

Nystagmus Network



ANNUAL REPORT

2010



Supporting people with the eye condition nystagmus

Registered charity 803440

“ I love what NN is doing, it is a very worthy charity and I know that my mum wouldn't have gotten through a lot of things if it wasn't for you and the rest of the team! ”

Louise, early 20s.

Cover photograph courtesy of Peter Jones:
Research Unit for Nystagmus open day,
Cardiff University School of Optometry
and Vision Science, April 2010.

Contents

	Page
Facts, figures and trustees	2
Structure, governance and management	3
President's report	4
Chair's report	5
Operating Report:	
How we help	6
Hospitals and the third sector	7
Schools and families	9
Open Day	10
Membership	11
New publications	12
Research	13
Website and Twitter	14
Treasurer's Report	16
Accounts	17

Nystagmus is an involuntary movement of the eyes which often seriously reduces vision. Few people with nystagmus can drive and most encounter difficulties in everyday life, education and employment.

Anyone can develop nystagmus. Every year hundreds of children are born to parents with no family history of the condition. And every year hundreds of adults develop nystagmus due to accidents or illnesses such as stroke or multiple sclerosis.

Facts and figures

Website	2009	2010
Visits	37,007	40,548
Page views	153,785	172,817
Average time on site	3.00 minutes	3.15 minutes
New members	67	114
Enquiries	500+	724
Financial highlights		
Income	£28,549	£37,830
Expenditure	£33,195	£37,305
Surplus/deficit	-£4,645	£525

In 2010 we also:

- Reprinted Early Onset Nystagmus, our guide for parents
- Sent leaflets and new posters to over 120 hospitals from Scotland to Gibraltar
- Funded eye tracking equipment for Cardiff University's Research Unit for Nystagmus

In 2011 we will:

- Print Northwick story cards to explain nystagmus in schools and hospitals
- Raise awareness by using Facebook and Twitter
- Expand our website resources for schools and hospitals

Trustees:

Vivien Jones (president), **Richard Wilson** (chair from June 2011), **Kathy Williams** (chair June 2009 – June 2011), **Graham Dickson** (from June 2011), **Claire Entwistle**, **Katy Faulkner**, **Tanya Hairman**, **Pam Jarman**, **Sam Jones**, **Steve McKay**, **James Taylor**. **Carol Bashford** and **Andy Machin** resigned in 2010 and March 2011 respectively.

Structure, governance and management

The Nystagmus Network became a charity in 1990 and is managed by a committee elected from the membership at the AGM. NN is run mainly by volunteers in their spare time plus one part-time employee. We rely largely on subscriptions and donations to fund our activities.

NN's objectives

The main objectives of the Nystagmus Network are to:

1. Help and support the 1 in 1,000 or more people estimated to have poor vision due to nystagmus.
2. Encourage medical and scientific research into nystagmus both with a view to finding treatments and a cure, as well as improving the everyday lives of those with the condition.
3. Raising awareness and understanding of nystagmus among professionals and the general population.

NN activities

The Nystagmus Network pursues a range of activities to achieve its objectives, including:

1. Telephone helpline and email support
2. Information and advice on:
 - a. Education
 - b. Employment
 - c. Discrimination and benefits
3. Peer support through events for people with nystagmus
4. Publishing leaflets and books
5. A quarterly newsletter
6. A regularly updated website and online forum
7. Training and talks for medical staff, teachers, charities and other professionals
8. Funding research
9. Facilitating research by supporting hospital and university grant applications and finding subjects for individual projects
10. Publicising developments in research and treatment

President's Report

What a year! Under Kathy Williams' leadership as our chairman, 2010 was a year of achievements.

Let me list just a few:

- Increased new member recruitment
- A highly successful Open Day
- Overhaul of the website
- Becoming the British Contact Lens Association's charity of the year
- Making a grant of £10,000 to Cardiff University to fund much-needed eye tracker equipment
- Reprinting of the detailed guide *Early Onset Nystagmus*
- Publication of our new Adult Information pack.

