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# Announcing... Family Weekend Conference 2013

## **Ribby Hall Village (near Blackpool), Lancashire**

We are delighted to announce our plans to run another family weekend conference. It will run from Friday 11<sup>th</sup> October to Monday 14<sup>th</sup> October 2013.

The event will begin with key social activities on Friday evening, a semi-formal conference on Saturday, whole family activities on Sunday, and the option to stay over to make a long-weekend of it until Monday.

The event will take place at Ribby Hall in Lancashire. The site offers an excellent range of accommodation types and facilities - a little like a mini Centerparcs.

Our conferences come highly recommended. It isn't just about the more formal parts; it's the chats over coffee, the children playing together and the relationships started with other families that can be so valuable. The conference is an opportunity to learn from others, share best practices and boost confidence and self-esteem. Many who once attended as children are now adult delegates. We cannot promise to find a solution to any question you may pose at the conference, but you will get a selection of the best tried and tested ideas from others who will have faced the same challenges.

A number of people have told me in the past that they were nervous and apprehensive before arriving at a conference. And then they add that they were so glad that they decided to attend. If you are undecided, ask others who have attended one of our conferences in the past; it could be a life changing opportunity for all of your family.

## **Programme**

We are still working on the programme of events, but it will include:

- A range of presentations on key topics relevant to albinism.
- An exhibition of equipment, aids and services.
- Family social activities.
- Leisure activities including music, arts and crafts workshops.
- A crèche and activities for older children during the main conference.

## Fri 11th – Mon 14th October

There will be reduced delegate fees for Albinism Fellowship members so if you are planning to come to the event and are not a member it's well worth joining now.

The delegate fee will cover catering during conference.

The people at Ribby Hall should be able to answer most of your queries regarding booking accommodation, but if you have any other queries please email these to [conference@albinism.org.uk](mailto:conference@albinism.org.uk) or call 01282 771900.

If you have any suggestions as to what you'd like to see at the conference please email them to [conference@albinism.org.uk](mailto:conference@albinism.org.uk).

### Accommodation

You can now book **accommodation** for the conference.

Accommodation is in a variety of different self-catering cottages on the village site. Prices range from £ 387.00 (4-berth) and £ 400.50 to £ 539.10 (6-berth) depending on the type of accommodation chosen. Cottages are priced for the whole weekend, Friday – Monday.

There is also an adult-only spa hotel and a 'Motel' style hotel on site. Ask the bookings team at Ribby Hall about this if you wish to choose this option. More details of the accommodation types available can be found on the [Ribby Hall Website](http://www.ribbyhall.co.uk) or [www.ribbyhall.co.uk](http://www.ribbyhall.co.uk).

### How to book

You can book accommodation by calling any member of the Reservations team on 01772 671111. You must state that you are calling to book a cottage held under **Albinism Group** or quote booking reference **7529** to make sure you receive the relevant discounts. All that is required now is to pay a £75 deposit per cottage. The balance will be due 6 weeks prior to the event (approximately the end of August).

You should be able to still book guaranteed accommodation at Ribby Hall. (It depends when this magazine reaches you). Soon the cottages currently reserved for Albinism Fellowship will be made available to the general public.

# Event round-up: Christmas Party

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The Christmas Party was a big hit with our youngsters.

The children's entertainer called Brek, had children dancing at one point and then spellbound the next. Adults watched and chatted, enjoying how this entertainer had captivated the children. He did some magic tricks, a finale that included pulling a rabbit out of a hat. Well, I can't actually remember what he pulled the rabbit out of, but I do remember that it was an albino rabbit! That was an interesting moment for all those watching, for all sorts of reasons!

(You may note that we think it permissible to define the rabbit as albino.)



## - with special guest

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We were very lucky to have a visit from Santa. Some people said that this was his helper and not the real one, but I think it was the actual man himself. He distributed presents to the children who were all very well behaved.

Many of the adults had a chance to swap stories and exchange ideas as the children were entertained.

Thanks to many people who helped out and to Lorna for organising the event.



# Nottingham AGM

We held our AGM in Nottingham this year. We try to move the AGM to different locations in order to allow more members to easily attend on at least one occasion. As you can see we had lots of fun here too. Check out



## - faces and friends

the expert face-painting, I can barely recognise what should be familiar faces. Once again, as the children were occupied, parents, grandparents and friends chatted. For some it was time for catching up, for others it was introductions. Thanks to Jo for the organising, we are hoping we may use this location again for a regional meeting.



