



VOLUME 11, ISSUE 1
FALL 2004

H.A.L.O. Reports

A Foundation for Children with Neurological Impairment



Therapists get creative at N.E.P.C.

Lunch and gym often top schoolchildren's list of favorite classes.

If the youngsters at New England Pediatric Care could speak, it is likely they would pick gym, too.

Physical Therapy Supervisor Lisa Troy recently invited H.A.L.O. to observe a creative bit of weekly programming at the 80-bed care center — Sensory Motor Group, known in school as "Gym". It was a ball game and a music fest, punctuated by squeals of delight, words of encouragement and new moves for children with severe neurological impairment.

Soccer Week was being held indoors because chilly weather adversely affects the medically fragile children, but in previous weeks they played "football" and "volleyball" outdoors.

Therapist Tricia Cormack matched four students — Shan, Danny, Shekan and Hanna — with able-bodied adults who are also teachers, therapists or assistants at the school. For an hour or more each Thursday, these students are



Hanna enjoys the game with teacher Amanda Butler.

freed from wheelchairs to sit upright in the arms of their assigned coach.

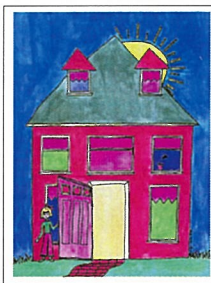
(Continued on page 4)

Can two parents build a House of Possibilities?

Being the parent of a child with special needs is a 24/7 job.

Soon after her son Timothy was born, Paula Kavolius realized that she and husband Mark would need occasional time-outs if they were going to care for him at home. Timmy, now 8, is non-verbal, emotionally volatile and can present challenging behaviors.

Paula discovered a desperate need for quality respite services when she went hunting for backup for those rare occasions when they wanted to accept a dinner invitation, or would need two days for a funeral or wedding. Massachusetts offers a small inventory of respite



homes, she said, but they were scattered across the map, had long waiting lists, and varied in the quality of programs offered.

"I wanted to bring Timmy to a place where I was confident he would be well cared for and engaged in activities that are fun and meaningful to him," said the Walpole, MA mother. "I needed a place where my son would be physically cared for, but also treated with dignity and respect."

The seed for the House of Possibilities was planted.

Enter Jack Ferris, a retiree whose 18-year-old son also has special needs.

(Continued on page 4)

Founder's Message:

Every cause has its champions

Dear Friends,

The intrepid 2004 Boston Red Sox did it! In the waning days of October, they finally "reversed" the 86-year old "Curse of the Bambino" to win the American League Championship Series, and then the World Series for the first time since 1918.

None of the players did it alone – not Curt Schilling or David Ortiz or Johnny Damon, Manny Ramirez, Tim Wakefield, Derek Lowe or Pedro. The eight straight wins (four to win the ALCS, four for the World Championship) that made baseball history were the result of the entire team's efforts and the support of the ever-faithful Red Sox Nation.

Children with neurological impairment also need a winning team to champion their cause. In this edition of *H.A.L.O. Reports* we feature efforts by a variety of team members — staff, families, facilities and non-profit organizations— who are diligently working to enhance the quality of life for profoundly impaired children.

We hope these everyday heroes inspire and move you to Help A Little One in whatever way you can. Please visit our new website at www.halo.org to review our expanding list of resources.

As always, we thank you for your continued support and wish you peace and happiness.

Sincerely yours,

Alan Pinshaw

**To learn more
about the
Help A Little One
Foundation
Visit us online
at
www.halo.org**

Seven Hills at Groton improves quality of life

Seven Hills of Groton, formerly Children's Extended Care Center operated by Children's Hospital of Boston, is undergoing a \$6.4 million transformation.

When complete, the facility will serve as a prototype nationally for other pediatric nursing homes. The expanded and renovated Seven Hills will offer a warmer, more dignified and welcoming environment for residents and their families, said Administrator Holly Jarek.

"The *Dignity by Design* campaign is based on the premise that all children have the right to live in an environment that feels like a home," Ms. Jarek said. The Seven Hills Foundation, which purchased the facility in January

2004, is raising \$2.5 million of the cost. In addition, the foundation plans a \$4 million programs upgrade.

