

NYSTAGMUS NETWORK (UK) NETLETTER
March 2004

Nystagmus Network Open Day and AGM 2004

We have a very full programme for our open day this year including key speakers for the morning and the afternoon, with a range of alternative activities for all ages during the day. Lunch will be available to order or you may bring your own. Further details will appear in the March edition of Focus.

Make a note in your diary now!

The date: **Saturday April 24th. 2004 from 10.30 to 4.30**

The place: **The Prince's Foundation Building,
19, Charlotte Road
Shoreditch
London EC2A 3SG**

This is a thoroughly modernised building approximately 5-10 minutes walk from Old Street Underground station. There will be a map in Focus, meanwhile directions from the station to the Prince's Foundation building are as follows,

Leave Old Street Underground station by exit 3. At the end of the tunnel turn left up the ramp onto Old Street then bear right onto Great Eastern Street. Cross the road at the first traffic lights, then take the narrow street in front of you and slightly to your right. This is Rivington Street. When you get to a cross road, turn right. The Prince's Foundation building (number 19 Charlotte Road) is a few yards down on the right hand side.

RNIB Vision 2004

The 12th RNIB Vision 2004 Exhibition is being held on Tuesday 6 April 2004 at Kensington Town Hall, London. Vision 2004 is an exhibition on education and employment issues for people with

sight problems, their families, carers and those working with them. Vision 2004 is free to enter and open to visitors of all ages! Exhibitors include technology companies, special schools and colleges, social services, voluntary societies, disability charities and well-known high street names! There will be live musical performances by blind and partially sighted people and two free workshops (details below) for blind and partially sighted children on music and art, a seminar programme on key topics as well as the opportunity to take part in a live fundraising event! Contact the Vision 2004 hotline on 020 7391 2315 or go to www.rnib.org.uk/vision2004exhibition for more information.

Art and Music Workshops for 8 – 16 year olds

Kids do you fancy taking part in Art and Music workshops in London during the Easter break?

The Ultimate Art Experience: For 11-16 year olds

Spend an afternoon with Rebecca Harris. Find out how Rebecca has become a successful artist, work alongside her and recreate one of her artworks or even make your own. Rebecca, who is partially sighted herself, creates her art through painting, sculpting and photography.

Or

The Handel House Experience: For 8-12 year olds

An introduction to the great composer Handel's house through a descriptive and sensory virtual tour, with activities. This will be followed by a singing workshop leading to a short performance, inspired by Handel's music and age.

The workshops take place at the Vision 2004 Education and Employment Exhibition on Tuesday 6 April 2004 at Kensington Town Hall, London. For further details and an application form to be returned by 24 February, call us now at the Vision hotline on 020 7391 2315, email vision@rnib.org.uk or go to <http://www.rnib.org.uk/vision2004exhibition>

The following item appeared on the Cardiff University website in February and in the Uni magazine <http://www.cf.ac.uk/news/03-04/040206.html>

Research tackles eye disorder

An eye condition, thought to affect around one in every 1,000 individuals worldwide, is being tackled by a University research student who herself is a sufferer.

PhD student Debbie Wiggins, of the University's School of Optometry and Vision Sciences, has nystagmus - an involuntary condition in which the eyes constantly move, and which can give rise to sight problems.

Nystagmus can appear in the first six months of life. This congenital form of the condition can be caused by a defect in the eye or the visual pathway from the eye to the brain, and certain types can be hereditary. Nystagmus can also develop later in life as a result of stroke, multiple sclerosis or head injury and, predominantly in South Wales, 'miner's nystagmus' was an occupational hazard of coal mining as a result of poor lighting underground.



Above: PhD student Debbie Wiggins and vice-president of the Nystagmus Network, John Sanders.

Nystagmus is highly variable, and therefore the problems associated with it can change from moment to moment. It is this

variability, particularly with direction of gaze, which Ms Wiggins will be studying.

"From the study we hope to increase our understanding of congenital nystagmus and identify new techniques to maximise the visual potential of people with the condition," she said.

Although nystagmus is not painful and does not lead to total blindness, it can affect sufferers in many different ways. John Sanders, vice president of the Nystagmus Network support group which helps those affected and encourages the search for a treatment and a cure, also has the condition.

