

# 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. Foundation appeal raises \$85,000*

**W**hen our daughter Sarah's illness resulted in her placement in a chronic care pediatric nursing home, Gayle and I realized that some families are unable to visit or provide special clothing or items of comfort or entertainment. Consequently, we established the H.A.L.O. Foundation in May 1993 to enrich the lives of neurologically impaired children everywhere.

Our initial appeal in December 1993 resulted in overwhelming donations totaling \$85,000. Your generosity is sincerely appreciated.

In May, the Board of Directors approved a \$10,000 disbursement to New England Pediatric Care, in North Billerica, MA, the facility where Sarah now resides. We are relying on Ellen O'Gorman, NEPC executive administrator, to spend the funds to directly provide for the pleasure and enjoyment of the 93 handicapped children nursed and/or educated by the home. H.A.L.O. also provided \$1,500 for holiday gifts at NEPC in December 1993, and expects to do so again this holiday season.

Your donations will *not* maintain the building or buy hospital equipment or medical treatment. NEPC is operated by a well-financed New England Medical Center, and residents are automatically eligible for Medicaid coverage. Instead, your donations may bring a teddy bear to a child who enjoys tactile sensation, or a computer that enriches the life of a young adult. Room decorations, tapes, boom boxes, and video cassette players are purchases suggested to evoke smiles and interest among the children. Switches — large on/off devices — may also be provided, to allow the children to manipulate music boxes, toys, televisions and radios.

We are still receiving donations nearly every week, and intend to renew our appeal. We plan to maintain a large sum as principal to provide disbursements into the future.

H.A.L.O. is a registered charity with the Commonwealth of Massachusetts and the U.S. government. Abrams, Little-Gill, Tishman & Witty, P.C., certified public accountants, is handling the finances. Our charter does not limit bequests to NEPC or any particular institution. At future board meetings we will examine the needs of the three other pediatric care facilities in Massachusetts, and review any requests presented by individuals and institutions in the United States and around the globe.

On behalf of H.A.L.O.'s Officers, Board of Directors and Advisors allow me to express our appreciation for your interest and kindness. When you Help A Little One, you help us all.

Sincerely yours,

*Alan Pinshaw*

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## New England Pediatric Care: A home for chronically ill children

**N**ew England Pediatric Care in North Billerica is the first recipient of funds from the H.A.L.O. Foundation.

It is one of four residential homes in Massachusetts for severely disabled or chronically ill children.

The 80-bed nursing home is owned by New England Medical Center, and provides 24-hour skilled nursing for children and young adults. Typically the children have been placed in the home because of neurological complications from illness, near drowning, head injuries, congenital disabilities, developmental delays, palsy or birth injuries, or because highly technical equipment must be used to sustain the child's life. Almost all placements are expected to be longterm, although 13 non-residential children with medical disabilities commute to the day school and receive care at NEPC.

The Massachusetts Medical Review Team, made up of a psychologist, social workers, educator and medical doctor, must evaluate and certify that a child functions below the development level of a one-year-old to be admitted to a pediatric nursing home, according to Ellen O'Gorman, NEPC executive director.

"Many of our children require sub-acute levels of care. Many have tracheostomies, special feeding tubes or specialized equipment," she said. "The face of the nursing home is changing. Ten years ago many of our children would have stayed in a hospital ICU (intensive care unit)."

New England Pediatric Care offers three components for its patients: skilled care; a private day school where small classes work toward objectives

### Things to know about living at NEPC.

Executive Director Ellen O'Gorman says the staff never judges why families place their children at New England Pediatric Care.



O'Gorman

"The children's comfort and medical needs come first here," she said. "We do not blame or criticize anyone for the frequency of visits or how they deal with their children."

Age, illness, transportation, geographic distance, and how individuals deal with emotional pain are all variables that affect familial involvement with NEPC patients.

"Most parents get to know their kids, accept them for what they are, and love them," said the executive director. The most difficult situations seem to be when a child becomes handicapped midstream, and the parents have to deal with lost

potential and their unfulfilled expectations for the children," she said.

"We don't have many unhappy children here. Sure some will cry or have a temper tantrum, don't most children? But on the whole they are pretty content. This (life at NEPC) is what's normal for these children."

Normality is maintained as close to outside routine as possible at NEPC.

