

Nystagmus Network (U.K.) Netletter. June/July 2008.



In this issue.

There is a great deal to celebrate in this issue, including the achievements of individuals with nystagmus, and the netletter's focus this month will be on some of these individuals.

Congratulations to the webmaster and forum members at www.nystagmus.co.uk. Their posts have passed the 4,000 mark. There

is a very stimulating report on the activities of www.nystagmusnet.org . Did you know that NN is very popular in Italy? This issue features news of the Open Day at Nottingham on 5th July 2008. There is still time to register. Follow the links on the home page at www.nystagmusnet.org . While visiting the site consider contributing to the funds for the September 2009 research workshop.

Big Brother makes an appearance, as does Oliver, who is coping with challenges at work. The thumbnail is of Paul White, the Information and Development Officer for NN. He has family experience of nystagmus and you can see examples of his creativity.

Computer games for VI children pose problems of accessibility, and the netletter indicates possible sources, as well as access to the visual arts for visually impaired of all ages. Holidays are coming. Have you thought of what a canal holiday might offer?

Open Day.

The Open Day offers the opportunity to meet people with nystagmus, find out about recent research, and disability living issues. It is exciting to meet in the 'real' world, and children will enjoy a variety of activities.

Research workshop.

Preparations are moving ahead for the second international nystagmus research workshop. The research committee of NN is working hard to generate funding, both for the workshop and the subsequent book, and responses to invitations to academics to attend, have had a very positive response so far. There may be more new faces from continental Europe this time.

Oliver Jones' Diary.

Monday June 18.

One of the worst moments of my life this afternoon. We had a compliance training session, so I was all ready for a siesta. Unfortunately the external trainer had different ideas and wanted us to read stuff out. Only, of course, the hand-outs she'd brought along were all in 10 point. I can read that size print if I hold it close and I'm not stressed.

But my stress levels were off the Richter Scale as I could see my turn coming and realised that I was going to struggle. So, of course, the

harder I tried, the more my eyes bolted about, and the more the print shrank and rock and rolled all over the page.

I tried to explain to the trainer that I have this thing wrong with my eyes-- which wasn't much fun in a room full of a dozen colleagues. Some knew vaguely about nystagmus, but most didn't. Anyway, I don't think that the trainer believed me. Pretty sure that she thinks that the bank has employed an illiterate or I'd been in the pub all over lunch.

The Websites.

It has been a very active time for both www.nystagmusnet.org and www.nystagmus.co.uk .

For www.nystagmusnet.org the webmaster created a Just Giving Appeal for the Research Workshop. The shop is being upgraded and it has been tested and modified. The Forum has been upgraded twice, and Google tracking added. The Research and the Research Workshop pages have been upgraded.

Google tracking shows that in the month of May there were 2,356 visitors to www.nystagmusnet.org . Nistagmo, the Italian link, was the most used search term leading to the website., although there were visitors from 73 countries. 63% of the visitors are from Italy, 16% from the U.K., and 14% from the U.S.A.

www.nystagmus.co.uk continues to enjoy a very high level of returning members, many of whom use the site to generate new topics for discussion. Its core members are very loyal, and supportive and imaginative in their responses to posts.

The webmaster has taken the step of altering the categories of membership on this site in response to the feeling that the term 'sufferer' was not acceptable. Currently anyone visiting the website will see 'has nystagmus' as a tag.

The Education Bulletin.

The Education Bulletin is an online education magazine distributed free of charge to anyone connected to, or involved in, education. It is non profit making. It will include specialist information from lawyers and psychologists, helping to find routes through the maze of educational difficulty. You can raise any issues, and may contact the Bulletin.

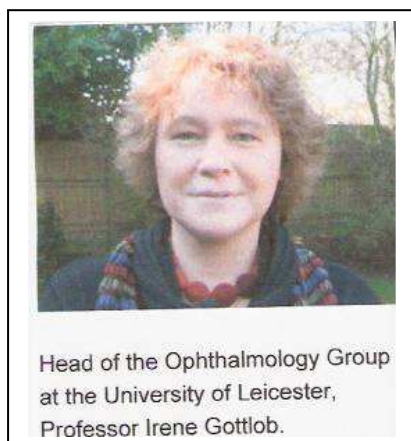
Although it will not be possible to answer all specific questions, issues will be addressed in focused articles.

<http://www.educationbulletin.co.uk>

Dates and events.