"Sufferers like me have very poor distance vision, so most of us can't drive," he said. "We also encounter problems in everyday life from not being able to see what's going on in school very well to struggling with signs in shops, for example.

"There's currently no cure for nystagmus, but the more we discover from research such as Debbie's, the more the Nystagmus Network support group can do to help people with this complex eye condition. Being from South Wales myself, I'm particularly pleased that Cardiff University is taking an interest in nystagmus."

Ms Wiggins, a graduate of the School of Optometry and Vision Sciences, was awarded second prize in the UK-wide Naylor Award Scheme for her optometry undergraduate project, which was also based on Nystagmus.

CALL FOR VOLUNTEERS

"Treatment of congenital nystagmus with medication"
By Professor Irene Gottlob (a medical adviser to the Nystagmus
Network)
Ophthalmology, University of Leicester

We have found that medication can improve the vision in some people with nystagmus. We are conducting a study to compare the effect of two different drugs in congenital nystagmus. We would also like to compare these drugs with a placebo (pills that contain no active drugs).

We have experience in using these medications and they usually do not cause problems.

We are looking for volunteers to participate. The study lasts for about 2 and ½ months, and involves coming to Leicester 5 times for examinations. During the study, you would be taking a pill for about 2 months. Our Pharmacist will assign randomly (as in tossing of a coin) which drug you will receive and you will not know whether you will receive one of the drugs or a placebo.

We hope that this study will improve vision in some people with nystagmus, and that we may also find out which medication and what dosage is best used for congenital nystagmus.

- To take part you must be aged 18 or above.
- You must have congenital nystagmus (we are not looking at people with acquired nystagmus in this study).
- We would need to examine you prior to the study to see what type of nystagmus you have
- You must have the time to travel to Leicester on five separate days over two months.
- Unfortunately, travel expenses cannot be refunded.

This study has full ethical approval from the Leicestershire Research Ethics Committee and is jointly funded by the University Hospital of Leicester and the Nystagmus Network.

If you are interested, then please call 0116 2586291 for further information.

An article entitled 'With a little help from my friends' by John Sanders (Honorary Vice President, Nystagmus Network) was published in February by Disability Studies Quarterly (DSQ) in the US.

The February edition of DSQ considers the Disability Culture in Children's Literature Symposium and is now online at www.dsqsds.org under "current issue" link. Disability Studies Quarterly: Winter 2004 Volume 24 No. 1 ISSN 1041-5718

This collection of studies by authors from UK, Australia, Canada, Spain, and the United States examines disability in children's picture books and novels.

The aim of this symposium is to promote further study and discussion within and between those interested in both children's literature and disability studies. Individual authors have given their contact emails for direct correspondence, and an open discussion facility is available at <http://www.topica.com/lists/dcl> if required.

Please circulate this information among your colleagues and contacts in communities involved with disability, children's literature, education, social sciences, writing and publishing, and any others who may be interested. Thank you.

http://www.afb.org/dsq/articles_html/2004/winter/dsq_w04_sanders.html

Disability Studies Quarterly
Winter 2004, Volume 24, No. 1
<www.dsqsds.org>
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A Little Help From My Friends

John Sanders
Honorary Vice President, Nystagmus Network
Cardiff, UK
E-mail: johnsanders@clara.co.uk

You won't find many references to nystagmus -- the eye condition I have -- in fiction or film. When you do, they're generally negative. For example, in his novel *The Citadel*, A.J. Cronin suggests that coal-miners fake nystagmus to sign off work as sick. The few screen actors with nystagmus are generally cast as villains, almost certainly because their wobbly eyes are deemed to give them an untrustworthy appearance.

