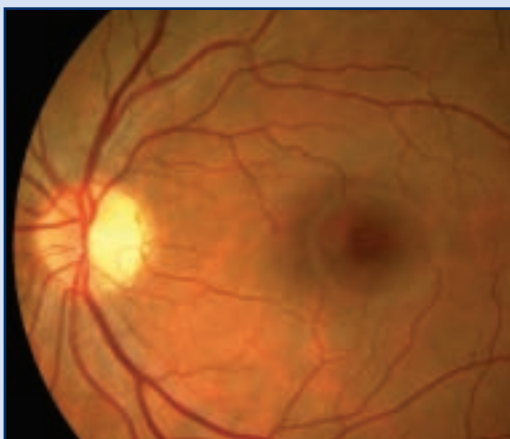


See fundraising page 18

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Look at me Ma, I'm on top of the world!



## Also in this issue:

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- ❖ *2006 AGM Report*
- ❖ *Northern Ireland event*
- ❖ *Latest from Moorfields*
- ❖ *Events for Summer 2007*

# Editorial

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The front page of our magazine has Kayleigh Schofield and her Uncle Joe standing upon the summit of Ben Nevis. It is a reminder, if any is ever needed, that we should all be encouraged to step out of our cosy circle at least once in a while and aim high. Daisy is another example, what a star! This Magazine has news of our summer events. I have written before that I think such opportunities to meet others with 'albinism in the family' are the most important function that the fellowship provides. Each time my family attends a BBQ we are meeting old friends, but I am also inspired by the quiet determination of others to not let obstacles stand in their way, and I always learn something. There is no one solution suits all and exchanging ideas with as many people as possible is invaluable. If you haven't yet attended one of our BBQs or a similar function, please do go that extra mile to join us, it may be a life changing event for all your family.

We have some news from Magella Neveu and Glen Jeffrey who are currently doing research into albinism. They are seeking volunteers to do more research, so if you are interested, why not give them a ring? It is quite painless, honest!

The Forum on the Fellowship's website has now gained momentum. At the time of writing there were 319 registered users and 830 articles. Dave Proctor is our current record holder. His initial posting in

November 2005 on Disability Living Allowance has generated 19 subsequent postings and has been viewed by 2969 people. A posting about sun creams that has 2815 views is not far behind! Clearly our forum is a popular form of communication. We have had some abuse by a very few people posting inappropriate subject matter. The Forum is monitored closely by a group of people in various ways. If you see offensive postings please do tell us and we will remove it. I would also stress to some new users that the General Forum is public and may be read by anyone on the internet. More personal comments may be exchanged between members in the Member's Forum, where only members of the Fellowship may gain access.

If you are interested in the Arts and not heard of VocalEyes, then we have a have something to set your soul singing. VocalEyes audio describe live performances and attempt to make the arts in general more accessible to blind and visually impaired people.

And finally, we publish minutes of our AGM, and as Mark has recognised we are 'punching above our weight'. We are a small organisation spread thinly throughout the country. Anyone that reads the replies to Dave Proctor's question on the forum should immediately realise that we are a fellowship of like-minded individuals who offer each other support. There is no better exemplar!

# Barbecue London

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**When :** Saturday 12th May, 2007

**Time :** 11.00am to 4.30pm (meeting 2.00 – 4.30pm)

**What:** The format will follow our normal pattern of fun, food, and informal get-together. There will be the usual chance to ask questions and share experiences in the afternoon meeting.

**Where :** Oaktree School  
Chase Side, Southgate, N14 4HN

**Oaktree School** is located on Chase Side between Oakhills Theological College and Middlesex Uni, opposite Bramley Road Sports Ground (see [www.albinism.org.uk](http://www.albinism.org.uk) for map)

**Travel :** Southgate Tube Station, Piccadilly Line  
From Bus stop G take the Bus 298 towards Potters Bar Ind. Est.  
or take tube to Cockfosters and ring Mark for a lift on 07949208785

**or** 3 miles from Junction 24 of the M25

**Parking :** Plenty in school car park

**Please bring :** What you wish to cook/eat plus a pudding or a salad to share – (crockery, drinks, condiments, cutlery etc. will be provided) There is plenty of space inside and out, with a fun area for children and space for games – so have the sun lotion handy!

*Everyone is welcome. Email us on [info@albinism.org.uk](mailto:info@albinism.org.uk) or just turn up!*



# Five Shires Event – New summer Event!

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**Time :** Gloucestershire, Oxfordshire, Worcestershire, South Warwickshire and Herefordshire

**Date:** Sunday 10th June 2007 from 11 a.m. – 2.30 p.m.

**Format:** We are hoping to have a social gathering and an information sharing event about all aspects of education which have been helpful to members. We are also planning to have a brief talk from Mrs P. Driscoll, Specialist Teacher for the Visually Impaired, who knows about local issues and resources.

