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H.A.L.O. Reports

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HALO
HELP A LITTLE ONE

A Foundation for Neurologically Impaired Children

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Dear Friends,

Snow squalls surprised New Englanders on the Sunday before Halloween this year. The sudden flurry of wet crystals hit splat on the ground, but didn't amount to much. Yet this unexpected taste of the upcoming winter season sent us a cold reminder of how suddenly warm, happy breezes can send chills through our complacent lives.

The family is the primary buffer against life's unfair moments. Husband and wife comfort one another in the face of disappointment and sorrow. They make things right for their children. The family stands together, no matter that the job was lost, the home burned down or the grandparent passed on. We nurture hope that together we can survive anything.

However, the family dynamic suffers when a child inexplicably becomes ill, his or her brain doesn't work, and it can't be fixed. There is blame and guilt, tiring physical care, and ceaseless emotional stress.

The Help a Little One Foundation has gradually widened its circle to encompass not only toys for children who have neurological impairments, but moral and practical support for their families. We observe these families cuddling their kids at New England Pediatric Care, Children's Extended Day, Cedarcrest, Mayflower or Northampton pediatric homes. We see them beam encouragement to children struggling to walk or communicate or just smile back at them. These families have moved through different stages—denial, mourning, anger and shock— with little preparation for future stress. They expected chicken pox, or maybe a broken arm or scraped knee, not this. Acceptance comes last, and hardest.

A year ago the H.A.L.O. board agreed that supporting the family is important to supporting the child. Our Family Circle programs are mushrooming beyond expectations. We have touched the nerve center

We hope you will continue to support H.A.L.O. in this endeavor. Thank you and best wishes for the holiday season.

Sincerely yours,

Alan and Gayle Pinshaw

A Foundation for Neurologically Impaired Children

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Cedarcrest responds to community need for short-term stays

KEENE, NH - Cedarcrest, a not-for-profit specialized medical facility and home for children with disabilities, has come nearly full circle since 1947 when its two founders agreed to provide care to a local family's child.

Founders Dorothy "Dot" Sawyer and Eleanor "Clemmie" Clement set out to help a neighbor, and today Cedarcrest is continuing that tradition by reaching out to families who care for children with special medical needs at home. A few years ago Cedarcrest began admitting children on a short-term basis. Today demand for the service is high. Ten children have stayed at Cedarcrest since July 1 of this year.

The idea of a home and school for a small number of children with disabilities was a radical concept back in 1947, but support within Northern New England has grown tremendously. By 1990 the medical needs of the children had advanced to a degree that the children at Cedarcrest required more complex medical equipment. A facility to meet those needs was built on Maple Avenue in Keene, NH.

Since it's early years, Cedarcrest has purposely limited its number of beds to 26 in order to provide its hallmark "caring touch" quality care for all the children within a home-like atmosphere.

Services at Cedarcrest include post-operative care, long-term care and comprehensive evaluations, as well as assistance with feeding disorders and conditions such as failure to thrive. The staff supports young residents (newborn to 16 years old) so they might one day be able to transition back to their families and communities.

Through the decades, Cedarcrest Inc. and Cedarcrest Foundation, Inc. volunteer Boards of Trustees have continued to recognize the challenges facing families with children who have disabilities. In 1998, Cedarcrest Foundation — which manages fund raising efforts for the home, and supports the broader mission of education and training of individuals working with children with multiple disabilities — brought staff members, trustees and community "stakeholders" together in a "Future Search" planning effort.

"Future Search" examined healthcare and special education changes over the past decade, and found that medical technology had improved the survival rate of medically fragile children, and that many more families were caring for them at home.

In 1999, Cedarcrest adopted new goals arising from the discussions. These included offering families the option to have their children stay at Cedarcrest for a short term visit, when they faced a gap in home based medical care

Access to 24-Hour Care

"Clearly, one of the biggest challenges facing families was responding to the demands of caregivers at home. Families needed a short term option," said Patty Farmer, Director of Development and Community Relations.

"Our research and discussions identified many families who have great difficulty obtaining consistent 24-hour in-home medical services, especially in the more sparsely populated New Hampshire and Vermont service area. When faced with overwhelming health or personal crises involving their child or another family member, families had no near-by place to turn." she said.

