

Events Photos – London & Five Shires



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Editorial

Those of you who have attended the Site Village Exhibition in Birmingham in July will know its value and I have commented on my day out. The Fellowship had a stall at this event for the 3 days of the exhibition. It was important for the Fellowship be seen as at this event as it was an ideal opportunity to maintain and raise our profile within the community we serve. A milestone of service has been notched up over the pond by our sister organisation in the United States. NOAH (National Organisation for Albinism and Hypopigmentation) who are celebrating their 25th anniversary on the 3rd November 2007. We have sent a letter of congratulations to them which I understand will be in their newsletter. I am sure they would welcome any individual birthday wishes even if they are a little late for the day. I remembered to send an email on the day to their website and perhaps you might like to send them one sometime too! We wish them well in their endeavours in helping people with albinism.

If inspiration was ever needed, you may have heard about our friend Miles-Hinton Barber who has addressed and inspired us on several occasions at conferences. To quote the Times, the 'blind British adventurer made a victory pass over Sydney Harbour this morning after flying more than halfway around the world in a microlight aircraft to raise funds to fight blindness in developing countries.' There he goes again 'stepping out of his 'comfort zone' circle'. Of course this is something that

we should all do once in a while. Inspiration in this issue of our magazine is provided by twelve year old Katie in the gymnastics arena and Sean O'Cathain who has cycled hundreds of miles and raised thousands of Euros in sponsorship. If you are a cyclist why not join in on 27th April for our sponsored family Bike Ride fun day out. We will not be going as far as Sean! And Julie Genders tells of her exploits, circling the Isle of Wight in a sailing boat with the Rona Trust. This 'can do' philosophy is admirable. We love to hear about your exploits, they are fantastic and an encouragement to us all. But please, remember; whether it is providing inspiration or raising money or both, take your camera and take some pictures, send them in and we will do our best publish them in our magazine.

Hilary Levett-Millett has recently taken over the role of Treasurer for the Fellowship from Duncan Morrisson. Being a treasurer is a demanding role, so a big welcome to Hilary and many thanks and good wishes go to Duncan for all his work over many years.

And lastly, it has certainly not escaped your notice that this edition is a little bit late. My apologies. I fear the gods were conspiring against us with this edition. Nothing at all to do with triskaidekaphobia.

**Our new treasurer
Hilary Levett-Millett**



Invitation to “A Cultural Afternoon in London”

Advance BOOKING is essential

- What?** This event is an opportunity to view the exhibition “A Visible Difference: skin, race and identity 1720-1820” which features albinism and to share your reactions to it. Also, to see an exciting new film portraying a personal account of albinism by Gemma Sherry and to attend and support the Fellowship’s Annual General Meeting. There will be some children’s activities.
- Where?** The Hunterian Museum
Royal College of Surgeons
35-43 Lincoln’s Inn Fields, London, WC2A 3PE
- Nearest underground station: Holborn (Piccadilly and Central lines).
See www.rcseng.ac.uk/museums
- When?** Saturday 1st December 2007 @ 1.00 p.m. to 4.30 p.m.
- Cost?** There will be a £5.00 charge per adult payable on the day. Children go free. But you must book in advance to attend this event.
- How to book** Email mark.sanderson@mencap.org.uk (preferred) to book or call Mark on 07810 548 798 (leave a message if he’s busy) with the number of children and adults who plan to attend the event, everyone’s names and the children’s ages by Tuesday 27th November 2007

Given the historical nature of the exhibition, some of the images portray albinism in ways that it is difficult to understand today and some people may find them upsetting. However, we encourage you to visit, as this exhibition is an interesting exploration into how albinism was historically portrayed. Our involvement has been to support the updating of the museums archives to show how the condition is (generally) and should be portrayed today.

If you can't make this time you could still visit the exhibition – it runs until 21st December and is free.

Jane Hughes from the museum is keen to record visitors’ responses, thoughts & feelings about the exhibition. So if you are planning a visit not on the day of the AGM, you may wish to contact her in advance on 0207 869 6561. And if you haven’t got a ‘Real Lives’ book yet you could buy one in their bookshop!

