



Also in this issue:

- ❖ Conference 2013 Highlights
- ❖ Kestenbaum - Nystagmus Surgery
- ❖ Vitamin D Debate
- ❖ Sound Tennis



Editorial

There is nothing like an Albinism conference to reaffirm the value of getting families together for the weekend. I have cherished memories of the Ribby Hall Conference that will stay with me for a long, long time. Many parents will have swapped tips and shared stories, learning from each other. But for me, it was the children, on the Saturday night, singing with our guest-star celebrity that was the pinnacle of the weekend. We have put it on the front of our magazine. (Those of you who were there may know that Hugh Maynard is a celebrity, he is quite famous!) There were other moments too, the drumming and the circus skills, giving the shared experience for all the families that was also special. People take different things from each conference. The previous conference was four years ago. The trustees' desire is to arrange the next one two years hence. Funding from grants has become much more difficult to acquire, so the efforts of many individuals during the past year have been more important than ever. We ask you to do whatever you can to raise funds, big or small, it all helps. The faster we secure sufficient funds, the more we can be sure of our planning, and the better the event.

This edition of our magazine is the usual mix of positive stories. We have some simple lay-man's advice about Vitamin D and where to find out more information. There is a review of a novel, 'Golden Boy', where the central character is a boy with albinism growing up in east Africa. It is a refreshing change for him not to have

been the baddie! I wonder if attitudes are changing in the media. A film out this year called 'The Heat' featured a good cop character with albinism. Whilst perhaps not the most accurate portrayal possible, it was some improvement on the notoriously bad Silas of the Da Vinci Code. Is it possible that attitudes are changing and the staid old stereotypes are melting? We hope so.

Sound Tennis, isn't that what Andy Murray plays? Actually, yes and no! Check out this game played by our youngsters at conference. It is on the back page. For inspiration or aspiration, or is it sheer exhaustion, you might attempt to follow Craig Hollowood in his swimming endeavours in order to raise money for the fellowship. Not only a long distance but cold that gives me the shivers just reading about it! More hair-raising and perhaps feeling a little cold after, is what Akeel Bari did, shaving his head, although the half-way point is what we found to be the most hilarious shot. The more sedate approach of growing a pony-tail, which Daniel (our illustrious webmaster) still has, at the time of writing is going the other way. Whatever your fundraising ideas, if you do some fundraising, please let us know and please send in a photo. We love photos! (And thank you in advance for what you do.) Roll on the next conference as soon as we secure the funding!

The Ponytail!



Conference - Facebook Feedback

Sometimes the best way to capture the essence of our conference is to look at the pictures. To see the happy smiling faces; the adults relaxing, conveying what went on. We have asked for feedback from all the delegates who attended and we have also asked for feedback from those who didn't attend. (We are interested in reasons for people not attending). Please do be honest and if there are things that you think we could improve, do tell us. The trustees do attempt to listen to the widest range of views possible, but we realise that is isn't always practical to get around to listen to everyone. This is your opportunity to give feedback about what went well and what could be improved. Not all things are possible, but a surprisingly large number of things are. Please fill the form in on-line; it should only take a few minutes. You should have had an email to direct you to the webpage on our site, if not (lost in your spam filter or inbox?) you could go direct to our webpage.

These are a few comments from our Facebook page...

Lizanne Keith - "We had a great weekend, thanks everyone!"

Helen Prevett - "What an excellent day it was, to finish off a brilliant weekend. We made mosaic pendants, did some African drumming and laughed a lot at the circus show! Thank you all for such a well organised, informative and enjoyable conference."

Nina Hindle - "Thank you to all involved, we had a great weekend."

Hazel Browne - "Thanks to everyone we wouldn't have missed it for the world. Great weekend xx"

Roselle Potts - "Our family had a great time- thanks to all who helped to set it up."

Sandra Watts - "Thanks a million for a great weekend and to all those involved in the effort put into making it happen. It was lovely to meet up with people again and to meet new friends. We're so glad we made the trip and look forward to the next time."

Simon Walker - "Thank you for a truly inspiring weekend. It was fantastic and I feel proud to have been a part of it. Roll on two years when we can do it all again, failing that, see you at the Christmas event!"

Lisa Needham - "Thank you so much for everything, it's been an amazing weekend and priceless for Jessica and Ben!!"

