

*Serving Children With Neurological Impairment Since 1993*

*A Message From the Founder*

## H.A.L.O. Is In Transition But Our Legacy Will Endure

*Dear Friends,*

*Our hearts were devastated when our three-year-old daughter was disabled by meningitis and encephalitis in the fall of 1991.*

*Those neurologic storms robbed Sarah of speech and control over her own body. Ultimately her persistent vegetative state and rampant seizures forced us to place her in a pediatric nursing home for medical care.*

*Our experience with other families at New England Pediatric Care inspired us to create the Help A Little One Foundation in 1993 to enhance quality of life for children with neurological disease.*

*For more than 30 years H.A.L.O. has provided tangible gifts and supported programs that increase physical comfort, facilitate social interaction and build acceptance in the greater community. Additionally we have endeavored to support the caregivers of these children.*

*As Sarah nears her 36th birthday, we are happy to report she is responsive to her environment, and seems pain free and content. But as she ages, we age, and we need to consider H.A.L.O.'s future.*

*Our family and H.A.L.O.'s Board of Directors are exploring ways to sunset the foundation in a way that honors Sarah and our mission. The goal is to structure this transition in a way that ensures that programs we have supported are not defunded abruptly and that H.A.L.O.'s assets will be applied as donors intended. We will keep you posted on these developments.*

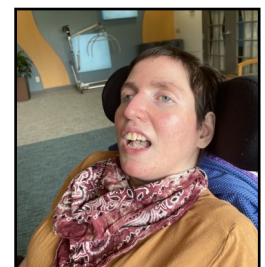
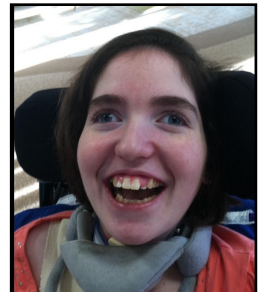
*Gayle and I continue to visit Sarah regularly. We fervently hope she feels safe, well cared for and well-loved, and that her peers have felt supported by H.A.L.O. on their personal journeys.*

*We are deeply grateful to the friends who have been by our side and for the donors small and large who have made these efforts possible.*

*Gratefully yours,*



*Alan Pinshaw, M.D.*



# *We Began With Small Gifts To ‘Little Ones’ In Pediatric Homes*

**H**.A.L.O.'s early efforts were focused on making direct, tangible gifts to residents in pediatric nursing homes to brighten their days. We wanted children to have not only the basics but also some comforts, and to feel remembered on birthdays, holidays and every day.

We soon realized that by subsidizing, activities and excursions we could help relieve boredom and motivate youngsters with severe impairment to connect with the world. Facilities in Massachusetts, New Hampshire and California were our primary recipients. .

**Holly Jarek**  
**CEO/Executive Director (retired)**  
**Seven Hills Pediatric Center (MA)**

Every fall for the past 30 years H.A.L.O. has given us a stipend to purchase gifts that suit each resident's abilities and interests.

I don't know if people appreciate the desperate needs of some of our residents. Like all children they outgrow clothing and need personal care items. Whether it be the lack of families or infrequent visits due to long travel distances, essentials can be overlooked.

H.A.L.O.'s generosity has provided teddy bears, but importantly the annual stipends have also provided a financial safety net so we can buy coats and comfortable outfits and hairbrushes for children whose needs go unfulfilled.

For the repeated kindnesses from the H.A.L.O. Foundation we will always be grateful.

**Ellen O'Gorman**  
**CEO /Executive Director (retired)**  
**New England Pediatric Care (MA)**

When I first started at NEPC, long-term care for medically-fragile children was primarily focused on medical and nursing care, staffing, cleanliness, safety and special education.

Gayle and Alan Pinshaw recognized that their daughter and her peers could also



*H.A.L.O. is a longtime sponsor of the annual hayride at New England Pediatric Care. Family members can ride along, but the kids have the most fun — a ride in the wheelchair lift AND a horse drawn wagon.*



*Whether it's the Red Sox or the local high school team, many typical children often visit a ballpark. Above, a resident at Cedarcrest Center in Keene, NH enjoys the same kind of experience.*

benefit from soft, homelike touches and experiences 'typical' children enjoy.

The foundation supported many activities throughout the years including overnight "glamping" trips to Cape Cod and New Hampshire, concerts, movies, zoo trips, and more. They helped us put a TV and music technologies in every patient room,

and made it possible to provide special items suited to specific children.

H.A.L.O. recognized that our young people were not only patients, they were children, and that improved the quality of their lives."

**Lauren Mazerall,**  
**President/Executive Director**  
**New England Pediatric Center (MA)**

It is very challenging to find donors and people who are committed to helping our very unique population. H.A.L.O. has done a great job uplifting the community, raising essential funds and "giving back" in ways that translate to joy for our residents and also our staff. Since I've been at NEPC I've seen that the fall hayride sponsored by H.A.L.O. is a major highlight every year.

H.A.L.O. has been a wonderful partner and we will need to seek additional funding sources as it makes this transition.

**Hilary Falkai, LCSW**  
**Palliative Care Social Worker**  
**Libertana Home Health (CA)**

Over the years H.A.L.O. has touched many lives in the Libertana Home Health palliative care program. We provide support for children with very complex medical conditions who are not in hospice care. When major weather interrupted services or events upset a family's financial safety net, H.A.L.O. has helped us provide diapers, baby wipes, adaptive equipment and therapies denied by Med-Cal (Medicaid) insurance. This has improved the comfort level for kids struggling with challenges and relieved their families stress levels.

