

## Nystagmus Network (U. K.) Netletter January 2008.

This letter has *beginnings* as its theme. Members of the committee were asked to submit their personal or Nystagmus centred resolutions for 2008, and these are interspersed among the other items. There is celebration of Northwick, and two young people, and a new diarist writes for the letter. The thumbnail features Peter Leon who is the Treasurer. There is now a netletter email address so that readers may respond or submit material for the next issue.

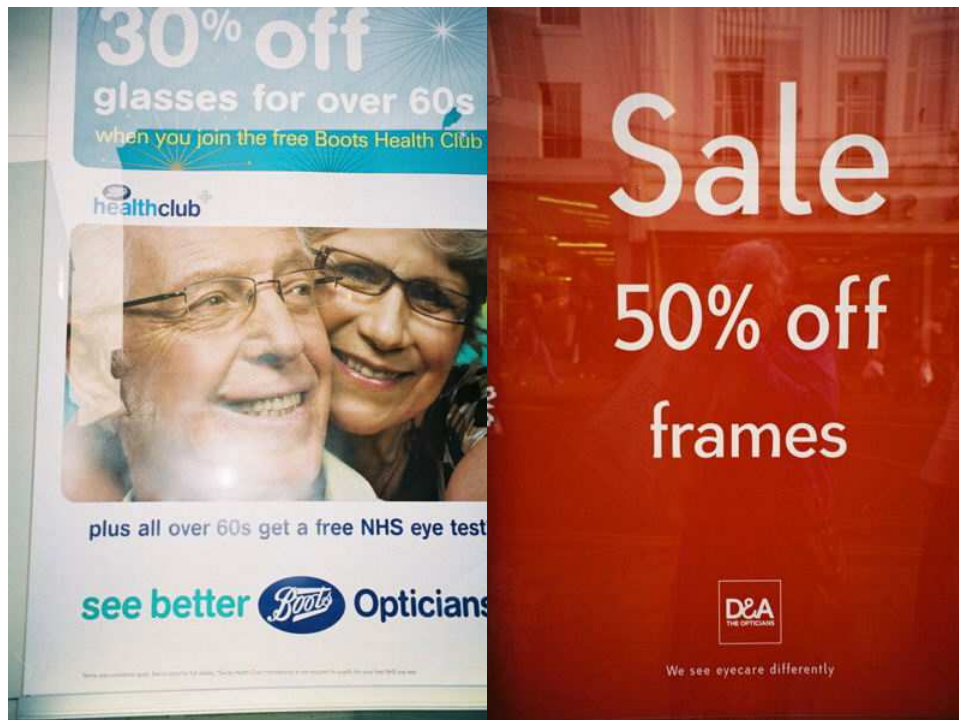
### Celebration!

In **Focus 78** there will be details of the exciting release of the Northwick stories on CD. Peter Leon and John Sanders have been involved in the recording and engineering of the stories into their new format. Remember that the shop has greeting cards featuring Northwick, appropriate for year round use.

### Winter Sales.



It is easy enough to choose whether or not to buy 2 for 3 cans of beans in the supermarket but has anyone found a way of evaluating the sales offers in glasses?



These are illustrations, not advertisements, but make the point that sometimes what is the right of the patient, like eye tests for the over 60s, may be presented as an extra lure.

**Resolution** : to buy a new monocular this year;  
To fulfil this resolution after making it for the last three years;  
to use a monocular effectively; to be more assertive with insensitive retail assistants.

### **Low Vision Leaflet.**

Opticians should hold low vision leaflets which are for self referral for advice on, and the supply of, low vision aids. Ask for one. You will get good advice and may not have to pay for the device.

**Resolution:** to lighten up!

### **Magni card.**

JML produce a credit card size magnifier for £4.99. It magnifies up to 2.5, has a led light, and a key ring attachment. It is sold by W. H. Smith and is usually displayed near the till point. (ref: 9678BM)  
[www.jmldirect.com](http://www.jmldirect.com).

## **RNIB.**

The name of the RNIB has been updated to the Royal National Institute of Blind People with the strapline 'Supporting blind and partially sighted people'. The logo has also been updated and is now the initials in a 'shaped' oblong.