# Young Driver Experience

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## Jack Fellows takes to the wheel of a Seat Mii at Stoneleigh Park near Warwick



A few years ago we read with interest an article about Karina Lang who took to the wheel at an off-road course and had a fantastic experience driving for the first time. This was one of those articles you read and think 'I will remember that for when Jack is older'. Well that time came recently; Jack's friends

are all talking about emergency stops, hill starts, theory tests and the like and whilst Jack scored higher than his friends in the theory test online he has not had the chance to experience driving a vehicle.

For Jack's 17th birthday we contacted 'Young Driver' via their website [www.youngdriver.eu](http://www.youngdriver.eu) to book a driving experience in the Midlands. We emailed Young Driver to determine what arrangements they have in place for youngsters with a visual impairment - they replied by return to say they would be delighted to host a session with Jack. They would make the driving instructor aware of Jack's visual acuity and he could drive with the other participants around the off road course. Fantastic - we booked the venue that day and just hoped the snow didn't return for Spring!

Stoneleigh Park in Warwickshire is a great venue for the youngsters. Plenty of track to drive around, two way traffic along with junctions and obstacles (see the tree to the right!!). Young Driver use new Seat



vehicles from across the range with dual control. The events are located across the UK and it seems are generally held in 'public' places that are large enough to set out a driving course. Jack, like all the youngsters on the day, had a one-to-one session with his instructor who took him through the basics of vehicle control and most importantly - how to stop the vehicle once in motion! Sessions are either 30 or 60 minutes and allow the 'recruits' the opportunity to experience handling and controlling a vehicle in a safe environment.



# Jack Fellows at Stonleigh Park

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Jack has always known his eyesight would prevent him from driving on UK roads and whilst he accepts this, he did want to know what some of his classmates were experiencing in their driving lessons. After 30 minutes of whizzing round the Stoneleigh Park course, the verdict from his instructor was 'He is a natural' - good clutch control, progressive braking and good awareness of other vehicles. (Jack did tell me though that he knew where the edge of the road was when he felt it through the steering wheel - glad it was a hired car!)



We had a great time with Young Driver at Stoneleigh Park and for the friends and family there was an old London Routemaster bus to shelter in with hot drinks on sale - the upper deck gave us a great view of the track.



If you have a teenager who would like the opportunity to experience driving in a safe environment then take look out for a one-to-one off road driving experience near you - see [www.youngdriver.eu](http://www.youngdriver.eu) for dates.

# Winchester GoalBall

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*In our last issue, we shared the story of brothers Adam and David Knott and their Paralympic experience. During the last month, our junior editor Lexi caught up with Adam again to find out what he's been up to since London. She had some questions to ask him:*

**It's been more than six months since London. When you look back what was the best bit for you?**

There were so many things that stick out for me – from arriving in the park, walking out for our first game to just an amazing crowd, scoring my first Paralympic goal, scoring a hat-trick against eventual winners Finland, to the closing ceremony – but if I had to pick one thing, it was right at the end: the “Greatest Team Parade”. No words can describe the feeling of seeing all those supporters cheering you through London. It was such a privilege to be part of such an incredible team!

**Did it take long for your life to get back to normal?**

It certainly wasn't easy. Straight after the Parade we went off to a reception with David Cameron, and much later returned to the athlete's village for one last night. I got home on the Tuesday, and had already missed a couple of days back at college. My Mum and Dad eventually persuaded me to go back on the Thursday, and my tutor group was great. They had a small celebration planned for me, but it really helped get me back into college and studying for my A level's again. Since then I've made some presentations at various events; from local sports awards, to many demonstrations at local primary schools. But six months on, and my main aim at the present time is to get my A' levels sorted so I can head off to Southampton University in October to study music.

**Have you got any big tournaments this year?**

We do. In September, we have the European C league Championships

# Q&A with Adam Knott

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that are going to be held in Worcester. It's a huge tournament for us, since we need to secure promotion to the "B" league. We need to make it to the "A" league to get into the Rio Games qualification tournament, so it all starts in September and I'm confident that with the squad we have now we can achieve promotion. In preparation, we have tournaments planned in Lithuania, Spain and Poland, as well as competing domestically across the country. It's going to be a busy year playing wise, but I wouldn't want it any other way.

## **I hear you've set up a new Goalball club – what made you do this?**

Yes, that's right. I really believe in trying to achieve a legacy of the London Games, and I am truly inspired by Goalball, and want to share this great game with more people. In fact, across the UK more than ten new Goalball clubs have been started! There was no club in Hampshire, so the best way for me to share my love of the game was to set a new club up. It is based in Winchester at my college, Peter Symonds, which has been really supportive of me and the sport. I've called the club simply: "Winchester Goalball Club".



