

Nystagmus Network (U. K.) Netletter, August/September 2008.

In this issue.

Although this is a double issue, it doesn't have double the content. Sight issues have been relatively quiet during the Summer, apart from the news about Lucentis, a treatment for wet macular degeneration disease, although details are still to be finalised.

The Open Day was a great success, and the NN stand at the Birmingham Sight Village proved an effective tool for meeting current members, enlisting new contacts, and receiving appreciative comments from specialist VI teachers on the usefulness of NN materials.

Arrangements for the Research Seminar/Workshop are advanced, so now is maybe the time to go to the home page of www.nystagmusnet.org and donate through the JustGiving link.

The new term in school and University poses more challenges, particularly because funding is getting tighter, funding agencies less generous, and the fight for equal access is fiercer. That is one reason why the advocacy partnership which NN is considering is so crucial.

Elsewhere the theme of The Book continues in 2008, the Year of Reading, and the Chinese connection is strong.

I do respond to feedback, which is why this edition of the netletter is in 16 point Arial font. Send any feedback or contributions to netletter@nystagmusnet.org.

The October deadline for contributions is 15th October 2008. Photographs are welcome.



The President of Nystagmus Network with her son, Sam, at the 2008 Open Day.

Congratulations.

City Synergy, a sports and social club for vision impaired people in the Brighton and Hove area, was delighted to receive an award as Charity of the Year (2008) from the local newspaper, **The Evening Argus**. The group has been going since 2002 and provides a varied programme for blind and partially sighted people of all ages.

On the presented plaque the citation read, "With hundreds of citations all vying for our money, it is difficult to choose which to support. But in City Synergy it has a gem".

Nystagmus Network member Paul Gillett said "We are absolutely thrilled and this award is a tribute to all our members and volunteers."

The group would warmly welcome any NN members who might be interested in going along to City Synergy.

www.citysynergy.org.uk

A new term.....

If you have asked for support for your child in school **do** ask the school or the class teacher to confirm that promised services are in place. Similarly any Fresher at University needs to remind the departmental secretary of his/her needs. Information does not always get through. Be assertive and check that any arrangements that have been made are viable. A CCTV reader needs to be portable, and any lecture notes that are to be transferred to a laptop, require that the appropriate technology is in place.

It may be necessary to insist that any handouts are re formatted in the appropriate font. It is not convenient to try to handle 'stuff' blown up onto A5 sheets. Make the disability officer your friend. Most are aware of mobility problems but may need sensitising to the needs of a VI student.

Ask for support in handling library technology. You may need support in addition to the general student orientation. Check on the University website for other opportunities to make your life easier. It may be that the University arranges for student support workers to walk over the campus/site to help you familiarise yourself with the routes that you will use. If this is not possible, remember to allow yourself time to do 'practise runs' so that you are comfortable that you can find your way around.

Visit <http://www.skills.org> which is a website for students with disabilities, promoting opportunities for young people in post-16 education. **SKILLS** is currently looking for 16-25 year olds to join a Steering Group, and an Information Development Group.

Advocacy.

At the NN Committee meeting of 13th September 2008, representatives of NEAP, the National Educational Advocacy Partnership, attended in order to explore the ways forward for NN in relation to the training and provision of volunteers in this area.

Any such service would be free to parents.

The support that Paul White, Information and Development Manager (info@nystagmusnet.org), has already provided, has proved invaluable in providing evidence to be used to support a VI child, and her parents' claim for formal recognition of her needs.

NN will take the Network's involvement further, initially by being represented at the NEAP Conference at Moorfields Hospital on 18th September.

(For an entertaining and insightful view of early motherhood with nystagmus, read **A Wobbly Introduction to Motherhood in Focus 79 Summer 2008**).

The Null Point

A social worker has commented that it is particularly difficult to get a Disabled Living Allowance for children with nystagmus. Assessors seem to think that if a child has a

null point, then their sight is fine. There is ignorance about the condition, even among some workers in the VI field.

Oliver Jones' Dairy.

(The implications of some of these nystagmus experiences are encountered in Oliver's diary).

Saturday, August 2

Isobel next door knocked at the door this afternoon. Could I help her son-in-law unload a couple of canoes from the roof rack of his car? Isobel's about four foot nine and her daughter's not much taller. She told me that height was a definite asset for this task. Sounded easy enough, so I said yes. Got outside to find that he'd only just bought the canoes, and had never unloaded them before.