30th June 2008. Prof Irene Gottlob gives a public lecture at Leicester University as part of their 50th Year celebrations. She will speak about the way, in collaboration with Cambridge University, the gene for congenital idiopathic nystagmus was discovered. There is a summary of the lecture at www2.le.ac.uk/ebulletin. Follow the links.

□



15th, 16th, 17th July 2008 Sight Village
Clarendon Suites, Hagley Road, Birmingham.
NN will again be sited next to the Albinism
Fellowship.

4th November 2008 Sight Village London. Details to follow.

What it's like.....John Sanders writes.

Explaining what it's like to have nystagmus is one of the most important things that we do at NN. Twice in the last few months I've talked to teachers and orthoptists in Hampshire. These training sessions are based on my own experiences of nystagmus and on conversations with hundreds of others over many years.

Professionals such as eye doctors and optometrists know that we have poor vision. But they often don't realise, -- because no one has ever told them, —how it affects everyday life. They don't know what it's like, for example, to learn at 16 or 17 that you won't be able to drive. They don't know what it is like to be hopeless at sport, or computer games, or all the other activities where good vision is essential.

They don't know what it is like to be called rude or stupid because you can't see something or you pass a friend in the street without saying "Hi!" They don't know what it is like to have the bus driver grumble at you because you flagged him down when he was only 20 yards from the stop.

They don't know what is like to need more time to see things. They don't know what it is like when people make fun of you because your eyes wobble or you hold your head at a funny angle. They don't know what it is like when you fail a job interview and wonder "was it because of my weird eyes?"

That's why I, and a few other people at NN, regularly stand in front of 20 or 30 people and talk about nystagmus. They may be medical people, teachers, social service professionals, charity workers, students, or parents of children with nystagmus. And even after all these years, it's not a one way process. I'm still learning.

At the session with the Hampshire teachers, for example, they came up with some new ideas about driving. On the positive side, they said that one benefit of not driving, was not having to worry about finding a parking space. They also suggested some reasons I've not heard of before why we would find it hard or dangerous to drive. One is the blinding glare of headlights at night. Another is the difficulty of seeing traffic lights.

How much difference do these training sessions make? That's hard to say. But the Hampshire teachers were kind enough to say that the feedback from all was extremely positive and "we learned so much from your presentation." Similarly, the orthoptists commented "Your presentation was so helpful for us as clinicians to understand and learn about the condition from your perspective."

The way it is.

There is a full and interesting account by a student with very limited vision at <http://student oulu.fi/vtatila/sight.html>

The Way it is 2.

An explanation of how the world looks to a person with nystagmus is illustrated at <http://www.omlab.org> . Go the teaching link at the bottom of the page, and then click on tenotomy. It is useful for oneself but also to help explain the condition to others. There is also an explanation of the tenotomy surgical process.

Have Fun with Strabismus!

An irresistible website link! It has useful information in relation to nystagmus.

<http://strabismus.n/node2>

Speed Racer.

Speed Racer (Warner Bros/Wii) is a psychedelic fast paced game, with plenty of opportunity to shunt others out of your way. Recommended for anyone who needs a substitute for 'real' driving.

OUCH!TALK: Making Eye Contact.

There is a discussion by young people about the challenge of trying to make eye contact at www.bbc.co.uk/dna/mbouch

"I have nystagmus. I'm conscious that I'm lacking in eye contact. I try to look in their direction, but I don't know if they feel that this is eye contact".

One post asks whether nystagmus is a disability – the subject of lively debate on www.nystagmus.co.uk . In his June Radio4 newsletter, Peter White also discusses whether disability is an 'enabling' concept. Groups of people who have a common purpose have a power not granted to the individual, both in a sense of identity and also in campaigning for rights.

Yeovil Low Vision Exhibition 13th June 2008.

Andy Machin attended this exhibition, and was able to distribute twelve membership packs. This included some to adults who had not heard of

NN, and a child with her teacher. The teacher hopes to order the teacher's pack. One visitor was a contact at Yeovil Hospital, and maybe the first sale of a Northwick CD was made.

In the News.

RNIB and iris recognition.

Shaun Leaman, who is Human Factors Scientist at the RNIB is now leading this project. He plans to arrange several regional centres where people with nystagmus can try out its iris recognition cameras to see whether or not our wobbly eyes will pose a problem.

Richard Clement.

