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Issue 1

The Help A Little One Foundation

H.A.L.O. Reports

Fall 2021

Serving Children With Neurological Impairment Since 1993

Our 'Little Ones' Reap The Benefits Of Your Generosity

Joseph has a condition that damages the membrane that insulates nerve cells in his brain. Before H.A.L.O. helped him acquire a communication device, it was exhausting to communicate his needs. His family says: "This tablet has made a world of difference in his ability to interact with those around him."

Physical therapy has always been challenging for L.J. but having his own adaptive tricycle is motivational. "My husband got L.J. out on the bike today and… he was all smiles! We feel so grateful to have this bike, " L.J.'s mom said.

Please visit www.halo.org to submit a request.

Five Reasons I Love Being a Pediatric Long Term Care Nurse

The staff at pediatric nursing homes are surrogate family for H.A.L.O.'s kids. When parents and guardians cannot be present – think Covid-19 – they lavish attention on "our" children.

Ashley Bertolami, RN, is one of these nurturers extraordinaire. She has been with Cedarcrest Center for Children with Disabilities 13 years: five years as a Licensed Practical Nurse and eight years as a Registered Nurse. Here are just a few reasons why she loves her job at the Keene, NH center:

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Founder's Message

Thirty Years Ago . . .

Dear Friends,

September 27th marked the 30th anniversary of our Sarah's illness. Your kind messages and memories of happy days with our funny little girl were much appreciated and brought smiles through our tears.

Sarah contracted meningitis in the fall of 1991 when she was two years and nine months old. Complications resulted in permanent neurological impairment, including the loss of her ability to speak, walk and consistently control her body.

Her eventual institutionalization inspired us to establish the Help A Little One Foundation in 1992 to enhance quality of life for similar children.

Gayle and I usually visit Sarah regularly, so isolation during the pandemic was tough on our girl. She had always been irritable when we missed visits, but once restrictions were eased at her nursing home she persistently refused to engage with us and only recently began sharing smiles.

We will never know if this rejection stemmed from lack of understanding or if was a residual effect from her own bout with Covid, but it is rewarding to once again hear her laughter as she watches videos of her gurgling new niece and her chattering young nephews.

Robbed of a better future, Sarah has made a unique contribution to the world by inspiring us to bring comfort and fulfillment to her peers.

H.A.L.O.'s board and our family are deeply grateful for your continued encouragement and support as we pursue quality of life for our Little Ones.

Thank you from the bottom of our hearts.

Sincerely,

Sarah at 3, and at 32.

Planning For Future Care of Aging Children Is Imperative

As parents age and life expectancy improves for children with severe neurological disability it is important to arrange for the continued care of adult children.

Whether a child is cared for in the family home or in a skilled nursing facility, the major concerns are guardianship, trusts for financial support and a family's preferences for future care.

"Don't wait until the child is approaching the age of majority, or services are expiring, or there are personal health concerns, " says attorney Rebecca Dalpe.

"Communicate your values and wishes for care, and involve family members, care providers and the child, if possible, in making your plan. Everything takes time, so plan sooner rather than later."

Rebecca volunteers with H.A.L.O. CAN (Children's Advisory Network) which helps families with limited resources navigate the complex regulations governing care of people with disabilities in Massachusetts.

"Being proactive is the best advice we can give," counsels Lauren Mazerall, Executive Director at New England Pediatric Care in Massachusetts.

Medicaid supports the majority of residents living in Massachusetts pediatric homes, but who will make future decisions about surgeries, medications and potential changes in living arrangements? Who will advocate and ensure quality of life? What resources will be available when government doesn't provide something?

"We start sharing information with families as soon as a child is admitted and stay in regular contact. As family situations change, plans need to change too," Lauren explains.

Denial, guilt, a belief that the child will pass away before the parents, as well as a lack of information about available resources all can be barriers to future planning, according to a study by McMasters University in Canada. Cultural and language isolation also prevent families from taking action.

The experts suggest families seek legal advice whenever possible to make informed and timely decisions on future care of their children.