- Children do not stay in bed unless they are ill.
- Three meals a day are served.
- School is conducted five days a week, but 52 weeks a year.
- Children grow and need bigger and seasonal clothing each year.
- Children enjoy a specially-equipped playground.
- Camping trips, mall excursions, swimming and field trips are part of the schedule, as are dental care, recreation programs and TV.

outlined in each Individual Education Plan; and a rehabilitation component, which provides occupational, physical, speech and recreational therapy.

Families are welcome to visit NEPC anytime, and are especially encouraged to be proactive — to monitor their child's progress, to ask questions, to meet with staff, said O'Gorman. The children enjoy interacting with their families on their own level, she said. Even a visit from a volunteer can evoke

a mood change or better cooperation in therapy.

"Our philosophy is to provide to the children and the young adults here the highest quality of life for them to live within their limitations," said O'Gorman.

"We try to optimize their learning, make them as comfortable and happy as we can, and keep them healthy. It's everybody's mission in life. They just have to live it a little differently."

Help A Little One Foundation, 1330 Boylston Street, Chestnut Hill, MA 02167

I'd like to help H.A.L.O. brighten the lives of neurologically impaired children. Enclosed is my check for \$\_\_\_\_\_.

Name \_\_\_\_\_  
Street \_\_\_\_\_ City \_\_\_\_\_ ZIP \_\_\_\_\_

Please contact me to: ☐ help administer the Foundation ☐ volunteer with children.



## Spotlight: NEPC physical therapy team targets realistic goals

**T**hree physical therapists work with patients at New England Pediatric Care to achieve goals established by the treatment teams.

Therapy runs the gamut from teaching children to walk, to just holding up their heads, sitting up or rolling over — things a baby might typically do, according to supervisor Pamela Eriksen.

Treatment is coordinated with speech, occupational and recreational therapy to achieve and maintain the highest function level possible for the individual child, she said. Therapists, the medical staff, the teacher, the social worker and the family all have input in determining priorities.

Lower functioning children may require positioning to strengthen muscles for head control. Others may concentrate on crawling or turning on a radio switch.

Therapist Sharon Vladyka explained that progress can be excruciatingly slow.

"With some children, we could work a year on arm movement and see no progress," she said. "The team might set a lower priority on therapy to invest more time on the educational component, if that's where the child can progress more.

"We promote awareness to the environment through therapy," Vladyka said. "If the child's head stays down, it is more difficult to accomplish educational objectives — to respond to computer programs or stay focused on a tangible goal like moving the on-switch for a toy.

"Sometimes we work on face-to-face positioning for better communication or group work," Vladyka said.

Therapists need good verbal and non-verbal communication skills, to work with the team and motivate the child, Eriksen said.

In addition to seeing each of their patients three or four times a week, therapists also: consult on situational needs, educate the staff to reinforce therapy goals, teach body mechanics to prevent staff injuries; make home visits; and coordinate treatment with orthopedists.

"The most rewarding aspect of the job for me is when I see a child become more independent," said Eriksen.

Joanne Halley, physical therapy assistant, is the third team member.



Courtney Ahearn, 6, learns to walk with physical therapist Sharon Vladyka at New England Pediatric Care. Courtney lives at home, but attends day school at NEPC.

## *H.A.L.O. advisor to create model for disabled services*

Dr. Leslie Rubin, friend and advisor to the H.A.L.O. Foundation, has become Medical Director and Vice President for Medical Affairs, Research and Training at the Marcus Center in Atlanta, Georgia.

Dr. Rubin expects to create a model program for delivering services to neurologically impaired and disabled children and young adults who are treated at the Marcus Center.

The non-residential Marcus Center provides clinics, toy libraries, outreach programs and consultations for families

of disabled young people. It was established with funding from Home Depot founder Bernard Marcus.

Families need assistance finding help within the complex medical and social service systems, according to Dr. Rubin.

"My goal is to build an infrastructure for delivering all necessary services ... so no one person has to operate in isolation," he said.

Dr. Rubin was formerly with Children's Hospital in Boston and Harvard University.



