

## Xeroderma Pigmentosa means Alex, 15, must shun the sun

**Alex Webb is a boy who can never feel the Sun on his face. He is not just sensitive to its rays - just minutes' exposure could cause irreparable damage.**

His school and car windows need protective films to make sure no ultraviolet (UV) light penetrates.

Alex has a rare condition called Xeroderma Pigmentosa (XP).

XP impairs the ability of the body to repair damage to DNA caused by UV light.

It affects about 100 people in the UK and can cause skin cancers, eye and neurological problems such as hearing loss, learning difficulties or difficulty walking.

Alex's mother, Sandra, first noticed her son had sun sensitivity when he burnt through the car window at the age of seven weeks.

And at the age of 11 months, he sustained a deep skin burn around his eyes, lips, nose and cheeks.

"We were on a holiday in Austria as we were living in Germany," she said. "It was the combination of sun and snow, and he really had a very severe sunburn.

"We thought there was something wrong, but we were fobbed off by the doctor. He just said, 'You mums don't know what the sun can do'. But Alex had full sun block on."

Sandra asked her UK doctor for advice and was told Alex probably had a sun allergy.

But at the age of four, on a family holiday to Tunisia, Alex, from Buckinghamshire, burnt and blistered his skin quite badly again and was finally tested for XP.

"When he was diagnosed we were just told he must avoid UV light.

"We were told he would not be able to go to school normally because he would need to be in a protective environment."

But the Webb family were determined their son, who is now 15, would have as normal a life as possible. So in 1998 they set up their own support group.

Sandra said: "Alex's schools have been brilliant. The council arranged for UV protection and when he was in the infants school he was helped with sunscreen, which needs to be reapplied every two hours.

“ He does take part in sports day and in between races he sits in a UV protective tent ”

Sandra Webb



The family take care with Alex's skin

"He can't do team sports, they are not practical - but he does take part in sports day, and in between races he sits in a UV protective tent.

"It is so much better for him to be in a mainstream school because he feels isolated anyway.

"When he goes out he looks different because of what he needs to wear, so he tends to stay indoors. But if he wants to go out, he will.

"A few weeks ago he met some friends to go to the cinema and sometimes he goes shopping. He is less sensitive than he used to be.

"And we still go on holiday where we choose.

"One of the best holidays we had was in Dubai, which is three hours ahead of us and is dark at 6.30pm when we were out playing tennis and swimming as it was lovely and warm."

Dr Bob Sarkany, a consultant dermatologist at St John's Institute of Dermatology (Guy's and

St Thomas'), said a careful skin routine was vital to prevent cancers.

"Every time a healthy person goes outside, UV light goes into their skin and causes damage to the cells that make the skin grow and function correctly," he said.

"That happens all the time, but that's OK because we have a repair system that repairs the damage.

"The problem with XP is you inherit a defect in that programme. When it does not work, the damage persists.

### **'Prognosis brighter'**

"Alex has had absolutely superb treatment from Sandra... and appears to have very healthy skin, but we have had patients as young as five to six with skin cancers."

Now Guy's and St Thomas', in collaboration with the University of Sussex and Ninewells Hospital Dundee, is to become the national centre for treating children with XP.

Sandra said the national centre would enable more data to be kept and shared on patients, adding that the prognosis was much brighter for children like Alex.

"Our children are living much longer and getting less symptoms, but there is still a lot we don't know," she said.

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Dr Bob Sarkany  
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