

H.A.L.O. Reports

A Publication from the Help A Little One Foundation



**A Foundation
for Children
with Neurological
Impairment**

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Founder's message

Technology gives Sarah a 'voice'

Dear Friends,

In March of 1991 we bought our first family computer. It cost a hefty \$3000, had 40 megabytes of memory and ran at about 25 hertz. It was awesome, but it was a Model T Ford by today's standards.

Recently, we purchased a replacement. It cost just half the price of the first one, has 40 gigabytes of memory and runs at 800 hertz — the equivalent of a sleek, modern sports car. Technology today is as pervasive as the telephone. Our vernacular is littered with techno-speak: E-mails, spamming, Internet surfing and buddy lists. Our lives are easier because we pay our bills, check the movie schedule, shop and even book vacations "on line."

About six months after we purchased that first computer, our daughter Sarah became ill and lost much of her neurological function. With her severe cognitive and physical impairment, we never dreamed she would be able to use a computer. Today, however, she and residents at pediatric facilities all over the U.S. use assistive technology devices to communicate and participate in school.

Sarah, who is thirteen, can "turn" the page of an electronic story book on the computer by triggering a switch with a head movement. Her teachers say her enjoyment of the story motivates her to produce the movement that advances the story. It is exciting to us that she demonstrates interest in her surroundings and makes a connection between her action and the result produced by the computer. Technology has given her a means of communication. She can express her will.

This year, one of the H.A.L.O. Foundation's gifts was a donation to purchase high quality technology devices for the children at Sarah's home, New England Pediatric Care, an affiliate of New England Medical Center in Boston, MA.

H.A.L.O. is always seeking ways to improve the quality of life for children in pediatric facilities. Please know that your donations are well utilized. As always, we thank you for your kind wishes and donations.

Sincerely yours,

Alan Pinshaw

A Foundation for Children with Neurological Impairment

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H.A.L.O. provides alternative means of communication

The H.A.L.O. Foundation broadened the scope of its gift program this year to include purchase of communication technology devices for students in the day school at New England Pediatric Care in North Billerica MA.

Since it's inception, H.A.L.O. has eschewed "equipment" donations in favor of providing items that comfort or enhance the lives of children with neurological impairment. The thought had been that the governing agency should provide the necessities of life, while H.A.L.O. served more personal needs.

Alan Pinshaw, H.A.L.O. founder, said he observed daughter Sarah using a mounted microlite switch to advance an electronic storybook and concluded that the switches and touch pads were more than "equipment" because they facilitate self-expression. The children can indicate "yes" or "no" or



Brenda, a teaching assistant at New England Pediatric Care, applauds Danny, age 7, for activating a "Big Mac" voice-output switch at the appropriate moment during story telling period.



Teaching assistant Liz asks John to respond to questions by applying ever so slight pressure to the sensor next to his hand. His response is "voiced" on the speakers in the foreground.

select pre-recorded messages to voice their feelings.

"H.A.L.O.'s donation goes a long way toward improving quality of life for our students, because the devices create an opportunity for students to communicate," said Jennifer McDonough, Director of Education at NEPC. "Today's more sensitive switches and touch pads allow even those children with significant physical limitations to turn on their music, "read" a book or change a television station."

NEPC had several basic devices children could use, but Jennifer said the donation allowed her to purchase a greater number and variety of devices. Some devices can cost up to \$250 each, due to the sensitive electronics housed inside the bright casings.

"Now we can have several different devices in each classroom, rather than moving them around, and this gives more access to more children on a regular basis," she said.

When a visitor toured a class for young teens, a charming Courtney clamored to "read" at the computer, while another student used one of the devices.

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The Bastianellis always maintain a positive outlook

The first time John Bastianelli held his prematurely-born twins, they were five weeks old and "I could slide my wedding band half way up Matthew's arm."

Melissa weighed only 1 pound 13 ounces and Matthew only 1 pound 9 ounces when they were born on November 24, 1995 at only 26 weeks gestational age. Doctors had forewarned the couple that the births were "high risk" because Lucia Bastianelli had developed toxemia during her pregnancy, but the parents admit now that they didn't know what to expect.

"We were so lucky," Lucia told a visitor to their sunny Newton, Massachusetts home in May. "It could have been much worse."

Today, the couple is grateful for what their children can do, and highly aware of the high cost of suitable equipment that enables Melissa and Matthew to achieve their potential.

Each day Lucia drives the twins to school at the Early Beginnings Center in Canton, MA, where they also ride horses, swim and receive physical, speech and occupational therapy.

The H.A.L.O. Foundation helped outfit the new family van with a special wheel chair lift and fittings that allow the children to ride side by side (most don't), and provide quick access in case of medical emergency or accident. This setup also made room for passengers in a third row of seats — frequently Lucia's mother "Nonna" comes along to help.