CEDARCREST

Cedarcrest developed procedures for admitting short term stays to fill this crucial service gap. Twenty-five beds are reserved for the children requiring longer-term care, but a 26th bed is held open in case a family is faced with a medical care crisis.

"Stays can range from 2 to 3 days up to 3 months. Beyond one month, more extensive evaluations are required by state agencies and Medicaid," according to Margaret "Peg" Knox, R.N., Director of Nursing Services.

Criteria Carefully Weighed

"Short term admission is more complicated than you might think," said Peg, who makes the admission decisions with Executive Director Cathy Gray, Medical Director Jan McGonagle, M.D. and Mary Priest, head of Social Services.

Cedarcrest offers 24-hour skilled nursing, physician services,

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Short stays offered

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therapists, an on-site State of New Hampshire-approved school and social activities. Administrators must evaluate the impact each short term child might have on care for other residents.

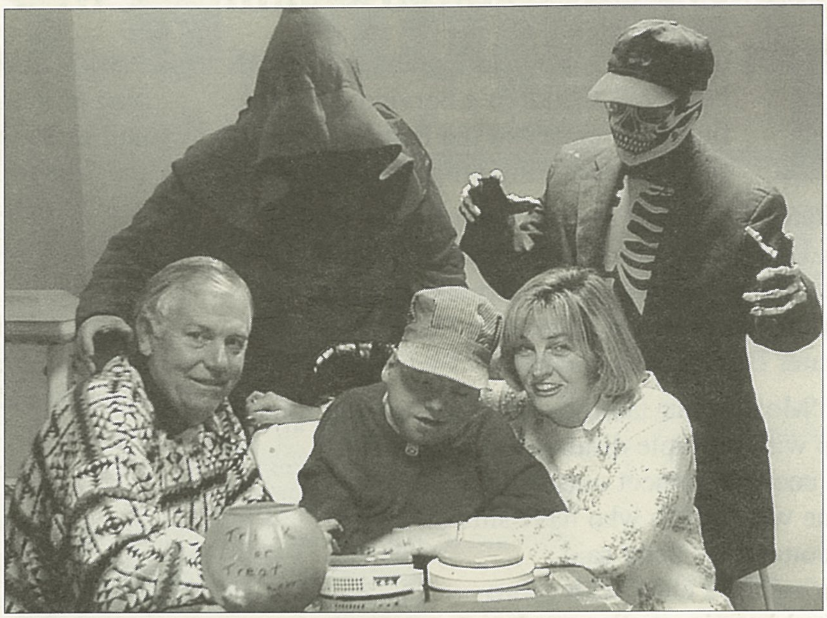
"To transition the child to Cedarcrest smoothly I need to know a child's complete medical history, review the list of medications and therapies required and we have to plan for appropriate nursing coverage. In some cases that means we have had to provide a specialized care in-service for our staff on the particular equipment or treatment in order to provide the best quality of care for a child," said Peg Knox.

Other factors involved in short-term admissions include whether specific equipment is available, whether the child has a contagious disease, and the child's unique requirements. For instance, Cedarcrest does not accept children for long or short term if their condition requires the use of a ventilator.

In an effort to stay ahead of the needs of families with children who have complex medical and developmental needs Cedarcrest is constantly striving to anticipate and complement the care of parents, physicians, nurses and therapists.

"We are hoping that this kind of service allows children to remain at home and in their communities for the majority of the time. When there is a gap in the availability of in-home medical care, we can be an option to support the children and their families," said Cathy Gray, Executive Director.

For more information about Cedarcrest, visit their website at www.cedarcrest4kids.org.



Children enjoy N.E.P.C. haunted house

(Above) The Stewart family gets spooked at the annual New England Pediatric Care Halloween Party and Haunted House. Residents, siblings and the children of staff members enjoyed the festivities on October 30th.

