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# H.A.L.O. Reports

*A Publication from the Help A Little One Foundation*

**Founder's message**

## *H.A.L.O. marks fourth year*

In May the Help A Little One Foundation marked its fourth anniversary as a benefactor to neurologically-impaired children.

Your generous contributions have continued to provide for the needs of a multitude of children and we thank you all.

At times I sense that people are curious whether time moves on for our family. In September, it will be five years since our daughter Sarah — H.A.L.O.'s inspiration — suffered major brain damage and lost her ability to eat, speak, move, laugh or do anything independently. The tremendous emotional pain continues for us, but Gayle, our other children, and I are adjusting to Sarah's illness. There is little choice.

People often ask: How old is Sarah? Truly, they may not know, because we favor a private family gathering on Sarah's birthday, instead of the more traditional horde of friends and pizza at — take your pick — Roller Kingdom, Chucky Cheese or the local Bowl-a-drome. Then again, is the question a genteel substitute for more delicate inquiries? How is Sarah's health? Does Sarah recognize you? Is Sarah still with us?

Sarah turned eight last December. Her condition is stable. We don't get much response from her and we have conceded hope for improvement. Recent months have been fairly serene as far as Sarah's health is concerned. She seems comfortable and well-cared for at New England Pediatric Care in North Billerica, MA. Gayle and I each visit Sarah three times a week; Danny and Julia see their sister twice a month. The three-hour round trip is difficult for teens laboring under the burden of school, sports and social obligations.

In a period of just six months this year, our family will have shared four major life celebrations with kin. Our own Daniel has already demonstrated his personal maturation and accomplishment by becoming a Bar Mitzvah on May 10th.

Yes, we grieve for Sarah's absence in these moments; but we savor their joy, also. Creating memories and bonds with those we love is what life is about. Those nuggets of happiness are what sustain us through the grim periods.

Engrave each precious minute in your heart this summer! Time moves on, whether you like it or not.

Thank you, as always, for your kindness and support.

Sincerely yours,

Alan Pinshaw

**INSIDE . . .**

***A Foundation for Neurologically Impaired Children***

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# H.A.L.O. supports Mayflower residents' trip to Disney

Where do ten neurologically-impaired kids, one geriatric patient and 14 staff members go in the middle of March?

Walt Disney World, of course!

This year the Help A Little One Foundation provided financial support for part of the $22,000 annual trip for residents of the Mayflower Nursing and Rehabilitation Center in Plymouth, Massachusetts. This third annual trip placed the group at the Polynesian Hotel inside Disney World, where excellent accessibility to the Monorail was available and first-floor, handicapped-accessible rooms were reserved.


Mayflower residents Logan Jameson and Amanda Holmes visit with Mickey Mouse at a Character's Breakfast at Walt Disney World in Orlando, Florida.

"We rode everything except Thunder Mountain and Splash Mountain," said Gabrielle Gaudreau, CTRS, Director of Therapeutic Recreation and Mayflower's trip coordinator. "From the Haunted House to Peter Pan to Pirates of the Caribbean and the studios and EPCOT. It was great!"

"People say to us that the kids won't know the difference, whether we take them to Disney or to any place, but it's not true," Ms. Gaudreau said. "We saw so many different reactions: smiles from some kids that don't normally react; one little guy laughing out loud as we flew on the plane; a response to the warmer temperatures. If nothing else, the kids are getting one-to-one attention, and no matter how we try, back home in a facility, there just aren't enough people to to that."

The families are very excited and grateful the kids get to make the trip, the coordinator said. The logistics of traveling alone with their child, and the prospect of emergency medical situations is daunting to most of them, so they appreciate the opportunity. This year one family accepted the invitation to accompany the group, she said.

Twenty-nine of the 59 youth residents at Mayflower have gone to Disney, and there is a good chance all will make the trip in the next few years.Children are selected based on their medical stability, permission from guardians and wheelchair tolerance, said Ms. Gaudreau. Families are asked for financial support, but no child is declined for financial reasons.

The children were able to participate in the traditional Polynesian luau, and other activities such as parades and fireworks displays. However, the workdays and nights were long for the staff. Mayflower staff fill out applications for the five-day, 24-hour a day assignment, and are matched up to the traveling resident's needs. One "extra" staff member provides relief and could act in emergencies, although there have been none to date, Ms. Gaudreau said.

Each "couple" - an attendant and a resident - shares a special room, located on the first floor and reserved about six months in advance. There is extra space between the bed and walls for the wheelchairs, shower chairs and railings in the bathrooms, and automatic doors.

Disney is particularly accommodating to those with disabilities, said the trip coordinator. Not only will they provide extra pillows for positioning, but they respond quickly to requests such as a tire pump, when a wheel chair got a flat on one trip, said Ms. Gaudreau. Help is always just a few steps or a phone call away, she said.

The kids in wheelchairs are allowed to enter rides through the exit gates, avoiding turnstiles and long lines. First aid/baby changing stations are available in every bathroom. Every two hours the staff meets at a designated area to give medications, allow the children to spend time outside the wheelchairs, and just check in.