There will be some examples of resources available and I'd like to encourage members to bring along examples or information about what has helped them or their children.

**Food:** Due to limited catering facilities, could guests please bring a packed lunch, though drinks will be provided.

**Venue:** St. David's School, East Street, Moreton in Marsh, GL56 0LQ.

**Parking:** Ample is available at the school.

**More Info:** Contact Sarah Fellows

Tel: 01608 812378 or email [ws.fellows@virgin.net](mailto:ws.fellows@virgin.net)

Moreton in Marsh has a station and bus links. It is on the junction of the Fosse Way (A429) and the A44. It is a beautiful North Cotswold town with plenty of shops, restaurants and antique centres to browse around, so why not make a day of it?

## Glasgow Family Event

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This fun family day will be held again this year on **Sunday 29th** July at Mugdock Country Park, 11am to 4pm. Barbecue & drinks provided, please bring along a sweet or salad to share. Similar format to last year with games and a raffle. **£10 per family.**

More info Contact Gemma Sherry at [gemmalouisesherry@hotmail.com](mailto:gemmalouisesherry@hotmail.com) or Tel: 0773 9707 584



# Albinism Day – Dublin 07

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**Time :** 23rd June 2007

**Venue:** St. John's G.A.A. Clubhouse, Grange Rd., Ballinteer, Dublin 16.  
(Also known as Cumann naomh Eoin, Baile an tSaoir)  
It is situated next to Marlay Park and almost directly across the road from new Lidl store (junction of Grange Rd. & Stonemason's Way).

**By Bus:** St. John's is accessible from bus routes **14A** or **48A** to terminal at Ballinteer – 8 minute walk along Stonemason's way towards Marlay Park.

Also the no. **16 bus** which crosses the city goes by the clubhouse.

**By Car:** If travelling on M50 take Ballinteer/Rathfarnham exit. Drive about 2.5KM along Brehonfield Rd. and the clubhouse will be on your left – look for black railings...entrance directly at the traffic lights junction of Stonemason's way and Grange Rd.

## Programme for the day

**Arrival:** 12:30 – 1.00pm

**Introduction & Update:**  
**Latest Albinism Fellowship news** 1.00 – 1.30pm

**BBQ:** 1.30 – 2.15pm

**Guest Speaker – Educational Psychologist:** 2.15 – 2.45pm  
Joan Curran

**Albinism Discussion Group**  
**and access to Mobile Resource Unit:** 2.45pm

**Conclusion** 3.30 – 4.30pm

Anyone wishing to attend please contact: Treasa O Callaghan on 0863789294.

Contributions of €5 from individuals and €12 from family towards the cost of the BBQ and venue would be appreciated before 30th May please. This is necessary as we need to plan for event.

We will have sports equipment, hoops, balls, skipping ropes and of course a parachute available for fun and games in Marlay Park, adjacent to clubhouse – weather permitting.

N.B. Parents /guardians need to supervise children at all times.

## Albinism Day – Dublin 07 continued

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**Left: Taste of the gathering in 2006 Right: Tom Cosgrove Star Cook in 2006!**

Help with sports events would be greatly appreciated.

There is also a playground right next to clubhouse suitable for very young children.

Teenagers are very welcome... so do come along.

If you can, please bring a cake or a salad we can share.

We hope to have a music session afterwards similar to last year's event... so bring a musical instrument if you can play – or just join in the singsong!!

Looking forward to meeting you on the day,

**Treasa O Callaghan**

## Flora Women's minimarathon – Ireland

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**Monday 4th June 2007**

People who are interested in raising money for Albinism Fellowship can get forms in the Evening Herald every Thursday and Saturday from March 1st 2007.

Alternatively you can enter online

[www.florawomensminimarathon.ie](http://www.florawomensminimarathon.ie)

CLOSING DATE for entries is 24th April 2007.

# Midland Event 2007

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## A Joint Event working with the Nystagmus Network

on Saturday July 7th 2007 at Queen Alexandra College in Birmingham.

This year we are having a Midlands event jointly with the Nystagmus Network and N.B.C.S (National Blind Children's Society). There will be a range of indoor and outdoor fun activities for children of all ages leaving the adults to get together to discuss matters of interest and share common experience.

A full day for people who have albinism and nystagmus, their friends and families which will include an update on findings in Nystagmus and Albinism research.

