

Nystagmus Network Netletter February 2008.

In this issue.

Oliver Jones is back!

The thumbnail this month is by Vivien Hepworth, who is a parent. Her son Sam is now twenty four. Vivien is one of the founder members of Nystagmus Network, a past Chairperson, and the current Hon. President. Her narrative makes a case for understanding and supporting children and parents with nystagmus but also she is a powerful advocate for a society which is much more aware of the potential there is within those who are impaired, and which may well not be exploited.

There is a poignant link with the character in the Archive slot.

Celebration....dates and festivals.

Pancake Day on 5th January; Chinese New Year starting on 7th January; Valentine's Day on 14th and then Leap Year and February 29th.

China not only has the largest population in the world but also has a very significant presentation of nystagmus especially in certain provinces. Some of this is associated with long term mining activities and there are also swathes of genetic/inherited nystagmus.

Also worth celebrating is an item on **EYESITE**. Research by the College of Ophthalmologists has found that children who wear glasses are now rarely the targets for bullies. Over a third of kids (34%) under sixteen say that their friends never mention their glasses at all, while 43% say their friends are positive about them, saying that they make them look 'clever, trendy, attractive and kind'.

EYESITE notes that this is a huge change for the better, because nearly two thirds of adults admit to being teased or bullied for wearing glasses when they were at school.

www.johnsanders.claranet/js17news

This will be of particular comfort to parents who will be sensitive to their children's handling of their nystagmus.

FOCUS will soon celebrate its first colour edition. It will certainly feature news from Debbie Wiggins on her research.

Open Day.

Open Day this year is on Saturday 5th July. The venue is Jury's Inn. Nottingham. Transport details are on www.Nystagmusnet.org, and the programme will include input from Rebecca McLean of Leicester University, and Debbie Wiggins of Cardiff University. There will be sessions on the Disabled Living Allowance and employment, with special provision for children and young people. There will be a crèche, and an exhibition of low vision aids.

To find out more on the pleasures of visiting Nottingham visit www.nottinghamcity.gov.uk/enjoy .

Website news from the Webmaster.

As the webmaster for www.nystagmusnet.org and www.nystagmus.co.uk I am finding it a very exciting time.

There are long term plans to develop online services to NN members. We have begun the initial planning of their foundation. Unfortunately there are unlikely to be any noticeable changes to the websites for members and visitors for some time because we feel that it is important to get it right first time round.

The Forum on www.nystagmus.co.uk has seen a burst of activity in the recent weeks, with hordes of posts covering a multitude of topics and issues relating to nystagmus.

James Taylor.

Website topics.

Current topics include work and allowances; drugs and operations; letter trails for identification on websites; and bullying at school. Members might find it useful to refer on the jobs front to the www.nystagmusnet.org Forum, which is a boost to the confidence of any job seeker.

Advice is particularly sought on www.nystagmus.co.uk on the problems of puberty and bullying. Apart from developing a high sense of self esteem in any adolescent together with sociability, confidence and charm, practical advice is still sought.

Nistagmo in Italia continues to thrive on www.nystagmus.co.uk

Paul White, Information and Development Manager draws your attention in particular to the Forum on www.nystagmus.co.uk and the post by Suzanne Nicol whose parents were members some years ago. Suzanne's current research will be completed in March. She is from Scotland but is studying in Sweden and is interested in the impact that different levels of light have on nystagmus sufferers. If you are interested in contributing to her research, email her through that website.

There has been a debate about whether a soap actor has nystagmus but enquiries have met with silence. Lord Croaker, however is very articulate about his reaction to joining the www.nystagmus.co.uk and sharing his experiences, especially as a golf enthusiast.

Things that have happened, unfortunate or funny and the pronunciation of nystagmus, have produced lively discussion but the topic which may be of most help to visitors to that site as well as sufferers is the topic which discusses the advantages and disadvantages of nystagmus. Disadvantages include skating into a wall, and the advantages include learning to put on mascara without looking in a mirror.

Bus Passes for local transport.

As from 1st April local transport in England will be free after 9.30 a. m. and at weekends for everybody over 60, and for certain categories of disabled users. Provision for such services has always been uneven, but in most areas travel for the blind/severely sight impaired has been free throughout the day. With this wider provision this advantage has been lost, because free travel is time restricted.

