

NYSTAGMUS NETWORK (UK) NETLETTER
May/June 2004

NN OPEN DAY

“Marvellous” was how one member described this year’s Open Day held on April 24th in London. The event attracted around 100 people and included workshops on low vision aids, research updates, sessions for young people and an opportunity to meet and talk to others with nystagmus.

Ophthalmologist David Calver shared his 25 years experience of nystagmus, including a reminder that when he started in practice there was no such thing as a paediatric ophthalmologist. David also gave some useful advice on education and the management of nystagmus.

NN scientific adviser Chris Harris and his colleague Faith Budge presented the initial findings from their social impact research. Members will be hearing a lot more about this project in the coming months. As part of the project, we will be sending out a questionnaire to all members and urge you to fill it in and return it.

A fuller account of the Open Day events will be included in the June edition of our Focus newsletter, which will be sent to all members.

A moment of fame during the London Marathon

You may have seen Kevin Smyth dressed as Elvis on TV during coverage of the London Marathon. Kevin’s son Lee has nystagmus and Kevin hopes to have raised £1000 for Nystagmus Network.

Kevin writes: ‘It was a fantastic day on Sunday and the crowd banter was excellent – if I had a pound for every time somebody shouted out “Elvis” I would be very rich. It was certainly a day I won’t forget in a hurry and running around Docklands with Scooby Doo and a giant chicken was just hilarious. I was very tired by the time I got to The Tower of London so was quite shocked and taken back to be pulled out by Sally Gunnall – I wish I could have said a bit more about NN (and also sung a better Elvis song !), but my

mind was just racing at the time unlike my legs and before I knew it I was off again.

If you would like to sponsor me, you may either send your cheques, payable to Nystagmus Network, directly to me at my work address below or send your payment to Sarah Rae (who runs the NN database and deals with donations). Alternatively, you can make a donation via the website <http://www.nystagmusnet.org>. If you do sponsor me through either of the latter two channels, please email me on kevin.smyth@heritable.co.uk just so I can add this to the total.'

Kevin Smyth.
Heritable Bank Limited
8 Hill Street
Berkeley Square
London
W1J 5NG.



The rain didn't do anything for Kevin's wig!

SCIENTIFIC CONFERENCE

The UK Nystagmus Network is organising the first ever scientific conference on nystagmus. The provisional date is autumn 2005. We plan to bring together 20-30 experts on nystagmus and other associated disciplines. The aims of the conference are:

To consider long term treatments and cures.
To encourage further research.

Please note that this conference will not be open to the public, but we do hope to publish a summary of the main points in our Focus newsletter, which is sent to all members of NN.

TEACHERS' PACK

Following on from our Parents' Pack, which is available to all members of NN, we will shortly be publishing an information pack for teachers working with children who have nystagmus.

At the moment, there is almost no information available (try a search on the Internet yourself if you don't believe me) about the educational needs of children with nystagmus. We are going to fill this gap with a 40 plus page pack written with the help of teachers, students, their parents and adults with nystagmus.

The Teachers' Pack will look at issues such as:

How does nystagmus affect students?
Ways to help in the classroom
Ways to help outside the classroom
Working with parents
Advice for Learning Support Assistants

Once the Teachers' Pack is published, details of how to order it will be posted on the NN website.

Here's one for Northern Ireland

You will be able to see some of our Nystagmus Network Literature on the RNC (Royal National College for the Blind) stand at the Seeing Better- Ireland exhibition in Belfast on Thursday 3rd and Friday 4th of June.

Nystagmus Network members Drew and Tracy Cunningham will be at the stand at some time on Friday 4th to talk to people who are interested in nystagmus.

Calling the NorthWest

Dawn Simm, a member of Nystagmus Network from Wigan, would like to set up a local NN support group in the NorthWest. If you live in that part of the world and are interested in joining her she would love to hear from you. You can email her at dawnsimm@tiscali.co.uk or telephone her on 07932352718

WORDS IN WALES

NN vice president John Sanders will be giving a presentation about nystagmus to parents and teachers on July 5th in Gwent, South Wales. The talk will focus on what it's like to have nystagmus and how to limit its effects. For further details, contact Ann Tansley at tansla@caerphilly.gov.uk

VISION 2020 WEBSITE

Vision 2020 has just updated its website. Find out more at: [View item on the VISION 2020 UK site](#)

REGISTRATION

The process of registering as partially sighted or blind in the UK is changing. The Nystagmus Network has updated its Fact Sheet on registration accordingly. The Fact Sheet is free to members and available to non-members through our website Shop.

