

# I.A.L.O. Reports

The Help A Little One Foundation for Children with Neurological Impairment















## "H.A.L.O.'s Gift Has Touched Us To The Core"

ear Help A Little One Foundation,

When our nine year old son would see groups of kids riding their bicycles past our home, he'd say that he wanted to ride something just like they were riding.

This broke our hearts. Because he has a chromosomal abnormality that causes major developmental delays, low muscle tone and other deficits, we don't know if Michael will ever have the balance or coordination to ride a standard bicycle. There are a lot of bicycles out there for children, but it had been hard to find one to meet Michael's needs.

We read about some modified cycles for children with special needs in the February 8, 2006 edition of H.A.L.O.'s Family Circle newsletter. The Junior Trike, manufactured by Worksman Cycles in New York, looked like it would be something that Michael would be able to ride. We never knew this type of cycle existed. We went to Somers, Connecticut where Matt White of the specialty store Fit to Ride



Michael loves his trike

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## Seven Hills Expansion Delivers 'Dignity By Design'

even Hills at Groton opened a 35,000 square foot addition in October, completing the first phase of its \$13 million expansion and renovation of living, learning and play spaces.

"The Dignity By Design project aims to create a warmer, more dignified and welcoming environment for our residents," said to Kathleen M. Reville, Vice President of Philanthropy and Special Projects, Seven Hills Foundation. "Dignity By Design is based on the premise that all children deserve to live in an environment that feels like a home."

The skilled nursing pediatric home, one of four in Massachusetts, is licensed to house 83 children with complex medical

conditions and severe developmental and neurological impairment. Its' accredited special needs day school provides services to 57 children.

"The next step will increase space in the day school, which will enable us to enroll more children from the greater-Groton area," said Ms. Reville. Presently, most local children who do not require residential care, must travel to other schools, she said.

Phase Two will also upgrade bedrooms in the original building, and carve remaining space into family-friendly communal areas, clinical procedure

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#### Founder's Message:

## Children Need Us More Than Ever

ear Friends,
Kosovo. Afghanistan. Pakistan. North Korea. Columbia. Mexico. Sudan.
Iraq. Today's headlines report unrest all over the globe.

Americans may not be rioting in North American streets, but threats to our comfortable existence blare from the television set each night: the looming threat of an influenza pandemic, E. coli in our leafy greens, Big Dig tunnels crushing our cars.

We do our best to protect and nurture family life in these turbulent times.

In this edition of H.A.L.O. Reports, we highlight two stories celebrating good will rather than ill will. The Sawyers share kind words on the impact one small tricycle had on the life of a little boy, and Seven Hills at Groton celebrates the opening of a new wing in the name of dignity and respect for H.A.L.O's children.

If such acts of kindness were usual, this might be a different world.

I thank you for your continued support and friendship as H.A.LO. seeks to enhance the quality of life for children with neurological impairment.

Sincerely yours, Alan Pinshaw

## **Help A Little One**

- Donate today
- Sponsor a H.A.L.O. Holiday

Call 617-423 HALO Visit www.halo.org Email:info@halo.org

## Parents: "His smile was a mile wide."

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measured Michael, outfitted him for his custom trike and let him pick his color.

Once the order came in he showed him how to ride. The entire staff there was amazing. We had Matt's undivided attention that Saturday afternoon when we went there.

To have been able to watch our son walk into a store and pick out his own cycle is a memory that we will cherish forever. His smile was a mile wide.



Matt adjusts Michael's trike.

We can't begin to tell you what H.A.L.O.'s gift of one of these adapted tricycles has meant to Michael. He's on it literally every day. As soon as Dad comes home from work, Michael wants to ride—so out we go!

It has been amazing for him. It was slow going at first -- he was a bit frightened, but he has now mastered it. To see the look of pride on his face as he speeds along is the most rewarding thing of all. The whole neighborhood is thrilled for him, and he knows it! This trike will be something that he will be able to use for years.

H.A.L.O.'s gift provides great exercise, but even more, it allows Michael to join in an activity with his friends, just like any other kid. It has boosted his self-confidence.

H.A.L.O.'s gift has touched us to the core. Thank you all so very much for your kindness and generosity! This has made a dream come true for our son!

Fondly,

Kathleen and Rich Sawyer

## MDPH Urges Families To Make Disaster Plans

atastrophic hurricanes, tsunamis and earthquakes around the world have underscored the need for disaster planning.