I don't want to sound complacent – we know there is lots more to do – but 2010 was a year of energy and activity in the NN. We did a lot of thinking about where we were and what we needed to do, and then we got on with it.

My thanks to the committee for all that they do; to our growing army of volunteers for all their help and to you, our members, for your encouragement, helpful feedback and support.

Invidious as it is to name names, it would be wrong if I did not personally thank Kathy Williams for her dynamic and constructive chairmanship of the NN, and John Sanders, our information and development manager, for his hard work and commitment to the cause. We are indebted to both of them.

What really came home to me throughout 2010 is that the need for NN is growing. Changes in education provision, a difficult economic environment and pressures on employment mean there is an increasing demand for advice – a challenge we are determined to meet. We are, as we should be, ambitious about the future role of NN – a topic we look forward to discussing with our members at the Annual Meeting

Vivien Jones



Vivien Jones

Chair's Report

Yet again the Nystagmus Network has managed the tension between developing its effectiveness in a world where the charity sector has become increasingly professional and competitive, yet has maintained the vitality and lateral thinking which comes from a wealth of very gifted and committed Trustees and volunteers. The move towards increased accountability within the Committee and sub committee structure has continued. Despite the resignation of two very valued Trustees, Carol Bashford and Andy Machin, it has been possible to extend Network activities with the recruitment of new Trustees and the extended use of volunteers.

We greatly value the links that our Trustees have with other charities and the public services, which allows for a rich interchange of information and enables us to share insights and resources. Our use of social networks in both our official and informal activities enhances our effectiveness. Indeed, with the recruitment of a Scottish Trustee, it is even hoped to extend our influence geographically.



Kathy Williams

This is a valedictory report for me, and I want to recall some of the highlights of the last year. This Annual Report will mention our institutional strengths, so I am indulging myself with a personal perspective, since, in the end, it is through these direct contacts that we are most effective.

I note that my local hospital now insists that 'behind every pair of eyes is a person' and it has put in place volunteer support at eye clinics. The whole clinical department attended a training session that I gave on nystagmus. I was thrilled to see the increased mobility and confidence of blind child E at the nystagmus baby and toddler group in May, and delighted to see the baby twin with nystagmus hitting all his developmental targets even ahead of his brother. All the mothers in the group have the 'can do' attitude that we foster, and most are members of the Network. I have listened to parents who have multi impaired children, but who foreground nystagmus, and who relish the chance to focus on Network support, and insist on not labelling their children as 'problems'. And I have felt for the older members who, maybe at the point of an enforced career change, or early retirement, want to accept the fact that their nystagmus has been one factor among many in their working life as they reflect.

The friendship of the Network Committee has been a great joy, and I would like to thank them for their wise support. I have also appreciated the tremendous work being done to support children with nystagmus by Local Education Authority Services, and would like to alert everyone to the fact that some Authorities are considering tendering out such services, or asking individual schools to pay for their support. The Nystagmus Network is deservedly flourishing but vigilance is required by everyone lest already tight resources are further reduced.

Kathy Williams

How we help people with nystagmus

What most people want when they contact NN is information and support. Parents ask us what it's like to see when you have nystagmus and which are the best hospitals for their child. Adults ask us for advice about vision related problems at work and how they can take part in research. Teachers and other professionals such as occupational therapists ask us what they can do to help children with nystagmus.

However, many simply want to talk to someone else who has nystagmus. The following comments show just how valuable this peer support is:

"Thank you for replying so quickly. It might sound weird but I am ecstatic about finally understanding why I have always had such lousy balance and also I am now beginning to understand why I have difficulty with my vision even though my glasses correct a fair amount. It is such a relief to understand what is going on even if there is not really any cure."

(Adult with early onset nystagmus)

"You're a very nice person to speak to. I didn't expect this when I rang this number. Even just talking to you has made me feel better."

