



JACC News

[Click here to help kids like Zachary Now!](#)



SUMMER 2018

Giving hope...when love is not enough

You May Remember Zachary...



Zachary, now 6-years-old, doesn't let his diagnosis of Snyder Robinson Syndrome stop him from enjoying the outdoors

ZACHARY is a cheerful young boy who loves the outdoors. You may recognize him from one of our previous newsletters when his Dad wrote in to thank you, our incredible supporters, for helping with the cost of Zachary's respite care.

Zachary was born with a rare genetic condition called Snyder Robinson Syndrome which has only been identified in about 35 other people in the world! This syndrome affects his mobility, speech and cognition. Zachary also suffers from Vision Impair-

ment and Osteoporosis, leaving his family worried that he might break a bone if he falls. We reached out to Zach's Dad to get an update on how he is doing and what is new in his life. Here's what he said:

"Zachary happily enjoys his classmates in Grade One. He has made many friends whom he loves to play with at recess and during gym class. His classmates make a special effort to make him feel included, which is wonderful. He spends part of his day doing physical

therapy exercises to keep him mobile, and we are working on strategies to help him stand. One day we hope he will get the knack of it, as he is growing like a weed!"

In these pictures, Zach is all dressed up for his Dad's wedding in September. He enjoys spending time with his stepmom and giving her lots of hugs. He is also very close with his big sister Hannah, who is always checking in on him.



Zachary and his family at his Dad's wedding in September 2017

"Life in the wheelchair, being tube-fed, and going to numerous appointments are the norm, but everyone is super supportive and only thinks of what might make Zach's day better and brighter. Fortunately, his time spent in the hospital seems less and less."

Tee Off for Kids at our Charity Golf Classic



ANNUAL
CHARITY Golf Classic

Dust off those clubs and join us for a day on the greens in support of JACC families! We've got an exciting day lined up, including:

- On-Course Games
- Beat the Pro Contest
- Silent Auction
- Prize table
- Prizes for **Best Dressed** individual and team!

DATE: Wed., June 20th, 2018

LOCATION: [Wooden Sticks Golf Club, Uxbridge, ON](#)

REGISTRATION: 6:30am - 7:15am

TEE OFF: 7:30am (shotgun start)

INCLUDES: 2 meals, snacks, beverages, welcome gift & prizes!

Lunch and Reception to follow.

Register online now at: JenAsh.org/golf

You turned Imagination into Reality!

We would like to extend a sincere thank you to everyone who attended JACC's 2018 Auction and Dinner. With the theme *Imagine*, it was a whimsical evening of music, visual arts, and inspiration.



The beautiful centerpieces created by our Auction and Dinner Committee

We challenged you to Imagine a world where no family with a sick child struggles to afford care, and you showed us just how powerful the imagination can be!

Thanks to your generosity, the event raised an incredible:

\$152,000.00

These funds will make an enormous difference in the lives of many seriously ill children in Ontario. On behalf of all our JACC families, **THANK YOU!**

"Imagination should be used not to escape reality, but to create it."

- Colin Wilson ★ ★ ★ ★ ★

An emotional and moving highlight of the evening was hearing from our parent speaker Laura who shared the story of her daughter Keira's battle with Brittle Bone Disease.



"The bones in the back of her head were fusing together — we had to drive to Ottawa every week to see the doctor. It was then we decided to put our pride aside and get some help. We were blessed that JACC provided us with money for gas during those long six months." - Keira's Mom



Keira with the Imagine cookie her Mom brought home for her



Where Are They Now?

In 2015, we introduced you to a vibrant 4-year-old named Lucas who has Cerebral Palsy. With your support, JACC has been able to help his family purchase a specially-adapted trike, as well as Speech



Lucas at 4 years old when JACC first assisted him.

and Physiotherapy. It had been a while since we received an update on Lucas, so we reached out to his Mom. Her response is a stark reminder that for many families, their battle is ongoing and their future full of uncertainty. It is support from compassionate people like you that gives them the hope, strength and optimism to continue along their journey.



