

# H.A.L.O. Reports

*Serving Children With Neurological Impairment Since 1993*

## *Sibshop Acknowledges Contributions, Role of Siblings*

**S**ibshop, H.A.L.O.'s newest offering, got off to a spectacular start this winter, according to the professionals at Jewish Family & Children's Service, who operate the program.

A full complement of 10 youngsters who have a brother or sister with neurological disabilities participated in the support sessions, which were funded entirely by the H.A.L.O. Foundation.

"Sibshop was very much in demand because it fills a void," said Angela Waring, MS, and Respite and Recreation Program Manager at JF&CS Boston. "No one else in the Boston area is offering this kind of sibling program."

The boys and girls, mostly 9-11 years old, met monthly for a 30-45 minute conversation facilitated by Angela and Sarah Marshall, MSW. Topics



*Sibshop participants demonstrate creativity on a visit to the Arlington Art Lounge.*

touched on situations the kids might experience, bullying for instance.

"But we don't just sit and talk; we set a tone that encourages kids to

share their personal stories with peers who understand the kind of challenges they live with. Then we pile in the van and go to a

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## *Young Adult Dance Strengthens Peer, Community Relationships*

**S**ocial relationships are essential to quality of life in a nursing home or anywhere.

This winter a Valentine Dance for the young adults at Seven Hills Pediatric Center created great excitement for residents and became a focal point for interaction among peers, staff, volunteers and community members.

"We are always trying to generate fresh ideas, said Monica Kleeman, Activities Manager and Community Coordinator at the Groton, MA skilled nursing home.

"But this dance for our over 22s



*An aide straightens a resident's tie for the Valentine Dance at Seven Hills Pediatric Center.*

inspired an unprecedented level of involvement."

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# Gifts Help "Little Ones" To Grow, Thrive, Enjoy



**Camila**, who has spastic quadriplegia, hydrocephaly, epilepsy, and chronic lung disease, requires oxygen most of the day, which causes her lips and mouth to be uncomfortably

dry. DenTips have proved to be the only effective intervention; but her insurance won't cover them. H.A.L.O. helped pay for a supply of DenTips to keep Camila comfortable and to prevent pneumonia.



**Zack**, who suffers from hypoxic-ischemic encephalopathy following a near drowning, is immobile and unable to reposition himself independently.

Turning him is critical for proper skincare, but Zack's scoliosis has worsened, causing increased discomfort, especially when he sits in his wheelchair. H.A.L.O.'s purchase of two Sundance fluidized positioner devices has greatly improved Zack's comfort and quality of life and have allowed him to take part in music therapy sessions.



**Emily**, who has congenital hydrocephalus, seizure disorder, unbalanced chromosomal translocation 9:18, and encephalopathy, is incontinent as a result of her conditions and susceptible to skin breakdown as a result. She uses more diapers than Medi-Cal and California Children's Services will authorize for payment and her family could not afford to pay out of pocket. H.A.L.O. 's assistance in purchasing a supply of diapers helped reduce the family's financial and emotional stress.

## Founder's Message

## We Are Making Their Days Meaningful

**D**ear Friends,

*None of us exists in a vacuum. At home, at work, at school or in a hospital room, we all are part of a continuum.*

*H.A.L.O. strives to enhance quality of life for children who have unique needs due to severe neurological impairment. We make direct gifts to individuals, but we also recognize that parents, siblings, teachers, doctors, nurses, therapists and other support staff make important contributions to their days and nights.*



*In this edition of H.A.L.O. Reports I am pleased to share the success of our new Sibshop program which addresses the sensitivities brothers and sisters develop when family life revolves around a sibling with complex needs.*

*Sibshop is facilitated by the professionals at Jewish Family & Children's Service, who also operate our outstanding Sunday Swim & Sing social and respite program. Their expertise enables us to strengthen the overall support system that enriches the lives of children with neurological impairment.*

*Additionally we are sharing a story about a nurse who has championed a boy with severe disabilities for 13 years. We are also highlighting innovative programming implemented by staff at two pediatric residential homes to engage our "little ones" with the world around them.*

*It is uplifting to recognize the people and programs that make the children's lives more meaningful.*

*Thank you, our friends and supporters, for keeping H.A.L.O. 's children in mind and in heart.*

*Yours truly,*

**Hailey**, who has anencephaly, cerebral palsy, chronic lung disease, seizure disorder, and diabetes insipidus, also received diapers via H.A.L.O. because her insurance would not authorize the brand of diapers that met her needs.



**Karapet**, who has spastic quadriplegia and chronic lung disease, requires constant breathing treatments via nebulizer to manage respiratory functioning. Prior to H.A.L.O.

purchasing a portable nebulizer, Karapet only had a stationary nebulizer, which

needed to be plugged into a power source at all times. As a result, Karapet was restricted to his home and was in danger during power outages. Karapet now has portable treatment and can enjoy the stimulation of different environments.



**F.A.**'s music therapist has noticed great improvement in her ability to mimic noises and create vocal sounds since H.A.L.O. helped finance the purchase of several musical toys and instruments for F.A.

