

The Golden Games: My Athens Experience

The Athens 2004
Paralympics....

by Claire Williams

A phase that has dominated my life for the past year and a half is now all but what seems like only a pleasant dream. I am a little puzzled as to where to even begin telling you my account, but in the words of wise Maria von Trapp, I'll start at the very beginning "because it's a very good place to start"!

Unlike the majority of the 160 strong Team GB, I had very little time to prepare for the Games.

I only realised the possibility of qualifying and competing in Athens in August of 2003 whilst competing along side many British Paralympians at my first international event, as a member of British Blind Sport at the IBSA (International Blind Sport Association) World Championships in Quebec, Canada. It soon became apparent with the standards set by UK:athletics that it wouldn't be easy and believe me, it wasn't!

Fortunately for me, at the end of August I was introduced to a man who



is genuinely one of the very best discus coaches in Great Britain, Jim Edwards. With the support of the Federation of Disability Sport Wales, it wasn't long before the possibility of participating in Athens became achievable and then came 2004, Olympic/Paralympic year... what a blur!

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- ❖ *Suncream Report*
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- ❖ *The Albinism Fellowship Day in Ireland*

Editorial

Congratulations to Treasa O'Callaghan and her team in Ireland for the successful event last September. We have a report and photographs from this event. The trustees of the Fellowship are seeking to support the development of such regional group meetings. We have groups based in Scotland and the London area and would like to widen the BBQ-type informal meetings to other parts of the country. We envisage the development of Contact People on a regional basis will help this process. This process is now actively moving forward and will be the focus of our next magazine. Another means of connecting people with albinism is the Forum which can be accessed via our website. We have an article in the magazine that gives you more details. We realise of course, that not everyone has or desires the internet facility, but for those who do have it, the Forum does have great potential to allow people to connect with each other in a way that was not possible before.

And for those of you thinking of connecting a mobile telephone service we have some ideas on what to look for in a mobile phone, a few models to ask for and some of the issues that anyone visually impaired buying a mobile might like to consider.

And of course, a major opportunity for connecting with others with albinism will be at the Albinism Fellowship Conference, more details inside. There are lots of reasons for making the effort to attend, but for me the most



Robin Spinks hands back the job of Presidency to Mark Sanderson (taken inside Raddison Hotel Edinburgh)

important is that my daughter grows up with an awareness that there are many others just like her.

We have some feedback from members who have shared their experience of which suncreams they prefer and why they like them.

Lorna Stacey asks 'What's stopping you?' with some personal experience of her challenges. We would love to hear of your own experiences that we know will give inspiration and confidence to others. Barabara Porter has news of her 'Ring of Hope' after cataracts.

Mark Sanderson is welcomed back as president and our thanks go to Robin Spinks for his spell in the top job. (see picture inset).

There is comment too on a comedian's joke and some thoughts on how we respond. We would be interested to hear your views on this and if you don't feel entirely confident about putting pen to paper, just tell us over

the phone and we could write it for you. Articles and photos are always very welcome. Any format, email, post or spoken word will do!

Editors are Martin Lang and Hilary Hill

We'd love to feature a page of photos of members involved in interesting activities or experiences in the next magazine – so please send in any of you or your children that you think we could use. Any format – electronic or print (all prints will be returned).

Ireland Day Report

Treasa O'Callaghan is the Albinism Fellowship contact person for Ireland. Treasa writes...

"The Albinism Fellowship Day on 11th September was a great success. Over sixty people were present from the four provinces of Ireland. We had the privilege of having Robin Spinks, Gill Walker and Lorna Stacey, of Albinism Fellowship present. They came all the way from London and from Edinburgh to join us!

Dr. Michael O Keefe F.R.C.S., consultant eye surgeon, Mater Private Hospital, Dublin enlightened us with his talk on albinism. He also answered a variety of questions with excellent professionalism and positiveness.

Robin's speech was indeed also very uplifting. A parent of a four year old boy commented that she was so happy that her boy would grow up and be like Robin!

I received positive feedback from people who sent me text messages like "congrats on Sat., great job, good day, well done" Patricia

"Many thanks for organising today. It was lovely to meet with the group and talk to someone who knows exactly



Treasa and Gill

what challenges we meet and mostly overcome. Kindest regards." Carmel.