Yet books and films such as "Rain Man," "My Left Foot," "Children of a Lesser God" and the Helen Keller story often present disability in a positive, even inspirational, way. Moreover, they tend to have greater

impact than other forms of information. For example, compare the following factual description of nystagmus:

Nystagmus is a form of visual impairment. It is an involuntary eye movement which cannot be corrected by spectacles or contact lenses (Nystagmus Network newsletter).

with the opening paragraph of a story about the condition:

The school hall was spinning wildly. The floor was coming up to meet the ceiling. All four walls were going off for a little meeting in one corner, then scurrying off somewhere else, now they were flying through the roof. The windows had crashed into the doors and were racing around the room in different directions. The lights were bouncing off the window panes and having a party somewhere behind Frank's eyes (Tales of Northwick, p. 29).

All The Lonely People

For disabled people too, sharing experiences is important. Reading, seeing, or hearing about how others live with the same challenges can help overcome feelings of isolation and loneliness. The following comment is typical of the responses to *Tales of Northwick*: "As a child I would have loved to have stories of a bear with wobbly eyes like mine, as I knew of no-one else like me" (email to author).

I had felt just as isolated until I became involved with the Nystagmus Network, the nystagmus support group in the UK. The group's fact sheets and information leaflets explain the practical aspects of nystagmus. However, it always rankled that I knew of no positive images of nystagmus in fiction or film. Raising the finance for a Hollywood blockbuster was a daunting task. As a journalist, the obvious thing to do instead was write.

The first Northwick story was intended as a quirky, one-off report about an Annual General Meeting for the Nystagmus Network newsletter. We know that people benefit from meeting others at these events. However, we also know that it takes a lot of courage to attend. In doing so, they are acknowledging that they or their child have a disability and that they are seeking experienced support. Consequently, my goal was to convey the positive, even exciting, atmosphere at these meetings. The last thing I wanted to do was paint a picture of a dry, tedious event dominated by formal votes, points of order and motions to the chair. It wasn't like that anyway. So, I described the meeting through the eyes of a teddy bear we raffled on the day. That emphasised both the fun element and that

the meeting was child friendly. Through the bear, I also introduced humour. That was important for me, since laughing about our disabilities helps us to get on with our lives. When visually impaired people get together, we often laugh about the problems we face. We even share that humour with fully sighted friends and family.

Paperback Writer

After that first story, encouraged by others, it was a small step to writing a story for the newsletter every three months. I stayed with children's stories because parents of children with nystagmus are the largest group within the Nystagmus Network. Nystagmus is often not inherited, so parents cannot turn to other family members for information. Likewise, most medical professionals focus on the clinical aspects of nystagmus and know little of its day-to-day impact. By drawing on my own experiences, I try to give parents and others an insight into what it's like to have nystagmus. The stories also aim to provide young children with the words to describe how they see. It is difficult for them to explain nystagmus, because to them their vision is normal.

In addition, the stories are a safe or neutral area. Parents and children can learn about and discuss nystagmus together through the characters in the stories, especially Northwick the Bear and his friend Frank. As one parent said: "Thanks so much for the stories. They have really helped Jake and I talk about things" (letter to author). That shared understanding of disability is vital to a child's development. The more the parents know, the happier they are and the better they can explain this complex condition to others. This is especially important, for example, when children start school and their teachers need to be aware of the needs of a disabled child.

The stories aren't just for children with nystagmus though. They are also useful for normally sighted children whose parents or brothers and sisters have nystagmus. They can even help adults with nystagmus, as one confided to me: "You have mentioned so many things I never knew were due to my eyes, like thinking cars were going to crash in car parks and those annoying lights on the floor in cinemas. Everyone else thought I was crazy when I asked if those lights made them feel dizzy" (letter to author).

Good Vibrations

As well as explaining the effects of nystagmus on vision, the stories address some of the social and emotional consequences of having

"wobbly eyes." Stories are ideal for this, because they offer a way of sharing and exploring experiences, including, happiness, sadness, frustration and disappointment. They also help children realise it's OK to have nystagmus. That's very important in a world where parents are often told that, because of poor vision, their child won't be able to drive, won't be able to play sports and may be limited in terms of opportunities in education and employment.

