Then and Now

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- Conference photos
- Research update – Wiring of the eye
- Brand’s Hatch Driving Experience
The conference more than lived up to my expectations on a personal level. It was so good to catch up with old friends and make some new ones. For new families I know the prospect of meeting so many new people can be daunting, but I hope it was worth it. The feedback was overwhelmingly positive, but we value it all. We reviewed a summary of the evaluation comments at the trustees meeting in January, as we are always seeking to improve what we do. Do let us know if there is something you wish to see included in the next conference programme. For example, Richard Orme’s ‘The Wealth of Possibilities’ was a new type of session that was especially valued and we will be seeking to build upon this in the future. We also discussed the feedback from the Dream Big session at the conference. This feedback will be helping us form our longer-term strategy for developing what the Fellowship should be doing in the future.

The photographs from the conference on the following pages tell a story in themselves. Look and you will see cool teenagers looking like they belong in Rock Band, children playing together, and adults of a similar age just sharing time together. Then there are the drummers who may be viewed in a video on the Facebook page. Our Facebook presence on the Internet is developing fast, and whilst it is perhaps not for everyone, many do value it highly. It’s the sharing experiences that bring people together and the value of our conferences in giving individuals a sense of belonging cannot be underestimated.

The more astute of you will already have realised that Bryony and Daisy have grown up. The iconic little girls of our posters and ad stand are no longer so little. (Front Cover photos) Magella Neveu in collaboration with Professor Glen Jeffery from Moorfields has kindly written an article covering their research on the anomalies of the wiring of the albinism eye. It is written in an accessible style of layman’s terms for us, no easy task, and we thank them kindly.

Sam tells us how contact lenses have helped her horse-riding, and closer to home for me, Karina has written about her driving experience at Brands Hatch. It was at Miles Hinton at our conference in Harrogate who encouraged us all to step out of our circle (or comfort zone). I never imagined I would see my daughter driving a car; it was a moving experience for both Karina and her parents!

If you have a story of someone stepping out and doing something unusual, please do tell us and please include a photograph, we love photos. If you aren’t too confident with typing or telling the story, we are only too happy to write it for you. Such tales are designed to give inspiration and aspiration to others who may get out there. It is about cascading the knowledge and experience for families.

When I look back upon the development of the Fellowship and the way in which people interacted and shared experience at the conference, I know the efforts of the conference team were worth it.
Conference 2009

There was mask-making and African drumming, discos and parties...

“I found it a wonderful experience and wished I’d done it before.”

The kids went on several outings. Seaworld was thoroughly enjoyed along with a ghost hunt around the town.

“Dear all, I would like to say a huge thank you for the fantastic conference. It was perfect for me and my daughter and we had a great time. Thank you for the amazing organization, it was like clockwork. We enjoyed everything from the workshops to the food and have met so many interesting and informative people. I have come away feeling renewed and refreshed and very hopeful about my daughter’s future.”
“it was a wonderful experience and it was beautiful to watch all the children playing together and for once being the majority instead of the minority, will certainly be attending again”

Great friendships were renewed and formed between old and young.

“It was well worth travelling from Ireland to attend.”

“What an incredible bunch of confident, happy, well adjusted young people”
"I really enjoyed the conference. I have come home much more assertive!!!!"

It was a privilege to once again have our great friend Rick Guidotti with us taking some fabulous photos and boosting everyone who walk in front of his camera’s self-esteem by the bucketload!
Albinism, can we make the connection?

Moorfields Eye Hospital in collaboration with Professor Glen Jeffery at the Institute of Ophthalmology have carried out a number of research studies to help gain a better understanding of the underlying causes of the visual problems associated with albinism. A few of these studies are detailed below.

In albinism the nerves that connect the eye to the brain are wired incorrectly at the optic chiasm (Figure 1). Normally approximately 50% of the nerves from one eye connect to the same side of the brain and the remaining 50% to the opposite side of the brain. In albinism however almost all nerves from one eye connect to the opposite side of the brain (Figure 1).

Albinism is also associated with other abnormalities in the eye that stem from a lack of pigment at the back of the eye. Retinal blood vessels which would normally be obscured by pigment are clearly seen (Figure 2). The central part of the retina, called the ‘fovea’, which is used for detailed vision, does not develop properly (Figure 2).

**Figure 1** The nerves that connect the eye to the brain.

**Normal**: Nerves originating from the left side of the eye (blue line) connect to the left side of the brain. Nerves originating from the right side of the eye (red line) connect to the right side of the brain.
to the left side of the brain. Nerves originating from the right side of the eye (red line) cross over at the optic chiasm and connect to the right side of the brain.

