

Nystagmus Network Netletter (U. K.) April 2008.



April 6th 2008.

In this issue.

Not many Spring stories, then!

At the national level the Vision2020 Strategy will be launched on 18th April, and NN will be well represented. Much effort has gone into the production of this document, and the Launch programme indicates that there will be further discussion of issues. There has been enough talk, and what is needed now is commitment from not just health professionals and service users but a political will at local and national level. There has to be a recognition that, with an ageing population, there is a need for increased finance.

On April 23rd **The Guardian** is producing a supplement on vision matters.

Oliver Jones is back and the thumbnail this month is of Andy Machin. You may not be familiar with his name but he is the hero who sends out mailings, Focus and all the Christmas cards. Members of the Committee recognise and admire his dedication.

The Archive section returns to Chris MacMillan who was featured last month, to her school days and the history of Exhall Grange School, Coventry, which was an excellent school, largely boarding, for the visually impaired.

The websites have been extraordinarily active. Open Day details are available on the Home page at www.nystagmusnet.org and www.nystagmus.co.uk has a forum offering insights and comments on a wide range of matters nystagmatic.

There has been some very good news about the proposed Research Seminar in the Autumn of 2009, and with at least one very generous donation. Donation information is on the home page of www.nystagmusnet.org

Oliver Jones' Diary.

Tuesday April 1

Well, I'll never know about the Bull Brothers job now. Who'd have thought a blue chip bank like that could go belly up? Not sure how CSNY will weather the credit crunch, but no-one seems too worried at the moment.

On the way into the office this morning someone thought that I was playing an April's Fool joke. I went to pass him on the left, but he moved in the same direction. I apologised and went right, but he went the same way again and so on several more times. Mentioned it to Em this evening. She says that it can be difficult to know which way I am going sometimes because of my eyes and how I look to one side.

Amazing story on TV about penguins migrating from the Antarctic to the Brazilian Rain forest for the summer. Or was it the winter?

Want a Career as a Health Professional?

The University of Birmingham Post Graduate Medical School, Wolverhampton Campus, is requesting applications for a new course for Physician Assistants. This is a new healthcare role.

Assistants will support G.P.s in the diagnosis and treatment of patients. The course will last two years, and candidates who apply before 30.05.08 and are successful will be given a book token for £200.00.

(www.medicine.bham.ac.uk/phyass.shtml)

Achieve Vision.

The British Olympic Association has appointed Sherylle Calder as its 'vision enhancer' specialist.

Sir Clive Woodward employed Calder while he was in charge of the English Rugby team, and has persuaded her to Britain again. She initially noticed that although Lawrence Dallaglio had worked hard on his weight training, no one had bothered with his eye muscles. 'Nothing', she pointed out, 'can happen on a sports pitch until the eyes have done their work'. It is necessary not only to see but to absorb and react to this information.

For the BOA she will work especially with Kelly Sotherton, and the badminton pair Nathan Roberts and Gail Emms. Calder noticed a flaw in Sotherton's binocular vision, which in part explains her poor javelin performance, because she has problems focusing on the target for her intended throw.

Calder has also worked generally on improving depth perception in athletes. Her input is vital because she not only improves the athletes' eyesight but also their self confidence.

A Blind Photographer.



This extraordinary picture was taken by Bruce Hall of Irvine, of a Garibaldi fish on a kelp bed at Santa Catarina Island, USA. Bruce is legally blind and has nystagmus. He is able to see only things very close to him. He uses a very wide angled lens and views the results of his pictures by using a computer screen. His enthusiasm started when he was a child and he has built up a formidable body of work.

His work is featured at
<http://sciencedude.freedomblogging.com/2008/02/09/legally-blind-photographer>

His website is www.visualsummit.com

All Children Have Different Eyes.

