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H.A.L.O. Reports

A Publication from the Help A Little One Foundation



A Foundation for Neurologically Impaired Children

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H.A.L.O. Foundation 1330 Boylston Street Chestnut Hill, MA. 02167 (617) 423-HALO Founder's message

H.A.L.O. directors plan for the future

t is two years since Gayle and I founded the Help a Little One Foundation, and nearly four years since our daughter Sarah's unfortunate illness.

We visit Sarah several times a week, and can now observe the small pleasures H.A.L.O. has been able to provide to other neurologically impaired children whose needs exceed institutional supplies. I am pleased to report that your generosity is making a positive impact on the lives of these less fortunate children.

We began our endeavor at New England Pediatric Care in North Billerica, where Sarah spends her days with therapists, educators and nurses. The children received television sets, video cassette recorders and players and audio equipment for stimulation and entertainment.

Last fall, we disbursed money to the Mayflower Pediatric Unit in Plymouth and the Northampton Nursing Home in Northampton. We are pleased that we are able to continue to reach out to children in these Massachusetts facilities.

Financial support continues. The Board of Directors is working with the Fidelity Charitable Gift Fund, and its new spin-off division Fidelity Charitable Advisory Service, to manage and invest H.A.L.O.'s assets, handle the tax and estate needs of contributors, and network us with the philanthropic world. To ensure growth of our assets and future aid to children, the Board is also consulting with a fund raiser to develop and implement a five-year plan for building capital. These steps were necessary to maintain and manage the H.A.L.O. Foundation, and to create visibility for our mission.

We welcome Dr. Leslie Rubin to our Advisory Board, and Dr. Michael Alper and Karin Alper to our Board of Directors, and we thank Dr. Joan L. Lasser for her tireless efforts on our behalf. The expertise of all the Board is invaluable as we move through this new phase of development.

Another contingent from The Fay School in Southborough visited New England Pediatric Care with me in June. I'm looking for additional ways to raise consciousness among the young regarding disabilities and charitable giving.

Thank you for your continued interest and support.

Sincerely yours,

Alan Pinshaw

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Volunteers reach out to Northampton Nursing Home

hildren at Northampton Nursing Home (NNH) are the very fortunate beneficiaries of long term support from college and community service groups in this Western Massachusetts city.

While the staff provides integrated team services to meet the educational, medical and social needs of the 43 residents, the volunteers enable NNH to emphasize "normalization," said administrator John Mahoney.

"Getting the kids out into the community, makes their lives special... but it's difficult to do without assistance."



John Mahoney Administrator

"Getting the kids out into the community makes their lives special . . . but its difficult to do without assistance. We are fortunate to be located in a community that reaches out to us."

Who volunteers?

The **Honor Court** organization van brings children in their adaptive wheelchairs to the YMCA for swimming sessions year 'round. (See adjacent story.)

The Eagles fraternal organization of Northampton has been the largest single contributor in recent years, taking children on medically-supported camping trips, and funding adaptive playground swings, Mahoney said.

Each spring interns from Stillpoint School of Massage provide one-to-one massage to the residents for 10 weeks.

For the past four years, the Boltwood Project at University of Massachusetts/Amherst has planned and conducted weekly activities with recreation staff supervision.

"This program draws a lot of caring and committed volunteers, who really want to work with our kids," said Piper Sagen, director of recreation. "It's nice to see growth on both sides."

The annual Smith Organization for Service (SOS) fair usually garners a half dozen Smith College students who assist staff in established activities, such as reading, baking, sensory stimulation and socializing. Individuals from Mount Holyoke College and volunteer nursing aide students from Smith Vocational High School in Northampton also provide people power. A student teacher from Becker Junior College in Westfield assists in the education program, also.

Individual musicians, pet owners and relatives of staff members reach out to the children at Northampton Nursing Home. For instance, **Tom Morin** of Springfield built handicapped accessible planters suspended from swing set support to allow wheelchair-bound kids to touch and smell earth and plants.

Mahoney said H.A.L.O. 's support in providing customized items to challenge and stimulate individuals has added yet another dimension to daily living. He expressed appreciation on behalf of the residents.

