

PROFILE

Being part of the cure for blindness

When Nicolas Celebre was born, his parents Steve and Jennifer had no idea that blindness was going to be part of their lives.

Jennifer shares their story to help raise awareness and funds for Fighting Blindness Canada so that one day Nicholas can have his sight restored.

As a parent, you only want the best for your children. Yet there are times when you discover that you're completely helpless.

When our son Nicholas was born, we discovered that he was deaf. Thankfully with the help of cochlear implants, he was able to hear at the age of 1. We thought we got lucky having caught the issue early. It turns out we were wrong – very wrong.

Soon after, Nicholas was diagnosed with Usher syndrome, Usher syndrome is a genetic disease that causes hearing loss, vision loss and sometimes balance problems. Usher syndrome is "recessive" which means that two of the same Usher genes must be inherited - one from the mother, one from the father - in order for the child to have Usher syndrome. Parents often do not know that they are carriers of the Usher syndrome gene because there is no family history of Usher syndrome. My son was going blind from a genetic eye disorder

called retinitis pigmentosa (RP) and there was nothing we could do to stop it.

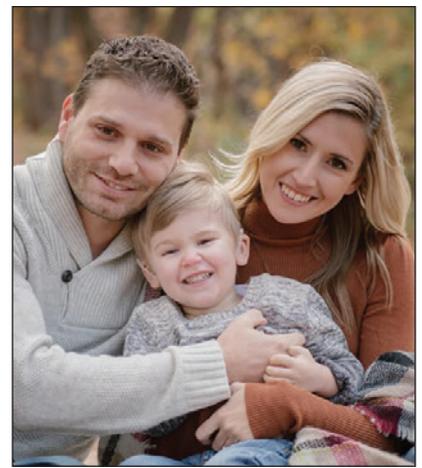
Finding out that Nicolas would lose his sight was utterly devastating. Even today, just thinking about the diagnosis brings us to tears.

Imagine being a parent and discovering your child is deaf – and about to lose their vision since there is no cure. It's heartbreaking.

Nicholas is only 3 years old and he's been through so much already. Yet, he remains a funny, bright kid who loves to make people laugh. I worry that may change if he loses his sight.

That's why Steve and I created "A Night for Nick," a fundraiser to benefit Fighting Blindness Canada. Our incredible family and friends packed a local Pub and enjoyed live music, participated in a silent auction, and raised some much-needed funds. The pub also generously donated 25% of the night's proceeds to the cause. I believe that we are standing on the brink of new therapies that could save or restore vision – and by raising funds for vision research with our friends and family we knew that we could help find a cure.

Fighting Blindness Canada funds research projects that will enable new



Diagnosed with Usher syndrome, 3-year-old Nicolas faces a future with deafness and vision loss

treatments and cures for eye diseases. One such research project is the development of a new vision test for very young children, so they can receive sight-saving treatments to improve their quality of life sooner. As well, Fighting Blindness Canada is funding another researcher who is investigating gene therapy and its potential for restoring vision for people with Usher syndrome. We find this truly exciting and that is why we support Fighting Blindness Canada.

There are so many people like Nicholas who are dealing with vision loss and blindness due to an eye disease. I worry that Nicholas will soon lose all of his sight. Our hope is that other Canadians will join us in supporting Fighting Blindness Canada.

Fighting Blindness Canada is the leading private charitable funder of vision research in Canada.

You can help cure blindness for more than 1.5 million Canadians living with a blinding eye disease. To learn more about how you can support cutting-edge vision research, please see the Fighting Blindness Canada advertisement and listings in this Guide.

*Submitted by
Fighting Blindness Canada*