Edie Glaser and Dr Marai Burgio have co authored a book of this title which deals with a variety of eye conditions which may lead to low vision in children. Ms Glaser is visually impaired and Dr Burgio is a child psychologist and they have addressed issues through telling the stories of Tommy and Wendy, who encounter problems like not being able to share a book in class, or being asked to get glasses that work.

Children as well as their parents want and need to know as much as they can about their sight. The book is being used in the States for visually impaired children, but also as a whole class reader, so that the understanding of other children is enhanced. The book is aimed at the 4-8 age range.

Details of the book are at www.lowvisionkids.com

There is also a free teachers' guide and a hand/eye coordination game.

The Eye Patch Kids.

This is a DVD aimed at young children and aims to make patching as much fun as possible, and may help frustrated parents cope with their children's resistance. It stars puppets and the creator, Kelly Harmsen, a parent of a son who was very resistant to wearing his patch, was inspired by seeing a pirate in a cartoon wearing an eye patch.

The DVD sells world wide. Although so far it is only recorded in English.

See www.bjortandcompany.com

<http://brightyeysnews.wordpress.com> hosted by Dr Bonilla-Warford is an interesting mixture of news, features, interviews, and narratives.

The site currently includes information about children who need bifocal, or reading glasses.

And Babies.

Lucy Cockroft in the **Daily Telegraph** of 04.04.08 reported that Professor Michael Belkin and Dr Yossi Mandel of Tel Aviv University have completed a very large scale study which indicates that babies born in June and July have a 24% higher risk of serious short sightedness than those born in December and January.. Genetic tendencies are accepted as the prime factor but light exposure after birth proves to be significant. Belkin says 'More sun equals less melatonin, equals a longer eye which is short sighted.

Results were adjusted for other known risk factors such as gender, education level and father's country of origin.

The findings are published in the April 2008 journal **Ophthalmology**.

And Teddy Bears.

Paddington is 50 years old in 2008. Michael Bond, who wrote the Paddington books, plans suitable celebrations, aided by Jeremy Clarkson, whose mother created the first and definitive Paddington prototype. In **Paddington here and now** the bear will be interviewed about his immigration status.

This story was featured in the **Guardian** of 2nd April so it may be that the paper missed April Fool's Day on the immigration story.

Northwick

But how old is Northwick?
And when is his birthday?

Revisiting Synaesthesia.

The March netletter introduced the topic of synaesthesia. Synaesthesia is a condition where an individual, who may be blind, colour blind or have limited vision, can 'hear' colours, and may attribute colours to voices, and music. The artist Kandinsky was one of the first to try to systematise the meanings of colours and their musical notes.

Dr Oliver Sachs has written about this phenomenon in 'The Case of the Colour Blind Painter' in **An Anthropologist on Mars** published by Picador in 1995. Although no longer in print it is still available in some shops.

On a lighter note Stuart Pawson in **Grief Encounters**, 2008, Allison and Busby, discusses the idea in a crime novel.

Voice recognition by a blind woman has been used in identification by reference to the 'colour' of the speaker's voice.

Art/Music.

Do you think that there could be a link between nystagmus and visual impairment and artistic and musical talent?

The netletter has already recorded the large number of American musicians with nystagmus.

The following sites allow a glimpse into the worlds of other artists and musicians who have nystagmus.

www.ulmer.nl

Alain is a French speaker who has congenital nystagmus and is a photographer.

Padraig Naughton is a tactile and visual artist working in Ireland.

<http://touchart.com/index.html>

Helen Thomas works and exhibits in England.

<http://www.toastedorange.co.uk/Painting/Pages/approaches.htm>

Janos Solyom is a concert pianist and conductor living in Stockholm, Sweden.

www.solyom.com

Role Models.

You and Yours, Radio 4 on Good Friday, featured an item on role models in children's literature for disabled children. The strand of discussion went on into the next week, although most examples suggested were from adult literature. John Sanders was able to access the programme makers in order to highlight our own Northwick.

Richard and Judy.