People enjoyed mingling and sharing experiences. The Doheny sisters from Limerick met other teenagers with albinism for the first time. Sandra Graham from Carlow who has albinism was delighted to get the opportunity to meet other adults with a similar condition. Sandra is also the parent of two young children with albinism.

One young lady commented that she dyes her hair red to conceal her albinism but after meeting and



listening to people at the albinism day she felt she no longer would do so.

I am looking forward to our next get together day in the summer. I am also hoping to attend the Albinism Fellowship Conference in Edinburgh in November this year.

Last year I raised €1,200 for Albinism Fellowship with the help of friends and associates. We walked the women's mini marathon. This year I am planning to do likewise. The money mainly goes towards the funding of the conferences. In the future, sometime, maybe a conference could be held Ireland!

As you are well aware, the Albinism Fellowship has achieved an awful lot and has opened a new world for many of us here in Ireland.

Sponsorship cards for the marathon can be obtained from me.

You may contact me at **treasaocallaghan1@eircom.net**.

The women's mini marathon takes place in Dublin on the 6th June 2005. Entry forms will be printed in Evening Herald from Thursday 10th March with the closing dates for entries being Friday 29th."

We would just like to add our thanks to Terasa and others who helped the day be so successful, may it be the first of many. Eds.



The Golden Games: My Athens Experience

by Claire Williams

Continued from front cover

In June every year I curse myself for not choosing rugby instead of Athletics because unlike rugby, the Athletics season begins in May and ends in September with the main competitions in Great Britain being end of May and through June and for anyone who has sat their GCSE's, AS or A-level exams, you'll understand what I mean when I say that this isn't exactly the best time of the year to have to compete. At the end of March I was whisked away to Lanzarote for 10 days of warm weather training, to come home just to have to pack my bags again for a fortnight of warm weather training in Paphos, Cyprus. Qualifying competitions began almost immediately as our squad arrived back from the sun. These took me all over the UK and to Belgium with the last and most important competition of all being the British trials in Birmingham, 8 days before my first GCSE exam.

At that time, having not thrown the qualifying standard, I felt almost as if the world was about to end with the prospect of being selected close to nothing and a detached feeling from the learning environment I left behind in March. Feeling cheated out of my exams – which should have been priority for me at the time – by the seemingly false hopes I had carried with me since the previous August, I

arrived home feeling sick with disappointment, with nothing to look forward to but a week of revision cramming and a month of exams. That was, until Thursday of that week when I received a phone call advising me to check the BBC Sport website where I found my name amongst the 36 names of athletes who had been selected to represent Great Britain in Athens 2004. Relieved, I happily continued with my week of revision cramming and exams knowing that whatever would come of my GCSE's, I had achieved one of my goals for 2004.

The three months left to prepare soon flew by and before I knew it with enough Adidas clothes to open my own warehouse, Boots' yearly supply of factor 60 and 4 A*'s, 6 A's and 1 B bagged, I was back on a plane to the Athletics team holding camp in Cyprus, but this time for the real deal. The hard work had been done and for the majority of athletes was about to pay off as confident and excited, the team in dribs and drabs – with me being the very first as I had to undergo classification – moved into the Olympic village in Athens, and boy was it impressive! A mini city set in the middle of the mountains, secluded and secure from the outside world. 10,000 volunteers, 4500 athletes and over 3000 team officials from 136 countries, a dining hall which sat 6000 and best of all... unlimited Coca-Cola and McDonalds!



Aware of the problems that had arisen for the organising committee before the Games; completion of venues, ticket sales, transport issues, what seemed a never ending list of problems that stood as a threat to spoil my experience of competing at my first Games soon disappeared as the Opening Ceremony proved to be nothing less than out of this world!!! For the first time in the history of the Paralympic Games, the athletes and team officials – all 7500 of us – were taken to the stadium by police escort along roads which had been closed off especially, privileges reserved for only Olympians at previous Games. There are very few occasions in my life when I have been left speechless, but one experience I will never find words for, is to describe is the way I felt walking into the Olympic Stadium filled to the roof with 95,000 spectators to the Cue of “Great Britain”. The deafening noise, the lights which literally lit up the sky around the stadium and the fireworks display like no other fireworks display I had ever seen before, were all tasters of the level at which Athens

2004 had been organised. Ultimately the fears and stories that surrounded the lead up to the Games proved unfounded as the Greek people put on a show that reminded us of what we were there to do; to represent our countries on the biggest sporting stage in the World, and so was lit the flame to mark the beginning of what has become known as the Golden Games.