For many blind people this may well have a serious impact on their capacity to work, since they may well have chosen work and home location with free transport in mind. If travel is costed in, then the advantage of working may disappear. Your local Councillors may be unaware of this anomaly, and it is worth approaching them.

www.rnib.org.uk has also been campaigning on transport matters.

Please note that regulations in Wales Scotland and N. Ireland may differ from the English example.

Tax website.

HM Revenue and Customs are making it easier for visually impaired people to use their website. Visually impaired visitors to the site should be able to use a screen reader or voice commands.

EYESITE at www.johnsanders.clara.net/js17news

Now that you have your offer.....money.

Now that letters with offers have been coming out from UCAS, you should use www.dirct.gov.uk/en to find out about possible benefits.

These include

- Disabled Students' Allowance
- Access to Learning Fund
- Incapacity Allowance.
- Disabled Living Allowance.

Depending on the level of your disability you may be able to claim for more than one of these.

Special Needs.

The Special Needs (Information) Bill received its Second Reading on 5th February. The Bill would amend the Education Act of 1996 to place a statutory requirement on the Secretary of State to collect and publish information relating to the outcomes for children with special educational needs.

To support this Bill please email your M. P. using the following link www.edcm.org.uk/Page.asp .

Which? Interview Handbook.

For those of you who are at the interview stage of University entry or who are applying for jobs Which? at www.which.co.uk has an Interview Handbook which indicates which kind of questions may appropriately be asked of an applicant.

Conferences and jobs at
www.Vision2020uk.org.uk

Four workshops are being held in late February which will look at National Occupational Standards for employers and employees in England. CWDC are organising the events. CWDC is part of the Skills for Care and Development of the Skills Council.

26th February Novotel, St Pancras, London.
27th February Crowne Plaza, Nottingham.
28th February Park Plaza, Leeds.
29th February Jury's Inn, Newcastle.

Contact number: 0113 390 7637.

Booking form on the Library section of www.viison2020uk.org.uk

The Macular Disease Society is currently advertising for two posts. The closing date for both posts is 18th February. The first is for a Group Development Manager, the second for a Community Support Manager. The salary for both is about £30,000 and details are at www.vision2020uk.org.uk/news

8th May 2008 10.00 a. m. till 4.00 p. m.

National Children's Conference: Are Children's Standards Slipping?

At The Together Trust,
The Together Trust Centre, Schools Hill,
Cheadle,
Cheshire.

The aim of the Conference is to establish the foundations of recommendations specifically to meet the needs of children, with the theme of Standards. The morning will have presentations and groups focusing on topic areas, and the afternoon will centre on Michael Clarke, Ophthalmologist on lazy eyes and eye patching. There is a two for one offer on fees and registration details are on the website.

There is a training course before this Conference which will be held on 13th March 2008

at
Queen Alexandra College,
Court oak Road,
Harborne,
Birmingham B17 9TG.

For information email m.bairstow@vision2020uk.org.uk

Vision2020uk.org.uk Library.

The Library section of the website at www.vision2020uk.org.uk has recently acquired a range of material particularly on child eye health. February items include articles on childhood visual screening; health inequalities in eye health in the U. K.; paediatric low vision assessment and management in a specialist clinic; a review of the key literature on Primary Care Services for Children and Young people, and the provision of these services for visually impaired youngsters.

International news.

By working together eight German organisations concerned with sight created special events for their sixth **Sight Week** , to raise awareness of the experience of the visually impaired. Extensive materials, including posters, brochures and patient information, PowerPoint presentations and press releases and ideas for activities were developed and the print media coverage was 27.5 million.

Anything to be learned here?

www.woche.des.sehens.de

Calendar: Sports and Sponsorship.

