# celebrations!

2018 Issue

You are making amazing things happen to improve children's care.

# Music **Brightens** Justin's Difficult Journey

Music gave Justin strength after doctors diagnosed him with cancer this past summer. Thank you for helping to nurture his passion during his fight.

A deep look of concentration falls across Justin's face and you know in this moment that he isn't thinking about cancer. He is entirely devoted to the music.

The warm, tangy sound of his mandolin fills every corner of his patient room at Children's Hospital, London Health Sciences Centre. His Music Therapist Karina joins him on her guitar after a few bars.

It's magic to see him and Karina playing Led Zeppelin's Battle of Evermore, one of the teen's favourite songs. No doubt, there has been heartbreak in Justin's hospital room but staff like Karina (whose role as music therapist you make possible) also make sure there is joy.

"Music has a way of motivating us, making a hard time better or speaking something that we can't always put into words," says Karina.

Justin became close with Karina after doctors diagnosed him with acute myelogenous leukemia, a cancer that starts in blood stem cells, in August of 2017. He was supposed to be starting his last year of high school in Belle River. Instead, he found himself fighting to survive. He endured months of draining chemotherapy treatment. He lost his hair and his eyebrows.

Music was his solace. It gave him comfort and helped cut the boredom. His hospital room was adorned with a Beatles decal and musical instruments filled the corner. A record player sat perched on the windowsill.

"Karina has been a positive influence on Justin and his music," says his mom Lorraine. "It's nice to see how they collaborate together."

Justin was diagnosed with cancer shortly before starting his last year of high school. During months of draining treatments, music was his solace. Pictured above, Justin plays his heart out on a mandolin from Long & McQuade.

(Click to Continue Story)

### **Because of You...**

- play sports, even though it didn't seem possible
- Jordyn can walk, run and
   Researchers are investigating the origins of devastating genetic diseases
- · Caleigh had a positive hospital experience

...and so much more!

<u>www.childhealth.ca</u> <u>facebook.com/CHFHope</u> H



# A Word from Our **President & CEO**, Scott Fortnum

Spring is an exciting time full of change and promise. As the warm sun filters into my office, it reminds me of the many exciting changes experienced by Children's Health Foundation and our partners over this past year.

Under strong volunteer leadership, we created a new strategic plan. We've landed on our mission, vision and values to guide us as we move forward, working to make a difference in children's lives.

### **Mission**

Inspiring caring people to donate to support excellence in children's health care and research at Children's Hospital, Thames Valley Children's Centre (TVCC) and Children's Health Research Institute (CHRI).

### **Vision**

Saving lives and improving children's health and quality of life.

### **Values**

Gratitude, Respect, Excellence, Authenticity, Trust

We are excited as we move into our next fiscal year. Excited because we see and hear daily the impact of the gifts our donors make for our health care partners. We are thrilled about new leadership. Children's Hospital has appointed Dr. Jackie Schleifer Taylor as President and Dr. Michael Rieder as Chief of Staff. Dr. Paul Woods has joined London Health Sciences Centre as President and CEO, bringing with him a strong understanding of the importance of philanthropy in today's health care system. It's a privilege to work with these incredible advocates and we look forward to enhancing Children's Hospital's impact on our community, together.

Excitement abounds at TVCC as it expands its services significantly throughout Southwestern Ontario. TVCC will bring its special quality of care and support to even more children which, of course, increases the need for community support...the role of Children's Health Foundation.

We are honoured to partner with CHRI and be a part of the wonderful work it is doing. CHRI, together with Children's Hospital and TVCC, is leading a children's health research collaborative to generate even more positive research outcomes to benefit children. Bringing together paediatric researchers from across London and beyond, they will reduce duplication and create strong synergies.

What is especially important though is to say thank you. Donor support, in the words of our partners, makes a huge difference. Without your gifts, critical equipment could not be purchased, and critical programs would not exist. On their behalf, and from our board and staff, thank you. Each time you attend an event, mail a cheque, text CHILD to 41010, support a Children's Miracle Network partner, or give a gift at <a href="https://www.childhealth.ca">www.childhealth.ca</a>, you are making a difference in the life of a child.

Feel good about the impact you have and know how much it is appreciated.

### **CHF** Fun Facts



3,500

Dr. Beary Goode visits at Children's Hospital last year



1,200

pieces of specialized equipment loaned at TVCC



25

instruments on the music therapy cart



105

scientists and associate scientists at CHRI

<− 2.75" →

Actual size of a diaper worn by some of the smallest patients in the NICU





## **Finding** Her Feet

You gave a young girl the ability to walk, run and play sports when it didn't seem possible.

When you meet Jordyn, she can be rather shy and quiet. Unless of course you ask her about sports. Then she gets this twinkle in her eye and a wide smile spreads across her face as she hurries to tell you about her favourites.

