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H.A.L.O. Reports

A Publication from the Help A Little One Foundation

INSIDE . . .

Founder's message

Celebrate each day of life

Our days start with frosty mornings and close with a crisp, cold good night this time of year. Visitors from near and far journey to New England to inhale the scents and enjoy the sights of our brilliant foliage extravaganza.

Carpe diem! Whether it's a golf weekend in Vermont, a Sunday afternoon drive along the Mohawk Trail or brunch and a steamboat cruise on the Connecticut River tourists are savoring the moment, and so should you.

Our family — Gayle, Daniel, Julia, Sarah and I — has learned to appreciate every day. We are healthy and happy and particularly grateful that Sarah's health has stablized following a bout with pneumonia in early October. We spent several sleepless nights at her side after she aspirated fluid into her lungs and was struggling to recovery. The positive thinking and prayers of many friends and a surgical procedure helped to stabilize Sarah's condition and put her on the road to recovery.

Friends often are timid about inquiring after Sarah. Don't be. We are delighted with your interest and support. We can share a small victory, or a nagging concern, just as you might discuss your own child's tonsillectomy or school work. We visit Sarah several times a week, and she is just as much a part of our lives as Daniel and Julia.

We particpated in a 5K Road Race this summer with other families whose children are residents at New England Pediatric Care. It wasn't really a race, but we walked and laughed and pushed some of our kids in wheelchairs. It was a show of solidarity for our children, and an afternoon of support for us.

Not every child has a family standing alongside. The H.A.L.O. Foundation tries to provide family-like support for children with neurological impairments. By bringing small pleasures into children's lives, we are trying to help them enjoy their days.

Sincerely yours,

Alan Pinshaw

A Foundation for Neurologically Impaired Children

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Treat disabled children the way you want to be treated

What if . . .

. . . Your four-year-old were disabled by meningitis?

. . . Your baby survived a near drowning in the family pool , but no longer had the ability to look into your eyes and tease you with her laugh?

. . . Your child had massive birth injuries?

How would you feel? Sad? Angry? Depressed? Alone?

You would be needing the support of family and friends.

Karen Savage, director of social services at New England Pediatric Care in North Billerica, MA . says this is often the time people bow out of your life.

"Most people have no idea what to say or do," said Karen. "Some people are always going to be uncomfortable . . . they want to do or say the right thing but don't know what that is, so they just disappear."

Unfairly, she says it places the onus on the bewildered parents to open themselves to support.

It is painful to see other people react, with fear, pity and flight, Karen said. By broaching the subject first, asking a friend "have you seen my most recent picture of Joey?" or confiding that Joey's most recent illness really left you drained, you give them permission to share feelings about your disabled child, she said.

Parents of a severely disabled child are not only emotionally vulnerable, but also face severe stress. One of the hardest decisions they face is whether to admit a child to an institution or care for the child at home.

"I always advise parents to do what is right for their situtation, and not worry about what other people think. There are so many judges, it really isn't fair," said Karen. "You can't know how it feels until you walk in another person's shoes."

The social worker admits these are the times when even a spouse or sibling pulls away. "Those on the threshold of adulthood might not want to spend time with a disabled sibling so they withdraw. I always suggest that parents keep the door open for future communication.

"I think the most important thing is that we try to treat people the way we would want to be treated," said Karen. "Envision yourself with the cognition of the person (affected) and think how can you interact."

"If you treat the child with dignity it takes the burden off you. If you are caring, and speak in a soothing manner to even a minimally responsive person, you won't feel guilty or uncomfortable," said Karen.

Families can be protective, but should also be alert to "teaching moments," said Karen. Taking a child to the mall, and investing energy and time in acquainting the curious with the person behind the disability can be rewarding, she said.

Outdoor pool at CECC offers fun, therapy

Andrea Howe, a therapist at Children's Extended Care Center in Groton, MA supports resident Meaghan Devaney in the outdoor pool at the home. Families can enjoy sunny afternoons at the pool. Sometimes residents have "pool parties" with relatives and neighborhood children who visit regularly.