A Richard and Judy Book Club choice guarantees considerable table or shelf display in Waterstones. Patrick Gale's **Pictures in an Exhibition** is one such book. However his publisher, Flamingo, has been encouraged to re-issue some of his earlier novels including **Little Bits of Children**. One of the central characters is a blind girl called Iras. She is a very positive child, and her treatment in the novel allows for a discussion in VI terms of being special, and gifted, as well as the question of identity.

Reading Through Audio.

This initiative embraces several charities which provide services for the visually impaired. A website currently gives information for professionals working with the sight impaired. It is currently in development and offers links to other sites.

A new leaflet **Carry on Reading** from the RNIB is due out.
www.readingthroughaudio.org.uk

Word Up Campaign.

At a time when Libraries are under great pressure, it is good to hear of the initiative of Barry Library in South Wales. Their intention is to spread awareness of the book reading access facilities available to visually impaired people. The scheme has been so successful that it is being rolled out through other Libraries, culminating in Cardiff in May.

Not only are books made accessible but some 18.000 CDs are available for borrowing. In Cardiff there is also a service for the housebound.

From 7th-20th July 2008 there will be the seventh 'Make a Noise in Libraries' fortnight which will aim to bring libraries and partially sighted/blind people together to exchange information and improve access to books.

The Housebound Library Service: 029 2076 3849
www.cibi.co.uk

For anyone experiencing problems with Library access, or even recognition of needs, this item may be of use in illustrating what a positive approach can achieve.

Ricability

This website gives information about aids and assistive technology. All assessments are carried out by disabled users. **What's New** can be accessed by phoning 0207 427 2460, or by emailing mail@ricability.org.uk

Postage

Postage rates have gone up again, and you may wonder who may use the 'Articles for the Blind' service.

A printed or handwritten label on the front must say 'Articles for the Blind'. The sender's address must be on the reverse of the envelope. Institutions serving the blind may send material in at least 16 point.

For individuals the same font size applies. Either sender or receiver must be registered as sight impaired. Additionally those whose close up vision is N12 or less may use the service, again if the font size is appropriate and necessary.

Thinking of a Holiday?

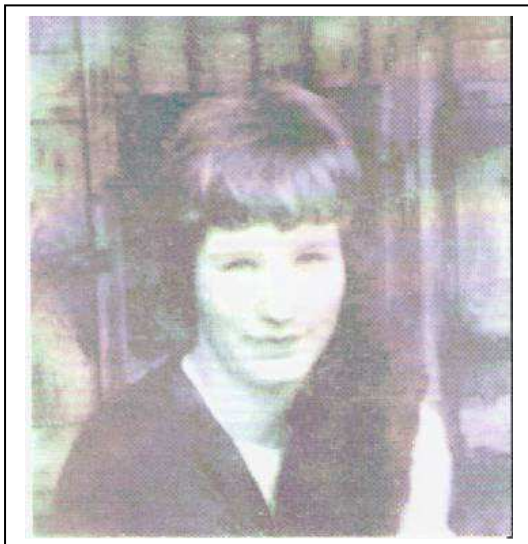
The Royal Blind Society organises 3000 holidays a year for people with a visual impairment. Carefully selected hotels offering top quality facilities are located in Newquay, Skegness, Bridlington, Blackpool, the Lake District and Scotland. Twelve 'researched' hotels in Jersey and Guernsey offer inclusive travel and accommodation guaranteeing a good holiday.

Contact Peter Hards 01827 722 574
www.royalblindsociety.org

Out of Sight-Out of Mind.

This service offers practical help for those searching for work and with a visual impairment.
0121 428 5037.

From the Archives.



Chris MacMillan
(nee Howman)

aged 17
photo probably
taken by Willi
Hamerton in 1969.

Chris is holding Erissa, a black lop rabbit.

Chris writes of her time at Exhall Grange School

‘We had a collection of animals to look after: rabbits, guinea pigs, guinea fowl, mice and a whole lot of aviary birds, including the most glorious golden tailed pheasant.’

