#### The quarterly newsletter of UR Medicine Golisano Children's Hospital

# Christine M. Burns CARES Center

Children's Health Home, Pediatric Complex Care, and Care Coordination

Autumn 2024 Newsletter

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On behalf of the Christine M Burns CARES Center, I thank all the individual and corporate donors for their generosity towards our 2024 Back-To-School Drive.

Through your contributions, over 100 kids were able to attend school with the needed supplies. Items like pens, notepads, crayons, backpacks, etc., may seem small in the scheme of things, but every little bit helps those families struggling daily to get by.

Despite the charm, rich history, and diversity Rochester has to offer, it is still one of the poorest metropolitan cities in the country. Over 48% of Rochester's children live in poverty. The US Census Bureau (May 2022) defines those in poverty living in Rochester as a family of 4 making less than \$27,750 a year. This does not provide much room for notepads and pens. So again, THANK YOU for helping us make a meaningful impact in the lives of the children we support.

As we approach the holiday season, our Team is gearing up for the annual CHEER Holiday fundraiser. Please consider donating to the CARES Center Program for the holiday season. Your contributions will not only assist us in our toy drive but also play a crucial role in meeting the ongoing needs of the families we support. We recently provided two twin mattresses to a family; a gesture made possible only because of your generous donations. Every dollar we receive goes directly to a family in need.

Thank you and have a wonderful holiday season.

Rui Ventura, Director

Care Coordination and Care Management Golisano Children's Hospital

# **CARES Center: In the Community**

#### Our Team

#### **Administration**

Rui Ventura, Director Dana Cromheecke, Quality Assurance Katie Birge, Administrative Assistant Michelle Tuohey, Referral Coordinator

#### Children's Health Home

Elizabeth Pietrantoni, Senior Social Worker Melissa Schauber, Team Lead Ashley Knittel, Team Lead Kelley Switzer, Enrollment Specialist Stephanie Lodato, Enrollment Specialist Cratrina Meeks, Care Manager Kelsey Melnyk, Care Manager Natalee Sherwood, Care Manager Sambridhi Shrestha, Care Manager Angela Kayhart, Care Manager Ashley Ryan, Care Manager Christine Loos, Care Manager Sean Bemont, Care Manager Isabelle Ceddia, Care Manager Elyse Pommenville, Care Manager Kalicia Conley, Care Manager Jackson Bright, Care Manager Al-Yash'a Wright, Care Manager Daniel Stetzel, Care Manager

# **Pediatric Complex Care**

Dr. Neil Herendeen, Medical Director Ayla Leary, Program Manager Amanda Paganello, NP Heather Shultz, RN Jacqlene Arce, Care Coordinator

#### **Care Coordination**

Jackie Powell, Team Lead, Green Team Cheryl Gordon-Barr, Yellow Team Katrina Dames, Orange Team Melissa Horton, Blue Team



# A Successful Start to the 2024-2025 School Year!



The Christine M. Burns CARES Center would like to extend a heartfelt THANK YOU to everyone who participated in our Back-to-School Supplies Drive. Our team provided much-needed school supplies to over 100 children this year. This would not have been possible without the generosity of UR/Golisano staff and community members who stepped up to donate! As always, we look forward to the continued partnership and support.





# DreamNight at the Seneca Park Zoo

The Christine M. Burns CARES Center Pediatric Complex Care Program was able to participate in Dream Night at the Seneca Park Zoo, for the second year in a row! This year, we were joined by the Golisano Children's Health Home Program.

The CARES Center was fortunate enough to be able to invite 165 children with chronic complex needs and their families to this wonderful event.

DreamNight is a cost-free evening for children with special health care needs and disabilities to enjoy the Zoo in an environment that is quieter than a normal day at the Zoo and with other families who understand their unique challenges.

Our team enjoyed meeting with attendees throughout the night and sharing how our programs are helping to promote healthy and happy lifestyles to families in our community.

We look forward to participating again next year!

#### Ayla Leary, Program Manager

Pediatric Complex Care

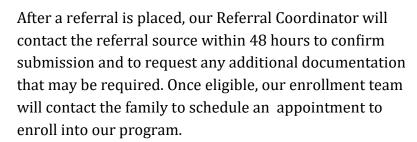
# Golisano Children's Health Home

#### Referrals to Children's Health Home

Anyone can place a referral to the Children's Health Home Program.

#### **Eligibility Criteria:**

- Under age 21
- Active Medicaid
- Reside in Monroe County
- Have 2 chronic conditions, a Serious Emotional Disturbance, Complex Trauma, Sickle Cell Disease, or HIV/AIDS.
- Behavioral, medical, developmental, or social risk factors



Referrals can be submitted via eRecord, faxed to 585-742-4228, or emailed to CHHReferrals@URMC.Rochester.edu.