Many people with nystagmus can register as partially sighted and a few can register as blind (although they will still have quite a lot of sight).

The new system of registration will make little or no difference to the benefits of registration (which include free or reduced public transport fares for example). In the long run, they should make the process of registration faster and more accessible.

New Nystagmus Network Publications

We will shortly have copies of our Nystagmus Factsheet available in Gujarati.

We have also updated our Factsheet on Registration as Partially Sighted or Blind.

These and other factsheets are available FREE for members (please send s.a.e to Nystagmus Network Shop, 77 Harrowes Road, Edgware, Middlesex, HA8 8RS). If you are not a member please include your cheque for £2 per factsheet.

Baby Sunglasses

Claire Kenyon who came to the AGM with her baby Archie has just posted information about these sun glasses into the Nystagmus mail list. She has got a pair and is much impressed with how her baby is taking to them. (No more fiddling with elastic and hairbands for girls and wondering what to do with the boys!).

<http://www.edirectory.co.uk/pf/pages/moreinfoa.asp?pe=HFEGFGQ+BabyBanz+and+KidzBanz+Sunglasses&cid=880>

HEAD POSTURE RESEARCH IN SWANSEA, UK

The research project below is being carried out by staff in the eye department of Singleton Hospital, Sketty Lane, Swansea, SA2 8QA, telephone 01792 205666.

This research involves just one visit to the hospital and is totally painless. The staff know, they've tried it on themselves already. As David Laws, the consultant in charge of the project told me, the only risk he can think of is possibly getting your hair mussed up a bit by the measuring equipment.

There are as usual a couple of things to point out:

1. You have to be older than 14 to take part in the research.
2. We hope to find people living in south Wales or who can easily travel to Swansea. However, if this isn't possible, we may look further afield.

John Sanders, Nystagmus Network

PATIENT INFORMATION LEAFLET - STUDY ON NYSTAGMUS AND HEAD POSTURE.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research publish a leaflet entitled "Medical research and You". This leaflet gives more information about medical research and looks at some questions you might want to ask. A copy may be obtained from CERES, P.O. Box 1365, London N16 0BW. Or on their website:

<http://members.netscapeonline.co.uk/coneres/>

Thank you for reading this.

What is the purpose of the Study?

Nystagmus is a condition that **affects 1 in 4,000 people**. It consists of eye movements which are involuntary or that cannot be controlled. There are different causes of nystagmus and it is usually a life long condition.

A significant number of people with nystagmus find that their vision is improved looking in a certain direction as this lessens the eye movements. Because of this many people with this condition hold their head in a certain way. This is known as a head posture. It is unknown whether such a head posture has any harmful effects on the neck and spine and if neck movement becomes limited with time.

Surgery can be done on the eyes to correct the abnormal head posture. However this surgery is not without risks and it would be beneficial to know what the long term benefit is in preventing neck problems.

Why have I been chosen?

All adults with nystagmus are being invited to participate in the study. (However those who have already had surgery to reduce their head posture and those **with some other neck problems are not being asked**).

Do I have to take part?

No. The choice is entirely yours.

What do I have to do if I decide I wish to take part/ be involved?

You will be asked to attend for some tests and to fill in a questionnaire. The tests involve measurement of your head position while reading and measuring your neck movements. The questionnaire asks how aware of the head posture you are and whether it has an effect on your quality of life. The questionnaire will be anonymous.

What will happen if I don't take part in the study?

Nothing. We respect your decision and appreciate the time you have taken to read this leaflet.

How are the tests carried out?

An inclinometer is used. This is a plastic device with a compass and spirit level. It has been designed to measure neck movements and head position. It fits around your head. This is entirely painless and takes less than 5 minutes. The measurements will be recorded by a doctor or orthoptist (specialist in eye movements). You will be sitting in a chair while the measurements are being taken.

What are the possible disadvantages and risks of taking part?

There are no risks in taking part. The study will take a small amount of your time and will involve you travelling to Singleton (in Swansea). There will be no other implications.

What are the possible benefits of taking part?

You have a **relatively common** eye condition. However little is known about the number of people with head posture and how this affects their lives. Although we operate on some patients it is unclear how many patients need this. If you take part in the study you will be helping by increasing our knowledge about this condition. Although this may not benefit you directly it may help other patients.

Will my taking part in this be confidential?

All information collected about you during the examination will be kept strictly confidential. Any information about you which leaves the hospital will have the name and address removed so that you will not be recognised from it.

What will happen to the research study?

The doctors and orthoptists carrying out this study are not receiving any financial benefits. The study will help show if head

posture because of nystagmus affects neck movement in any way and how head posture affects quality of life.