Richard is a vision researcher at Great Ormond Street, and has self published a book, **Seeing the World**, to show what can be done by using <http://www.lulu.com/uk>

Guide for ophthalmologists.

At last, a book advising eye doctors on how to break bad news to people with vision loss. Ophthalmologist Anne Sinclair and optometrist Barbara Ryan have written **Low Vision---the Essential Guide for Ophthalmologists.**

Real Lives.

This book reflects the lives of twelve people with albinism through accounts and pictures. It deals with key questions about stigma, and about how differences in appearance can affect relationships in school and in the adult world.

The book is available directly from the Albinism Fellowship :

Real Lives

Albinism Fellowship, PO Box 77, Burnley, Lancs. BB11 5GN.

It costs £12.00 including p and p.

RNIB Assembly.

The Assembly business included a report and update on the concerns about access to information for families with young children, and it was agreed that there should be cooperation with **LOOK**, the charity for families with visually impaired children.

The **Right to Read** Campaign is concentrating on the provision of textbooks for school children. Despite their stated support for the strategy, the Government has been tardy in its response.

There are to be two events, **A year Older not Wiser**, and a **School Report**, assessing the lack of progress in providing textbooks in alternative formats.

The Campaign to alert people to their rights to an Attendance Allowance at 65 is to be heightened. The forms are immensely complicated, and it is hoped that volunteers may be used to help with the application process.

Directory Enquiries.

There is a new freephone number for directory enquiries.

Use 0800 100 100 rather than the 118 118 pay-to-use number. The service is funded by advertisers, so you will have to listen to 20 seconds of advertising.

Remember that if you are registered as VI you are entitled to an operator aided free service on 195 + personal number identification.

Blindness/Visual Impairment Resources.

Last updated on 24th March 2008

<http://www.icom.net/Oedipus/blind>, will take you to a comprehensive resource of international sources from legislation, through education, to technology.

On a lighter note.

International affairs impact on Paddington in the latest Bond book, **Paddington Here and Now**. Michael Bond's daughter, Karen, experienced childhood disability, and it has been revealed that the original Paddington wore glasses.

Fighting Blindness: Ireland.

Fancy a long walk in Tanzania? **Fighting Blindness** is raising money from sponsorship from people prepared for a long walk in Tanzania.

Alternatively you might consider New Zealand in November 2008, or Panama in Spring 2009.

<http://uk.mc281.mail.yahoo.com/mc/showMessage?&fid>

Achromatopsia Day.

Information about the American Achromatopsia Day, hearing colours, is at <http://newswiretoday.com/news/35250>

VocalEyes.

VocalEyes provides access to the best of the arts for visually impaired people. This may be painting, theatre, ballet, a cultural site, or an aspect of the environment. During the London Festival of Architecture 2008 there will be a series of Audio Described Tours. The news section of the website has a list of events.

In conjunction with the RNIB, a Talking Images Research Project has been completed which has looked at improving access in museums, galleries and heritage sites. The resulting book, **Talking Images Guide** is available. Its ISBN is 185878588X.

<http://www.vocaleyeyes.co.uk>

Art through Touch.

This organisation is expanding, but currently London based. It aims to create access to the arts for visually impaired people, and also to make arts centred information more readily available.

<http://members.aol.com/ATTouch>

Low Vision Art.



Low Vision Art by registered Blind and Deaf Artist, Barrie Goodfellow. Acrylic, water colour and tactile artist.

Useful websites and resources can be found at www.lowvisionart.org/links_to_other_websites_of_interest

This site is intended for amateur painters.

Soccer.

Another culture, but Soccer Sight intends to bring the excitement of matches to the visually impaired. Cardiff City is one of the first clubs to use volunteers to commentate for those who can't see the action.

www.rnib.org.uk/soccersight

Accessible computer games.

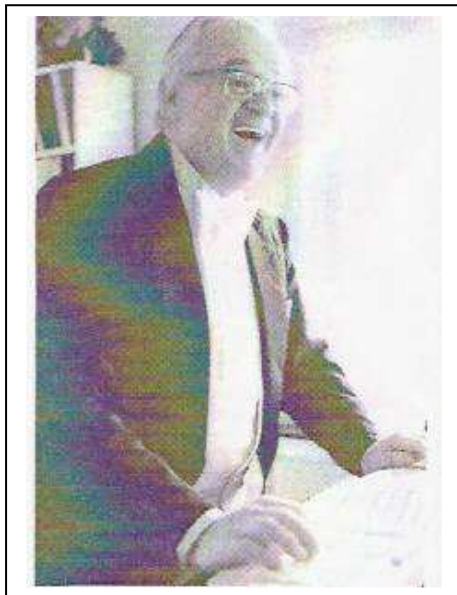
A resource for accessible games is www.pcsgames.net/games.co .
<http://cordis.europa.eu/ictresults/popup> is a site which aims to present computer games for visually impaired children free on the internet, creating new games and adapting existing games. Some of these will be prototypes from commercial producers, but it intended to keep costs as low as possible.