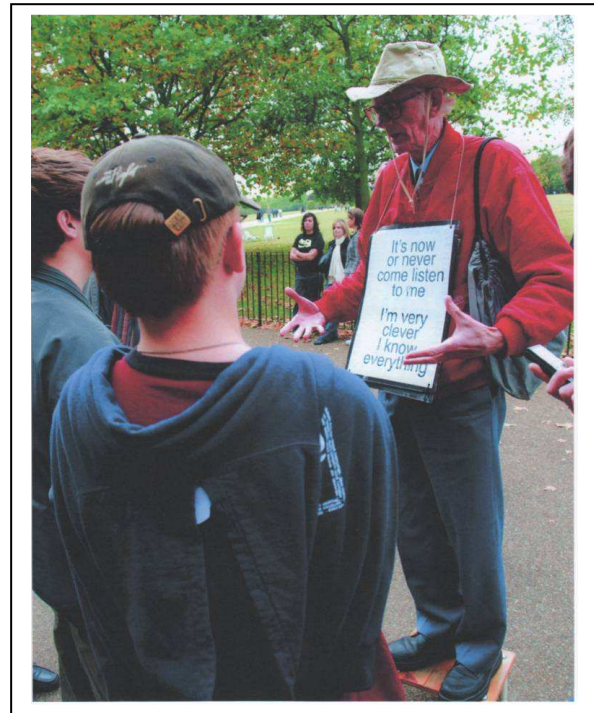
Twenty minutes later, both of us were still struggling with the strap buckles and I was reminded of light bulb jokes- as in "How many Californians.....?" Of course it didn't help that I couldn't really see what I was doing. And the harder I tried, the less I saw.

He eventually loosened a strap, and we got the canoes down, but not without me nearly dropping one. Carrying them into the garage involved much manoeuvring through the garden around pots, plants and other paraphernalia. I was convinced I'd kick something over. I've noticed that other people seem able to see everything around them at the same time. But if I concentrate on looking where to put my right foot, for example, then I'm very likely to barge into something with my left elbow.

So, next time someone knocks on the door asking for a favour, maybe I should mention my sight as well as my

height? Trouble is, they'd probably think that I was being lazy and rude.

Research Workshop.



'I'm very clever. I know everything!' Oh, no, he doesn't! So many things about nystagmus are yet to be discovered.

NN has gained funding from the RNIB and Guide Dogs to help fund the exciting research workshop/seminar in September 2009. NN is contributing a further £10,000.

Some thirty experts from around the world have been invited so donations towards the remaining £10,000 are

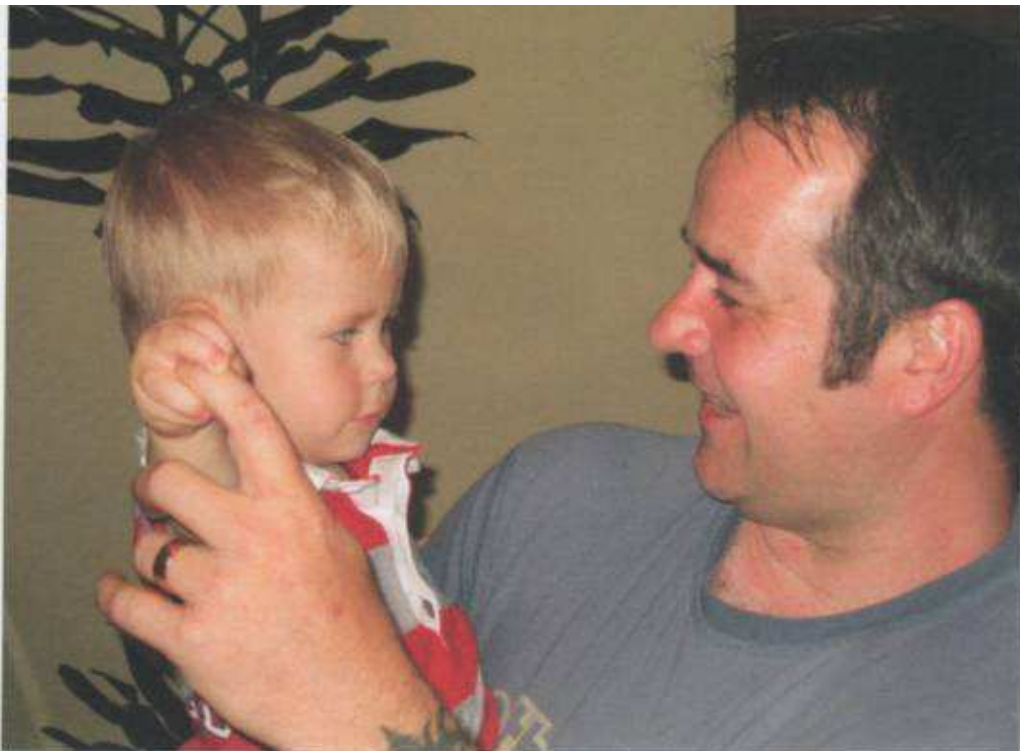
still required and you can donate by visiting the JustGiving link on the home page of www.nystagmusnet.org