**Albinism:** The majority of nerves from both sides of the eye (blue and red lines) cross over at the optic chiasm and connect to the opposite side of the brain. The squiggly lines at the bottom of the figure are the VEP signals that we record from both sides of the brain.

**How do we test for misrouting of the nerves in the brain (optic chiasm)?**

A test called ‘visual evoked potentials’ (VEP) enables us to assess how the nerves from each eye connect to the brain. The subject is asked to look at a pattern or a flashing light and we record the signals from the brain using small electrodes placed on the back of the head. The squiggly lines at the bottom of Figure 1 show what these signals look like. They are similar to ECG signals that are recorded from the heart. When the nerves are connected correctly the responses from both sides of the brain are similar. In albinism the response from one side of the brain is much bigger than the response from the other side because most of the nerves from one eye go to only one side of the brain.

**Figure 2: Photographs of the back of the eye.**

**Normal:** Photograph shows a dark area in the centre called the fovea and normal pigment in the retinal pigment epithelium.

**Albinism:** Photograph shows the lack of a fovea (no darkened central area). The back of the eye lacks pigment and blood vessels which are normally obscured by pigment, are visible.

**How do the nerves from one eye know which side of the brain to go to?**

When the nerves from each eye travel towards the brain they meet in the region called the optic chiasm. Research studies on animals have shown that when a nerve from one eye meets a nerve from the other eye they ‘talk to each other’ and this
'conversation' helps to determine whether the nerve will go to the right side of the brain or to the left.

Q. What happens when there’s only one eye and the nerves from that eye don’t have nerves from the other eye ‘to talk to’?

When the animal is born without one eye the nerves from the remaining eye all cross over to the opposite side of the brain.

Q. What happens to the nerves in humans who are born with only one eye?

We recorded VEPs in individuals who have a disorder called anophthalmia. These individuals are born with only one eye, therefore they only have nerves from one eye passing through the optic chiasm. The VEP responses from left side of the brain were similar to the responses from the right side of the brain. Therefore the nerves from one eye were still travelling to both sides of the brain. This suggests that the nerves ‘know’ which side of the brain to go to and they are connected correctly even if there is only one eye present at birth. Therefore in humans, nerves from one eye do not need ‘to talk to’ nerves from the other eye to connect to the brain correctly.

Individuals with a disorder called aniridia also have a poorly developed central retina. The iris in these individuals does not form properly, but they have normal levels of pigment in the eye and the skin. When we compared the VEPs from individuals with albinism with VEPs from individuals with aniridia we found that VEPs from individuals with aniridia were completely normal. Therefore a poorly developed central retina does not necessarily lead to abnormal connections between the eye and the brain. The abnormal nerve connections in albinism therefore are not caused solely by poor development of the central retina.

Do the abnormal connections between the eye and the brain in albinism affect the structure of the visual part of the brain?

We know that in both albinism and aniridia the central part of the retina called the fovea does not develop properly. We performed MRI scans (Magnetic Resonance Imaging) on these individuals and compared them to MRI scans from individuals with normal vision. This study was carried out in collaboration with Professor Anthony Morland at the Royal Holloway Hospital.

The scans from individuals with albinism and aniridia showed that the visual part of the brain (located at the back of the brain) is structured
differently to individuals with normal vision. This is shown in Figure 3. The visual part of the brain in individuals with albinism and aniridia was shorter compared with individuals with normal vision. We believe that the poorly developed central retina causes this abnormally shortened structure of the visual part of the brain in albinism and aniridia.

What does this all mean in terms of what individuals with albinism can see?

Individuals with albinism often have abnormal eye movements called ‘nystagmus’. Amazingly the brain adapts out the effects of the eye movement and a ‘stable’ world is seen, rather a ‘moving’ one.

Figure 3: MRI brain scans from individuals with normal vision (top, red), albinism (middle, green) and aniridia (bottom, yellow). The graph shows the length of the visual part of the brain for these three groups. The visual part of the brain in individuals with albinism and aniridia is shorter than in individuals with normal vision.

Q. How do individuals with nystagmus see moving objects?
We carried out a study to examine how individuals with albinism view moving...
objects. We compared results from individuals with albinism and nystagmus to individuals with albinism but without nystagmus. All subjects were asked to look at small objects moving in the horizontal or vertical direction. Individuals with albinism and nystagmus found it difficult to distinguish the movement of small objects, whereas individuals with albinism but without nystagmus could detect these small movements easily. Both groups of subjects have a lack of pigment, hence the problems that individuals with albinism and nystagmus have with detecting moving objects is primarily due to their nystagmus. Although their world is ‘stable’ they may have difficulty following ‘a fast moving ball’.