#### **For Health Home Information:**

**Call Us:** [585] 275-4242 option 1

**E-Mail:** ChildrensHealthHome@URMC.Rochester.edu

Visit our Website: Golisano.urmc.edu/CaresHealthHome

# **Care Coordination**

Our Patient Navigators on the CARES Center Care Coordination Team engage a wide range of patients daily to facilitate access to care. With over 13,000 patients affiliated with the GCH pediatric outpatient clinic, each patient and family is uniquely supported to address individual needs. Through these interactions, the Patient Navigators develop a special relationship with families, and in turn, families routinely reach out to them because families can count on their support.

"This service is very important to me. I have been caring for my disabled grandson since birth. In 2021 I had a stroke and am now blind. Cheryl Gordon-Barr, Patient Navigator, has been excellent setting up services and transportation for me. I've worked with Cheryl for years and she's very good. Services have been very helpful and accommodating, especially with my vision issues.

You have been very supportive and kind."

# **Pediatric Complex Care**

Pediatric Complex Care is happy to share that we have been able to purchase 50 Tytocare home devices that will be distributed to our most complex patients and their families.

The Tytocare home device is a tool that will help provide safe and efficient medical care while keeping our patients home and away from potential exposures. By providing these units, we hope to remove barriers that prevent the home from being a place where quality care can be accessed.

Our goal is to provide a Tytocare home device to as many of our enrolled patients as possible and to partner with other Golisano Pediatric Specialties that would benefit from our patients' use of the devices.





#### Ayla Leary, Program Manager

Pediatric Complex Care



# Pediatric Complex Care would like to welcome Jacqlene Arce to the team as our new Care Coordinator!

Jacqlene is passionate about patient care and is excited to put her skills to use, supporting our patients by assisting with scheduling appointments and transportation and providing access to much-needed community resources. Jacqlene is looking forward to connecting with our patients and their families and getting to know and address their individual needs!

# **For Complex Care Information:**

Call Us: [585] 275-4242 Option 2

Visit our Website: Golisano.urmc.edu/

Complex Cares

**Email Us:** 

CARESPeds CC@URMC. Rochester. edu

# Are you Ready for Cold/Flu Season?

Fall is a busy time with back to school and the upcoming Holidays. It is also a time of increased community-acquired viral illnesses. Due to the complex medical diagnoses of our patients, they are at increased risk and severity of viral illnesses.

Help keep yourself, your family, and our patients free from illness by washing your hands frequently, wearing a mask, getting enough sleep, and getting recommended vaccines.

Please contact our team or your child's PCP if you have any questions regarding vaccines they are eligible for. Thanks in advance for your assistance in keeping our patients healthy and out of the hospital.

**Heather Shultz, RN**Pediatric Complex Care



# **CARES Center-Client Success Corner**

"Throughout my time as a care manager, one of the greatest feelings is being able to see the progress the child and family have made since the start of joining our program.

I am currently working with a family of twin boys who were referred, as the family was clearly overwhelmed with the children's behaviors and was willing to accept any level of assistance and support. These children were three years old, diagnosed with autism spectrum disorder, and presented with an array of behaviors that made leaving the home challenging and caused enormous stress for the parent. Due to shortages, these children were never placed in a school and never received therapies stated within their IEPs (OT, PT, Speech).

The care manager connected the family to an educational attorney and worked together to ensure the children were placed within an extended school year program and received all the therapies listed on their IEP. The twins are now placed in a full-time preschool program receiving OT, PT, and speech therapy services in a reduced-size classroom to support their behavioral and developmental needs. The care manager is working with the family to get applied behavior analysis (ABA) therapy to provide an additional level of support to improve their behaviors.

The family has come a long way since their enrollment within our program and are continuing to make strides and tackle numerous challenging barriers that have come their way.

It's been an honor to work with our families and see the first-hand progress that has been made."





"As a remote worker, I can recognize families/parents by their voices because most of my communication is by phone. Since going into the office on Monday afternoons for my Blue Team huddle, I have had the pleasure of meeting families in person like the J children and their mother D, M and her mother S, T and mother R. It was great to be able to put a face to the name and voices of families that I have worked with for over four years. I know that they appreciate the pediatric clinic and care management team in all that we do. "

