

The Mom & Caregiver™



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Losing Sight,
But Not Hope
...how one family is
fighting blindness

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A Free Magazine for PARENTS and CAREGIVERS

Losing Sight, But Not Hope

For many of us, our children's health is something we are, of course, deeply grateful for but also something we may take for granted. Every mother wishes for a healthy child "with ten fingers and ten toes," and once that perfect little baby is born, we breathe a sigh of relief. But life can change in the blink of an eye. One day your child is healthy and well and the next thing you know, something changes. This is exactly what happened to one London mother. Joan Milroy's story deeply moved us, and we'd like to share them with you here.

Imagine yourself on a perfect summer day...you are sitting in a canoe with your husband and two boys. There is not a cloud in the sky and the sun is warm on your skin. You are paddling happily when you come across some ducks that you point out to your family. Everyone stops to look and comment. However, the words that come out of your youngest son's mouth are enough to make your heart skip a beat. He says, "I don't see any ducks." At first you think he is joking, as the ducks are less than twenty feet away. How can he not see them? You follow his gaze to ensure that he is looking in the right direction and this is when your heart skips another beat. You don't want to alarm him so you let it go and paddle on. Your light heart has now been replaced with worry.



A visit to the optometrist is met with, "you need to have an ophthalmologist see him right away." Two days later your 11 year old is sitting in the chair and being examined. Your heart is pounding as the ophthalmologist is asking him what letters he can see. You remember that the BIG E on the chart used to make you chuckle because who possibly couldn't see that huge letter. Today there is nothing funny about it as your son struggles with these large letters. You are trying to hold the tears back...What is happening here? Why can't he see that? You are told that your son will never drive a car and that you need to go to Sick Children's Hospital to investigate what is going on. You leave the room, hoping that this is a bad dream, a nightmare that you are going to wake from...but you don't. This is your new reality, except that you don't want it. You want to hand it back and say, "No thank you!" You get into your car and wonder how you are going to drive home with the tears streaming down your face, with a heart that truly feels broken. All you want to do is crawl into your husband's arms, cry and scream and do whatever you have to do to relieve this incredible pain that is so overwhelming...

It's been six years since my son was diagnosed with retinitis pigmentosa, a genetic eye disease that promises to steal his sight over time. With this condition, the first symptoms are loss of vision at night and loss of peripheral vision. But even though Neil is losing vision, our family is not losing hope.

Neil Milroy is now a grade 11 student at A.B. Lucas High School and is legally blind. He finds everyday activities such as using a vending machine or reading a restaurant menu—activities most people take for granted—impossible. He once dreamed of getting his driver's licence, as most teens do, but had had to put that dream on hold for now. Neil has hope that one day there will be a cure for his blindness.

The Milroy family is just one of thousands of families across Canada affected by a retinal eye disease. Just over 30 years ago, retinitis pigmentosa, macular degeneration and other retinal dystrophies were thought to be incurable. But today, vision researchers are confident that cures are in sight.

The Foundation Fighting Blindness (FFB) is the only organization in Canada dedicated solely to funding research to discover causes, treatments and cures for genetic eye diseases that cause blindness, such as retinitis pigmentosa. Since the Foundation's inception in 1974, it has given more than \$16 million to vision research.

Comic Vision is one of the Foundation's primary fundraising initiatives. A national comedy fundraiser in support of the FFB, Comic Vision has raised close to \$1 million for the Foundation since it began in 1999. This year, London kicks off the cross-country comedy tour when Comic Vision stops at the Carousel Room at the Western Fair Grounds on Tuesday, April 29. Tickets are \$75 each. For tickets contact: Wendy McDonald at (519) 660-1797 or go to www.comicvision.ca.