



COMMUNITY

9-month-old Holly needs your help

Trust fund set up for baby missing quarter of her brain

By Stephanie Thiessen
CANADIAN CHAMPION STAFF

A month before their wedding, most young couples are busy comparing tablecloth colours and deciding whether to go with red wine or white.

Not rural Milton residents Courtney McLauchlan, 23, and Ken Taylor, 26, who are getting married in November.

Since finding out their nine-month-old daughter, Holly, has schizencephaly, a rare developmental birth defect, the couple's life has been about one thing and one thing only: doing all they can for their precious little girl.

Taylor works 14-hour days as a construction foreman, while McLauchlan's days are filled with a slew of therapist appointments for Holly on top of the normal care a new baby requires.

Three nights a week, to earn some extra money while on maternity leave, McLauchlan cleans cars at a local detailing shop.

The routine that's quickly become the couple's new norm leaves little time for wedding planning, and the constant thinking about Holly's well-being doesn't leave much room for excitement about their upcoming nuptials.

McLauchlan is the first to tell you she's willing to do whatever it takes to give her daughter every chance at a good life.

"I've had 23 years where it's been all about me," she said.

Now, it's all about Holly.

Parents knew something wrong

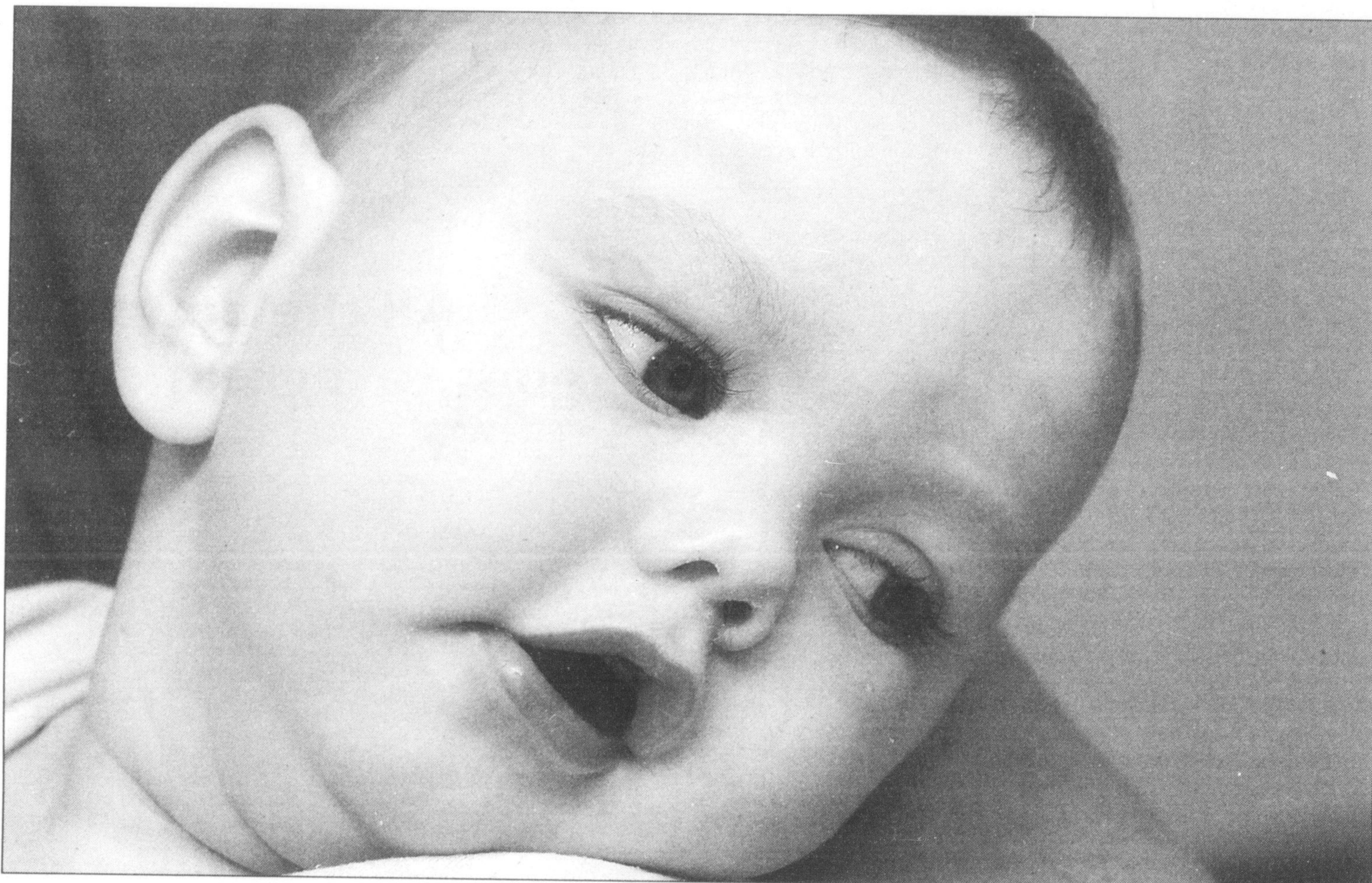
Up until seven months ago, Holly seemed perfectly normal, McLauchlan said. But then it became clear that something was wrong.

