

2020 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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**Just to say that the virtual nystagmus Open Day is absolutely fabulous ... well done all.
- a delegate**



Tim Cuddeford
Chairman of
the Nystagmus
Network

CHAIRMAN'S MESSAGE

Despite the challenges of Covid, I am pleased to report that 2020 was another positive year for the Nystagmus Network, thanks to the flexibility, innovation and resourcefulness of our staff, volunteers, trustees and supporters. You will see from the reports included here from each sub-committee, we have been able to uphold the aims and mandate of the charity in terms of providing support to our community, funding research and raising awareness.

All of our regular activity went online and while traditional fundraising efforts dried up (large group events like marathons), we

were able to benefit from alternative funding via **grants**, the very successful **BBC Radio 4 appeal** and then fantastic individual, socially distanced and virtual fundraising by our supporters. That, combined with careful cost management, means we finish the year on plan in terms of income, expenditure and reserves.

Nystagmus Awareness Day was virtual with a lot of diverse activity and we held our first **Open Day** by Zoom, which led to it being our highest ever attended event. We also hosted our first Open Day dinner, albeit also by Zoom.

Even during a pandemic we managed to maintain our commitments to the nystagmus community

Thanks to the efforts and energies of our intrepid fundraisers, we have been able to maintain our commitment to funding research into nystagmus. In September we once again hosted a very productive virtual **Research Workshop**.

Education Advocacy continues to be an important aspect of our help to parents and carers. Again, we have moved to Zoom calls for groups and individual families to further knowledge share and empower parents to access the support in education children with nystagmus need to reach their potential.

We are very grateful to the many **National Lottery** players following the receipt of COVID-19 related **Community Funding** to support the changing needs of the nystagmus community during the pandemic.

We have had three new trustees join in 2020, strengthening our governance and trustee skill set.

At the time of writing, it is not clear how "back to normal" we will be in 2021, but please rest assured we will continue to hold both virtual and physical events and to support the nystagmus community in any way we can. Thanks again to all our members and fundraisers. We look forward to your continued support.

Tim Cuddeford

Tim Cuddeford Chairman



"With thanks to the Nystagmus Network for the sense you help to make of what having nystagmus means and how we and families like ours can support our children to lead amazing lives." a parent



TRUSTEES SERVING IN 2020

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, Honorary President

Tim Cuddeford, Chair

Peter Greenwood, Vice Chair

Vicky Pitman, Treasurer

Sam Jones, Secretary

Frances Lilley, Education Advocate

Claire Brinn, Education Advocate

Marie Travers

Daniel Williams

Richard Blackman

Karen Chu

Kathryn Swanston



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 more 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.

"This fantastic charity provides support for adults and children living with nystagmus as well as the families. The amount they do is unbelievable and they can only carry on doing this with money from fundraisers like us" - a fundraiser

SUPPORTING THE NYSTAGMUS COMMUNITY

The Nystagmus Network provides a wide range of support. During the pandemic, people's need for support and information was even greater.



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.

"Just wanted to thank you for setting up the call last night. I thought it was excellent and great to hear from other parents." a member of our parents' forum

AWARENESS AND SUPPORT COMMITTEE

537

PEOPLE
RECEIVING
SUPPORT

New challenges

In 2020, we faced the new challenges presented by the Covid-19 pandemic and had to rapidly adjust our support and awareness capability to support members in several key areas thanks to funding from the **National Lottery Community Fund**.

Social isolation - we expanded our services to meet the needs of people who would not normally

turn to the charity for help and those living alone during lockdown to combat loneliness and potential mental health issues. People with nystagmus were struggling to cope with day-to-day living, making full use of their time outside, food shopping without a guide and maintaining social distance as well as greater isolation.

Hospital appointments - with non-emergency hospital appointments cancelled or postponed and departments closed during the pandemic, nystagmus patients were going undiagnosed or receiving no follow up consultations. This caused adult patients and parents/carers to be left with multiple unanswered questions and anxiety. We delivered a series of videos, live webinars, forums and Q+As with nystagmus experts, Paediatric Ophthalmologists, Orthoptists, researchers and senior university lecturers.