Pre-ordered lunches will be available from the college catering service and transport will be provided in the morning from the railway station to the college and back again in the afternoon by executive coach.

Full details of the programme will appear on the website shortly and in the March edition of Focus (Nystagmus Network's Magazine)

For further information please phone Paul on 01636 627004 or email [info@nystagmusnet.org](mailto:info@nystagmusnet.org) or [info@albinism.org.uk](mailto:info@albinism.org.uk)

### National Children's Blind Society

For those of you who do not yet know, the NCBS provide large print books. Their service is called CustomEyes, where books are tailored to suit the child's eye condition.

They are priced the same as the originals and are formatted, literally customised for the individual! You are able to request the style and size of font, spacing and background as well as the size of the book. My daughter particularly liked the A5 format for her copy of Mice and Men by John Steinbeck. NCBS have an increasingly large library of books to choose from. They have novels, school books, revision guides and many editions that are recently published. To take advantage of this service you will need to register with them initially, but once this is done, they run a quick and easy service for you, where books may be ordered over the phone using a credit card.

The CustomEyes telephone number is 01278 764767 Julia Elswood will discuss your requirements and the various alternatives.

The website address is: <http://www.nbcs.org.uk/>



# Northern Ireland Event 2006 Report

Rosaleen Dempsey, our new Contact Person in Northern Ireland, organised our first ever Family Day in Belfast on Saturday 25th November 2006.

The event was well attended and a great success with 25+ adults and children there. We hope you enjoy the photos of the day. It was held at the RNIB NI resource centre right in the heart of Belfast. People attending had the opportunity to:

- See a variety of aids and equipment for partially sighted people at the RNIB resource centre.
- Listen to an interesting, inspiring and funny talk from Robin Spinks. He spoke about his experiences as a global business traveller with albinism, and about the people with albinism he has met and worked with in Africa in his role with Sightsavers International. For more information look up [www.sightsavers.org](http://www.sightsavers.org)
- Learn about the benefits to membership of RNIB NI. For more information look up [www.rnib.org.uk](http://www.rnib.org.uk) or call 08457 66 99 99.
- Enjoy lots of opportunity for informal chat with everyone, to share experiences and learn lots about albinism.
- Finally but importantly to attend our 2006 AGM. See separate article.

Everybody seemed to enjoy the day. Through Rosie, and also Treasa



**Ireland Event**

O'Callaghan, our Contact Person in Dublin, we are reaching more people and raising our profile in Ireland. This is excellent work!

Well done and congratulations to Rosie for the 25th November event and thanks also to RNIB NI for enabling us to have the event at their centre and a special thank you to the following people who helped Rosie on the day.

Fionnuala Dempsey, Laura Slater and John McGuinness of RNIB and Lee McQuade of The Blind Centre NI, the leading local charity working for people with severe sight problems living across NI. For more information look up [www.bcni.co.uk](http://www.bcni.co.uk) or call 02890 650 001.

In 2006 we successfully held regional events in London, Glasgow, Dublin & Belfast and we plan more for 2007. If you want to help our Contact Persons organise an event please let us know at [info@albinism.org.uk](mailto:info@albinism.org.uk) or on 01282 771900.

**Mark Sanderson, President**

# Latest From Moorfields – Research

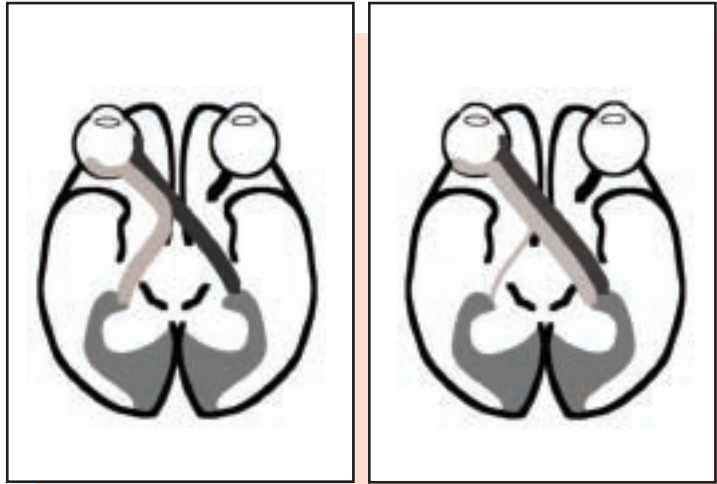
Magella and Glen have written an article for us...

Moorfields Eye Hospital in conjunction with the Institute of Ophthalmology have a great interest in investigating the visual problems experienced in albinism and try to get a better understanding of how and why these problems occur. We are indebted to the members of the Albinism Fellowship for volunteering to take part in these studies. Indeed, we wouldn't have anything to say if it wasn't for the wonderful volunteers. Below is an update of some of the research we've been carrying out and what we're hoping to do in the future.