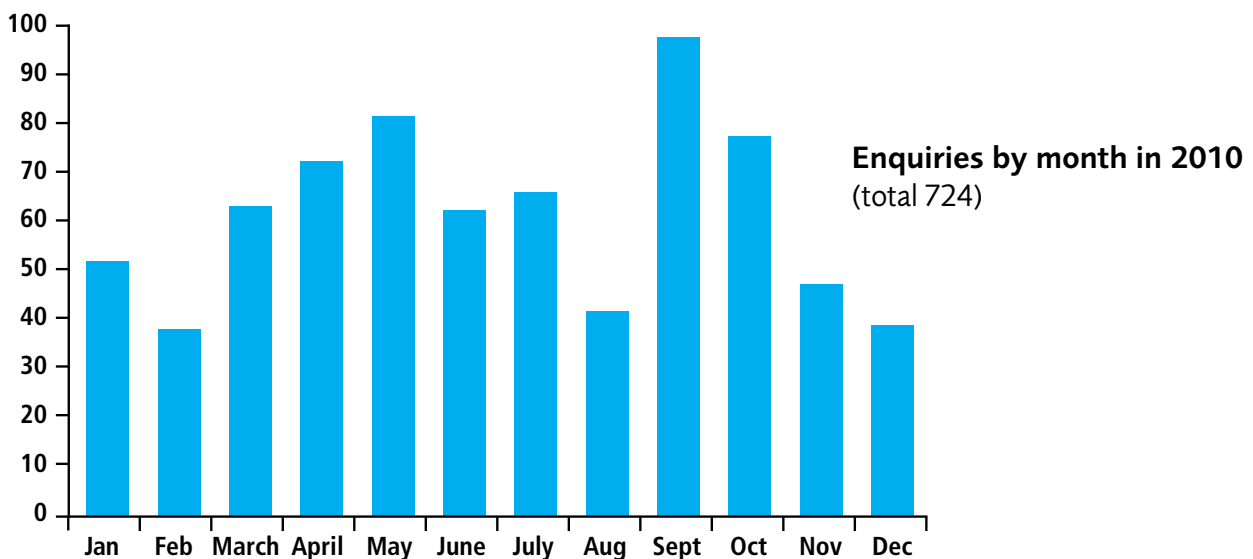
(Woman with late onset nystagmus)

Although the almost 50 per cent surge in enquiries in 2010 was encouraging, we believe we are still not reaching many of those who would benefit from our help. Often, for example, adults with nystagmus do not find out about NN soon enough, as the following email shows:

"I just wish I had known years ago what I know now about nystagmus. It would have made such a difference."

(Adult with early onset nystagmus)

So, we took steps during 2010 to raise our profile, as the following section shows.



Working with hospitals and the third sector

One reason why more people emailed and phoned for information, support and advice last year was the success of our publicity campaign with leaflets and posters. Staff in over 120 hospital eye departments contacted us. We are particularly grateful to orthoptists for spreading the word about the Nystagmus Network.

"Posters and leaflets are wonderful, thank you, and I've handed out the newsletter to be circulated in-department. Could I be really cheeky and ask for a couple more posters? I'd love to be able to put one in each clinic room if possible, to make sure the parents and patients see them."

(Milton Keynes orthoptist)



Sheffield orthoptics lecturers with NN publications

Another way we raise awareness of nystagmus and how it affects people is through talks and training sessions. John Sanders, our Information and Development Manager, talked about nystagmus to optometry students in Cardiff and to orthoptists at their annual scientific research conference in Oxford. John also gave talks to hospital staff in Abergavenny, Brighton, Cardiff, London and Sheffield. In addition, Kathy Williams, our chair until June 2011, raised awareness of nystagmus in the Midlands with talks to hospital staff and teachers.

"Everyone was very enthusiastic about your visit here - and some colleagues asked for leaflets before I could even put them on the rack for patients."

