

# Roots of Empathy Program A "Lifesaver" For Local Mom

For Christine Godby, whose daughter Margaret was diagnosed with a rare disorder, a much-needed helping hand came in an unexpected form – a group of enthusiastic Grade One and Two students and a program called Roots of Empathy.

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For moms of young babies, the simplest things can act as lifesavers. A cup of coffee with a friend, a visit from Grandma to allow Mom a brief nap, a casserole from a generous neighbour on a night when Mom is just too exhausted to cook – all of these things conspire to make mothers of

little ones breathe a little bit easier. It's a difficult time, thanks to lack of sleep, the demands of older children, and the many responsibilities that come along with being a mother, wife and community member, and a helping hand can come in many different forms.

For Christine Godby, that much-needed helping hand came in an unexpected form – a group of enthusiastic Grade One and

Two students and a program called Roots of Empathy.

Roots of Empathy (ROE) represents a partnership between numerous agencies, including the Regional Municipality of Wood Buffalo, the public and Catholic school boards, Northern Lights Regional Health district, Keyano College and several others. The goal of the program, in which mothers bring babies between two and four months old into a classroom every month for nine months, seeks to build empathy and reduce bullying and aggression in children. The program has been in place in Alberta since 2002 and since that time, has reached nearly 43,000 students across the province.

Godby became involved with ROE when she chanced across a poster advertising the program. Godby, mother to four children including a son with ADHD, understands the importance of building empathy in children. "My son was diagnosed with ADHD and some serious sensory and behaviour issues when he was in Grade 2," Godby recalls. "When adults see a child misbehaving at a restaurant, they tend to be really disapproving. I knew from having a child with behaviour issues that it can be really challenging – some kids just can't behave, it's not in their chemistry. Children are always really understanding but once they grow up, they tend to become much more judgmental, and it's hard on anyone who has something out of the ordinary."

"We've experienced [the importance] of

empathy firsthand because of my son's issues, so we knew what it means to be empathetic," she adds.

Godby wasted no time signing herself and her tiny daughter, 4-month old Margaret, up for the program, and in October 2010 the pair made their first foray into the Grade 1/2 classroom at Westview Elementary School.

"Everything was fine – the kids were great, the teacher was great," says Godby.

On January 17, however, the Godbys' lives changed

drastically and permanently. It began with a seemingly innocuous case of hiccups. While most babies suffer a harmless case of the hiccups from time to time, the severity of little Margaret's hiccups alarmed her mother. When the attack happened again, Godby videotaped it and went immediately to the emergency room.

"I just knew something wasn't right," Godby recalls. "I Googled her symptoms, and the more I read, the more my heart sank."

Godby's internet search suggested Margaret had something far worse than a harmless case of the hiccups, and ER doctors agreed. Shortly after doctors diagnosed the baby with infantile spasms, otherwise known as West Syndrome, Margaret was sent by air ambulance to the Stollery Hospital in Edmonton for treatment.

The rare disorder is classified as a catastrophic childhood illness, a parent's worst nightmare. The jerky, hiccup-like movements Margaret was showing were actual-



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ly seizures affecting her entire brain. Unlike epilepsy, which only affects a single part of the brain, infantile spasms are much more serious, and without treatment, will stop and even reverse a baby's development.

As the Godby family watched in helpless horror, Margaret's development slowed and then stopped. "She was sitting up, smiling, grabbing for toys, and all of that just stopped," her mother remembers.

Doctors treated baby Margaret with high doses of prednisone and, while the drug stopped the seizures and the relentless backward march of Margaret's development, it caused a disturbing side effect.

"It's called 'prednisone moon face,'" says Godby. "She developed a big, fat face, with huge puffy cheeks. It was awful to see."

Along with the facial swelling, the drug caused Margaret's immune system to suffer. For the baby's own safety, doctors forbade Godby from bringing Margaret anywhere. "We had no contact with anyone. We couldn't go to the grocery store or anywhere. The only place we were allowed to go was the doctor," Godby says.

The only exception was the ROE program. Mindful of the importance of that social link for Godby and Margaret, doctors allowed the pair to continue their classroom visits, with strict handwashing and contact rules in place.

For Godby, that monthly visit became a lifesaver. "It was so difficult for myself, for Margaret and for the whole family, going through this horrible traumatic time where Margaret was losing skills and we didn't know what was going to happen," Godby says, her voice breaking with emotion. "Just being able to go into that classroom and see those kids and the love they had for Margaret...it was amazing. It was one normal thing that hadn't been disrupted."

The students responded with the natural curiosity of childhood when they saw Margaret's swollen face, but once Godby explained her illness, they accepted Margaret's new appearance as a matter of course, delighted to have the baby in their midst once again.

"They were concerned, but in a caring way," Godby says. "The kids were so welcoming – they were a model for how we

ABOVE: Margaret and mother Christine enjoy a quiet moment on the swings at the park near where they live. LEFT: Margaret's sweet face has lost its puffiness now that she is off the prednisone. PHOTOS: Courtney Palmer for CONNECT

should act as adults. We forget about the innocence of youth. They asked what was wrong, then they moved on and treated Margaret as if she were normal. They didn't focus [on her illness], they were just happy that she was back, regardless of what she looked like."

Margaret was taken off prednisone after a time, and her face gradually lost its puffiness. The baby recently celebrated her first birthday and while her development is still slightly behind where it should be, thanks to the delay caused by her illness, she's doing remarkably well. "She's able to sit on her own and she's certainly interested in everything around her," says Godby. "She doesn't say words yet but she's babbling, and she's not crawling but you can tell she really wants to."

While 70% of infants with West Syndrome go on to have seizure disorders in the future, Godby says the family remains hopeful for baby Margaret's future. "There's no indication of a genetic problem, so we're just taking it day by day. We're hoping she'll be fine, but we know she may develop a seizure disorder as she gets older and if she does, we'll deal with that," Godby says. "Hopefully people will be empathetic towards her. Adults can learn from [the students in the ROE program]'s example – that's what we hope."

In the meantime, Godby says she encourages anyone considering the ROE program to get involved. "Certainly I would recommend anyone to go share that experience," she says. "The kids asked so many great questions and the way they interacted with Margaret, it was a really wonderful thing to be a part of."

"It really reconnected us, the power of the love from those kids," she continues. "Up here in Fort McMurray, we have absolutely no family, and those kids, because they took her in as 'their' baby, it really made us feel part of the community. The impact it had on our family was very uplifting – even though we don't know what's going to happen, it gave us hope."

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