Competitions began within a day of the Opening Ceremony, but for those of us who didn't have to miss the ceremony because of competing so close to it, it was just a matter of waiting from then on. I had already reached my sporting goal for the year, to qualify for the Games was all I had to do, no emphasis had been put on my competition as I had been taken to gain experience in preparation for Beijing, so I found myself getting a lot more nervous for my team mates – many of whom had become close friends by then – as I knew the work that they had put in over the last four years and more, all for 6 throws or 100metres or two lengths of a swimming pool, to prove themselves the best in the world. Our accommodation in the village was apartment blocks with up to 8 in each apartment. When you are living within such close proximity to 7 other athletes who are all feeling the same pressure, the same nervousness but who deal with it in all their own ways, it is very easy to let yourself get carried away in their emotions. I found myself sharing the highs and the lows, the sheer boredom to the feeling of being on top of the world, but there came a point where I had to switch off, because the day came when it was



my turn to compete. Surprisingly I felt nothing but excitement, because at that point I knew there was nothing more I could do which would have any effect on the outcome of the competition. My aim was to throw the discus to the best of my ability.

Frustratingly, I was unable to see any of the score boards around the stadium, but that was what I did, having thrown in the third round the second best throw of my life to finish fifth in the competition out of nine. I couldn't have cared less about the finishing positions because all I was interested in at the time was the satisfaction I got from knowing that I had succeeded to perform under those conditions, something that I am able to take on with me to Beijing, the Games where I will be in serious contention for the top spot on the podium.

Time soon flew after my competition and before I knew it, a walk to the Acropolis, a Closing Ceremony and a few thousand Big Mac's later, I was 17 (wondering of course by then where 16 had gone to) and arriving back in Gatwick to a press conference and a mad attempt to try and catch up on

the month of AS work I'd missed.... yet even knowing what I know now with 10 weeks before my AS exams and slightly regretting not being in those lessons, I would gladly miss them all over again! Athens was something that I'll never forget and is only the beginning. With all that I learnt and the experience that I gained from having the opportunity to compete at the Games and with the support that I have behind me, I have the belief and the determination to go on and be able to achieve what ever it is I want to achieve and what I want is to be the best in Beijing. I don't feel there would be a point in me continuing if I didn't aim to be the very best that I can be; World champion, World record holder, Paralympic champion, and as far as I'm concerned that is true for anything in life. Whether or not I become World champion or World record holder or even a rocket scientist, for that matter is another thing, but I refuse to let common belief determine what I am able to achieve. I set my own limitations and will continue to do so until maybe one day in 2083 when I will be a little old lady in my rocking chair and someone will notice my Athens 2004 tattoo and think, wow she really achieved something in her life. Writing this has given me a great opportunity to reflect on the year gone by and is a happy end to what has been a wonderful chapter in my life. Thanks for letting me share with you some of my many cherished memories of representing Great Britain in Athens 2004.

Claire Williams

Suncream Report

We asked in a previous magazine for you to tell us about the suncream you like to use. I have to report that we weren't exactly overwhelmed with replies, but it is still worth sharing what you have told us. I also posted a question on the forum on our website (see other article). Thanks for your input too.

Deirdre tells us that they use Vichy with a SPF of 60. Treasa O'Callaghan's family use Vichy 60+ and like it because it goes on smoothly and works in water. Bryony (aged 9 years) likes Sensense Ultra, from EGO Pharmaceuticals (UK) Ltd, SPF60. She likes this because 'it goes on very easily and is milky not gloopy. Non whitening and smells nice.' This was made originally for the Australian market and is the one that the Lang family use. We used to get this in 400ml bottles with a push dispenser. We haven't been able to get it in the larger size for a while, getting smaller sizes via Boots sometimes takes a week or two since they have to order it for us. The smaller roll-on size is particularly useful since it fits in a handbag, good for teenage girls. Brigitte likes 'the roll-on which is great for my kids because they like doing everything themselves and I don't have to get my hands sticky!'

Robert Crisp (also 9 years old) uses 'a Proderm mousse (Factor 30). I wear it between February and September. I really like it because it doesn't sting and it soaks in'. Genevieve Crisp, (that's mum) notes 'we've tried

various sun screens, but find the Proderm definitely the best.