## Donors write ...

One does not know why these tragedies occur and unfortunately they change lives in significant ways on a permanent basis . . . I commend you and your family for that which you are doing. J. B., Encino, CA

There are none among us who are never touched so deeply as when a disease such as this strikes a young child. Fate seems like it knows no boundaries, and fairness is certainly not one of its rules. Dennis F. Feeley, Allentown, PA

It is wonderful that you have transformed ...pain into actions that will benefit so many others. Dr. Lisa Gruenberg, Boston, MA

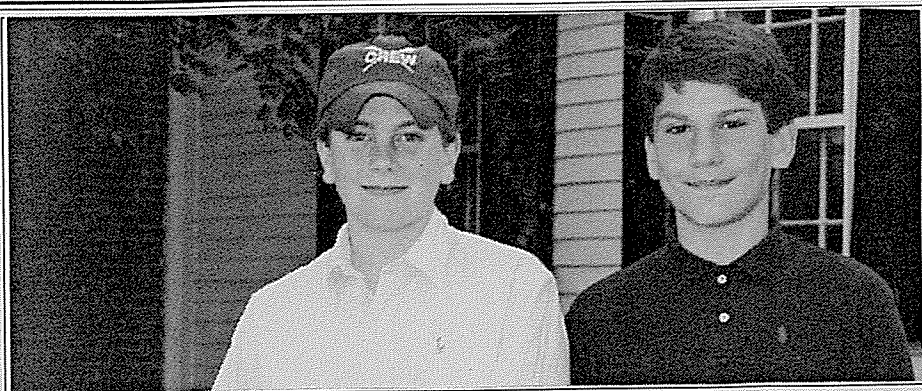
Reading your letter reminded us once again that the truly important blessings in our lives are our children and that we should really treasure our time with them - even those day-to-day mundane or chaotic ones! Ron & Patte Granchelli, Framingham, MA

Because of my regular contact with these children, I feel strongly about adequate and appropriate long-term care for them. Despite our common delusions over life's value, few tasks that we do really "matter." Yours does. Jerome Kalur, Cleveland, OH

I personally can identify with you . . . since my first child, who is now 35, was born quadriplegic and microcephalic (C.P.). . . doesn't know me. . . Even after 35 years the pain is still there. L.P., M.D.

I have had both the privilege and responsibility of representing many children who suffer from serious neurological injuries and understand full well not only their needs but the tremendous amount of costs associated in fulfilling those needs. Neal A. Roth, attorney, Grossman and Roth, P.A., Miami, and Boca Raton, FL

This is in lieu of giving Christmas presents. (My fortunate family) have all they need and your little ones can benefit from their "gifts." Anne M. Tisdell, Peabody, MA



Zachary Schwartz, left, and Jonathan Sabatini visited New England Pediatric Care.

## Sixth graders donate \$200 to H.A.L.O.

**T**he sixth grade class at The Fay School in Southborough, MA, is donating half its earnings this year to the H.A.L.O. Foundation.

The money was raised through a bake sale and raffles, according to Zachary Schwartz, class president, and Jonathan Sabatini, class secretary. The twelve-year-olds were part of a group of Fay students who visited New England Pediatric Care to learn about the lives of neurologically impaired children.

"I felt so lucky afterwards, knowing I could go outside and run, or go to a movie," said Zachary. "I have all those things those children don't, but I've been taking them for granted."

Dr. Alan Pinshaw prepared them for the tour, explaining how a virus had destroyed his daughter Sarah's brain function. He also discussed the types of impairments they might see at the pediatric facility, and how they might have happened.

The group toured the classrooms, therapy areas, adapted swimming pool and kitchen where patients with advanced skills learn to prepare food. With classmate Julie Pinshaw and her brother Daniel, they visited Sarah, who lives at NEPC, and was the inspiration for the H.A.L.O. Foundation.

"Sarah looked normal. It was hard to understand that she didn't know we were there," said Zachary. "Lots of the kids are blind, or deaf. Even when they are not, when you look at them, they

have a dazed look, and you know they aren't very aware of what's going on in the greater world."

The boys were impressed that some residents have learned to adapt, for instance creating their own sign language to express their needs, or using their head to buzz the nurses, if their arms or legs don't work.

"Some of these kids are smart, they can think. They just have no control over their bodies," said Jonathan.

"Everybody was upset, depressed really, at the end of the tour," he said. "Dr. Pinshaw said we weren't going to like it, and we didn't, but it was a good experience. It was definitely educational."

"We weren't afraid of the patients, just sad for them," said Zachary.

The boys were deeply impressed with the experience of one patient, whom they were told had lost brain function following an allergic reaction.

"You realize that this happens to people, real people, in every day life. They just were not lucky," Jonathan said.

The boys recommended a visit to NEPC for other classmates, but advised that children should be screened for maturity. "Some kids are too emotional, and would cry," said Jonathan.

Zachary said Dr. Pinshaw's introduction should be required. "It would have meant nothing if we hadn't known the why and how behind the people there."