



Natalie Ladly
March 11, 2024



Introduction

- CDKL5 Canada was established in 2012 by Sangeeta Staley
- We have 7 board members: 4 Ontario, 2 Calgary, 1 Newfoundland

Mission Statement

To pursue research into finding a cure and treatments for CDKL5 disorder and to raise public awareness of the disorder, while providing support to those affected by CDKL5 in Canada.

Vision and Values

We are committed to funding innovative research to find a cure for CDKL5 disorder. We believe in the power of collaboration and helping to unite efforts in curing this devastating disease. And are dedicated to raise vitally needed public awareness, to advocate and provide support and information to all who deal with the hardships of this disorder.



Support for Families

CDKL5 Centres of Care

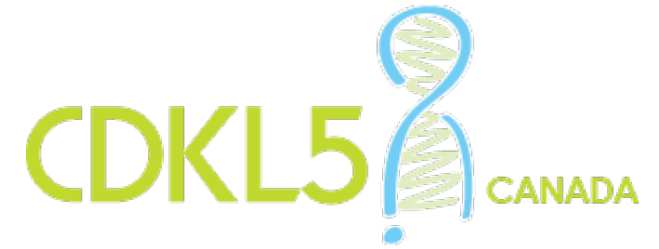
- Holland Bloorview Kids Rehabilitation Hospital – Toronto, Ontario
[Complex Care RS Pathway Clinic](#)

Facebook Support Groups

- CDKL5 Canada official page
- CDKL5 Canada Parent Support Group
- CDKL5 Quebec Parent Support Group – French speaking



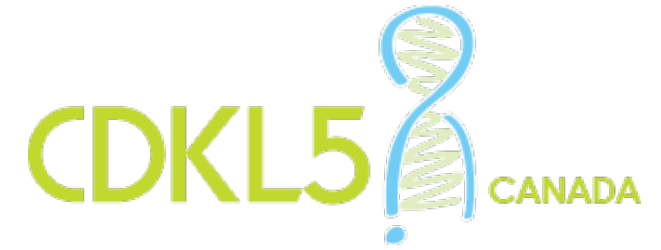
Support For Families Cont'd



- **Quarterly Newsletter – Rare Reality**
 - Includes family spotlight, fundraising events, CDKL5 events, research updates, awareness, etc.
- **Raw Talk**
 - Awareness initiative aimed at presenting various topics about the CDD journey for families - the videos are intended to be raw and unplugged
 - Topics are chosen and a request is posted on social media for families to submit videos
- **Link Canada**
 - Canadian CDKL5 registry – launched in 2021 with the goal of organizing the CDD community to assist in facilitating research, clinical trials and accessing treatments
 - We are aware of approx. 50 families diagnosed with CDD but believe there must be many more who have not reached out based on our population



Awareness Initiatives



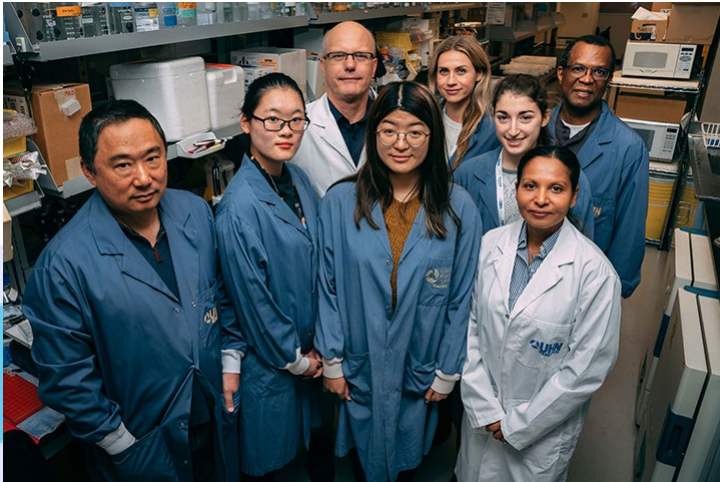
- CDKL5 Awareness Day
 - 7 Canadian landmarks are illuminated last June 17th – over 10 planned for 2024

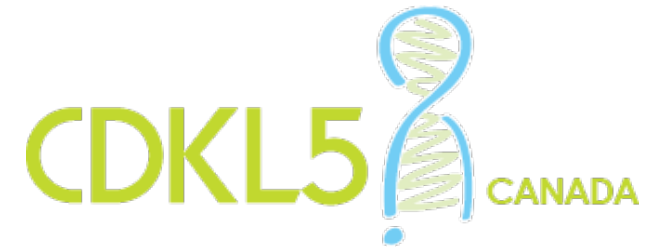


- We create an awareness video each year – highlight that families look forward to
 - We encourage families to wear green, use CDKL5Canada hashtags, create awareness through social media to family/friends, host fundraisers
- Celebrate Rare Disease Day – February 28/29th (last day of February)
- Celebrate Purple Day – March 26th

Fundraising & Grants

- We host an annual fundraising walk which raise bulk of our funds; we encourage families to host small independent fundraisers
- In 2019 we awarded our first grant to Dr. James Eubanks laboratory at the Krembil Research Institute in Toronto – Trainee Fellowship Grant of \$50,000
- Dr. Eubanks has been actively researching CDD since 2014 and gives lectures nationally and internationally on his work at CDKL5 and scientific conferences and at CDKL5 advocacy group meetings





Request to Council

THAT Council of Town of The Blue Mountains receives and supports the request of Natalie Ladly, CDKL5 Canada, to identify the month of June as CDKL5 Awareness Month.







Application for Proclamation

POL.COR.21.01

Please complete and submit your completed form to the Town Clerk at least **3 weeks** in advance of the occasion.

Organization Name	CDKLS Canada
Contact Name	Natalie Ladly.
Address	[REDACTED]
Phone Number	[REDACTED]
Email Address	nladly@cdklsCanada.ca

Proclamation Requested (Name/Title of Proclamation)
CDKLS Awareness Month

Dates of Proclamation (Please check and insert dates)

Day(s)	Week	<input checked="" type="checkbox"/> Month
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Purpose of Proclamation (Please check all that apply)

<input type="checkbox"/> Civic Promotions	<input type="checkbox"/> Public Awareness Campaign	<input checked="" type="checkbox"/> Charitable Fundraising Campaign
<input type="checkbox"/> Arts and Cultural Celebration	<input type="checkbox"/> Special Honour for Individual/Organization	<input type="checkbox"/> Other (please specify)

Description of Your Organization (Please include a brief description and any other relevant information related to your request. Additional information/documentation may be attached to this application.)

CDKLS Canada is a registered charity committed to creating awareness for CDKLS, supporting families and funding research. CDKLS is a neurodevelopmental disorder that causes seizures, motor deficiencies, many are nonverbal and visually impaired. Bryan Ladly is an 8 year old that is a resident with CDKLS. This proclamation would be a tremendous source of support and awareness.

POL.COR.21.01 Flag Protocol and Proclamation Policy
Schedule C

Has the same or a similar proclamation been requested of the Town of The Blue Mountains Council in the past?

☐ Yes (insert date of previous request) _____

☒ No

Please provide the draft wording for your proclamation for Council consideration in order to receive an official signed proclamation from the Mayor.

☐ **Proclamation Flag** (please provide photo of the proposed flag if applicable)

Signature: _____

Date: _____

Feb 11/24.

FOR OFFICE USE ONLY

Date Request Received _____

Proclamation Outcome

☐ Approved

☐ Denied

☐ Other

Approved/Denied By _____

Approval Date _____

Additional Comments _____