

Paralympic News



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Editorial by Andrew Bennett

Our guest writer is Andrew Bennett; journalist, P.R. consultant and father of Jessica (aged five) and Rebecca (aged two) both living with albinism – and proud of it!

Now the Paralympics is over, there's been plenty of time to reflect. Many of us must be wondering – what will be the long-term legacy of London 2012? Or, *will there* be one?

It's a safe bet most of us in the Albinism Fellowship, including me, thought it was a fantastic event. I've been looking at media coverage to gauge whether the dedication of those athletes has changed attitudes towards people with disabilities. It helped that the games were screened on TV (Channel 4); while BBC coverage as with the Olympics would have been better, I can't recall previous Paralympics getting that kind of billing from a major broadcaster.

Nor does such widespread, overwhelmingly positive, media coverage come to mind from past events.

Disability rights seemed to have a potent champion when a *Daily Mail* online editorial in August said: "The powerful and rather moving message of the Paralympic Games is that disabled people do not wish to be either patronised or discriminated against. We obviously still have some distance to go before these two aims are fully attained."

The Mail was critical of 'a special, costly 0844 phone line' to book seats, which it called 'betrayal of a noble spirit'.

The Paralympic spectacle also captured the imagination of broadcasters, with BBC News correspondent Damon Rose commenting: "Some 2.7 million tickets were sold for the Paralympic Games and the amount of media and television coverage was unprecedented....After winning the final track gold medal of the Games in the Olympic Stadium on Saturday night, South African 'bladerunner' Oscar Pistorius said he hoped the success of London 2012 would boost the profile of parasport."

Following the games, sadly, it's been back down to earth, with a *Guardian* column about forthcoming cuts to disability benefits saying: "Just weeks ago, we were crowing over our Paralympians and discussing a new-found appreciation of disability.

"But always lurking were the looming cuts and a hardening of the public mood (towards people with disabilities receiving benefit)."

So while we perhaps took a few steps forward, attitudes still have some way to go.

- Contact Andrew via Twitter: @bennettwords or via his website, bennettwords.biz



Ireland Conference

The Albinism Fellowship held their first ever Albinism Ireland Mini-Conference in September. It was a great success, 200 people attended and many thanks must go to Rosie Dempsey and Treasa O'Callaghan for all their hard work. Thanks must also go to the Sensory Engagement Project, RNIB Northern Ireland and the Community Foundation for Ireland who generously supported the event. Thanks go to all the RNIB and NCBI staff and volunteers who made this event possible. Thanks to Patricia, Roisin, Danny, Joanne, Kirsty and Paula who helped or exhibited on the day. Thanks also to those who helped to make the day possible with database or promotion work; Ciara, Thomas, Joe and Marian Lewis who arranged and funded transport for several people travelling to the conference from the North-West.

The conference included a talk about the basics of albinism as well as discussion based panel-led sessions and an exhibition and a crèche for the children.

Rosaleen Dempsey, Albinism Fellowship Trustee and Contact Person for Northern Ireland said, "This was an exciting opportunity to raise the profile of albinism in both Northern Ireland and the Republic of Ireland and to let people living here learn more about the support and services available to them."

Sarah Chamney, Registrar in the Ophthalmology Department of the Royal Victoria Hospital, Belfast, previewed her research studies that have yet to be published. This was followed by a parent and pre-school panel discussion. Panellists were parents of children with albinism or parents with albinism.

Joan Curran, an Educational Psychologist working in the Republic of Ireland gave a talk on educational assessment for children with low vision associated with albinism. Her talk included useful tips for parents of children at both primary and secondary school and the Powerpoint she created for this is available on our website.

A 'Living with Albinism' panel was made up of adults with albinism involved in Paralympic sport, music, higher education and campaigning.

The exhibition area hosted services for both Northern Ireland and the Republic of Ireland. Among these services were RNIB Northern Ireland, The National Council for the Blind of Ireland, specialist schools for children with sight loss, parent support organisations and assistive and adaptive technology companies.



London Barbecue

On a perfect June day for people with albinism (i.e. not too much sun!) we had many of the usual crowd and some new additions to our usual summer-time gathering. As usual the children enjoyed the facilities. There was lots of informal chatting and sharing as well as a short circle time.



