

## Leslie's story: Living with porphyria

Meet Leslie, an avid photographer with a love for gardening and curling, who lives with porphyria. This skin condition causes a serious sensitivity to light that results in painful swelling, burning, itching, redness and blistering of the skin.

Interviewed by Sheri Pilon



### Tell us about yourself.

Stony Plain, Alberta is my home. Photography is my passion. I work at a camera store, which gives me the safety of being indoors while surrounded by photographers. I try to stay active and would love to do more in the summer, but being sun sensitive makes many activities impossible. I prefer the winter with the lower UV index.

At the age of six, I began showing signs of being sensitive to direct and indirect light. It took almost nine more years before I was diagnosed with erythropoietic protoporphyria (EPP), a type of porphyria.

### How do you manage your condition?

For the most part, I need to avoid sunlight altogether. Because EPP is skin based, if any part is exposed it is likely to start a reaction within 15 minutes of continuous exposure. When I am outside for long periods of time, I am covered head to toe with clothes or sunscreen. I also pack beverages; hydration helps me prolong my activities.

Patients with EPP are very sensitive to heat and cold. It feels like we are being burned from the inside out.


The skin swells, making the movement of any extremities painful.

my hands are sensitive to light. Theme parks or fairs are the worst, as there is next to no shade. I cannot go camping, fishing, biking, take long walks or stay outside on a nice day to read. My family and friends are very supportive and accommodating to my EPP. The hardest part about living with EPP is dreaming about all I could do if only the sun were not out.

### Has porphyria hindered you in doing what you wanted?

As a child at a summer camp, within a day I was unable to participate in midday activities because of the sun. As an adult, I am very hesitant about going on holidays overseas. I am interested in ancient Egypt and would love to visit but, sadly, there is not a lot of shade in the desert. Perhaps one day there will be a cure or a viable treatment option to help patients safely spend more time outside.

### What education and support have you received?

Most of what I learned about EPP was from the Canadian Association of Porphyria (CAP) and the American Porphyria Association. In return, I now work with CAP to help others understand and prevent reactions with the sun-based porphyria types. 

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Blood blisters can follow, which can last from three to 14 days, with sensitivity lasting over a year. Also, EPP causes stress on the liver, so annual blood tests are required.

### How does your condition influence your daily living?

Any outdoor function must be scrutinized and planned. When driving to work, I wear gloves since

To learn more about porphyria, see page 15 or email [canadianassocforporphyria.acp@gmail.com](mailto:canadianassocforporphyria.acp@gmail.com)