

FALL 2009

HALO HELP A LITTLE ON













H.A.L.O. Reports

Serving Children With Neurological Impairment Since 1993

Volunteer Is 'Not Afraid to Love' Fragile Kids

bout a year ago
Kristene Whitehouse
read that a pediatric
nursing home was seeking
donations to buy a gait
trainer for a child with
disabilities.

She didn't have extra money, so she volunteered to make an afghan for a raffle. That's how she connected with New England Pediatric Care, a skilled nursing facility for children with complex medical issues.

Kristene started spending a few hours here and there at NEPC; now she helps out regularly in the special education day school.

"I just love being with the kids. I have a rare syndrome and birth defects, not life altering, but after surgery in my 20s I developed cardiac



Kristene Whitehouse enjoys a laugh at New England Pediatric Care.

problems. I don t have the stamina to work all day, but spending time with the kids just makes my whole week," said Kristene. It's also a break from caring for her invalid mother, she said.

Mostly Kristene works oneon-one with individual children in the classrooms. She also accompanies classes to the Boston Aquarium or Museum of Science and helps at holiday parties and events.

"Kristene understands that our kids work at a multisensory level. She brings tactile things from outside to

(Continued on page 3)

Family Circle Coordinator Is Adding Respite Staff

The new coordinator of H.A.L.O.'s Family Circle program started as a volunteer in the Newton Sunday Respite Program four years ago.

Sara Freedman, a 2008 graduate of Northwestern University's School of Education and Social Policy, plans no programmatic changes.

"In our most recent consumer survey, families who use the respite program reported 100% satisfaction," she said.

However, Sara is hiring additional

staff and seeking more volunteers to expand services at the Newton site to accommodate families transferring from the Stoughton respite program.

Jewish Family & Children's Services of Greater Boston, which manages Family Circle for HALO, recently discontinued services in Stoughton as part of fiscal belt tightening.

Family Circle offers low-cost social programming and support for families whose children have neurological impairment and other disabilities. Sara replaces Pat Ludwig, who retired earlier this year.

Call Sara at 781-647-5327 Ext. 4174 or email familycircle@halofoundation.org

Founder's Message

Welcome to the H.A.L.O. Team

ear Friends,

It takes a whole team of people to enhance the lives of children with severe disabilities. Families and friends are important members of the team, but many others contribute to the well being of our kids.

First and foremost are those who maintain their health — an especially tough job in this year's flu season. In this issue of $\underline{\text{H.A.L.O.}}$ Reports we are also featuring training programs that increase student nurses' awareness about children with neurological impairment and community outreach events organized by some of the nursing homes we support.

The new coordinator of H.A.L.O.'s Family Circle respite program is perpetually building and rebuilding teams of volunteers to interact with young people who are isolated because of their disabilities. Volunteers like Kristene Whitehouse provide social interaction that is very important to children who can't connect on their own.

Thank you for keeping children with neurological impairment in your thoughts. You, too, are part of our team.

Sincerely yours,

Alan Pinshaw

"Kidstock 2009" Drew in the NH Community

Forty years ago Woodstock rocked the nation.

Most of the staff at Cedarcrest Center for Children weren't old enough to take part in this legendary music extravaganza, but that didn't stop them from staging KidStock 2009 at the Keene, NH children's center.

Staff and volunteers helped residents tie-dye t-shirts, headbands and neckerchiefs to give the Big Day an authentic 1969 feel. Attendees could get love beads and "tattoos" at Abby's Tattoo Bus at the event.

Families and community members sang and danced enthusiastically and contributed to a Kidstock community art project.

Competition for the "best" tie-dye was so fierce that some people are already working on next year's outfits. Kidstock will be an annual

event. Visit www.cedarcrest4kids.org for information about Cedarcrest.

Efficiency: (i fish'nsee)

n. The ability to achieve a desired result without wasted energy or effort.

H.A.L.O. is transitioning to an E-mail newsletter to increase efficiency and reduce costs.

Please send an E-mail to info@halofoundation.org so that we can continue to keep you informed about people and programs that enhance the lives of children with neurological impairment.

Write SUBSCRIBE in the subject line. Thanks for your support.



Event organizer Chris Hadley on guitar and Cedarcrest Center CEO Cathy Gray kick off KidStock 2009

Students Nurses Learn How to Care for Non-Verbal Patients

Nursing schools are sending students to pediatric nursing homes to learn how to work with children who are medically fragile.

Over the past year New England Pediatric Care in Billerica, MA has hosted rotations for Salem State College, Northern Essex Community College, Bunker Hill Community College, Shawsheen Technical School and Greater Lowell Technical School in Massachusetts, and Rivier College and St Joseph's in New Hampshire.

