

H.A.L.O. Reports

A Publication from the Help A Little One Foundation



A Foundation for
Neurologically
Impaired Children

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Founder's message

H.A.L.O. Reaches Out with More Help

Dear Friends,



We are delighted to announce a new initiative as part of H.A.L.O.'s mission to "Help A Little One." This is the formation of a support group for families in need - the H.A.L.O.

Family Circle.

Since its founding, H.A.L.O. has dedicated itself to making a positive and discernable difference to children who live in the pediatric nursing homes of New England. The effort started in 1993 when our daughter Sarah was placed in New England Pediatric Care in Billerica, Massachusetts following a bout of encephalitis.

H.A.L.O.'s already established programs will continue to help society's needy children in perpetuity. They reflect the caring we all feel and which your generous contributions make possible.

However, our experiences have brought to light another pressing need not just for the children but for their families. Accidents, near-drownings, illnesses, congenital defects and birth injuries bring devastating news without warning. Family members need to face the shock of an unwelcome and often unexpected diagnosis. They face isolation, distance from each other and friends, the burden of frequent hospital visits and crushed hopes.

Broken hearts and spirits abound, but now H.A.L.O.'s *Family Circle* will create a circle of friends who have had similar experiences.

The H.A.L.O. Foundation has made a three-year commitment to fund the *Family Circle* mentoring program in partnership with Jewish Family & Children's Service (JF&CS) of Greater Boston. JF&CS will recruit, train and pair up families as well as run the administrative side. This is a non-denominational program, available free of charge to all. If you know of a family who can help or a family in need of support, please contact us.

We want to thank you for helping H.A.L.O. make a difference in so many young lives. Now hopefully our expanding umbrella will ease some of the pain families endure. Your continued financial and moral support has enabled us to help Little Ones and now to help Families. H.A.L.O.'s Officers, Board of Directors and Advisors join us in thanking you for your generosity, your kindness and your financial support.

When you help even a little, you Help A Little One. When you Help A Little One, you help us all.

Sincerely yours, *Alan and Gayle Pinshaw*

A Foundation for Neurologically Impaired Children

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(617) 423-HALO
(888) 423-HALO

Field trips waken senses . .

The Field Trip looms large on most school children's list of favorite activities.

It certainly seems the case at New England Pediatric Care, a nursing facility that is home and school to 88 children who require physical and medical support in daily living.

"It's an opportunity to move beyond the usual four walls, to see and experience life. The kids get enormous benefit from the sensory experience that even a walk in the rain can bring — new sights for the sighted, new smells and sounds for the others, the feeling of rain or wind or sun on the skin," said Laura Pica, Therapeutic Recreation Supervisor at NEPC in Billerica, Massachusetts.

"We get the biggest smiles and see some unexpected improvements when we take our kids out on trips," she said. "They clearly enjoy it. Can you imagine living (here) and never seeing the outside world?"

Kids at N.E.P.C. have the opportunity to go camping, visit Rye Beach and Canobie Lake Park in New Hampshire and to attend movies, plays and concerts this year. Groups have also attended gone on picnics, to minor league baseball games and the circus, bowled and explored apple orchards. The children have also been exposed to the awe of nature on the occasional whale watch or visit to The Butterfly Place, a garden of butterflies, flowers and sun.

A favorite fall trip is to Yankee Candle in Deerfield, Massachusetts, where the Disney-esque displays, scented candles and music are very stimulating. The "Snow Room" where simulated flakes fall on trees is a favorite with staff and kids.

It takes weeks, sometimes months to plan trips to accommodate the special needs of the children, said Laura. Transportation and aides for one-to-one support must be scheduled. Sites are always notified of the visit, and most welcome the group by providing private rooms for changing diapers, feeding and rest. A nurse also accompanies the children on any trip over four hours to administer medications, or when a child with a ventilator or tracheostomy goes along.

"Our goal is to take trips with everyone who is

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TOP: Rebecca Larivee enjoys her turn sitting on the throne on a field trip to Yankee Candle in Deerfield, MA. BOTTOM: Dawn Mariano helps Ashley Disantis fly a jet at Canobie Lake Park, NH.



.. and improve quality of life

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able, as often as we can," said Laura. "Sadly, there are a handful of children whose participation is limited because their condition restricts them to a flat gurney, which is difficult to secure safely in the vans."

Some children participate in an eight-week rotation riding horses at Ironstone Farm in North Andover from May to September. After being cleared by physical therapy, each child is assisted by an aide and a professional trainer in riding on the horse.