Education Support - before the lockdown, Frances Lilley and Claire Brinn, our volunteer IPSEA-trained SEN advisers, ran two final "Parent Power" events in Cambridge and Bristol, funded by the National Lottery Community Fund. The events provided 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. Frances and Claire also provided specific information on how to "build a case" to secure support in education and supported 21 families with one to one advice.

CET Webinars for Eyecare Professionals

In 2020, we expanded our reach to engage with eyecare professionals to raise awareness of the charity and encourage referrals from eyecare professionals by launching a series of CET webinars. Topics covered included: A Clinician's Guide to Nystagmus; Diagnosing Nystagmus; Testing, Dispensing and Supporting Patients with Nystagmus.

contd.

Nystagmus Network

**Virtual
OPEN
DAY
2020**

**Saturday
3rd
October**



What seems to be the trouble?
What happens when your health problem just doesn't tick the boxes?
The woman's quest for a treatment - any treatment - that would help
Claire Entwistle

Nothing will *stop* us!

£35,013

FUNDRAISING

Nystagmus Awareness Day

Our annual awareness day also ran with a virtual format:

- How amazing are you? – showcasing our nystagmus heroes who shared their success stories
- Wobbly photography competition – 'The View from My Window' - judged by nystagmus superhero, David Katz
- Wobbly quiz night – our biggest and best virtual quiz of the year

Thank you to everyone who participated and supported Nystagmus Awareness Day.

Open Day

Because of the pandemic we moved our annual open day to a virtual format. Despite not being able to meet up with our amazing members and supporters, the online sessions proved highly successful and enabled us to reach a much wider audience (over 600 people). We included all the usual research updates, advice sessions and inspirational presentations along with some recorded interviews.

The day closed with a 'Night in with Nystagmus Network', an opportunity to enjoy a cocktail, a virtual dinner and networking with other members, trustees, researchers and VIPs. Hugely successful and enjoyable, the evening included our guest speaker, Mike Larcombe (see p13).



Fundraising

Despite the pandemic, 2020 was another stellar year for fundraising with over £35,000 raised by our amazing members and supporters. A few highlights included:

- Mike Larcombe walked the entire length of New Zealand from December 2019 to March 2020. His 'Walk for Wiggly Eyes' raised almost £2,500 and a huge amount of awareness along the way
- Alysha and George Patel walked or ran 1000km during lockdown for their little son, Rory and raised over £1,000
- Milly, Zoe and Toby Greenslade ran or cycled 100 miles each in 30 days – a great way to spend their allocated time outdoors - raising over £1,500 in honour of Milly's daughter, Florence
- Claire Mason finally completed her sky dive to raise £420 and make her son, Zak very proud

Open Day



Nystagmus Awareness Day



We received over £9,000 from the BBC Radio 4 Appeal read by TV producer, presenter and author, Richard Osman – thank you to Richard for presenting on our behalf and for everyone who donated.

And finally, thank you to everyone who raised money and awareness for the Nystagmus Network in 2020 – we simply could not deliver on our research commitments and support services without you.