Because it soaks in, it doesn't leave a 'ghostly' shadow, and it provides up to 6 hours' protection. This year, we braved warmer climes on holiday for the first time ever (Canary Islands in April and Northern Portugal in August), and despite many hours in the pool, the sun screen did the trick (together with sun hat and sun suit) Robert didn't catch the sun. Some sun screens have caused a transient stinging on Robert's face – the Proderm isn't brilliant for this, but Robert tolerates it because he likes the mousse preparation so much.'

Sam Brian uses Simple's Children's Sun Cream SPF 35. She is allergic to perfume, paraben preservatives and some oils and lotions. 'I have the least rash reaction from this to all others'. They won't allow it on prescription here unfortunately. It costs £11, for Sam who is an adult and sons aged 11 and 8.

Most people in the Fellowship get suncream on prescription from their GP. Children under 16 or in full time education are exempt from prescription charges in the UK. It appears that in Ireland you have to pay for them. Martin Hill tells me he prefers Sensense if he can get it, otherwise he uses Ambre Solaire Kids SPF 60, which he finds it quite thick to apply but its fairly odourless, and Jane agrees, she has been using Ambre Solaire 30, 'It is ok. I hate all suncreams, they make you sticky and

ruin your clothes. Hoping someone might come up with a good one’.

Una writes on the forum that ‘we have just started using Ambre Solaire Kids ultra milk, SPF 60, thin & fragrance free, presume it is new out as says new on the bottle!! Have been using No Ad factor 45 odourless for Dan, very thick though and No Ad kids factor 30+ for Katie as it is really thin and smells of bubblegum.’

‘Coppertone sun & splash factor 30 is a 6 hour waterproof cream that works really well too but the smell screams sunscreen. I have given up with E45, too thick and ruins everything, also ROC as Dan became allergic to it. By the way do you know Asda sell both the Ambre Solaire & No Ad for less than £3 a bottle, handy if you are in a hurry, I didn’t bother with a script this year and No Ad protected them well in Arizona. I wasn’t so happy with the coloured ambre solaire that I sent into school, she came out with green collars every day!! Ambre Solaire is only £2.98 in Asda too.’

Helen P picked up on earlier parts of the discussion in the forum to say that ‘For the past 2 summers we have used No Ad from Asda because it is cheap and effective – nice big bottles too! Someone gave me a bottle of the coloured Ambre Solaire which was great as we could see where we had been when spreading it on the children, but it is a bit expensive to buy normally. Oh yes, I forgot about that – the coloured Ambre Solaire stained my daughter’s clothes too! The No Ad is the winner then, in our house!’

And finally Ozan says ‘our son was born in USA and his paediatrician recommended Waterbabies SPF 45. We have been using that one. But it is very thick and ideal for swimming. We are also happy with Nivea Children’s sun spray 30.’

Thankyou everyone for your comments and my apologies if I have misquoted you in my attempt to make the sunscreen flow and soak in... groan, groan!

Hi

I’m Michael. I like to ski and I am six years old. It was very bright and sunny in France so I had to wear sun specs under my goggles and lots of sun cream. My mum had a suit that I could see but I sometimes still got lost. We saw a lady with a bright orange jacket that I could see and it was easier to see.

We got very dark goggles but unfortunately we got them at the end of the ski holiday, which was irritating. The chairs were fast, very fast, so they had to help me on. When there was a hole in the snow, I didn’t see it but as I got closer, I saw it and turned away.

We had lunch inside so I didn’t get burnt and I wore a helmet so my head didn’t get burnt. I did a few black runs and even the hardest one in the resort!

Michael Hudson aged 6, Edinburgh

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For preferential rates, why not join Albinism Fellowship now?

See www.albinism.org.uk or call 01282 771900 for joining details.

MORE INFORMATION

- Registration details will be mailed to members of Albinism Fellowship Summer 2005 and will be on our website in July.
- To view travel & hotel details, the provisional programme, exhibitor and sponsorship opportunities, or to see how you can help, look up www.albinism.org.uk

New Trustees for the Fellowship

The Fellowship is seeking three new trustees to join our team.

In particular, we are looking for individuals who can demonstrate knowledge, personal or professional experience, skills, ability and interest in one or more of:

Fundraising: Co-ordinating fundraising for our priorities, encouraging fundraising amongst our members, as well as practically applying for grants from trusts and donations from companies.

Website & Print Information: Updating our print and web based information regularly. PC skills are required but you don't need to have knowledge of

web design, as you'd liaise with our Webmaster.