"The sensory component is wonderful — some kids sit up straighter, hold their heads up and improve in mobility, strength and balance," said Laura. The children are continually evaluated for progress and benefits. If they become exhausted, or unable to handle the physical demands, another resident gets the opportunity.

The camping trip to Tuxbury Pond in New Hampshire was a challenge this year, but the campground owner's child had been a resident at N.E.P.C. and "he knew everything we needed, and even built a ramp for easy wheelchair access to the water's edge. It was a lot of work, but the children enjoyed the experience," said Laura.

The community has responded with a wonderful outpouring of generosity, including annual donations of tickets to the New England Youth Ballet's performance of *The Nutcracker*, the Bruins' alumni hockey games, the New England Flower Show, and the rollicking *Sesame Street Live* production, plus other events courtesy of the N.E.P.C. Fundraising Committee. A local doctor has donated a week at her Rye, NH beach house. The children's families and the N.E.P.C. staff also raise money to pay for transportation and extra help on fieldtrips. Donations from organizations including H.A.L.O. also support field trips.

Does anyone ever have a problem with the field trips? Occasionally a community member at the mall or other site might appear uncomfortable with exposure to children with disabling conditions, said Laura, or a child might ask an awkward question.

"We hope these can be teaching opportunities for everyone. The bottom line is that field trips improve the quality of our kids' lives by providing new experiences." *Laura can be contacted at NEPC (978) 667-5123.*



TOP: Kerri Lynn Wood and Ray Drew enjoy a camping trip with the help of staffers Amy Currier and Tricia Brauer. BOTTOM: Brian Liberacki enjoys snuggling with a ferret from Ed Laquidara's Petting Zoo.



Family Circle project expands H.A.L.O.'s mission

HA.L.O. is expanding its mission to include not only children with neurological impairment, but also their families.

When a child is born or diagnosed with severe neurological impairments it is traumatic and confusing. Parents face a range of medical, educational and psychological issues. They also have to cope with physical and mental exhaustion, social isolation, guilt over medical decisions, and loss of control in the life of their child.

Organizations such as the National Down Syndrome Association offer a "First Call" program, so that when a baby is born with Down Syndrome, with family permission, a trained parent who also has a child with Down Syndrome visits them, and helps provide a sense that they are not alone in their situation.

"Over the past few years, I've felt a need to move beyond the Teddy Bear mode, beyond gift giving, to something more practical," said H.A.L.O. founder Alan Pinshaw. "Our original purpose was to provide the extras to the children whose families were not available or did not have the resources."

"But in the numerous trips to our daughter Sarah's home, and visits to facilities around New England, we realized that the families themselves have deep emotional and psychological needs."

For these reasons, H.A.L.O. is pleased to announce the debut of the H.A.L.O. *Family Circle*, a family-to-family program which is being administered in partnership with the Jewish Family & Children's Service (JF&CS). As this newsletter went to the printer, coordinator Patty Reardon was scheduled to initiate the first phase - information and recruitment - beginning November 1.

The H.A.L.O. *Family Circle* will be based in the JF&CS Norwood offices for at least the first year, but participants will be sought from the Greater Boston area.

"In this first phase we want to identify experienced families who can serve as partners with families going through medical or educational crisis for the first time," said Donna Frodyma, administrator. "Working with both experienced and new families, we'll try to identify the kinds of needs they have, and train the experienced families how to help."

There are three components to the project:

- 1 **Family Training:** Identify 10 to 15 parents of children with severe neurological impairment who have indicated their willingness to be trained as support parents, and provide a minimum one-year commitment.
- 2 **Family Support:** Provide support groups for both the volunteer families to discuss issues and the families receiving support to socialize and help each other.
- 3 **Child Care Reimbursement:** Families who participate in either support group will be reimbursed for respite/child care to enable them to attend support group meetings.

H.A.L.O. supporters, pediatricians, pediatric care facilities and medical establishments specializing in the care and treatment of children with severe neurological impairments are invited to submit names of candidates for participation. Contact Coordinator Patty Reardon at (781) 551-0405.

The program is non-denominational and offered free of charge.

Surveys will be conducted before and after training to determine the effectiveness of the H.A.L.O. *Family Circle* program.

The H.A.L.O. Foundation has committed to a three-year trial for the *Family Circle*, but will also continue the current mission to fund "extras" for the children in pediatric care facilities.