Shore home readied for NEPC kids

An anonymous benefactor is preparing his seashore vacation home in Mattapoisett, MA for use by children living at New England Pediatric Care in North Billerica, MA.

The home offers direct access to the beach, and will be equipped with both access ramps for wheelchairs and sundecks where the wheelchair bound can enjoy the sights, smells and sounds of the ocean.

Several children and accompanying staff can be accommodated. Bathrooms will be adapted to the needs of the children, and oxygen and assistive equipment will be stocked at the home.

The family will offer a schedule to accommodate the children, while also allowing them to enjoy the property with family members.

Keelin Gorman passes on

Keelin Gorman, who was featured in the last editon of H.A.L.O. Reports, passed away in September of complications following surgery. Condolences may be addressed to Mr. and Mrs. Paul Gorman, in care of: The U.S. Sports and Fitness Center for the Disabled, 29 Elmwood Road, Swampscott, MA 01907.

Tish is a human being first, then disabled, says mother

Angela DiFlumeri delivered a shoplifter into police hands at T.J. Maxx, then rushed home from Saugus one Friday night in September just in time to greet a visitor to her neat tan and turquoise two-family home on Belle Isle Inlet in Winthrop, Massachusetts.

Angela, 69, swept briskly up the stairs, the same stairs she must climb carrying 95-pound Letitia on alternate weekends away from the nursing home.

"I do aerobics," she smiles, letting the visitor into a hall lined with art work created by her husband Albert, a retired contractor. "Gotta take care of myself for Tish."

Not breaking stride, she drops her bags into a chair, pours water into the tea kettle and gives the visitor a "tour" of the feminine pink bedroom she has decorated for Tish at the front of the house. There's a queen size bed, shelves packed with diapers and wipes for her 36-year-old daughter, who was born with a fractured skull and suffered multiple disabilities following oxygen deprivation during birth.The bureau is lined with framed photos, a sentimental Christmas card (composed by Albert on Tish's behalf) dolls and other frills.

Angela DiFlumeri shares a moment with her daughter Tish.

"I want everything to be convenient and pretty for Tish. Tish doesn't miss a holiday at home," Angela is proud to say. "This will always be her home, even though she lives up at the nursing home (New England Pediatric Care) now."

* * *

For fourteen and a half years, Angela cared for Tish at home. Family photo albums testify to her determination that Tish should experience everything children without disabilities experience. There's Tish in the stroller with Aimee, the sister who was adopted just seven months before Tish's birth. (Letitia and Aimee both are names that mean happiness, says Angela.) Here's Tish lounging on the patio chaise at a Fourth of July barbeque. Everywhere Tish is surrounded with love.

"I took her everywhere, still do. She likes the outdoors. I put snow in her hands. We rigged up a bicycle and swing because she loves movement," Angela said. She recalled an incident from her own childhood when she realized a neighbor hid her retarded sibling in the closet when Angela came to play. "Nobody was going to hide my daughter in a closet. "I waited seven-and-a-half years for her. I love her. If I am remembered for anything, I'd like to be remembered as a mother who loves her daughter. Tish is not someone to hide."

* * *

Only one bad experience in the community comes to mind, said Angela. Several whispering, pointing teenagers mocked her daughter one day. "I told them to go to church and thank God they were born with normal minds and bodies," she recalled indignantly. "I don't think they forgot the experience."

* * *

It took some people a while to accept what society called a "damaged" child in the '60's. Angela's parents and friends became her support system. They took turns caring for Tish so she could spend time with Aimee and bring her to art and skating lessons and school events. Angela's friend Gert Honan helped with the "patterning" (movement of arms and legs in prescribed patterns several times a day, thought to improve brain function in children with neurological impairments.) Angela's mother and father sat on the floor and played with Tish right from the start. "We taught Tish to drink, to eat hand-over-hand. My mother became especially close to Tish."