Events: You would assist Mark Sanderson with this year's conference, and gradually get involved in organising future ones, as well as encouraging and publicising local events being run by our Contact Persons. Experience of managing events would be helpful.

Interested? Then call Mark Sanderson for an informal discussion, see our website or telephone 01282 771900 for an application pack.

Closing date is Thursday 30th June 2005

Real Lives Conference: Ways to Help

We need volunteers to help with the following aspects of this year's conference.

Registration: Two people to assist Joan + Les Sanderson with the Registration & Information Desk.

Exhibition: One person to assist Lorna Stacey in arranging our exhibition & supporting our exhibitor's at the event.

Panellists: Three people with albinism and three parents of all stages and ages related to the condition for a family issues panel.

Also for a panel, people with experience of early years, education and work issues related to albinism.

Hosts: People with experience of the conference to 'buddy' new visitors.

Chairpersons: Three people to chair discussion groups for people with albinism, families and friends, and young people.

Fundraisers: We still have money to raise, to make the event possible, even taking into account delegate's fees. We aim to only pass on the costs of catering at the event to delegates. If you can fundraise specifically for the conference please assist.

Can you help? If so, email info@albinism.org.uk or call 01282 771900 to tell us how.

Choosing a mobile phone

In the autumn of last year when we were planning for this magazine, I too hastily volunteered to write an article on mobile phones. I don't have a mobile, but I thought... my daughter's getting one, so I will be researching information about them. I thought that after my research I would be able to recommend a few good examples in different price bands. Not so.

I looked around and monopolised shop assistants time midweek when they weren't so busy. I decided on one that was probably the best buy for her in our price bracket. It had clear fonts, giving good contrast on quite a large screen. So one Saturday we went to town and we saw, as luck would have it, this phone at half the price in a shop that I hadn't visited.

My elation soon evaporated when Karina had difficulty reading the screen. There were despondent looks between dad, daughter and the helpful shop manager. The texting facility is of course, crucial for teenagers. We explained what we needed and the manager went to rummage in the back of the shop and returned with one of a new delivery of phones with which he wasn't yet familiar. This one, a Sendo, has white writing on a dark background and was just what we wanted.

The buttons are very small, even for me, but Karina quickly learned the keypad. The screen was more important than the keypad as many

teenagers will tell you that they can send text with their eyes closed. As a parent of a teenager with albinism I still get surprises. What I thought would be ideal was actually of no use at all.

The phones are changing so quickly that any specific advice is likely to be quickly obsolete. So my advice is to shop around. If you are looking right now or soon, you might start by looking at the Sendo, Nokia 9000, and a Nokia 3510i (although this is a bit old now).

Robin Spinks informs me that the Samsung E700 is the mobile of the moment for people with albinism, he has one now and has met four others with the same phone who like it because it is very easy to read the large text TFT display. And a comment from Lorna was interesting too – she wouldn't change her phone because she knows how everything works without looking, and to learn a new format would be a nuisance, so she has kept her phone. So if you are buying one, consider that you might wish to buy a better one and keep it for longer.

I have posted a question on the Forum asking which phones people use and which ones they would recommend.

And of course, don't forget to ask about what the small print says. Comparing the tariffs is another story.

Martin

The Fellowship Answerphone

If you phone the Fellowship answerphone we do our best to get back to you within the four days or at most a week. As we become more widely known we do get some calls from people that fall outside the scope of our remit. On more than one occasion we have had people phone up desperately seeking 'albinos' for one thing or another. (If you have albinism and you want to be a model or actor/actress then you should get on an agency's book, since you will pick up some work, if our telephone calls are to be believed). There is sometimes reassurance that it is all in the 'best possible taste' and 'could you organise it for tomorrow?' Sometimes we don't know whether to wince, cringe, get angry or laugh at their incredulity.

By way of contrast, not long ago a journalist inquired if we knew about the Kuna Indians of Central America. Well I knew a little, I knew the incidence of albinism in their people

was high, but specifically I didn't know whether there were more boys than girls. This journalist had spent several days with them, but had only realised back home that she had not met any girls with albinism. She was wishing to double-check her facts and doing a very thorough job (If only all journalists were so professional and sensitive in their approach). After some research consulting a geneticist, our Rick Guidotti was able to confirm for us, and her, that he has photographed girls with albinism in the Kuna People. So one question answered, but another one raised, why hadn't she seen any girls with albinism on her visit?

