Volume 4
Issue 1
November 1997

H.A.L.O. Reports

A Publication from the Help A Little One Foundation

HALO
HELP A LITTLE ONE

INSIDE . . .

Founder's message

Some days everyone cries

At the end of the summer, our family was enjoying time at the seaside in Mattapoisett, Massachusetts. The day I have in mind was cold and gray and windy.

Our daughter Sarah had traveled almost three hours from her nursing home in North Billerica to the coast accompanied by Steve, her nurse. This afternoon she sat by the open door, listening intently to waves roll onto the beach just steps from the house. Daniel and Julia, our other children, were tramping about with the other "summer" kids. Gayle and I were relaxing. It was very much a family day.

When the time came for Sarah to go, it took two of us to get her into her wheelchair. Sarah stiffened and screamed and screamed. We were all in tears. It was good to know she loves being with us, but it was heart-wrenching for us all, even her nurse, to send her back to New England Pediatric Care, her home for a little over five years now.

Some days more than others, it is very difficult to accept that we cannot care for our brain-damaged daughter by ourselves. We force ourselves to find solace in knowing that an efficient and attentive staff cares for Sarah, and our friends and family care about us.

We make an effort to do something positive through the Help A Little One Foundation, bringing small comforts to those children who are wards of the state, or whose families live so far away they cannot share the happy moments or the difficult ones.

Whatever holidays you celebrate, where ever you happen to travel this coming season, we hope you will pause to share a little happiness with care-worn friends or strangers. Kind thoughts and warm smiles multiply in proportion to the giver's good intentions.

Best wishes and thank you, as always, for your support.

Sincerely yours,

Alan Pinshaw

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LifeLinks is tearing down the walls for long-time residents

What if you moved into a house at an early age, and rarely left the yard for the rest of your life?

Pediatric chronic care *used to* mean meals, school, therapy, medical treatment and personal care —such as haircuts — within the same four walls, for a long time, if not forever. Occasionally, there were forays into the community, but few relationships were forged, social contact was irregular, and the unfamiliar routines frightened or over-excited some residents.

Programs such as LifeLinks have changed all that, according to Joelle Barton, coordinator of the Young Adult Program for residents over 22 years of age at New England Pediatric Care (NEPC) in North Billerica, Massachusetts.

Every week day, a LifeLinks van transports ten NEPC residents (and soon more) to a center in North Chelmsford, Massachusetts, where residents "work" and interact with one another and people from outside the nursing home. Participants are the highest-functioning retarded 25 to 36-year-olds entitled to care at the nursing home. Due to their advanced age, they no longer qualify for state-funded educational programs that provided stimulation in younger years.

"Our goal is to have community integration, plus socializing and skill development," Joelle said of LifeLinks, which has been in place since April. "It is wonderful to be able to provide this opportunity."

The "workers" are divided into skill groups taught by paid staff, volunteers and community mentors. The day starts about 8:30 a.m. when the process of loading wheelchairs starts outside NEPC's front door, and ends about 2:30 p.m. Each resident follows a personal schedule organized around his/her Individual Service Plan, which is mandated by the state. Activities include: cooking, sign language, personal care or animal care — a very popular part of the day.

"When residents work on money sorting or stocking shelves, they are actually improving sensory, motor and cognitive skills," Joelle said. "Eating lunch is an opportunity for peer socialization. Every activity is part of the process of "normalization" — helping the residents function as close as possible to life in the larger community."

LifeLinks is funded in part by the Massachusetts Department of Mental Retardation and through Medicaid. The staff/resident ratio is 2/1. NEPC has an excellent 3/1 ratio, but LifeLinks provides much-needed diversion, said Joelle.

Evaluation of the success of the program is easy because participants, though mostly non-verbal, use their eyes, hand signals, smile or other body language to communicate their enthusiasm and willingness to learn.

"They get upset if they have to miss a day to go to a doctor appointment," she said. "All the residents definitely have ways to let us know if they don't like something." As always, approval for participation must be obtained from families or guardians.

One of the few snags caused by LifeLinks has been the loneliness of residents left behind.

"Now many of their friends are disappearing for a good part of the day. We are working to find additional opportunities for all the young adults at NEPC," Joelle said.

In some cases, LifeLinks and NEPC had to coordinate complicated Individual Service Plans to meet the needs of the individual residents. The only other noticeable side effect has been simple tiredness, according to Joelle. Residents snatch quick naps "but it's definitely more activity than they are used to. It's a good tired, however. It's how we feel when we go home at the end of the day."