The nerves from the eye to the brain are wired differently in albinism. We know that approximately 90% (the majority) of nerve fibres from one eye cross in the brain and end up in the opposite side of the brain (Figure 1).

This is different to people with normal vision, where 50% of fibres go the same side of the brain and 50% to the opposite side. The abnormal crossing in albinism suggests that the fibres in the connections in the visual part of the brain may be different too.

So we carried out a study to first examine if there is any change in the brain's responses with increasing age. The study showed definite changes, but the good news is that these changes do not result in decreasing vision (see *Albinism Life*, Issue 4 – Autumn 2003).



**Left: Normal vision, Right: Albinism**

**Figure 1.** Connections from the eye to the brain in normal vision (Left picture) and albinism (Right picture).

Left Picture: The thick light grey line shows the nerve fibres that come from the eye and go to the same side of the brain (approximately 50%) and the thick dark grey line show the nerve fibres that go from the eye to the opposite of the brain (approximately 50%).

Right picture: the majority of nerve fibres that should go to the same side of the brain, now cross over to the other side (thick light grey line). Therefore the majority of nerve fibres from one eye go to the opposite side of the brain.

More recently we've concentrated on the blood vessels in the back of the eye to see if they are any different in albinism. It's well understood that the central part of the eye responsible for detailed vision, called the fovea, does not develop properly in albinism.

## Latest From Moorfields – Research continued

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This is why reading, detailed vision and seeing things at a distance can be difficult.

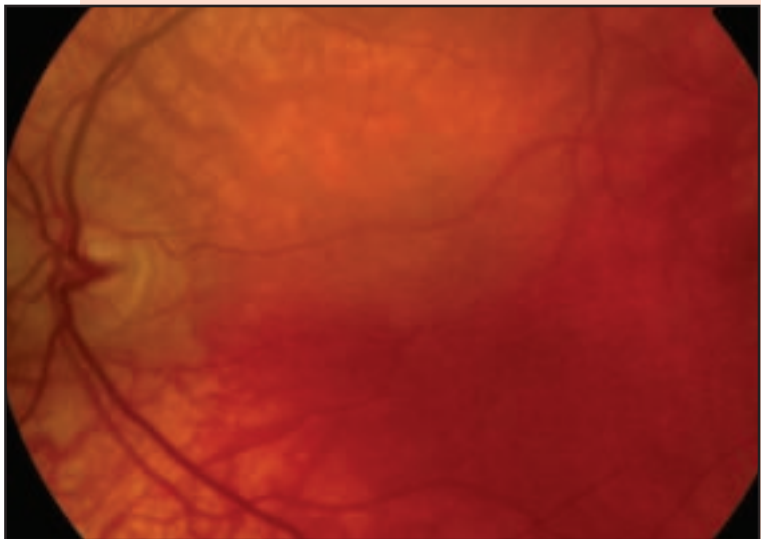
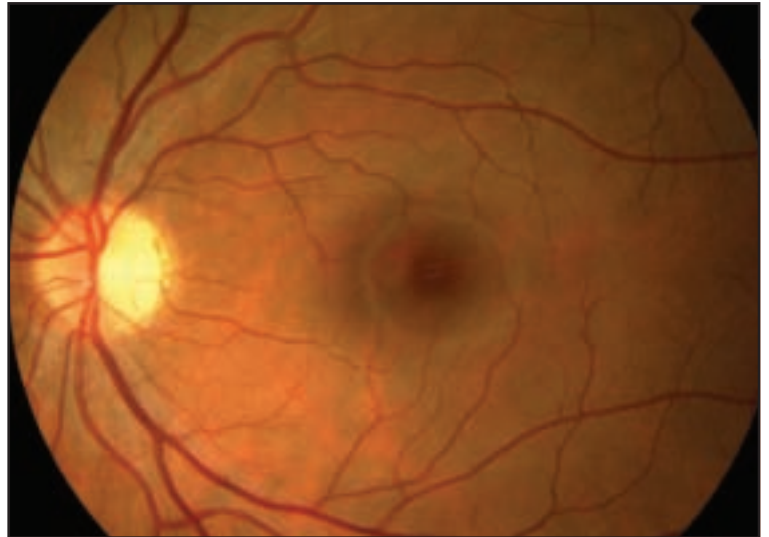
There is one other disorder where the fovea doesn't develop and that is 'aniridia'. In aniridia, individuals are born without irises (the coloured part of the eye). So we took lots of photographs of the back of the eye from people with albinism and aniridia, then we compared these with photographs from people with normal vision.

