

Living with albinism

Often misunderstood, albinism combines vision problems alongside visual distinctiveness. Here Daniel Hill describes growing up with oculocutaneous albinism, but first Robin Spinks from the Albinism Fellowship, helps to demystify this complex condition

What is albinism?

People with albinism are born with little or no pigment in their eyes, skin and hair although in some cases the reduced pigmentation only affects the eyes. In the UK, one in 17 000 children are born with some type of albinism.

Albinism is a genetic condition passed from parents to children. In almost all types of albinism, both parents must carry an albinism gene to have a child with albinism, but many parents carrying the gene will themselves have normal pigmentation.

Albinism has a number of different variants but there are two main categories: oculocutaneous albinism (OCA) which involves the eyes, hair and skin; and ocular albinism (OA) which involves primarily the eyes, although some people may have slightly lighter skin and hair compared with other family members.

How does albinism affect children?

Oculocutaneous albinism (OCA) is the most common variant of albinism. Children with type 1 OCA have no pigmentation at all in their hair and skin. Their hair will generally appear white or platinum coloured and their skin will be very pale. Their eyes will appear pale blue or blue/grey and most will have a significant visual impairment.

Children with type 2 OCA have a lack of pigmentation in their skin and hair. However, this will not normally be as marked as with

type 1, and they will have some visible pigmentation. Generally children with this type of albinism will have pale blonde hair and blue or sometimes light brown eyes, and generally their vision will be less severely affected.

Children with ocular albinism (OA) will generally not display a significantly reduced level of pigmentation although the eye problems associated with albinism will be present.

In addition, a very rare type of albinism called Hermansky Pudlak Syndrome (HPS) exists involving a variety of complications associated with bleeding and respiratory disorders.

So how does albinism affect the eyes?

Albinism is a stable condition – it won't get better or worse – although in practice people will learn coping strategies which make the condition easier to live with. Children with albinism may have nystagmus – an involuntary movement of the eyes, usually from side to side but sometimes also up and down; strabismus – which causes children to have a squint and also to use each eye separately rather than together; and photophobia – extreme discomfort and glare in bright light.

What strategies can children use?

Low vision aids such as hand-held magnifiers for reading small print; a monocular or telescope for viewing distant objects; and a range of electronic aids such as video

magnifiers/CCTVs are useful. Trying out different types of tinted lenses can be helpful to find out which offers the most comfortable level of protection from glare. Regular trips to the ophthalmologist will ensure that prescriptions for spectacles and contact lenses remain up to date. A high factor UV block sunscreen is recommended for exposed areas of skin, to prevent skin damage. A hat with a peak offers sun protection and a means of shading the eyes from bright light. Encouraging your child to wear a hat when outdoors is a good idea. Having a wide variety of fashionable and funky hats to choose from might make this easier to achieve!

- **Robin Spinks**

The Albinism Fellowship is a voluntary organisation supporting people with albinism in the UK and Ireland www.albinism.org.uk

Albinism and me

Daniel Hill is 26 and a Software Developer for the Bank of England. He spoke to Insight about growing up with albinism and its impact on school and working life

I have oculocutaneous albinism which means there is a reduction in the amount of pigment I have in my skin, hair and eyes, and that I have poor vision. People would need to be about six feet in front of me before I would recognise them, although if there is lots of glare this would drop down to about two feet. Of course, this brings its own frustrations. Someone can say hi to me in the corridor and they've already walked past by the time I've worked out who it is. Like all things, you develop your own strategies. My friends know I'm not going to be able to recognise them across the road and they will yell out to me, or even phone me on my mobile, so we can meet up.

Insight



Daniel (right) with brother Martin

My younger brother Martin also has albinism. (See page 38.) I suppose it was good growing up with someone who understood what it was like to have the condition. We never sat down and talked about how it affected us though, we just got on with it, and probably spent more time arguing and fighting like most brothers. My parents don't have albinism and I suppose it came as a shock to them when it became clear that we did, but they are the type of people who just take things in their stride. For them, joining the Albinism Fellowship when I was two was a pivotal moment. It enabled them not only to understand how albinism might affect us, but to gain access to a wider support network, understand what support was available for us, and to talk to others who knew the pitfalls and techniques of applying for that support. I'm thankful to my parents for fighting to ensure we got all that we were entitled to, including Disability Living Allowance, support at school and Statements of SEN.

My education

School was a mixed experience for me. I attended mainstream schools which meant I was able to interact with a wide range of children from my local area which definitely helped my social skills. At the same time the school had sensory support units attached which meant I had lots of support in ensuring the curriculum was accessible. There was no

issue with work being enlarged, or having someone there to take notes off the board, and offer extra help in science or technology for example with fine detail work or instrument reading. But while I didn't feel at a disadvantage educationally, I did have other problems at school. When you stand out in a crowd as much as I do, you can be a bit of a target for bullies and I had quite a few problems with name calling and general unpleasantness, although nothing too physical. I was singled out perhaps more so because I wanted to learn and get on. In fact, in the end, the decision was made to skip me up a year. My new class was fantastic – very friendly and with a more mature approach to learning, and I made some good friends there.

After A Levels I went on to study Computer Science at Oxford and apart from the same issues I face anywhere – trying to meet people in crowded bars and so on – my experience was wholly positive. My college tutor emailed all my lecturers before my arrival letting them know that I'd need enlargements, and wouldn't be able to copy off the board etc. All had notes ready for me when I started, even those who usually worked off handwritten notes, and I even had notes for a course I wasn't actually taking!

Support to do my job

I've been fortunate that the pattern of excellent support has continued into my working life. I've worked for the Bank of England for five years as a software developer. My employer couldn't be more accommodating. Even at the interview stage I was telephoned ahead of time so that they could make sure I would have all the support in place I needed. I now have two large screen monitors, an accessible workstation, and a desk appropriately positioned to avoid glare and reflections on my monitor. I'm also on the

Disabled Staff Network – an internal employee forum which enables me to represent the needs of staff with sight problems (and other disabilities) working at the bank.

Being comfortable with my condition

I would say that today I'm quite a confident person, but this hasn't always been the case. I was shy at school, but I've come to realise that sometimes you have to just jump in. In my working role I need to confidently answer queries on the phone, attend meetings, and put my point across. I've learnt to assert myself. I'm proud of what I have achieved and having albinism has not held me back. I have a good degree, a prestigious job, and a healthy social life. I may have had problems with bullies, but I wonder what those bullies are doing today.

I'm fairly upfront about my albinism. Although there are issues with negative and inaccurate portrayals of albinism in the media, for me the main issue is that people just don't know what the condition is. I do talk about it when I meet people so that they are aware of what it might involve for me, or for the way I will work with them. I tend to use humour – I might tell someone that I'm having an occasional blond moment – it works at diffusing tension. I try to show people that I'm comfortable with my condition and that they should be too.

I've had to come to terms with disappointments of course. It's frustrating that I won't be able to drive, but it's no hindrance in London. There's very little else I don't feel that I could have a really good stab at. Albinism isn't a limiting condition, and I hope my experiences might serve as some inspiration for other young people reading this that you can achieve anything you set your mind to. ■