Five Shires

A glorious autumn day welcomed the Five Shires event to Moreton-in-Marsh. This was the first of our events advertised and subscribed to via Groupspaces and we are pleased to say that the event was well attended with over 30 adults and children.

This was a chance for families to meet and share information. Everything from sunglasses and sunblock to educational matters. Many thanks to Sarah's mum for providing entertainment for the children so the adults had time to talk - all those years in education were invaluable!

There was a short presentation on Sarah and Jack's experiences of the school system from primary to GCSE's, offering their thoughts on how they had overcome some of the challenges. A lively discussion followed. Parents reported back they enjoyed this section and found the debate useful.

You can download the presentation from our website (PDF).

Many thanks to everyone who took the time to attend the Five Shires event and contribute to a really successful day.



Do you have an interesting story?

We are always looking for stories, tips, advice and opinions that would be worthy of sharing with others in the albinism community. Everyone has got something, they just don't realise it and we can all learn something from each other. If you are not good with words we can help you write it, or write it for you entirely if you wish. Not sure? Drop us a line or two or leave a message on the phone line and we will get back to you. Male and female, young and old, your editors await!

The Knott - Paralympic Experience by



The David Bowie anthem rang out as Paralympics GB walked into the stadium. It wasn't this that woke us, more the fireworks that went with it! "You Can Be Heroes; Just For One Day" sang the crowd as Peter Norfolk, our flag bearer led our team on a lap of the stadium as the London 2012 Paralympics finally got underway! If we're honest, David and I were a little disappointed we couldn't join the rest of our "Greatest Team", but we had enjoyed a short Goalball squad opening ceremony earlier in the day, all dressed in our white space suits with gold lined hoodies! Given we were due to compete in less than 12 hours we understood the decision for the team not to attend the ceremony, knowing our time to be "heroes" (not that we would call ourselves this) was almost upon us!

In the lead up to the Games our story had been fairly well documented. As competing brothers we had been fortunate to catch the eye of the media. We featured in a slot on BBC Breakfast, Meridian TV, Adam's video diary on C4 Paralympics website, and even had a full page in the Times on our family. Each had reported how our Dad, back in the middle of 2010,



On TV (Note camera on left!)

Adam & David aged 18 & 15

had seen short piece on the BBC about how Paralympics GB were looking for potential future Paralympians. Their aim was to ensure that, as the home nation, we would be able to have competitive teams in all events, even if this meant building a new team from scratch. The only criteria for attending the Talent Assessment Day was that you had to be "tall, sporting" and of course "have a disability". While I, Adam, was only 15 at the time, I did enjoy paying junior rugby and VI cricket. Fortunately at 6' 4" I was also tall! I tried out for blind football, and despite also being asked back for blind judo, I waited with hope for a call-back from Goalball which despite being some months later, duly came. And as they say, from that moment on my life changed. My Dad tells me there is a film called "Sliding doors", whereby John Hannah makes a choice of door to walk through, and on walking through his future path is set. Maybe that 5-minute clip on BBC breakfast was mine and David's "Sliding Door"!

The last two years have been a whirlwind of training, competing and more training. Although it was only in the last 15 months that David really got involved with Goalball, and only in the last 12 months, with the GB squad. Initially, David was simply someone to throw the ball back to me during my training sessions, but it soon became apparent that David also had a flair for the sport and it became natural to train together. David was asked to stand in for a sick GB player at the opening of the Copper Box at the Olympic Park, and perhaps this was David's "Sliding

door" moment.

We took up a training schedule of six days a week, and if we could persuade Mum or Dad to provide lifts, would even on some occasions get a couple of training sessions in on some days! Our training has consisted of gym training, particularly strength and conditioning and technical game training. We have also been very fortunate to have support not only from our parents, but also our school, Thornden in Chandler's Ford, and my now college, Peter Symonds in Winchester, who have also allowed the GB Goalball squad to train in their sports hall free of charge.