In *Tales of Northwick* the emphasis is on what we can do, instead of what we can't do. Each story explores one or more of the problems of having nystagmus, while also suggesting solutions and presenting positive images. Where things are truly difficult, such as in playing fast moving sports, the stories show an alternative, as the following comment illustrates: "I've just read your latest story to my five year old son who sat (unusually) quietly and listened to every word. Tom has nystagmus and ocular albinism and has found life quite difficult during the [2002 football] World Cup...We've all done our very best to assure him that it's OK not to be interested in football, but I think that he's still felt pretty isolated at times...Thank you for making it OK not to like football" (letter to author).

Reading Between the Lines

Finally, because nystagmus is not always an obvious disability, another aim of the stories is to show that the problems are genuine, that they are shared by others and that there are no quick medical solutions. Sometimes it's easier, or perhaps more diplomatic and credible, to get that message across in the written rather than the spoken word. Several people have told me the book is an effective way to tell their relations and friends about the condition. As one of my younger readers explained far better than I ever could: "I am probably going to get my friends to read it so that they can find out more about nystagmus without knowing it" (email to author).

References:

Nystagmus Network newsletter, April 2003.

Sanders, J. 2001. *Tales of Northwick*, published by the Nystagmus Network, Cardiff. To order a copy of tales of Northwick, please go to www.nystagmusnet.org or Northwick, 25 Pen-y-Lan Terrace, Cardiff, CF23 9EU, UK.

Other quotes are from confidential correspondence through the

Nystagmus Network.

Subheadings: With thanks to The Beatles.

Biographical note:

John Sanders was born in Cornwall, England, in 1957 and was soon diagnosed with nystagmus. It was 27 years before he talked to anyone else with the condition. Much of his spare time is taken up by voluntary work for the Nystagmus Network, RNIB Cymru and Cardiff Institute for the Blind. Sanders graduated in German, French and Business Studies from Liverpool Polytechnic in 1979. He has been a journalist, editor and translator for over 20 years, including 10 years with the Reuters news agency. He lives and works as a freelance writer in Cardiff. His email address is johnsanders@clara.co.uk.

Note: Anyone requesting *DSQ's* permission to publish this article elsewhere is asked to notify John Sanders also.

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>.

SPOKEN TEXT MESSAGES 'LIVE WITHIN WEEKS'.

The telecoms giant BT (<http://www.bt.com>) is set to launch "within weeks" a new service allowing text messages from mobile phones to be sent as synthesized voice messages to fixed-line phones.

The service represents an important breakthrough in mobile technology for the blind and partially sighted. "Until recently, SMS [the system used to send text messages] has been a no-go area for blind people," says Julie Howell, digital development policy officer at the RNIB (<http://www.rnib.org.uk>). "But if you can use a landline to receive speech-enabled text messages from mobile users, that represents an interesting opportunity."

Users with voicemail can have messages delivered directly into their mailboxes and for those who don't have voicemail, a synthesized voice will deliver the text message to them in an automated phone call.

BT Wholesale (<http://www.btwholesale.com>), the network services arm of BT, will offer the SMS-to-voice service to other fixed line and mobile operators in the UK. A number of mobile operators have participated in trials and have already signed up for the live service. "We fully expect all of them to come on board," says Andy Jugg, head of messaging products at BT Wholesale. The operators can then determine their own pricing for the service to consumers.

BT says the new service could not only benefit people with sight problems who have not been able to use SMS to date, but also business users and parents who aren't comfortable with texting but want to keep in touch with their children. "This is a great example of a technology that happens to be particularly useful for the blind and partially sighted, but also has some great mainstream applications," says Howell.

SHINING EXAMPLES:

The RNIB is inviting nominations for its 'Simply the best' awards that recognise employers, companies and organisations that have enhanced the lives of people with impaired vision. Categories include 'accessible information', including web sites, and 'accessible TV, film, books and leisure'. Nominations must be submitted by 31 March, with awards presented in May:
<http://fastlink.headstar.com/rnib4> .

ONE FORMAT:

Free 'style sheet' files that allow users of the Internet Explorer web browser to quickly and easily view web sites in their preferred colours and font sizes can be downloaded from the 'One Format' site created by Daljit Singh. The style sheets cover five font sizes, 10 colour combinations and the option to add or remove underlining and bold text; and they can be used with or instead of screen magnification software: <http://www.oneformat.com> .

FOCUS NEWSLETTER

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

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

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