"Disney is very child-centered. The staff is very well trained, and they take the time to really accommodate the kids' needs. They will stop a ride if one of the kids needs to get off. They let them come first.

"Our kids really enjoy the character visits. The staff knows all about touching and making sure kids respond — they wait for the response."

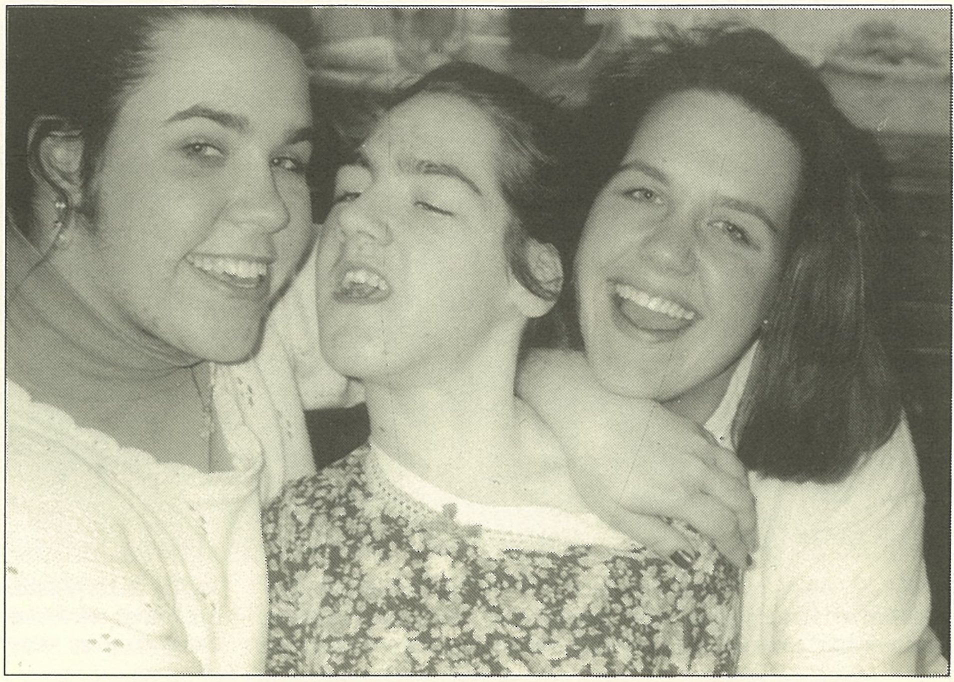
What's the most difficult part of the trip? Apart from leaving, it's airplane travel, said Ms. Gaudreau. Wheelchairs don't fit on board the plane, so the kids have to be transferred one by one in "skinny" chairs that fit in airplane aisles.

What's unexpected? "A lot of people come up to the kids. A little guy from Quincy, whose disabilities are not as severe as our kids, and his Dad have kept in touch. He picked us out of the crowd and now he's a friend."

## *Hot news: H.A.L.O. wins grant*

At press time, the H.A.L.O. Foundation had just received notification that our efforts to support neurologically-impaired children have been recognized with a generous grant from the Charles A. Frueann Foundation of Little Rock, Arkansas. More on that next time.

# *The Riley family gives new meaning to 'support system'*



The Riley sisters, from left, Bridget, Katie and Molly, are close even when they live miles apart.

The Riley family of Melrose could be one of those TV families, clustered around the kitchen table in a modest two-story home in the suburbs. Zoom in on some honest talk, spotlight some warmth, turn up the volume on laughter.

On the left, there's Lewis, a construction worker whose gruff exterior belies a a kind and gentle soul; to the right is Norma, a school secretary now, but the big-hearted, cookie-baking kind of Mom who welcomed all the neighborhood kids; center stage is daughter Bridget, 23, number two of four sisters and the only one home tonight. She's the one with dancing eyes, shiny black curls, and a passion for everything in life.

*This episode:* Bridget has written a letter to the H.A.L.O. Foundation applauding her parents' dedication to their family.

"My parents have been changing diapers for 26 years and have never once complained about it. I am writing this letter because I think my parents deserve some praise to be able to raise two severely handicapped children at home. Having Katie and Shannon with us has made us an extremely caring and loving family, and all the thanks is owed to my parents," penned Bridget. H.A.L.O. sends a visitor to chronicle their story.

*Fade to one of those hazy, dream-like scenes; voice over by Norma:* "I had the three girls at home. Molly, who was four, Bridget, two, and Shannon, two weeks. Everything was as normal as things can be with three young children. Lewis went off reluctantly to his job on the Alaskan pipeline, while we stayed in Medford. The seizures came out of nowhere it seemed. Looking back, I see now that Shannon would stare off into space, or stiffen up, but I didn't realize those were early signals."

Shannon swiftly developed a disabling seizure disorder, her body convulsing and eyes rolling as successive episodes blocked her brain's development. Doctors at Boston's best hospitals delivered an unhappy diagnosis to the distraught parents: Shannon's problem was unpreventable, incurable and had a one in four chance of being rooted in a genetic defect. Severe damage had been done and would continue. The most severe outward signs of seizure could be controlled with heavy medication, but the doctors recommended institutionalization for Shannon, and no more children for the Rileys.