If you would like to talk to someone we are here to help and even if we don't know the answer off the top of our head, we will do our best to find it out. Just one request – if you leave a message, speak slowly when giving the contact details.

The Forum on our Website

The Forum is a new way for members to interact by posting questions, replies and comments to each other. There are three discussion forums. A general forum where members may post comments and anyone on the internet can read the comments. A members area where only members of the fellowship (after registering) may post or read comments and a forum for committee members. In each of these forums there are many different discussions. For example, I initiated a discussion last autumn in the general forum asking which suncream people use. Many people have followed on after my initial question and added to the discussion by offering their own advice from their own experience. The postings stay up for other people to read and to add comments. I have used some of the comments made in the general forum in the article on suncreams.

For me, such sharing of information is invaluable. Most discussions have, so far, taken place in the general forum, but you may, if you wish, have the discussion closed so that only Fellowship members read it and not just anyone from on the internet. When I visited the Forum in February, there were 67 people who had signed up to the Forum. If you have internet access, do have a look at the forum. It did take me a little time to understand how it all worked, but now I think it has great potential. For example, we had an inquiry in February from a family intending to go to Tenerife at Easter. They wondered if any other families in the Fellowship may have already visited Tenerife and if they had any advice to pass on about UV protection levels and places to visit. I have placed several questions to ask if anyone has any advice on several issues. Not only can you learn about what others have found useful, it is also a way of 'paying it forward', offering useful advice to others. Perhaps a word or two of caution is in order. Although we haven't experienced any difficulties so far, it is worth mentioning that on the net some people are not what or who they purport to be. The members area, though not as immediately accessible, is a more secure place in which to exchange views.

I should perhaps just add that the site is monitored by moderators who check that there is nothing inappropriate in any of the comments. If anyone did write anything inappropriate, the facility does exist to remove the comments and block the individual from the forum in the future. Current issues and questions to whet your appetite are suncream use, mobile telephones, a good place to visit, hot sunny climes and cheap flights to Edinburgh in November.

The Joke's on Jimmy

Some of you may have seen the comedian Jimmy Carr on Jonathan Ross' Friday night TV show in the autumn. Being a guest on the show, the programme viewed a couple of his jokes from his video that was on sale before Christmas. The second of these jokes left me with my jaw on the floor, and a mixture of bewilderment and anger. Some of the jokes involved real adverts that he had put in personal columns. One of these was, "Albino, seeks similar". His punch-line was, 'If I get two replies, I'll fix them up on a blind date'.

I am not for censorship and I do recognise that there is humour in everything. When my daughter walks or bumps into something, it is something of a family joke of who will be first to say 'get your eyes tested'. Of course, we are attempting to laugh it off with her, rather than make a joke at her expense.

As I reflected upon Jimmy Carr's joke in the days that followed, I wondered why people laughed at the joke. Was it somehow the image of two people turning up on a blind date with white hair or were they just laughing at

people who are different? Or did the audience understand the play on words for 'blind date' and people with albinism being partially sighted? And I thought, does that mean that most of the population understand that people with albinism have poor sight? If it does, that in itself would be interesting. I am still left with the feeling that to laugh at someone, with any disability is in poor taste. Needless to say I didn't buy his video.

And as for his replies to the advert, being in the small print ads (N8?), I doubt any people with albinism will actually have read it, since it would have need to be in larger print! Someone should tell Jimmy that those who laugh last, laugh longest.

Martin Lang

The Fellowship does challenge prejudices/attitudes where we think it is appropriate. There are however, some instances where individuals intentionally set out to offend and it is obvious that no amount of persuasion will alter their poor judgement. Some people are rude and won't ever apologise and the damage has been done. Sometimes it is better to spend energy in a direction that will yield positive results.

If something has offended or upset you we encourage you to respond to the people or organisation concerned and copy it to us.

Letters

We are very interested in the Bioptic Driving for our 12 year old son Shane, like Sebastian (From the article) Shane is mad about cars, always has been. So please keep us updated! Shane was diagnosed with albinism when he was six weeks. We lived in the Netherlands at the time. We are very impressed with all the help Shane has received in school (in the U.K. we moved when he was 2). From the age of 7 Shane has had touch typing lessons in school. When he started senior school in September he was ready to use a laptop in school for most of his class work. Shane is a child who is not afraid to try anything new and his vision has never stopped him from cycling or playing sports. We cycled to Junior School most days of the week and after carefully observing him for a number of years I am very happy now to let him cycle to Senior School on his own. It gives him great independence too.

