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H.A.L.O. Reports

A Publication from the Help A Little One Foundation

HALO
HELP A LITTLE ONE

Founders message

We need your help!

Welcome to Spring, the season of new beginnings, verdant growth and happy times in the sunshine.

This is the time of year when families gather to enjoy their children's baseball games, soccer matches, and bicycle parades. Gayle and I find ourselves on the playing fields quite often, watching the efforts of our son, Danny, and daughter, Julia, but of course Sarah isn't out there. She's been in a pediatric nursing home for nearly four years now, unable to move herself or communicate since illness destroyed much of her brain function.

Not only will Sarah's seven-year-old legs never kick a goal, they'll never walk again. Our pride in her efforts and accomplishments is still strong, but it is transferred from the usual childhood victories to more personal ones: breathing and responding to stimuli.

The occasions for sharing an activity with Sarah are very limited. As distressing as her situation continues to be, she needs, and we need, happy times together. Recently all five of us were able to participate in a family swim at New England Pediatric Care, her home in North Billerica, Massachusetts. What a pleasure to see Sarah respond to the water! The theory is that it's almost a return to the environment of the womb, a very soothing experience. We've included a story on page four about the social and physical benefits of aquatic therapy.

We need your help now. We at H.A.L.O. have been working hard to address the personal, emotional and intellectual needs of children in pediatric nursing homes. We know, however, there are many children with similar needs who are living with their families. Since they spend less time with professional staff, we have had few referrals from this particular group. Please inform your friends, associates and clients about H.A.L.O.'s effort to provide support to children with neurological impairment, and share their names with us if they consent. Our hearts and hands are open to all.

I want to thank all of you for helping the H.A.L.O. Foundation make a difference in many young lives. Your continued financial and moral support enables us to help the kids — and they are kids just like your own children and grandchildren — to experience the pleasures of Summer, Fall, Winter and Spring.

Sincerely yours,

Alan Pinshaw

A Foundation for Neurologically Impaired Children

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Keelin's dad wants fitness for impaired athletes

Keelin Gorman lives at New England Pediatric Care, a long-term nursing home for children, but she's at the heart of the U.S. Sports and Fitness Center for the Disabled.

Keelin was born six years ago with multiple physical and neurological disabilities. Her needs prompted her father — a former teacher of the disabled, professional runner, athletic director and former member of the U.S. Track and Field Team — to found the USSF in 1992.

As a parent, Paul Gorman knows that physical activities such as the family swim program (related story page 4) at his daughter's Billerica, Massachusetts nursing home strengthen his family's sense of well being and as an athletic professional he knows how important fitness is to Keelin's health. As USSF executive director, Paul is working to increase that understanding amongst athletic professionals and to create exercise programs and facilities accessible to athletes with disabilities.

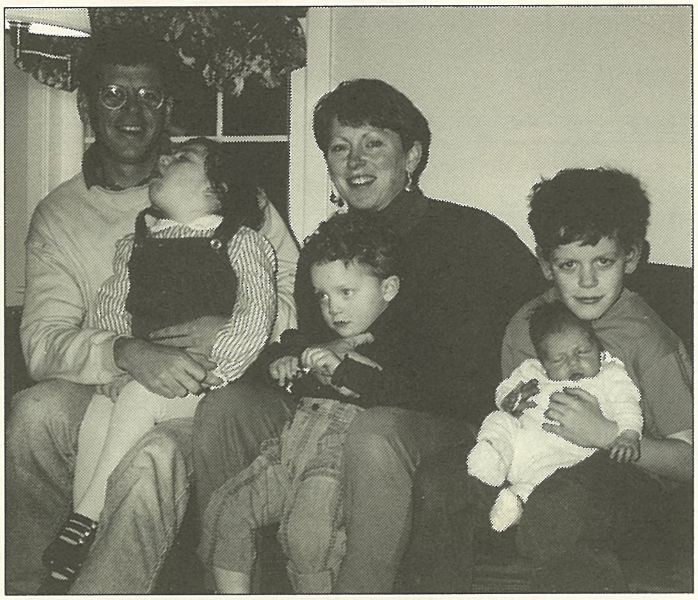
Paul toured Variety Village outside Toronto, Canada when he was athletic director for the North Shore Jewish Community Center in Marblehead, Massachusetts. He proposes to build a similar facility for fitness and competitive training in the Greater Boston area. The proposed 140,000 square foot center would accommodate athletes with and without disabilities, especially women and children, whose need for strong bodies and spirits seem to have gone unaddressed, Paul said.

