



VOLUME 12, ISSUE 1  
FALL/WINTER 2005

# H.A.L.O. Reports

*A Foundation for Children with Neurological Impairment*



## ***“Day Hab” program encourages independence***

**H**alloween — in fact every holiday — is an opportunity for personal growth at the Hallmark Day Habilitation program in Northampton, Massachusetts.

“Day Hab” provides specialized services to help people age 22 or older function with as much self-determination and independence as possible. The program is one of many services offered at the Hallmark Development Center at Northampton Rehabilitation and Nursing Center.

“One of the things we try to do in Day Hab is to stimulate the senses — so our young adults can know and feel what other people feel,” said Irene Feliciano, coordinator. “We base our activities on the holidays, the seasons,

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Day Hab Coordinator Irene Feliciano helps Marisol experience a pumpkin inside and out.

## **Two families learn that people care deeply**

*The Help A Little One Foundation supports and empowers families through its Family Circle partnership with the Greater Boston Jewish Family & Children’s Service. Recently, two Family Circle participants experienced an outpouring of support from their local communities. Here are their stories.*

### **The Flaherty Family**

**M**ore than 1,000 people turned out for an autumn fundraiser for children with special needs organized by the Boston Laborers Union Local 223 and friends and family of Michael and Kerry Flaherty.

The proceeds will help families like the Flahertys care for their children who have complex medical and developmental needs.

The young couple and older son Kevin had warmly anticipated the birth of twins in 2004, but things did not proceed smoothly.

Twenty weeks into the pregnancy, a test revealed that the one twin was failing to thrive because a rare blood-flow disorder, Twin-to-Twin Syndrome, was causing only his brother to receive the nutrients necessary for development.

*In utero* surgery was successful. Justin and Tommy were born prematurely, but healthy.

Nine days later, Tommy developed colitis. Kerry said the resulting infection and low blood pressure left him with cerebral palsy and other neurological

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Please visit us  
at  
[www.halo.org](http://www.halo.org)

Founder's Message:

## Help us increase community compassion

Dear Friends,

Malcolm Gladwell is the author of two entertaining best-sellers that explore the factors that influence and manipulate our behavior and decision making.

In *The Tipping Point: How Little Things Can Make a Big Difference* he proposes that ideas spread like viruses, and cites case studies to demonstrate how trends ripple outward until they reach critical mass -- the "tipping point" -- and become accepted in the mainstream. In *Blink: The Power of Thinking Without Thinking*, Gladwell delves into what really influences our "snap" judgments. He suggests that instincts are actually our "adaptive unconscious" reacting in the background with previously gathered information.

What does this have to do with H.A.L.O.? If we can determine what triggers compassion, and bring it to a "tipping point" in the larger community, we can nurture and expand the community of people who support and care about children with neurological impairment.

In this edition, we highlight two Family Circle participants who seem to have "tipped" a few thousand people towards compassion. We also profile the "Day Hab" unit for young adults in a Northampton, Massachusetts nursing home.

As always, I thank you for your support and good wishes.

Sincerely yours,

*Alan Pinshaw*

## H.A.L.O holiday gift program marks 13th year

Since its inception, the Help A Little One Foundation has funded holiday gifts to cheer children whose needs are best served in pediatric skilled nursing homes.

The grants are based on the number of children residing in each facility. Last year H.A.L.O. touched the lives of several hundred children residing in pediatric homes in New Hampshire and Massachusetts.

Brenda Conlon of the Recreation Department at New England Pediatric Care (Billerica, MA) outlined the process NEPC uses to select the gifts for residents.

In October, recreation staffers visit residents' rooms to determine if TVs, boom boxes or clothing needs to be updated or replaced.

"We divvy up the kids and consult with their particular teachers, and therapists, assistants and nurses for suggestions and any preferences they have observed," Brenda said. "Then we have the fun part -- we go shopping!"

Colorful or fuzzy items from Old Navy, are popular with the residents, along with music CD's and movie videos.

The gift buyers hunt for the latest hits-- last year *Shrek*,

*Finding Nemo* and *Harry Potter* topped the movie lists -- but there's room for individual taste, too. For instance, one resident's favorite movie "What About Bob?" has been replaced at least two or three times, said Brenda. "We're hoping DVD's hold up longer."

Administrator Ellen O'Gorman said she will consider replacing some resident's outdated VHS players with inexpensive DVD/VHS combinations this year now that most movies are now sold in the DVD format.

Other popular gifts include scented luxury lotions, hair

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## Two families learn that the community cares

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impairments. Tommy's doctors told them their son would be blind, deaf, and most likely never know his family, she said.

The outlook was very bleak, but once Tommy came home, he began to respond to family voices, and reward them with smiles.

Tommy has had surgery for intestinal problems, and the Flahertys expect there will be more hospitalizations in the future.

The Flahertys have experienced gaps in health insurance coverage due to the nature of Michael's employment as a laborer, and absences due to Tommy's frequent medical crises, Kerry said. While it is difficult to accept charity, she said it is comforting to know that the special needs fund will provide a safety net.

Kerry hopes some of the proceeds can be used to develop a bank of babysitters skilled and confident in caring for a child with special needs.