Sue Harris - "Thanks to all involved helping make our first albinism wkend friendly happy and inspirational.x"

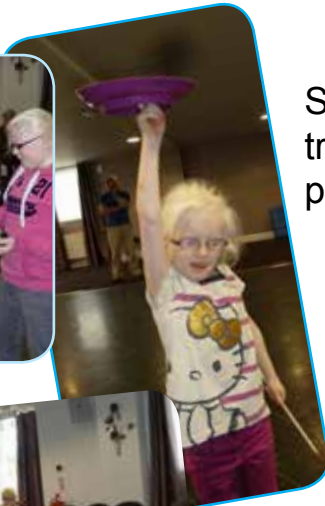
Lena Briant - "We had a fantastic time at the conference, thank you for a great time x"

Zoe Briant - "Thank you, the whole weekend was very well organised, well done to the whole team x"

Conference Highlights



Title



Spinning plates, great fun. If you try this at home please kids, use the plastic plates.



Relaxing at the Gala Dinner



Hugh holds the attention of the audience. Recognise him? Perhaps you saw him in the 'Lion King'?

In the drumming workshop, there looks to be much concentration.



Left: Lots of people for Tennis. Some clowning around and making stuff

Usually we feature pics from around our events in this issue, but as the only photos we have for them are already on line along with a report on the website we thought we'd cram conference photos in this issue of the magazine.

Kestenbaum - Nystagmus Surgery

At the Albinism conference, the team from Leicester hospital talked about the 'Kestenbaum' operation, which is used to correct for the head position sometimes adopted due to nystagmus associated with albinism. Alex had this operation in June 2012 at Great Ormond Street hospital when he was almost 5.

Before - looking over glasses



Alex had quite a marked adopted head position, to facilitate the use of his 'null point' and to maximise his vision. He held his chin down (looking up), but also turned his face to the left and tilted his face to the side.

In addition to the cosmetic nature of this issue, it also meant that it was almost impossible for him to look through his glasses. He also fell over all the time, as with his head down, he was actually looking up and not seeing any low obstacles in his way.

Alex also had a divergent squint, which was not very obvious due to the nystagmus, but became obvious in photographs of him. The consultant aimed to correct both the squint and the head position, but thought it would take two operations (vertical and horizontal muscles separately).

The consultant took measurements of the head position, which was quite difficult with Alex trying to crawl under the chairs in his office (how come he suddenly always has had enough of the day out in London when we get into the consultant's office?). He did this by holding up prisms in front of Alex's eyes, and suddenly his head was held straight!

The procedure itself apparently involves cutting the eye muscles that hold the eye in place, and sewing them back in a different position (not a very technical description). Performing this operation can also have the effect of dampening down the nystagmus itself and therefore improving vision, although I'm not sure that it is known why this is the case.

Whilst Alex was in theatre, I waited for a much longer time than I was expecting and began to get very worried that something had gone wrong, but it had all gone smoothly. He was brought up to a recovery ward, but really didn't want to wake up when the doctors wanted to examine him and so slept for the whole afternoon. By evening he still hadn't opened his eyes so I helped him with eating, walking, using the toilet etc.



Before - no glasses chin down

By the morning, he was very upset, saying, "I didn't want to be blind", which made me feel dreadful for putting him through the surgery. We were sent down to outpatients with Alex in a wheelchair, to see the doctor who was running a clinic. They were able to put some local anesthetic into his eyes, and prized them open.

- by Lizanne Keith

The doctor thought that all looked well, but with his eyes completely red, and the muscles stitched, to the untrained person they looked dreadful!

He needed a week off school, and lots of eye drops (we roped in his head teacher to encourage him to use his eye drops). Despite the redness, which lasted for a couple of weeks, he seemed to manage remarkably well, and got over the trauma of not being able to open his eyes, almost straight away.

After- 2 weeks ago waiting at GOSH - looking through glasses, slight squint still but great head position



The benefits from the operation were dramatic and immediate. The same week, he had comments that he was taller, but this was simply that he was holding his head up and looking straight ahead without dropping his chin down, and looking up. The consultant had in fact managed to correct the head position, and improve the squint, in one single operation. Alex's nystagmus was not measured before and after, as this was not the reason for the operation, however it is definitely less marked now, and as a result of the operation his sight has improved by a line on the sight chart!

