

Speaking of Children's



SPRING 2016

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Supporting Youth with Diabetes to Live Vibrantly

Nathan Finch is an 18 year old from Exeter, Ontario who knows how to survive in the wilderness, save lives in the water and maintain good grades, while also working an after school job. Since 2009, Nathan and his family have known he has Type 1 diabetes. So far, Nathan has done an exceptional job of ensuring his condition does not hold him back from doing the things he loves. His family acknowledges that a great deal of Nathan's success can be attributed to the incredible patient- and family-centred support he receives through the Diabetes Program at Children's Hospital, London Health Sciences Centre.

Before Nathan's first visit to the Diabetes Program, he experienced inexplicable weight loss, an unquenchable thirst and fatigue. This was a frightening time for his family, and they knew he needed help. Since December 1, 2009, Nathan's care team has taught him to always carry Jelly Beans to regulate his blood sugar, to accurately read and replenish his insulin levels, and to eat nutritious meals to conquer his endless list of activities. Nathan admits that, at times, dealing with diabetes can be "depressing and overwhelming" but, "Children's Hospital has been so

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Nathan racing at London's Forest City Velodrome.

Supporting Youth with Diabetes to Live Vibrantly...continued

supportive – the whole team is always there. Even when I am not willing to help myself, they are there to help me,” he explains.

Nathan is at a pivotal time in his young life. Not only will he be graduating from high school this year, but he will also be graduating from paediatric to adult care. For many teenagers, this transition can be extraordinarily difficult, and up to 41 per cent of transition-aged youth with Type 1 diabetes drop out of care within the first year. This puts young people at an increased risk for critical illnesses associated with diabetes, which can include heart disease, blindness, kidney disease and the loss of limbs.

Thanks to the generosity of Children’s Health Foundation donors, over the last several months, Children’s Hospital

has been able to offer more than 40 patients, like Nathan, additional support as they transition into adult care. The Transition Readiness Adolescent Complications Clinic (TRACC) augments efforts on transition readiness in a stream-lined stand-alone diabetes clinic. TRACC is creating a culture of transition through assessment and education services that were not previously achievable in the all-ages clinic.

Your support enables TRACC to help an increasing number of adolescents to remain engaged in the management of their diabetes, encouraging them to live optimally during the most formative years of their lives. For Nathan and his family, this means that he will continue to be a mentor, a cyclist and an apprentice electrician because as he states, “Nothing – especially my diabetes – will stop me!”

Parent Mentors: A Strong Voice and a Helping Hand for our Kids and Families

Emma Rutherford is a vibrant young woman who has a great sense of humour and an incredible zest for life. However, at times, the significant challenges presented by Dravet syndrome and epilepsy have threatened to dull her sparkle. Dravet syndrome is a rare genetic disorder defined by frequent debilitating seizures. When Emma was seven months old, her mom, Mary, looked on in horror as Emma seized for 20 minutes. Her next one lasted more than an hour, and Emma was rushed to Children’s Hospital where she was intubated and heavily medicated to mitigate the consequences of her seizure. It was a week before Emma could even open her eyes and Mary shares, “I thought she wasn’t coming back and that the baby I knew was gone for good.”

As a parent faced with the difficult reality of a young child who would have up to 40 seizures each month, Mary embarked on an unexpected journey that led her to Thames Valley Children’s Centre (TVCC), the regional rehabilitation centre for children and youth with physical, communication or developmental needs. Within the warm and welcoming walls of TVCC, Mary discovered the Parent Mentor Program.

Throughout her life, Emma has experienced some developmental delays, however, her mom recognizes Emma’s infinite potential and refuses to settle for anything less than what her daughter requires to thrive – especially when it comes to her education. “It may be more challenging to educate a child with special needs, but that doesn’t make it any less important or imperative that it happens,” Emma’s loving mom asserts.

Amongst the general public there is a lack of understanding regarding the ways in which Emma’s condition impacts cognitive development and academic performance. “There have been times when things really fell apart. Given the incredible challenges Emma faces when it comes to learning, there have been years when she was continuously being failed in things I knew she could do,” shares Mary. TVCC’s Parent Mentor Program helped Mary to better understand her and Emma’s rights. Parent mentors bring their knowledge and

experiences to help support parents in their advocacy role. “Every parent wants what is best for their child, but you need everyone involved in their developmental journey to listen to each other and really understand the needs of the child. These mentors helped to set the tone to motivate everyone to pursue solutions that would support Emma to be her best,” Mary explains.

With encouragement from TVCC’s mentorship program, which is supported by Children’s Health Foundation donors, Mary and Emma have overcome many obstacles, and now Emma is “really thriving.” The benefits of effective advocacy have far exceeded Mary’s expectations; Emma’s stress has decreased, which has significantly reduced the frequency of her seizures – a gift that Mary could not be more thankful for.

Children’s Health Foundation sincerely appreciates our donors who recognize that every child deserves the chance to pursue an enriching life. Support of the Parent Mentor Program at Thames Valley Children’s Centre is a current funding priority, and your contributions to this initiative will help kids, like Emma, to learn, grow and play optimally. Please visit www.childhealth.ca/donate to create a culture of compassion and understanding for our kids and families, so they may pursue their endless potential.



Emma and Mary this past summer.