The woman behind the idea is Dominique Archimbault of the Universite Pierre et Marie Curie in Paris.

Alain Ulmer.

Although born in France, in 1949 Alain, who has nystagmus, has chosen since 1970 to work in the Netherlands, where he is a photographer. He says “My disability forces me to pay extra attention to everything that I see, especially beautiful compositions and forms...Someone with imperfect eyesight like me can see the most important things.”
www.ulmer.nl . This is a stunning site.

The Wide-Spectrum Pianist.



Janos Solyon is Hungarian by birth but has lived in Sweden for 40 years. He has nystagmus. He is a classical pianist who is famous in his adopted country. He has recorded widely, and performed world wide, particularly in the U.K. He has an infectious and irreverent approach to music which

makes it accessible to everybody. As well as being a pianist, conductor, publisher, and improviser, he is a member of the Royal Swedish Academy of Music, and has been decorated by the King of Sweden “for outstanding achievements in the culture of the country”. He is married to Camilla Lundberg, Head of Music at Swedish State Television.

www.solyon.com

Big Brother and Blind Radio.

‘Mikey’ Michael Hughes is the first visually impaired person in the Big Brother house. Partially sighted d j Stephen Scott says that he was an inspiration to him when Scott was struggling with his own impairment.

Michael has been with Insight Radio from its early days. Insight is Europe’s first radio station dedicated to blind and partially sighted people.

The station has won a SONY Award and is available to listeners in the Glasgow area. Michael is both a presenter in the studio and an interviewer. He enjoys ‘hard’ stories, but also the frivolous and fun items.



www.insightradio.co.uk

www.blindradioco.uk

Watch out!

If you are coping with the shared space in towns, you are about to be faced with a further challenge. There are to be pilot schemes in some cities which would allow cyclists to go the ‘wrong’ way down one way streets. Drivers would be responsible for any accidents. And no one has

thought of the visually challenged individual who will have no idea from which direction a bicycle may come. The article in **The Times** of 4th June ignores the pedestrian, but asks whether the scheme is facing up to the reality of what already happens, or is letting law breakers win.

Avoiding road traffic: the canal system.

As long as someone in the 'crew' has a driving licence, a canal holiday can be attractive to anyone with a visual impairment. There is all the exercise with managing locks, and plentiful canal side pubs. Dogs are welcome. Most towpaths are well maintained, and steering a narrow boat is an adventure. Towns and country look very different from the water, and the wild life is often comfortable with 'water' people, and coming closer, it is possible to observe what would normally be too far off.

Canals have different features. At Hatton, on the Grand Union Canal there is a flight of 21 locks. In the canal café (open every day from 10,00a.m.-5p.m.) there is an excellent audio guide of this extraordinary system, together with a tactile map and a large print guide.

These materials have been produced with some lottery funding, and support from British Waterways, the Fieldfare Trust and Red Kite Environmental, Milton Keynes VI Club, and Birmingham Eye to Eye Group.

www.britishwaterways.co.uk

If you go by canal to Stratford upon Avon you'll find a Riverbank walk which has been designed for those with visual impairments. It has reference posts, and tactile signs. A tape cassette explaining the walk is free from the Butterfly Farm on Swan's Nest Lane.

Canal boats too tame?

Scott and his partner, Pam, became the first legally blind couple to sail across the Pacific Ocean. As a boy, living in California, Scott was desolated to think that he would not drive, not exult in owning his first car. It was at this time that he went on a sailing holiday. "All of a sudden I could be in charge of driving something! It was exquisite and exhilarating". He has nystagmus.

The idea was born to circumnavigate the world, and in 2002 he took the first step by buying a suitable boat. In 2004 he set off with Pamela Habek to try to become the first blind couple to sail round the world with no

sighted support. They are still on their way, working to support the cruising by working in adaptive technology.

