

# Medically Complex Program



We'd like to go over anything we can help you with for this upcoming fiscal year (July 1<sup>st</sup> – June 30<sup>th</sup>). Some of you have already gone over your Family Support Plans for the year and some have not. We would like to go over them with you. We may be calling, emailing or even texting (as some of you have asked) to schedule a time to talk. If you haven't had any of these communitons please reach out to your family support advisor or Shanell Stewart at [ShanellStewart@nemasketgroup.org](mailto:ShanellStewart@nemasketgroup.org) 508-999-4436 x 161

With that said as we are moving into the beginning of our new year, and we are looking for some information we may not have gotten. This information can help us help you through this journey. I know we have spoken to most of you and have a great idea of your wants and needs but let's make it official, so we know everything that will let you get the best out of us. If you can please fill out this survey (it's on google forms) we will be very grateful. Once this is done we will have enough information to put together some ideas on how to help with our future. This should not take you more than 5 minutes to complete. For your time we are holding a **\$25 visa gift card raffle** for taking your time in filling this out. The raffle winner will be told by August 31<sup>st</sup>. If you have any questions at all please contact [ShanellStewart@nemasketgroup.org](mailto:ShanellStewart@nemasketgroup.org) 508-999-4436 x 161

<https://docs.google.com/forms/d/e/1FAIpQLSdNGsbNmkjVdTloc9bXx5VZ4a-QLaeJZwAfqlSrj0KGEJ12rw/viewform?vc=0&c=0&w=1&flr=0>

## Medically Complex Program at The Nemasket Group

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# When There is No Perfect Solution: Return-to-school and Kids with Special Healthcare Needs

*By: Margaret Storey, parent advocate for children with medical complexity and disability*

Right about now, parents across our country are wrestling with complicated and uncertain plans for kids returning to school during the COVID-19 pandemic. Some may have already sent their children back to face-to-face classrooms; others are choosing between that and remote options; yet more are in districts that are only conducting remote education.



No matter what, many of us are feeling that there are no good choices. But this reality is especially true for families whose children have medical complexity and disability, for whom return to school poses particular challenges and hard decisions.

I know these dilemmas all too well. My daughter, Josie, 17, has Aicardi Syndrome, a complex condition of epilepsy that causes intractable seizures and significant physical and intellectual disabilities. She is non-verbal and non-ambulatory, and requires supports with all activities of daily living.

And she loves school.

My husband and I are lucky that Josie is able to attend an excellent public school for students with disabilities—it provides a rich mix of academic and therapeutic education, delivered by a talented and compassionate faculty and staff.

One of the things that makes her school so exceptional is that she is supported in *all* the ways she needs—but many of those ways are physical. The intimacy of contact at school (feeding, toileting, medication administration, positioning) create contacts that are higher risk than a typical child experiences at school. And even if Josie isn't at higher risk for contracting the virus, the consequences of contracting it could be severe—for her, potentially worsening her underlying neurological condition and the consequences of that.



But there's also the consideration of our family. Her dad and I, both in our fifties, are her primary caregivers, and should one of us become ill (or worse), the challenge of caring for her is daunting. The way we understand "risk" is really not just about the virus itself. But it's about the ways that the virus could destabilize the structures we've put in place to keep Josie living with us at home.

These considerations are ones that we developed in consultation with Josie's physicians, and with her school team. We asked lots of questions, read whatever we could get our hands on, and talked to other parents. Because we are fortunate to have home-based personal support worker for Josie, and both work from home, we are in a position to choose to keep her home and do remote schooling this fall, an option that our school district has offered. But this isn't a decision that can or would work for everyone, and that's why at Lurie Children's, our parent-physician team has worked to outline medical information, common questions, and useful resources that can help other families make the best determination possible for their kids, given your local and personal circumstances.



No one impresses me like the families of kids like Josie, whose grit, courage, love, and patience are so central to their kids' health and happiness. This is a really challenging time, and I wish you all the best as you navigate this new, difficult territory!

# Down Syndrome Virtual New-Family Social



August 8, 2021

10 a.m.

Massachusetts' Down Syndrome Congress

For families of children with Down syndrome under four, and their siblings, as well as expectant families, are invited to join MDSC staff and other new families for an informal get-together with light refreshments.

- Grandparents also welcome.
- Meet other families and learn more about MDSC and helpful resources.
- **This program is part of the MDSC's Parents First Call Program** – a national model for serving and supporting parents of children with Down syndrome, including new & expectant parents.
- Parents First Call provides opportunities to connect with others who have had the same experience to listen, share, answer questions, and provide valuable information.
- The MDSC family support team is now actively supporting families virtually and has many online support groups now forming.