He still uses a side head turn occasionally when he is really concentrating on seeing something, but at all other times, he has straight head position, and is now able to see through, rather than over, his glasses. Although it was not a 'walk in the park' at the time, the operation was successful and worthwhile, and now at the age of 6 Alex cannot really remember much about it.

One year on - Scotland, Half term Head up straight looking through his transition lens glasses



If you wish to know more about this procedure do contact us and we'll put you in contact

Laughter - the best defence sometimes

Robyn Blake from our Australian counterpart the Albinism Fellowship of Australia is collecting light-hearted amusing stories and anecdotes that she calls 'Beyond Blonde,' for their quarterly bulletin. Like: walking into the Public Convenience to see urinals! It is an 'oops' moment. We thought this could be amusing too. Have you or your family experienced a 'Blonde Moment'. Please drop us a line, anonymously if you wish, to raise a smile. After all, sometimes you just have to laugh.

The Vitamin D Debate

Do people with Albinism need to take action with regard to Vitamin D?

You may know that there is talk at the moment about vitamin D and whether people with albinism need to take a supplement to boost their vitamin D. I am not a medic, but here is what I have understood so far, in very simple, lay-man's terms.

Vitamin D is important for the human body, essential for the development of strong bones as well as many other functions that are only now starting to be appreciated. We can get Vitamin D from certain foods and sunshine. Of course, sunshine is something from which many of us, especially people with albinism, quite rightly and wisely shy away. Decades of health advice have ingrained a 'Slip, slop, slap' policy of covering up and slapping on sunscreen for very good reasons. It is important that people with albinism take care with regard to sunshine and take their skincare seriously.

But what about 'moderation in all things', perhaps a little sunshine is good for us? Michael Hollick in his book, 'The Vitamin D Solution' gives advice about how much is the right amount. It depends upon a combination of factors like: latitude, the time of year, the time of day, cloud cover, as well as how much or how little pigment you have in your skin. It may be very difficult to get a little sunshine without getting redness, which is too much and may damage your skin! With no pigment in your skin, your body is able to make Vitamin D faster than others with pigmented skin, so there is a slight advantage in that people with albinism make the Vitamin D

faster. It is important note that sunscreens will screen out the rays that 'make' the Vitamin D.

Whilst the optimum amount of Vitamin D is not totally agreed upon, the following statement below represents the views of the British Association of Dermatologists, Cancer Research UK, Diabetes UK, the Multiple Sclerosis Society, the National Heart Forum, the National Osteoporosis Society and the Primary Care Dermatology Society:

'Vitamin D is essential for good bone health and for most people sunlight is the most important source of Vitamin D. The time required to make sufficient Vitamin D varies according to a number of environmental, physical and personal factors, but is typically short and less than the amount of time needed for skin to redden and burn. Enjoying the sun safely, while taking care not to burn, can help to provide the benefits of Vitamin D without unduly raising the risk of skin cancer. Vitamin D supplements and specific foods can help to maintain sufficient levels of Vitamin D, particularly in people at risk of deficiency.'

So it seems a little bit of sunshine is good, but don't over-do it. At midday, in the height of summer, even in this country, that might mean just a matter of minutes. Many people choose to err on the side of caution and to not risk it.

So instead you could look for foods rich in Vitamin D. They are oily fish, (wild salmon has higher levels than farmed salmon), mackerel and herring, eggs, liver and some mushrooms.

The British Association of Dermatologists on their website, www.bad.org.uk (honest, that is their website address!) write 'Even people with genetic disorders that necessitate sun avoidance can maintain sufficient vitamin D levels through diet'. They also note, 'Foods can certainly contribute to vitamin D status, but on their own, it is unclear if they can sufficiently raise levels of 25(OH)D (that is a measure of Vitamin D) in people who experience deficiency'. So it appears that if your body is deficient in Vitamin D you may need supplements, but otherwise a healthy balance maybe maintained with a healthy diet. If you are concerned, there are supplements of Vitamin D available, but I would advise taking expert medical advice first, eg your doctor or GP.

At our conference in October, Professor Zulf Mughal (big public thank you to him for his contribution) shed light on the complexities involved with Vitamin D. We have more detailed information and links on our website if you wish to know more. Please have a look and share what you know.

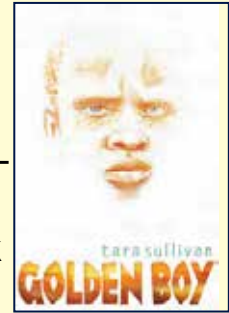
I am a little surprised that no one has ever thought to look at vitamin D levels in people with albinism. That is one paper I would very much like to read.