At the Autumn meeting of the Assembly it was announced that the Institute had recently finalised a good practice report on access to social care, which will be used as a basis for campaigning. A series of events on access to information had taken place which brought service providers and users together. There has been very little move on Disabled Living Allowance. The Shared Space initiative continued to provide ineffective safeguards for blind and partially sighted pedestrians, and be problematic for others, for instance the elderly and children.

**Resolution:** to drink more and better wine; to drink more wine...

## **Vision2020uk.org.uk**

NN members attended the meetings in London and Birmingham. The London meeting focused on the problematic structure of the paper, and internal repetition. The importance of information at diagnosis was stressed, with support for parents. The Birmingham meeting was very robust in tone. It was felt that there has been little thought as to the target readership, and the practicality of intended outcomes. G.Ps and rehab workers were not mentioned, and neither was the question of the post code lottery. The project managers appeared to be optimistic about to outcomes in Wales and Scotland but not in the English case.

## **Readers' Groups.**

The [www.Vision2020uk.org.uk](http://www.Vision2020uk.org.uk) website has details of reader groups where those who use large print and audio can share in a book group. The provision of large print books in libraries has fallen in line with other text items as investment in IT and audio has increased. Could you encourage your library to greater investment in LP books?

**Resolution:** to organise digital photographs; to instigate a mighty shelf and cupboard tidying exercise to reduce the amount of time spent looking for things and instead use the time for more useful/pleasurable activities.

## **BTec Course .**

Throughout the U. K. the RNIB holds courses for teaching assistants for VI children. These are called Partners in Learning and details are at [DSTraining@rnib.org.uk](mailto:DSTraining@rnib.org.uk). They are of interest to parents.

Training events for anyone involved with VI children, including parents are held country wide. Details at [www.rnib.org.uk/training](http://www.rnib.org.uk/training)

## **Audio Description.**

[www.Viison2020uk.org.uk/Library](http://www.Viison2020uk.org.uk/Library) has a list of those theatres offering audio description of their performances.

## **Mobile Phones.**

The Nokia 6310i ([www.nokia6310i.co.uk.index.html](http://www.nokia6310i.co.uk.index.html)) may be of some use to those looking for a robust phone with a well spaced and clear keyboard. Although it is no longer produced it has been so popular that this website provides information on buying these reconditioned phones.

**Resolution:** to challenge those agencies and publishers who produce material with inadequate colour contrast.

## **Voice recognition.**

Technology used in call centres is beginning to move into the area of personal use, for dictating notes, and diary entries. Look out for [www.Spinvox.com](http://www.Spinvox.com) and [www.reQall.com](http://www.reQall.com).

## **UCAS.**

Starting University is a major step, and the process of applying can be daunting. For any student it is useful to go to Open Days and trawl the websites. While many Universities have managed their

access for mobility impaired students well, facilities for sight impaired students have taken longer to develop.

On websites look for those facilities which are centrally provided, such as large screen monitors in Libraries, and supernova screenreaders/enlargement at computer access points. Be clear what your needs are, and recognise that individual equipment will be provided through the Disabled Student's Allowance. Check out your rights. Ask within Departments about their experience with VI and get a 'feel' for their level of sympathy. Departmental secretaries are often very important!

Assistance in transition to University in mobility, study aids, and mentoring in Departments may be available. Use any visit to clarify website issues. Don't be afraid to ask!

An example of a University with good provision may be viewed at [www2.warwick.ac.uk/services/tutors/disability/visuyal-impairment](http://www2.warwick.ac.uk/services/tutors/disability/visuyal-impairment) .

## **Revealweb.**

[www.Revealweb.org.uk](http://www.Revealweb.org.uk) is a means of finding academic resources in a medium which is appropriate to the user. The Catalogue lists these. It gives contact details of organisations that hold titles in accessible formats and the terms under which they can be supplied. It is an information source, not a supplier and is backed by the RNIB.

**Resolution:** to plan to spend at least ten minutes a day doing exercises to reduce head-posture related pain; to take more exercise.