London and Irish BBQ's – captured moments





These photographs are from the Northern Ireland and the London BBQs which took place this year. We are informal in our gatherings, but do have a spot for a short meeting as well. But for many it is a time for catching up with old friends and feasting!



Coming up soon – Northern Ireland Event

You are invited to an
ALBINISM FELLOWSHIP DAY

On **Saturday 24th November**
at RNIB Northern Ireland

Time: 11:00am–3:00pm

A chance to meet & talk, with an
update on Albinism Fellowship news.
Lunch will be provided.
Toys and games for children on hand.

If you wish to attend please contact:
Rosaleen Dempsey
(AF Local Contact Person)

c/o RNIB Northern Ireland,
40 Linenhall Street, Belfast. BT2 8BA

Tel: 028 90329373
Mob: 07939 300949

Email: Rosaleen.Dempsey@rnib.org.uk



**Rosalie our NI Contact Person
would love to hear from you.**

Sorry for the short notice!

Ouch, what's that?

Ouch, the website from the BBC that reflects the lives and experiences of disabled people have asked us to tell you about a new disability and parenting message board. Ouch already has regular columns, features, quizzes, a monthly near-cult podcast, a blog or two amongst other stuff. The website has a bit of a wacky style. Here is a quote from their front page about themselves.

“All contributors, well, 99% of them, are disabled – and Ouch’s editorial team is rather wonky and deserve big fat special badges too”

The front page of their website is a mix of witty humour and sharp thought-provoking insight and certainly worth a look, although it may not be everyone’s cup of tea!

<http://www.bbc.co.uk/ouch/about>

Cool Shades from Baby Banz – Look it up! www.Sun-Togs.co.uk/Banz



One of our youngest members modelling Baby Banz for you!



I wish there had been something like this when my daughter was a baby! If you check out the website of this company you will find what looks like many interesting products. Learning from others and picking up on their best ideas is what the BBQs are for (ed).

UV Protective Clothing

At the London BBQ Sunsibility had a selection of clothing from their range of one hundred and fifty sun protective products to help you stay safe in the sun. It is UV Protective Clothing that fuses fashion with function and makes outdoor activities easier & more enjoyable. Clothing ranges from sportswear and headgear to posh parasols. If you missed it you can check them out at <http://www.sunsibility.co.uk>.