What we found was very interesting. In the eye of someone with normal vision, the blood vessels arc around the central region called the fovea (Figure 1, top picture) and this pattern of arcing is very distinct.

However, because people with albinism and aniridia lack a fovea, the blood vessels in these individuals have an abnormal pattern. Rather than arcing around the central area they tend to go off in different directions (Figure 1, bottom picture).

Although the patterns are abnormal, there is no suggestion that the blood supply to the eye is compromised.

The interesting point is that people with aniridia have normal levels of pigment in the back of the eye, which suggests that the poor development of the fovea is not solely dependant on having pigment at the back of the eye.



**Figure 1:** Photograph of the back of the eye, taken from someone with normal vision (top picture) and someone with albinism (bottom picture).

The blood vessels are the dark red lines arcing around the central part of the photograph. The central point, which is a dark red spot, is called the fovea. This dot is missing in the photograph on the left and the blood vessels do not arc around this central region. Rather they appear to be spreading out, rather than arcing in.

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The study we are currently working on is to investigate how well people with albinism are able to detect motion. The processing of motion is very complex and there is a distinct part of the brain that deals solely with motion. As we suggested, the visual part of the brain may be wired differently in albinism, therefore as motion requires complex processing, it may be more susceptible to abnormalities in neural architecture.



**Glen and Maj (Moorfields)**

The results so far have shown that people with albinism are less able to detect some forms of motion than people with normal vision. Speaking to our wonderful volunteers who endured the tests, they said that they didn't

seem to experience any problems with seeing moving objects. This suggests that the brain may be compensating for this in some way.

Again, we'd like to thank all those who have taken part in these studies. Your contribution has been invaluable. We'll keep you posted as new data emerge, in the hope of better understanding how critical pigment is to visual development and then hopefully apply that to the management and treatment of albinism in the future.

Many thanks

*Magella Neveu and Glen Jeffery*

## **Volunteers Wanted**

If anyone would like to take part in the current study at Moorfields – examining 'motion detection' in albinism they are looking for volunteers.

A recent study suggested that some types of motion detection are impaired in albinism. The test involves looking at a moving pattern on a screen and saying whether the pattern is moving 'up', 'down', 'left' or 'right'. The test takes about 2 hours to perform and it's carried out at the Institute of Ophthalmology (just behind the hospital). We'd be happy to pay for any travel expenses.

**Contact Magella (Maj) Tel: 020 7566 2120  
or email [Magella.Neveu@moorfields.nhs.uk](mailto:Magella.Neveu@moorfields.nhs.uk)**

# Report of 2006 Annual General Meeting

We like to move our AGM venue around and for 2006 took it across the water to Belfast, Northern Ireland.

Those of us travelling from the mainland took early morning flights from Manchester or London and apart from the odd slight delay arrived in one piece. We mention the successful family day of which the AGM was a part on Saturday 25th November in another magazine report.

We don't want to take up valuable space in your magazine with all the details of the AGM so will keep them to a minimum. You can see a full copy of our annual report and accounts for the year ended 31 March 2006 at [www.albinism.org.uk](http://www.albinism.org.uk) or if you don't have access to the Internet and want a print copy please call to request one on 01282 771900.

Here are some of the highlights for your information.

## Our finances for 2005-06

### Income

Subscriptions	£2,434
Donations & grants	£8,204
Fund-raising	£2,262
Sale of literature, merchandise Real Lives book & training	£8,640
Bank interest	£199
<b>Total income</b>	<b>£21,739</b>

### Expenditure

Conference costs	£15,769
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Secretarial, stationery & computer costs	£1,265
Magazine expenses	£1,498
Regional events & trustee meetings	£495
Purchase of literature, merchandise & exhibition stands	£2,169
Contact person's recruitment & training	£4,157
Real Lives book project	£3,113
Other (promotion, marketing, depreciation & costs of generating training income)	£618
<b>Total expenditure</b>	<b>£29,084</b>
Surplus/(deficit) for the year	<b>(-£7,345)</b>

### We received most of our money from:

- Membership fees, which mainly cover the costs of our magazine, Albinism Life
- Donations and fund-raising, although this was much less than last year so we continue to need your support with fund-raising please



**Rosalie and Joan with one of our new exhibition stands**

- Developing and delivering 6 albinism related training events through RNIB regional centres which has helped us reach over 60 education professionals. Mark & Robin gave their time free to deliver these
- Researching, writing, printing, distributing and selling our Real Lives book, which has had a very positive response and considerably raised awareness and understanding of albinism in the UK, Ireland and internationally