(ECLO (Eye Clinic Link Officer) London)

Trustee Sam Jones gave a talk about nystagmus in High Wycombe and represented NN at events in Manchester (pictured above right) and the LOOK charity Family Weekend in Great Yarmouth. Trustee Pam Jarman ensured that nystagmus remains on the agenda of the Voluntary Sector Forum, while Katy Faulkner represented NN on the LVIF (London Visual Impairment Forum). In addition, John Sanders is honorary chair of the Wales Low Vision Development Group.



We took part in several other events during 2010 too, including the BCLA annual conference in Birmingham, Sight Village, also in Birmingham, and the Welsh Eye Care Conference.



Working with schools and families

Our programme of presentations and talks extends to schools as well. Last year, John travelled to schools in Basingstoke and Rotherham and gave a presentation to educational psychologists in London. He also visited Lincolnshire to talk about nystagmus to the local society for the visually impaired and teachers of the visually impaired in the county.

"Thanks for the info, it's exactly what I needed. Hopefully now the school will have a better understanding of Georgia and her eyes."

(Parent of child with nystagmus)

At an individual level, we helped a number of children with nystagmus who faced challenges in school. Although support in the classroom is often (but not always) better than it used to be, we still regularly hear of problems outside the classroom. For example, children with nystagmus often can't see what's happening in assembly, in the playground or when swimming. Some even get told off when they have no idea they've done something a teacher considers wrong.



NN's Northwick Bear with staff from UCAN, a theatre group working with visually impaired children

We responded to requests for advice from teachers, SENCOs and LSAs working with children who have nystagmus. Here are three of the key messages we aim to get across:

- Normal measures of visual acuity underestimate nystagmus and fail to take account of the effects of stress, fatigue, etc.
- Nystagmus is a dynamic condition so its effects vary throughout the day.
- Children with nystagmus are often deemed to "cope" in school. In reality they are under-achieving.

The family support we provide is mostly about reducing the anxiety and uncertainty faced by parents of a newly diagnosed child. But we also help parents with nystagmus too:

"Our adoption home study is going much better now our social worker is more positive toward us. Have given her information on Nystagmus & she is doing some research in to how many people with visual impairments have been successful in adoption. Thanks for your support will keep you posted with our progress."

(adult with nystagmus)

Open Day

Our annual Open Day moved to Birmingham last year and attracted over 100 people. One Dad told us: "When I booked the Open Day I was dreading it," before adding, "but I'm glad I came now. It's great. Thank you."

As well as the Open Day talks, it was peer group support and the chance to meet others with nystagmus or parents of children with nystagmus which people valued most. In the words of one parent: "It's understanding we are facing similar problems to lots of others. Understanding there is support available."



Membership

We welcomed over 100 new members last year, taking the total to over 600 and reversing the downward trend of recent years. New members included former members won back by our more vibrant website.

"We always read the newsletter and have found NN so helpful. We're members of the Albinism Fellowship too. NN caters for the eyes while AF deals generally with how you look."

(Parent of a child with nystagmus)



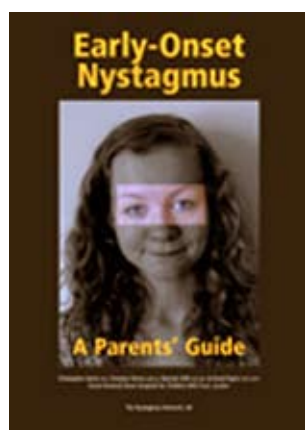
New publications

Printed publications remain important to us. During the year we filled a gap with the addition of an **information pack for adults**. This 20 page pack complements our existing information packs for parents and teachers and goes to all new adult members.

In the autumn with the help of Professor Chris Harris, our scientific adviser, we re-printed "**Early Onset Nystagmus: A Parents' Guide**" which had been unavailable for several years. Although the text is unchanged, this re-print has an expanded index, making it an even more useful source of information for both parents and professionals.

We also updated our easy to use two sides A4 **information card for teachers** (our yellow card), as well as our information hand-outs on **nystagmus and driving, research, treatments and cures**, and **registration as sight impaired**.