Breanna with Music Therapist, Karina Charczuk.

Battling the “Big C” with a Little Do-Re-Mi

Before March 2015, the Barnims did not even own a thermometer because their children had always been so healthy. However, when Cyndi’s seven-year-old daughter became so ill she needed her brother to carry her home from school, the Barnims knew that it was more than just a common cold draining Breanna’s vitality. Cyndi and Breanna visited their family doctor, and she immediately called an ambulance. Moments later, the Barnims headed to the Paediatric Emergency Department at Children’s Hospital.

It was there, amidst the hustle and bustle of emergency admissions, the Barnims discovered that their little girl had cancer. When they received the news, Breanna looked at Cyndi and said, “Mommy, you look like you just got punched in the face.” A very frightened Cyndi and confused Breanna were admitted to the Children’s Inpatient Floor where they remained for two weeks.

Luckily, Breanna didn’t have to wait long to find the silver lining of her overwhelming diagnosis. The very next day, the hospital’s new Music Therapist, Karina Charczuk, visited Breanna with a gift that the family will never forget – the healing power of musical expression. At first, Breanna and Karina just spoke about the new patient’s experiences, but then the two fast friends began to explore all of the restorative potential of Music Therapy

by singing, playing and creating songs. Karina visited Breanna almost daily during her two-week stay, and she continued to spend time with her whenever Breanna needed to return for an emergency visit or follow-up appointment.

One very special occasion that Breanna and her mom will never forget occurred when Breanna was in clinic receiving chemotherapy. Karina and Breanna were strumming a ukulele when a little boy peeked his head around the curtain, hoping he could join in. Breanna and Karina welcomed the newest addition to their band and he began to play along with a shaker. Moments later, a boy in his late teens also joined in the musical collaboration. “Music just brings you together and shows the kids that they are not alone in this. Everyone in the clinic who came across this heart-warming scene had to stop and stare at the magic that was taking place,” Cyndi shares.

Children’s Health Foundation is delighted to celebrate the second year of Children’s Hospital’s incredible Music Therapy Program, a transformative initiative that was only made possible through the generosity of our community members. Your continuing support helps to fill young patients’ most difficult days with notes of hope and joy. Thank you for creating magic in our hospital.

Your support makes miracles happen!

Do you remember our friend Archer who spent a full year receiving critical care at Children's Hospital? Archer's family knew he was a fighter, but when their brave little boy finally took his first steps, there was no shortage of celebratory tears.

Thanks to CRH Canada Group Inc. and its partners who matched donations up to \$45,000 in our holiday appeal to help provide specialized programs at Children's. Our donors joined in and more than double that amount was raised! Now, with the support of his care team and the donors who empower them to deliver exceptional care, Archer will continue to pursue his endless potential to live, grow and play.

"On numerous occasions, Children's Hospital has saved Archer's life – without them, Archer wouldn't be here. We're still living this – it's not done and over. Children's Hospital will be a part of our lives for a long time," Archer's mom, Jen, shares. Visit www.childhealth.ca to read Archer's incredible story.



Archer celebrating his second Easter.

Community Support Creates Safe Spaces for Fragile Newborns

Each and every baby enters the world in their own unique way. Some infants, including 932 from across our region, require specialized intensive care to get the best possible start in life. TD Banking Group employee, Jeremy Powers, and his wife Rachel met several of these newborns in the Neonatal Intensive Care Unit (NICU) at Children's Hospital during their time as foster parents through the Children's Aid Society. Over the course of a year, the Powers family visited four different babies in the NICU until they finally met Zoe, the beautiful little baby girl who would find her forever home with Jeremy, Rachel and their two daughters.

Zoe was born four weeks prematurely on November 11, 2012, weighing just four pounds nine ounces. At the beginning of her hospital stay, Zoe's weight dropped to four pounds two ounces, and she relied on nutritional and breathing support until she was able to get back up to five pounds. On November 27, the Powers were able to take Zoe home. Jeremy describes their experiences in the NICU as "fantastic and uneventful," however, due to their multiple trips to the NICU, he recognizes that many families face extraordinarily tough care journeys, with their infants requiring extensive support to thrive.

"Every parent just wants what is best for their child. While each family is going through a different situation, we all have the same goal – a happy, healthy baby," Jeremy shares. With

the support of the incredible staff and specialized equipment within the NICU, the Powers achieved this goal. Nowadays, Zoe's family calls her "the chosen one" because she is thriving, outgoing and always cheerful.

Recently, the Powers revisited the NICU so they could show Zoe her very first home. During their visit, Jeremy was reminded of just how peaceful the care environment seemed. "Whenever we went to visit, I always thought there would be more crying, but the NICU is comfortable and quiet," he explains. Our caregivers work diligently to maintain this atmosphere because mimicking the mother's cozy womb is absolutely essential to nurture infants' optimal care outcomes.

Children's Miracle Network (CMN) supporters, including our friends at TD, help to create the perfect "first home" for our region's most fragile newborns by supporting care improvement initiatives and the purchase of specialized equipment. Over time, TD employees and customers have raised over \$7 million for the kids and families who visit Children's Hospital to receive life-saving and enriching care. We can't thank TD enough for their ongoing support – together, we are creating a place of hope for our region's families whose only wish is to bring home a vibrant bundle of joy.



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