Peter Greenwood

Peter Greenwood

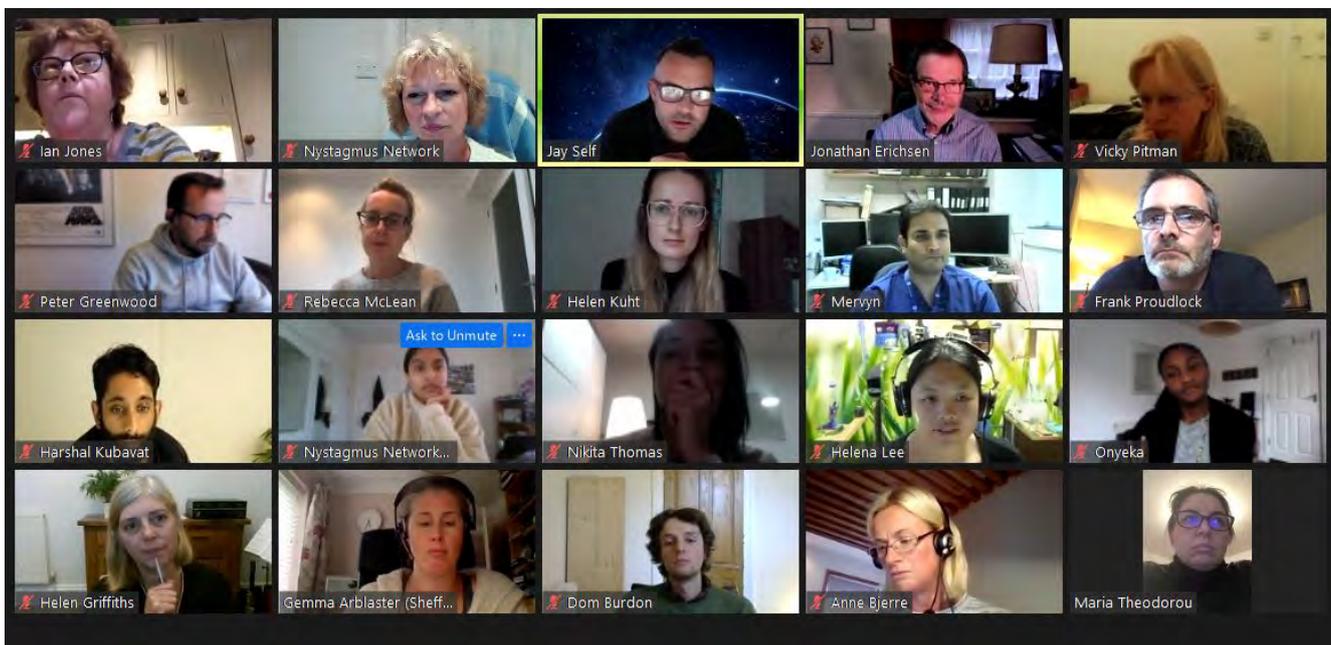
Chair of Awareness and Support Committee

Fundraising

RESEARCH COMMITTEE

**IMPROVING
QUALITY OF LIFE
THROUGH
RESEARCH**

The Nystagmus Network research workshop 2020 went ahead virtually



Despite the pandemic, the Research Committee was able to function pretty normally during 2020. But of course the research centres, where so much important work is carried out, were inevitably affected by Covid-19 as they couldn't see patients to collect data as they normally would. Please read more on that and our funding of an important study which came up with an ingenious solution to that problem later in this report.

We have been funding nystagmus

research for more than 30 years and 2020 was no exception with an investment of £26,500.

Our work with Fight for Sight – with whom we partner on some of our research projects – means that our funds are doubled through match funding.

Joint projects with Fight for Sight this year included a small grant to a team at the University of Leicester to investigate the development of AI to monitor and track nystagmus eye movements.

In 2020 we invested £26,500 in research

"It was lovely to have the opportunity to speak to the Nystagmus Network community. Whilst COVID has presented us all with challenges, it was great to see how many people could be reached and included in an online event. It felt like people who wouldn't have been able to attend a weekend in person were able to be included this year, which was very impressive." - an orthoptist



Our major project, also in collaboration with Fight for Sight, was setting up a new nystagmus PhD post. Applications for this post were received in 2020 with shortlisting in early 2021. This project is a 'first' for the Nystagmus Network – funding a long-term research placement is a major commitment and one we are delighted to make.

During the year, we made an approach to the National Institute for Health Research, the UK government agency which funds research into health and care. Our hope was that by suggesting areas of research we might persuade them to fund research into nystagmus. Areas we suggested – based on a survey of

our members - included the physical and psychological effects of nystagmus and the effect of nystagmus on daily living. Approaching NIHR is a long game – we don't expect to hear for some time but very much hope for success.

Thanks to Zoom, we were able to hold our annual Research Workshop as usual at the end of September. It was a successful event with representation from all six nystagmus research centres. There was a detailed discussion on the day of pre-recorded presentations submitted in advance and there was a sense of ever greater collaboration between the different teams.