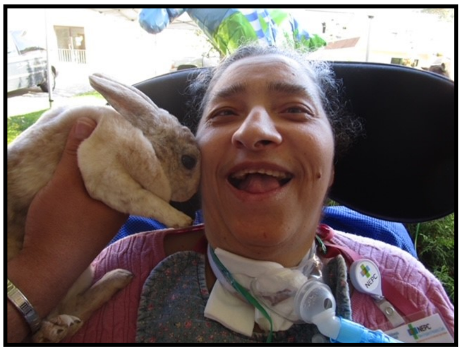
For information about H.A.L.O. CAN contact the administrator of your child's pediatric facility or visit www. halo.org.

NEPC's Fall Festival Adds Dimension, Variety To Our Little Ones Lives

Each fall the New England Pediatric Care team organizes a "Fall Funtastic" event in mid-October to bring residents together for autumn-themed activities. This year residents were treated to a visit from "Enchanted Animals."

Young and older kids alike enjoyed cuddling the animals under the supervision of an interdisciplinary team of nurses, teachers, instructors, therapists and Certified Nursing Assistants. Covid-19 protocols were strictly observed.

"Residents of all ages participated in typical fall activities such as pumpkin painting, door decorating and enjoying the tastes or scents of apple cider donuts and hot chocolate in the beautiful fall weather," said Amy Gagnon, Director of Education at the pediatric skilled nursing facility in Massachusetts.



NEPC provides a full spectrum of services for children and young adults with complex medical and learning needs, including a special education day school, rehabilitation and therapeutic recreation services.

Socializing and helping residents feel part of a community are important aspects to quality of life, Amy explained.

"Our team is always very creative in designing inclusive experiences that can be enjoyed by different individuals."

Additionally, everyone took part in the NEPC version of Trick or Treating. Activities included a pumpkin stroll around the building to view carved pumpkins and a multisensory Halloween extravaganza that offered music, costumes and a technology-based Halloween light display adapted for the residents to engage in independently.

The fall festival event is just one implementation of NEPC's efforts to enable each child to have a full and happy life. Such events complement H.A.L.O.'s mission of enhancing quality of life for children with neurological impairment.

Kids Practice Skills, Enjoy The Outdoors At Field Day

Field Day at Seven Hills Pediatric Center and Special Education School in Massachusetts was a day of laughter and learning in September.

The five classrooms competed for a trophy and medals in activities designed for their skill levels. They enjoyed parachute games (above) and an exciting toy duck race, with the competitors decorated by each classroom, the school nurses, the office and physical and occupational therapists.

Leading up to event, each classroom exercised decision- making, communication and motor skills as they tie dyed t-shirts in team colors to wear as uniforms on the big day. Best of all, the staff reported, there was excellent engagement and lots of interaction among students, staff and peers.

Nurse: Why I Love Pediatric Long Term Care

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1. The bonds that are made with the children.

"Learning what makes them smile, how to fix their frowns and how they communicate is so fulfilling. Walking down the hall at the start of my shift and seeing them smile when they first see me is the absolute best feeling in the world!!! It's an honor to get to witness first steps, big goals met, see them wean off ventilators or beam with pride as they show off their new wheelchair in a color of their choosing. Getting to know the children well is so important. When they are unable to tell you what might be bothering them, you can tell quickly when something is off."

2. I am always learning , both in the big-life-lessons kind of way, and as a professional.

"While I work in long term care, things are always changing and the acuity of care is increasing. New diagnoses, respiratory care and neurological changes are always happening. My education never feels stagnant."

3. I love getting to know the families.

"The parents put so much trust in me to care for their child, and that isn't something to take lightly. Talking to a parent who is scared for their child is delicate and an art form, to be both compassionate and honest. These families are some of the strongest people I know (perhaps only second to their child). I have learned so much from them on how to be a strong advocate."

4. The fun we have!!

"Some days are stressful and intense, but at the end of the day, we work with KIDS. Laughing and being silly can truly be the best medicine. Working with the team that I do is amazing. We are all there 1000% for the kids and love to make things crazy and fun for them."

5. Working with other professionals is another reason I love being a nurse.

"Both in-house, and with physicians within the children's different specialties, being able to bounce ideas around, provide input on treatments and advocating for the kids makes me feel like a valued team member."

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A Foundation for Children with Neurological Impairment

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