

## QoLA Care Newsletter - March 2021

### Dear Families,

Spring is in the air and with the sunshine and warmer days ahead we hope that many things may start to feel a bit lighter and brighter

### Rare Diseases Day 2021: "We are rare, we are strong, we are proud"



February 28, 2021 marked Rare Diseases Day around the world. The CN Tower was lit up in the colours of Rare Diseases Day (blue, pink and purple) to bring awareness to the 3 million Canadians living with a rare disease. Thank you CORD for your ongoing advocacy <https://www.raredisorders.ca/>. For more information on Rare Diseases Day view the group's advocacy video above or [here](#).

### Caregiver Wellness Meeting



March's **Caregiver Wellness Meeting** will be held virtually **this Friday** March 26th from 12:30-1:30pm.

Here's the Link. We hope to see you!

<https://hhsc.zoom.us/j/67624081814?pwd=TFJDaWJWUUpzUEI5V0d3R3hmKzlxZz09>

### Becoming an Adult with a Complex Medical Condition

Key Concepts to know for Caregivers of Youth Ages 16 and Up



#### Transition

At the age of 18 children with complex medical conditions begin the shift to adult health care supports. This, in and of itself, is a major shift for youth and caregivers alike as it very often means new health care providers, new systems to navigate, new changes in available programs, and new paperwork! Government financial supports also shift to adult supports. Soon after school programming shifts to adult programming. It all adds up to a lot going on at once. We want to help your teenager have a successful, informed transition. To discuss how we can help, please email: [golacare@hhsc.ca](mailto:golacare@hhsc.ca)

#### **Transitioning to Adulthood: When the Dependant Child Reaches Adulthood**

(March 31, 8pm)

Click on the link to register:

<https://courageousparentsnetwork.org/blog/please-join-us-for-four-upcoming-live-events>

The Courageous Parents Network also offers a **free Guidebook** called: [Planning Transition from Pediatric to Adult Providers for the Fully-Dependent Child](#). To download this guide please click [here](#)



### Guardianship

Also at age 18, for many patients we care for, there comes a need for caregivers to consider pursuing Guardianship of their adult child. Power of Attorney can be given by a capable adult to another capable adult, and changed as often as the individual wishes. Guardianship different. It is the identification of someone who has the **incapable adult's** best interest at heart and who will act on that adult's behalf—typically this is a parent or an adult sibling. Guardianship is recommended so that you maintain the ability to act on your adult child's behalf with government agencies (Service Ontario, Revenue Canada, banks even in some health care and education providers). You may be asked to show your guardianship paperwork in order to act on your adult child's behalf. We encourage you to learn if pursuing Guardianship is right for your family.

#### **Ken Pope LLB on Adult Guardianship**

Last month we introduced to you the resources on Ken Pope's website <https://kpopelaw.com/>. There are excellent resources on Guardianship there as well including a downloadable parent guide for this topic! This guide [Adult Guardianship Ebook](#) is available for free on the site. Ken describes the issue on this YouTube podcast and provides a case example which helps illustrate the importance of the topic. We encourage you to choose any local, informed professional to assist you—we share Ken's resources because he makes them accessible to everyone.



### What's Up for Respite & Summer Fun?

We are on the lookout for supports for your children and youth this summer

#### **Respite Facilities are Operating**

Some respite centres that care for children with Medical Complexity are now (or very soon) accepting one or two overnight respite clients at a time. Kids Country Club Cambridge, Kids Country Inn Brantford and Hopewell homes in Guelph are already accepting or soon will be accepting a small number of overnight respite requests. Emily's House, Toronto continues to accept overnight urgent respite requests for all regions. Please reach out to your favorite respite providers directly for their centre-specific information.

#### **Easter Seals Ontario is offering virtual and off-line camp for April Break--April 11th to 17th.**

Registration is now underway for the Spring Break Camp April 11-17 to be offered both virtually and offline (materials delivered). Summer camps are also in the works. Contact Camp Director, Kate, by email at [kgoodfellow@easterseals.org](mailto:kgoodfellow@easterseals.org) or by phone (613-267-1244) for more details

There will be no overnight camping this summer, but Easter Seals is looking into whether or not they will be able to offer their clients free access to the Perth and London cabins and facilities. Again, email Kate Goodfellow for more information

### Your QoLA Care Team's Information

Families new to our team will soon receive a "Welcome Letter" that includes some key information we wanted every new family to have about QoLA Care. For those of you who have been with QoLA Care for awhile, we thought it would still be handy for you to see and have. You will find this document as a separate attachment sent with this email.



Heidi Tigchelaar, Social Worker from McMaster Children's Hospital's NICU and Women's Health teams, joined QoLA Care for a learning rotation early this year. She will be leaving us on April 7th, 2021 and returning to her work in the NICU & Women's Health, as planned. We will miss her and have enjoyed her help and insights! Heidi, we are thankful for you, and all that you do.

**Stay safe, be well, and please reach out if we can help**

Sincerely,

Dr. Dave, Dr. Greg, Dr. Jo, Jen, Kate, Bri and Cindy

