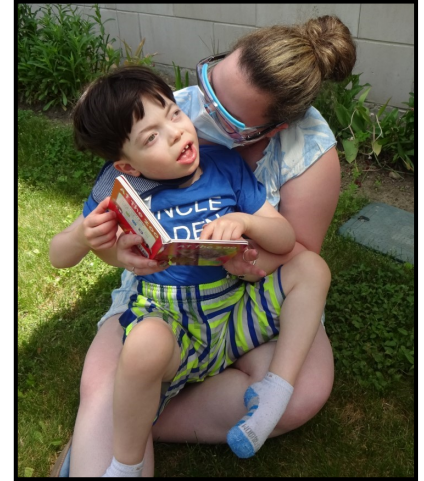


Scout brings pandemic comfort to kids in nursing home



Abbie Axon, far right, and volunteers unload boxes of comfort items. Right: A staffer reads one of the books with Zaden, a resident.

Community support is extremely important to pediatric nursing homes.

"We want our residents to be welcomed members of their community," said Monica Kleeman, M.S. Ed., Director of Education and Activities at Seven Hills Pediatric Center.

Abbie Axon, 18, is a shining example of community acceptance, she said.

For her Eagle Scout project, which had to be completed during the COVID pandemic before she aged out of Boy Scouts of America, Abbie decided to raise money to purchase lap blankets, lip balm, socks and sensory toys, crafts and books for the young people with medically-complex conditions who live at the Groton, MA center.

"I picked this project because I am passionate about kids and

wanted to do something to benefit them during such a difficult and scary time," Abbie said. Previously she had 'a positive experience' when her Girl Scout troop played games with the residents.

Abbie joined Boy Scouts of America (BSA) the first day girls were eligible - February 1, 2019 -after years of watching her brother broaden his horizons as he completed the seven ranks. (Continued on page 2)

Songs bring out the musical child in all of us

Baseball fans have commandeered Neil Diamond's song "Sweet Caroline" as their anthem at Red Sox games.

Music therapist Sarah Blacker, MT-BC, adapted the familiar lyrics for her recreational music sessions during the pandemic:

"Touching hands, washing hands... reaching out, touching me (point to

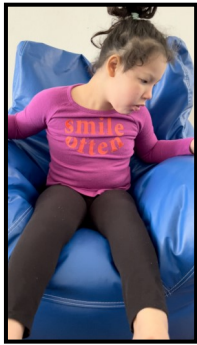


self) NOT touching you," she sings.

The familiar tune struck a chord with many of her participants. Some tried to sing along, others expressed enthusiasm through vocalizations or swaying in their wheelchairs, Sarah said.

Her goal is to activate 'the musical child that is in all of us' and help everyone feel good about their efforts.

(Continued on page 4)



Lluvia



Julius



Anand

Founder's Message

Our Little Ones still need us

*D*ear Friends,

As Covid restrictions are lifted, people around the world are embracing a return to 'normal' but 'normal' is relative. For some it is dining in restaurants and going to theaters; for others having enough to eat; for our Little Ones it might be G-tubes and wheelchairs and pain.

Families and guardians do their best to meet their child's needs, but resources can stretch only so far. The Help A Little One Foundation is here to help them provide quality of life enhancements. Some of our recent recipients include twins Lluvia and Julius, who have multiple physical and developmental conditions and chromosomal abnormalities. Their Vibro acoustic cloud chairs keep them safe and comfortable at home. Anand is an older child who requires complete assistance for all activities of daily living. He is aware of his cerebral palsy and continuing physical deterioration. The Chill Out Roll'er Chair supportive seating system has relieved back and chest pain caused by his wheelchair; his family reports his depression has improved.

These gifts may seem insignificant in the face of severe challenges, but they make daily life more bearable.

Throughout the pandemic we have strived to make gifts to children and to continue supportive programs through our partnership with Jewish Family & Children's Service in the Boston area.

