

NYSTAGMUS NETWORK (UK) NETLETTER
April 2004

Nystagmus Open Day

Medical and social research updates, advice on Low Vision Aids and Disability Living Allowance plus a children's drama workshop are some of the highlights planned for the Nystagmus Network's 2004 Open Day. Speakers include consultant ophthalmologist David Calver and NN scientific adviser Professor Chris Harris.

Claire Entwistle, NN acting chairman, said: "To celebrate our 20th anniversary we have arranged our biggest and most ambitious programme ever. The day will offer something for everyone interested in nystagmus, whether young or old, professional or parent."

Events and workshops include:

- Discussion group for parents
- Dr Brian Evans on "Improving eyesight using the Star chart"
- Drama workshop for young people
- Getting on at school and college
- Working with nystagmus using Cranial Osteopathy and Kinesiology by Richard Holding
- Low Vision Aids workshop with Pretty Garrett
- Working in graphic design with a visual impairment
- Advice on Disabled Living Allowance (DLA)

The Open Day takes place on Saturday, April 24th at the Prince's Foundation Building, Charlotte Road, London (nearest tube station Old Street) between 10.00 am and 4.30 pm. Lunch and refreshments are available for a small charge.

As the name suggests, this event is open to everyone and newcomers to NN will be able to join on the day. Booking forms are available from NN Information and Development Manager Paul White (contact details below).

For further information contact:

Paul White, NN Information and Development Manager
Tel: 01636 627004

Email: info@nystagmusnet.org.

Kevin 'Elvis' Smyth to run the London Marathon for NN

My name is Kevin Smyth and I'm running the London Marathon on 18 April to raise money for the Nystagmus Network (NN). What makes my run that little bit extra poignant is that my 11 year old son, Lee, has nystagmus and therefore I am dedicating my run to Lee. I have ran the marathon several times before for other charities, but have found that as each year passes, so it becomes harder to raise decent amounts - my friends tend to avoid me at this time of year for some reason !! Being honest though, if I'd known about NN earlier, I would have ran the marathon for your charity then, but it has only been just recently that my wife and I discovered your website and all of the support that goes with. How comforting this has been to us, I can't tell you !

To try to attract extra awareness this time round and to help raise funds, I will be running the marathon dressed as Elvis, that's the full attire, wig and glasses - don't ask !! I thought one for the money, two for the show.....see, I'm getting into the spirit already !!

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 through the website <http://www.nystagmusnet.org>. If you do sponsor me through either of the latter two channels, if you could just email me on kevin.smyth@heritable.co.uk just so I can add this to the total.

Please sponsor me if you can and I will happily accept donations whether you are reading this before or after the London Marathon.

Thank you for your support. I attach a photo of Lee and myself (I'm the one in the yellow shirt !) and I will also attach one from the Marathon, in my Elvis gear, at a later date.

Kevin Smyth.
Heritable Bank Limited

8 Hill Street
Berkeley Square
London
W1J 5NG.



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

Can you help us?

The following article was written by Professor Chris Harris of the University of Plymouth, one of our scientific advisers, and his colleague Faith Budge. We are funding this project and, as Chris and Faith say, our help with the forthcoming questionnaire stage of the research is very important. Chris and Faith will be talking about their findings at our 2004 Open Day on April 24th.

Your Help is needed!

THE SOCIAL IMPACTS OF CONGENITAL NYSTAGMUS : UPDATE

In February 2003 we began a study to explore the social impacts of congenital nystagmus (CN). We wanted to find out how CN affected people's daily lives. Much of the research on CN is of a medical nature and there is very little information about how people cope on an everyday basis. We wanted to know -what are people's

personal experiences of this condition? For the first stage of this study we conducted a series of in depth interviews with three groups - 1) parents of under 8s with CN; 2) parents of 8-18 yrs with CN and the young people themselves; 3) adults with CN. All of our participants lived in either Devon or Cornwall, as we are based in Plymouth. All participants were screened at the University of Plymouth and given a medical examination of their nystagmus by Prof. Chris Harris prior to the interview. Most interviews were undertaken in participants' own homes. These were audio taped and transcribed and all names and other identifying features, such as school attended, changed to protect confidentiality. The interviews were very informative and some interesting results were found.