Lewis was angered by the suggestion of tearing his daughter away from her home. Norma vowed to make a "normal" life for the girls, and did, with help from family and friends.

Then life handed the Rileys another surprise. When Shannon was approaching two, Norma learned she was pregnant again. At birth, Katie was determined to be healthy, but Norma watched her vigilantly.

At three months and three weeks, she observed her youngest in the obvious throes of a seizure. "I couldn't deny it. It had happened again. It was devastating," she said.

Katie responded well to the steroids that had eventually been effective in controlling Shannon's seizures. Her medical problems were less severe than her sister's. The Rileys learned to be aggressive in asking questions and getting treatment for the girls. Norma's sister Joan, a nurse, helped them grasp the jargon of pediatric neurology; subsequently, Norma's acquired expertise on the girls' issues and medications earned respect from many of the doctors.

Norma says she once saw a note in Shannon's file: " Mother likes to be in charge." The entire Riley clan likes to get involved when the children have been hospitalized or when there have been emergencies at home. Everyone shares a stake in the girls' futures.

Once a grandparent admonished Molly and Bridget along of the lines of "we can't do that, because of Shannon and Katie." Norma set that record straight — "Nobody misses out on anything, just because the sisters are handicapped." She timed the girls schedules so that she could attend Molly's and Bridget's presentations at school. She took them to dancing lessons, Girl Scouts, and church. The family vacationed at Disney World.

"We had friends over the house all the time, we decorated for Halloween, peeled grape "eyes" and all," said Bridget. "Mom baked, we played. We had a lot of (medical) equipment in the house but everyone got used to it. Some of the kids even learned to help. No one

*(Continued on page 4)*

**H.A.L.O. helps out:** A gift from the H.A.L.O. Foundation enabled New England Pediatric Care to purchase duplicate equipment to make transfers, positioning and ambulation easier for these young adults attending a vocational program sponsored by the Lowell Association for Retarded Citizens. Waiting to board the morning bus, from left, are: Justine Nevers, Frank Marrone, Missy Hatch, Shelly Draper, Michael Rousseau, Kenny Lyons, Lynn Mertz, Sean Queen and Vera Bemberry.

# Riley kids applaud their parents for teaching them about love

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ever said anything negative."

Norma answered all the children's questions honestly, on a level they could understand. "The only thing I ever asked the girls was to love their sisters," she said. "They do."

It was an incredibly sad loss when Shannon died at age nine. By then, Katie was going to day school at New England Pediatric Care in North Billerica, Massachusetts, and the older girls were in traditional school all day. Norma lost heart, became depressed, but eventually took a job to keep her going.

Tirelessly, the family has continued to devote their time to Katie's health and happiness. Lewis, for instance, gets up at 5 a.m. to medicate, then feed Katie, so she can rest before the van picks her up for school and he goes to work.

"I'm a construction worker, I do hard work, but Katie can run me ragged," Lewis said. The family nodded knowingly when he referred to a Saturday night when he had to give Katie her bath, alone. He filled the tub, prepared Katie, carried her to the tub, washed her, carried her to the towel, dried her, dressed her. She loved the bath, Lewis said, "but I was wringing wet and exhausted." Those who have done this know how difficult it can be to maneuver a spastic or stiffened limb through clothing.

"But the smile is worth everything," said Lewis.

It's no secret that Molly — an Ohio State graduate, married and living in Chicago just now — was inspired by her sisters' conditions to pursue a genetics career. Bridget surprised herself and her family, however, when she earned her degree in Public Relations and Speech Communication, then decided to tackle medical school. She often came home from college to spend time with her sister and credits their relationship for her career goal. Bridget is working as an assistant researcher at Massachusetts General Hospital while she accrues the necessary science and math credits for medical school

"Katie brings a lot of joy to our family, I can't imagine life without her," said Bridget.

The Rileys have had disappointments; for instance, Katie missed Bridget's graduation from Syracuse University because she was in the hospital. The medical logistics were almost impossible anyway, but her absence left a hole in their happiness.

Katie holds an important place in all the Riley hearts. "When I get in a bad mood, and I look at Katie and she smiles, nothing else matters. What else could be so important?" said Norma.

When Katie is hospitalized, Norma is there everyday, overseeing her care, and family members typically visit on a rotating schedule, to avoid tiring her. Once home, the Rileys keep Katie out of school until she builds up her strength. They also hire a nurse to help Katie.

Now 18, Katie has severe brain damage, severe scoliosis, respiratory problems and a tendency to get infections. She has been hospitalized more and more frequently.

*Closing scene:* The Rileys are back at the kitchen table. Finally they explain Katie's absence — she's been in the hospital again, and is having ups and downs. The older she gets, the worse the prognosis is, says Norma with a catch in her voice. Bridget looks away. A tearful, Lewis, unashamed, meets the visitor's eyes with sadness.

These Rileys are resilient, however. They blink away their concern, and quickly run to get photographs of Katie before their visitor leaves. "Please use this one," says Bridget. "Katie was so happy that day. We were all together."

*Katie returned to school at the end of May.*