Thank you for all your magazines.

Mrs Leanne Dickinson.

What's Stopping You?

So here I am at the grand age of 21 (ha ha) and I am learning to roller blade. You might think I am revisiting my childhood. I used to have some smart blue roller boots with orange wheels and could go all the way down my road backwards. Actually I should say pavement in case my mum reads this. As an adult I am much more wary of falling over although so far this has only happened indoors at a party! I also have a much better understanding of how having albinism makes some aspects of skating more difficult.

The amount of sunshine, glare and shadows can affect how fast I feel safe skating and also how easy it is to notice and judge bumps in the ground and if you look down all the time it is hard to be in the right position. Actually speed is a big issue, as I haven't quite mastered how to stop! But I am getting there and this is because I have a great teacher and have found a safe place to skate on a basketball court in a local park. I think I have got to a point in my life where I am no longer self conscious about doing things the same way as everyone else and I just want to enjoy myself. Wearing the right protective clothing is important because I am more likely to fall over having skated over a twig I haven't spotted (wet twigs are better than dry ones). I have found getting the right sunglasses difficult.

As a child, cycling was a big issue for my family and me. It was the cause of many arguments. I now have a silver bike with 'respect' written in red and I have learnt to respect some of my own limitations and my parents concerns. I avoid right turns and roundabouts and don't cycle in traffic and use cycle paths if possible. On holiday last year I cycled 34 miles on a disused railway line and I would recommend this as a great way to cycle or to try cycling without the worry of traffic (I always wear a helmet with a visor).

Some of the other activities I have tried have been Llama trekking and white water rafting I belong to an outdoor activity group and can often be seen getting caught in yet another unspotted bramble. I would advise anyone wanting to try something new to give it a go but also to get good information about the activity so you can try to overcome any difficulties by discussion and planning ahead. Sometimes it is hard to know if something is impossible or will open up a whole new world unless you give it a try. PS don't forget sun protection and a camera just in case it is an experience you don't want to repeat.

Lorna Stacey



**Jenny Walker-Morrison
skating with Lorna**

“RING OF HOPE”

Barbara Porter writes about her experience...

Having survived albinism and its associated difficulties for nearly 64 years when there were no special aids or counseling available, I was under the impression that my sight would NOT deteriorate. So when objects as big as our Town Hall clock disappeared from view I decided that I'd better get some new spectacles.

Imagine my feelings then when the optician told me that I had aggressive double cataracts, and laid out the options frankly and fairly. Having a totally blind husband who depends on my own partial sight, I decided that I would pay to see a specialist, rather than be put on a hospital waiting list as time was not on my side.

To cut the story short I saw Mr Lavin at his consulting rooms in Manchester. He told me that although there were the inevitable risks, he could put light reducing discs behind the iris that would cut down the light entering the eyes when the defective cataract lens was removed. I said that because he had given me such hope, that I would pay for him to do the operation. This was in March.

By the time I entered Manchester Royal Hospital in May, the vision had deteriorated to hand movements only in both eyes. It was decided to do the right eye first, as it had always been the worst. By the time I left the unit, I

could read three lines down, and was told that the vision would improve.

At the time of writing I can read the large print from advertisements across the room as I'm still waiting for my right eye to have a lens added to my specs to bring it up to maximum acuity. A provisional date for the second eye has been arranged for September.

The light sensitivity in that eye has been considerably reduced, and I could peg out the washing without sun-glasses [on one of our rare sunny June days], and when the other eye has had TLC from skilled hands there should be a much bigger improvement.

If any more of you “out there” are having similar difficulties, I would suggest that you mention these discs to your consultant, because they have bought a great improvement in the eye that has been operated on.

One does have to put drops in for a month, but that is just a minor inconvenience compared to benefit that the operation brings.

After reading this Michael Lavin FRCS FRCOphth wrote this letter back to Barbara...

“Thank you so much for kindly writing regarding your experience. I thought your article was very well written and should encourage other people with your problems to proceed with surgery which certainly can be helpful.”

Fundraising Update...



Sally Evans with James
on the Flora run

Sally ran the Flora Marathon in temperatures over 30°C and raised a marvellous £311.

(We still have some of these T-shirts to sell – enquire if you'd like one... **SALE PRICE £7!**)

Many thanks too to all those who have fundraised for us or sent donations.