This information has not been collected before and would be very useful in making decisions on surgery to correct the head posture.

The findings of this study may be published in a medical journal to inform other health care workers of the results.

Who has reviewed the study?

The Research Ethics Committee has reviewed the study.

Contact for further information:

Singleton Hospital switchboard is 01792 205666 and then ask for one of the following:

Miss Vicky Smith,
Orthoptic Department,
Singleton Hospital,
Extension 5213,

Ms. Brid Morris
Specialist Registrar in Ophthalmology,
Singleton Hospital.
Ophthalmology Department Ext. 5912.

Mr David Laws
Consultant Ophthalmologist,
Singleton Hospital,
Ophthalmology Dept. Ext 5912
david.laws@swansea-tr.wales.nhs.uk

Should you wear a medical alert pendant or bracelet?

Nystagmus may be a relatively common eye condition but it is still not widely understood by all medical personnel. NN have heard of people who have had to explain to worried A & E staff, that their eye movements are normal for them and not the sign of brain damage.

For this reason, you may like to consider carrying a medical alert pendant or bracelet. These are frequently used by diabetics and others who may need to alert medical staff to pre-existing conditions at a time when they may not be able to speak for themselves.

Medical alert pendants and bracelets are available to order from High Street chemists and jewellers. Some contain a long piece of paper, cleverly concertinaed to fit into a very small space; there is ample room on the paper to write your medical details. Others use an engraved message. Completed correctly, the information is said to be understood internationally.

BIOPTICS AND DRIVING

The Bioptic Driving Network is holding its first International conference on June 18th to 20th in London. They have a full programme of speakers from the United States and mainland Europe. You can see full details on their website <http://www.biopticdriving.org/conference>

Bioptic lenses are similar to a small pair of binoculars. They can be fitted to glasses – or worn on a separate frame if you don't need glasses. Two key points you should note:

- 1) Driving while wearing bioptic glasses is NOT permitted in the U.K.
- 2) Your peripheral vision would be greatly restricted.

Driving while wearing bioptic glasses is allowed, under certain conditions in some other countries, in particular the U.S. Driving conditions in parts of the U.S. are very different from the UK.

In the UK, most members of the Nystagmus Network do not drive because they do not see well enough to meet the requirements of a UK driving licence.

The use of bioptic glasses would be unlikely to have any effect on the wearer's nystagmus, but might improve their distance vision to the point where they could read a car number plate at the required

distance. However, just like looking through binoculars, your field of vision would be very limited.

The subject of wearing bioptic lenses is controversial and gives rise to many arguments. If you have any opinion for or against the idea or principle of wearing bioptics for driving please let us know and we will consider your comments for use in a future edition of this NetLetter or our quarterly FOCUS newsletter.

The Nystagmus Network produces a fact sheet on driving in the UK. See our “shop” for details on how to order.

Booktouch

Booktrust, aided by a grant from the Roald Dahl Foundation, is developing a new project: Booktouch. This project aims to get blind and partially-sighted babies and toddlers ‘bookstarted’.

A free pack, containing specially selected books and advice to help families enjoy reading together, is now available.

The research done around Bookstart over the last ten years has clearly shown that giving babies an understanding of books and reading from the earliest age makes an enormous difference to language development, emotional intelligence, reading and writing skills in later years, as well as fostering a life-long love of books. Booktrust wants to extend these benefits to blind and partially sighted children.

Accessibility of information is a great problem for many blind and partially sighted people. There are many organisations which offer services and support for reading including RNIB which has a huge library of audio books; the National Library for the Blind, which lends Braille books; public libraries, of course; and the ClearVision library, which lends picture books for the youngest children - with Braille added on the page in clear plastic alongside the written text. As part of the Booktouch pack is a leaflet to help alert families right from the start to the services available.

Introducing any baby to books helps them to learn the concept of how a book works, which way to hold it, how to turn the pages and

eventually to associate the marks on the page with language. The same is certainly true for blind and partially sighted children, many of whom will eventually be able to read large print. And for those who go on to learn Braille it is helpful to begin early in familiarising them with the concept of gathering information through touch and to begin learning the skills they'll need to track the Braille dots across a page.

Touch and Feel books are a great way to encourage children to get information through their fingers and add extra excitement to the reading experience, especially for those children who cannot appreciate the pictures. Booktrust hope to be able to include a Touch and Feel book in each pack and also a list of recommended touch and feel and audio books for this age group. A Booktouch pack may also include a picture book with Braille text, such those lent by ClearVision. The extent to which blind and partially sighted children will be able to appreciate pictures varies enormously - clear, bold, high contrast pictures are easier to see.