"For such a long time people with disabililties have been dictated to by the able bodied," Paul said in a recent interview. "There are so many different disabilities their ability to make an impact has been fragmented. As a group, people with disabilities have not been able to collectively capture the philanthropic community. But there is a great need and a great frustration out there."

A limited number of facilities provide separate rooms or equipment that can be adapted to those with special needs, Paul said, but segregation creates artifical barriers and heightens the sense of isolation from the day to day world. Athletes with disabilities also need respect, acceptance and support from other athletes, he said. USSF needs to address the issue of transportation and financial access to facilities. Paul said 66% of disabled people are on a fixed income.

Paul has formulated a three-year plan to develop resources and funding for the center and integrated programs at other facilities. He has also put together an influential advisory board and powerful partnerships between USSF and the fitness and athletic world.

In May, The Newhouse Foundation awarded USSF a three-year, $1 million grant as a result of Paul's effort. The grant will seed educational programs for coaches, trainers and athletic directors; support research into the physiology of exercise for people with disabilties; create models and fund pilot programs integrating athletes with different capabilities.



The Gorman family at home: Paul holding Keelin, 6, Clare holding Tyler, 4, Connor, 9, holding Tess, 1. Paul founded the U.S.Sports and Fitness Center for the Disabled to create facilities and programs accessible to athletes with disabilities.

Springfield College in Springfield, Massachusetts, a school focusing on athletic professionals, will match the Newhouse grant with $1 million in funding and services. USSF and the College are planning a National Center to educate and certify present and future sports, fitness, physical education and health professionals about exercise for people with disabilities. The College will also share its vast alumni network to disseminate information, raise consciousness and provide opportuntities for recreation and fitness training for people with disabilities and utilize its unique 110-year affiliation with the YMCA of the USA. USSF and the Greater Boston YMCA have already laid the groundwork to offer integrated sports clinics and practices at the Reggie Lewis Track and Athletic Center in Roxbury, Massachusetts.

The Springfield College partnership will also produce a symposium for education, sports and fitness professionals, offer camps for teams preparing for the 1996 Paralympic Games in Atlanta and a youth sports development camp to develop and inspire future athletes with disabilities, and sponsor events for teams whose members have disabilities.

With valuable advice from a dedicated board of directors, financial support from individuals such as Wynn and Catherine Newhouse and foundations including the Mugar and Perini Foundations and in-kind services from successful firms such as Goodwin, Procter & Hoar and Arthur Andersen, Inc., Paul is aggressively pursuing his mission. USSF has identified several potential sites for the Center within the Route 128 ring around Boston. Feasibility studies and fundraising efforts are under consideration, Paul said.

Contact the USSF Center for the Disabled at 19 Elmwood Road, Swampscott, MA 01907. Telephone (617) 581-7775. FAX (617)581-7810.

Maryhelen strives to play like other children

One day Maryhelen Fabiszewski, 11, came home from school and cried her eyes out.

"They won't let me play in gym," she told her mother, after some coaxing. "They make me sit there and just watch."

Maureen and John Fabiszewski brought their daughter's concerns to public school administrators in Everett where she is enrolled in special education classes. School officials required the parents to sign a responsibility waiver before Maryhelen was allowed to participate in physical education activities. Maryhelen was born with spina bifida — an incomplete formation of the spinal cord — and developed accompanying hydrocephalus and learning disabilities, including speech impairment.

Maryhelen Fabiszewski demonstrates the Rock N Roll cycle she received from the H.A.L.O. Foundation.

"We asked the school to let Maryhelen be a regular child," said Maureen Fabiszewski. "If there's something she can't do — she wears leg braces up to her waist, and she has a shunt to prevent fluid build-up on the brain — let her participate in another way. . . be a helper, or something.

"The school was looking at her handicaps and assuming she can't do these things . . . John and I said she should, anybody should, be able to try. If Maryhelen falls, then she falls. If she gets hurt, well, she'll get her share of bruises. We want Maryhelen to have the experiences that children without handicaps have as much as she can," said Maureen, who left her job of 15 years to advocate for her child after her birth.

"We tell Maryhelen not to get mad at herself for being handicapped when things like that happen. We tell her to be strong. She's usually a happy and outgoing person. We tell her it's not her fault that she's handicapped and she has to continue to tell us what's going on."

One of Maryhelen's heartfelt desires has been to ride a bicycle with the other children in "the projects" neighborhood where the Fabiszewskis relocated due to the financial pressures associated with supporting Maryhelen. ("We were saving for our own home, but insurance doesn't cover everything. Maryhelen is our only child, we want to give her everything she needs," Maureen said.)