Built as a community hospital in 1951, the buildings that make up the facility have never had any substantial structural renovations.

"The stark nursing home environment has been the only real complaint from families," said Ms. Jarek. Every improvement will enhance quality of life, she said.

The new rooms will be lighter, brighter, warmer or cooler according to each resident's needs; they will have ample electrical outlets, piped in suction and oxygen, and the latest medical technology. Other updates include:

- A maximum of 2 beds in each room (some now have 3 or 4)
- A private living room and a stay over room for visiting families in each of four units
- A water therapy pool
- A new physical therapy area
- Clinical spaces (for dental, cardiology, orthopedic visits)
- Separate units for younger children and over 22 residents
- A cooking/dining area for residents
- A staff dining/meeting room)
- Modern support services

The Seven Hills Foundation is based in Worcester, MA and funds and manages a continuum of support and services for individuals with disabilities, "from birth . . . through life."

For more information, call Seven Hills at Groton at (978) 448-3388 or visit www.SevenHills.org.

Handi Kids Riding Center opens up a new dimension

Left. Right. Walk. Whoa.

Sounds boring, but six professional instructors and 60 volunteers at Handi Kids in Bridgewater, Massachusetts make therapeutic horseback riding exciting and beneficial for thousands of children and young adults with physical and cognitive challenges.

"We work with children with a wide range of disabilities such as Cerebral Palsy, Multiple Sclerosis, low muscle tone - and many, many autistic children," said Nicole Birkholzer, Riding Director for the non-profit recreational facility.

Handi Kids offers both indoor and outdoor arenas on 35 acres, and is accredited by the North American Riding for the Handicapped Association (NARHA).

Sometimes children who have not spoken say their first words to their horse.

Each 40-minute lesson is tailored to the special needs of the rider by integrating cognitive, physical and occupational therapies over an eight-week session.

"When you sit on a horse, you can really relax. Some of the kids just have a blanket between them and their horse, so they feel the warmth of the animal. When the horse walks, they "walk" because their nerves and muscles are stimulated and it may actually promote growth and lead to walking for some children," Nicole said.

The program aims to improve the rider's muscle tone, but also targets self esteem.

"Early on, we teach the child that the rider is in charge of the horse," she explained. "We want to create a sense of mastery. Whenever possible the leader might step aside briefly so that the child feels in charge." Typically a leader and one or two volunteers walk beside the horse to make sure the rider

doesn't slip during a lesson.

Parents can watch a riding lesson from the centrally located viewing room at the riding arena. Horses are carefully screened for temperament and movement to insure the children's safety and to maximize results from the rider's experience.

Sometimes children who have not spoken say their first words to their horse. The riding center makes every effort to build on existing skills and to motivate children in potential growth areas. The arena is decorated with many colors, letters, pictures and words for sequencing with children with learning disabilities.

Horseback riding creates a new dimension in lives that can be overwhelmed with medical needs and families who have to dress, lift and manage the riders' lives, Nicole said. For this reason Handi Kids also offers a four-week Buddy program, when special needs riders can take lessons with their parents, siblings and friends. The children can share the experience with their loved ones and demonstrate their newfound skills.

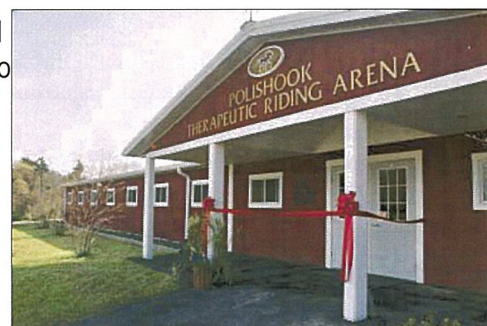
The program could not survive without the many trained high school and horse community volunteers who help groom the 12 horses, clean stalls and accompany the 111 riders six days a week. Volunteers also enhance the other Handi Kids offerings, including Summer Camp, Saturday Camp, School Vacation Camp, Vocational Training, Boy Scout and Girl Scout troops, teen programs and special events.

A minimal fee is charged for programs, and sometimes there is a waiting list. Handi Kids offers financial aid to qualified families.