**We spent most of our money on:**

- Albinism Life, our 2-3 times a year 16 page full colour magazine, which has all kinds of useful information and articles for people affected by albinism
- Developing and printing the Real Lives book

- Delivering our 5th very successful family weekend conference, this time in Edinburgh
- Recruiting, providing initial information materials and training for, and supporting our local Contact Persons
- Purchasing exhibition stands and other materials to help raise awareness of the Fellowship across the UK & Ireland at our conferences and local events

The accounts show that at the 31st March 2006 we had spent £7345 more than we had received in the year. This does not mean that we have had an overdraft or a loan. At the end of the year before (2004-05) we already had £15,037 in the bank; some of which had been raised specifically for and set aside to cover the costs of the conference.

# Report of 2006 Annual General Meeting continued

We also received other money in 2005-06 specifically towards the costs of the conference. This included two grants; one from the National Lottery Awards for All and one from the Nancie Massey Charitable Trust.

The total cost of the conference is in the region of £25,000 but we receive some income from fees from the people attending. The £15,769 above is purely the Fellowship's contribution towards the costs of the event.

Our balance sheet shows that at the end of March 2006 we had stock (mostly made up of Real Lives books still to be sold) of £8,685 and had £7,692 in the bank.

## Our other achievements for 2005-06

We achieved a great deal in 2005-06. We called our annual report 'Punching above our weight'. This means that despite being a small organisation with limited human and financial resources somehow we manage to achieve much more than people might think we would. Thank you very much to all of the following who enable us to punch above our weight again and again and again:

- Our members
- Contact Persons
- Fund-raisers and donors
- Committee members (trustees)
- The families of all of the above
- And other people who support us in any way. Thank you to you all!



**Contact Persons.** Gemma Sherry held her first BBQ/Family Day in Glasgow as our new Contact Person. Rosaleen Dempsey also joined us as Contact Person for Northern Ireland.

**Events.** We ran successful day events in London, Glasgow, & Dublin. Thanks to Jim & Helen Orros for their continued support with the London event. Also, to Treasa O'Callaghan for doing such wonderful for us work in Ireland. We also had our 5th biannual conference in Edinburgh. Thanks to the Walker-Morrison's for being our 'official' hosts. Well done to everyone involved! We are planning '07 events too. If you want to help a Contact Person provide an event let us know.

**Committee (trustees).** Sadly, Gill Walker has decided to step down as Contact Person Co-ordinator. We all thank Gill very much for all her hard work and support. Gill will continue to help us with advocacy work as an active member. That's great!

We have had some interest in a number of vacant trustee roles which we will be pursuing over coming months. Interested? For details see [www.albinism.org.uk](http://www.albinism.org.uk) or call Mark on 01282 771900.

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**Website.** Dan Hill continues to do a great job as our Webmaster and we are also grateful to Una O'Connor and Martin Hill for acting as Moderators. Thanks a million!

**PR & Media.** Robin has really successfully raised the profile of the Fellowship with the media and deals with all the approaches we get very professionally. In particular, we had some great positive media coverage in response to the launch of the film *The Da Vinci Code*. We had at least 7 radio interviews and 5 newspaper articles in the couple of weeks around the launch of the film. Robin is planning to establish an informal Advocacy Group to help develop this work. Cheers Robin!

**Helpline, Email & Magazine.** Last but certainly not least Hilary Hill and Martin & Karen Lang continue to do a fabulous job answering telephone calls, emails and editing our magazine, *Albinism Life*. Thanks guys! Keep your articles, snippets, ideas for the magazine coming to [info@albinism.org.uk](mailto:info@albinism.org.uk) or to P O Box 77, Burnley, Lancs, BB11 5GN.

### Future plans

We reviewed our long-term vision, mission and objectives during the last year. Our new objectives will cover the period 2006-08. You can read about these at [www.albinsim.org.uk](http://www.albinsim.org.uk) or in our annual report & accounts for 2005-06.

As well as our day to day work & events, in the next year or so we

aim to:

- Increase our membership
- Provide development opportunities for our Contact Persons
- Recruit more committee members (trustees)
- Promote and sell more copies of the *Real Lives* book
- Develop and sell our training services
- Update some of our policies, guidance and other important documents

If you can help us with fund-raising, here are some of the things we'd like to raise money for in the next year or so.

Contact Persons training, networking & support event	£2,000
Next proposed conference in May 2008	£25,000
Exhibition banners to promote Albinism Fellowship at key events	£1,000
Develop training materials	£1,000
New PC's to support our work	£1,500

We hope you enjoyed this brief journey through our finances, achievements and plans for the last and next year. If you have any comments to help us plan for the future always let us know by post, email or phone. Within the resources we have we want to provide what you want because this is your fellowship.