Angela is convinced that Tish has formed bonds with the people who love her. When she struggled against having an x-ray, Angela spoke and sang in Italian, as was her mother's custom. Tish settled down immediately.

The day Angela's mother died Tish demonstated an uncanny sense of melancholy.

"My mother's heart stopped beating at twenty minutes before 12 noon time. Later I went up to the home to see Tish. One of the nurses told me that Tish was very sad that morning. She maneuvered herself in her wheelchair over to the window and stared out into the sky. The nurse said she happened to look at her watch. It was twenty to 12. I think Tish knew on some level she had lost her grandmother. She was saying good bye to her spirit."

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H.A.L.O. Foundation honored for service to children

The H.A.L.O Foundation has been for recognized for outstanding service to disabled citizens living in Massachusetts nursing facilities.

The Massachusetts Extended Care Federation awarded a Certificate of Appreciation to H.A.L.O. on September 25th in response to a nomination by Mayflower Pediatric Center, Plymouth, MA.

"I nominated H.A.L.O. for the significant monetary support the foundation provides to us in times of need," said Gabrielle Gaudreau.

H.A.L.O.'s contributions "have allowed numerous children with special needs from several different nursing facilities to experience the pleasures of everyday life that many of us take for granted," she said in her nomination.

"Specifically, at Mayflower Pediatric Center, the H.A.L.O. Foundation has generously contributed to our Christmas Project which enabled all 60 of our residents to open new gifts on Christmas Day. These gifts were not only new toys, but leisure devices which promote learning and a greater sense of independence."

H.A.L.O.s advocacy and the H.A.L.O. Reports newsletter were also cited for connecting nursing homes with the communities. The state recognition was part of a national "Volunteer of the Year" program sponsored by the American Health Care Association.

Children respond to computer games

Jimmy Bedford, left, and Wendy Duggan laugh as they prepare to play a computer game at New England Pediatric Care, a residential home for children in North Billerica, MA. The computer was purchased with a grant from the Massachusetts Department of Education.

Tish's mother: 'She'll be understood as long as I'm alive'

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Angela is pleased her 15-year-old granddaughter Nicole has forged a special relationship with Tish.

Each period of separation has been difficult, Angela said. At first there were illnesses and hospitalizations, then surgeries; and respite day care.

"You ask yourself will they know what she needs (when she's away)?" worried Angela. When she discovered that one facility didn't change Tish's diapers all day, Angela vowed no one would ever degrade her daughter again.

"I've learned a lot . . .The first thing I learned was from a wonderful pediatrician we had when Tish was born. He taught me to treat Tish like a human being first, then as a disabled person. I won't accept less than human treatment for Tish, and neither will she."

Eventually Tish required more medical support, therapies and attention than the family could provide at home. Reluctantly, Tish was placed at the predecessor to New England Pediatric Care.

Angela says she is satisfied with the care and programs at NEPC. Tish is clean and comfortable. The staff stimulates her senses with music, art, gardening and field trip experiences. Programs entertain the residents and help them stretch their capabilties. Tish has limited sight, but can hear, taste and smell. The van drivers tell Angela that Tish becomes alert when she hears the planes at Logan Airport, right in her back yard. "I think she knows when she's near home."

When Tish comes home, Angela always sleeps in her bed. She holds her and is generous with kisses and hugs. She massages scented creams into her skin. Angela said Tish responds by touching her face and "scrunching her toes around my leg."

Angela is a realist. "Every parent prays that they (the children with disabilities) go first. It sounds terrible but you cannot expect your other children to do what you did after you die."

On that autumn evening when the visitor has come to learn how a mother loves her very special daughter, Angela DiFlumeri pulls a new Dr. Seuss book My Many Colored Days from the parcels she brought home.

"I like to read to Tish. She responds to my voice. The pages of this book have different colors for different moods on different days. Tish has moods, don't you? Just think, what if you couldn't tell me you were in pain, or that I wasn't paying attention to you. What if you wanted to hear music, but couldn't tell me? Tish will be understood, as long as I am alive. I speak for her. Someone has to."