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,

Blizzard bake sale does not deter scouts: motto is 'be prepared'

(Continued from page 1)

"Girl Scouting provides amazing experiences, but it is different because it is structured around age," she explained. "Boy Scouts is about mastering skills, learning how to manage the world and becoming a leader."

Eagle is the ultimate rank in BSA. One requirement is to plan and complete a project to benefit the community. Abbie worked remotely with Monica Kleeman to identify items to comfort and entertain the Seven Hills residents while they were isolated in their rooms for safety during the pandemic.

Once the council approved Abbie's plans, she had to raise the funds, recruit, motivate and supervise volunteers, log all their hours, and track expenditures. Her GoFundMe campaign on the internet



Camden cuddles a sensory toy.

raised triple her goal, but to make a more personal effort she also organized volunteers and bakers for a drive-thru COVID- safe bake sale. Together she amassed nearly \$2000 despite a blizzard

on sale day.

"I had already done the advertising and we are Scouts, after all. Our motto is be prepared, so everyone still came through," she laughed.

With the additional funds Abbie was also able to create a virtual library of books tailored to residents' special needs. Located on a private internet site with Google slides and YouTube video links, the staff can access content for residents using QR readers.

Abbie and her volunteers logged more than 116 hours on the project. In the fall Abbie heads to the University of Massachusetts Amherst campus to study communication disorders and speech therapy.

Administrators: Nurture your team, watch the budget, advocate

Three long-time administrators of pediatric nursing facilities in New England are retiring this year having witnessed life altering changes over the past two decades.

Ellen O’Gorman, MA, NHA, retired from New England Pediatric Care in Billerica, MA, on June 1st after 29 years. She served as Executive Director since 1993. **Cathy Gray**, MA, NHA, President and CEO at Cedarcrest Center for Children with Disabilities in Keene, NH, for 25 years will depart later this year. **Holly Jarek**, DSc VP/NHA, will end her tenure in November after 20 years at Seven Hills Pediatric Center in Groton, MA.



Holly Jarek

nurse. Despite the heavier workload to prevent the spread of Covid, she said her team overcame their personal concerns and continued to provide excellent care. “It was key to our success.”

Cathy, a skilled collaborator and organizational innovator, is highly regarded in her state for regional leadership in workforce development – vital since there has been a widespread shortage of health care workers for years.

Covid was indisputably the biggest challenge all the directors have faced due to constantly shifting regulations and procedures. Ironically, the pandemic may have finally convinced legislators of the need for increased funding, they said.

“Keeping a nursing home financially stable on Medicaid funding has been a major struggle,” noted Holly. Over the past 17 years she has embraced number crunching and the problem solving and strategic thinking aspects of the job.

Advocacy has also been central for all three executives. Cathy, for instance, is lauded as a tenacious champion for increased Medicaid funding for pediatric complex care in New Hampshire. In addition to her work leading the organization she has also cultivated community partnerships.

Ellen was a founding member in 1997 of what has become the Pediatric Complex Care Association and is currently an At Large Director. Holly is immediate Past President; Cathy is currently Treasurer and Education Co-chair.

The organization provides a national voice for children requiring complex care and works to educate and share expertise with regulators and health agencies.

What has changed in two decades?

Acute care: Due to medical innovations children are admitted to residential care with more complicated conditions – many more require supports such as ventilators to breathe and G-tubes for nourishment.

Technology: From electronic medical records to medical monitoring and alerts, just about everything operates on a computer chip, requiring expensive equipment and continuous staff training.