# A Word in Your Ear

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On a Saturday last November, my daughter went to see Billy Elliot, the musical at London's Victoria Palace Theatre. It was a birthday treat for her and one of her friends. The performance was a special one for her and many others since it was audio described. Audio description provides a live verbal commentary on the visual elements of a production, delivered as the performance unfolds. It is delivered via a simple and discreet headset. Providing the commentary is a highly skilled task, since it has to be delivered with the appropriate timing and not over the top of dialogue. In addition to the audio

description, Karina was given a touch tour which included such things as the miner's lamp and other props with some of the characters and costumes.

We have found audio description to be a great innovation. For us to try and explain what is going on stage would be very difficult, since we don't know what is coming up, we might be disturbing others in the audience and miss something as we speak. We also don't have the vocabulary ready in preparation to explain succinctly. These special performances mean all the family can enjoy the experience together and talk about all aspects of the performance later.

However, my daughter's birthday was not the event being celebrated that day. It was the 500th performance that was audio described by VocalEyes, the charity that provides this most excellent service. I understand there are plans to audio-describe the Billy Elliot performance again this summer, so you may get another chance if you missed this one. There are many other performances that are audio described. We now look out for audio described performances and Karina has been to a few of them including a pantomime, the Lion King and Phantom of the Opera.

In an initiative that was launched at the House of Lords in January, VocalEyes are developing their work with STAGETEXT, an organisation that provides captioning for deaf, deafened and hard of hearing people in live performances. Karina and I were invited to this event hosted by Lord Harrison of Chester. Speeches were made, canapés consumed and conversations exchanged. To our delight we and a few others were given a tour of the Palace of Westminster by Lord Harrison. (Ask me about this at the next BBQ when you see me...please.....I just love telling people!) VocalEyes also offer their services for some museums, galleries and heritage sites.

**Martin Lang**

*To find out more about VocalEyes see info on the backpage*

# Letters...

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## One of our stars...

**Angela Stoner emailed recently with encouragement...**

"Daisy our daughter was featured in your campaign to promote awareness a couple of years ago, after a successful photo shoot in London.

This email really is for new parents who are trying hard to imagine that their child will be able to live a normal life. Daisy now aged 10, is appearing in her first professional Pantomime of Cinderella in Dorking at the moment, she auditioned along with about 100 children and was selected immediately. She's having a great time and is hoping to go on to bigger and better things.

So I think it is safe to say that at the moment she is enjoying life to the full!!"



**Our Star – Daisy Stoner in Cinderella**

## And another...

**Proud mum Treasa OCallaghan writes...**

"Deirdre is being nominated by her school to go forward for the Bank Of Ireland Awards for people with disabilities achievement awards.

They feel she is coping very well and participates in all activities.

She is one of 70 children who received top marks in Junior Cert German in Ireland and has been invited to German Embassy for an interview in order to apply for a free course in Germany for 2/3 weeks! They will choose 24 of the 70 to go forward if they are interested.

She also has to answer questions...she is mentioning her attendance to two Albinism Fellowship conferences etc....this will be an opportunity to mention the AF...etc

We are delighted with her."

**Lorna Hudson emailed us this useful piece of information....**

At the Edinburgh Albinism conference in November 2005 we bought some protective clothes from Lion in the Sun for Michael (9). Last autumn we decided to brave our first 'sunny' holiday with Michael and were thrilled with the protection offered by the clothes with one exception. Both the swim suit and swim shirts stopped mid forearm.

When we came home we wrote to Lion in the Sun and they have

## Letters... continued

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decided to introduce a couple of long sleeved shirts for Spring 2007 for kids and adults as a trial. They are going to do them in unisex colours, silver and sky blue, and they will be available from mid-February. I promised Lion in the Sun that I would let others in the Albinism Fellowship know. They are offering a discount to the readers of Albinism Life. Use the code ALBFEL07 to get 10% off everything on site. [www.lioninthesun.com](http://www.lioninthesun.com) We will certainly be ordering!

**Lion in Sun** came to the last London BBQ

*Do keep sending us your news and we love PHOTOS! Don't be shy now we love to brighten up the mag with your shots – eds*

## Fundraising Roundup

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*See front page photo...*

**Kayleigh Schofield** raised a staggering £3878 for us by walking up Ben Nevis at the end of May with her Dad, Uncle Joe and Pete.