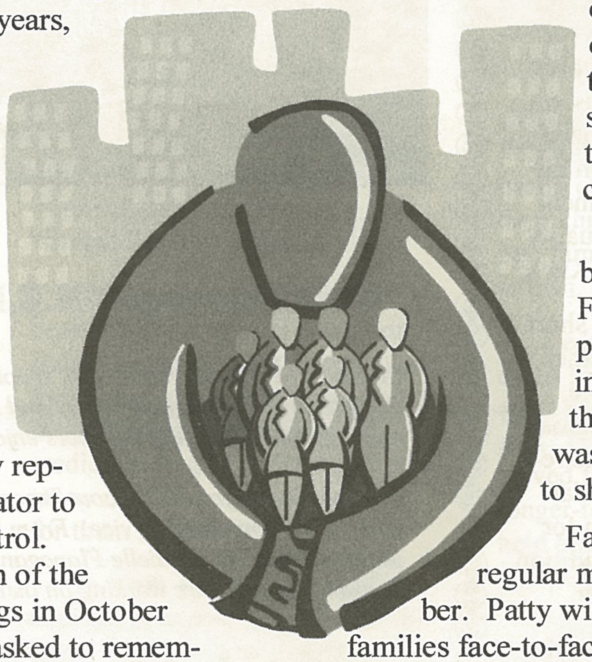
(Below) Chelmsford Girl Scout Troop 992 staffed the game booths at the party as a community service. From left: Danielle Robbins, Emily Cue, Meghan Westcott, Danielle Flanagan, Amanda Lucas and Krystle Brown. The girls are working on their Leadership badge.

H.A.L.O., JF&CS mark Family Circle's first anniversary

The HA.L.O. Foundation and the Jewish Family & Children's Service mark the first anniversary of the Family Circle support/mentoring program this month..

Patty Reardon, Program Coordinator for the H.A.L.O.-funded project, proudly reports that the partnership has provided information, social connection and practical support to 59 families in the Greater Boston area to date.

"Most of our families have been caring for children with multiple disabilities for years, and need to connect outside the home with others who have similar concerns," Patty said. "Caring for a child with neurological impairment is very intense; parents don't have a lot of time. I try to make each gathering as useful as possible."



The latest project is *Parent Journey*—a nurturing program for parents. Funded by a grant, *Parent Journey* brought 12 family representatives together with a facilitator to learn self reflection and stress control. There was a different focus at each of the eight consecutive weekly gatherings in October and November: Parents might be asked to remember their childhoods at one meeting, and to learn how to relax at another. Weekly rituals were repeated to reinforce self esteem. How did you nurture yourself this week? the parents were asked. What did you handle well this week?

"It's an opportunity for parents to sit down and take care of themselves," said Patty. "We serve them dinner — it's rare they get waited on — and help them set personal goals, for instance. We would have liked both spouses to attend together but it was pretty impossible for them."

Patty has compiled a confidential Parent Directory which lists families by name, address and telephone number, and provides a brief account of their child's challenges. Families who submit an entry can contact any other family in the book and share their experiences. Another valuable tool is Patty's Resource Directory where she files magazine articles, adaptive equipment ads, parent tips, and website information. "Many parents don't have the time to sift through the many resources available to them, so I keep finding information for them. We don't have our own website yet, but this connection is also blossoming," Patty said.

In July Family Circle sponsored an evening dinner and comedy event that brought together seven couples and three single parents to enjoy a carefree evening. Family Circle even paid for the babysitting. Some of the parents said they had not been out together in years, and are clamoring for more events.

In August families brought their children to the Family Circle office to experience music therapy and introduce their children to their new friends. The event was also another opportunity to share and support each other.

Family Circle will return to regular monthly meetings in December. Patty will continue to meet with families face-to-face on their turf, if they live too far to attend the meetings at Family Circle's offices in Norwood, MA.

"This is a wonderfully rewarding position," Patty said. "I'm getting the word out through 53 referring agencies, but I still worry that we aren't reaching everyone."

Of late, Patty is using her skills to evaluate respite centers that have come to her attention. A respite center is staffed and equipped to "baby-sit" a child who has special medical or developmental needs. Patty is also attending workshops to bring back new information to busy parents. Recent topics have been "Sexuality for the very involved child" and "Pain management therapy."

Contact Patty Reardon at (781) 551-040.