

## Cycling and Albinism

As a parent of a ten-year-old daughter with albinism, the recent conference provided me with lots of opportunities to talk to and learn for others. For me cycling is an interesting and challenging issue. My daughter has been able to ride a bike from an early age of three or four and is a keen cyclist. When she was younger we donned her in all the garb of helmet, elbow and kneepads for the inevitable tumbles that all children have. The lamppost that she crashed into on a sunny day and her remark about not having a 'bottom-pad' still causes us all amusement. When she was young, I could walk and jog a little next to her and steer her around any obstacles. However, as the wheels got bigger and the bicycle faster, I could no longer just reach out and grab the base of her saddle. I needed my bike to keep up with her and give the running commentary for possible hazards. Dogs on a long lead can be tricky, Karina will see the person and perhaps the dog, but not the lead in between until it is too late on a bicycle. Even cycling a metre behind her gives me palpitations whilst Karina of course, is blissfully unaware of many of the dangers. I'm caught between my own anxiety, the very real risks and the need and desire for her to 'step out of her circle'.

My father-in-law who adapted a bike to go on to the back of my bike provided one solution. The photograph shows the bike he made for us.



The bolts are special ones that are used on aeroplanes and therefore very strong. The device is fully gimballed, that is, it moves up and down as well as from side to side. This is useful when going over rough ground. The flag on the back is for when we go on roads, so that car drivers can clearly see her. The device is also detachable, taking only a minute to fix together or take apart. Similar devices can be purchased in cycle shops. It takes a little while to get used to, making allowances for the person behind and care is needed when approaching sharp corners. A mirror is a useful addition. It allows a view of my 'passenger', to check whether they are freewheeling or indeed hanging on to both of the handlebars all of the time! I would recommend this type of device for confidence building; going down long hills Karina would shout 'Faster!' as I applied the brakes. She liked the sense of speed and the wind in her hair, going a lot faster than she would on a bike by herself.

She now wants to go on her own bike more of the time. It seems that I miss too many puddles. We are lucky where we live because the minor roads are quiet and there are lots of cycle paths. We are able to easily go on bike rides in quiet countryside or the relative safety of cycle-paths. Familiar areas are of course, generally safe, because she knows most of the hazards.

After speaking to others at the conference it seems to me that cycling is an interesting issue for parents of children with albinism to negotiate. I don't want to say no completely, I search for a compromise that allows her to cycle in relatively safe environments. For some people with albinism it is something they would just rather not do, whilst others cycle on quite busy roads. I am always interested to hear about the way in which people overcome the obstacles in life. Next year, I know Karina will want to attempt her Cycling Proficiency Badge at school and that will involve going out on roads. I 'm not at all sure that she will be able to complete the badge given her level of sight. I don't wish to stand in her way, there will no doubt, be a way for her to do this. If you have done that, I'd be interested to know how you got on.

Despite the obvious hazards we will continue to cycle, although I am always with her, giving the commentary or very close by. We have had a few close ones, like the brand new Mercedes parked under a shady tree, on a bright day, in quiet country lane, near the end of a long (for us) bike ride. I saw it in the distance, but only

realised that Karina hadn't seen it, when she was a short distance away! 'Car!' I yelled, to which she did I deft little serve. 'It's OK dad, I saw it' she said, smiling coolly.

So have you actually had any accidents? I can hear you thinking. In September, when on separate bikes, I glanced back to look for Karina, whilst turning in a car park. I didn't see the wet leaves, skidded, came off and belly-flopped across the car park! The irony was not lost on my daughter! 'You should have been more careful Dad!'

Such are the joys of being a parent.

If you cycle and have albinism in your family, I would be interested to how you get on and what tips and advice you might have to pass on to others.

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