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H.A.L.O. Reports

A Foundation for Children with Neurological Impairment



Moveable floor, hi-tech features make pool accessible

Elizabeth Barrett can't walk on her own two feet yet, but she's getting closer.

Since March, the five-year-old has participated in weekly aquatic therapy sessions in the new, hi-tech pool at the Franciscan Hospital for Children in Brighton, Massachusetts.

Underwater cameras record her movements as therapists teach her muscles the mechanics of walking. Doctors can review her progress on site, or call up video later to analyze her progress.

Elizabeth has been going to land-based therapy since she was 10 or 12 months old

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PT/OT Director Carrie Barlow and Elizabeth work on muscle tone in the new therapeutic pool at the Franciscan Hospital for Children.

Vacation: "It was a time to feel almost normal!"

New England Pediatric Care utilizes grant funds to send families on vacation with full support for their medically-fragile children. H.A.L.O. co-founder Gayle Pinshaw wrote to administrator Ellen O'Gorman following her vacation with daughter Sarah.

Dear Ellen,

When I think about having the luxury of being able to vacation with one's normally institutionalized, disabled child, I am filled with a yearning and an anticipation that belies simple vacationing. The joy of being able to spend time as a family for more than a day or a few hours is not something I take for granted.

The first time Sarah and I participated in the Cape trip, I cried frequently, just to be able to push her in her chair along the pathways in such a beautiful place. I would quickly wipe my eyes before some other family would swoop by on their bicycles, giving a quick nod of acknowledgement as they passed us. Thank God for sunglasses! I didn't even know that I missed this experience. It had been thirteen years. To be able to read, or nap, and not feel that you are "wasting" precious time with your child is so counter to our usual existence.

Sarah visibly relaxed. She slept under an umbrella in the sun and gave spontaneous

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Please visit us
at
www.halo.org

Founder's Message:

Everyone has the potential to 'give back'

Dear Friends,

Diana, Princess of Wales, once said: "Everyone needs to be valued. Everyone has the potential to give something back."

It is unclear whether she was speaking of donors or recipients.

Donors make it possible for the Help A Little One Foundation to enhance the quality of life for children with neurological impairment. Recipients, despite their challenges, give us renewed patience, reordered priorities and increased appreciation for what we have.

In this edition of H.A.L.O. Reports we share gifts given and received amongst our H.A.L.O. community. Family Circle's dream date contest winners (back cover) didn't ask for much in return for being on call 24/7 for their medically-complex children — just an evening with their spouses and a competent babysitter at home. Excerpts are on the back cover.

The front page features an innovative therapy pool at the Franciscan Hospital for Children, where children can strengthen muscles and experience movement not possible on their own. My wife and co-founder Gayle Pinshaw tells in a letter how she rediscovered feelings on a medically-supported vacation with our daughter Sarah.

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

Sincerely yours,

Alan Pinshaw

What motivates a H.A.L.O. donor?

Kate Miller, a Vice President with Fidelity Investments, is one of many dedicated donors to the Help a Little One Foundation.

H.A.L.O.: How did you learn of the H.A.L.O. Foundation?

KATE: I first met Dr. Pinshaw (founder) in his professional capacity. I am indebted and grateful to him and his colleagues for being alive today. At one point I noticed a family photo in his office, and he told me about his daughter Sarah, whose illness and subsequent neurological impairment was the inspiration for H.A.L.O.



"We are fortunate to be where we are in life. If I don't contribute to folks with challenges, who will?"

H.A.L.O.: Why does H.A.L.O. touch your heart?

KATE: I am grateful for my healthy children. A friend gave birth at 27 weeks with complications, and seeing how different our lives are brought it close to home.

H.A.L.O.: Why do you give?

KATE: I have always contributed to different

charities. Fidelity has a workplace giving program similar to United Way and others — you pick your charity and it is delivered painlessly by payroll deduction. In the past I gave to Aids Action, food banks and other worthy causes. In 2003 I thought of Alan Pinshaw and said this makes sense.

Accessible pool is 'out of this world'

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due to motor and orthopedic issues, according to her mother, Jean Barrett. She said Elizabeth's muscles are too weak to support her body.

"Water therapy is wonderful because Elizabeth is in a wheel chair most of the day. There are other contraptions to put her in a standing position, but she finds them confining," Jean said. "In the water, because she's naturally buoyant, she can hold her own."

"You've got to see this (*Richard and Susan Smith Family Therapeutic*) pool! It's unbelievable. I recommend it highly," says Jean Barrett. "They've created a setting that is just out of this world, and the therapists are exceptional."

The water temperature is a relaxing 82 to 92 degrees. Elizabeth is fortunate, she

can slide into the pool from a sitting position on the edge. Engineers and designers collaborated with clinicians and therapists to remove the barriers that have traditionally challenged wheelchair users and people with disabilities.