Illness meant we missed our target of publishing a book based on our 2009 international research workshop. However, we are making good progress with this project in 2011.



Research

Last year, we donated £10,000 towards the purchase of eye tracking equipment by the Research Unit for Nystagmus at Cardiff University's School of Optometry and Vision Science.

We continued to help the main nystagmus research centres in the UK (Leicester, Cardiff, Southampton and Plymouth) find subjects to take part in their work. We also welcomed a new centre, the University of Ulster, which is studying the effects of nystagmus on children and adults, and worked with Imperial College London.

We set up a research sub-committee with a view to taking a more active role in determining the future direction of nystagmus research. We supported a funding application by two universities for funding research to Guide Dogs, but this was unfortunately unsuccessful.



Cardiff Open Day

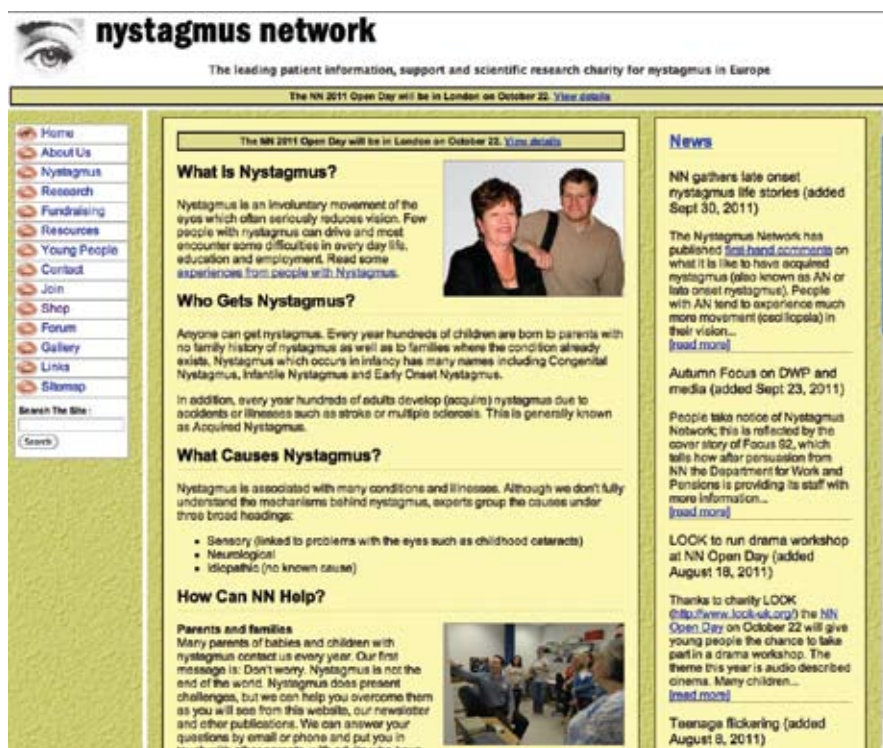
Website and Twitter

The number of hits on our website topped 40,500 last year, up from 37,000. The website (www.nystagmusnet.org) is an increasingly important point of contact with people who have nystagmus and also with professionals who have an interest in the condition. During the year we therefore devoted time to updating the website's content. We began with the home page and then added:

- Resource sections for hospitals and schools
- 16 news stories
- Research pages
- New pages for children
- Photographs of events and committee members

As part of the website overhaul, we increased activity on our online forum by providing faster and more comprehensive responses to new posts. This raised the typical number of active topics and the number of visitors.

Interestingly, our website attracts more hits from Italy than any other country (as the table to the right based on Google Analytics data shows). This is mainly because we host an Italian language forum on our UK website (the only other national support group is in the USA and that is much smaller than NN UK).



home page of
www.nystagmusnet.org

Visits to NN UK website www.nystagmusnet.org in 2010.

Source: Google Analytics.