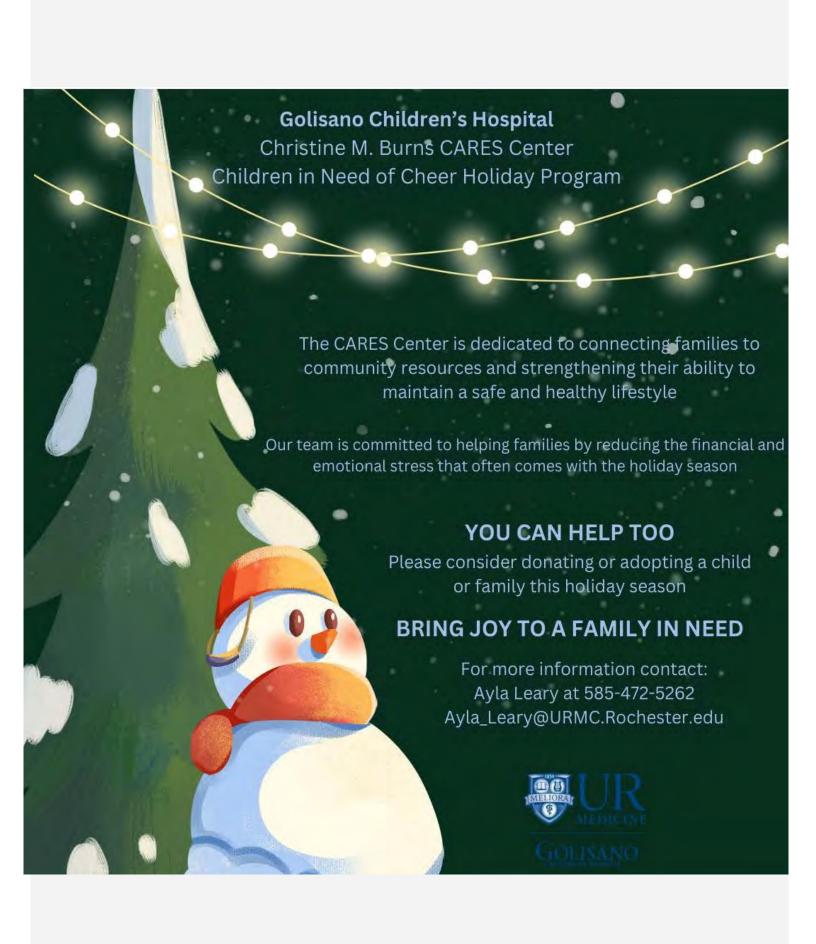
#### -Melissa Horton, Patient Navigator

"Earlier this year, I began working with a child with mobility impairments and in need of environmental modifications in the home. This child has been in a wheelchair for a great portion of her life and was utilizing a portable wheelchair ramp and an inaccessible bathroom in the home. This environment was not accommodating to her condition and placed a lot of physical strain on her caregivers.

Since being a part of her care team, I was able to identify a contractor in the area who could install a vertical platform lift and make accommodations to the bathroom, such as a walk-in shower and handrails, and overall, make the bathroom more "wheelchair friendly." This process took a great deal of communication not only between myself and the contractor but also between the insurance agency and the family, whose care team involvement and self-sufficiency have grown throughout this process.

When this newsletter goes out, the vertical platform lift will have been installed, and we are waiting on parts for the bathroom modifications. As a care manager who has not tackled the world of EMODS prior to this, helping make this dream a reality not only for this child but also for her caregivers has been very special and a reminder of how impactful this job can be."

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# Christine M. Burns CARES Center at UR Medicine Golisano Children's Hopsital



# Ways to Help

**Physical Donations:** Donations of new clothing, toys, school supplies, toiletries, diapers, winter coats/hats, and other items. Please note, all items need to be new in their original packing. We are unable to accept homemade items.

**Gift Cards:** You can purchase a gift card, and our team will do the shopping. Target, Walmart, Aldi, Wegmans, Tops, Amazon, and Visa gift cards are most purchased.

Monetary Donation: A monetary donation can also be made to our program to purchase gifts. This can be done straight from our website Golisano.urmc.edu/HealthHomes via our secure online form. You may also mail your donation to us at 601 Elmwood Ave Box 777 Rochester NY 14642. Checks can be made payable to Golisano Children's Hospital Health Home Program. Please call our main number at 585-275-4242 to arrange drop off/pick up.

# **CARES Center Wish List**

- \* Non-perishable Food Pantry Items
- School Supplies
- \* Beds
- Winter Coats and Hats
- \* RTS Bus Passes; daily and monthly
- \* Toiletries/ hygiene products
- Household cleaning supplies
- \* Household child safety
- \* Diapers
- Clothing
- School uniforms
- \* Age appropriate toys
- Sensory toys/fidget toys
- Recreational activities; Strong Museum of Play,
   Seneca Park Zoo, Museum and Science Center
- Gift Cards: Visa, Goodwill, Aldi, Wegmans, Tops,
   Walmart

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