



SUMMER 2008



The Help A Little One Foundation

# H.A.L.O. Reports

*Serving Children With Neurological Impairment Since 1993*

## *Picture This: A Nursing Home That Looks Like Home*

An artist at a pediatric nursing home in Massachusetts is creating a portrait gallery of residents to make the facility more homelike.

The faces of more than 50 young people with complex medical needs and severe neurological impairments will welcome visitors to New England Pediatric Care (NEPC) in N. Billerica when recreational aide Theresa Munnis is done.

The gallery was the brainchild of Anthony Terrasi, a designer hired to move the institutional décor "to the next level."

"This is a residence – a home – for kids. What home doesn't have pictures of its children?" said Anthony. "Theresa



Theresa Munnis is creating a portrait gallery at NEPC.

creates amazing likenesses – she brings out their soul!"

Theresa typically spends just one to three hours sketching an individual in pencil. Although her subjects have little stamina to "pose," she is able to capture their personalities because she has worked at NEPC for 12 years and known

many residents since her childhood when her father and brother worked there.

"I have drawn ever since I could pick up a pencil," says Theresa. "I started to draw portraits on my own time to give to families whose children had passed away."

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## Respite Program Adds Adaptive Aquatics

Family Circle's Sunday Respite Program added an Adaptive Aquatics instructor and more extensive Music Therapy and Art Therapy in June, thanks to a grant from the Carl and Ruth Shapiro Family Foundation.

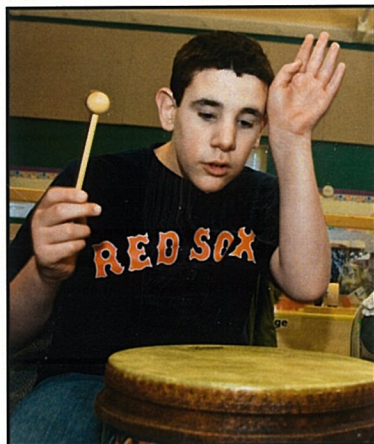
The two-year grant provides \$30,000 per year to expand recreational

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Participants benefit from increased strength and mobility.





#### Founder's Message

## *Compassion Drives Our Mission*

**D**ear Friends,

Is the H.A.L.O. Foundation doing all it can to enhance the lives of children with neurological impairment?

We embarked on this journey after our daughter Sarah was disabled by meningitis in the fall of 1991. The scope of our mission has expanded over the years as compassionate friends brought the needs of facilities and families to our attention.

This edition of H.A.L.O Reports celebrates caring individuals and organizations who are identifying needs and doing something about them for the benefit of our target audience.

Theresa Munnis, a recreational aide at the nursing home where our daughter Sarah resides, decided to use her artistic talent to console families who lost a child. A designer working at the facility was captivated by her portraits and is creating a gallery to focus attention on residents.

A synagogue in Central Massachusetts saw that families whose children had disabilities felt estranged from the community. They are training teen volunteers to expand the "Friendship Circle."

The professionals are innovating: long term care administrators have developed guidelines to ensure quality care for our young people, and our own Family Circle coordinators wrote a successful grant to boost respite programs.

Do YOU have an idea to help our children? We welcome your suggestions, and thank you for your continued support.

Sincerely yours,

*Alan Pinshaw*

## **Family Circle Is Beneficiary Of Grant**

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opportunities for young adults with disabilities.

"We are very excited to be able to respond to parents' requests for aquatic therapy in our Sunday Respite program," said Doreen Cummings, one of two *Family Circle* coordinators. Adaptive aquatics is more beneficial than unstructured water play, she said, because it improves strength and mobility.

The Shapiro grant will provide additional supplies and instruction

for art and music therapy sessions, and increase program capacity.

Presently, up to 15 individuals can participate in the three-hour sessions held at the Leventhal-Sidman Jewish Community Center in Newton, MA. Families must make advance reservations and pay a nominal fee.

Jewish Family & Children's Service of Boston operates the Sunday Respite program for H.A.L.O.'s Family Circle and was responsible for obtaining the grant.

# Teens Befriend Socially Isolated Children

**T**he boisterous children exploring Lake Chauncy on a recent Friday afternoon were celebrating more than the Memorial Day weekend – they were celebrating friendship.

The Friendship Circle barbeque was one of the monthly events the Jewish Chabad of Westboro, MA organizes for Central Massachusetts children and families who are socially isolated because of physical, emotional or behavioral disabilities.