Arrangements are well ahead of schedule for this exciting and necessary development in NN's work, and research profile.

Iris Recognition.

Several members have contributed so far into the research project on iris recognition. Participation takes from 45-60 minutes, and is painless, if a little uncomfortable, and disconcerting! It involves testing two machines, to compare accuracy in recognition. Since Iris Recognition is the future in identity recognition, if you take part in the exercise you may influence the equipment finally chosen. If you would like to join the project, email shaun.leaman@rnib.org.uk

Open Day, 5th July 2008.



Father and son: Open Day

Open Day 2008 was very successful, with its mix of information for adults, activities for children, and the time for members, old and new, to meet and mingle. Some 100 people attended, -- and a dog!

Readers of the netletter may have ideas about the form such a day might take in 2009, its location and content. Please send any comments to info@nystagmusnet.org

Some Open Day Impressions.

Attendees. Smiling faces and happy people. Relieved parents on seeing adults with nystagmus. Longstanding members, new parents and new adults,---including at least one who'd only recently found out about NN. .

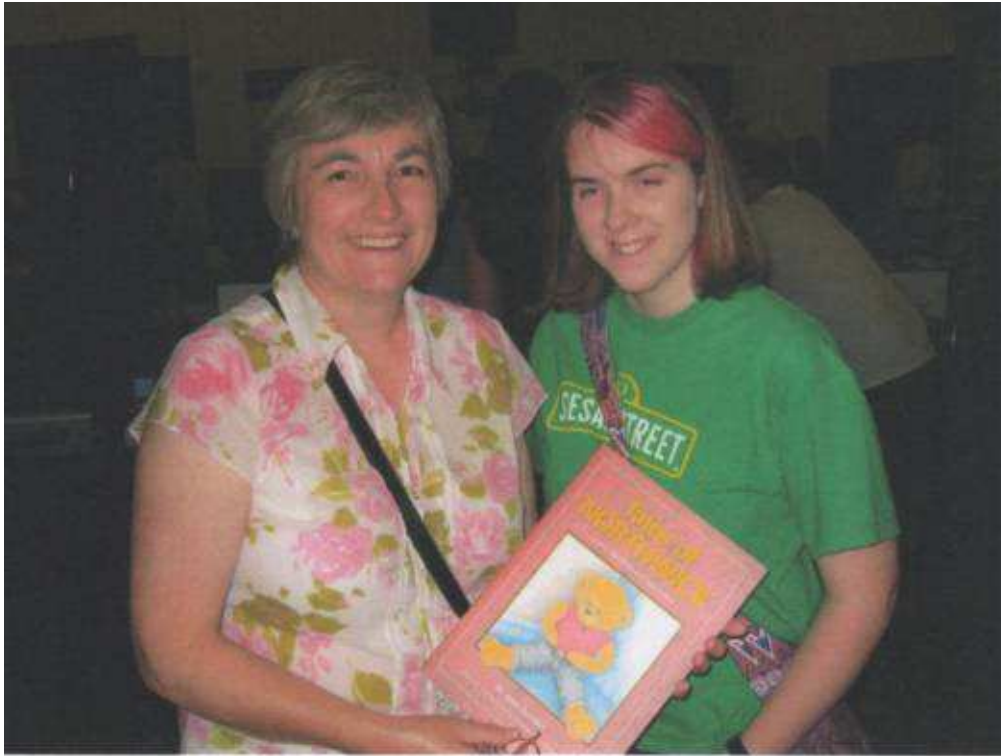
Informed. One mum is a pharmacist so was well versed in some of the issues surrounding drug trials such as dosage, availability of drugs for trials. One dad worked in Health and Safety, and pointed out that everyone's sight deteriorates on hearing a fire alarm. (Debbie Wiggins was talking about her stress research at the time).