H.A.L.O. also funded a changing table to diaper



John demonstrates the ease of using the wheelchair lift made possible by gifts from H.A.L.O. and other organizations.



The Bastianelli Family enjoys a laugh, from left: Melissa, John, Lucia and Matthew.

the six-year-olds. "We are so lucky."

Doctors at St. Margaret's Women's Center, a division of St. Elizabeth's Hospital in Brighton, MA, discovered bleeding on the twins brains in their first few days of life. Their prognosis covered a wide range of developmental and physical disabilities.

"It was a shock. We wondered what was going to be the end result," said John.

At age six, both children are spastic, small for their age and developmentally disabled; they must use wheelchairs and have received botox treatments to loosen up their muscles.

Melissa has had two hip surgeries, but uses a gait trainer and walker to move. She enjoys Brownie Scouts, books, coloring, socializing and nail painting.

Matthew's disabilities include seizures and vision problems. He cannot stand independently, but is a whiz in his walker. He enjoys all types of music; but recordings by Italian opera star Andreas Bocelli send him into reverie. He comes back to earth in hardware stores. The mere mention of a trip to Home Depot® puts a major grin on his face.

Lucia said the twins enjoy general good health. She repeats her mantra: "We are so lucky."

Although both children respond to English and Italian, their parents say communication can be a challenge. "Sometimes you have to ask a million times for them to process the question, and answer," said John.

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"We are not going to hold Melissa and Matthew back"

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The young father is emphatic that the twins will have the same opportunities as more able children. "We are not going to hold them back. We are going to challenge them as much as possible."

The couple has taken the children snowmobiling, and hope to try adaptive skiing soon. Last summer they drove to Canada by car. The trip was such a success Lucia enlisted a student helper from Boston University's Sargent College for Occupational Therapy to take the twins to a wedding at Disney World.

Every Saturday for several years now, BU students Jill, Christina, Linda, Michelle or Danielle have come to help feed and bathe the children, take them to the playground, and just give the parents a break.

John and Lucia said they spend a lot of time researching opportunities and making connections (some through H.A.L.O.'s Family Circle program) for the children. "Tired is normal for us," said Lucia. "It



Occupational Therapy student Michelle, joins Matthew and a friend for lunch.

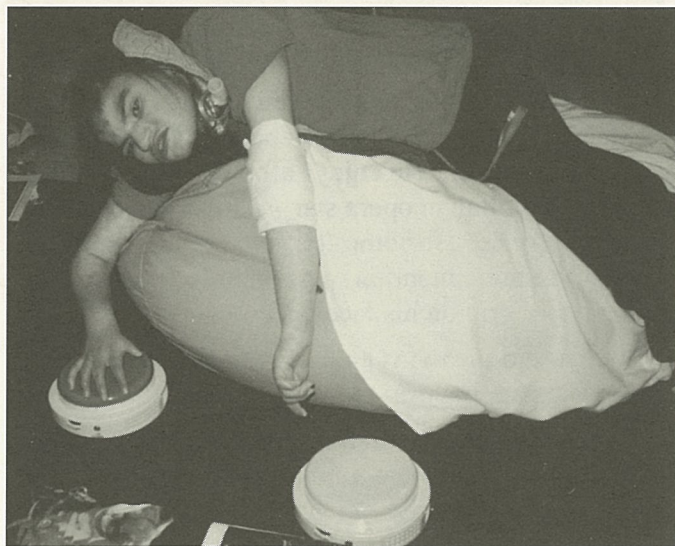
isn't always easy, but I wouldn't change a thing."

"We are so lucky."

Devices Give NEPC students ability to express preferences

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When a staff member asked whether John might like his fan turned on, the young man indicated his preference by pressing his finger ever so slightly to a highly sensitive switch.



Becky identifies a photograph of a crab from the comfort of her beanbag. NEPC students are re-positioned on mats, beanbags and other supports throughout the day to relieve the restriction of their wheelchairs.

The power of the computer chip enables a child to play an active, rather than a passive, role in the classroom. Becky, for instance was observed using a Big Mac device to correctly identify a crab, and then a fish. Other students with advanced motor skills use over-sized keyboards to interact with computer programs.

H.A.L.O.'s grant gave NEPC the flexibility to choose from available technology, including:

- **Big Mac voice-output switches**, used primarily as a communication tool
- **Powerlink Boxes**, essential to activate everyday items such as TVs and radios
- **One-Step Communicators**, a differently shaped switch from the Big Mac, offering different options for the children
- **Intelli-Keys**, the over-sized keyboard (includes Sensor Switches and Mounting switches)
- **Microlite touch sensitive switches** for students who have minimal physical strength, and
- **Sensor and Mounting switches** for the lightest touches, and attachment to headrests.