‘The rabbit that I am holding was one of two really placid Black Rex. She hadn’t a bad thing about her.’

‘Like most teenage girls I was mad about some sorts of music, and a friend who came to stay with me was mad about Marianne Faithful. Somehow we discovered where Marianne’s mum lived, in the next road to my grandparents with whom I was living because my mum had died.

‘I met Marianne a few times in the next three years and the rabbit was called Erisa after her mum who was a real life Baroness. My family didn’t really agree with this sort of friendship: to them show biz was ‘bad’, so a rabbit with a history.’

Chris was at Exhall Grange, then a large boarding school for visually impaired children, during the reign of George Marshall, the first charismatic and challenging headmaster. He made a great impact on the welfare of the visually impaired nationally. There have only been three head teachers during the history of the school. This history reflects the different thinking about teaching children with special needs, and their increasing inclusion in mainstream education. The school was the first special school to gain specialist science status and now caters for a wide range of disabilities and multi disabled children, nearly all local to the Coventry area.

www.axis.co.uk/24979

home.clara.net/jwardell/

This is the contact page for old students and provides a fascinating social history of the school. You can compare the life of Chris and her friends with the video clip of the first Exhall Grange Prom in 2007.

Calendar: Sports and Sponsorship.

27th April 2008 Rotary Shakespeare Marathon and Half Marathon

www.shakespearemarathon.org.uk

10th May 2008 Sorbopthane Blackpool Marathon and Half Marathon

www.blackpoolmarathon.com

10th May 2008 **JUST WALK** is an exciting new sponsored UK charity walk for anyone wanting to fund raise for a charity of their choice. So walk for NN on England’s South Downs.

www.just-walk.co.uk

1st June 2008 The 2008 Great Midlands Run will be staged at Sutton Coldfield. Registration forms at

www.greatmidlandsrn.com

29th June 2008 Humber Bridge Marathon

www.humber-half.org

1st July 2008 Acorns Great Malvern Triple Run

www.malvernrun.org

Now donate to NN. Just go to the Home Page of www.nystagmusnet.org And follow the simple links. If you are a tax payer then it is simple to add to your donation at no extra cost through Gift Aid.

Research Workshop/Seminar.

Plans for the workshop continue, as do our efforts to raise the funds necessary for this dynamic project. While you can donate to the general NN fund, using the links above, you can also give to the Workshop directly. If you intend your donation to be for the Research Seminar then make this clear when you donate. Please indicate if you need a receipt.

Childhood Cataracts.

A group of parents and friends have set up a very impressive website. Its members include all those with an interest in childhood cataracts, including those who are now young people, or adults, and it encourages the involvement of health professionals.

The aim is to be the best and most accessible hub possible through the website. Currently there is no organisation which supports this group.

<http://www.childhoodcataracts.org.uk>

Training.

Readers may be interested in the free Certificate in Interpersonal Skills being offered by the University of Wales, Lampeter. This is a distance learning opportunity. It is free at the moment as long as applicants are not already studying for a degree or higher qualification. The course is fully assessed, not by formal examinations, and the start date is monthly. The course is fully accredited and may lead to a B. A. degree in Voluntary Sector Services.

<http://www.volstudy.ac.uk>

Events.

9th - 13th June **Seeing Better, Ireland.**

- 10th -11th June **DSC Charity Fair**, Central Hall, Westminster.
- 13th June **Low Vision Exhibition** Westland Leisure Complex,
Yeovil.
- 14th June **Together with Vision Support Day.**
Welsh College of Horticulture, Northop.
- 19th June **Vision2020uk Conference.**
Details www.vision2020uk.org.uk
- 28th June - Wednesday 2nd July.
World Ophthalmology Congress, Hong Kong.

Genetic Interest Group.