We would like to thank all the participants who took part in this first phase of the research and also thank you to all those who offered to take part but who lived too far away to participate.

We are now asking for everyone's participation, regardless of where you live, for the second phase of this project. We will shortly be sending out a questionnaire through Nystagmus Network (we will not have any of your addresses or personal details). We would very much appreciate it if you could complete the questionnaire and send it back to us as soon as possible - you do not have to put your name or address on the form when you return it. The results will be presented to Nystagmus Network and also will be disseminated at various meetings such as the NN annual meeting, RNIB meetings and published in relevant journals. We hope that with your experiences we can help make a difference in terms of

how people with CN are treated, by for example the medical system, education system and in employment.

We cannot do this without the help of the people like yourselves who really know what it is like to live with CN, so we would really appreciate it if you could find the time to fill in the questionnaire when you receive it.

Thank you very much

Faith Budge

Chris Harris

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

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>.

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.

A MOUNTAIN TO CLIMB.

by Dan Jellinek and Derek Parkinson.

The annual 'Better Connected' survey provides a useful snapshot of local e-government across the UK. Conducted on behalf of the Society of IT managers (Socitm - <http://www.socitm.gov.uk>), the survey looks at each of the 467 council web sites in England, Wales, Scotland and Northern Ireland and assesses the range, design and sophistication of online services.

This year, Better Connected has tested all the sites for accessibility against standards set out by the international World Wide Web Consortium's Web Accessibility Initiative (<http://www.w3.org/WAI>), which rates sites as 'A' for basic accessibility; 'AA' for higher level accessibility and 'AAA' for near-perfection.

These standards form the cornerstone of UK policy on web accessibility. In the government's guidance for the third round of council 'implementing electronic government' (IEG) statements (<http://fastlink.headstar.com/ieg3>), councils are urged to work towards 'AA' standards.

All web sites were initially tested using automated software tools, and those that passed were then subjected to thorough manual tests by a team that included specialist consultants from RNIB. The Socitm report finds that just 18

councils achieve level 'A' conformance, and of the 23 sites assessed as transactional, only three achieve level 'A': Surrey, Tameside and Wrexham. Only one site - Tameside - achieves 'AAA' standard.

Around half of council sites fail to attain very basic accessibility levels due a lack of meaningful text tags for images on their sites; and many sites failed latter stages because when accessed by a browser that does not support JavaScript, the functionality did not work and there was no alternative provided. 'Text-only' alternative sites are not much help either; of the 143 council web sites with a text-only alternative, just seven reached 'A' standard overall.

While awareness of accessibility has improved greatly among UK councils, the survey shows that many are failing to translate this into effective results. According to Helen Williams of the Socitm Insight team, this could be because councils are under more pressure to launch transactional services and publish a wider range of content on their sites. "For example, more councils are publishing data like council tax bandings on their sites in the form of tables. But they often forget to include table header codes for screen readers," she said.

The general trend is a widening gap between those councils getting to grips with accessibility, and those that are failing to act, according to RNIB consultant Donna Smillie. "The sites that were doing well were doing very well. Even some that failed are paying a great deal of attention to accessibility," she says. "But some that get it wrong get it very wrong." According to Smillie, this may be because some councils can't meet staff training requirements, or because a completely redesigned site is in the pipeline, soaking up all available resources.

"With accessibility, there is clearly a mountain to climb," says Martin Greenwood, who leads the Better Connected project for Socitm. "I don't think there's any chance of councils achieving 'AA' within two years." Councils that had made efforts to meet accessibility standards were "very concerned" about the amount of effort involved, Greenwood says, with particular problems arising where councils were trying to make sites accessible that had not had accessibility in mind when first created.

"But in a sense, they don't have a choice," he says. "The fact is that there is a law about accessibility - the Disability Discrimination Act - so it would seem single 'A' accessibility is a minimum."

Note: A version of this feature appeared first in our sister publication, E-Government Bulletin (<http://www.headstar.com/egb>).

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@taylor.uk.com

For information about joining the Nystagmus Network please ***click here.***