Reference :

The Vitamin D Solution
By M F Hollick Ph.D, MD
ISBN 987-0-452-29688-6

By Tara Sullivan

Golden Boy is a novel set with the main character being a teenage boy growing up in east Africa. It is a book which sympathetically describes his condition, a welcome change from the usual media diet of people with albinism being the evil and sinister baddie. The central character Habo, is not accepted and treated well by some members of his family and some others in his society. As you may know, in this part of Africa, people with albinism are sometimes hunted down and are 'sought after' because they have albinism. Habo flees this from this danger. For this reason I wouldn't recommend this book to young or sensitive children with albinism. It is more suitable for teenagers.



The author has done her research and understands her subject; Habo's difficulties with his eyesight and the stigma directed towards him are accurately conveyed in many situations. However, on a number of other occasions I felt that a few scenarios were scarcely believable for a person with such poor eyesight. If this and some other remarkable coincidences can be overlooked, then the story may be enjoyed. I certainly wanted to read to the end.

It is about time that someone wrote a positive narrative for a person with albinism and 'Golden Boy' has set a benchmark for others to improve upon. If you do read it, please let us know what you think. We would value the input of others.

Craig swims, Akeel shaves and they raise £££'s



Craig wrote on his Justgiving page... "I'm Swimming across Lake Windermere for Albinism Fellowship because I wanted to give something back"
He raised a brilliant £200!

Akeel Bari our new trustee also decided to raise some funds - can you tell how he raised an amazing £1,800+ ?
He kept it this way for one week and had to use public transport and not go to work by car. He said, "I did get some funny looks during this week."



Survey - Can you help?

AF member Jim Morey is an MSc Transport Planning student at Southampton University. He is currently conducting research into travel and transport accessibility issues.

Jim would like to hear the travel experiences of a wide range of people with disabilities.

In particular, Jim is interested in the 'accessibility improvement measures' being implemented by transport companies and local authorities in order to comply with the Disability Discrimination / Equalities Acts (examples of which might be the installation of ramps and lifts, audio 'next stop' announcements on buses, tactile paving on urban streets, better training of staff, etc.).

The research intends to establish which accessibility measures have had a genuine effect on people's mobility and to understand how they have affected people's travel patterns and lifestyles.

This part of the research will take the form of a survey. The survey will be available in both on-line and paper formats. Alternatively, the survey could be carried out by interview (either over the telephone or in person).

For more information and to take part in the survey, please contact Jim Morey on:
ajpm2g11@soton.ac.uk (email)

Patrick's Sailing Adventure



Patrick is 10 now and has been sailing for 3 years.

Initially he crewed with his dad in a small 2 person dinghy where he learned the basics.

Patrick very much wanted to learn to sail single-handed but was struggling to find the appropriate coaching at our club. We were starting to wonder whether this might be an unrealistic goal given his visual impairment.

But "Never say never", so we took some advice from the experts and approached the RYA Sailability team at this years Dinghy Show. They recommended Scaling Dam Sailing

Club as a local club with expertise for VI sailors.

We were amazed at the enthusiasm of the representatives at the club who seemed to embrace the challenge of teaching Patrick to sail.

Initially the club sought advice from VI sailing coach Adam McGovern. He gave tips to the club sailing instructors and also did a sailing session with Patrick. Thanks to lots of positivity and hard work from the Youth Sailing Co-ordinator Mandy Clarkson and her team of young coaches Patrick was able to achieve his RYA level 1 and 2. We saw his confidence soar as he achieved each of these goals and his pleasure at becoming part of a club of likeminded young people.

Patrick recently sailed his first regatta in an Optimist dinghy, with a few more lined up in the coming months. He needs help to find the buoys and marks on the water, which is provided by a coach alongside in a powerboat. His aim is to make it to the Optimist Nationals in Summer 2014.

We can't quite believe that Patrick has learnt to sail single-handed in such a short space of time and feel it's a combination of the right help and support and of course his own positive attitude and a bit of stubbornness at times.

We realise that not everyone has email and is able or desires to participate in on-line chat. But there may be some of you that wish to make a short pertinent comment. If you wish to do this you may write to us at the usual PO box address and we would be pleased to include the short comment or anecdote.