The pool floor is raised at the beginning of the session so there is initially about a foot of water. Elizabeth works on supporting her weight on her knees — a challenge for her — then gradually the floor is lowered so that she can "walk" circuits in deeper water.

"Elizabeth is more willing to work at therapy because it is play-based," said Jean. "She gets a lot of enjoyment from the pool activity."

. Other pool features include:

► **A submersible wheelchair**

► **Variable water depths:** the pool floor can be raised and lowered for safe entry and to individualize therapy for each patient's height and weight bearing needs

► **A multi-speed underwater treadmill** to implement cardiovascular and gait training in a weightless environment

► **Underwater video monitoring** to facilitate proper biomechanics and to assess movement patterns

► **Resistance jets with 450 different intensities** to tailor exercise for upper and lower extremities and stabilization

► **A massage hose** to ease pain and reduce the ill effects of lactic acid accumulation in muscles

► **Removable support bars**

"We are delighted to be able to offer this service as an outpatient program," said William Burgey, Marketing and Public Relations Coordinator. "We have found that it allows therapists to be more creative in their treatment and it motivates their patients. Our environment is built for kids."

To discuss whether the Franciscan Hospital's aquatic therapy program is suitable for your child, call Physical Therapy at (617) 254-3800, x 1280 or visit: www.franciscanhospital.org.



The submersible wheelchair gives Adrian easier access to the pool.

"Almost normal"

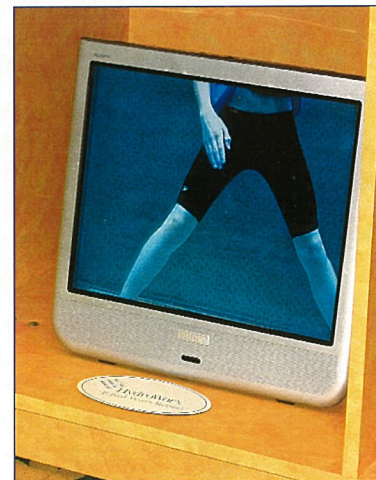
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little smiles to her grateful mother. The second visit was rainy. The house was so densely quiet she stayed wide-eyed and at attention well into the night.

This was a time to understand my child's daily routine in a more intimate way. Sharing a room, I became more aware of the staff tiptoeing at night, adjusting position every two hours, changing diapers, monitoring vital signs with flashlights, checking feeding tubes. I knew all these things happened, but I understand them in a new way now. More than ever I appreciate how the nurses and staff assumed the burdens of heavy lifting and endless care!

It was a time of camaraderie with people who know your pain, if not your story, with families also caught in fate's web, and grateful for the respite from the noise and clutter of institutional living. It was a time to feel almost normal.

It was a time that was and continues to be intensely precious. I look forward to going again and am very thankful to have experienced it twice. *Gayle*



Underwater cameras record therapy sessions.



A Foundation for Children with Neurological Impairment

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Family Circle dream dates awarded to five couples

Time together is always at a premium when a family has a child with complex medical issues.

Family Circle, in partnership with the H.A.L.O. Foundation, recently awarded an eight hour Dream Date with paid child care to five lucky couples who wanted to catch their breath and recapture romance. Here are excerpts from their entries:



Heidi: "Monster seats for two at Fenway; 1 hot dog, 1 popcorn, 1 beer, 1 water and 1 WIN!!!!"



Michelle: "Nothing fancy here, — just a chance to get a babysitter for an afternoon/evening to go to the American Repertory Theater and see the current play. (Dinner would be nice too!)"

Rose: "If I could have a night out (or even a day!) I would love to see "Les Miserables with my husband."



My husband deserves a night out much more than I do. He does the main care taking for our four year old daughter. . . gives her all her meds by g-tube, suction her, gives her asthma treatments, dresses her, bathes her, feeds her, combs her hair and most importantly gives her lots of love. . . . We hardly ever get time alone, due to my work schedule. We really miss each other sometimes. Thank you so much."

For information about Family Circle support and resource programs in Greater Boston, call (781) 551-0405.



Nala: "For our dream date I would go into Boston in the spring, have lunch at a nice restaurant, take a walk through the public garden and see the flowers in bloom; take a ride on the swan boats and pay a visit to the Museum of Fine Arts. If we have any money left over, we would go to the Parker House for afternoon tea. It's something I think of every spring but have never gotten around to doing."

Helen: "Romance for me is relaxing. How about a stone massage for two? Simply being with one another, maybe even winking or giggling at each other like on a first date again. After, we can float effortlessly out of the building and have an eloquent lunch in a romantic café, sitting on big comfy chairs and . . . actually have a conversation or cuddle."



HALO Family Circle
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