A gift from the H.A.L.O. Foundation made it possible to purchase duplicate equipment for the young adults to ease their transition to the LifeLinks program.

Pediatric nursing homes working together

Pediatric nursing homes in New England have created an administrators' networking group which greatly benefits programming for the children in their facilities.

"We are working together to provide the best treatment and service models for all our residents," said Ellen O'Gorman, Director of New England Pediatric Care (NEPC), in N. Billerica, Massachusetts. "We are watching activity in the various legislative and regulatory bodies, and we are also learning from each other's experience.

The administrators have been meeting every other month, often joined by nursing, rehabilitation, social work or educational directors, in conjunction with topics on the announced agendas.

Agenda topics have included:

- Tours of the seven member facilities
- Program descriptions of each facility
- Comparison of personnel policies
- Comparison of numerous clinical policies
- Hiring issues, particularly shortages of qualified staff
- Regulation interpretation
- Family work
- Admission process for children (Massachusetts facilities only)
- Medicaid reimbursement and insurance/HMO issues
- Survey process and results; accreditation
- Vendors: exchange of information, possibility of consolidation
- Involvement in state/federal advocacy agencies, for instance the Massachusetts Extended Care Federation
- Sharing of professional development and continuing education seminars and conference information

The group is planning a leadership training session for late November, and an update of a Guide to Pediatric Nursing Homes. Representatives attended the first annual conference on "Care of the Medically Fragile Child" held in Portland, Oregon in September and shared information with the other administrators in the group.

Members of the New England Pediatric Nursing Group are: NEPC, Children's Extended Care Center, Northampton Nursing Home and Mayflower Pediatric Center, all in Massachusetts; Crotched Mountain (Greenfield,NH), Cedarcrest (Keene, NH) and the Tavares Center (Providence, RI).

Cynthia Krumme chronicles 'awesome burdens' of medical decisions

Catherine Krumme dreamed of having hot chocolate on the Champs de L'Elysee while she was being treated for leukemia. Eventually she did. Pictured in France, from left, are: brother Matt, Catherine, and her parents, David and Cynthia Krumme.

Cynthia Krumme started a journal on September 26, 1980, when her four-year-old daughter Catherine was at the beginning of her battle with leukemia.

At the end, she turned those reflections into a book, Having Leukemia Isn't So Bad/ Of course it wouldn't be my first choice. It's a story of hope, because Catherine is now completing her senior year at Colorado College.

Cynthia Krumme

"I wrote the book because I couldn't find a single book or story of survival at the time Catherine was diagnosed," said Cynthia. "I never thought she wouldn't be cured, but I desperately wanted to know a survivor; to get a full view of what she would look like at 20."

It is also a story of finding ways to maintain control, manage loneliness, function in daily life, and live with guilt over choices made, or not made. These are issues any family might face when a child has a serious illness or disability, said Cynthia in an interview.

"Catherine, even at four, was able to understand a lot, and we made sure she was educated and advised on all procedures, except when there was an emergency."

"It is the ultimate indignity not to know the long term prognosis and to have to ask your child to do extremely difficult things," Cynthia said. "We tried to give her control when we could. She dreaded spinal taps, and after a particularly difficult one she told the team 'don't hold me down.' She promised to curl her spine and not move if they would let her sit for the procedure. After that they never held her down."

The clinic personnel — especially a nurse named Sue — became like family. The Krummes had moved from Berkeley, California to Winchester, Massachusetts only a year and half before the diagnosis; their parents and siblings were scattered across the country.

"We found New England somewhat lonely," Cynthia said. A few close friends gave them "incredible" support, especially taking care of Matt, who was six when it all started.

"When you have a child who is very sick, you tend to view your other child as healthy, but we knew Matt needed attention, too," said Cynthia. She recalled her shock when Matt developed osteomyletis in his leg at age 14. He was hospitalized and treated with powerful antibiotics for 21 days to save his leg.

"But I'm the sick one, Catherine told us. I guess we all viewed it that way," Cynthia said.

Despite having a "sick child," Cynthia and her husband David, a professor at Tufts University, were determined that the family get the most from every day.

Catherine went to preschool, and missed elementary school only when reactions to the noxious chemicals were overwhelming, or when she was hospitalized, or chicken pox contagion threatened her compromised immune system.

She played soccer regularly on the in-town team. The Krummes continued to travel widely, convincing doctors to accommodate their adventures in the treatment schedule.