While the training has been hard, and the commitment to the game has meant we have also perhaps missed time with family and friends, the reward of walking out in the "Copper Box" and representing our country aged only 17 and 15 is something neither David nor I would ever swap. We didn't start out wanting to be "heroes", we hadn't even started out thinking we would make it to London! We simply wanted to play sport, and play a sport to the best level we could. Goalball gave us that opportunity. With all the players wearing eyeshades, even the advantage of our limited sight is taken away and all players are then equal. In rugby, which we both played, while at a junior level our sight hadn't been too much of a disadvantage, that would have changed as we grew older, and I suspect our rugby careers may have been time limited and we would have ended up as only supporters, which

Cont...

we still are. We've probably become "accidental" Goalballers, but our parents have always encouraged us to try as many sports as possible, and we would encourage any youngster to do the same. Try as many sports as you can because you never know if you'll like it, or be good at it until you try it.



So what about the Games, what were our highlights? In fact there were so many! Walking out for our first game against World Champions Lithuania with 7,500 people cheering for US! In fact walking out for all five of our games to this incredible crowd (sadly we never qualified out of our group to the quarter-finals, but as the youngest team in London we will use this as a stepping stone to future success); Me scoring my first goal against Sweden and a hat trick against eventual Gold medallists, Finland! David playing a part in four of the five matches while only 15 and being watched by not just his schools mates, but a certain Prince Will and Kate! The closing ceremony was just incredible, Coldplay were

just amazing! It was just a privilege to be in the athletes' village with so many talented individuals, including our own Fellowship's, Aileen McGlynn who won silver in the visually impaired time-trial cycling and Claire Williams who won a bronze in the discus. But when we look back in years to come I think it will be the people who came to London that stand out for us! Signing autographs is not something either of us had ever experienced before, and I'm sure David's first autograph was nothing like his last! We've never been asked to have our photo taken by so many people, "Can we get you and your brother together?" and this wasn't just young children asking this! And who can forget Monday's parade through London? Words cannot describe just what an amazing and humbling experience this was. We're sure the number of million spectators was vastly underestimated, certainly by how many we counted anyway!

Lord Coe had asked that Team GB and Paralympics GB inspire a generation. After one game we had our photo taken with taken with a little boy called Arthur, who has only 5% vision (see back page). We're not sure if we inspired him, we think we did, we hope we did, but moments like that have inspired us to want to achieve more in our sporting careers. We still believe we are part of a generation that has so much to achieve. Our albinism has never held us back, nor should it hold you back. When you approach that sliding door, take hold of the handle, open it and walk on though, you never know where it may take you!

Lexi interviews Katie...



Katie O'Connor is a 12 year old gymnast from Kent. Earlier this year, she was a VIP guest at the London Prepares Rhythmic Gymnastics Test Event as a member of the National Disability Rhythmic Squad. It was the final round of qualifiers for the Olympics and Katie saw some Olympians perform. She also took part in the 2012 Olympic School Games. I asked her some questions about being a gymnast with albinism.

Do you go to mainstream school?

Yes I do but my school has a VI unit. I go to the unit once a week for touch typing with my VI teacher and Sir checks everything is going OK with my other lessons but most of the time I'm in mainstream classes. I get my adapted work and VI equipment from the unit when I need it; that's why I chose my school: they have lots of equipment that I can use – well, that and there are loads of girls with blonde hair and glasses! I have a teaching assistant in the class for practical lessons but she only helps when I need it. Otherwise, she just lets me do things on my own.

How do you feel about gymnastics not being in the Paralympics?

It makes me sad because I know how hard the gymnasts have worked to be on the National Squad.

Do you think gymnastics will ever be a Paralympic sport?

There are lots of people working very hard to get gymnastics into the Paralympics. I hope that it happens soon.

How did you get involved in London 2012?

My coach is the National Disability Rhythmic Coach.

How does doing gymnastics make you feel?

When I perform my routine and I do it properly without mistakes, it feels cool because I know how hard it was for me to do; it makes up for the bad days when it all goes wrong.

Do you have any sporting idols or inspirations?

I don't really have any sporting idols or inspirations

because I don't watch sport – it's easier to take part than watch – but I like to prove that I can do things that everyone thinks I can't!

Do you have any advice for aspiring athletes reading the magazine?

Never say never #justinbieber

Would you recommend sports, or specifically, gymnastics, to people with albinism?

Yes, I would! I love sport and I've tried loads of different sports and activities. At school I've played netball, tag rugby and rounders; my teacher would make sure my team was playing with our backs to the sun which helped a lot. I've tried lots of different sports with the Kent Association for the Blind too, including basketball, football, taekwondo and gliding. I've also done judo, athletics, golf, horse riding, street dance, musical theatre and Irish dancing and I love swimming, bowling, cycling and goalball.