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RESEARCH, continued

An ingenious solution to the challenges of the global pandemic

At the end of the year, we awarded a grant to Cardiff University to purchase equipment for use in home testing so that data collection and research could re-start. Because of Covid-19, research participants could no longer come on site for this - getting them to test themselves at home would mean that research could continue. We judged this an excellent project,

allowing research work to go forward.

We know that 2021 will see the creation of a new charity funded PhD post focused on research into nystagmus – a major milestone for the Nystagmus Network.

Vivien Jones

VIVIEN JONES
Chair of Research Committee

The team from the University of Southampton delivered their research update on screen for delegates at virtual Open Day 2020



OUR KEY PROJECTS

In 2020 the Nystagmus Network continued to strive towards our stated goals: supporting the nystagmus community, raising awareness and funding research amid a global pandemic.



Awareness

We celebrated a virtual Nystagmus Awareness Day on 20 June



Communication

Daily Facebook posts and Tweets helped us reach an audience of 12,700 people



Research

We invested £26,500 in nystagmus research



Support

537 enquiries were dealt with, from adults with CN and AN, parents, teachers and ECLOs



Fundraising

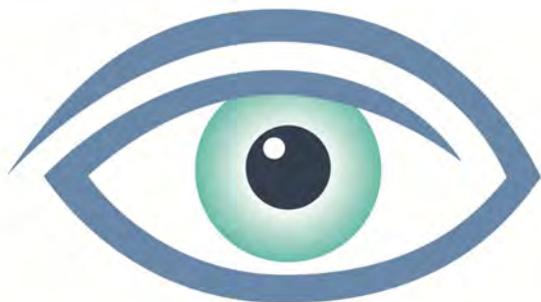
With much of the year spent in lockdown, our fabulous supporters still managed to raise £35,163 with virtual events



Advocacy

Our volunteer education advocates supported 9 families with issues at school

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

"I am a new member and have not attended an Open Day before. I have already learned so much. The Acquired Nystagmus Forum was amazing. I felt such relief meeting others who have the same problems." - a member



There's nothing quite like the feeling of belonging, to know that you're part of a community and among friends, all working for the same goals.

That's why the Nystagmus Network is a membership organisation.

The more people we represent who are living with nystagmus, or have an interest in the condition, the better able the charity will be to influence real change and to make your voice heard.

Membership benefits include:

- Priority booking at events and a FREE place at Open Day
- Access to our education advocacy service
- Referral to bespoke advice and guidance on benefits
- Notification of our Annual General Meeting
- A proportion of your subscription will go directly into research

We offer affordable membership to anyone living with nystagmus. Together we can all make a difference.

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

Careful cost management ensures that the charity is in a strong position

Despite the significant downturn in fundraising income (a 44% fall compared with 2019), we are delighted to report that the charity raised over £100,000 of income during the year ending 31 December 2020, a similar level to last year.

The main source of income is traditionally from fundraising, but unfortunately, due to the cancellation of fundraising events caused by the pandemic, fundraising income totalled £35,000 compared with £63,000 last year. Fortunately, we were able to make up the shortfall by securing grant income of £28,000. Other sources of income included £17,000 from donations, £11,000 from membership subscriptions and £5,000

from gifts in wills. We are incredibly 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.

As a result of the challenges of 2020, trustees took the decision to amend the reserves policy, putting aside free cash reserves of 6 months' cover for annual expenses (reduced from 9 months). As a result, total spending for the year was £100,000 to break even, ending the year with total cash reserves of £78,000.

Careful cost management ensures that the charity is in a strong position to continue

navigating the uncertainties of the year ahead.

Our partnership with Fight for Sight goes from strength to strength and in 2020 the Nystagmus Network allocated £27,000 towards research expenditure.

The charity continues to look

at new ways of raising funds and creating partnerships in order to maintain our charitable services, chiefly supporting those living with nystagmus in the UK.

