

# H.A.L.O. Reports

*A Publication from the Help A Little One Foundation*



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### Founder's message

## **H.A.L.O. broadens its mission**

Dear Friends,

**R**ecently, board members spent time reviewing and evaluating the mission of the Help A Little One Foundation. H.A.L.O. was founded in 1993 following the devastating neurological illness of our youngest child, Sarah, to provide toys and home comforts to children with neurological impairment.

Early on, most of the children we supported lived in the rather austere environment of pediatric nursing homes, where the medical and support staffs were - and still remain - dedicated and attentive to their needs. Our original mission is still being carried out successfully. The children are well stocked with teddy bears and holiday gifts and other accoutrements. Requests for adaptive tricycles and similar specialty items continue to be fulfilled, as do other needs, for instance donations toward the purchase of a fully-equipped wheelchair van (see page 3) or occasional transportation subsidies to bring families together for special events, or even "field trips" to broaden the experiences of the children.

Last year H.A.L.O. teamed up with the Jewish Family and Children's Service to provide non-denominational support to families who have a child with neurological impairment.

Program coordinator Patty Reardon has reported on the first cycle of the Family Circle mentoring program (see page 2). These positive beginnings inspired the board to review another outreach proposal — a Family Support Program proposed by the Neonatal Intensive Care Unit at Boston's Beth Israel-Deaconess Medical Center. If a team of medical and social work professionals is able to obtain matching funds, H.A.L.O. has pledged support for the portion of the program mentoring families with neurologically impaired newborns.

Please send us your suggestions. We look forward to your input. As always, we are grateful and indebted to you for your continued generosity and moral support.

Sincerely yours,

*Alan and Gayle Pinshaw*

### *A Foundation for Neurologically Impaired Children*

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## *Family Circle is building bridges with 47 families*

**T**he Family Circle mentoring program supported by the Help a Little One Foundation focused its first six months on identifying parents of children experiencing neurological impairment.

Patty Reardon, program coordinator, reports that 47 families whose children have multiple disabilities, including neurological impairment, have signed on to share their experiences and be trained as mentors to other families facing similar challenges.

While privacy issues restrict access to patient information, Family Circle has built bridges to and continues to receive referrals from social service agencies, schools, advisory groups, hospitals, doctors and nurses, special educators and other groups.

H.A.L.O. joined forces with the Jewish Family and Children's Service (JF&CS) to create and fund Family Circle. To date, Family Circle has provided a monthly meeting place in the Norwood JF&CS building and brought together an average of 5 to 10 families to participate at seven group meetings so far.

Family Circle reaches out to families throughout Eastern Massachusetts. The demands of caring for children with multiple disabilities are recognized, so Family Circle maintains contact with families by mail, email and telephone. Once the program establishes a track record and



Patty Reardon, Program Coordinator

can accommodate larger numbers of families, additional locations will be considered.

Patty is conducting face-to-face interviews with each of the families. She has met with more than half the volunteers so far. The next cycle will involve training and matching families.

"No two children and no two families are exactly alike, but there are many similar issues, and methods and strategies that parents can impart to one another," said Patty.

The H.A.L.O. grant makes it possible to provide the training sessions and continuing support at no cost to any of the families. Family Circle will also provide funding for respite care so that families can attend the workshops and meet with each other more easily.

"Many parents become housebound by the pressures of care for a child with involved needs. It is our hope that the

mentoring program would provide those parents with an opportunity to share their expertise and experience with another family outside the home," Patty said.

Also in the works is a parent to parent directory. Listings will be shared only with Family Circle participants, and are strictly voluntary. Families can include as much or as little information as they wish to share. Some categories parents find helpful in looking for support include: community where they reside, age of child, age of siblings, types of neurological challenges faced, and so forth.

Family Circle plans additional workshops and speakers in the fall. Fifty-four agencies continue to refer families, and Patty plans to address the needs of as many as possible.

Originally Family Circle targeted the families of children in the 3 to 18 year-old age range. However, families with newborns and young adults have also expressed interest, so the range was expanded to birth to 28+ years.

The partnerships are evolving, and Patty finds that one family can both be a mentor, yet need a mentor to hear new issues, or old ones raised by the partnership.

If you or someone you know is interested in finding out more about Family Circle programs, please contact Patty Reardon at (781) 551-0405.



## *The Sniders' dream car has room for wheelchairs and people*

**J**oAnne Snider's dream car isn't a sporty red convertible, or a luxurious Lexus, or even a trendy Sports Utility Vehicle (SUV). JoAnne's wish come true is a fully equipped van to transport her twin sons and nine-and-a-half year old daughter to doctor appointments, lessons and activities

There are plenty of those doctor appointments. Both Samuel and Maxwell have multiple medical issues, including cerebral palsy, frequent seizures, and G (gastro-intestinal)-tubes for feeding. Both twins are also blind.

"Doctors told me we were facing long term wheelchair use if the boys were unable to raise their heads by one-and-a-half years," JoAnne said.

The 33-year-old mother of three has learned to take her children's challenges in stride, and makes a career of advocating for them. JoAnne learned to give injections and how to give medication via g-tube—the twins require it 14 times a day. She also administers oxygen for respiratory problems, and suctions mucus from their breathing passages so often it seems routine to her.