I think gymnastics is good for everyone as there are lots of types to try. Albinism does make it harder but then most things are harder when you have albinism. I started trampolining when I was one. I couldn't see the cross in the middle and I just knew I had to stay on the white bit! When I started artistic gymnastics at the age of 5, I did trampolining too. Some things that help are the same for everything else I do, like if I am being told to do something, it is better for the coach to call my name before telling me what to do because I can't tell if she is pointing at me or not unless she is next to me (well, sometimes I can tell – it depends on what colour top she is wearing). I need to stand closer to the coach to copy the moves and it does help if the coach says what they are doing, like 'put your right leg in front of the left' because that is hard to see unless they are wearing odd socks! Walking on a beam was really scary at first but I learnt to walk on a bench first and then the beam. I tilt my head to make my vision better like lots of people with albinism do and don't even know they do it, so when I have to stand or walk with my head straight I can't see as well as I do normally. My balance has improved but it is still not as good as people with normal vision, and because I only have a mild nystagmus some of the time, I really notice my eyes flickering when it gets bad and that makes me lose my balance easily. Using a brightly coloured mat on the springboard in front of the vault makes it easier to see where to jump when you are running towards it.



Bars are the hardest part of artistic gymnastics because you can't see when you go over them but they are fun. I do better on bars at competitions because I wear a glasses strap to stop my glasses sliding down but I don't like wearing my glasses strap normally because it squashes my eyelashes.

I changed from artistic to rhythmic gymnastics last October but I still train in trampoline too. My mum thought that rhythmic gymnastics would be too hard for me because it involves throwing apparatus in the air and attempting to catch it; I don't always do it because it's so hard for people with albinism to track fast moving objects.

Some of the moves are much harder for me because of the abnormal wiring from the eye to the brain and even when I have learnt the move, I can't always do it, especially if I am tired or unwell as my eyes do their own thing and balancing on one leg is more difficult for people with albinism. My photophobia is very bad and both my eyes are affected by strabismus (squints) from the abnormal wiring and wander outwards. This makes it really hard to see the apparatus especially against the bright lights but I have sparkly tape on my hoop to make it glisten and I use a ball that is a colour that I can see against the ceiling and floor. I have black tape on the white wand of my ribbon to help but I can't always see the wand. When designing my leotards for rhythmic gymnastics competitions, we had to think about the apparatus and make the sleeves a different colour to the apparatus for contrast to help me see which is which.

Gymnastics is very tiring and I fall asleep as soon as I get home when I train all day, especially after National Squad training because I have to really concentrate on watching the apparatus, trying to see who is doing what and the lighting gives me headaches but I love it. I train in a mixed class because my gym club is for mainstream and special needs but I compete in disability gymnastics because they have a physical/sensory impairment category.

The British Blind Sport Junior 5-a-side Championships

with teams competing from regions all over the UK was held at the Futsal Birmingham International Arena on 12th May 2012.

One of our members - Jack Salt (back row 2nd from right) played in the winning team.

It was a fantastic day and Cheshire FC won 3 games and drew 1 to get through to the semi final. Jack scored the winning goal against Arsenal in the semis to get through to the final and he also scored the winning goal in the final against New College Worcester.

The photo is taken with John McDougal and Josh Pugh from the England Partially Sighted football team who kindly attended the event.



Sent in by proud mum – Katherine Salt

Life with Albinism in Malawi



Bonnie leading a discussion with parents, gathering their views on how best to support the education of their children with albinism

Dr Pat Lund, Faculty of Health and Life Sciences, Coventry University

p.lund@coventry.ac.uk writes... In September I visited western Malawi in the company of Bonnie Massah, a leading advocate in The Albino Association of Malawi (TAAM), together information on the education of young people with albinism. Around urban areas there are specialist teachers and resource centres supporting the education of visually impaired pupils. We wanted to find out what was happening in more remote rural areas. Local fuel costs are crippling, causing prices of even basic commodities to spiral upwards. A second-hand hat in the local market in the capital costs about £5, a significant outlay for many families; we met many children without even this basic protective item. A US based company has donated UV-

protective hats to TAAM and Bonnie hopes soon to have these to distribute.