For Scott's philosophy on managing visual impairment see

www.blindsailing.com/About%20Scott.htm

Beside the sea: surfing.

Zachary Mason, 7, is spending his Summer at the Surf Central Surf Camp, in Stuart, Florida. He has nystagmus, can make out shapes and colours, but his vision is blurred, and he has some oscillation. The Camp Director, Harvey Cupaiuoli, says that he is the first sight impaired child he has taught, but unless his mother had explained Zach's condition, he would not have recognised him as having a problem.

“Within an hour he was on his own board and catching his own waves, and honestly I've never seen anybody get it that fast,” says Harvey.

Zach says that he uses his other senses. He listens and feels the waves approaching.

www.wptv.com/news/local/story

<http://tcpalm.com/news/2008/jun/18/no-headline>

Tour de Cure, and a Mr Cure.

A young cyclist with nystagmus, 16 year old Nathan Wassenberg from Ann Arbor, USA, is taking part in the Brighton Tour de Cure. This is the biggest of the Cure charity rides, inspired by the Tour de France. There will be 900 riders with 100 volunteers, and aims to raise \$340,000.

Meantime in Oxford, England, Director of the Oxfordshire Association for the Blind, Colin Cure, is cycling round the county to encourage awareness of visual disability. It is a sponsored 150 mile ride. Latest figures in Oxfordshire put the registered Visually Impaired at 3,700 but Colin Cure thinks that the figure should be nearer 10,000.

www.oxfordmail.net/misc/print.php

A Blind Triathlete.

Maggie Bowes of Warwick, 57, failed to win a medal at the World Triathlon Championships this month in Vancouver. She did not do so because she had a male guide. She battled 6 foot waves, and raced

downhill at more than 45 miles an hour. She finished 10th, and second in the British team.

www.leafingtoncourier.com

Actionnaires.

Contact your local club to find out what is being arranged for the Summer. For example in Nottingham there will be swimming, climbing, archery, fencing and goalball.

www.actionnaires.org

Word play.

Some scientists and doctors had nystagmus syndromes named after them and their discoveries.

Jean-Martin Charcot 1825-1893 human geneticist.

Charcot's triad 1: nystagmus, tremor, scanning speech.

JeanJacques Lhermite 1877-1959

Lhermite's syndrome: ocular palsy with nystagmus.

Aldur Wictor Eriksson b1927 human geneticist.

Fornius-Eriksson syndrome: fundalbinism, nystagmus, myopia.

Really challenging.

An Elegant Ophthalmic Film on Nystagmus by Davis Seifi

“and as we melted into a spoon on the settee
The fire yawned and fell asleep.....”

<http://blogs.warwick.ac.uk>

A medical howler.

A sure fail student in the Malaysian medical Clinical Finals, when asked how to examine a patient for nystagmus, merely pointed his index finger at the patient and made circular motions around the patient's eyes.

You can check the proper way of examining for nystagmus at

<http://medicine.com.my/wp/>

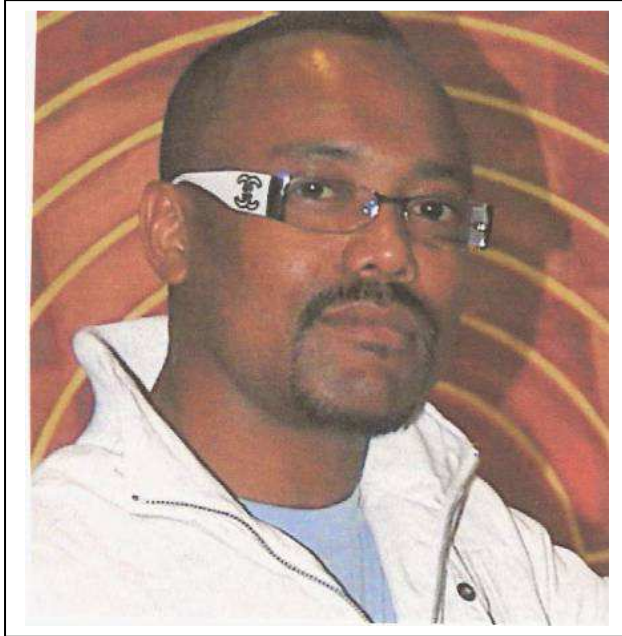
Apl.de.ap

Apl.de.ap is a hip hop artist. He is one of the original members of the Black Eyed Peas. Born in the Philippines, he now lives in Los Angeles, USA. He was sponsored by the Pearl Buck Foundation which cared for children abandoned by their American fathers, and was originally brought

to the States in an attempt to treat his nystagmus. He was eventually adopted by his sponsor.