THANK YOU!!

We would like to say a huge THANK YOU!! to all members of the albinism fellowship who kindly volunteered for the numerous studies detailed above... we greatly appreciate their willingness to spend hours and hours looking at squares, circles, flashes of light and many other weird and wonderful things... thank you!!

Magella Neveu
and Glen Jeffery

Articles


Early midline interactions are important in mouse optic chiasm formation but are not critical in man: a significant distinction between man and mouse. Neveu MM, Holder GE, Ragge NK, Sloper JJ, Collin JR, Jeffery G. European Journal of Neuroscience. 2006 Jun;23(11):3034-42.


Forthcoming Events

Watch out for these events – full details on the website www.albinism.org.uk

**London BBQ**

Saturday 5th June 2010 11am - 4pm

Our normal format of food, fun and friendship at Oaktree School, Chase Side, Southgate, N14 4HN

Bring something to barbecue and a salad or pudding to share.

Nearest tube: Cockfosters. Parking on-site.

**Belfast Event**

Saturday 5th June at RNIB, 40 Linenhall Street, Belfast BT2 8BA.

**Dublin Event**

End of June – watch the website for details

**5 Shires Event**

Saturday 3rd July, 2010 1-5pm

St David's Centre, East Street, Moreton in Marsh, Gloucestershire, GL56 0LT

Speaker (TBA), tea and cake, raffle and informal time, outside play area. Parking. Train station direct from London (Paddington), Reading, Oxford, Malvern, Worcester and Hereford.

For more information contact Sarah 01608 812378
email: ws.fellows@virgin.net

Moreton in Marsh is a pretty Cotswold market town with cafes, antique shops, a park. It is 5 minutes by car from Batsford Arboretum. 10-15 minutes from Stow on the Wold and Bourton on the Water. Why not make a day of it.

**Christmas Party & AGM**

Saturday 4th December 2-5pm

Caversham Heights Methodist Church, 74 Highmoor Road, Reading, RG4 7BG

The Website

If you haven’t been recently it’s well worth a visit to our new-look website. It has had a makeover and now has regular updates and news of events – look out for LifeTech – a new experimental video podcast from the Albinism Fellowship. In each edition, we will be looking at a selection of 'gadgets' and the accessibility features that they provide for people with albinism or other low vision conditions.

In the first edition, Robin Spinks examines the accessibility features of three modern smartphones and a look at the iMagnify application for the iPhone 3GS, which uses the phone's camera to turn it into a portable magnifier.
Contact Lenses

My daughter Charlotte has just been given contact lenses to try and is really enjoying the freedom of being able to do horse riding without glasses and I think it will really help her at school with sport, the contact lenses are slightly tinted to help with glare and the eye hospital has suggested that she uses glasses just for reading. With the help of a magnified mirror she is even able to put them in by herself.

Celia Nickson

Thank You’s

It is appropriate to acknowledge here and write a big thank you to Children in Need who gave us some money towards the conference childcare.

The Website run by Martin Lewis also gave us a donation to help us with the conference last November.

Thank you to everyone who has paid their subs this year. Those of you who pay by standing order need to know that we have had to close the accounts that take standing orders. Some of you will have had letters to say that the standing order didn’t go out (those of you with very old standing orders to the Bank of Scotland). Anyone else who is with the Abbey will find that if they do not stop the standing order your subs will not go out next year January (2011). We are still having difficulties setting up a Direct Debit Facility and still looking into ways to do this. Hopefully there will be more news of this later on this year. Meanwhile you can always send a cheque or better still, if you wish to do it on-line use www.justgiving.com/albinism please make sure to declare for giftaid if you pay tax.

Don’t forget to use Justgiving if you do any fundraising for us too!

From the email

John turned "50" and ran the "Great North Run" in September. To celebrate his birthday he asked friends to sponsor him on behalf of Albinism Fellowship. They generously donated £760. I’m sure the Fellowship will put it to good use.

Regards Lorna, John, Rachel & Hannah Mess

Well done, John - eds

Sam & horse
Sighted People

“Just to say a big thank you for giving me so many hours of pleasure. I truly don’t know how I would have coped with my loss of sight without National Talking Newspapers and Magazines.”

Noreen Gill, subscriber

There’s a whole world of news and entertainment at your fingertips, thanks to a unique charity, National Talking Newspapers and Magazines.

The charity offers access to more than 200 popular newspaper and magazine titles in a variety of accessible formats. Titles cover a wide variety of subjects and interests – from Readers Digest to Woman’s Weekly, The Wisden Cricketer to BBC Gardeners World, Private Eye to People’s Friend to name just a few. This large range of titles means that there’s something for everyone. As listener, June Dobbin, explains: “I thought my world had come to an end when I lost my sight. Through your readers I can keep in touch with fashion, love stories, cooking etc all which I enjoyed when sighted.”