Malawi has been dubbed the Warm Heart of Africa. It is a fitting description. Among the inspiring people I met on this trip was Makulata, a woman with three children, two with albinism, who had been told that children with albinism 'will die young so it is not worth investing in them'. *'But I realized that it was because of lack of care so I gave my children that care, so that they could be examples to other people.'* Virginia, her first born, has just completed her teacher's training. At another village we met a young 17 year old woman who had never been to school, despite the school being right across the road from her hut. When we arrived in the village she was crossing the road to collect water from the communal pump, with no hat on. Her skin is hardened and

Stories from abroad

badly sunburnt. Her younger brother is exceptionally bright, 'number one' in the mosque school where he is studying the Quran, but was not attending school, partly because he did not have a school uniform to wear. We went with him and his mother to visit the headmaster and hope that he will soon be back in class. Bonnie says that in some rural communities there is emphasis on 'commerce rather than education', with pressure on young people to participate in fishing and farming to help support the family, rather than attending school.

With support from the Commonwealth Secretariat and Sightsavers in Malawi, Bonnie, Paul Lynch at Birmingham University and I are drafting a report on the education of young people with albinism in Malawi and working together with the Ministry of Education to draft recommendations to support their education.

A young girl with albinism wears one of the hats from the local market



From Gustavo Gonzalez in Cost Rica who wrote...

'I am an OCA1B. I am 33 years old and want to thank you for all the information I have gathered from this site. I want congratulate you for all this effort. I was born in the same year as the Fellowship started (1979). I am very happy to see all those pictures with people looking like me. I am a son of God and know we all are specials but seeing them cause me a feeling I can't describe. If you are an albino you will understand me perfectly. I live in Costa Rica, and there are very few people like me. I do not know what efforts you are doing in Latin America but if so let me know. I do not know about any group in the region, but will continue searching.'

After reading this we asked Gustavo



for a photo (we like photos) Where possible we do try to link people who live in geographical proximity so that they may make connections and contact a similar way to what we do in Ireland and the UK. When this is not possible, the internet can be a lifeline.

Eds

The British Gas Great East Swim June 2012



Carolyn Richardson writes...

The prospect of a one mile mid-Summer swim in Alton Water Reservoir was very appealing when I signed up for it in March! Hours were spent clocking up lengths in my local indoor pool, spare time was spent on a rowing machine strengthening my arms, and by June I was ready for my challenge. As the day approached and the storms broke the attraction started to wear off. I am not sure if it was a relief with less than 24 hours to go to find it was postponed by a day due to adverse weather conditions or whether that extra day of psychological adjustment just prolonged my anxiety. Luckily a motivational speech by my son Tristan the night before got me settled and I focussed on how much money had been pledged for the Albinism Fellowship.

Arriving at Alton Water on Sunday morning my heart sank when I saw the choppy water. I soon met up with my swim buddy Alison Knox-Johnston and we shared each other's nerves. Quickly kitted out in our wetsuits and co-ordinating pink hats (for the 10:30 start group) we anxiously watched

the preceding group set off and got ourselves ready for action. A safety briefing was rapidly followed by a five second countdown and we waded, as braver people ran, into the water and headed off into the wind. It was very worrying then to find myself unable to swim properly for the first time since I learned in primary school. I was unable to co-ordinate my strokes and breathing, either hyperventilating or choking on cold murky water. All plans to swim front crawl were soon written off, I settled for survival breaststroke and for the first fifteen minutes I faced the hardest swim of my life. After reaching the 600 metre mark the course changed and the wind and waves were kinder. I caught up with some other swimmers including Alison and knew I just had to keep going. Having the finish line in site helped during the final leg but I struggled to keep on course due to large waves rolling in from my side. I was delighted to see the '200m to go' marker and tried to give it all I had but was deterred by another couple of episodes of choking from which I managed to recover in time to swim a strong final pool length to the finish line.

I was pleased with my time of 45 mins which is just a bit slower than I could swim in a pool. My sponsorship raised £462 for the Albinism Fellowship and I feel every pound was well and truly earned. Tristan was diagnosed with OCA four years ago when he was six and I the information I found via the Albinism Fellowship was invaluable. I am delighted to be able to give something back.

