice (IPSEA),

Frances gives parents and carers legally-based advice and support on how to negotiate the education system in England, so that young people with nystagmus can access support across all stages of education. In 2016, she provided direct Educational Advocacy support to over 40 families. Looking ahead, she is working on an online Education Route Map. This outstanding service can only be provided thanks to the generosity of our members and fundraisers.



OUR FUNDRAISING

During 2016 over 50 events were held for the Nystagmus Network which helped raise both funds and awareness for the charity. The total raised through fundraising by our community was £42,684.

Events ranged from cake sales to golf days and enabled us to raise awareness to lots of different people. The diverse group of events shows how varied and dedicated our supporter base is.



The first Wednesday in November each and every year is the Nystagmus Networks' national and international nystagmus awareness-raising day, Wobbly Wednesday. In 2016 the event had a "What will you wobble?" theme and we encouraged our supporters to take part to raise awareness of nystagmus.



Other key fundraising highlights include our London Marathon runners who in total raised over £10,000 for the charity and Upchurch River Valley Golf Club who nominated the Nystagmus Network as their charity of the year and raised £7,000.





OUR MEMBER FEEDBACK



PARENT

of a young child with nystagmus

"It's lovely to hear from someone who 'understands' - it makes an enormous difference to us."



PARENT

of a young adult with nystagmus

"I just wanted to say thank you very much for your help and for all the information you provided."



SON

Parent has acquired nystagmus

"Thank you VERY much for this. I may be in touch again! "



ADULT

With congenital nystagmus

"Thank you. You have helped at a worrying time. "



TEACHER

of a child with nystagmus

"Thank you for having this excellent information available and free of charge. I will make use of it when working with young children with nystagmus and their families."



CAMPAIGNER

Disability rights campaigner

"Thank you so much for your lovely comments and the support really means a lot. I would love to write an article for the newsletter and would love to give as much support as I can, as you have supported me."

CONFERENCES

The Nystagmus Network attended conferences throughout the year.



AWARENESS

The Nystagmus Network is committed to raising awareness of nystagmus.



FUNDRAISING

The Nystagmus Network is fortunate to have a dedicated group of supporters.



TREASURER'S REPORT

We are immensely grateful to all who fundraise and support us financially.

2016 was another active year for the Nystagmus Network. The charity attracted £70,888 in income. This is a decrease of 29% compared with income at the end of December 2015, but was expected as a downturn in all the charity's income streams was noted during the year, particularly in those most relied on - fundraising, donations, and membership subscriptions.


Meanwhile expenditure fell by 48.72% to £82,843. This seems a large reduction, but the 2015 spend was unusually high due to a grant of £53,000 from the Giles Warman Foundation. The grant was used to fund research projects early in 2015. If the GWF grant is put to one side, the overall reduction in expenditure was 23.68%. This was achieved by bringing some

products and services in-house, thereby reducing costs. You may have noticed, for example, that Focus is now an e-newsletter and we have a new website.

We've continued to receive donations from our members and friends. Our London Marathon runners were extremely successful in their fundraising. This, along with other races and events, provided us with valuable income which the charity depends on. We are immensely grateful to all who fundraise and support us financially and continue to ensure the funds are spent in the most effective ways to benefit the nystagmus community.

Fola Tayo

FOLA TAYO
Treasurer



During 2016 the Nystagmus Network introduced a new financial management system called Paxton online. This is a big step for the charity as it enables us to use a market standard system to record and report our income and expenditure.

Nystagmus

The Nystagmus Network had an annual income of £70,888 during 2016 and expenditure of £82,843. This left the charity with a total reserve of £103,571.



MANAGEMENT ACCOUNTS 2016

	2015		2016	
	£	£	£	£
Income				
Fundraising	49,218		42,684	
Grants	14,830		1,474	
General donations	21,869		15,517	
Subscriptions	8,175		7,366	
Shop sales	1,559		596	
Bank interest	173		91	
Open Day	3,195		3,021	
Other	2,127		139	
		101,146		70,888
Expenditure				
Office & admin	51,561		56,963	
Committee	1,657		980	
Newsletter	6,528		1,167	
Research	22,600		0	
Giles Warman	54,710		0	
Shop expenditure	36		1,032	
Fundraising costs	12,047		11,603	
Open Day	12,291		10,829	
Research	105		269	
		161,534		82,834
Net surplus/(deficit) for the year		-60,388		-11,955
Cash at the bank 31st December				
General fund		111,006		99,051
Giles Warman Fund		4,520		4,520
		115,526		103,571

Accounts prepared by: Fola Tayo (Treasurer)

Accounts examined by: Andrew Black A.C.A.



THE CHARITY'S LEGAL DETAILS

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 which the charity has funded.

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.

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

Chairman

NYSTAGMUS NETWORK



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MORE INFORMATION

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