Skool School

I am a teenager. This means that I'm obsessed with my favourite bands, I spend way too much time on the Internet and I really want to dye my hair an extremely obnoxious colour. Also, I go to school - albeit reluctantly - and have albinism, so I have decided to write an informative article for 'young persons' or parents of said 'young persons' that combines both: this is a summary of what, in my experience, actually helps to have or do at school if you have albinism.

Firstly, let's delve into the classroom. On my desk (which is, of course, on the front row, as centrally located as possible) I always have a laptop and camera set up. The laptop is nothing special and the camera is a Magni-Link LVI Student Edition that connects to the laptop via USB. They do take up quite a bit of space, which is very annoying, but I'm so glad I have them! I used to have a ViewTech (just a camera and a screen) but before I moved to upper school I got a laptop and camera so I could use the laptop to write with; I'm perfectly capable of writing by hand. However, I lean very close to the desk to see what I'm writing, sometimes even resting my head on my arm, and I was starting to get awful back pain! With the laptop having a vertical screen, my back isn't strained anymore (yay!).

For every lesson in which everyone else has an exercise book, I now have a folder, so I can save my work onto a memory stick, print it off, hole-punch it and clip it in - I think it's actually better than a book because I can also put worksheets in the same way and take pages out if I need to. The only lesson this doesn't work for is maths,

since there are so many calculations etc. that I just can't type out, so I have a stack of exercise books with 1cm squares in that nobody else is allowed to use.

Now onto textbooks: I have some electronic books on my school laptop that I got from the school - I even have the play we're studying in English on it - and several revision guides on my home laptop. I didn't use to need these, but now I'm doing my GCSEs they are so useful. Lots of publishers provide their books in electronic form on the internet, some for free and some to buy, and others the school has to contact to get PDF versions of. My mum has asked me to stress that it's really surprising just how many there are on the internet, and an especially good website is 'Load-2Learn', a site that specially provides electronic books for students who are visually impaired or dyslexic, though your school has to register before you can access them.

For quite a few of my subjects, I have entire enlarged textbooks, which is sometimes nice, but other times terribly annoying, what with the stacks of volumes and not knowing which one the relevant pages are in! If I don't have an electronic version of a book on my laptop, the teacher usually enlarges the pages I need for that lesson - this is the same for worksheets too - and, if they don't, I always get my own book because while I would share if I could, I have to get really close to be able to read the text.

At my school, PE is called 'games', which sounds deceptively fun. In my

first year of upper school, we didn't get to choose what we did, so the beginning of a lot of lessons was started by my telling the teacher I couldn't take part because I was visually impaired, To be honest, I probably could have, but I'm not sporty and I've been hit in the head before more times than I'd like to mention by a stray ball. At the subject taster day, (nope, not even induction day yet), a classmate threw a Frisbee... and it hit me in the face... don't you start laughing, it was painful! However, last year, we got to choose options, so all of mine included no flying objects whatsoever (except badminton, because a shuttlecock wouldn't hurt, right?). I enjoyed games way more last year, and I already have my options chosen for this year.

I am sadly lacking in extra-curriculars, though I do go to a drama group and do archery outside of school. I have bass guitar lessons every week at school and I'm the only bassist in guitar group (because I'm just that cool). I started bass when I moved up to upper school, so I've only been playing for two years, but I have improved a lot. As I'm sure you know, a visual impairment is no excuse for not learning a an instrument or new skill, and it's so much fun, especially when you get together with others and collaborate.

My GCSEs are coming up at the end of this year (aaaah!) and my exam arrangements include extra time and doing my exams in rooms with other people who also have extra time, instead of in an exam hall. I have specially modified question papers. For coursework that I'm doing

throughout some subject courses, I have to do essays, which I type out on my laptop and print off, instead of writing by hand.

For the moment, this is my take on school with albinism. If you think I missed anything out or you have something else entirely to say to your fellow readers, please send us an article! It doesn't have to be long, but I know I'm not the only one who loves reading others' points of view in this wonderful (I'm totally not biased because I'm on the editing team) magazine.

Lexi is featured on the front cover with her dad after winning one of the great raffle prizes at the conference - a set of After Shotz headphones, kindly donated by one of our exhibitors at the conference.

New AF Trustee Roselle asks for volunteers...

I am a foster parent of Precious, a 5 year old with Albinism. I am eager to learn what might aid her reach her full potential but have not find much written info.