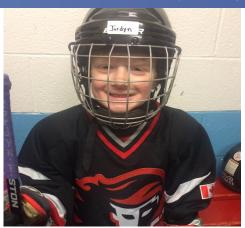
Hockey, baseball, soccer and dance are at the top of her list – she adores participating in them all.

But there was a point in her young life when her family didn't think she would be able to walk, let alone run, skate or twirl. That's where you came in.

Jordyn was referred to TVCC's Splinting and Casting Program, which is offered at no cost to families thanks to your donations. The team at TVCC determined the three-year-old's heel cords were too tight and needed to be loosened for her to walk. After multiple sets of casts and splints over two months, Jordyn took her very first steps.

"I was so happy walking around," Jordyn recalls. "Now the next thing I wanted to learn was to run, but my legs weren't strong enough yet."

Jordyn continued using the Splinting and Casting Program and also learned important stretches and exercises from the staff at TVCC. She was finally able to play sports for the first time a year later. She loved it! Now seven, she practices her heart out to excel on the ice, the field and the dance floor.



Jordyn dreamed of being able to run around and play like her friends, but her legs wouldn't let her. Your support got her the help she needed to walk, run and eventually skate!

She is a determined little girl but most importantly she is happy and confident.

"I can do anything," she says. "I know that I will rise to any challenge that I am faced with and fulfill my hopes and dreams."

### Why We Give

Donors share what inspires them to help strengthen children's health care in our community.

September 26, 2003 was a day that changed our lives forever. Krista, our 16-year-old daughter, was returning to school after lunch when she was involved in a tragic car accident – we, as parents, and our 13-year-old son Kyle lost Krista that day.



Sue and Bill donate in honour of their daughter who tragically passed away in a car accident.

To honour our daughter, friends got together the followingyearandorganized a golf tournament, named The Krista. The event started with 30 golfers and has grown to over 100. As of 2017, we have raised close to \$115,000 for Children's Hospital. Children's Health Foundation is so supportive of us. It gives us peace of mind to know that we are helping other children.

-Sue Decker & Bill Reidhead

PORTERS FOR SMILES all started with a Kuerig coffeemaker.

My mom had just passed away from cancer and a raffle for the coffeemaker seemed like a great way to raise money to say thank you for the great care she received.

Because of all the work our porters did, the raffle was a huge success! And it really took off after that. All the porters really get into the fundraising aspect of our campaigns and try their best to make each campaign better than the one before.

The result of their hard work and dedication is more than \$30,000 raised for Child Life and Paediatric Oncology. We hope to continue with fundraising so more children and parents can find a little bit of happiness while in the hospital's care.

-Steve Richardson on behalf of PORTERS FOR SMILES



Porters are important members of the hospital team, helping the facility to run smoothly by moving patients, equipment and other essential medical supplies where they are needed.

Want to share your "Why We Give" story?
We'd love to hear it! Please email us at:
info@childhealth.ca

## Music Brightens Justin's Difficult Journey (continued)

Having loved music since he was a child, it meant a lot to Justin to be able to jam with Karina, his Music Therapist, and talk in-depth with her about his passion. Karina was also there for him to share his feelings and frustrations about his medical journey.

"Music has been something that has supported Justin throughout his treatment and oftentimes was the only thing getting him out of bed on those really tough days," remembers Karina.

"The power of music was evident every time when I went to see

Justin for a music therapy session. Despite not feeling well, he would pick up his guitar without hesitation and I could help him express himself, forget about everything going on or simply get lost in the beautiful melodies."

Today, Justin is doing well following a bone marrow transplant. Children's Hospital will continue to see him for appointments and hopefully soon, he will be able to announce that he is cancer free!



"Music was the only thing getting Justin out of bed on those really tough days," recalls Music Therapist Karina (left).

Watch Justin and Karina's jam session at www.childhealth.ca/music

# Caleigh Wants to Thank You When I was four years old a taxi ran off Programs that

When I was four years old a taxi ran off the road in downtown London and hit my grandmother and me.

We had been spending a nice afternoon together, like we did most Fridays, when it happened. I was rushed to Children's Hospital where doctors put me in a medically induced coma, giving my brain time to heal.

I was in a coma for nine days. In that time the doctors had discovered that I had broken my right femur and had an injury to the right side of my brain. I stayed in hospital for five weeks after that.

I wasn't aware of it at the time, but I now realize that I was at the best place I could have been. The care I received at the hospital was incredible and you were part of that. Thank you!

"The care I received at the hospital was incredible and you were part of that." Programs that you generously support, like Child Life, really helped throughout this experience. At that age I loved going to school to learn new things and play with my friends. Since I was in the hospital, I couldn't attend school and that made me sad.

However, I did get to visit the Child Life room daily to play with the toys and meet kids who were going through similar experiences. I became good friends with another four-year-old girl. We played while our parents talked over a cup of coffee. It was great for not only me but my parents too. They had never experienced anything like this before and they needed the support the other parents provided.

