

Speaking of Children's



Keanna, age 9
London, ON

childhealth.ca



Helping Lilah Get Home

As a newborn, Lilah couldn't move like other children her age. She wasn't able to hold up her head or kick her feet; she was as floppy as a rag doll.

Her parents, Nicole and Eric, sought medical advice, but as the months passed, the questions persisted and Lilah's muscles continued to deteriorate until she had difficulty breathing and swallowing.

"At five months old, she started turning blue at home and choking on her food," recalls Nicole, adding at that point her local hospital in Windsor sent Lilah to be treated in London.

"As soon as we got to Children's Hospital, London Health Sciences Centre we found out

Lilah had a partially collapsed lung. She was rushed to the Paediatric Critical Care Unit and 12 hours later both of her lungs collapsed."

After two weeks in hospital, Lilah was diagnosed with the most severe form of spinal muscular atrophy (SMA). This terminal, degenerative disease affects the part of the nervous system that controls voluntary muscle movement. Medical professionals shared they didn't expect Lilah to survive the year.

While in hospital, the chubby-cheeked infant had to endure an MRI, four surgeries, four lumbar punctures, five ultrasounds, 64 x-rays and 119 pokes.

Because of You!

- Teens with anxiety will get immediate support
- TVCC can continue to add a special touch to clients' wheelchairs, bikes and more
- Annie and her family are able to give back to the Eating Disorder Program
- Our 2016 events were so special. We can't wait to see you again this year!

Meet Children's
Health Foundation's
new President and
CEO!

Read More Inside...

Meet CHF's NEW CEO!

Children's Health Foundation is pleased to welcome Scott Fortnum as our new President and CEO.

Recognized as a philanthropic leader, Scott brings extensive health care, education and NGO fundraising experience.

Children's Health Foundation already holds a place in his heart, as both of Scott's children have benefitted from the exceptional care they received at Children's Hospital. He knows firsthand just how important our paediatric health care partners are to kids and families in our community, and beyond, in their time of need.

With Scott's dedication and passion for kids' health, we are excited for this next chapter at Children's Health Foundation. Welcome to the team, Scott!



Get to Know Scott...

Q: When you were a kid, what did you want to be when you grew up?

A: "When I graduated from grade eight we had to answer this question. Other kids picked firefighter, police officer, astronaut, etc. I was the odd man out because I put 'happy and successful' and I am, I'm proud to say."

Q: If you could be any animal, which one would you choose?

A: "I've always liked owls because they fly silently, they observe, and they are wise."

Q: As a kid, what was your favourite thing to do in London?

A: "Each summer, the Public Utilities Commission would organize fun activities in all of the neighbourhood parks. Walking or riding my bike to the park to hang out was my favourite part of the summer."

Helping Lilah Get Home

Continued

Fortunately, after six months she was stable enough to finally return home.

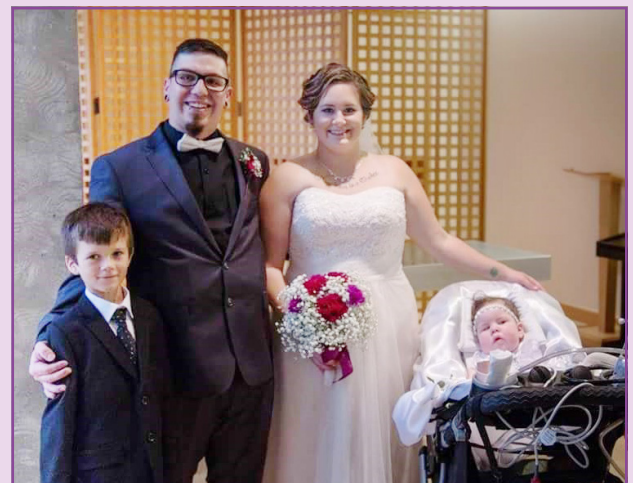
Eric, Nicole, and other family members had to get extensive training to meet her care needs. Lilah relies on a ventilator so medical professionals taught the family how to operate this life-giving machine using artificial "lungs" and a training ventilator, which was purchased thanks to a donor like you. Since they were able to become experts in hospital, the family was able to go home as soon as their government-funded machine arrived.

The couple also learned to use a cough assist to clear Lilah's lungs of fluid, perform daily tasks such as lifting and bathing her, and spot signs of concern.

"It was exciting and nerve-wracking," Nicole says about bringing Lilah home.

The family visits Children's Hospital every four months to see Lilah's specialists. Lilah is currently taking an experimental medication, called Nusinersen, which will hopefully slow the progression of the disease and help her to live better. Her family says they've seen improvement, with Lilah being able to wiggle her legs for the first time, shake her head yes and no, and lift her arms.