MORAL- everyone should pay attention to fire evacuation notices, but VI people even more perhaps.

Experiences. Post code lottery: in terms of both educational and medical support. Some people reported excellent support and information from, for instance, St Thomas's Hospital in London. Others talked of zero

interest from the local VI support unit, even though their child had more than just nystagmus.

Sight Village.



Mother and Daughter with nystagmus at Sight Village.

This was held in Birmingham from 15th-17th July 2008. It is a huge event in every sense with exhibitors from voluntary associations, charities, and suppliers of aids and equipment for the visually impaired. For anyone with nystagmus, the lighting and 'busyness' of the venue, made for a challenging, but exhilarating experience. NN had a stand next to the Albinism Fellowship, and one satisfying aspect of the Sight Village was being able to share experiences with other exhibitors. There was also a great sense of co operation and shared endeavour.

Many specialist teachers of VI children visited the stand. They said that more than 50% of their children had nystagmus. They were very appreciative of NN literature, especially the nystagmus simulation decal on the front page of **Early Onset Nystagmus**.

Would any members be interested in forming a group to support fathers of newly diagnosed children? One teacher thought that this was a significant gap in support.

Teachers and members of NN, both parents and children, called at the stand to express their appreciation of NN and the last Open Day.

Membership packs were distributed, and useful links were made. Two hospital optometrists said that they would be happy to receive referrals, and Dawn Hartgen continues to offer support for those claiming DLA. So far all the claims that she has made on behalf of NN members, have been successful. A long time member of NN who now works in employment matters with the RINB, Dawn will forward information from a new project that she is developing to NN.

Rosie Howell, a teenager from Cambridgeshire, has nystagmus, and runs her own radio show for Girl Guides, **Surprise Yourself** on Cambridge 209 radio.

If you missed this Sight Village, the next one will be held in London at Kensington Town Hall on Tuesday 4th November. It is organised by Queen Alexandra College, Birmingham, and sponsored by View Plus Technologies. Andy Machin will be on the NN stand and will be very happy to see you there.

Inclusive Fitness,

One caller at the Sight Village NN stand was Michelle Dent of the Inclusive fitness Initiative (IFI).

The IFI is designed to support the fitness industry to become more inclusive.

It is designed round four key areas.

- Accessible facilities
- Inclusive fitness equipment
- Staff with appropriate skills
- The development of inclusive marketing strategies.

Anyone wishing to find out more can email Michelle on michelle@inclusivefitness.org .

Is your local authority leisure centre user friendly for the visually impaired? Are timetables available in large print? Are pathways and instructions in a clear format? It is not enough to be referred to a website which is of little use when it is impossible to find changing lockers, or the way to and from the pool, or even where the changing rooms are. Have you encountered prejudice along health and safety lines if you have made your impairment known?

RNIB

Pam Jarman represents NN at the RNIB Assembly. At the last Assembly the Chief Executive of RNIB, Lesley Alexander, said that there would be a further lobby of Parliament on 15th October in relation to DLA (the Disabled Living Allowance). 2009 will be the bi-centenary of the birth of Louis Braille, and this would be used to mount a strong campaign about the lack of Braille books, and teachers of Braille.

Fazilet Hadi gave an update on the Vision Strategy. Each organisation needs to campaign for its implementation.

It is possible that the EU will reduce the VAT on audio books.

See www.rnib.org.uk and follow the links for documents.

Vision2020.

Vision 2020uk continues to campaign for the implementation of the Vision Strategy world wide. A list of events and courses, and library resources in the UK may be found at www.vision2020uk.org.uk

Sir John Major is currently one of Vision2020's Global Ambassadors, and has recorded videos to support Vision2020's aims.

The second Thursday in each October is World Sight Day. This year this is 9th October. The theme is **preventing blindness especially among the old**. Information about the organisations that make up Vision2020 world wide can be found at www.vision2020.org. If you would like to contribute to the Vision 2020 newsletter, the email address is communications@v2020.org

Inspirations.