"She didn't do anything babies should," McLauchlan explained.

The next few months were a nightmare for Taylor and McLauchlan, who tried unsuccessfully to convince Holly's pediatrician something was wrong.

But McLauchlan acted on her instincts. She got a second opinion, and that pediatrician took notice when Holly started choking whenever she tried to eat solid food. He also realized Holly wasn't where she should be developmentally.

After several assessments and meetings



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Nobody really knows what the future holds for Holly Taylor, who was diagnosed last month with a rare birth defect.

with therapists, the young parents were told Holly needed an MRI as soon as possible.

But Toronto's Hospital for Sick Kids told Taylor and McLauchlan that Holly would have to wait several months for an appointment.

Deciding to take matters into their own hands, Holly's parents found a private MRI clinic in Calgary that not only could see them immediately, but also could take an MRI without anesthetic.

"Not knowing what was wrong, I was concerned the anesthetic would have a bad outcome," McLauchlan said.

The trio traveled to Calgary last month, a trip that cost \$3,000. But finally doctors were able to diagnose Holly.

Birth defect extremely rare

Schizencephaly is an extremely rare developmental birth defect characterized by abnormal slits, or clefts, in the cerebral hemispheres of the brain.

"I don't like to say 'brain damage', because there's nothing to be damaged. It's underdeveloped," McLauchlan said.

Essentially, Holly's missing about one-quarter of the front hemisphere of her brain,

McLauchlan said — something that was apparent looking at the MRI.

"It was like we were looking at a volleyball and (part of it) was blacked out with a permanent marker," she said.

Now that she's been diagnosed, Holly's getting the care she needs back home.

A group of therapists come to the house on a rotating basis to work with Holly, and are "lifesavers", McLauchlan said.

But as far as what the future holds, nobody really knows. Doctors have told the couple there's not much more they could do for Holly, McLauchlan said.

According to the National Institute of Neurological Disorders and Stroke, people with schizencephaly typically experience developmental delays, delays in speech and language skills and problems with brain-spinal cord communication. They may also have an abnormally small head, partial or complete paralysis or poor muscle tone. Most experience seizures.

"She'll likely be severely mentally retarded," McLauchlan said.

Fortunately, Holly's showing some positive signs. Contrary to what doctors first

thought, she's not blind — only very far sighted — and can hear.

"Medically, she shouldn't be able to hear or see," McLauchlan explained.

Financial stress taking toll

But financial pressures are adding to the couple's stress load.

First there was the \$3,000 for the trip to Calgary. And it's become obvious that the parents will soon need to have a home and vehicle that are wheelchair accessible, McLauchlan said. There are also expensive machines and pieces of equipment that can help Holly develop.

So family and friends of Taylor and McLauchlan have set up a trust fund at CIBC — the Help for Holly fund — to help with their past and future expenses related to Holly's condition.

The CIBC trust fund account number is 00162-010-57-09512. Donations can be made at any branch of the bank in Canada.

For more information on Holly and how to help, visit <http://helpforholly.blogspot.com>.

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