Now he is so successful he has set up a Foundation to help educate deprived children, and hopes to extend its work into the Phillipines.

<http://globalnation.inquirer.net/diaspora/view/20080331>



Allan Pineda.
Apl.de.Ap.

Big Walter Horton.

Walter Horton has been incorporated into the Blues Trail, Memphis, Tennessee. Said to be the best blues harmonica player ever, Horton had nystagmus, and was nicknamed Tangle Eyes, or Shakey, because he had a head shake. He played with many solo artists and groups including Muddy Waters and Fleetwood Mac.

He died in 1981 in Chicago.

Two of his grandsons were at the dedication.

<http://www.commercialappeal.com/news/2008/jun/21/big-walter>

From the archives 1.

<http://homepage.ntlworld.com/r.e.brennan/fullindex> is about the Pontypool Hospital Project. It tells the story of the foundation of the hospital, and its association with the development, and then the decline, of the mining industry, and also has accounts of the miners who feared nystagmus.

Joe Rees held a first aid certificate, and managed to hold onto his job in tending injured miners while often the miners themselves were made redundant. Regulations said that there had to be one first aider to thirty or forty miners. Joe himself developed nystagmus and had to leave the mines. However his experience got him a job at the hospital where he was in much demand to give miners injections, because they wouldn't let 'a slip of a girl to see their bum'!

From the archives 2.

This article is drawn from the forum at www.nystagmusnet.org, and is a tribute to an extraordinary man. Amy wanted his story to be shared.

It is by AFK from Colorado, USA.

I wanted to tell you about my father, who had nystagmus from birth – I hope that some of you may find hope and light in his story. My father passed away two years ago at the age of 82. He was an amazing man. He was raised in a small coal mining town in West Virginia, during the Great Depression.

My father's condition was immediately obvious and familiar in the family as my great, great, grandfather also manifested it, but it was relatively unknown to the medical community and unfamiliar to the folks in his home town. He was legally blind, with 20/200 vision corrected. He was extremely intelligent and was fortunate to have a mother who advocated for him throughout his school days—she got him glasses at an early age, and made sure that his teachers understood his condition.

He didn't seem to suffer socially, although he was somewhat shy with women. He had one embarrassing tale related to his vision from his childhood, but mostly stories that he found funny (like when his best friend tried to teach him to drive).

At any rate he went to college. His mother, ever the advocate, took the train to his college to insist that they give him a reading lamp as they told him he could not have one, and he could not study without one. He received several graduate degrees, and became the theological librarian at Duke University. He retained this position for more than 50 years, and developed the foremost theological collection in the country, acquiring over 100,000 volumes. And he read them all. He used a magnifying glass, his glasses and had a bright light, and still squinted.

In mid career he was awarded a Ph.D.

His condition was all that he had known, so it didn't bother me. If someone dropped a tiny object he would say 'Trust the blind!' He'd get down on the floor and find it. He loved watching football, equipped with binoculars, and was a phenomenal photographer.

As a teenager I occasionally used his poor vision to my advantage when he found me in a place where I wasn't supposed to be. If I stayed very still he wouldn't notice me.

Only in his final years did his vision limit him. He became unsure of his steps. My mother was his love and constant support. I miss him every day and am so proud of having him as an example of facing adversity.

I now have a daughter who is ten, and there is the chance that I have the carrier gene and a chance that I have passed it along to her as well. She adored her Granddaddy, as he did her, but I would hope that genetic testing would reach the point that it could more accurately detect the presence of the carrier gene for this condition by the time she considers having kids.

Thank you.

Amy

Thumbnail: Paul White.

