



Parley

Parents And Relatives
Listening and Empathising
with You

CaZ's Story

My son was diagnosed at 9 months with Ocular Albinism, now he is 7 and last year we were told he has Oca type 2 (Oculocutaneous Albinism) which was after his skin burnt after being out in the sun for 15 min and it was only April at the time.

(It is a comparatively rare genetically inherited group of condition which results in a reduction or complete lack of pigment (colour) in the skin, hair and eyes of people with the condition. This can result in pale skin which burns easily in the sun, virtually white hair, very severe short-sight and photophobia (a severe sensitivity to light).

It is hard as there is not much support or info on this and there is virtually no help out there.

When my son was first diagnosed we were never told what to expect and because he was only a baby we never looked into the condition.

There are support groups but they weren't much help unless you paid to become a member. These groups are on facebook and you can leave a message for other members to contact you, but at the moment I am still learning and constantly down at my son's school to help him apply his sunscreen. The hardest thing is he can't just go outside without his sunscreen applied his cap on and glasses which help protect his eyes from the light.

He can go on holiday's abroad but he has to stay out of the sun as much as possible and to me it is not a holiday for him, holiday's over in this country is the same but we have more rainy days than sunny days.

But he is a happy boy who has lots of friends who has accepted him for him and we take each day as it comes.

Many thanks

CaZ

ps if anyone would like to contact me please do.



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