Dr Amy Hunter has emailed NN to ask anyone who is concerned about the Human Fertilisation and Embryology Bill, currently going through Parliament, to consider whether they might like to give their views to their M. P. The Bill will allow further research into embryonic stem cells research to proceed, properly regulated. There is considerable pressure being applied about certain aspects of the Bill, and this group is anxious that the rights of the patient are kept uppermost.

You can go to www.theyworkforyou.com and click on 'Your MP' or contact GIG at www.gig.org.uk

Websites.

Both websites flourish, and in particular the Forum elements. www.nystagmusnet.org receives many requests for information, especially from the newly diagnosed. The Forum on www.nystagmus.co.uk has almost exploded with posts! The webmaster of both is working under great pressure to respond to all the posts. His update says that there have been 3,000 posts so far. There were 1,000 posts in the last two months. The webmaster is interested in finding out how everyone found the website, and what they think of it. Please respond. Both sites are being regularly updated.

The quality of the content of both Forums is very high. As a resource of information, narratives on nystagmus experience, and reflections on those experiences, the Forums provide a vast resource. The May netletter will attempt to address some of the issues raised during the last year. The contributions of regular posters is much appreciated, and the amount of effort and research that goes into

their replies to requests for information makes a real difference to the quality of life on others with nystagmus.

Thumbnail: AndyMachin.

I was born on 10th December in 1947 in Stoke-on-Trent, Staffordshire. My parents soon spotted that there was something wrong with my eyes because they wouldn't stay still.

By the age of eighteen months, the condition had been diagnosed as Congenital Nystagmus. My parents knew nothing of the condition and it is no exaggeration to say that my education suffered badly. Not only did my parents know nothing about nystagmus or understand it, but neither did any of the teachers I encountered.

In 1961 I started my working life training to be a butcher., and after some years I joined Dewhursts, the Master Butchers. I was then working long days but gaining experience in window dressing and eventually into shop management.

In 1968 I took on the management of my first shop in Crewe, Cheshire.

In 1971 I joined Kew House Retail, the retail division of Crossfield and Calthorp, as manager of one of their ninety shops, and in 1972 became training manager for all ninety shops working from Walsall.

1975 found me working in West Somerset for a very large retail and catering butchers. During the next few years my eyesight increasingly affected my working life and problems emerged such as reading orders written down on paper.

When computers were introduced they proved an additional challenge, and the world of butchering became very difficult for me, but it was also an infection picked up from pork bones, as well as my poor eyesight, that ended my working life as a butcher.

Being sick and not now able to work, I had spare time on my hands that I could put to use. I then found the Nystagmus Network, and in September 2000 I started posting out all the printed copies of **Focus** to our members. Since then I have introduced the tape version and two versions of **Focus** on CD. Most of our literature has been transferred onto tape or CD for members preferring that format.

2005 brought about big changes to what I do for NN. I took over the ordering and sales of our Christmas cards. This work has brought great joy to me, as I know that every pack of cards sold helps to bring in much needed money to help run such an organisation as Nystagmus Network. I am looking forward to breaking all records this year with the possible addition of the two new designs I hope to bring in line for Christmas 2008. Finally one more sales push. If you would like to raise more money for the Network, then you can always purchase our splendid Northwick greetings cards from me at any time. Just send a note with your requirements, and payments made to Nystagmus Network to

Andy Machin
99 Park Barn Drive
Guilford
Surrey GU2 8ER

Cards are £3.50 for a pack of five which includes postage in the U. K.
Alternatively you can order from the website
<http://www.nystagmusnet.org>
All orders will be dispatched by return post.

Andy Machin.

And Finally.

Thanks for contributions go to Andy, Chris, James, John, and Paul.
For the enthusiasm to stay motivated thanks go to Forum members Larry,
Victoria, Sofie, Emma, Tom, Tony

The final date for items for the next netletter is 6th May.

Comments and feedback to netletter@nystagmusnet.org

Kathy Williams
Editor.