Please contact Sarah at [familysupport@mdsc.org](mailto:familysupport@mdsc.org) to learn more about any of the gatherings below and to let us know how we can help.

**RSVP for this event to** [scullen@mdsc.org](mailto:scullen@mdsc.org) or 781- 221-0024 x206 or visit <https://mdsc.org/event/> and scroll to your desired event

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## What is the Emergency Broadband Benefit Program?

The Emergency Broadband Benefit Program is a Federal Communications Commission (FCC) program that provides a temporary discount on monthly broadband bills for qualifying low-income households. If your household is eligible, you can receive:

- Up to a \$50/month discount on your broadband service and associated equipment rentals
- Up to a \$75/month discount if your household is on qualifying Tribal lands
- A one-time discount of up to \$100 for a laptop, tablet, or desktop computer (with a co-payment of more than \$10 but less than \$50)

Only one monthly service discount and one device discount is allowed per household. To receive the connected device discount, consumers need to enroll in the EBB Program with a participating provider that offers connected devices (not all service providers offer device discounts). The service provider will provide the discount to the consumer.

The program will end when the fund runs out of money, or six months after the Department of Health and Human Services declares an end to the COVID-19 health emergency, whichever is sooner.

You are eligible through a dependent that takes part in SSI, Food Stamps, Free lunch, etc....

<https://getemergencybroadband.org/>

# Summer Fair For Kids With Disabilities



**August 8th, 2021**

9:30 to 11:30 a.m.

**Chelmsford**

Free to Kids with disabilities and their families. Typical age of those attending is 5 – 30. Over 17 games, a craft corner, parachutes activities and prizes awarded.

Sponsored and run by the Knights of Columbus of the Greater Chelmsford communities.

For more information, visit [www.kofc9275.org/index.htm](http://www.kofc9275.org/index.htm)

**Register required to by August 1st, 2021, to Ken Desilets: (978) 692 6866 or [kgdesigned@gmail.com](mailto:kgdesigned@gmail.com)**

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## “Morningstar Access” Boston Children’s Museum



**August 9th, 2021.**

Program offers children with special and medical needs the opportunity to enjoy the Boston Children’s Museum in an uncrowded environment, with few other visitors and less concern about infections and large crowds.

**COVID-19 Protocols:** To accommodate different needs related to the COVID-19 pandemic, there are now **two different versions of Morningstar.**

\* Please select the one that works best for your family.

- 1. All Masks On!** All staff and visitors ages 2 and older are required to wear masks.
  - This session happens when the Museum is freshly cleaned with no visitors prior to the scheduled time. No mask exceptions will be considered.
  - Families with any needs are welcome as long as they can follow this strict mask rule, which is in place to create a medically safer environment.
  - **Dates/times**
    - Tuesday June 29, 2021, 9-11am
    - Monday August 9, 2021, 10am-12pm
- 2. Mask Exceptions Considered:** All staff and visitors ages 2 and older are required to wear masks.
  - However, mask exceptions will be considered in advance at registration for children who have sensory needs or other types of needs that prevent them from keeping their masks on.
  - **Dates/times**
    - Tuesday June 29, 2021, 1-3pm
    - Friday July 16, 2021, 5:30-7:30pm
    - Monday August 9, 2021, 1-3pm

Morningstar Access Admission: A link to pay online will be sent a week prior to your visit.

Half price general admission (\$9.00 per person)

Free for Museum members

Other discounts may apply (such as the EBT/WIC discount)

**Pre-registration is required** to <https://bostonchildrensmuseum.org/morningstar-program-registration-form> or contact [Iwamoto@BostonChildrensMuseum.org](mailto:Iwamoto@BostonChildrensMuseum.org) or call 617-986-3697.

# URI Respite Program

The University of Rhode Island Physical Therapy and Nursing students, under the supervision of faculty, is providing care and therapeutic play activities so caregivers can have a break. Respite programs for children allows parents and caregivers for a child with disabilities and special needs to take time off from care giving.

For more information, please contact Christine McGrane, MS, RN, CNE, at [cmcgrane@uri.edu](mailto:cmcgrane@uri.edu)

## URI Respite Program

Sundays Noon-4pm

Kids must bring their own snacks and drinks

Independence Square

25 West Independence Way, Kingston -  
(parking behind the building)

July 25

August 8, 22

September 19

October 3, 17

November 7, 21

December 5