To learn more about the Handi Kids riding center and other programs call 508-697-7557 or visit www.handikids.org.



Each rider is accompanied by a leader and at least one volunteer.



Riders with special needs can take lessons in the arena or outdoors.

N.E.P.C. staff livens up sensory motor class

(Continued from page 1)

They mimic the motions of the selected game: throwing, catching, and kicking the ball as best as they can.

"The goal is to improve flexibility and range of motion," Tricia explained. "We try to support the kids in alternate positions, and to strengthen any movement they have."

Occupational Therapy Assistant Tina Monaco coaxes Danny, for instance, to "Catch the ball." She guides the boy's arms around a large red plastic globe, and supports him as he attempts to hang on to it. Later, Tina gently bounces the ball in front of his braced legs, and patiently encourages him to "kick it" into a netted hoop on the floor. Despite his clear intentions, it takes several attempts before Danny's spastic muscles respond to his brain's directions. When he "scores" the group celebrates Danny's efforts.



Shan waits her turn at soccer.

Across the room, classroom teacher Amanda Butler sneaks one of Hanna's educational goals into the game. She records a message "Kick the ball, Danny" then asks Hanna to "use your voice" to encourage Danny. Eventually Hanna succeeds at turning his head and pressing his cheek to the modified switch on the recorder, sending the cheer out to Danny.

This group is for 5 to 10 year olds. Once or twice a month, they join up with the older kids for a bigger game and social interaction with different people.

It is not unusual for students to have seizures during class. When this occurs, the staff calmly monitors the student and life support systems and reports the occurrence to the nearby nurse. Many residents at NEPC utilize respirators and other life support systems because they cannot breathe, eat, speak or move independently.

"We can tell by their responses, their smiles and eye contact, that the kids enjoy these sessions," Tricia said. "That is important, and the staff can enjoy the kids, too."

Contact New England Pediatric Care at 978-667-5123.

More than a dream — this house is possible

(Continued from page 1)

He too recognized what a lifesaver the proposed respite center could be for families in a constant state of crisis.

The duo established the House of Possibilities, Inc., (HOPE) almost two years ago for the purpose of building a state-of-the-art facility where children with special needs can be cared for in the most homelike environment possible by compassionate and skilled staffers who strive to enhance the lives of children with special needs. Equally important, the facility would enable parents to take well-deserved breaks to recharge their minds and spirits, and fulfill other obligations

HOPE has since raised nearly half of the \$872,000 estimated cost for building a 6,000 to 8,000 square foot home to serve special needs families in communities south west of Boston. Tradesmen have volunteered to complete

finish work at cost; retailers have offered to provide kitchen appliances; others will match donations.

"The biggest challenge now is to secure the right location," said Jack. He is seeking a land donor with holdings in a welcoming community, where religious, civic and youth groups might volunteer time and befriend HOPE guests.

HOPE also needs to stabilize a steady revenue stream to fund the staff and to offer programs to all families regardless of income.

While fundraising continues, Paula and Jack are compiling a database of families in need of respite services to prove need to major grant programs. HOPE is also offering a pilot respite program on alternate Saturdays at the Massachusetts Hospital School in Waltham.

Contact Paula at 508 668-7032 or Jack at 781-551-0747 or email: houseofpossibilities@comcast.net

VOLUME 11, ISSUE 1
FALL 2004



**A
Foundation
for Children
with
Neurological
Impairment**

OFFICERS

Alan Pinshaw, M.D.
Founder and President

Paul Chervin, M.D.
Vice President

Barrie E. Little-Gill, C.P.A.
Treasurer

Robert Snider, Esq.
Clerk

BOARD OF DIRECTORS

Karin Alper

Michael Alper, M.D.

Gayle Pinshaw

ADVISORS

The Honorable Elizabeth Butler

Sy Friedland, Ph.D.

Leslie Rubin, M.D.

Benjamin P. Sachs, M.D.

Rabbi Donald M. Splansky

CERTIFIED PUBLIC ACCOUNTANTS

Abrams, Little-Gill, Loberfeld, P.C.

H.A.L.O. Foundation
1330 Boylston Street
Chestnut Hill, MA. 02467
(617) 423-HALO