



Hi! I'm Neva and I have Albinism. I want to explain to all of my Prep friends about my Albinism in a letter because some bits are tricky for kids to understand but hopefully it will answer some of the questions you and your parents have. I would love to answer your questions if you have any and my Mum Amy will help me too!

Since most people don't know what Albinism is I will start by explaining – it is kind of technical though! Albinism is a genetic condition (this means it came from both of my parents) that affects 1 in 17,000-20,000 people in Australia – so I am one of only about 1200 people with Albinism in Australia – pretty cool huh!! Albinism affects my body's ability to produce melanin (what gives your skin, hair and eyes pigment/colour, and provides your skin with protection from the sun) which is why I have light coloured skin and white hair. My two older siblings Erich (grade 1) and Cuora (grade 3) don't have Albinism.

Albinism also causes vision impairment which can vary from person to person. You will probably have noticed that I can run, jump and play just like you – sometimes, well a lot of the time I am clumsy and fall over or run into things or people. But I still join in because I love to be involved as much as the other kids!

Because I have no pigment in my eyes, I have trouble seeing in bright light and sunburn very easily. I wear tinted glasses outside, but even the classroom lights are bright and reflected light (glare) hurts my eyes too – you will often see me squinting even when I'm inside although the light isn't bothering you. I wear sunglasses and my hat whenever I am outside because it is so bright – even rainy days can be glary and hurt my eyes. Some days it is so bright that my eyes hurt even with the sun glasses. Lots of people believe people with Albinism have red eyes we don't!! My eyes are actually blue but if the light gets in and reflects off the back of my eye like a flash or at night time, it can look like my eyes are red!

It's difficult to explain how I see or what I see but things look pretty fuzzy like they are out of focus. I can even see some little things if they are really close. I use a slope board on my desk for reading and writing to bring things closer to my eyes so I don't get a sore neck and back from trying to get close enough to see. You may see me using a magnifying glass or a bar magnifier to

enlarge the words in a book or on a worksheet – **I like to have things in big print as they are much easier for me to see (like this!).**

I sit at the front when we are on the mat so I can get as close as I need to the board or book.

Sometimes I might get in your way trying to see the board or a book – it can be tricky for me to get in a good position where I am close enough to see and able to focus. It is easier for me to have a copy of the book but please don't be upset if I don't want to share; sharing a book is hard when you need to get close to it. You might have noticed that my eyes shake a lot – this is called Nystagmus – it doesn't hurt my eyes or make me feel dizzy, but it does make it difficult for me to try to focus on things and can make me feel quite tired too.

One of the hardest things for me is social interactions. I can't see how you are feeling so I need you to use words – it is no good giving me your cranky face or smiling at me from across the room as I can't see your face clearly. If you wave at me and I don't answer I'm not being rude I just haven't seen you. If you call out my name I will wave but probably in the wrong direction! I also can't tell if you are talking to me in a group so you can help me by saying my name first so I know to pay attention. Finding friends or teachers in a crowd is hard too – especially since you all wear the same uniform. I use clues about you like your body shape and voice to guess who I see – sometimes I call out the wrong name so please just politely correct me! Unlike you I can't scan a room with my eyes to find people or things that are "over there", please keep this in mind if I ask where to find someone or something and give me clear directions – like Charlie is in the sandpit next to the slide, or the pencil tins are on the left hand side of the grey bench under the window.

I have no depth perception which means that often I can't tell when the ground changes – for me dark colours on the ground can look like a hole, yellow sand looks close when I am on the playground (I might jump not knowing how far away the ground is), and concrete steps look the same as the concrete path. Once I know where steps are I can usually remember but if I am somewhere new it can be scary!

Albinism is just a small part of who I am – most of all I'm a little girl who loves to have fun with friends, run around and go crazy. I have the same feelings as you and hate to feel alone or left out. I get embarrassed when people laugh at me for falling so please think about how you would feel if it was you!

PS. Please don't call me an Albino – I am a person with Albinism.

Thanks for reading

Love from Neva