#### Speak up now

The Massachusetts
Department of Public
Health (MDPH) Center
for Emergency
Preparedness urges
families to contact their
local disaster directors
before emergencies
occur, to ensure that
their child's needs will
be addressed in
disaster plans.

In 2005, the Center's "Special Populations" workgroup found that fewer than 10 % of families whose children have complex health care needs have emergency plans in place. Fewer than 20% said they knew who to

Massachusetts Disaster Planning Resources

MassSupport (Family Emergency Cards) Toll Free: 1 866 237-8274 www.mass.gov/samh

Family TIES 1 800 905-TIES (8437) www.massfamilyties.org

#### 9-1-1 Disability Indicator Program:

Statewide Emergency
Telecommunications Board
Telephone: 508 828-2911
TTY 508 828- 4572
www.mass.gov/c99/muni.htm

#### MDPH Center for Emergency Preparedness:

Special Populations Liaison Jeff Timperi 617 624-5275 Jeffrey.Timperi@state.ma.us

call in the event of a natural disaster.

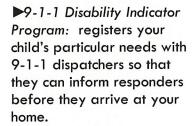
#### Responders are unaware

In a later survey, local emergency responders said they do not know which families in their communities would require special assistance. Public schools and community venues do have disaster plans in place, but few have provided for children with complex needs, according to MDPH.

#### Resources are available

Available resources include:

- ►Directions: Resources for Your Child's Care: See this brochure's emergency planning section.
- Special Populations Risk Communications: a course for individuals, organizations or intermediaries who provide direct services or information to special population groups in Massachusetts.



Compiled from publications of the Massachusetts Center for Emergency Preparedness.



Saglio Photography

## Tips From The Center For Emergency Preparedness

- ▶Talk now to your **local** director of disaster planning about your child's needs. Ask your City Hall who to call.
- ▶Notify **local** first responders (Emergency Medical Service (EMS), fire, or police) of your child's needs.
- ▶Develop a Family Disaster Plan. Mass Support and Family TIES have samples.
- ▶ Prepare a Disaster Kit for your home, car, work place and school or childcare.
- ► Complete Family Emergency Cards.
- ▶Register with the 9-1-1 Disability Indicator Program so that first responders

- are knowledgeable when they arrive at your home.
- ▶If your child uses life-sustaining technology, contact your utility companies about service during power interruptions.
- ▶Talk to your pharmacy about obtaining medications during a disaster.
- ▶ Participate in school-based emergency planning activities and know how to communicate in emergencies.
- Ask neighbors to help your child if a disaster occurs. Be sure at least one other person can explain your child's needs.
- Note the location of accessible shelters.



### Seven Hills At Groton Aims To Be 'Home'

(Continued from page 1)

rooms, private consultation areas and a dining hall large enough for staff meetings.

The facility was built as a community hospital in 1951 and operated by Children's Hospital of Boston as Children's Extended Care Center Children's Hospital until 2004 when the Seven Hills Foundation assumed operations. Both administrations expressed concerns about the stark, utilitarian environment and lack of appropriate spaces and technology.

All of the 48 new bedrooms are designed for adjustable furniture and have built-in cabinets to keep ventilators, nebulizers, feeding tubes and other equipment out of the way. Each room has natural light, soft colors and individual climate control.

"We are thrilled with the new space, and I think the common areas are going to promote more interaction between families and all the kids," said one parent.

The new wing has ample electrical outlets, piped-in suction and oxygen, and the latest computer technology to maintain resident health. Each room has a ceiling-mounted power lift to move residents safely and comfortably — important, because most are not mobile. A sophisticated patient monitoring system replaces the older model that startled other residents.

The expansion and renovation



Families celebrate the expansion at Seven Hills at Groton. Saglio Photography

is made possible by support from the Seven Hills Foundation, contributions from individuals and residents' families, and private organizations such as the Massachusetts Knights of Columbus, Children's Hospital



Residents' new bedrooms are homelike.

Boston, Sean McDonough
Foundation, Agnes Lindsay
Trust, Deluxe Foundation,
Flagship Bank, Rogers Family
Foundation, Middlesex
Savings Charitable
Foundation, CVS/pharmacy
Charitable Trust, New
England Business Systems,
and Wal-Mart Stores.

The Seven Hills Foundation is a 501(c)3 non-profit organization supporting children and adults with physical, emotional, developmental, social and other significant life challenges. For more information, please visit www.sevenhills.org or call (978) 448-3388.

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A Foundation for Children with Neurological Impairment

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"The new space is better suited to the needs of the kids. I think the common areas in particular are going to promote more interaction between families and kids."

**Parent**