# Artist Of The Month Project Energizes Children, Staff and Community

**A**n innovative Artist of the Month project recently energized classrooms at the New England Pediatric Care (NEPC) Special Education School.

"The Education Department always strives to provide appropriate, meaningful, special education services to our students," said Amy Gagnon, NEPC Director of Education. "Because their cognitive and alertness states vary, we are constantly seeking ways to engage their attention in activities that target their individualized goals."

Artist of the Month brought out the inner artist in everyone because it provided a fresh and flexible focus, said veteran Instructor Kristen Moulaison, who took the lead on this facility wide project.

Every month teachers selected a painting from a collection of prints by acclaimed artists: Monet, Picasso, Andy Warhol, Michelangelo and many more. Employing verbal cues and hand over hand assistance they helped students interpret and reproduce unique versions of the masterpiece using paint, glue and textured materials including felt, mesh, tissue paper and bristle brush.

Individuals made choices, practiced controlling their movements, sustained lengthy attention spans, and utilized their senses and voice output devices to express themselves, Kristen explained.

All these activities can be used to demonstrate access to and progress in the statewide Common Core Standards. The project made the special needs curriculum more equal to the standard curriculum.

"This art appreciation unit is almost identical to various cross curricular activities in public schools," noted Amy. "Developmentally appropriate lessons do not always align this way. This unit gives the kids access to math, English Language Arts and writing."

NEPC Executive Director Ellen O'Gorman said that Artist of the Month generated so much enthusiasm throughout the building



*Kristen Moulaison helps a student express his creativity in his classroom's rendition of a Picasso.*

it was replicated in the recreational program for Young Adults (over 22).

Many class masterpieces were in demand

as gifts and several now decorate NEPC's walls – an honor equivalent to posting a child's artwork on the family refrigerator.

## Valentine Dance Connects Residents, Community

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The three-month effort involved procuring flowers, music and formal clothes for the residents. A photo booth was donated to capture the night's splendor for the 36 young adults in the program.

Each classroom was festooned with decorations and balloons lined the halls.

"The enthusiasm was contagious, and there wasn't a dry eye as residents basked in the attention the event generated," said Adult Services Instructor Diane Larsen, who was instrumental in creating the magical experience.

Logistics were complex because the staff needed to coordinate individual schedules for medication, personal care and therapy so all the young adults could participate.

Many Certified Nursing Assistants and nurses volunteered their time off to make it work.

Students from Groton-Dunstable and North Middlesex Regional high schools donated dresses and whirled residents' wheel chairs.

"We were rewarded by big smiles, chortles of laughter and longer than usual attention spans," Monica reported.

The "buzz" generated by the dance continues. Families treasure the photos; the staff is motivated to bring other life experiences to the residents.

Some of the high school volunteers have taken summer jobs at the center, according to Monica—a win for everyone!



# Nurse Becomes Advocate for Young Sean

*I t takes just one person to make a difference.*

We hear this all the time.

For 13-year-old Sean, that one person is Vicki, a nurse who has advocated for him since she spotted him in the hospital nursery where she cared for babies awaiting foster care.

Sean's prognosis was dire: hydroencephaly inhibited his brain development -- but he was responsive and Vicki fell in love.

She received permission to cuddle him in her time off, brought him toys and clothing and gave him the kind of one-to-one attention that makes us all feel loved. When Sean was finally released, she visited him in foster care and in group homes and supported him through shunt revisions, central lines, physical therapy and more.

"I would have liked to adopt Sean," said Vicki. "My kids were in college, and my husband was amenable, but I couldn't work and provide the 24/7 care he needed."

She also learned that if she took him home, he would permanently lose critical health care funding because she lives in a bordering state.

So, Vicki was awarded permanent, unrestricted access to Sean, and given the status of Care Through Kin. This status usually assigns decision making to a relative, but since Sean is technically a ward of the state decisions are made collaboratively by Vicki



*Sean and Vicki enjoy mild weather on the deck.*

and the Department of Children and Families.

Sean lives and attends school at a skilled nursing home in Massachusetts, but Vicki remains heavily involved in his care in conjunction with the home and DCF.

Every five or six days Vicki drives one hour and ten minutes to hold Sean's hand, share stories and maybe a laugh. They listen to Celtic Sojourn and blue grass music, and enjoy being together. "Just like with my other kids."

Sean appears in family photos and rides in a family car purchased specifically to accommodate his wheelchair. The plucky young boy has inspired one of his foster sisters to study occupational therapy.

"Vicki's whole family has been very involved with Sean ever since he was a baby," said Linda White, Director of Education at his school. "They are just fantastic!"

she said.

Sibshop follows the successful Don Meyer national Sibshop model but JF&CS adds a spin by going out into the community.

For information about Sibshop call Angela Waring at 781-697-7232 or email [awaring@jfcsboston.org](mailto:awaring@jfcsboston.org).

## A Foundation for Children with Neurological Impairment

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## New Sibling Program Helps Kids, Families To Bond

*(Continued from page 1)*

trampoline park or other fun venue where they can just have fun," said Angela.

Parents report their kids have newfound confidence and blossom in different ways after having three hours focused only on them. Sibshop has also facilitated individual and family friendships outside the sessions,