The pack will also include a leaflet with helpful tips about sharing books. Some of these tips will be the same as for any child, for example all young children will enjoy it if you make sound effects to go with a story. But there are obviously a few more considerations involved in reading with blind and partially sighted children.

It is important to think about how much of a book's contents a child has direct experience of – he or she may not be familiar with many of the objects and concepts which a sighted child absorbs from seeing the world around them. For example, to help a toddler to understand a story about the seaside, you could remind them about their own trip to the beach and have some sand and water at hand for the child to touch as you read.

Bookstart works from the premise that support for literacy and enjoyment of the wonderful world of books should be available to all children and should not depend upon whether or not a child grows up in a family that has a tradition of valuing reading. It is equally important that similar support is provided for those children for whom there may be barriers to reading.

For more information on Booktouch please contact Yvonne Hook
e-mail: yvonne@booktrust.org.uk tel 020 8516 2993

Safer Streets campaign Guide Dogs launches A-Z Guide to Obstacles

Over one million blind and partially-sighted people risk serious injury every time they walk in pedestrian areas. Guide Dogs is therefore launching an A-Z Guide to Street Obstacles, during its Safer Streets campaign for blind and partially-sighted people.

The A-Z publication features a pop-up pavement, with three-dimensional pedestrian obstructions - Slalom Street. It offers practical suggestions for an obstacle-free alternative, including cutting back overhanging hedges, and avoiding blocked walkways by removing badly positioned A-boards and wheelie bins.

Tom Pey, Guide Dogs' Director of Policy, explains: "We know of cases where vision-impaired people have received serious facial injuries from sharp, overhanging branches, or have stumbled on uneven pavements. Frequently we hear of clients walking into A-boards, whilst others have been forced into the road - close to traffic they cannot see - because cars are parked, blocking pavements.

"We're working with local authorities, MPs, retailers, drivers and other residents to make a difference."

This is the A-Z list of obstacles that guide dog owners and other blind and partially sighted people have to navigate every day.

A = Advertising boards

B = Bollards

C = Cyclists on pavements and cycles left outside shops

D = Debris from building work, e.g. piles of sand

E = Electric and other cables

F = Food (discarded food can distract guide dogs)

G = Gum (discarded chewing gum can stick to guide dogs' hair)

H = Hedges overgrown

I = Irregular walking surfaces

J = Jagged glass – broken bottles (broken glass can cut guide dogs' paws)
K = Kerb stones
L = Lamp-posts
M = Mess from other dogs
N = Narrow walkways as a result of obstructions
O = OBSTACLES
P = Pot-holes in badly maintained pavements
Q = Queues
R = Roadworks – badly fenced
S = Scaffolding
T = Trash – discarded bin bags and loose rubbish
U = Umbrellas
V = Vehicles parked on pavements
W = Wheelie bins
X = X-ings (Crossings) - lack of aids for vision-impaired people
Y = Youngsters on roller-blades and skateboards
Z = Zig-zagging around unnecessary street obstacles

More details at <http://www.guidedogs.org.uk/saferstreets>

The following items are taken from e-access bulletin, a free monthly e-mail newsletter. For further information and to subscribe, please go to: <http://www.headstar.com/eab>.

RESEARCH QUESTIONNAIRE:

Duncan Glendinning, a final year computer science student at Bath University, writes in to ask for some help with a research project on internet accessibility. "As part of my project, I have posted a questionnaire online for vision-impaired internet users. I would be hugely grateful if some of your readers could visit it and take a little time to respond": <http://www.dunkweb.co.uk/emailform/forms.html>

APPLES TO SPEAK.

Speech technology is to be integrated into new versions of the Apple Macintosh operating system, providing blind and vision-

impaired users with access to its computers for the first time, technology giant Apple has announced.

The technology, known as Spoken Interface (<http://www.apple.com/accessibility/spokeninterface>), includes voice output, sound cues, and enhanced keyboard functions to help users navigate through desktop items, menus, toolbars, palettes and other on-screen objects that were previously unavailable to them, and to help them use applications more easily. According to Apple, Spoken Interface will be integrated into the next major release of the operating system OSX.

For many blind computer users this will be their first chance to access Mac applications, since most developers of text-to-speech screenreaders have focused their efforts on desktop computers running Windows. The situation was made still worse last year when the specialist US access technology firm ALVA, creator of what has been until now the most widely available screen-reader for Macs 'OutSPOKEN', announced it was to discontinue the product from the beginning of 2004, while honouring all warranties and service agreements which still apply.