Precious is Nigerian. It is very clear to me that people from African (and other non-white) backgrounds with Albinism face additional challenges, especially at school.

As part of an OU course on Childhood and Youth studies, I need to conduct some research with children or young people.

I am planning to interview young people with albinism about their school experiences. I wish to find out what really helped, what hindered and what may be done to improve the school experience. My wish is that the completed research findings could be published in a leaflet/booklet for parents/teachers/kids in the future.

If you can help (or would just like to know more) contact Roselle on 07926379128.

Adam introduces himself...



Hi - I'm Adam Duffy. I was the big 1 on July 22nd. I now share my birthday with the new Prince George! I live in Monaghan in Ireland. I have a great big sister Erin. As you can see I'm a bit of a cool dude. My mammy and daddy (Catherine & Val) would like to thank everyone at The Albinism Fellowship UK and Ireland especially Treasa and Rosaleen for organising events and the other parents they met at the conference in Dundalk when I was only ten weeks old! Mammy thinks the other mummies are great and very helpful (Thanks Sandra & Yvonne!) and that the kids are great. (Hi Christopher and Ciaran, fellow cool dudes). This isn't just my 1st birthday, it also marks my family's first year being part of this great community.

The Albinism Fellowship has helped to educate my family and friends not only about the condition but about the reality of people with the condition. My family knew nothing about it before I was born last year. They now know people with albinism are beautiful, can see, are determined, intelligent, strong and kind because they have met them through the Albinism Fellowship. When I was born last year my parents were worried about me because of their lack of knowledge. They now look forward to seeing all the things I will do and hope I turn out like some of the other kids they have met that have albinism. After they learned the truth behind the stereotype they were able to get on with enjoying me, Adam, their wee man about the house.

I am nearly walking! I am wrecking the place! I have broken a vase and two frames this week alone!! This is because I love exploring and seeing what I

can get away with. You wouldn't know where you might find me. I am quick on my knees! I am teething a good few months now and bite all round me including your shoulder if you look for a cuddle! I am a milk addict. I am doing the same (if not a bit more damage about the house) than my sister was at this age. I can even type!

Mammy wants to let new parents of kids like me know their children will get on great and to enjoy them because if they are anything like me they will be so cute and so much fun!

Katy



Our daughter Katy Kemish, 16yrs old, attends Toynbee School in Chandlers Ford Southampton. She has OCA2 and has had the opportunity to learn to play Boccia at school. For the past 2 years she has represented the South of England for the under 21's (visual impairment category) in the National Boccia Championships.

This year the competition took place at Nottingham University on 3rd July. To our delight she won and is the National Champion in her category. Katy also practices Judo and is now a green belt.

We are very proud of her and hope that she continues to do well in her activities. When Katy was diagnosed at 4 months old we thought that life would be difficult for her and us but Katy takes everything in her stride and works hard to achieve good results.

She is in her last year at school before she goes to college, we want to support her to develop into an independent young person and believe in herself.

If you have a story or tale to tell, let us know. We can help you write it if you like, or write it all for you. Long or short almost anything related to albinism can be included. Done some fundraising? Please tell us and include some pictures, we love pictures.

A sound way to try out a new sport

It originated in Japan, it's particularly big in the south and east of England and may even be part of the Paralympics in future. 'It' is sound tennis, a fairly new sport for people with visual impairments (VI), and there was a great opportunity for younger Albinism Fellowship 2013 conference-goers to try it out at Ribby Hall Village.

Young members of the fellowship enjoyed a sound tennis session in the sports centre at the Ribby Hall complex on the Saturday of conference, hosted by Vicky Smith of Look.

Sound tennis, like other sports for people with VI, has a grading of 1-4, so it is suitable for those with the least and the most sight, and those in between.

It's thought to be a great alternative to goalball as the game is less rough, according to Fiona from promoters Vision4Growth, so it is suitable for the whole family.

The game, which has been around for about seven years and was invented by a man who lost his sight, is championed by an organisation called Vision4Growth, based in Hertfordshire. This organisation has

set up groups in both Hertfordshire and Cambridge, and has advised on establishing new groups elsewhere in the country.

- Anyone who would like to set up a sound tennis group in their area is welcome to contact VisionforGrowth (www.vision4growth.org.uk) or email: enquiries@vision4growth.org.uk)

By Andrew Bennett, PR advisor to the Albinism Fellowship



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