27th April 2008 Rotary Shakespeare Marathon and Half Marathon

www.shakespearemarathon.org.uk

27th April 2008 Sorbothane Blackpool Marathon and Half Marathon

www.blackpoolmarathon.com

5th May 2008 Deep RiverRock Belfast City Marathon

www.belfastcitymarathon.com

10th May 2008. JUST WALK is an exciting new sponsored UK charity walk for anyone wanting to fundraise for the charity of their choice. So get the walking boots out and walk for NN on England's South Downs. Details and registration at

www.just-walk.co.uk

1st June 2008. The 2008 Great Midlands Run will be staged at Sutton Coldfield. Entry forms are available from mid February from

www.greatmidlandsfunrun.com

29th June 2008. Humber Bridge Marathon.
www.humber-half.org.uk

1st July 2008. Acorns Great Malvern Triple Run.
www.malvernrun.org.uk

Don't forget how easy it is to donate to Nystagmus Network. Just go to the home page of www.nystagmusnet.org and follow the simple links. If you are a tax payer then it is equally easy to make sure that your donation goes further. And the publicity for the charity grows!

Actionnaires sport.

With all this projected athletic activity, children might enjoy an Actionnaires project. Actionnaires is the largest national sports project for blind and partially sighted children and young people aged 8 to 16, in the U. K.

If you follow the links at www.actionforblindpeople.otherworks.com/children you will be able to find your nearest club, listen and look at videos of children and what they say about Actinnaires.

Children under 8 are very welcome as long as they are accompanied, and fully sighted siblings and friends are welcome.

Coincidentally there was an item on the Actionnaires Clubs on Radio 4, The Learning Curve, on 11th February at 8.30 p.m. Children interviewed played soccer, went swimming, and enjoyed trampolining and judo. Their philosophy was very much a 'can do' one, with the confidence gained and the enjoyment carried over into main schooling.

Listen again on www.bbc.co.uk/radio4 and follow the links.

The Primary Club.

Anyone who listens to Test Match Special on Radio 4 long wave will have heard of the Primary Club which is open to any cricketer who has been out for a duck. Andrew Strauss is President of the Junior Primary Club.

What may be less well known is the work that the Club does in providing sports facilities for schools and clubs for the visually impaired all over the country. Grant applications are straight forward.

One of the biggest projects has been the gift of The Golden Duck, a converted canal boat to the London Society for the Blind. 12 children and their carers can stay for overnight trips. It puts fun and excitement into the children's lives. On a smaller and rural scale a riding stables in Warwickshire provides classes for 12 young riders on a four day dressage course. Other activities include swimming, drumming, fencing, go carting, obstacle courses, soccer and, of course, cricket.

More information at www.primaryclub.org/clubprojects

Books and Reading.

The Talking Bookshop in Wigmore Street, London, is an audio bookstore solely for audio formats.

Contact frances@talkingbooks.co.uk
www.talkingbooks.co.uk

Naxos Audio is expanding its audio range and has very moderate prices with good quality recordings, including entire texts.

www.naxosaudiobooks.com has a large catalogue and books are available to be downloaded as MP3s.

Book Reviews.

Out in paperback this month is

Simon Ings **The Eye** Bloomsbury £8.99 .

The book is not for anyone with a good grasp of the 'science' of eyes but it is an energetic and easy to read social history of the eye. History, zoology, mathematics, folklore and fact is included. He's obviously a doting father, and his asides are irritating but this reader found some insights into her nystagmus for the first time, which made it very worth the read.

Stuart Clark **Vanities of the Eye** Oxford University Press £35.00 is an altogether heavier book, taking as its theme the idea that since the Renaissance the eye has been assumed to see the truth of what it observes. Clark disagrees, and argues both for the primacy of sight but

also that this misunderstanding has led to the linking of seeing and understanding/intelligence. A hard read but heartening

Podcasts.

In the month of pancakes it is interesting to note that a pancake mix which is supposed to be good for you is the sponsor of the podcast of News from Lake Woebegone by Garrison Keiller.

(www.prairiehome.publicradio.org) His voice is as mellow as ever.

In contrast there is a site for all those who have never seen their eyes flicker. This is an ongoing topic on www.nystagmus.co.uk Forum. It is not for the squeamish because the first item is a surgical procedure and the examples of differing nystagmus movements are probably quite extreme. You have been warned!

www.youtube.com/watch?v with links to ORLivedotcom.

Computer Problems?