Honor Court gives kids the royal treatment

henever the children at Northampton Nursing Home need transportation to the Easter Seals swim program at the YMCA, Honor Court is there to drive them.

"The Honor Court is there all the time, working with our day care program, pre-school integrated play groups, and taking the kids to the park, the mall and the Shriners Circus . . . They are really accommodating and we are extremely grateful," said

Trips would be severely limited without Honor Court, due to the prohibitively high cost of transporting children in adaptive wheelchairs, Mahoney said.

Administrator John Mahoney.

So who are these Honor Court heroes?

"We are a family of recovering substance abusers getting our lives together through public service," according to Director Phillip Robinson.

"We believe you can live a straight life and a sober life by helping others," said Robinson, a graduate of the program himself. He said an elderly woman's thank you for a meal he delivered years ago was the spark

that turned his life around. "I really felt she appreciated what I did, and I felt worth something," he said.

Honor Court stresses community service as the vehicle for building self esteem and helping the substance abuser find a place in the community, Robinson said.

Kevin Powers is a perfect example of someone getting his life together through service, said Robinson.

"I've been driving those kids from the (Northampton) nursing home to the Y every Saturday for the last four or five years," said Powers. "It started out as a twelve-week program, but then we kept bringing them to other places. "I've become good friends with the staff and very attached to some of the kids there. I enjoy bringing those kids in the van more than any of the jobs I do," said Powers.

"It's better than money," he said. Honor Court is supported by private donations, plus funding from the state for monitoring probation terms. In addition to public service, residents must also participate in four mandatory meetings each week, and stay off drugs, alcohol and addictive substances.

Fidelity Investments manages H.A.L.O. assets

he Board of Directors has assigned investment of H.A.L.O.'s assets to Fidelity Investments' Charitable Gift Fund.

wildest dreams," said founder Alan Pinshaw of the gifts made in the past two years. "We have been extremely pleased with the efforts of our accountants, Abrams, Little-Gill Tishman and Witty, P.C., who will continue to handle day-today operations and all other aspects."

H.A.L.O.'s position as a foundation with assets under \$10 million has inspired Fidelity to create a spin-off division, the Fidelity Charitable Advisory Service (FCAS).

"H.A.L.O. was the major catalyst in recognizing the need for marketing, administrative and investment services and advice to the smaller foundation," according to Jaime B. Jaffee, Charitable Gift Fund President. Fidelity believes it is the first and only national organization to offer these services.

Fidelity will invest present assets and future funds to be raised in H.A.L.O.'s development campaign. It will process paper work and donor tax receipts.

H.A.L.O. will gain visibility by being included in the Fidelity Charitable Gift Fund listing to donors and will benefit from Fidelity's marketing amongst philanthropists.

"The Charitable Gift Fund works on behalf of donors. Through our joint work, Gift Fund donors may make gifts to H.A.L.O." Jaffee said, noting that an immediate tax deduction is allowed because the Gift Fund is an IRS-approved public charity.

Almost 2,300 donors have contributed approximately \$140 million to the Gift Fund in its first three years of existence, according to Fidelity's CGF annual report. Nearly \$30 million has been distributed in the form of grants to 6,000 charitable organizations. The report lists national and community nonprofit groups of all sizes and purposes as recipients.

"It is our intention to raise the

awareness of the foundation, service the Board and become a partner with H.A.L.O. in fundraising," Jaffee said.

FCAS will provide the means to "We've accumulated assets beyond our accomplish H.A.L.O.'s mission beyond the service of the current Board and relieve directors of day-to-day investment responsibility, yet maintain their policy making role, she said.

"It is exciting to teach people about the values and attributes of charitable giving. Those invested in the Gift Fund meet a tax need, but also provide for future philanthropy," said Jaffee.

H.A.L.O. is all about making children happy



Five-year-old Nicholas Colarusso experiences a therapeutic horseback ride with instructor Dawn Lebreck at Ironstone Farms in Andover while Irene Hassard of New England Pediatric Care's recreation therapy department looks on. NEPC therapy includes positioning, head control, straight sitting and sensory feedback from the movement of the horses, as well as the feedback from petting the animal. NEPC is a recipient of H.A.L.O. funds.