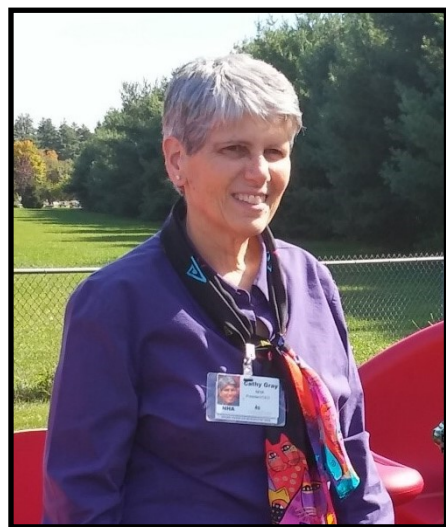
Augmentive communication innovation: Computers and handheld devices have opened new avenues of learning and communication for children who are legally blind, hearing impaired and developmentally and physically disabled.



Ellen O’Gorman

“Telemedicine also has been a positive change because it reduced uncomfortable travel for the kids and staff time away from the facility,” explained Holly. Skype, Facetime and email have opened additional communication channels for families.

What does the future look like? There will always be a need for pediatric nursing homes, said Ellen. Recent events have raised awareness and underscored the need for strategic efforts to ensure continuity and future programs, she said.



Cathy Gray

Why such longevity? Simply put: the children, their families, and truly dedicated staff who are committed to their wellbeing.

Ellen, who started out as an occupational therapist, explained that while the director is not involved in direct care, the children are always just outside the door.

“I celebrate their accomplishments, share their smiles and collaborate with their families to achieve the best possible outcomes for the children.”

Equally, the team spirit and work ethic of the staff has been inspirational for all.

“The staff dedication was incredible when we were in the thick of the pandemic,” praised Holly, who began as a registered

Visibility continues to be important for ‘our’ kids

H.A.L.O. strives to keep our Little Ones visible in the community and to highlight initiatives that involve community members.

On April 22nd the Green Classroom at the Cedarcrest School planted an Adams Crabapple tree in downtown Keene, NH in honor of Earth Day and the Green Up Keene initiative.

The class has been studying trees and their impact on urban areas.

The students bundled up and braved a cool morning on the town’s Main Street, meeting up with the head of the city’s public works department and staff.

The flowering tree graces a corner of Main Street that abuts Keene State College’s Wyman Way.

The project was also supported by teachers, a trip nurse and other staff at



Classroom assistant Jo-Ellen and a student participate in the tree planting.

Cedarcrest Center for Children with Disabilities.

Making music activates every part of the brain

(Continued from page 1)

“As a music therapist my goal is to create a fun, multi-sensory and success-oriented experience,” she explained.

She collects feedback from every participant and tries to tailor sessions to address the unique goals of every individual.

H.A.L.O.’s Sunday Swim & Sing class has provided meaningful recreation and socialization for young people with neurological and physical disabilities for the past two decades. It is facilitated through our partnership with Jewish Family & Children’s Service, a non-sectarian agency which administers 40 social service programs in Greater Boston.

“Using Zoom video technology during pandemic restrictions actually allowed more individuals to access the service from a distance than is possible in person,” according to Angela Waring, MS, JF&CS Director of Social and Behavioral Supports.

Although the pool activities were suspended during Covid, participants received 229 music service hours since October, she reported.

Individuals in Sarah’s classes live with their families, and have complex physical, developmental and communication disorders.

Families are incredibly positive about the sessions.

One grateful father wrote: “I don’t know what you offered in today’s program, but it certainly elicited an enthusiastic response from

the kids – particularly Ellen. We couldn’t remember a time when she enjoyed herself so much. Thanks for a great program and a happy start to our Sunday.”

Sarah is emphatic about the healing power of music.

“Your brain can’t experience pain at the same time as pleasure,” she explained. “If you’re engaged in making music, it activates every part of your brain, and a lot of the pleasure centers.”

A graduate of Berklee College of Music’s music therapy program, Sarah has earned many honors as a performing artist, including Female Performer of the Year in the New England Music Awards.

To learn more, please visit www.jfcsboston.org/About/Community-Programs.

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A Foundation for Children with Neurological Impairment

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