Enitan Ajayi at Computer Care People Help (CCPH) is at hand. This service is dedicated to helping blind and partially sighted people with training, suitability of software, compatibility of support equipment, and anything else to do with computers.

Contact: www.ccph.co.uk

Telephone: 07939 133406.

Looky and Optelec

For those who are feeling affluent, then consider one of the new mini CCTV readers now available. These function as magnifiers but also give greater freedom in focal length adjustment, and allow frames to be frozen so that information can be read which would ordinarily be inaccessible. Both these models are compact and very easy to use.

The Looky weighs only 200 grams, the picture is always sharp and can be in colour, black on white or white on black, and the handle folds away. The model comes complete with its battery charger, and the angle of the handle enables the viewer to use it to write.

The screen is 3.5 inches, and magnification is between 3x to 8x.

The cost is £400.00.

www.vanlentsystems.nl/Looky/rehani

The Optelec Compact+ has variable magnification up to 10x optical zoom. It views in full colour and has a wide range of reading contrast

modes. It also has freeze features. It was launched at the 2007 Sight Village and won the Independent Living Award.

The cost is £440.00

www.optelec.co.uk

At the other end of the scale Waterstones is now selling two devices from

www.ifUK.co.uk

The first is a bookmark with an inbuilt magnifier, the Mangif-i at £1.99

And a magnifier with light which takes three AAA batteries with a 3x magnification is £3.99.

Now you see it, and now...





It is sometimes difficult to explain that sometimes there can be too much information for a nystagmus sufferer, and reflections and the sun low in the sky in the Winter can make life challenging.

In contrast there is no indication of step edges or of the drop involved in the picture below. Vertigo ensues. Aesthetically pleasing rather than nystagmus/visually impaired user friendly.



Driving.

The debate about driving, and in particular with an optical aid continues. Information on standards is available at www.direct.gov.uk/Motoring/DriverLicensing/MedicalRules.

The Netherlands is the first EU country to embark on research into assisted driving. There appears to be a very low causal relationship between visual acuity and road traffic accidents. Research shows that drivers can use a monocular effectively after training. Subjects in the Dutch research had visual acuity between 0.16 and 0.5. A battery of tests was carried out on volunteers, and the final 19 were taught to use a monocular (3x), and they were then tested under the official protocol. Over 50% of the selected subjects fulfilled the inclusion criteria. This success has led an Advisory Committee to publish a report for the Secretary of State for Transport to ask for a change in driving legislation.

Contact [www.visio.org\(nw\)](http://www.visio.org(nw)) for information. The results of this research were published in Spring, 2007.

From the archives.

Cisco Houston (1918-1961)

“Cisco Houston’s dead and gone.
Left me here to sing this song”.

“I remember his humility, his easy smile, his seagoing stride, the strange look of his eyes.” Bill Wolff.

In the Depression in Los Angeles Cisco Houston joined a theatre group which considered itself anti fascist, playing guitar, singing and acting and meeting Will Geer, an established actor. Together they ‘discovered ‘ Woody Guthrie, and took off for the migrant worker camps in California. Later they worked in Manhattan singing in anything from union halls to nightclubs. They went to sea together in the Merchant Marine before Pearl Harbour, and during the War were torpedoed. Cisco went back to sea on his own and was torpedoed twice more. He had tried to enlist but was turned down because of bad eye sight.

His friends did not realise that Cisco was virtually blind, and colour blind but also suffered from “a tragic, incurable condition called nystagmus”. Some thought Cisco absent-minded. Others thought that it was due to shyness, introversion or reserve.

Bill Wolff reports that Cisco was well read but could only read with the book held at an oblique angle and in dim light. When he acquired special contact lenses he was able to walk about with confidence. He knew that his nystagmus was both inherited and congenital and both his brothers had the condition.

(Source **Cisco Houston – the End of the Road** by Bill Wolff based on a series published in the bulletin of the Los Angeles Folk Music Society in 1961)

www.ciscohouston.com/essays/bill_wolff_on_cisco

Oliver Jones’ Diary Part Two.

Saturday, January 12, 2008.