## **How is the club progressing?**

We meet every other Saturday morning, and we're now up to 12 members aged from 8 to 43. But from small beginnings great things can happen. I've been fortunate that our local Rotary Club have given us some funding, so that's got the club off to a really good start.

I love coaching new players, and one of my new stars is young James in the photo, who I first met at one of the Paralympic Sports Fest's soon after the Games. I'm hoping to have a team playing in a novice tournament very soon, and I think James may be one of our future stars. Maybe we'll have a GB team of Fellowship members!

## **So how can members of our fellowship get involved in Goalball if they want to give it a try?**

The best place is to look on the Goalball UK website:

<http://www.goalballuk.com>

If you just click on the "Club Team+" link you'll see there are now over twenty teams across the UK. I'd just encourage anyone who may be interested to go along and give it a try.

## **Someone told me that all of Team GB and Paralympics GB are off to see the Queen this year – is that right?**

We are, and it was a real surprise. It's either going to be in late May or June; they haven't confirmed the date yet, but I'm really looking forward

## Q&A cont...

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to it. It's so lucky that both David and I were both in the team, as we're only allowed to take one guest, so fortunately both Mum and Dad can join us.

### **So what will you wear?**

Before the Games we had a launch event, and were each presented with a suit from Next, so all the team will be in their suits. David may have bit of a struggle though, as he's grown probably another 4" since then, and now his trousers are ankle bashers! I did ask mum what she was going to wear, but she said to me: "Adam, I don't even *own* what I'm going to wear yet"!

### **Can you send us some pictures to share next time?**

Sure (that's assuming we're allowed to take some photos). I'm looking forward to meeting up with lots of the Paralympics GB squad again, also our Olympic team – and who knows, I might even ask Kate if she's expecting a girl or a boy!

### **Can you get me Prince Harry's phone number?**

That might be bit of a tough one Lexi, but if I can't, will my brother David's number do?

**Thank you so much Adam, it's been great to catch up, and if you'll invite me perhaps next time I can come down to Winchester and join you in a club session one Saturday morning? Then I can get David's number for myself as well...**

## Fundraising

Many people fundraise and send us the money and we thank them. We would like to do more than this, thanking you in the magazine to give you a proper big thank you and to encourage and inspire others to do the same. So if you do something for us, please don't be bashful, send us a picture and the back-story and we will do our best to praise you and encourage others.

Thank you to everybody who has done any fundraising for the fellowship, big or small, it all adds up. This becomes especially important with the conference not far away. The more we are able to raise beforehand, the better the conference we are able to deliver.

Dan Hill our intrepid webmaster is growing his pony tail for us! (Photo next newsletter!) For each day he receives sponsorship he will not be cutting his hair, until conference when there will be a ceremonial snip to remove it. We are not sure who will make the cut, if you are a hairdresser, you may like to offer your services.

# Epic Electronics - by James Evans



**Over the past year** I have used three pieces of equipment that have really helped me and I want to share them with other people with albinism. I can only see a maximum of two metres in front of me and I read font size 36.

The Scala rider is a device that is designed to fit under helmets. It is normally used by motorcyclists so the driver can speak to their passenger. It has speakers next to your ears on the underside of the helmet and a boom microphone near your mouth. It means you can speak to someone far away without having to shout at them. I used a Scala Rider TeamSetPro for skiing so I could hear what my mum was instructing me to do. She was able to tell me when there were obstacles on the piste or steep drops on the side. Whilst we were there I managed to ski down my first red run. It helped me lots during the holiday.

The iPad has a camera function which means you can zoom in on what you want to see. I used this when I went to the Olympics and when I went to the pantomime at Christmas. The theatre staff were very understanding and we promised that we would not record the show. It meant that I could see everything that was happening on the stage.

I have had the problem of going on holiday and having to carry a ton of books with me. I now have a Kindle Fire HD which is like a miniature library so I can carry all the books I want. Also, I don't have to wait for my enlarged books to arrive from the RNIB library, I can just download them from the online shop. Usually, I can't read in the dark, but the Kindle has its own light source built into the screen, which makes reading in bed easier.

I hope this information is helpful for you and you will benefit from using these gadgets as much as I have.

# Still Going Strong (I think) - Bob Wright

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I am now seventy eight and am still going strong (I think!).