Woking Run raises money

Jane Boyce told us of her run that raised £105 when her aim was to raise £50, so she was very pleased and we're very grateful – well done, Jane!



Jane Running

Early Years - a Postcode Lottery?

You may remember last year that the fellowship distributed some questionnaires on behalf of the National Children's Blind Society. We have been allowed to have sneak preview. It looked at the 'support needs of parents of children with a visual impairment under the age of five'. The 10,000 word report makes interesting reading and contains some perhaps so not surprising statistics. For instance, upon diagnosis, 57% of parents did not receive any literature that was specific to their child's eye condition. (Giving the appropriate amount of information

takes skill, too much may overload parents, too little and they can be left floundering, but the aim must surely be to give some specific information?) The report emphasised the need for Clear Pathways for parents, signposting from hospitals to statutory services or voluntary agencies. The report is concerned with the length of wait for a diagnosis and the anxiety and difficulties that this brings to families, even though the importance of early intervention is recognised. 'Starting Point', a leaflet produced by NCBS and its partners is attempting to address this by being distributing information in hospitals. A pilot of the Newborn Infant Physical Examination Programme (NIPE) a check on all children 72 hours after birth, will hopefully improve upon the current situation. The report noted the lack of provision for mobility and a postcode of lottery of mobility support. NCBS are attempting to address such issues with their Movement Matters initiative. For those of us longer in tooth, the report doesn't produce any surprises; but it does confirm what many of us thought to be the case from anecdotal evidence. If you listen to talk at our meetings you will realise that there is a large variation in the provision of services from different parts of the country. Early intervention and help can make a big difference, and this report brings this issue into closer focus. We welcome this report. Well done NCBS! and many thanks to Eleanor Richens the author of the report. If you would like to read more about this, please contact us.

Jadine - Genius Art with an Apple



Apple Inc has completely blossomed over the years in it's technology and creativity, releasing the famous iPad. The iPad has been a treasure for gamers, holiday makers and educators alike, but I'd like to tell you about how the use of the iPad has completely changed *my* life, a nearly 15 year old student with oculocutaneous albinism.

Here's my story...

I'm Jayd (or Jadine to most) and I was born with the condition on the 19th of September 1997 in Jersey.

I wasn't fully aware I was a girl with albinism until I went into year 3 at my school. To help me out in the class, I was given a huge laptop, along with a stand with a camera known as a Magnilink (some of you may be familiar?)

To be honest, it was great. I picked up on how to use this with ease, zooming in and out on the whiteboard and all that jazz. It was very efficient in Primary School, but... when Secondary School

came around the corner, what then? Soon I was in year 7 in Senior School and I was beginning to get a little... teenager like. It was not ideal to carry around the heavy weight of the laptop and Magnilink to the various different classes, and I felt kind of embarrassed, and, my shoulder was killing me! I tried my hardest to use it, but I simply couldn't!

I was determined to find something more efficient for secondary, something smaller, smarter, more modern, something that will get me back on track with my school work.

My support tutor eventually mentioned the iPad 2, this immediately excited me. Towards the end of year 8, one of my Apple in Education Loving IT teachers got involved (@JerseyITGuy on twitter) and he lent me an iPad, just to see how it would work for me... and well... It was amazing! I had never felt so free with my learning! I even gained a passion for iPad Art (Captain Jack



Sparrow was my first painting!). I'm starting year 10 now, and I have the New iPad under my belt. I have never



Legend of Zelda

A link to my website:

