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# RARE REALITY



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## 2018 CDKL5 Canada Walk for a Cure

The 2018 CDKL5 Canada Walk for a Cure was a huge success. This year the walk was held in Thornbury, Ontario on Saturday, October 6th. The event drew just over 150 people and raised just over \$32,000 all benefiting CDKL5 Canada!

We were happy to have four CDKL5 families in attendance and we hope to see even more in the years to come. The event would not have been possible without our generous sponsors: Pharmasave Thornbury, Advanced Aluminum, 13forty, KearnsPaara Team, and Eagles Weed Control. We were also very lucky to have live entertainment before and after the walk provided by The Dust Jackets. They donated their time and talents to the event and did an incredible job at keeping everyone entertained. Our attendees also enjoyed a BBQ lunch and raffle prizes, and they were able to learn more about CDKL5 from our guest speaker Dr. James Eubanks.

It was a wonderful event and great to see so many people coming out to support our Canadian CDKL5 families. Stay tuned for next year's date and location!



Donations to CDKL5 Canada can be made online at [www.cdkl5canada.ca](http://www.cdkl5canada.ca). CDKL5 Canada is a registered charity.

"Giving hope through research and support to families living with CDKL5 Deficiency Disorder"



## CDKL5 Spotlight: Brynn Ladly

The people who know Brynn, know that she is a bit of a princess. We joke around that in many ways she has it better than anyone. With our first two kids we were tough love parents. We never let them sleep in our room, we let them cry themselves to sleep, and we never splurged for the fancy stroller. But when Brynn came along, we were forced to change our tune. We dote on her day in and day out. She has slept in our bed more often than her brother and sister combined, we spend hours agonizing over what pieces of equipment to buy, and at 3 years old we still carry her, change her, and feed her. And when Brynn cries, all four of us come running. She loves attention! She loves cuddles, the adoration of her brother and sister, massages, and having people sing to her.

To strangers, it may appear that she watches the world go on around her. After all, she can't sit, stand, walk or talk, but she listens. What she can't say in words, she says with her eyes. I marvel at how easily we can communicate despite her silence. Her brother and sister get so excited when she responds to their chatter or expresses her happiness. They understand the language of Brynn just like everyone in her circle of care.

Brynn doesn't have an easy life but we try to keep things in perspective. It's easy to get caught up with the constant documentation, medication, appointments and therapies. The list is always growing and so is Brynn. She is growing and changing and developing. We celebrate the little things, and her challenges make her accomplishments so much sweeter. We look for the silver linings in life and have discovered that they are out there, you just have to look for them. We continue to hope for a cure and to work towards an improved quality of life for Brynn and all of her fellow CDKL5 warriors.

## New Board Members

We are pleased to announce our most recent additions to the CDKL5 Canada Board of Directors. Clockwise from left we welcome: Emily Turner of Halifax, Nova Scotia, Jean-Francois Nadeau of Sherbrooke, Quebec, and Sara Spence of Winnipeg, Manitoba.

These three individuals are all parents to children diagnosed with CDKL5 Deficiency Disorder (CDD) and support our mandate of collaboration, awareness, and advocacy.

Their bring diverse life experiences to the table and they also represent three different provinces. We hope that this will add new perspectives to our Board and help us better support our families across Canada. We look forward to working with these amazing individuals as we continue to pursue our goals.



## The Marigold Study

The Marigold Study is a global, double-blind, randomized, placebo-controlled trial of ganaxolone treatment in children and young adults with CDKL5 Deficiency Disorder (CDD). The trial consists of a 6-week prospective baseline period to collect seizure data, followed by a 17-week double-blind treatment phase, which is then followed by a long-term open-label phase.

It is hypothesized that treatment with ganaxolone, an investigational medication, will increase and improve GABAA mediated signaling by boosting the signaling capacity of existing receptors and improve not only seizure control, but also other behavioral abnormalities in children with the CDKL5 mutation.

To learn more about The Marigold Study or to find out if you child is eligible visit [www.themarigoldstudy.com](http://www.themarigoldstudy.com).

You never know how strong you are until being strong is the only choice you have.

## CDKL5 Alliance

CDKL5 Canada is proud to be a member of the CDKL5 Alliance. The Alliance was formed in Rome in 2017 at the 4th International Congress for CDKL5 Research. The goal was to form what was coined as the "perfect alliance" – a membership organization which would raise awareness of CDD amongst the medical, scientific and pharmaceutical communities, whilst ultimately supporting our children and families.