The website of Douglas Sidialo of Kenya calls him **The most Celebrated Blind Cyclist and Mountain Climber in Africa!** He is also a motivational speaker and raises money to help the visually impaired. He was the first blind African to climb to the summit of Mt Kilimanjaro. He has cycled across 10 African countries, during the Tour d'Afrique, covering 12,000 kilometres in 95 days. As a result of the publicity associated with the ride, a friend donated 50 cycles for the use of visually impaired children in Kenya. He is a UN Ambassador for Safer Cities.

Molly Clairemont of Zane Trace High School, Ross County, USA, who has nystagmus, has graduated as top student, the valetudinarian. Registered blind, she has always required an aide as she worked her way through school, and had to explain to her friends from the beginning why she had this adult 'hanging around'. Nothing has deterred her. She intends to continue with Physics, possibly double majoring with Maths at Oberlin College.

The websites.

Although James Taylor is temporarily unable to manage the website at www.nystagmusnet.org it continues to be an active tool for NN. There are to be exciting developments on the site with new shop arrangements. Negotiations for this work are advanced.

Jo-Anne Winston remains on the committee but her other commitments mean that she has had to give up her work with the shop, and Peter Leon, the Treasurer of NN has taken over that role.

Everybody at NN is immensely grateful for the long standing hard work that Jo-Anne has done for the Network.

Readers of **FOCUS 79** will know that our Italian link is moderated by Lorenzo Sutton. This is a very active and successful branch of the Network. Lorenzo is 29, has Congenital Nystagmus, works for a musical foundation, and is married to Giulia.

Nistagmo in Italia has huge social implications, because the forum members share their experience. Its success is an extraordinary achievement for one determined man!

The Forums at www.nystagmusnet.org often focus on the experiences of the newly diagnosed child, and parental concerns. The website allows communication to develop through private messages, so that there can be a level of confidentiality, and over time an ongoing relationship can develop.

www.nystagmus.co.uk continues to be very active and its forum members communicate across topics, asking for information, sharing experiences and celebrating their virtual community. For anyone who needs to find out about school experiences, rights to travel and work support, or who just wants to laugh at eccentric things that can happen to someone with nystagmus, then the forums are a delight. The last post in the school experience topic came from a high school student in New York, and proved that similar nystagmus experiences occur worldwide.

The website also responds to its members' feedback. There has been an ongoing discussion about the term 'sufferer' which most members disliked, so on those boards' members are referred to now as 'having nystagmus'.

www.nystagmus.co.uk has nearly 300 members, and is approaching 5000 posts. With all this 'bean counting' one member reflected on the number of times that his eyes have flickered....

If you visit www.bbb.co.uk/dna/mbouch, the BBC Disability website, you will find discussions about nystagmus, and may wish to post comments and add information.

Events.

Tuesday 16th September: RNIB Nottingham. Low Vision Services Day.

The Council House,
Old Market Square, Nottingham.
Nystagmus Network will be exhibiting.

Thursday 25th September: Sight NE Exhibition.
Swallow Hotel, High West Street, Gateshead.
Nystagmus Network will be exhibiting.

Wednesday 8th October: Southend Blind Society Exhibition

SAVS Centre, Alexandra Street, Southend.
Nystagmus Network will be exhibiting.

Tuesday 4th November: Sight Village, London.
Kensington Town Hall, London.
Nystagmus Network will be exhibiting.

Thursday 20th November: **Contact a Family** AGM.
Contact a Family has just launched a new image website. It includes a number of useful podcasts and more will be added.
<http://www.cafamily.org.uk/news/podcasts.html>.

Tactile Graphics 2008.

The 2008 Conference will be held at Jurys Inn, Birmingham on 3rd-5th December.

<http://netd.prg.uk/Conference/Conf2008/index.asp>

The Book Shelf.

JISC TechDis has joined forces with the Publishers' Association to provide resources which will have the potential to transform the delivery of learning materials to disabled students and staff.

Publisher Lookup UK will enable providers and publishers to source electronic formats of textbooks more quickly and efficiently. It will provide mechanisms for simplifying request, delivery and access processes amongst all sectors. Currently it provides links to 150 imprints and additional advice on making PDFs available.

www.publisherslookup.org.uk

In Touch.

Over the Summer there was an item on **In Touch**, asking for information about the availability of large print books to retail booksellers. The discussion was generated by a bookseller from Chichester, who wanted to supply books at the request of the parents of a VI child. It was difficult enough to find suppliers like Chivers, but also the search proved frustrating because such print runs were so small that only library provision was considered. Many large print books were therefore unobtainable. In the **Year of the Book 2008** there is need for better provision.