Before Max and Sam were born, the Sniders coped with a high risk pregnancy and a lengthy pre-natal hospitalization. They endured a five-month separation from the babies, making daily visits to Massachusetts General Hospital in Boston while the doctors and nurses coaxed the twins up to term weight. The boys made a premature entrance into the world on July 25, 1997, just 26 weeks into the pregnancy. They weighed less than two pounds each!

JoAnne said one of the most difficult parts of this experience has been the family's loss of privacy.

The Sniders had to open their



JoAnne Snider and daughter Alexandria load Max and Sam into the new van H.A.L.O. helped buy.

lives to private duty nurses 16 hours a day in order to bring, and keep, Sam and Max at home. (JoAnne takes on the evening shift herself while husband Neal, 37, works second shift for an electronics manufacturer. Sometimes that means calling a neighbor to stay with Alex during a midnight crisis.)

"It's scary. Anything can happen," said JoAnne. "But you get used to it."

The family might as well have a revolving door to accommodate the parade of special education teachers, physical therapists, nurses, friends and family who provide services and respite. Of course Alex's friends are in and out, too, but they seem almost immune to the constant traffic.

Alex was one of the reasons the Sniders sought help buying the van. "I couldn't fit everyone in the car anymore," JoAnne said. "She was missing activities like gymnastics, dance and birthday parties."

The family sorely needed a vehicle that could seat them all. They

also needed space for oxygen tanks, locks to hold the wheelchairs in place, and a cargo area not only for Max and Sam's gear, but also Alex's.

"I am determined that Alex will have as normal a life as possible," JoAnne said. "We don't want her brothers to hold her back."

The Sniders had been determined to handle most challenges by themselves, but agreed to ask for help when they learned the van's cost.

The family told their story to the Lawrence Eagle Tribune and the Boston Globe. A torrent of moral support and money followed. A local DJ donated his services for the fundraiser. Businesses provided items for the silent auction. Hotel and chef services were made available at no charge.

Hundreds of people in the Lawrence, Massachusetts area opened their wallets to give a total of \$15,000 at the dance organized by JoAnne's sister Susan McCusker.

*(Continued on the next page)*



## Teenagers donate charity concert proceeds to H.A.L.O.

**S**ix young men with musical ability, dreams and lots of drive organized a charity concert this past March, making the H.A.L.O. Foundation the major beneficiary.

Hal Savar, singer, songwriter, musician and founder of the fledgling band *Prophet*, said he was looking for a venue for his band, and "if it was for a good cause, all the better."

Serendipity and a local music shop connected *Prophet's* lead guitarist, Karl Hendrickson of Framingham High School, with Daniel Pinshaw, a student at St. Mark's High School in Southborough, Massachusetts.

When Daniel, a drummer, joined the band, he mentioned his sister Sarah, who is neurologically-impaired and the inspiration for his parents' Help A Little One foundation. *Prophet* decided to help H.A.L.O. support kids and families dealing with neurological impairment.

The other members of *Prophet* are keyboard player Neil Saber, rhythm guitarist Sam Kornstein, and base player Kyle Hendrickson, all of Framingham High.

*Prophet* had only played a couple of private house parties until Christmas time 1999, when Hal asked music theory teacher George Perrone for help in booking a public performance. Before anyone could say "millennium," they had a New Years Eve gig at a local art museum. They distributed 500 flyers to teens in the area, and things snowballed from there. *Prophet* moved on to paying jobs at St. Marks, a local nursing home and a synagogue party.

"I had an idea about a concert a long time ago, but truthfully, I just wanted to play in an auditorium,"



Prophet band members

said Hal, the force behind the fundraiser. "I included some other bands from my high school because I understand how much they love to play, and it gave them an opportunity to perform. Also, the more bands, the more friends and family members who might come."

The teenagers reserved the Framingham High auditorium, posted notices about the charity event, and had it announced on the student cable TV news show. More than 200 paying customers rocked to the

sounds of alternative band *Access Denied*, blues band *Premiere* and the ten-piece swing band *Three Cent Thrill* on March 10th. *Prophet* headlined the three-and-a-half hour show.

The boys raised nearly \$1000 for H.A.L.O. and also gave funds to a local food pantry.

Graduation, summer plans and jobs have put a question mark in the band's future together, but Hal summed it up on a positive note: "We had a lot of fun."

## H.A.L.O. helps the Sniders get a van

(Continued from previous page)

The remainder was funded by two large donors, H.A.L.O., and friends and family.

"People have really come through for us," JoAnne said. "We are so grateful to everyone, including the H.A.L.O. Foundation, for making this possible."

"I've had to put my pride aside to make sure my children get what they need. It was worth it."

JoAnne has shared her fundraising

notes with other parents, including a group at Perkins School for the Blind, where she has found moral support.

When she isn't caring for the children, she researches lower drug prices (one prescription from Canada costs about \$300 a month) on the internet, processes many insurance claims, schedules and goes to numerous doctor appointments and buys supplies.

And she drives a shiny, new van.