Lucas, now 8-years-old, usually has a smile on his face — even in the hospital after major surgery

His Mom wrote:

“In March Lucas had to undergo an 8.5 hour surgery because his hip was dislocated. They reconstructed his hip joint and lengthened his hamstrings and calf muscles. He remained in casts for 6 weeks. For the next few months he will have to wear all his equipment to bed.



Lucas working to improve his mobility following his recent hip surgery

Lucas loves music and hip hop dance choreography. To encourage his love, we often have “dance parties” in our living room together. He may enjoy dancing differently than others but he loves to dance in his stander, dance in my arms, dance in his wheelchair or when relaxing on the floor.”

“Each day I learn from Lucas’ patience, friendliness and resilience. I can’t wait to see where the future takes him!

- One proud Mama, Nicole ”



Lucas enjoying a day at the pool

(Zachary’s Story Continued...)



Zachary at age 4, when JACC first assisted with his respite care.

We asked his Dad what Zachary likes to do for fun, and here’s what he shared:

“Zach has started going to the pool with school and loves splashing in the water. He is also happy that spring is here and loves going for walks. He often runs into people who know him. You can hear his happy talk from a distance when he is on the way home. Zachary will be going to a cottage for a week this summer. He likes the outdoors and the beach, so this will be a fun adventure for him. It will be interesting to see how he reacts to the campfire and the stars!

- Phil, Zachary’s Dad

Follow JACC on [Facebook](#), [Instagram](#) and [Twitter](#) to read more stories like Lucas and Zach’s.

Volunteer Spotlight: Tyler Alden



Tyler making friends with Andrew, one of our JACC kids, at the Country BBQ

Tyler is a volunteer we are grateful to call part of the JACC family. He always shows up with a smile on his face and eager to help. Here's what he had to say about volunteering with JACC:

How many years have you been volunteering for JACC?

Tyler: *I have been volunteering for*

JACC for 3 years. It has been an amazing experience and I will continue to do it for a very long time.

Why do you volunteer for JACC?

Tyler: *The main reason I volunteer is to see the look on all the kids faces who have been helped, and to see how much fun they have after all they have gone through. It is an amazing feeling knowing that I have helped a kid who suffers almost every day to smile, be happy, and have a great time. It is the most priceless feeling in the world.*

What is your favourite memory as a JACC Volunteer?

Tyler: *My all time favourite memory was when a young boy on crutches came up to my brother and I and wanted to play. For our game,*

you had to shoot a water gun into a cup and try to get it to the other side. I was playing against this little boy and my brother counted down from three. As he said go, I looked down and I was soaked. The little boy shot me with water instead of his cup! The young boy looked like he was having the best time of his life. He was smiling and laughing. I have never forgotten and will never forget that moment.

Mark Your Calendar!

June 20, 2018

JACC Golf Classic at Wooden Sticks Golf Club, Uxbridge

August 19 - Sept 15, 2018

Look for JACC coin boxes in LCBO stores across Ontario

August 25, 2018

JACC Annual Country BBQ at Prince Lee Acres Farm

To learn about volunteer opportunities, email volunteercoordinator@jenash.org

Support From the Community

McHappy Day

May 2nd was McHappy Day and we couldn't be more honoured to receive proceeds from the Uxbridge and Port Perry McDonald's locations! A huge thank you to the



Words can not express how grateful we are for this support.



Durham Regional Police collecting donations for JACC at the McDonald's Drive Thru

McMaster OT/PT/SLP Charity Ball

A special thanks to Suzanne Dickie, a longtime JACC volunteer and student at McMaster's School of Rehabilitation Science, for taking the lead on promoting JACC as a worthy recipient of the proceeds

from their Charity Ball. The event took place on May 11th, bringing together faculty and students in Occupational Therapy, Physiotherapy, and Speech Language Pathology — the three types of therapy JACC helps families with. We are thrilled to be receiving over \$7000.00 as a result of their hard work. THANK YOU McMaster OT, PT and SLP graduate students!



McDonald's staff who went above and beyond to raise money, and to all of the generous volunteers who gave their time. In total, an incredible **\$29,078** was raised!