She writes... "It was a very very cold day (windchill factor -10°C and snowing – from notes on back of photo) with fresh snow on last 1000ft. Dad, Uncle Joe and Pete guided me really well and even let me get to the top first. I've enclosed some pictures for you to see, we took lots as I could not see the view but I have looked at the pictures loads..."

My school nominated me for the Princess Diana Memorial Award which I received on 19th July 2006. I wasn't expecting it so it came as a real shock."

**Noriko Elliott** raised £131 running the Great Manchester Run for us in May last year and **Clifford Barnes** sent us £635 from his Nike "Run London" 10K Run. Well done to both of you and a big THANK YOU to these and to the many others who have sent donations.



# Membership fee renewals

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Membership fees for 2007 are due now. These are £15.00 UK, and €25 in Ireland and £25 rest of the world (must be paid in £'s). Life membership is £250. These fees incorporate a small increase from last year and we believe are competitive with similar support organisations and represent value for money. Remember fees are per individual named member and are intended to cover the member and their immediate family only.

We wrote to most of you recently to invite you to renew your membership of the fellowship. If you did not get a letter, it means that we think your fees are up to date so welcome to a new year of membership.

Your membership fees enable us to continue to provide our core vital services for you and your family such as our helpline & email enquiry service, website, and magazine.

If you are able to make an extra personal donation or to fundraise for us this would be fantastic and helps us to provide other services such as our Contact Person network, mid year family days, weekend conferences, and exhibiting at appropriate events.

How to pay if you have not?

If you pay by cheque, please send your cheque made payable to Albinism Fellowship as soon as possible to us at:

Albinism Fellowship,  
P O Box 298,  
Farnham, Surrey, GU10 4XR.

If you are paying by standing order, we may not have been receiving the right amount from you and also our fees have increased slightly this year. Please take a moment to check your standing order and please send us a cheque for the extra amount if you can.

If you are finding it hard to pay your fees but want to remain a member please let us know in confidence and we will do what we can to help.

Finally, if you think we have any of your membership details incorrect, please tell us so that we can correct our mistake. This includes your email address!

We hope you continue to enjoy the benefits of membership of and supporting the valuable work of Albinism Fellowship and that you have a wonderful year as part of our special community.



# Other Useful Contacts/Websites

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## VocalEyes

Website: [www.vocaleyeyes.co.uk](http://www.vocaleyeyes.co.uk)

This website has a useful 'Enlarge Text' option in the top centre of each page. You will find details there of the events that VocalEyes are audio describing in your area by using the search option. Or you may wish to receive their newsletter by post.

VocalEyes First Floor, 54,  
Commercial Street, London. E1 6LT.  
Tel: 020 7375 1043

## Working Vision

Website: [www.workingvision.org.uk](http://www.workingvision.org.uk)

Working vision is a new employment consortium based in the West Midlands area that provides an employment preparation programme specifically designed to support blind and partially sighted job seekers in to work.

## STOP PRESS

Just in – Vocaleyeyes upcoming events...

*Wicked* at the Appollo Victoria;  
*Mamma Mia* at the Prince of Wales;  
*The Magic Flute* at Leeds Grand, Newcastle, The Lowry and Nottingham;  
*Billy Elliot* at Victoria Palace;  
*Swan Lake* at the RAH;  
*Glass Eels* at Hampstead Theatre;  
*Betrayal* at the Donmar Warehouse;  
*We That Are Left Behind* at Watford Palace;  
*Big White Fog* at Almeida Theatre.  
*Love's Labour Lost, Othello and the Merchant of Venice* at the Globe.



Special Offer  
to members!!  
Order now... £15  
only including P&P!

## Backpage Event Roundup

There are quite a few events coming up so we thought you'd like to have a slip you could tear off and put on your notice board for quick reference!

- Saturday 12th May** London BBQ and Social Oak Chase Farm School, Southgate
- Monday 4th June** Flora Women's minimarathon – Ireland
- Saturday 9th June** Mark Sanderson is speaking at an event in Sandwell
- Sunday 10th June** Five Shires Event St. David's School, East Street, Moreton in Marsh, GL56 0LQ
- Saturday 23rd June** Albinism Family Day Dublin St. John's G.A.A. Clubhouse, Grange Rd., Ballinteer, Dublin 16
- Saturday 7th July** Midlands Joint Event with Nystagmus Net & N.B.C.S Queen Alexandra College, Birmingham
- Sunday 29th July** Glasgow Family Day at Mugdock Country Park in Glasgow

More details and some maps of these events and some other events of interest can be found on the Website: [www.albinism.org.uk](http://www.albinism.org.uk)  
Email: [info@albinism.org.uk](mailto:info@albinism.org.uk) or Tel: 01282 771900