Got stuck in the usual traffic jam on Balham High Street this evening-- reminded me to ask Emily about drivers waving to pedestrians across the road. She said that drivers did it all the time, but it was no surprise to her that I couldn’t see them. When I asked why, she went a bit coy.

Eventually admitted that she had apologised to several neighbours.

Seems that they think I am rude for not returning their cheery waves as

they drive past. Clearly never occurred to them that not everyone has 20/20 vision.

Tuesday, January 29, 2008.

Apparently epilepsy is a problem when looking for work because if you have fits then you can't drive. That's what some expert said on the news this morning anyway. Strange how people don't always make the link between driving, work and nystagmus.

Saturday, February 2, 2008.

In two minds about applying for a job with Bull Brothers. Still in derivatives settlements, but looks more interesting than current job with CSNY. Possible project work to analyse cause/effect of failed settlements. And more spondulicks. On the other hand could be risky moving now given the market jitters -- and there's the issue of eye contact if I get an interview.

Thumbnail by Vivien Hepworth.

It was after my son Sam was born that I embarked on a journey of discovery about nystagmus. I suppose that you could say initially a journey of non-discovery. When a problem with Sam's sight was diagnosed at 15 weeks, my husband Ian and I could find hardly any information of use. It was dreadfully upsetting as our minds wandered over all sorts of possibilities and we could get no answers. It was nearly another two years before our son's eye condition was diagnosed properly- he has cone dystrophy which means that he is acutely light sensitive and has little or no colour vision.

Getting a diagnosis did at least mean that we were able to provide Sam with highly protective dark glasses-- he walked outside in daylight for the first time at 23 months, a moment I will never forget. Up to that point the light sensitivity meant that he was effectively blinded in daylight yet very clearly sighted indoors.

From then on the road got easier. We were given very good advice by the Institute of Optometry, then Guy's and we were also extremely well supported by our local opticians who made special glasses for Sam.

I suppose that you could say that everything was transformed by the arrival of tinted contact lenses when Sam was six or seven, and for the

first time he went out without people asking him why he was wearing such dark glasses.

Sam is grown up now-- 24 years old! I have learnt so much over the years, including the fact that most people with visual impairment learn to conceal them so effectively that most people don't realise how significant they are. Sam has been to University, and now has a good job. He cycles to work every day. I don't want it to sound as if everything is now easy-- it's not like that in life generally, for anyone, and those with a disability face a permanent daily challenge. When do you tell future employers about the issue? How will they respond? What support is available?

I feel very strongly that getting more awareness of how people with disabilities can work effectively and to their full level of ability is still desperately needed. For employers it is an area that they know relatively little about and are uncertain how to help. I think that there is so much lost potential in the world from those who would love to contribute if only society, - us - , would make it easier for them to do so.

The first meeting of NN was at the end of 1984, when Sam was just a year old. I remember it very clearly, not least because of the relief I experienced at meeting others with nystagmus and hearing first hand how they handled their jobs, - and their lives! Many had had struggles, but they had also battled through them, worked through education, got interesting and good jobs. It helped me more than I can adequately express. It geared me up for some of the battles we were to face with Sam's education a bit later. I should add, however, that Sam's education was well supported by our local authority. I worry now that parents are facing a harder time as provision and expertise fragment.

As for me, well I am not sure what you would like to know! After many years as a journalist I went into business and I now run a public affairs business, Grayling Political Strategy. I do have other interests. I am a member of the Press Complaints Commission and I have recently become involved in a local charity. (I live in Lingfield, Surrey), which looks after retired clergy. Variety is the spice of life! Ian and I have another son, Max, who has just graduated, and started work. He is still at home, and we see Sam most weekends.

The job keeps me busy, - I am based in London but at the time of writing I have been dispatched to Graylings' Hong Kong office for three weeks! This is giving me an entirely new perspective on everything! Of all the

things in my life I would have to say that NN has given me more than I could ever describe.

Vivien Hepworth.

Feedback and Contributions.

Please send contributions and comments to netletter@nystagmusnet.org by 7th March 2008.

Late News!

FOCUS 78 update!

LVAs for children.

Debbie Wiggins's stressful research.

An NBCS case study based on their work with a teenager with nystagmus,

Northwick and more.....

Kathy Williams

Editor

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