Following my hospital stay, I endured a long journey of recovery. I am now 16 years old and to this day Children's Hospital is still a huge part of my life. I have regular visits to see my neurologist and my orthopedist. Thank you for helping to make Children's Hospital a welcoming place. My health care journey wouldn't have been as positive without your generosity.



#### Children's Health Foundation

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

Tell us about yourself:
Full Name
Address
City Postal Code
Phone Email
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)
Option B: One Time Gift
Enclosed is my gift of \$
Credit Card Information
VISA Mastercard.
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.
I would like to receive information about leaving a legacy gift to Children's Health Foundation in my will.
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

Save young lives this year

# Hospital Has **Pressing** Equipment Needs

If a child you know was sick or injured – their life hanging in the balance – how far would you go to ensure they have access to the best possible health care?

### You'd move a mountain, wouldn't you?

This year, we need your help to do just that for thousands of kids. The hospital is asking for community support to purchase vital pieces of equipment that will strengthen the care they provide.

### These include:

# Equipment to **Build**Ontario's Third Academic Paediatric Sleep Lab

Disrupted sleep or sleep-disordered breathing can have serious consequences in a child's life. It can result in behavioural issues, decreased academic performance, mental health challenges and more.

Currently, there are only two academic paediatric sleep labs in Ontario and wait times can be more than a year. Your support would help purchase equipment to build a sleep lab here in London to help our kids live better.



### High-tech Oxygen Monitors for Timelier Care

Your support will help buy more than 60 monitors to improve care on inpatient units.

These high-tech monitors will send real-time notifications to nurses' work phones, allowing them to immediately respond to life-threatening changes in a patient's oxygen levels.



\$10,800 each

Together we can move a mountain to save and improve kids' lives.

Please make a gift today.

<u>Donate online at www.childhealth.ca/donate</u> or text **CHILD** to **41010** 

## **Pinpointing** the Problem

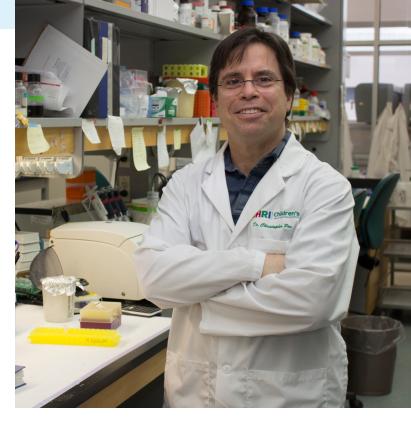
We sat down with CHRI scientist Chris Pin to talk about his division's work in uncovering the origins of devastating genetic diseases.

Your division is conducting research that could impact the lives of children with genetic diseases. Can you tell me about your work?

Our research is best summed up in a situation that I encountered a few years ago. A distraught mother had contacted me for help. Her daughter was suffering from a debilitating form of pancreatitis - her pancreas was essentially eating itself. We sequenced her DNA and her mother's and found that they both had the exact same mutation that is associated with this disease. Except, the mother had never developed pancreatitis. We still don't know why the daughter (who is doing better now) was impacted and the mother wasn't. But, we suspect there could be two reasons: either she has mutations in her other genes or she was exposed to environmental conditions that caused a negative reaction in her body. My lab and other teams within CHRI are now exploring this idea to determine how these two things - mutations and environment - impact functions in the body and cause genetic disease in some patients but not others.

### What do you hope to achieve?

Currently, we are working with Children's Hospital to identify patients with genetic disorders and sequence their DNA. Using a sample of the patient's blood, we obtain cells that we can then reprogram to revert to their original state - before they become a specialized cell, such as a pancreatic, skin or muscle cell, etc. We then closely follow the cells as they grow so we can identify how the gene mutation affects development and function of specific tissues and gain an understanding of the causes and underlying mechanisms of the disease.



Chris Pin is chair of the division of Genetics and Development at Children's Health Research Institute.

### How will your research impact children who are living with devastating diseases?

The diagnosis of a genetic disorder in a child is devastating and can leave parents with many unanswered questions. As we begin to pinpoint the causes of these diseases, we can develop new or better therapies to alleviate some of the symptoms. We may also be able to reduce a child's risk for developing a disease in the first place or determine if a patient is likely to develop additional conditions later in life. Perhaps more importantly, it will provide a stepping stone so we can find cures in the future, creating better lives for our kids.



### **May is For Miracles Campaigns**

Local Costco locations - May 1 - June 4 Local Walmart locations - May 17 - June 9

#### **Month of Miracles**

RE/MAX Realties - August

### **Miracle Treat Day**

Local DQ locations - August 9

**Extra Life - Game Dav** 

November 3



# Community **Events**

June 6 - Siskinds Golf Play Day

July 8 - Children's Family Fun Day

September 9 - 16 - Tim Horton's Smile Cookie Week

September 10 - 16 – Freedom 55 Financial Championship

December 7 - Magical Winter Ball

Get more event details at childhealth.ca