In addition to audio CDs and tapes, National Talking Newspapers and Magazines also offers publications in digital full-text format. So, if you own a computer and screen reading software, this service enables you to access the full-text of up to nearly 100 different publications. So whether you have a tape cassette player, CD player, MP3 player or a computer, you can access the printed word easily and quickly, listening at a pace that suits you.

Most titles are recorded in the charity’s studios in East Sussex, where a small army of 200 volunteer readers give a voice to the publications. All recordings are made digitally and are ninety minutes long. In an average week some 100 different publications are recorded in seven studios, five days a week for more than 6,500 listeners across the UK and abroad.

Recording the Talking Articles

Publications are offered on an annual subscription basis. Prices start at just £11 per year for a monthly publication on audio CD or tape. If you would like to take out a subscription or learn more about the range of publications available from National Talking Newspapers & Magazines, please call 01435 866102 or email: info@tnauk.org.uk

A free catalogue and a sample recording of the publication of your choice is also available.
After my surprise 18th Birthday present from my parents, I was officially allowed to comment on my dad’s driving and in passing conversation could say “Three-point turns are easy!” This was because my parents took me to Brands Hatch, the race track, so that I could drive a car.

Legally I could never drive a car on the road in the UK as my eye sight is too poor. It never really bothered me until I was about 17 and all my friends were having driving conversations, which I could never add to, because I had no experience of driving a car. As of now, I do.

My parents had pretended were going to visit family friends, and that we had got lost, so my dad had to stop and ask for directions. I had just woken up, looking around and said “Hey there is a massive bit of tarmac that would be so much fun to drive on.” To which my parents said “You are!” I don’t think I have ever woken up that quickly before in my life.

We got out of our car and walked over to the area where this event was happening. It was arranged by group called Action for Blind People. They have driving experience where blind and partially sighted people could drive.

It turned out I was going to be driving a BMW 1 series, so a pretty nice car, as far as cars go. (Dad has not driven a beamer, so I was already one up on him!) I got in the front seat with a huge grin on my face, hands on the steering wheel, instructor on one side, who did have control just in case, and just turned the key in the engine.

There were three in our group and we swapped around. We started with a quick lesson in what each of the peddles do and then from there we processed to drive around the track. In
and out of cones, three-points turns, reversing. Reaching speeds of 40mph. By the end of the 3 hour session, I had mastered the gear change, and the unique relationship between the clutch and the accelerator.

Meanwhile my mum and dad stood on the side taking pictures to prove I can actually drive. The photo is me with the car I drove.

The driving experience is worth doing, and comes highly recommended from me, for anyone that wants to know just what driving is like. I know I will never be able to drive legally on the road and I have expected that since I was little, but just knowing I can drive without stalling, it still something to be proud; to me it is like passing the driving test.

Karina Lang

Dad writes.

We had always told Karina from a very young age that she wouldn’t be able to drive a car. My wife and I felt it better that way, rather than have her dreams shattered later in life. At Legoland, young children can get a ‘driving licence’ and I remember saying, half joking so her, that it will be the only driving licence that she will ever get. I wanted it to sink in at an early age. So she had grown up with the realisation that there are a few things that won’t be possible; airline pilot, driving licence in the UK at least, being two of them. As parents we recognised that the lack of driving experience meant that she was ostracised from conversations. You can’t expect, nor would want her friends to have a taboo subject of driving around her. I searched for possibilities like airfields, deserted car parks, trading estates, and considered isolated rural roads a quiet Sunday morning so that she might have that everyday experience to share. I had discounted all of the above, not just because of the illegality, but the safety as well. It was then that I discovered the Action For Blind People scheme that gave driving experience for Blind and Partially sighted people. Karina’s driving experience cost £80 and was worth every single penny. She now comments whenever I scrunch the gearbox, since she now understands what I have done wrong, and I have to wince at the criticism, but I wouldn’t have it any other way!

If you would like to have a similar driving experience contact:

Action for blind people
Part of RNIB Group

Action for Blind People
RNIB Group
105 Judd Street, London, WC1H 9NE
Text Telephone: 020 7874 1314 prefix with 18002 for hearing caller
Mobile: 07908 527468 (Text only)
Fax: 020 7391 2195
www.actionforblindpeople.org.uk

Martin Lang
Drummond: Conference quote…
“I am familiar with the Snellen Chart but I can’t say I’ve ever seen it”