## **TNAUK Auto Download Service Update.**

From 11<sup>th</sup> December 2007 TNAUK will be making all audio publications available via their download service. A list of available publications is available at

[www.tnauk.org.uk/Pages/tape\\_categories.html](http://www.tnauk.org.uk/Pages/tape_categories.html).

A few items will not be immediately available. Additions will appear as the latest edition and it may take a month for them to be listed.

For a sample go to [www.talkingnewspapers.org/examples/gaurdian.html](http://www.talkingnewspapers.org/examples/gaurdian.html) . There is no need for a password.

### **Crosswords.**

Waterstones gave up supplying large print books because of low demand but they do hold one crossword book in stock.

Douglas R. Fink (1999) **The Everything Easy Large Print Crossword Book.** Adams Media, Mass.

**Resolution:** to remember a mini magnifier for the supermarket so that less food is bought too near its sell by date.

### **Nystagmus.**

We may not have accurate information about the incidence of nystagmus in the population, but Websters **Dictionary** states that the word (noun) nystagmus ranks 106,044 in word occurrence in English out of every 100,000,000 words used.

([www.websters-online-dictionary.org/Ny/Nystagmus](http://www.websters-online-dictionary.org/Ny/Nystagmus)).

### **Poetry Patched.**

A poetry competition is being held for children who wear a patch . One class is for 9 year olds and under and the other for 10-16 year olds. The poem should be 250 words maximum, and the closing date is 19<sup>th</sup> March 2008. The winner will get a £25.00 gift voucher, their poem read at the May Children's Low Vision Conference, and it will go up on the Low vision Website. Information and submissions should go to [l.beaumont@vision2020uk.org.uk](mailto:l.beaumont@vision2020uk.org.uk), and there is an entry form on the website at [www.vision2020uk.org.uk](http://www.vision2020uk.org.uk). The entry should include name, address, email address, and a phone number.

### **Children in the News.**

Millie Moody,5, of Stamford, who has nystagmus, was the face of the charity Sense which supports the deaf/blind this Christmas.

Her story was reported by Mark Pearson at  
[www.peterboroughtoday.co.uk/news/Amazing-Millie\)](http://www.peterboroughtoday.co.uk/news/Amazing-Millie)

[www.thisisgrimsby.co.uk/news/util/content](http://www.thisisgrimsby.co.uk/news/util/content) reported on 07.01.08 reported that Jack Unwin, 13, had 'defied the odds' by being given a Diana Award for sporting achievement. Jack has nystagmus but plays football and cricket.

The Diana Awards Scheme is a national programme which recognises and celebrates the outstanding qualities and contributions made by young people.

Jack lives in North Somercotes and goes to the Birkbeck School.

**Resolution:** not to beat myself up over clumsiness; to stop apologising if I can't see, -- even to the ATM!

### **You may not have known...**

Robert Barany, born near Vienna, (1876-1936) won the Nobel Prize for physiology/medicine in 1914, while he was a prisoner of war. He specialised in otology, diseases of the ear, but his work was concerned with balance, and with the incidence/severity/direction of nystagmus. Prince Carl of Sweden interceded to gain his release and he went on to spend the rest of his career working at the University of Uppsala.

([www.fags.org/health/bios/14/Robert-B-r-ny.html](http://www.fags.org/health/bios/14/Robert-B-r-ny.html))

### **You may not want to know.....**

There is a trance/psychedelic band called Nystagmus. Downloads available at [www.mp3tune.com/mp3s-nystagmus](http://www.mp3tune.com/mp3s-nystagmus).

### **From the Archives.**

In 1933 the bodies of Thomas and Mary Lynn were discovered, dead and with horrible injuries at their home at 5 Cook's Buildings, Whickham, Co Durham. Thomas had been a miner but was receiving compensation from the colliery. He had not worked for two years because he had nystagmus. It appeared that he had killed Mary while depressed and then had killed himself.

Alma Willis lived nearby as a child and knew the Lynns well. She remembered her father saying 'He didn't murder his wife, he took her with him'.