**Jay Hayston**  
**President/CEO**  
**Cedarcrest Center for Children (NH)**

H.A.L.O.'s long-standing support has been so appreciated here at Cedarcrest. Your commitment to featuring children with complex needs in a positive and affirming manner is inspiring. Thank you for empowering these children and their families."



# H.A.L.O. Embraced Home-Based Children And Their Families, Too

In 1999 H.A.L.O. partnered with Jewish Family & Children's Service (JF&CS) of Boston to found Family Circle to address the needs of families caring at home for children with neurological impairment.

## Family Circle

Initially Family Circle' brought caregivers together to share experiences and learn about resources.

When families told us there was a desperate need for social activities for young people isolated by their complex medical needs, the Family Circle **Sunday Swim and Sing** program was born..

For over 20 years this low-cost, weekly, music and swimming activity engaged and energized participants at two Greater Boston locations. Social workers, music therapists and lifeguards ensured a safe, fun environment while families enjoyed a three-hour respite from their responsibilities. Trained volunteers befriended and supported the young adults on a one-to-one basis, tailoring the experiences to their needs.

## SibShop

In 2018, H.A.L.O. and JF&CS introduced the **SibShop** support group for brothers



*Family Circle programs addressed the needs of the children, siblings and caregivers.*

and sisters to explore their complicated feelings about growing up with a sibling with a severe disability. Professionals facilitated conversations about situations the kids might face and helped them deal with sadness, resentment and anger.

## H.A.L.O. CAN

H.A.L.O. established the **Children's Advisory Network (CAN)** in 2010 to help families navigate the complex regulations governing care of people with disabilities in Massachusetts.

Lawyers specializing in disability law volunteered their time to:

- Help families understand and file forms at appropriate times, including guardianship paperwork
- Provide emergency legal services such as appeals on denials of medical devices, medications, or short-term stays in nursing homes
- Direct families where to obtain legal advice beyond H.A.L.O.'s scope.

## What Gifts Do Families Request? Equipment To Make Life Easier!



*Josue's ostomy belt means he can go out without worrying about his bag leaking.*

**H**.A.L.O. has made hundreds of matching gifts to individuals to improve their quality of life in the family home.

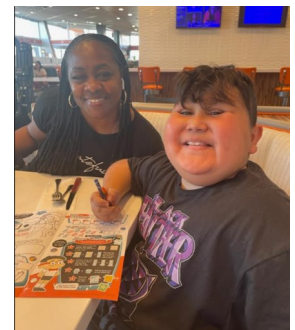
Adaptive gear has always topped the list of requests. Popular items include special bath chairs, strollers and seating systems that insurers typically deny, despite evidence they increase comfort levels or make it easier to bathe a child with flaccid muscle tone.

We have helped many families purchase and install wheelchair lifts

for their vans so they can transport their children. We've also purchased one-off items such as a portable nebulizer because it enabled a housebound youngster to leave his home.

Custom-fitted adaptive tricycles have been popular because they encourage exercise and interaction with peers..

Applicants are required to submit medical verification of their child's condition, and must match our contribution.



*An air conditioning unit was life changing for Hunter during the extreme heat in Los Angeles this summer.*

# H.A.L.O. Supports Technology That Empowers Kids

Technology has transformed learning and communication for people with severe neurological impairment.

Over the past 30 years H.A.L.O. has helped individuals and groups of children procure hundreds of devices ranging from smart boards and headphones to computers, iPads and other technology to improve quality of life for our kids.

This newsletter has highlighted many positive benefits related to technology innovation:

**Family Connection:** Children in pediatric nursing homes benefit from family support, but it can be challenging for families to interact with a child who cannot communicate. Playing games, showing photos or even watching cat videos on devices help siblings and parents find common ground.

**Learning:** Teachers employ a wide variety of “apps” to help individuals focus on lessons designed for their unique cognition level. Programs can reinforce therapeutic goals and facilitate exploration and collaboration in the classroom.

**Speech:** Speech is important for personal growth, building relationships and self expression. The inability to articulate needs and desires inhibits self esteem and can contribute to social isolation and depression. Advancements in artificial intelligence have enabled computers to synthesize human-like speech. This can empower people with brain injuries if they can use breath activated or touch enabled systems to direct computers



*Innovations like eye gaze technology can promote skill development in people with spinal cord injuries and genetic diseases.*



*Children can use a touch screen in school.*

**Sensory management:** Children with sensory processing challenges or neurodiverse conditions can be affected by sights and sounds in the environment.



*A child adjusts light and sound by manipulating a high tech, toy-like cube in the Anya’s Light Sensory Space at Seven Hills Pediatric Center.*

Sensory rooms are specially-designed spaces where therapists can control stimuli using a laptop. They can adjust lighting, project colored patterns on the walls and play soothing sounds reduce anxiety in overstimulated individuals. Similarly bubble tubes, vibrating mats and energizing music can draw responses from understimulated people.

It is our hope that future technology will contribute to increased ability and mobility for people with neurological conditions.



## A Foundation for Children with Neurological Impairment

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**H.A.L.O. Foundation**  
822 Boylston Street  
Suite 300  
Chestnut Hill, MA. 02467  
[WWW.HALO.ORG](http://WWW.HALO.ORG)