Resource Reminder.

Children's books may be found at www.calibre.org.uk Full length books in cassette or digital format, available to borrow. Tel:1296 432339

Cue and Review provides magazines on tape, including **Kerrang**, as audio downloads and through the radio button of their website.

www.cueandreview.org.uk Tel: 0141 563 0306

LOOK offers assistance and support for children with a visual impairment.

www.look-uk.org Tel: 0121 428 5038.

VICTA Children Ltd offers advice and guidance, grants for equipment, and helps set up support groups too.

www.victa.org.uk

A Chinese Link: China Vision.

A long time member of NN and contributor to the netletter, Chris McMillan, writes about the charity she set up with some friends in 1999.

China Vision is a small charity set up to form a bridge between people in the UK and China, who are concerned about improving educational opportunities for the visually impaired in the People's Republic of China.

Two immediate projects were to collect 'no longer needed' equipment such as Perkins Brailers, and white canes, and Braille material, to form a library. Currently these are all housed in our own library and centre in Beijing where a weekly radio programme, similar to our own **In Touch** is recorded by visually impaired broadcasters, and broadcast throughout China via a franchise system which currently stands at 60 or so radio stations.

'Articles for the Blind' allows us to send via air mail any materials in Braille and print over 16 point. We prefer to take out any equipment ourselves so that it doesn't go missing in the post.

Magazines serve several purposes, -- general reading practice for adults and children, points for discussion used in the radio programme, and where educational matters are involved, a fortnightly newsletter produced in mandarin for visually impaired teachers and other interested visually impaired people throughout mainland China.

If anyone has any books in Braille or large print and would like them to have a very good home, please contact Chris McMillan on 0118 926 5450, or email chris.mcmillan@ntlworld.com

Audio Books.

The numbers of audio books is growing, as is the number of publishers who produce whole unedited texts. www.timesonline.co.uk/booksfirst has a useful list of recent recorded books.

Downloading seems to be the way that technology is going. The Book Marketing Society and the **Guardian** newspaper recently drew up a list of the top 40 audio books and any of these titles can be downloaded for £7.99 at www.audible.co.uk/top40 .

The Reader.

Sony has produced an ebook reader. It hopes that this device will revolutionise reading. It is on sale at Waterstones at £199.00.

What will you get for your money?

Almost most importantly the Reader will increase font by up to three times. The page is resized so that there is no need to scroll. It weighs less than 260gms. One battery charge would allow 5 readings of **War and Peace**. One

charge gives 6,800 page turns, because power is only used for page turning. The screen is grey. It comes with a free CD with 100 classic ebooks, and the device remembers the page when you stopped reading. Non book and music files can be stored and extra capacity added by using a memory stick.

A Guide to Obtaining Textbooks in Alternative Formats.

Disability law protects disabled students, including allowing the provision of alternative formats in a timely manner.

www.techdis.ac.uk/getaltformat

Further information from Philip Pothen (JISC) on 07887 564 006.

New Air Regulations.

For ten years the European Blind Union has been working to improve travel by air for blind and partially sighted people, as well as those with multiple disabilities. From 28th July 2008 new regulations come into force across Europe. These include the requirement for staff to be trained in awareness of visual impairment.

It is crucial that the new regulations are monitored effectively. The regulations may be accessed at nfbuk@nfbuk.org

The Paralympic Games, Beijing.

Currently the UK team is lying second to China, and among the competitors is Anne Dunham, who has nystagmus and is riding in the dressage team.

The Dog Whisperer.

The Dog Whisperer notes that it is very important for dog owners to avoid eye contact with their animal while training, especially in achieving dominance. A totally unscientific sample of members on NN would suggest a natural affinity with, and success in, training dogs. Might this be the unintentional result of the problems of people with Nystagmus in achieving eye contact?

<http://nationalgeographic.com/dog-whisperer>

Possibly a Scam.

Some American parents with nystagmus/ONH have been funding trips to China for an experimental treatment which they believe will cure their children of Optic Nerve Hypoplasia, which includes nystagmus. This involves the use of stem cells. Two ophthalmologists at Washington University School of Medicine in St Louis, have called it a 'snake oil scam'.