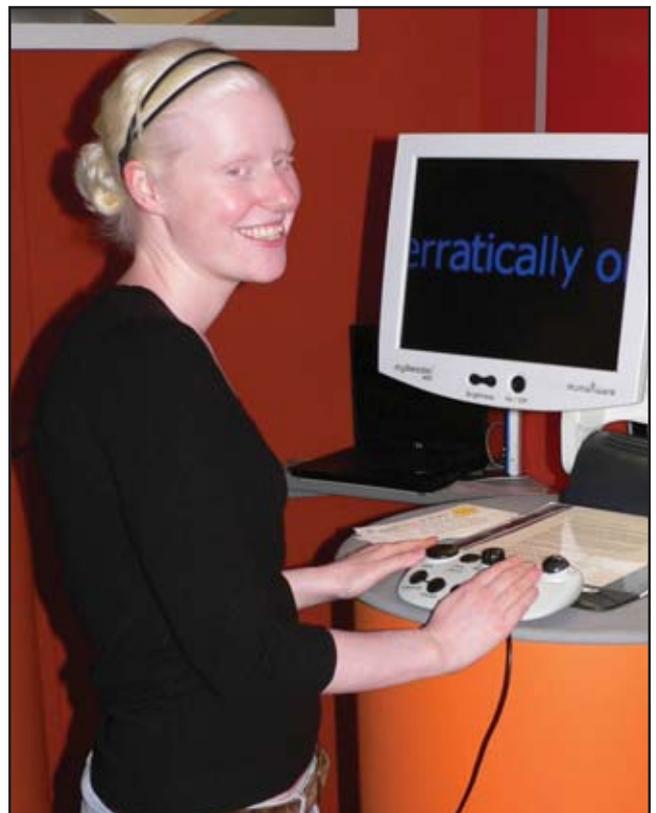
Sight Village

In mid July, Queen Alexandra College was the place to be if you were searching for solutions for blind and partially sighted people. The Fellowship had a stall there for the three days next to Nystagmus Network. It was the first time that we had attended as an organisation. Very many people filed past and took some information and some stopped to chat for a while. It is impossible to assess the impact that our attendance had at this event in raising awareness. We don't know how many people we may have reached because of our presence at the event.

The consensus amongst us was that it was very worthwhile and that we should certainly be there again next year. Every organisation in the Blind and Visually Impaired field appeared to be represented, as well as a myriad of companies selling or advertising their products. Indeed, there was a bewildering range of products that could be tried out and researched there on the spot.

I manned the stall with Hilary Hill for one of the days and in the breaks toured the exhibitions. I would strongly recommend the experience, particularly if you wish to know what sort of products are out there. But this recommendation comes with a caveat, have a guide who knows more than you and can give some advice. I was lucky enough to bump into Sarah Butler who gave me a personal view of many of the products that were on offer. I was viewing these with my 16 year old daughter in mind. Sarah was

there giving some help to another of our members with their parents and who were looking for a particular product. Past experience has taught me that the use of visual aids is a highly specific to the individual and what I think might be useful, even knowing her needs, may not be useful at all, so next year dad and daughter are both going to attend!



Sarah showed me her favourite piece of equipment which was on one of the stalls.

I trawled the stalls looking for a home telephone with a clear display that my daughter could use in the same way as the rest of the family. I didn't find one with a suitable display. An RNIB representative told me that what I wanted wasn't on the market yet, but she was hopeful that one would be on the market soon! This was in itself a

Sight Village continued

very useful piece of information because I was able to stop looking sure in the knowledge that I wasn't going to find what I was seeking!

The photograph shows some of our members who attended the exhibition on the Wednesday with Robin and Hilary.

Martin Lang



Disability, Pregnancy & Parenthood International



New Resources for Visually Impaired Parents and Education Professionals are now available in large print, Braille, audio and DAISY CD, containing a wealth of information on how best to overcome barriers to parents' involvement in their children's education.

Topics include: Choosing and applying for schools, supporting children at school, education resources and contacts

"Reading the Guides as a visually impaired parent, I realise how much easier life would have been if they had been published nine years ago. ... Having a reference guide in the format I preferred would have enabled me to find and read through the information at the time when I needed it." – a visually impaired parent.

The guides are available free to parents or at £6 each to professionals and organisations

For further information or to make an order, go to the DPPI website at, or contact the DPPI Information Service at:

Tel: 0800 018 4730 Text: 0800 018 9949

Feel the Breeze



The Donald Searle

The Rona Trust – London Sailing Project, is a charity which was established in 1960. It is for young people aged between 16 and 25 and is also the largest yacht based provider of offshore sail training for disabled people in the UK (any age). No previous experience is necessary and if you are blind or partially sighted and looking for a taste of adventure then this might be for you. Special VI trips are run and you can sail on board the project's big boat 'Donald Searle', the cost is very reasonable and includes all meals etc on board.

I went on my first trip in May this year and found it a very interesting and exciting experience. Having met up with a small group of people at Waterloo station (who I did not previously know) we travelled down to Southampton and had a good chat all the way. We were shown round the yacht and divided into watches as there are about 20 people on the boat. Port watch and Starboard watch were to do different duties on board taking turns to have a go at anything and everything if you so wished. About half of us were VI and there

were helpers and people who really knew how to sail the boat. Everyone helped everyone as we were all in the same boat. Quite a number of us were on board for the first time. The first sail was from Southampton to Cowes which was tremendously exciting as the yacht was keeling quite a long way over. There were special clips and lines to secure us to the yacht when we were on deck and we were all kitted out in wet weather gear and life jackets (all lent out if needed).

