

'IT'S EXTREMELY HEART-WRENCHING'

BABY WITH RARE BRAIN DISORDER GIVEN MONTHS TO LIVE

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The odds of it happening were incredibly slim; a 1 in 250,000 chance. So rare that this Georgetown family's pediatrician hadn't actually seen a case in over 30 years of practising medicine.

But for new parents Andrew and Cheryl Herbert, Krabbe disease has become an all-consuming part of their daily lives. Their seven-month-old son Lincoln was recently diagnosed with the fatal metabolic disorder that destroys the

protective coating of nerve cells in the brain and throughout the nervous system.

While the couple was originally told he would have about two years to live, the genetic disease is progressing quickly and recently started causing Lincoln to have infantile spasms (seizures), reducing his life expectancy to mere months.

"We've been told he might not make it to his first birthday," said Andrew. "It's extremely heart-wrenching. Every day, every minute we have with him is precious."

The Herberts have spent much of the past two months at Sick Kids, staying at Lincoln's side in shifts due to hospital visitor restrictions amid the coronavirus pandemic.

The pair first became concerned about their



Herbert family photo

Seven-month-old Lincoln Herbert, who's been diagnosed with Krabbe disease.

son's health when he was around five months old. Lincoln wasn't holding his head up, rolling over or grasping for toys, and had become inconsolable almost all the time.

"He could be screaming uncontrollably for 22 hours (out of 24)," recalled Andrew. "You couldn't put the poor guy down without him screaming."

The couple worked with

their pediatrician to treat what was believed to be severe colic symptoms with a variety of methods. But nothing worked.

One night, after Lincoln had been hysterical from midnight until 9 a.m. the next morning, they were advised to take him to McMaster or Sick Kids for an ultrasound.

The experts at Sick Kids quickly recognized the baby's condition was neurological and booked him for a three-hour MRI that revealed the fatal disorder.

"The biggest challenge I've had to overcome was hearing the heart-wrenching news that my innocent, beautiful baby boy will one day pass away," said Cheryl. "My hope is for this terrible nightmare to end, but I know deep inside that this is now reality for us."

The Georgetown woman spent her first Mother's Day in the hospital, with Andrew and the nurses decorating the room to make the bittersweet occasion as special as possible.

The couple has been learning all of the skills they need to keep Lincoln safe and comfortable when he comes home from the hospital, including how to suction the saliva that he now struggles to swallow.

With several of the medications and supplies required for patients with Krabbe disease not covered by OHIP, and Lincoln requiring 24-hour care, the Herberts have launched a GoFundMe page (go-fundme.com/f/hope-for-lincoln) to help cover some of their costs — a campaign that's raised over \$20,000 so far.

Initially they had hoped some of the funds could help them travel a bit with Lincoln and visit family and friends further afield, but his quick decline has left them unsure if that can happen.

"My biggest hope for Lincoln is that he lives for as long as possible with little pain," said Cheryl. "He's my everything; my beautiful, blue-eyed baby."

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