Hi all

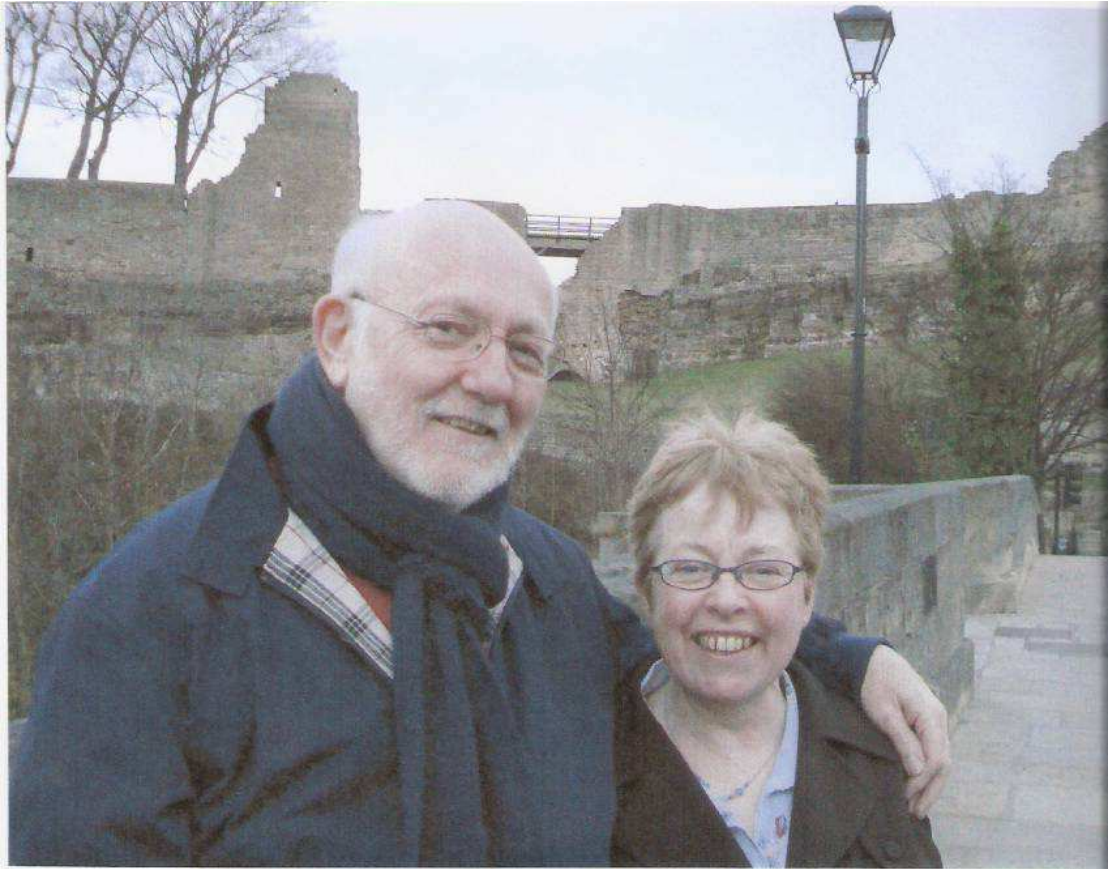
I have had the pleasure of working part time for NN since April 2003. I must admit that, being a slightly older than Cliff Richard, I was a little surprised to get the Information and Development Manager job. But, touch wood (I'm holding a pencil), I am in good health, though not as fit as Sir Cliff, and have been able to really enjoy the work. As a young man I had a number of occupations including Merchant Navy apprentice and woodworking machinery salesman, but in 1968 I settled for the teaching profession and stayed there until my retirement. I taught in schools, colleges and latterly in adult education. Adult education was my favourite phase of education and teaching pottery my favourite subject area.

Here is a picture of two of my pots.



I live in a Lincolnshire village, - very tranquil, with one school, one church, two pubs, one corner shop, and a very good butchers. Barbara, my wife, has recently retired from teaching and we are hoping to do a bit of travelling here and abroad, by train and boat wherever possible. We have two adult sons, both of whom have CN, one still at home attending University, and the other working full time in Teesside.

Here's a picture of Barbara and me in Barnard Castle recently. We went by car.



The End.

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And Finally.....

Listeners to **In Touch** on Radio 4, will have heard Peter White on his China travels.

This has been particularly rewarding for Chris McMillan of NN because she heard friends from her charity ChinaVision during the programme on blind radio, and one of them directed the programme itself. It was exciting to hear how significant the contribution of the charity is to the visually impaired in China.

www.chinavision.org

Any contributions or feedback on the netletter would be welcome at netletter@nystagmusnet.org. The final date for contributions for the next issue August/September 2008 is 25th August.

I would like to thank Amy, Andy, Chris, Claire, James, John, Pam and Paul for their considerable contributions to this netletter. Any errors are mine.

Kathy Williams
Editor.

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