Development plans are under consideration

it raises more money than expected in its first few years, but not enough to build a permanent endowment?

Plan for the future, of course.

The Board of Directors is considering plans to launch a three to five year campaign to build a nucleus fund large enough to throw off enough interest to carry the basic mission of H.A.L.O. in perpetuity.

Several development professionals are being consulted. Directors are quick

hat does a foundation do when to note that growth can occur without a major fundraising effort, but a campaign would alleviate them of the necessity of a vearly effort.

> Once the anticipated endowment of \$250,000 to \$500,000 would be achieved, the Board could commit more time to giving and be less consumed by fundraising.

> Some of the proposals being discussed

- A focus on major gifts.
- Targeting other foundations to make gifts to H.A.L.O.

(Continued on page 4)

Mayflower goals are communication and mobility

ommunication and mobility are the cornerstones of the program at the Mayflower Pediatric Center in Plymouth, Massachusetts.

When H.A.L.O. directors visited Mayflower recently, the staff emphasized that enabling residents to reach maximum capability in these areas gives them more opportunity to interact with the world.

Mayflower can accommodate up to 62 children and young adults with highly specialized needs: compromised respiratory status, severe orthopedic problems, complex seizure disorders, complicated dietary and digestive problems and neurological disabilities.

"If residents can attain some of their life skills, some may be able to move into a more inclusive environment in the community," said Gerald C. La-Belle, Pediatric Program Manager.

In most cases, however, the smaller victories over everyday life boost spirits and result in improved health. LaBelle said H.A.L.O.'s gifts have helped produce these victories. Audio and video equipment stimulate the senses and sometimes provide incentives for therapy or behavior modification.

Nearly all Mayflower residents utilize the bright and roomy renovated physical therapy room several times each week. They work at sensory integration equipment stations and on special equipment to improve gross motor control, head control and sometimes just the ability to achieve better position.

"Our focus is mobility . . . whenever possible to have the child control some of his or her mobility," said Liz Baker, Director of Physical Therapy.

Therapists don't work alone. The educational component of the program focuses on helping individuals to master functional activities and providing opportunities for growth, said Cheryl Piwarunas, M. Ed., Director of Education. Teachers and therapists work together to prioritize and coordinate their efforts with the children.

Three unusual devices have been important in expanding communication skills, said Mayflower director of speech therapy Susan Donovan. The Communications Display Board allows an individual to point or to use a light to designate a picture of a family member, a food item, a toy or other preference on a display board designed just for him or her. The Light Talker pronounces the name of the designated item in an electronic voice when a child uses a hand or head switch to activate lights on a board of pictures.

"The Light Talker is a wonderful learning tool and provides an individual who is otherwise unable to speak with a voice, it even allows them to make a phone call to family members," Donovan said.

Mayflower's *Speak Easy* actually allows a therapist to record 12 personalized messages in a voice matching age and gender of the resident, who then uses it to convey messages at the touch of a switch.

"When we go to Friendly's Ice

Cream, the individual can "say" 'I would like a vanilla ice cream cone," according to Donovan.

"It's been nice because the people in the community respond well (to the Speak Easy). They will interact directly with the children as opposed to the staff people as interpreters," said Donovan. "They've made a real difference in the children's lives."

Board studies five year plan

(Continued from page 3)

- Approaching corporate philanthropists who have demonstrated past support for education and enrichment of disabled children.
- Reviewing and broadening H.A.L.O.'s mission
- Networking with other foundations, such as the Make-A-Wish
 Foundation, established by families who also experienced tragedies.
- Build an internal capacity for fundraising by learning the ropes from a professional.

H.A.L.O.'s assignment of investment responsibilities to the Fidelity Charitable Gift Fund was an important first step in formalizing the foundation. It also set the stage for reviewing development proposals.

A large endowment would allow H.A.L.O. to exist in perpetuity, separate from the founding family. Should interest wane in future generations, the Foundation would continue to make gifts to neurologically impaired children and fulfill the mission of its founders.

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