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The Paulsons: Carrying a Light Burden

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Imagine sunrays streaming through rich hues at dusk or light snows gilding everything they touch. Imagine always enjoying them from a darkened window. Such is the life for six-year-old Brianna Paulson and eighteen-month-old Ashley Paulson, of Franklin Township, who are allergic to sun and light.

Long before Ashley was born, the Paulsons received their first indication that Brianna had an unusual condition. One afternoon in April, 2003, when Brianna was 3 1/2, she went to play outside at her grandmother's house in Colorado Springs, home to the entire Paulson family. After playing in the sun she developed a severe sunburn that changed from blisters to freckles to redness over a period of weeks. Brianna's paediatrician recommended the usual prescription: avoid sun between 10 am and 4 pm; load her skin with sunscreen, wear clothing that covers her arms, legs and face. They followed it. She continued to burn.

Brianna's mother, Corinne, became concerned. She was sure the high altitude was contributing to Brianna's strong reaction to sunlight. She began to pray; as she did, she felt no peace about staying in the altitude, where sunlight is more intense. She and her husband, Allen, began looking for a state meeting certain conditions: low altitude, favourable home school laws and for Allen, a job in the auto racing industry. Indiana was a perfect fit. Allen contacted a number of companies and with two interviews pending the Paulsons were on their way to Indianapolis.

It wasn't easy reaching that conclusion. Family and friends--even some doctors--felt the Paulsons were overreacting. Still, Brianna went through a full battery of tests to determine the cause of her reactions. She tested negative for Lupus, porphyria and xeroderma pigmentosum, a life threatening disease leading to skin cancer.

Just this year, Brianna's little sister, Ashley, began to show similar symptoms. By August it became clear that eighteen-month-old Ashley is also allergic to artificial light and sunlight.

Brianna's and Ashley's is a very rare condition, often downplayed because it is not life threatening. But it is very real. They have a unique set of symptoms most like polymorphic light eruptions.

What are polymorphic light eruptions? A recurrent, abnormal, delayed reaction to sunlight. The most prominent symptoms are a pimple-like rash or plaques on the skin. PMLE tends to appear at the beginning of warm weather; in most cases the patient's skin hardens and adjusts to the sun exposure and symptoms disappear in the cooler months.

Brianna and Ashley have a variant form of PMLE: their symptoms persist year-round. Additionally, they have symptoms atypical of PMLE: visible light can hurt their eyes and produce a bruised look to their eyelids; exposure to light can produce stomach aches and diarrhea. Brianna's skin has become thin and dry. Bright lighting makes her tired and irritable at times.

The Paulson family has learned to cope, trying to make life as normal as possible. Brianna and Ashley do not live in darkness. In the last year the Paulsons tinted their house windows to block 96-98% of the ultraviolet light and 88% visible light. Due to their medical condition, the Paulsons were able to tint their family's van windows darker than normally allowed by law. When Corinne questions levels of light, whether natural or artificial, she checks it with a light meter. Recently, the Paulsons converted their garage into a playroom with walls painted as a lovely meadow on a summer afternoon. It is a perfect respite from hours of home schooling, the educational alternative that fits Brianna, who requires quite a bit of sleep. Finally, when Brianna and

Ashley travel, they each wear custom made suits constructed of a hood with built in ski goggles or eye screen, special shirts, pants and gloves. Indoors they wear hats and sun glasses.

Walking through a store or parking lot can be emotionally painful. Most children are merely curious and ask accompanying adults why the girls are covered. Some adults nervously laugh; others joke; still others make rude comments. Corinne is often stunned but wants to tell them about her daughters' allergy to sun and light. One of her goals is to raise awareness among the public and thus protect her daughters. She invites anyone in the township interested in learning more to email her. (Email address appeared in article.)

The girls' condition affects the entire family. Nathan, 11, and Noah, 8, and Matthew, 4, can play outside without reaction. Sometimes they feel guilty that they are able but their sisters are unable. Also, the boys do not participate in as many activities as they might: activities separate their family for hours at a time. Nathan sometimes becomes frustrated that his sisters' condition is not a popular cause. Other diseases receive publicity but his sisters' does not.

How do the Paulsons find strength to cope? Two ways: one is through the xeroderma pigmentosum society, and online support group networking parents and resources (www.xps.org). The Paulsons travelled to New York State this past summer to attend a week at Camp Sundown, a camp conducted indoors during daylight and outdoors after dark for families who have children with light disorders. Not only was it great fun; it was a great help to the whole family. They plan to return annually.

The greater strength comes from their faith. They are Christians who depend on God to give them the ability to keep going and to make good decisions. When their faith is challenged, they take solace in knowing that God is present and that he has sent people who do care and want to help.