"She has already surpassed the time they gave her with us so that's very exciting and she seems to only be getting better from here," says Nicole. "It's very promising."



Eric and Nicole got married at London Health Sciences Centre so their daughter Lilah, who was hospitalized, could attend.

Technology Gives Teens an **APP**etite for Nutrition

The statistics are staggering; in a world full of sugary drinks and deep fried snacks, children and youth are surrounded daily with unhealthy food choices.

As a result, fewer than half of Canadians over 12 eat the recommended daily servings of fruits and vegetables. Twenty-two per cent of calories consumed by Canadian children aged four to 18 do not fall under any of the categories of Canada's Food Guide.

What if getting your teen to eat better was as simple as downloading an app? Soon it can be, as researchers at Children's Health Research Institute are redeveloping an innovative smartphone app, called SmartAPPetite, to improve youth's nutrition knowledge and food purchasing habits.

How it works:

The app sends dietitian-approved messages based on the users' personal dietary goals, eating schedule and location. Messages are connected, starting with tips about healthy eating, with links to recipes and nearby food vendors that offer healthy, locally-sourced options. SmartAPPetite uses an interactive method to nudge teens to make healthy eating a part of their everyday routine.

Donor support helps to fund innovation like SmartAPPetite, to improve the health and wellness of our children and youth.



You Made Michael Smile

From healthy cooking to navigation, Thames Valley Children's Centre (TVCC) teaches teens with special needs important life skills to build their independence.

Youth for Youth holds events throughout the year for clients, aged 12 to 21, who are interested in trying new things.

Nineteen-year-old Michael has been attending the group for the last six years. Diagnosed with a complex genetic condition called Prader-Willi syndrome, Michael has low muscle tone and an insatiable appetite.

"Food is a big focus for Michael," explains his mom Rosa. "It's important to keep him active and going."

Youth for Youth does just that for Michael. Through the group, he has gone bowling, swimming, volunteered, and attended special holiday parties. One of his favourite events was the Master Chef Cooking Challenge, where teens had to purchase groceries and prepare food

Losing Control to Overcome Anorexia

For Annie to overcome and survive anorexia, she had to lose control over her life.

At 15 years old, Annie was admitted to the Child and Adolescent Mental Health Care Program at Children's Hospital. As an inpatient, staff kept a close eye on her to prevent her from hiding or vomiting up food her body desperately needed. She also couldn't expend any energy – even short strolls would be dangerous for her health.

"It was really difficult," recalls Annie. "I didn't want to be monitored and told what to do all the time, and that's exactly what had to happen for me to get better."

It started in January 2013 when Annie began withdrawing socially, missing school, and not sleeping well. To find a sense of control, she restricted what she ate. Her sudden weight loss concerned her parents so they brought her to Children's Hospital where she was admitted to the Eating Disorder Program, a division of the Child and Adolescent Mental Health Care Program.

"Annie was very ill; her organs shut down, her brain, everything in her body atrophied," says her mom, Amanda.

Annie's medical team of psychiatrists, dieticians and other health care professionals worked to get her physically well, but they also helped her to find a healthier mindset.

"Over time, I stopped punishing my body and found time to do things that made me genuinely happy. I no longer obsess about food; now I'm always looking forward to my next meal!" shares Annie.

The team didn't just care for Annie, they cared for her family. To help them navigate their frightening reality, staff provided them with education and support as to how to move forward.

Today, Annie has been accepted to university and has a bright future ahead of her, which Amanda credits to the programs and care at Children's Hospital.



Michael sports his Halloween costume at one of Youth for Youth's holiday events.

before sharing a meal together. Rosa says the challenge taught her son about healthy eating, a message he brought home with him.

"I think Youth for Youth is wonderful. It provides youth with varying abilities the opportunity to participate in events within the community. It just gives them that independence," shares Rosa.

This life-enhancing program is offered thanks to donor support!



"Over time, I stopped punishing my body and found time to do things that made me genuinely happy," shares Annie.

"I am so very grateful. Annie wouldn't be here if they hadn't helped her, and our family," says Amanda.

To express their gratitude, the family partners with Foster Townsend Lawyers to run *Mind Games*, a trivia fundraiser in support of Children's Health Foundation (photos on right). The fifth annual event took place on March 31 to benefit the Eating Disorder Program that helped Annie recover.

Thank you to everyone who attended and supported this fun event!



**Foster Townsend LLP
PERSONAL INJURY LAWYERS
PRESENTS THEIR 5TH ANNUAL
MIND GAMES**

What is **Legacy Giving**?

Planning your legacy is a chance to tell your life story and a wonderful way to make a charitable gift that benefits you, your family, and a charitable cause that's close to your heart. Speak to a professional financial or estate planner to get details on how you can minimize taxes and maximize estate benefits.