"There are many challenges with a baby like Tommy, but one of the hardest is knowing that people are afraid to be left alone with him, because of seizures and other complications," she said. She tries to impose as little as possible, but depends on trusted family members to help out.

The list of thank yous is long, but Kerry said the Flahertys are grateful to all the organizers of the benefit and especially the grandmothers and other family members for loving and supporting all their children.

"It's so hard for people like us to ask for and accept help from others," Kerry said. "It's a miracle that Tommy is here. We are so grateful that other people care."

### The Johnson Family

**O**n Halloween weekend close to 1,500 people attended a yard sale in a

Medfield, MA warehouse to raise money to cure Spinal Muscular Atrophy.

SMA is a genetic motor neuron disease that affects the voluntary muscles used for crawling, walking, head and neck control and swallowing. About 1 in 6,000 babies born are affected. (See [www.fsma.org](http://www.fsma.org).)

Already, SMA has robbed 5-year-old William Johnson of his ability to walk, but it didn't prevent him from whipping through the yard sale crowd in his motorized platform wheelchair. Half a dozen other kids with SMA were there, too, selling bracelets, tee-shirts and food alongside Families of Spinal Muscular Atrophy organizers, including William's siblings and parents, Heidi and "Trip" Johnson.

Energy crackled in the room, as TV reporters interviewed Heidi and cameramen filmed Red Sox pitcher Curt Schilling signing autographs for the cause. Schilling befriended the Johnsons after a neighbor introduced him to the die-hard Red Sox supporters.

The yard sale turnout was a great spirit booster, but there is more!

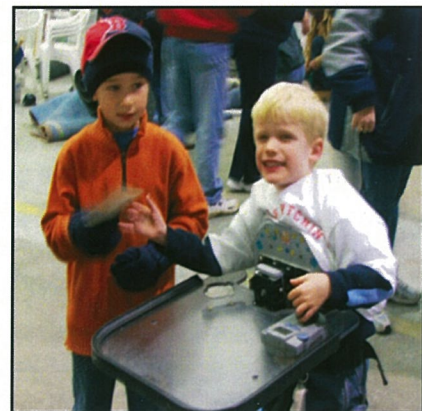
Friends and family raised \$30,000 to build a much needed handicapped-accessible bathroom for William. Work was already underway when ABC Television's *Extreme Makeover Home Edition* notified the Johnsons that they had been selected for a complete rebuild of their older, farmhouse. Heidi's sister Erica Stahler had nominated the Johnsons for the show.

ABC sent the family on vacation for a week, and invited the Families of SMA New England Chapter to have a role in the makeover. The FSMA team unloaded trucks and moved furniture - and left a special gift as well.

The program is tentatively scheduled to be aired Sunday, November 20th at 8 p.m.



Norwood, MA firefighters Tom Starr, left, and Ed Fitzgerald, right, hold Tommy and Justin Flaherty while big brother Kevin looks on. The firemen contributed to a fundraiser that will benefit children with special needs.



Patrick Connelley, left, donated his personal savings to the FMSA yard sale, and wrote a personal note to William Johnson, his pre-school classmate.



## Holiday themes enliven "Day Hab"

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birthdays -- anything that might be meaningful or connect participants with the everyday world."

A week before Halloween, the large Day Hab room was ablaze in orange pumpkins.

"We carve the pumpkins then help the residents to touch and react to the rough outside, wet inside and musky odor," Irene said. Residents who are tactilely defensive may participate by using a switch to activate recorded questions or cheers.

There is one staff member for every three Day Hab participants. Presently, half of the 32 residents in Hallmark's pediatric unit are enrolled. The young adults range from 22 to 32 years and most have been residents since early childhood. All have complex medical conditions and significant development delays.

Staff members focus on enhancing skills and increasing each individual's ability to perform activities and manage daily living. Areas include: self-help, sensory-motor, communication, social, independent living, affective, behavioral and vocational skills.

An interdisciplinary team from nursing, social services, day hab, rehabilitation and recreation departments creates an integrated service plan with goals and strategies for each individual. Staff members address and reinforce these

objectives during interactions.

Classroom units stimulate the senses through arts and crafts, and activities such as cooking, and include tasks to improve range of motion. Improved movement makes it easier for individuals to access technology that can improve quality of their lives. Bowling, wheelchair dancing and relay races are designed to improve social interaction skills. Other activities focus on alternative methods of communication, including eye gazes, pointing and facial expression.

Day Hab also reinforces behavior and social skills during trips to shopping malls, the Eastern States (Big E) Exposition, parks and local resources such as zoos, museums and community programs.

*Hallmark Day Habilitation is a program of the Hallmark Development Center at Northampton (MA) Rehabilitation and Nursing Center, (formerly Northampton Nursing Home). Call (413)586-3300 for information.*

### Checking the gift list

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accessories and motion-activated toys, according to Brenda.

Most purchases are made before Thanksgiving, to ensure good selection. The residents help to wrap the gifts during group (relaxation) time.

This year, individuals will not only receive, but also make gifts or cards for family members.

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Certified Nursing Assistant Yahaira Haddock carves a pumpkin for Darcy.