“Our goal is to make these children and their families feel more integrated with the community,” said Rabbi Yaron Kimelman who recruits and matches the volunteers in partnership with his wife Yona Rivka. “This experience enriches the lives of everyone involved, from the teenagers who learn about the power of giving to the children who get to experience the fun of friendship.”

“We now have over twenty amazingly devoted teen volunteers and a growing number of families who are seeking friendship for their special needs children.”

**What do Teens and Families say?**  
(Pseudonyms have been used to maintain anonymity.)

**Andrew's mom:** “I guess I was surprised to find out that there are actually teenagers who want to do this kind of thing. I have two sons on the autism spectrum, and am always looking to make connections for them . . . Andrew is great with adults, but has trouble interacting with kids, and transitions can be very tough. I always feel people are staring at us. At the picnic he made quite a scene; last week it was at the grocery store. David's visit each week gives me a break

from keeping Andrew occupied.”

**David, 14:** “I go to the Academy of Mathematics and Science, and was just looking for something different to do. I found out I really enjoy playing with Andrew. I feel like I am helping someone.”

**Michael's mom:** “It's nice for Michael' to be with someone who isn't going to make him learn something or answer questions. Two teenagers alternate weekly visits, and this gives Michael two new friends. He is not a kid who plays well with his peer group so it's less stressful for him to be with an older child who will give him some slack.”

**Hank, 14:** “Sometimes Michael can be challenging, but I have learned what to do to keep him calm. (When Michael scraped his toe while climbing on rocks at the beach, Hank redirected his attention to avoid an outburst, then gave him a piggyback ride to the first aid station.) I didn't know I would like this. It's turned out to be a great opportunity to work with people I like and care about.”

**Rita's mom:** “Friendship Circle is very good for my daughter Rita. For the first time she has a friend she can laugh with and share secrets. Most other children don't know how to communicate with her. Her 'friend' makes an effort.”

Rabbi Kimelman said Friendship Circle embraces children with a wide range of disabilities.

There are more than 100 independent, Chabad-sponsored circles across the United States and Canada. Participants need not be associated with Chabad – or even be Jewish – to take part.

*For more information, contact Rabbi Yaron Kimelman at (508) 410-3831 or email [ykimelman@gmail.com](mailto:ykimelman@gmail.com) or visit [www.fc.chabadwestboro.org](http://www.fc.chabadwestboro.org).*





# Guidelines Established for Long Term Care

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For the first time, model practices have been established to ensure quality long term care for young people.

A 14-member team representing a variety of pediatric disciplines and facilities across the U.S. spent nearly six years developing the guidelines which were presented to more than 180 professionals at the April 2008 conference "Navigating the Care of the Medically Fragile Child" in Atlanta, GA.

Until now, model practices in nursing homes focused on geriatric patients who had previously been fully functioning adults, according to Ellen O'Gorman, Executive Director of New England Pediatric Care in Massachusetts, and one



of the guideline authors.

"The needs of children in long-term care today are starkly different than those of older adults," she said. "Most will be dependent on others throughout their lives. These young people need life skills - habilitation - more than rehabilitation, which is a focus in geriatric homes."

Today's pediatric residents have very complex medical conditions compared to 30 years ago, when pediatric homes were

populated mostly by individuals with developmental disabilities, she said.

As community based-options were developed for those individuals, their beds were filled by children rescued by new technology. The newer residents require highly skilled nursing, life sustaining equipment such as ventilators and feeding tubes and intense therapeutic intervention to survive.

As individuals "age out" of state-funded support in pediatric homes, O'Gorman said the new guidelines will provide a critical framework for determining which adult options will best meet the needs of each individual.

Call Ellen O'Gorman at (978) 667-5123 or visit [eogorman@nepediatriccare.org](mailto:eogorman@nepediatriccare.org)



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## Staffer Creates Portrait Gallery At Nursing Home

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When NEPC Executive Director Ellen O'Gorman became aware of Theresa's talent, she involved her in building beautification projects; for instance, Theresa painted the door to the Snoozelin® room -



a sensory refuge for residents and staff.

"We want to create an atmosphere that is whimsical but not juvenile, so that both residents and staff feel good when they are here," O'Gorman said.

Other NEPC enhancements include new paint and cheerful flags to identify classrooms and offices. Also, the family of resident Ryan Stewart recently initiated the "Tiles for Smiles"



Whimsical ceiling tiles and flags brighten NEPC

campaign to provide visual variety for children who spend hours reclining in bed or in wheelchairs.

For information call (978) 667-5123 or visit [www.nepediatriccare.org](http://www.nepediatriccare.org).