Vicky Pitman

VICKY PITMAN FCA Treasurer

The winning photo in our Nystagmus Awareness Day competition - the view from my window by Wilson, aged 15



FINANCIAL ACCOUNTS 2020

Nystagmus Network - Financial Accounts 2020

	2020		2019	
	£	£	£	£
Income				
Fundraising	35,163		63,299	
Grants	28,447		9,790	
Wills	4,593		0	
General Donations	17,387		13,483	
Subscriptions	11,490		10,667	
Shop Sales	2,012		3,140	
Open Day	1,453		446	
Bank Interest	48		116	
		100,592		100,941
Expenditure				
Office and Administration	20,444		14,249	
Trustee expenses	1,140		303	
Communications	21,060		17,708	
Research	26,500		27,775	
Support services	1,810		1,457	
Fundraising Costs	27,168		22,431	
Open Day	2,382		13,349	
		100,504		97,272
Net Surplus/(Deficit) for the year		<u>88</u>		<u>3,669</u>
<i>Total Staff costs included above</i>	<i>£44,724</i>		<i>£44,269</i>	
General reserves at 31st December		£61,053		£71,033
Restricted reserves at 31st December		£17,230		£7,161
Cash at the Bank 31st December		<u>£78,283</u>		<u>£78,194</u>

Accounts Prepared by

Vicki Pitman 29.01.2021
 Vicky Pitman FCA (Treasurer)

Accounts Examined by

AR Black 29.01.2021
 Andrew Black ACA

Resourceful and creative supporters found inventive ways to continue to fundraise for the Nystagmus Network during lockdown



**"I haven't missed an Open Day since 1990 and I'm not going to stop now."
– a longstanding member**

It is the policy of the Trustees to keep Free Cash reserves of 6 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

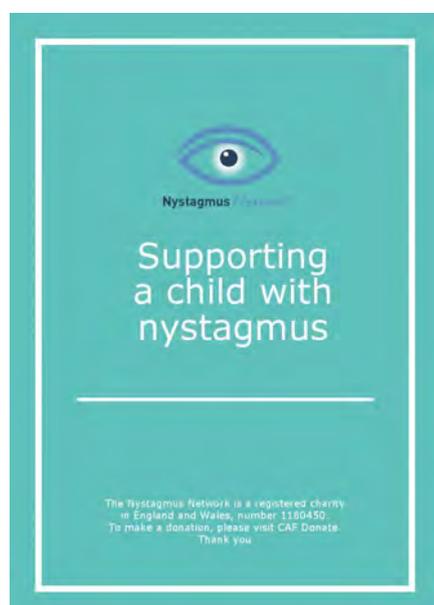
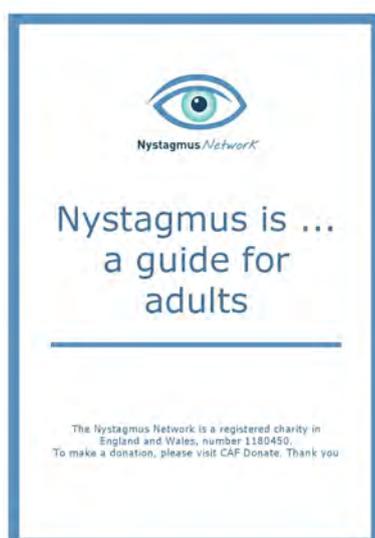
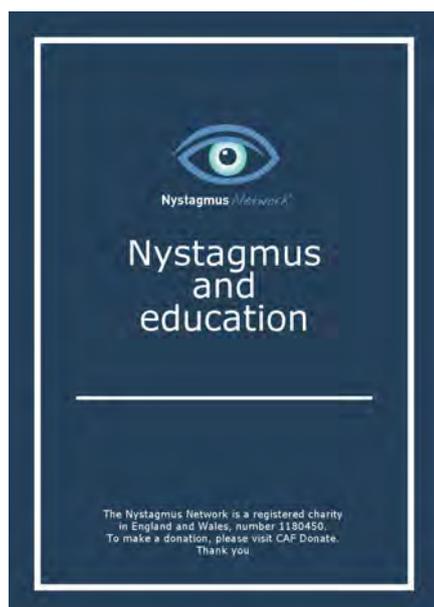
The charity's objects focus on the relief of nystagmus (visual impairment) sufferers and their families. The objects also focus on advancing the education of the public in and to promote research into the condition known as nystagmus and to publish the useful results of any such research which the charity 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

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