([www.webwanderers.org/2006/03/a\\_sad\\_childhood\\_memory.html](http://www.webwanderers.org/2006/03/a_sad_childhood_memory.html))

## **Dates to make a note of....**

26<sup>th</sup> March 2008 Reveal Exhibition, Leeds.  
Venue: Pudsey Civic Centre, Leeds  
Contact: [www.softwareexpress.com/exhibitions](http://www.softwareexpress.com/exhibitions).

3<sup>rd</sup> April 2008 Wales and West Vision Day.  
Venue: University of Newport,  
Newport,  
South Wales.

Contact: Nirmala Pisavada  
Tel: 01495 763650  
Email: [Nirmala.Pisavada@gwentblind.org](mailto:Nirmala.Pisavada@gwentblind.org)

We welcome Oliver to the netletter.

## **Oliver Jones' Diary.**

### **Thursday 3 2008: Trolley trauma.**

Drivers. They are so unpredictable. Tesco car park on a wet Thursday evening. Hardly my idea of fun. I just want to get the trolley back to the car—Emily has gone ahead to open the boot—and get home. Spot a car reversing so head for the gap. Big mistake. Car suddenly stops with me caught like a rabbit in the headlights and no room for the trolley to squeeze through.

Eventually make out pale thing flapping about behind windscreen. Can't normally see into cars, but Tesco helpfully lights up car-park with flood-lamps (probably have the eco police onto them). Realise that pale flapping object is driver's hand. He's changed his mind, wants to go forward and is ushering me aside.

No idea what the Highway Code has to say on right of way in such cases, but refuse to give ground. Driver eventually edges back a

few inches. Probably thinks I'm a moron. But how often do I miss drivers waving me cheerily, or otherwise, on? Will ask Emily.

**Northwick overcome at the news of his imminent CD fame!**



## **Thumbnail**

**Peter Leon.**

I heard about Nystagmus Network in 1995 when I went for a check up and to take part in a research project. Until then I had never met or heard of anyone else with nystagmus. I became an NN member and a few years later joined the Committee. In 2000 I became Treasurer.

I have congenital idiopathic nystagmus. In other words no one knows why. Mine is the typical story of parents being worried as to what was wrong with my eyes and not getting information. This was exacerbated by wartime (born 1943) and it was not until I was

2 years old, when my mother reconnected with a distant uncle who was an eye surgeon, that he answer finally came. He took one look and said "Nystagmus,-- nothing you can do. Don't worry!" By then of course I was happily playing with toys and picking up crumbs placed in front of me to test my eye sight.

In classrooms I always sat in the front and sometimes had to walk from my desk to stand in front of the blackboard when the teacher's writing was particularly 'bad'. I learned to ignore comments, (mostly from teachers), about getting new glasses. I listened more to lessons, and wrote my own notes, rather than reading from the blackboard. I do the same for presentations now and while I sit as near the screen as possible, I rely on listening and making my own notes, (hurriedly scribbled and then gone over afterwards).

As treasurer it falls to me to sound warning notes about any 'reckless' spending (large or small). However I am keenly aware that, apart from our daily running costs, we do need to spend money on updating systems (e.g. the website and **Focus**), to make them modern, attractive and not too great a burden on the volunteers who give their time to running the show. We also need money for the big ticket items of research and the 2009 workshop. I am retired but the companies that I have known, primarily in investment banking are very generous to charities, especially if they are asked by someone they know. If you don't ask, you don't get!

With the help of John Sanders I am currently arranging a CD of the **Tales of Northwick** stories. This could only have come about through the kind donation of time from the talented actress Lizzie Roper, and the studio owner Elaine Stern. People are very generous: you only have to ask

Peter Leon  
December 2007

### **A final Resolution:**

"I have resolved to let the year take care of itself."  
(Ann Widdecombe: **The Times** 5.1.7)

## **Websites.**

[www.nystagmusnetwork.org](http://www.nystagmusnetwork.org)

[www.nystagmus.co.uk](http://www.nystagmus.co.uk)

Both websites continue to be usefully active. A recent member is from the Ukraine.

In addition if you have any feedback on the netletter, or contributions for future editions you may now make contact at [netletter@nystagmusnet.org](mailto:netletter@nystagmusnet.org)

Are there any cartoonists out there?

## **Stop press.....**

Final submission date for February netletter 5<sup>th</sup> February.

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