"The kids include her all the time. Maryhelen has lots of friends. But when they all go riding their bikes — the backyards are all flat and run into each other — it was something Maryhelen just couldn't do. We tried a regular bike, but she kept falling ," said Maureen. Maryhelen is ambulatory only with her braces. She has little sensation in her legs because of her spinal cord deformity, despite nine surgeries and years of treatment.

Serendipity put Maureen in the appointment book of H.A.L.O. founder Dr. Alan Pinshaw, for a checkup last year. Doctor and patient chatted about their children, who both have neurological impairments. Result: the H.A.L.O. Foundation was able to give Maryhelen a specialized hand-operated tricycle with supportive seat in her favorite color, pink.

"What a big deal the other kids and mothers and fathers have made in the neighborhood. Maryhelen feels very special about her Rock N Roll cycle. She can join in with the other kids. We are all very excited. We want to thank you all very much," said Maureen. She is quick to credit her husband with assembling the complex cycle. "John never did this before, but he sat down with those directions and worked on it 'till it was finally together," she said.

Maryhelen sports a big smile now when the kids go bike riding. "Maryhelen is doing so much more than doctors told us she might. There are different degrees of spina bifida. She could have been very retarded. She might never have walked or been able to sit. This is all like a miracle. It's unbelievable," said Maureen.

The Fabiszewskis have struggled to improve the sensitivity of educators and other people who meet Maryhelen. Teachers were unaware, for example, how mortified Maryhelen was when they escorted her and required her to sit in a chair on the stage for a singing performance while the others walked on and sang in place. "She could walk and stand," said Maureen. "There's no need to make her look or feel different."

Parents of children with disabilities need to love their children, to learn all they can about their treatments, and to be advocates for them. The Fabiszewskis have had support from the Spina Bifida Association of Massachusetts, Children's Hospital, Harvard Community Health Plan and a strong extended family, but even in the midst of Maureen 's recent bout with cancer, she said she struggled to teach Maryhelen about catheterizing herself. "I didn't want to die and leave it to someone else. I'm her mother. I should be the one teaching her."

"I only have a 12th grade education, but I love her so much. God hasn't blessed us with other children. John and I feel we are going to learn everything and do everything we can to help Maryhelen, " said Maureen. "All parents need to do this for their children."

Resident/staff relationships add meaning to long term care

Condensed from an article by Melissa Cole and Bob Marek of Mayflower Pediatric Social Services

Sometimes people who work in healthcare settings can become "numb" to clients or residents and not view them as people. Staff members often need to put distance between themselves and the person they are "caring" for because they fear forming an attachment to someone who may leave them or even die.

Gabrielle Gaudreau, director of recreation at Mayflower Nursing Home, helps Thomas LaRoche while nursing aide Christine Lyman steadies his swing.

However, the Department of Public Health requires that skilled nursing care facilities regularly assign the same personnel to care for a long term patient, setting the scene for beneficial relationships for those who choose to extend friendship beyond the clinical setting.

For staff, a relationship with a patient can improve job satisfaction, and increase feelings of pride and self worth. For a child the bond with a staff member can be a motivator, an encouragement and a support when challenges arise. Just knowing someone will share successes and failures can add meaning to life.

It becomes a source of comfort for family members to know that their relative is being cared for by someone who truly cares and has an interest in their well being. Family members feel more comfortable discussing personal issues with someone who is involved.

Tracey Packard, seated, enjoys a laugh with Melissa Cole, social worker, and Bob Marek, director of pediatric social services at Mayflower Nursing Home.

Caring is an aspect of a relationship that cannot be mandated, it can only be supported. It is important to remember that people need people.

N.E.P.C. aquatic program is a therapeutic and social experience

Disabilities float away at least once a week at New England Pediatric Care when residents glide into the indoor swimming pool for a two hour therapeutic and social swim.

The children, who have multiple disabilities and limited ability for independent movement, break into smiles and happy sounds as they trade their wheelchairs for the experience of floating, bouncing and whirling with the therapists, or even using flotation devices by themselves

"Movement through the water is soothing, almost a return to the womb environment," says Cristan Cassano, certified recreational therapist and aquatics director. "Most of the kids get excited when they know they are coming to the pool."

Breathing and feeding apparatus are protected from stray splashes, and a nurse or guardian is always present for the recreation. At least one staffer is in the pool for every 2.5 children, Cristan said.

"After even a short time in the pool we can see the improvement the warm water and movement works on range of motion (tense muscles)," the aquatics director explained. "We also try to work on other therapy goals, encouraging speech during a game, for instance."

Nancy Hawkins, director of rehabilitation at N.E.P.C. adds that the classes and family swim times create socialization opportunities and add fun to children's lives.

Aquatics instructor Cristan Cassano gives a water ride to Sonia Throwe, a resident at New England Pediatric Care.