"There aren't many clinical rotations where students can get experience with G-tubes and tracheostomies in a pediatric setting," says Cassie Fenlon, N.E.P.C. staff development coordinator. The 80-bed affiliate of Boston's Floating Hospital for Children provides skilled nursing, rehabilitation, therapeutic, recreation and special education services to children who have complex medical issues.

Sometimes students who are not acquainted with our population are overwhelmed by residents needs, said Cassie. "I tell them that after they spend some time here, they won't see residents' disabilities when they walk through our doors, the first thing they'll see will be their smiles. They often come back and tell me I was right."

Holly Bergeron, an instructor at Rivier College, brings groups of student nurses to N.E.P.C. for 8 week rotations.

"N.E.P.C. gives students a valuable opportunity to work with patients who can't verbalize discomfort."

Holly assigns each student to a weekly shift with a patient. Under her careful supervision, the students assist in daily care and learn to administer medication, suction, perform trach care and similar procedures.

Student nurse Katy
Baratta, from Rivier
College, recently
completed her rotation,
which she said was both
eye-opening and
rewarding. She spent a
12 hour shift (7 a.m. to 7
p.m.) with her patient
every Wednesday.

"It's important to treat these children as any one you would encounter walking down the street because that's such a meaningful benefit for them, she said.

Mary Whalen R.N., Director of Nursing said the nursing staff enjoys sharing their experience with the students and feel that residents also benefit greatly from the program.

For more information about N.E.P.C. call 978-667-5123 or visit www.nepediatriccare.org



A student and instructor from Northern Essex Community College work with a resident at New England Pediatric Care.

Volunteer: "Love Them for the Time You Have"

(Continued from page 1)

share and has great ideas," said Kim Stopper, the teacher she works with most often. "If am working with one child, she'll take a group and read a story or help them on the computers. She knows each child's goals and is able to document progress for the Individual Education Plans."

Last year Kristene brought an aunt to N.E.P.C.'s fall festival to see crafts

projects "her kids" were selling. The aunt was so charmed by the kids she bought all 10 ornaments.

"Aren't you afraid of loving them?" she asked. Kristene said "That's the point, you are supposed to love them for the time you have. None of us knows what's around the corner.

To volunteer at N.E.P.C., contact Laura Kirk at lkirk@nepediatriccare.org or call 508 667-5123.

Team Work Makes Radius Festival a Success

The first Fall Festival at Radius Pediatric Center in Plymouth MA was an opportunity for pediatric residents to experience an event just like any one else.

"It was a great team building exercise, too," said Beth Barton, Director of Pediatrics. "Each department — nursing, social services, therapists, education — enthusiastically took on a piece of the haunted house and it went off without a hitch."

The festival included



pony rides, magic, pumpkin carving, face painting and cookie decorating. The event was so successful, in bringing families together, Radius is planning to make it an annual event, Beth said.

For more information about Radius please visit http://radiushealthcarecenters.com/pediatric

Vaccinations Protect Residents From Flu

President Obama has declared the swine flu outbreak a national emergency.

Most healthy people will recover from the flu after a week, but young people between 6 months and 25 years, and people who are chronically ill or have compromised immune systems are at increased risk of dying from the H1N1 virus, according to the federal Centers for Disease Control (CDC).

Amy Stevens, Nurse Practitioner at Seven Hills Pediatric Center in Groton, MA reports that most states provide both flu vaccines free of charge to high risk groups, including children in long term care facilities.

"Vaccination for all residents and staff is the cornerstone of our influenza program," she said. "If we can get 85% vaccinated, then we should be able to protect the few who are unable or choose not to be vaccinated."

Long term care facilities follow established guidelines to deal with

influenza, said Amy. When a child at Seven Hills shows symptoms of an influenza-like illness the staff sets up a respiratory isolation buffer zone (3 feet) and observes precautionary measures including wearing gowns, gloves and face masks.

Staff members who have a fever are asked not to come to work. Public health protocol in Massachusetts requires health care workers to stay home a minimum of five days if they have the flu, said Amy, or be at least 24 hours without fever.

Seven Hills Pediatric Center is one of more than a thousand Sentinel Surveillance Sites that submit weekly reports to the CDC and state health agencies to track the spread of influenza.

For more information about vaccination and seasonal and H1N1 influenza, visit www.cdc.gov.

To learn more about Seven Hills Pediatric Center, visit http://www.sevenhills.org/affiliates/ clinicalResidOver.php. VOLUME 16, ISSUE 1 FALL 2009



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