	Country	Visits	Pages/ Visited	Avg. Time on Site	% New Visits
1.	Italy	13,475	2.59	00:02:18	70.30%
2.	United Kingdom	12,049	6.01	00:04:12	63.89%
3.	United States	7,647	4.52	00:03:38	72.50%
4.	Canada	925	3.45	00:02:20	81.84%
5.	Australia	883	4.52	00:03:30	81.43%
6.	India	438	4.11	00:03:21	86.53%
7.	Ireland	424	3.74	00:03:35	79.95%
8.	Germany	332	3.73	00:01:35	90.36%
9.	Netherlands	247	4.98	00:02:31	76.52%
10.	France	212	3.43	00:01:16	84.43%

Towards the end of the year, we started using Twitter and have since created a #nystagmus hash tag. Find us on Twitter at <http://twitter.com/nullpoint15> and http://twitter.com/press_nystagmus.



Treasurer's Report

2010 was a good year for NN financially and we ended the year with a modest surplus of approximately £500. Our overall finances are on a par with the previous couple of years, standing at about £90K in our current and savings accounts. The 2010 accounts were audited and signed off by Andrew Black in July 2011.

It was a conservative year for spending, compared with the research workshop of 2009, but there were two notable areas of expenditure. 2010 saw our first purchase of marathon places

as a means of generating fundraising - the results of which will come to fruition in 2011. The other expenditure to note was on information and publications, in particular the re-printing of the Early Onset Nystagmus book.

The majority of our income has come through fundraising efforts of individuals and generous donations. We are grateful for such support and hope it continues as we work towards strategies of research, and ways of supporting the Nystagmus community in the coming years.

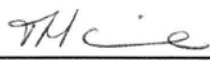
Tanya Hairman



Jack (who has nystagmus) and great grandmother raising funds for NN at an 80th birthday party.

	2009		2010	
INCOME	£	£	£	£
Grants				
Subscriptions	9,858		10,718	
Donations & Fundraising	13,074		22,681	
Wobbly Eyes + Leaflets	340		138	
Early Onset Nystagmus Book	193		295	
Xmas Cards	812		1,060	
Northwick (Book & CD)	632		472	
Northwick Cards	118		55	
Teachers & Parents Packs	420		663	
Postage	0		0	
Bank Interest	608		165	
Open Day	1,640		1,165	
Other	855		421	
		28,549		37,830
EXPENDITURE				
Office	22,826		20,152	
Committee	1,936		801	
AGM & Newsletter	5,656		5,572	
Leaflets	1,204		724	
Wobbly Eyes	0		0	
C Harris Book	0		2,235	
Xmas Cards	323		972	
Northwick	0		0	
Northwick Cards	0		0	
Open Day	1,119		3,550	
Other	129		3,300	
		33,195		37,305
Net Operating Surplus/Deficit		-4,645		525
Research and Workshop				
Workshop income	11,793	11,793	0	0
Research expenditure	13,700		0	
Workshop expenditure	25,162	38,862	0	0
Net Special Income		-27,069		0
Net Surplus/Deficit		-31,714		525
Cash at the Bank 31st December		£91,970		£92,496

Accounts Prepared by

 29/7/2011
Tanya Hairman

Accounts Certified by

 21/7/2011
Andrew Black ACA

What is Nystagmus?

- Nystagmus is a form of visual impairment which cannot be corrected by glasses or contact lenses.
- Nystagmus affects 1 in 1,000 people and is the most common form of serious visual impairment among school age children.
- The Nystagmus Network promotes awareness of nystagmus and encourages research into this complex eye condition.

Email: info@nystagmusnet.org

Web: www.nystagmusnet.org

Phone: 0845 634 2630 or 029 2045 4242

“As soon as I read your article I was nodding away to myself saying yes, yes, yes. Here's somebody who knows what it's like to have nystagmus”

adult comment to telephone helpline

Twitter: <http://twitter.com/nullpoint15> & http://twitter.com/press_nystagmus

Facebook: <http://www.facebook.com/pages/Nystagmus-Network/216838805015328>