"Until now, Apple's record on accessibility has been dreadful," assistive technology consultant Peter Boshier told E-Access Bulletin this month. "There is some ability to change the size and type of screen fonts and on-screen switches, but that's about it. Blind people have had to avoid Apple Macs like the plague."

In particular, the new Macs will open up possibilities for blind people to use sound recording and editing equipment which is generally perceived as the music industry standard, Boshier said. "In recording studios Macs rather than PCs are the computers of choice. They are everywhere," he said.

TECHSHARE DATES

Techshare, the annual international conference on technologies for vision-impaired people, is to be held this year on 18 and 19 November 2004 at the Jury's Inn hotel, Birmingham, with pre-conference workshops to be held on 17 November. The RNIB event is aimed at professionals supporting people with vision impairment and costs 195 pounds, with an 'early bird' rate of 130

pounds for those enrolling by 1 October:

<http://www.rnib.org.uk/techshare> .

ACCESSIBLE MUSEUMS

Museums must consult people with disabilities before implementing new technologies, Peter Berridge, head of Colchester Museums

(<http://www.colchestermuseums.org.uk>) told a conference on the accessibility of cultural institutions last month.

'Is your museum fully accessible?' was organised by the Museums Association (<http://www.museumsassociation.org>) with the Museums, Libraries and Archives Council (MLA - <http://www.mla.gov.uk>). It aimed to provide practical advice for museums working towards the Disability Discrimination Act, which comes into full force in October 2004.

Berridge said Colchester Museums' own experience of introducing induction loops for people with hearing difficulties had taught it valuable lessons about introducing new technology. The museums only realised that deaf users received conflicting commentaries for audio-visual presentations when people complained, as the technology hadn't been sufficiently tested on users prior to implementation.

"This was a key turning point for us," he said. "Never again would we spend scarce resources on technology without consulting users first." Colchester Museums has since established an access advisory group called Portal, with a membership of nine people with visual, hearing, physical and other impairments. The group, whose members are paid for their services, ensures that accessibility is now built into all new projects at the museum from the outset.

Colchester Museums is currently exploring the use of different technologies to make visiting its exhibitions more rewarding for people with impaired vision. These include audio guides delivered through handsets; Braille labelling; a greater emphasis on touch in its displays; and an accessible web site, due to be launched in a few weeks' time.

The MLA has produced a guide offering museums advice on how they can use technology to provide better services to disabled people (http://www.resource.gov.uk/documents/dis_guide07.pdf).

ACCESSIBLE CINEMA SET TO TREBLE.

Audio description and subtitling equipment is set to be installed in 78 cinemas across England, more than trebling the number of accessible cinemas in the country, the UK Film Council (<http://www.ukfilmcouncil.org.uk>) has announced.

The project, which is part of the council's 500,000 pound National Lottery-funded Cinema Access Programme, will enable thousands of people with sight and hearing impairments to enjoy movies, from the latest blockbusters to independent releases.

The majority of popular film releases are now distributed with an audio description narrative and subtitles embedded in digital files. However, until now only around 30 cinemas in the UK and Ireland have been equipped to read these files so that audio description can be broadcast through personal, wireless headphones, and subtitles can be projected on to the screen.

Some 350,000 pounds has been allocated to buy and install the equipment, covering 50 per cent of its costs; cinemas will have to provide the other 50 per cent themselves. The equipment costs between 5,000 and 8,000 pounds per screen, although a cinema would typically only need to install it on one screen.

"When 'silent' movies were replaced by 'talkies' over 70 years ago, people with visual impairments began to enjoy the cinema experience," says Derek Brandon, editor of [yourlocalcinema.com](http://www.yourlocalcinema.com) (<http://www.yourlocalcinema.com>), a web site which informs people with sight and hearing problems about local cinema screenings. "But for those with hearing impairments, the loss of captions on the screen to explain the plot was the end of their cinema enjoyment," he said. "This year, over 100 cinemas nationwide will become fully accessible again for people with sight and hearing problems." Brandon's site has now received 50,000 pounds of funding over three years to help publicise the new services.

The new equipment will only be installed in cinemas in England, although the UK Film Council is working with the Northern Ireland Film and Television Commission (<http://www.niftc.co.uk>), Scottish Screen (<http://www.scottishscreen.com>) and Sgrîn Cymru Wales (<http://www.sgrin.co.uk>) to ensure that similar services can be provided across the UK.

FOCUS NEWSLETTER

Please send articles, letters and comments for the next edition of Focus to the editor, Sue Turner, at sueturner@creativecomm.co.uk

Please send contributions, ideas or links for the NetLetter to Gill Taylor at gill@taylors.uk.com