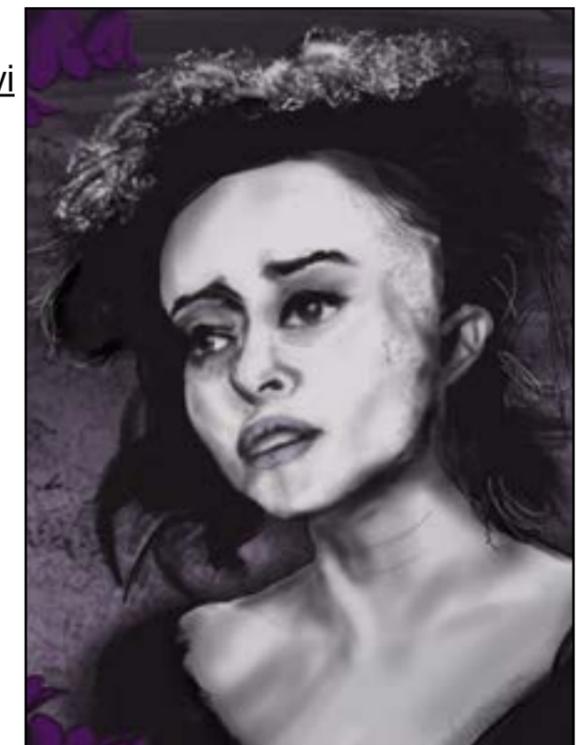
www.jaydalex Ingram.wix.com/appleofmyi

Follow me on twitter: @JaydAlexIngram

A is for... Apple,
anecdotes,
accolades,
acronyms,
articles,
all about albinism
Albinism Life!
Anthem - anyone?

felt more prepared for the year ahead, and I've had such great support from my teachers and parents, especially my IT teacher, who is always recommending me apps and helping me even further. What exactly do I use my iPad for? I snapshot photos of board work, I have digital textbooks and I create exercise books with Pages, I draw and sketch and all sorts! The iPad is a really brilliant tool for me, letting me work at a better pace and letting me feel a sense of freedom!

Want to know a bit more? I've created a website giving a more in depth sight on how Apple in Education has helped me and how it can help you. I really hope I can inspire more young people to endure the brilliance of Apple's creation and how it can really help in the schooling world. It truly has changed my life, I hope it can change yours. Thank you for reading!



Helen Bonhem-Carter

European Collaboration.

On the last weekend in October Mark Sanderson went to Paris, on the Fellowship's behalf. Here he attended a meeting organised by our French counterparts Genespoir. They had organised an international conference bringing together representatives from many of our European Organisations for albinism. If you were at the London BBQ you may remember Antoine Gliksohn who spoke briefly to explain the purpose of the meeting. It also brought together researchers in the field from all over Europe. On the first day the researchers exchanged ideas with each other while the representatives of the organisations swapped good practice and shared their thoughts. On the second day the researchers and organisations mixed in together. It was all very successful and really quite encouraging. Opening the lines of communication, sharing ideas so you know what others are doing is not only good for the researchers, it is also good for the organisations who face remarkably similar challenges. Our thanks go to Antoine and Genespoir.



The Member Associations representatives



The whole group including researchers at the conference

Christmas Party

New Editor

Children's Christmas Party & Family Get-Together

Saturday 8th December 2012

Time: 3.00pm - 5.00pm

Place:

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

What's on:

Party food for children
Children's entertainer
Catch up & chat with friends old and new
Mince pies and drinks for everyone

Booking:

This event must be pre booked by November 30th, to enable us to be organised.

How:

By replying using the buttons on the Groupsaces email sent out on 16th November

or:

For more information or to book a place please contact Lorna Stacey on:

Email ljstacey@ntlworld.com

Lexi (Alexa Greer) joins the Albinism Life team of Ed's



My name is Lexi and I'm the new Junior Editor of Albinism Life! I'm 14 years old and I live in Bedfordshire. In my spare time I like to play bass guitar, go on my computer and watch TV. I also like photography and editing the pictures. My favourite genres of music are pop and alternative with a dash of rock. When I'm older I would love to be a meteorologist and a life aim of mine is to visit all seven continents. I hope to bring a younger pair of eyes to the magazine and I hope you enjoy reading it!

Announcing...

Our next

Family Weekend Conference

Fri 11th – Mon 14th October 2013

Ribby Hall Village (near Blackpool), Lancashire

We are delighted to announce our plans to run another family weekend conference from Friday 11th – Monday 14th 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 for anyone familiar with that concept).

Details of how to book, including special rates, will follow but for now if you want a taster of what is on offer, look up www.ribbyhall.co.uk.

Further details will be posted to the website and directly to members when they become available as planning progresses in the autumn.

For now we are undertaking a major piece of work to identify sufficient funds to make the event possible. See how you can help by looking at:

The BIG Difference Fundraising Push on the website.

If you have any suggestions as to what you'd like to see at the conference please email them to conference@albinism.org.uk.



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