"We didn't want Catherine to feel she had missed anything," Cynthia said. "She was tired after the traveling, but we felt it was worth it."

In the '60s few children beat leukemia; by the '80s the survival rate was about 50%. But a relapse — which Catherine had at the very end of her treatment — significantly. reduced the survival rate at that time. (Today more than 70% of children survive.)

Bleak didn't begin to describe the day after Catherine's last spinal tap in the three-year course of treatment.

"They found just seven blasts in the spinal fluid, but even one was bad," said Cynthia. "The relapse was a larger shock than the diagnosis."

The second three years of treatment were more invasive. The first time, there was a round of heavy treatment in the hospital, followed by

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". . . I'm the sick one!"

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clinic treatment and eventually the Krummes administered chemo at home. After the relapse, a very strict "St. Jude's" protocol was selected. It included cranial and spinal radiation to kill hidden cells.

"If just one cancer cell finds sanctuary in the brain or bones it can be devastating," Cynthia explained. "With acute lymphocytic leukemia cells multiply in geometric progression."

Treatment demanded more of Catherine's internal resources. She felt ill more often. She had a violent reaction to one of the chemicals used, and the spectre of death hung over the family as they relived in their minds the losses many of their clinic friends had suffered.

"I believe in your last moments, something gets through, nice smells, pleasant thoughts, a hug, a presence," said Cynthia of those desperate hours.

Doctors outline programs of treatment and sometimes make recommendations, but ultimately, the final responsibility for choosing a course of action rests on the parents' shoulders, Cynthia said.

"The burden of making medical decisions is awesome when you have a sick child," said Cynthia. "Families who might be touched by the H.A.L.O. Foundation probably second guess some of their decisions, as we did."

Leukemia had an impact on everyone in the Krumme family. Matt, now a 23-year-old law student at Cornell, is still very close to Catherine. Cynthia said she and David probably have a greater appreciation of life in general and are grateful not to have to think about illness any more.

"It's impossible to have such a significant life event not have an impact on your life," Cynthia said. She attributes Catherine's great ability to concentrate on her studies to the character she developed in cancer treatment. "She always had a feisty personality. Who knows what she would have been like if she didn't have cancer?"

Siblings reflect on Sarah

Daniel Pinshaw, 13, was just seven years old when his baby sister Sarah, became ill. Recently, he shared some thoughts:

"Usually we see Sarah in the lobby (of the nursing home.) If it's warm we go outside, and wheel her chair around the building. Mom or Dad always take her out of her wheel chair and hold her.

Daniel

I tell Sarah whatever has been happening in the last few days. Sometimes I get a book from her room and read to her. When Sarah hears my voice she sometimes tries to look at me.

If Sarah's happy, she doesn't cry. If she's tired she just falls asleep. She seems happy after she gets food. She used to like to eat yogurt or soft food, but not lately.

I guess I am kind of accepting of what happened. I was young and didn't really know much about what was going on. I don't usually tell people about Sarah, so not all my friends know because I go to a different school now. If friends from before ask about Sarah, I tell them."

Julia Pinshaw, 16, is thoughtful and pragmatic about her relationship with her sister:

"I'd like to say I visit Sarah every two weeks, but that's stretching it a bit. I go to school six days a week and have a heavy schedule.

Julia

When I do visit, I discuss how things are going, just as I would talk to anyone I haven't seen in a while. Sometimes when we leave she starts to cry. I try not to feel bad because I know I can always come back and see Sarah, and she knows we will come back. I think it's different for my mother. She cries sometimes.

I don't mind the long ride to visit Sarah, because if she were at home, if she lived here, I'd make time for her. I keep things as normal as possible. I'm really open about Sarah. I told everyone; all my good friends have seen her and know her. She's part of my life.

It was the six-year anniversary (of Sarah's illness and brain damage) recently. I've accepted that this is how it is going to be. People ask sometimes if I went through a questioning period: Why is this happening to us? Is it going to happen to me? I guess I feel that things have taken their own course, and we have to move on."

President Clinton salutes H.A.L.O.

The H.A.L.O. foundation recently received the following letter from President Bill Clinton:

"Congratulations for being nominated for the 1997 President's Service Award.

"Although you were not chosen as an award recipient this year, being nominated for the award is an honor, and I commend you for your outstanding efforts. It is through service like yours that we will solve our country's most critical problems. Your exemplary service benefits the nation, building the spirit of community and the ethic of helping those in need.

On behalf of all Americans, thank you for your commitment and dedication."