I have had a wonderful life. That this is so is largely because of my good fortune in the many people who have supported me.

First, my parents who fought over many years to ensure that I had opportunities to succeed. They ensured (along with two great head teachers) that I had a mainstream education at primary and grammar school level. This is all the more remarkable bearing in mind this coincided with the Second World War and the period of austerity up to 1952.

My education enabled me to train as a teacher and led to forty two years in education teaching up to deputy head level and to ten years as a peripatetic teacher supporting visually impaired children, the final six being head of the visual impairment service in Coventry.

I found a wonderful wife who has supported me wonderfully and wages a constant war to make sure that I do

not get too big for my boots. I have a grown up son and daughter and two grandchildren (none of whom have albinism).



Since retirement, I have worked for Art-Sense, a charity working for better access to art for visually impaired people and for a local mental health charity.

I have sung in good choirs for over fifty years. I love reading, art galleries, good beer and steam railways.

Yes, I have had a wonderful life. The keys are:

- Find people who believe in you and will support you (and that includes telling you the truth when you need to hear it).
- Never taking 'no' for an answer.
- Accepting that you have to work harder than most in order to achieve.
- Remembering that the glass really is half full!

## Medals for Christopher - see front & back page photos

**Congratulations** to Christopher Swatts who has been doing judo and entered his first big competition on Sunday - the Waterford Open. His coaches had entered him into his weight category but when the family arrived on the day they discovered that there was also a Judo Assist (Special Needs) category and the man running this arranged with his coaches for him to take part in this category also. He did very well on the day, winning the Gold medal in the Judo Assist category and then Bronze in the general competition for his weight range.

Well done Christopher! As his mom Sandra states, people should be encouraged to participate in activities that interest them.

# EVENTS - Irish Galore!

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## **Dublin Albinism Day & BBQ** **Saturday 8th June 2013, 1pm-4pm**

St. John's GAA Clubhouse/Cumann Naomh Eoin,  
Grange Rd. Ballinteer Dublin 16

Contributions of €5 individuals and €12 family towards  
cost of BBQ and venue will be requested on the day.

Please bring a cake or a salad to share.

**Booking required** - Please Contact:

Treasa O Callaghan, Contact Person (Republic of Ireland)

Phone: 086 3789294

email: treasaocallaghan1@gmail.com

## **Connect Albinism Information Days**

**Derry/Londonderry,  
Northern Ireland**

**Saturday 28th September 2013,**

**11am-4pm**

RNIB NI

First Floor

Embassy Building

3, Strand Road

L'Derry

BT48 7BH

**Newtownabbey  
(close to Belfast)**

**Saturday 25th May 2013,**

**11am-4pm**

Jordanstown Schools for children  
with auditory or visual impairments

85, Jordanstown Road

Newtownabbey

Co Antrim

BT37 0QE

Our annual event in the North-West.  
Information available and guest  
speakers provided on the day. Toys  
and games for children available.  
Lunch provided.

Your chance to see Northern  
Ireland's Specialist School for  
children with sight or hearing loss.  
Talks and information on services  
available on the day.  
Lunch provided.

**Booking required for *both* above Connect events -**  
Please contact;  
Rosaleen Dempsey, Contact Person (Northern Ireland)  
028 9033 4116 (Direct Line) 078 9574 0993 (Mobile)  
email: rosaleen.dempsey@rnib.org.uk

## London

**Summer Meeting & BBQ  
Saturday 15th June 2013,  
11-4pm**

Oaktree School  
Chase Side  
Southgate  
London N14 4HN

The format will follow our normal pattern of fun, food, and informal get-together.

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!

e-mail [info@albinism.org.uk](mailto:info@albinism.org.uk)  
or just turn up!



Christopher in action - see page 14

## Family Weekend Conference

### Albinism Fellowship

**Fri 11th – Mon 14th October**

Ribby Hall Village (near Blackpool),  
Lancashire

see pages 8 & 9 and website for  
more details.

We hope to see you there!

*Remember these don't happen  
every year so make the most  
of this chance!*

We need to raise at least £10,000 to make the conference what we want it to be. Can you help?

If we can raise this we can include in the event:

- Family activity workshops
- Crèche
- High quality sessions with speakers from around the world
- Social activities

If we raise more we can also offset catering costs which will bring delegate fees down for you.

Fundraising ideas or ways to help are on the conference page on the website.

If you can help, do let us know via [conference@albinism.org.uk](mailto:conference@albinism.org.uk) now!



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