The large variety of planned gift types available allows you to leave a lasting legacy appropriate to your financial situation. You can choose to direct your gift to an area of health care, research, or rehabilitation that has special significance for you, or you can simply choose to support the highest priority needs.

The decisions you make today will help save and improve our kids' lives for years to come.

For more information on Legacy Giving, please contact:

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I want support top priority needs to help save and improve kids' lives with a special gift:

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Option A: Regular Monthly Gift*



Pre-authorized giving from my bank account *(please include a void cheque)*

Gift \$ _____ (on or about the 15th of each month)



Pre-authorized giving from my credit card

Gift \$ _____ (on or about the 15th of each month)

***minimum \$10/month for monthly gift**

Option B: One Time Gift



Enclosed is my gift of \$ _____

(Please make your cheque payable to Children's Health Foundation)



Please charge my credit card \$ _____

(Please complete credit card information)

Credit Card Information



Credit Card Number

Expiry Date (MM/YY)

Print cardholder's name as it appears on card.

Cardholder's Signature

Month/Day/Year



I wish to remain anonymous.



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I have already included Children's Health Foundation in my Estate.

We respect your privacy. For more information on our privacy statement, visit www.childhealth.ca/privacy

Charitable Registration Number: 11885 2482 RR0001

Donate online at www.childhealth.ca/donate



Adding a **Special Touch** to Bikes, Sleds and More

For the past 15 years, Mike has been employed as an upholsterer for Thames Valley Children's Centre (TVCC). After all this time, he still beams when he's asked to share how he and the Adaptive Technology Service (ATS) team support children with special needs.

Tucked in a specialty workshop at the back of TVCC, Mike and the ATS team use their considerable talents and ingenuity to customize commercially available equipment and even specially design pieces to meet their clients' needs.

From wheelchairs and school chairs to bikes and toboggans, they make individualized adjustments so that children and youth, no matter their disability, can be comfortable and participate in some of the most memorable and enjoyable aspects of childhood.

Watching the team create customized seating for wheelchairs is a fascinating process. First, the child sits on a bean bag chair so it can be vacuum-suctioned to hold their imprint, which the team then plasters. Next, a specialized machine follows the design of the mold while simultaneously creating a replica out of ethafoam. Memory foam is added over top and then Mike sews a cover for the cushion.

Mike brings personality to the pieces by using fabrics with bright colours, flames, sports logos and more to reflect the child's tastes. "We're creating these for kids, they should be fun!" Mike explains.

This year, donor support will help us purchase a new sewing machine, valued at \$2,000, for Mike and the ATS team. After more than 20 years of hard use, the current machine is on its last legs.



You Are Providing Mental Health Support

While there is a growing conversation surrounding mental illness in our society, stigma continues to play a powerful role in a teen's decision to seek care.

Heartbreakingly, 63% of youth identify embarrassment, fear or stigma as most likely to prevent a person their age from receiving treatment.

Recognizing the importance of early intervention, three psychologists within the Child and Adolescent Mental Health Care Program at Children's Hospital have developed, piloted and are now evaluating a mobile app for teens with anxiety – the most common mental health concern in Canada.

"Am I anxious?" will reach teens where they are, helping them learn about anxiety and explore whether it is a problem for them through psycho-educational materials and therapeutic exercises.

The hope is that as teens progress through the app, they will realize how treatment can improve their lives and feel greater encouragement to seek further help.

"Am I anxious?" will also be used with children and youth waiting for mental health services within the hospital. The app is scheduled to be released on iTunes, Google Play and other online platforms.

Thanks to donors, this initiative will deliver important mental health information and resources into the hands of our youth!



Kerry Collins, Julie Eichstedt and Devita Singh, psychologists within the Child and Adolescent Mental Health Care Program.



**Children's
Miracle Network**

Put your money where the miracles are and support the Children's Miracle Network Balloon Campaign at your local Walmart (**May 14 - June 5**) and Costco (**May 1 - June 4**) as part of May is for Miracles.

From May 29 to June 18, TD will host a variety of in-branch initiatives to fundraise for CMN during their Give A Little, They Get A Lot Campaign!

August is the Month of Miracles for RE/MAX, where they celebrate the Miracle Home Program in support of Children's Hospital.

Mark your calendar for DQ Miracle Treat Day on **Thursday, August 10** and purchase your favourite DQ Blizzard Treat in support of Children's.

**Get more
event details at
childhealth.ca**

Upcoming Events

June 7 – Golf Play Day

July 9 – Children's Golf Classic Family Tournament

September 10 - 17 – Tim Horton's Smile Cookie Week

September 14 - 17 – Freedom 55 Financial Championship

December 8 – Magical Winter Ball



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