We set off from Cowes to go round the Isle of Wight quite early the next day and were right out in the channel when the winds became very strong, this is when you find out whether you really have sea legs or not. By the time we got to Yarmouth the weather had calmed down and it turned into a lovely evening. The following morning there was very little wind at all and a beautiful sunny morning. I was (with supervision) able to take the wheel of the yacht some of the time as we were going back up to Southampton which was really good fun. I was very pleased to have had the opportunity to try offshore sailing and it also gives the confidence levels a good boost too.

Julia Genders

The website is ronatrust.com and it gives a lot of info about the project and also about the VI sailing trips. Julia is happy to chat – contact us if you want to know more.



Sponsored Family Bike Ride

Come join us raising funds for the fellowship and having a wonderful day out along the Jubilee River, Windsor followed by a Pasta Party at Burnham Park Hall on Sunday 27th April 2008

The bike ride will start from 10.30am at Dorney and will follow a planned route which follows the river down to the playing fields at Eton.

Along the way you can stop and view the wonderful bird sanctuary with its wild life and flora. The route is about 11 miles long. Those who are keen can do it twice, the rest of us will do as much as we can. Those without bikes can walk. The important thing is to come along and help us raise badly needed funds. Afterwards join us to rest and celebrate at our Pasta Party, where prizes will be awarded.



Entry is £5 per adult and free to those under 18. Please register today giving your name, address and phone number:

by email: bikeride@albinism.org.uk

by phone: 01282 771900 (answer phone)

Entry forms and sponsorship details will be sent out in January (and will be up on the website).



There is a wide path all along the route and away from the edge of the river, making it very safe for all ages and abilities.



Fundraising and Donations

We need to say thank-you to people and organisations who should have been thanked in the previous magazine. Mr and Mrs J Smallwood had a 'bit of a do' last Christmas and raised £300. Fran Beaton raised £938 with a raffle and Quiz Night. Lorraine McTavish in conjunction with Lloyds TSB in Falkirk also had a Quiz Night and raised £438. Thanks also go to F. Birtles for their efforts in a Staff matching scheme with Lloyds TSB that raised £500. Lloyds TSB in Tavistock in Devon sent in a donation of £388. Thank you too to BAE Systems who donated £250 back in February and to the Cosham Solent Masonic Lodge for their generosity via Mr R Macriner.

Stephanie Kerr (aged 15) didn't have any time to take pictures when her mum, sister, grandma and friends held a tabletop sale. Stephanie tells me that they had items to sell and sold lots of her own things as well and that 'it was harder work than I imagined'. Still it was worth it, they raised £200. Trish Hall's staff at Queen's Road School raised £25 for us by not sending each other Christmas cards and making a donation instead.

Clifford Barnes ran the 'Nike "Run London" event' in Hyde Park in 2006 and raised £635. He tells us Abbie is 13 years old and attends Dartford Grammar School for girls where she is doing very well.



Clifford Barnes and daughter Abbie

Sean O Cathain, brother in law of Treasa (our Republic of Ireland Contact Person) did a sponsored cycle in August in aid of Albinism Fellowship and Kerry Hospice Foundation. He travelled from west Dingle or An Daingean to Baile Bhuirne, Cork. He continued east to An Rinn, Waterford and then headed north east to Rath Chairn, Meath. He then cycled west to Conamara, Galway before heading north through Tur Mhic Eadaigh, Mayo to Dun na nGall, Donegal, covering over 600 miles in just five days! Well done and thank you Sean! Thank you also to those who sponsored Sean. He hopes to have €4000 for Albinism Fellowship and he is still accepting sponsorship money!

Inspirational stuff Sean – even if we English can't pronounce where you've been, we know it's a long way - we looked it up! (Ed's)



Sean on his bike



We heartily and warmly thank everyone above for their contributions, big and small. All I would ask for is a few photographs of doing what you have done so well.