<http://www.whatisstemcell.blogspot.com/2008/07/stemcell-shoax-chinas-cb-for-ner>

From the Archives.

Photographs of old, mouldering bottle ovens belching forth thick smoke and colliery headgears silhouetted against evening skies continue to charm history enthusiasts. But

not everybody becomes dewy eyed with nostalgia when recalling the halcyon days of North Staffordshire industry.

There was often a price to pay for having a steady job in the Six Towns,-- and some people are still paying today. A common sound in many homes was the hacking cough of a man with pneumoconiosis, variously known as potter's cough, potter's asthma, or silicosis.

In Longton asthma and consumption were widespread, whilst there were outbreaks of cholera and dysentery elsewhere. Background dust hung around factory workshops in light but deadly concentrations. The 1851 Census shows that nearly 90% of Longton potters died before they reached the age of 45, and that a third of them were dead before they reached the age of 15. Lead poisoning was an occupational hazard until 1913, and dermatitis affected potters as well as miners, although the advent of pit head baths at collieries effectively reduced the incidence of skin diseases, although nystagmus remained a distressing complaint, characterised by abnormal movements of the eyeball, usually triggered by eye strain caused through poor light.

A miner says 'Anything can be the matter with as man working in steel, just as it can with a man i' the pit: dust, nystagmus, a broken back...'

From: The Sentinel Stoke on Trent (Abridged) July 2008.

ProQuest Information and Learning.

If you can add anything to this resource about the Five Towns, email jenny.amphlett@thesentinel.co.uk

Working Can Damage your Health.

Peter Homan is a retired community pharmacist who has studied occupational illnesses, amongst them miner's nystagmus. His theory is that the darting eyes were caused by the miner having to constantly look upwards. Because of the narrowness of the shafts he might also develop miner's back, a form of lumbago.

From **The Pharmaceutical Journal Vol 263 No7076**

<http://wqww.pjonline.com/Editorial>

For a moving account of the progress of this acquired version of the disease go to

<http://www.rhondda.co.uk/disease/nystagmus> .

'The first symptom is failure of sight. Later the sufferer complains of lights and other objects dancing before his eyes. He then complains of giddiness and headache, particularly across the temples and at the back of the head, inability to see at night, and dread of light.'

Thumbnail.

Claire Entwhistle.

I have had a long and happy association with NN since the early nineties when Bill Gates changed my life by introducing Microsoft Windows. Until then I had been managing fine working as an IT database developer for a charity. I sat close to the computer and became so familiar with the screen layouts and keyboard that I could write programs without concentrating much on the screen. When all the computers were changed to Windows, I had to concentrate a lot harder and became aware that the screen was wobbling. I started to get such bad headaches and dizziness that I had to declare a problem and seek help. This led me to an assessment with the RNIB, learning the word 'nystagmus' for the first time, contact with the Nystagmus Network, and a visit to my first

Open day. The next thing I knew, I was a committee member, Treasurer, Development Worker, Vice Chair, then back to being a committee member.

At the last Open Day I was talking to the parents of a young baby with nystagmus, and trying to think how much it really affected my life. It does and it doesn't. Being involved with NN has certainly affected my life, and mostly for the better, because I've met people and found out about things that would never have come my way otherwise. There are other less direct effects. The change in my ability to work on computers for long periods gradually led to my going part-time as a database consultant and doing other things, first with the NN job, and then researching the employment prospects of young blind people in Thailand, then qualifying and working part-time as a psychotherapist. I'm now doing a Masters degree and learning to sing, but I don't think that my interest in these activities has much to do with my eye condition.

At the moment I live in London with my partner and my cat, and we have a long term dream of moving somewhere beautiful like St Ives in Cornwall (at least Steve and I do: the cat may not share the dream). But it seems that there are always good reasons to stay in London: family, friends, work and relatively good transport. My eye condition does put some limitations on where I would choose to move, because I can't drive and would not like to live somewhere where a car was essential. But that leaves plenty of lovely places. My sporting options are rather limited by not being able to follow a moving ball, but I have a great tolerance of cold water, and one of the attractions of living by the sea is the endless opportunity for swimming. St Ives has a train station and a wonderful beach.

I expect I will be back for NN committee meetings though, if the dream ever happens.

Ooooooooo0000000000oooooooooooo0

Kathy Williams.
Editor.

I wish to thank Chris, John, Paul and Pam for their contributions, and James and Pam for the technical support.