If you'd like to fundraise for us and require any materials or literature for it do contact us!

A ready-made sponsorship form can be downloaded from the website
www.albinism.org.uk

Money Matters

Thank you to all those who now have a standing order for £12 set up with the Abbey. The money will have been debited from your account on the 1st January 05 (unless it was a new instruction for this year and came out later).

We notice that some of you still have a standing order for £7 or £9 with the Bank of Scotland. This too will have been debited from your account on the 1st January 05. If this is your only standing order this needs to be updated to £12. Some of you have this and a new standing order with

the Abbey. This is fine by us – we really appreciate the extra donations, but we thought we should point it out as a matter of courtesy, just in case it was left there in error.

Thank you too, to all those who have now paid your subs for 2005.

If you haven't paid your £12 subs yet, please do so ASAP or else we will not continue to send you the magazine. The subs cover the cost of this and the various other mailings that we send out along with our (kept to minimal) admin costs.

Want to check out the UV index in the UK?

www.nrpb.org/radiation_topics/ultraviolet/uv_/data/index.htm

This webpage has a graph that shows how the UV radiations changes throughout the day. You can choose between several sites in the UK. It could be a useful aid for judging UV intensity both at different parts of the day and year.

London Summer Meeting and AGM

BARBECUE

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

When: Saturday 11th June, 2005

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 for map)

Travel: $\frac{3}{4}$ mile walk from Southgate Tube Station, Piccadilly Line or $3\frac{3}{4}$ miles from Junction 24 of the M25

Parking: Plenty in school car park

Time: 11.00am to 4.30pm including the meeting from 2.00 – 4.30pm

Everyone is welcome. Email us on info@albinism.org.uk or just turn up!

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!

Family Albinism Day Ireland 05

Date: Saturday 25th June 2005

Time: 1:30 - 4.30 (Arrival: 1:00pm)

Venue: St.John's G.A.A.Clubhouse,
Ballinteer, Dublin 16

Dundrum's new shopping centre, the biggest in Ireland is just 5 minutes drive down the road! Marley park is adjacent to clubhouse.

Directions: If travelling by M50, take Rathfarnham exit. Entrance is on the left at the 4th set of traffic lights a mile

from exit. The entrance is directly where Stonemasons way and Grange Rd. join.

The No.16 bus passes the clubhouse.

Bus Nos 14, 14A or 48A - take to terminus in Ballinteer and walk up Stonemasons Way towards Marley Park (about 8 minutes walk)

Tea, coffee, minerals and sandwiches will be provided.

Further info: N.C.B.I news magazine (after Easter) & www.albinism.org.uk

Treasa O'Callaghan



USEFUL CONTACT DETAILS



addresses / telephone nos. / websites / email...

Albinism Fellowship

PO Box 77
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01282 771900

Helpline: Tues & Fri 2.00 – 3.00pm

info@albinism.org.uk

www.albinism.org.uk

Membership Co-ordinator

(for any membership enquiries)

Hilary Hill
Albinism Fellowship

PO Box 298

Farnham, Surrey GU9 4XR

membership@albinism.org.uk

Albinism International

An online group for people to discuss their experiences of albinism.

www.groups.yahoo.com/group/Albinism_International

RNIB

105 Judd Street, London WC1H 9NE

020 7388 1266

www.rnib.org

Partially Sighted Society

Queens Road
Doncaster DN1 2XA

01302 323132

www.leeder.demon.co.uk/LHON/uk-pss.htm

Nystagmus Network

13, Tinsley Close,
Claypole

Newark

Notts NG23 5BS

01636 627004

info@nystagmusnet.org

www.nystagmusnet.org

Positive Exposure Project

Rick Guidotti

43 East 20th St.,
6th Floor

New York, NY 10003

001 212 420 1931

rick@positiveexposure.org

www.rickguidotti.com

RNIB Learning & living with Albinism events

The Fellowship's have been commissioned by RNIB to provide 5 one day training events about albinism and education issues.

Cardiff	Tuesday 14 June 2005	029 2045 0440
Edinburgh	Friday 9 September 2005	0131 311 8500
Leeds	Tuesday 27 September 2005	0113 274 8855
London	Monday 21 November 2005	0207 391 2245
Birmingham	Wednesday 8 March 2006	021 665 4200

The events are open to parents as well as education professionals. To find out more or to book a place call the above numbers.