Actionnaires

Whilst on the stand at the Site Village we were approached by some people from Actionnaires. This is an organisation that offers unique sports clubs to blind and partially sighted children and young people with the chance to take part in sport, make friends, keep fit and have fun! The clubs are open to children and young people aged 8–16 (under 8s welcome if accompanied by an adult), free to attend and run by professional coaches. As well as weekly Actionnaires club sessions, there are sports festivals and competitions throughout the year. There are currently 25 Actionnaires clubs operating throughout the UK. Actionnaires multi sports clubs are run by the national charity, Action for Blind People.

For more information and to find your nearest club you may call Action for Blind People's National Freephone Helpline on 0800 915 4666

or visit

www.actionforblindpeople.org.uk/children



Callum Shooter in action at Actionnaires

Una lobbies MP's

Una would like to say thank you for everyone's responses for the Right to Read campaign. The Right to Read Lobby took place on March 28th when they visited parliament to put the case to MP's. Una writes:

"Hi everyone,

Thank you all for your responses, I printed them off and handed them to my MP, Dr Howard Stoate (Dartford constituency, NW Kent).

He is very enthusiastic about the campaign and has already brought it to the attention of our local press long before I spoke to him. As he is a GP he says that he often gets listened to more than the other MPs when it comes to medically related debates and he wants to keep in touch for updates, so that has to be a good sign.

I asked Daniel's school to estimate how long it took to scan all his text books into his laptop – it took every Friday morning for the best part of the school year and he isn't statemented!

I took along one of Dan's revision guides and one of his English Literature books (well, half a volume) to highlight how big these books from the NBCS are once adapted – I think he was pretty shocked. They were about 6 or so albinism families there that I noticed (Katie was albinism spotting – typical 6 year old!), I got time to meet up with 2 of them and there was a good turnout overall. Katie was delighted, the author Jacqueline Wilson was there, (see the photograph). The NBCS gave

away free copies of her book, so Katie got hers signed and had her photo taken too.

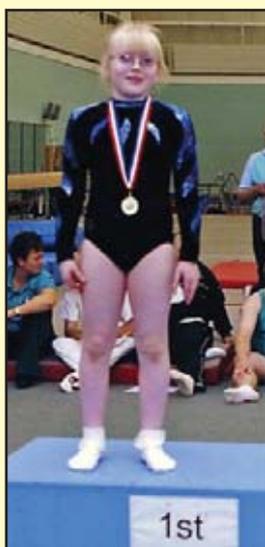


The NBCS have a draft letter if anyone wants to send their difficulties to their own MP.



This photograph, we understand, was taken in the lobby of the Houses of Parliament, where they shouldn't really be taking them! Ah well, too late now. Una tells me that she met two other families, hopefully you recognize who you are!

Katie at the Bar



The photo above shows Katie with the medal that she has won in the under 12s trampolining event in the sensory impairment section at a competition in Poole, Dorset. Una writes:

“Katie goes to a brilliant all inclusive gymnastics club called Falcon Spartak in Sidcup on the London/Kent border. She has been at the club for about 18 months and we were a little apprehensive at first but she loves it. The beam has been the biggest challenge especially as they are supposed to hold their head straight!! Katie has overcome her fear and whilst it has taken her a little longer than children with normal vision she is managing both the beam and the vault.”

Well done Katie. We are impressed; you wouldn't catch us dancing on a beam! (Ed.s)

It has come to our attention that a few people, we will spare their blushes, have been photocopying our newsletter and distributing numerous copies. Whilst we like the idea of raising our profile and circulation, and are pleased that people are keen to read what we write, it really is rather naughty! Obviously we want people to be informed and we want to reach as many people as possible. We don't object to people occasionally copying an article to introduce us to others, knowing that it may encourage people to become members. We don't want to be heavy with copyright issues, but please recognise that most people contribute for their copy by being members of the organisation. So, if you are reading this as a photocopy, we ask that you consider becoming a member to get your own copy and support us (see the website for details as to how). Fair comment?

Ed's

Albinism Fellowship

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www.albinism.org.uk

email: info@albinism.org.uk

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Fellowship in the Shires (Five Shires Event 2007)