



VOLUME 25  
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The Help A Little One Foundation

# H.A.L.O. Reports

Serving Children With Neurological Impairment Since 1993



SUMMER  
2019

## Sarah's Strength And Laughter Continue To Inspire Us



Sarah Pinshaw was three years old when she contracted meningitis in the fall of 1991. Complications from her illness resulted in permanent neurological impairment, including the loss of her ability to speak, walk and consistently control her body.

Sarah's eventual institutionalization inspired her parents to establish the Help A Little One (H.A.L.O.) Foundation to enhance quality of life for similar children living in pediatric nursing homes or with their families.



Sarah laughs with her sister Julia and revels in one-to-one float time with Mom in the pool at New England Pediatric Care where she lives and thrives.

(Continued on page 2)



## Volunteers Say: "You Quickly Realize We Are All Human"

Community members are warmly welcomed at Seven Hills Pediatric Center in Groton MA.

Their friendship and interaction with the children and young adults who live there is much appreciated, says Monica Kleeman, Activities Manager and Community Coordinator.

"We have a great group of 'regulars' right now," Monica said. "Their visits help dispel social isolation for our residents, who have complex medical needs and profound developmental delays."

Sisters **Heather Carroll** and **Lindsey Carroll** are rising seniors at Groton-Dunstable High School where they participate in Best Buddies, a program that facilitates friendships with individuals with disabilities.

After meeting Seven Hills residents

at the annual Groton Fest, they decided to visit with them.



Heather

"It's a different kind of relationship with someone who cannot communicate the way we do, but you quickly realize we are all human and can enjoy a good time," explained Heather, who plans to be a nurse. "I appreciate the residents for their love of life."



Lindsey

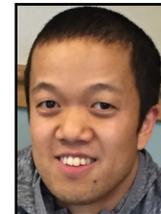
Lindsey says she really enjoys helping people, especially the elderly. She is exploring different careers and her experiences with the residents are helping her narrow down her

options.

"I am in the Service Learning class at school. Volunteering at Seven Hills has helped me understand how to engage with different people, she explained.

"It was challenging at first, but the more I visit, the more comfortable I feel and that makes me more confident in the outside world."

For her Service Learning project this year Lindsey ran a successful fundraiser to collect toiletries for the residents.



Ori

**Daniel "Ori" Aum**, graduated from university four years ago, and lives in Groton. He works as an art director and photographer for a creative agency and is in training in the sport of fencing. He previously

(Continued on page 2)



*Founder's Message*

## Our Legacy Is The Next Generation

**D**ear Friends,

*In Judaism there is something called L'dor Vador. Loosely translated it means that the generations fold over each other, and they also fold into each other.*

*Having recently become a grandfather I am now more keenly aware than ever that life truly is a continuum.*

*While we mortals tend to count corporeal days, what really matters is how we choose to live those days, and how we pass down those values to the next generation.*

*Ever since our daughter Sarah's illness, our family has been dedicated to the comfort and wellbeing of children living with similar disabilities. We strive to increase their visibility and participation in the mainstream of humanity.*

*H.A.L.O. is also Sarah's legacy, our kindnesses are performed in her honor.*

*Thank you to all who join us in this effort. You make our gifts and programs possible.*

Sincerely,

## Volunteering Feels Good And Gives Perspective

*(Continued from page 1)*

worked with students at Perkins School for the Blind.

"We usually have a central activity. As we fold origami or arrange flowers, I like to talk with the residents because it keeps them engaged," he explains. He also tries to reinforce their personal goals, i.e., making choices or sitting up.

Ori says he is a very reserved person, but he tries to be more extroverted because he has observed that residents' involvement increases with his level of enthusiasm.

Volunteering at Seven Hills gives him perspective on what is important, and it makes him feel good. "I get back ten-fold what I give."



Maddie

**Maddie Donahue** is a rising senior at Groton-Dunstable High, with a strong interest in the biomedical field. She has been doing arts and crafts with residents for almost a year.

"The community is really nice, everyone there is focused on making the residents happy and healthy. I love getting to know what makes each resident special."

One memorable episode was a bowling night when Christopher managed to knock down several pins. "We played Mary Poppins, his favorite song. The happiness in his eyes was so pure."



*A resident at Seven Hills Pediatric Center snuggles up with the quilt a Lawrence Academy student designed just for her.*

Community Coordinator Monica Kleeman mentioned that a variety of groups volunteer with residents. For instance, students from Lawrence Academy met with six residents, learned about their favorite things, then learned to sew, specifically to create personal quilts for them for this year's Winterim project.

Monica stresses that there is no mandatory schedule or commitment for volunteers. They take the initiative.

"Volunteers of all ages are spending time with our residents on *their* schedule because they want to be here."

For more information, email Monica at [mkleeman@sevenhills.org](mailto:mkleeman@sevenhills.org).

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## Sarah's Stable Health And Joie de Vive Continue To Inspire H.A.L.O.'s Work

*(Continued from page 1)*

Sarah is generally healthy, free of pain, responsive to their efforts, and she appears to be content.

Mom Gayle reports that Sarah loves sitting outside and listening to the birds. She speculates it might be a throwback to when she was a baby and she reveled

in the chirping of the family's parakeets in the kitchen.

Sarah also seems to enjoy listening to the music that her Dad plays for her, especially waltzes and marches with a strong beat. If she is especially motivated, she will "sing" along, too.

Gayle often reads stories to Sarah, and

reports that she seems to be listening. Other delights are "spa time" with her mother: manicures, facials and occasional haircuts. She also relishes the sensations of time in the pool.

Family members visit Sarah regularly and celebrate her joys and accomplishments, large and small.

# H.A.L.O.'s iPad Donation Sparks Technology Initiative At NEPC's School

**T**wo dynamic teachers are leading students and educators deeper into the digital mainstream at New England Pediatric Care 's day school near Boston.

Susan Lunt, M. Ed. EdS., and Lily Altshuler, MS. Ed., have been researching "apps," updating software and troubleshooting technology problems ever since the purchase of 12 new iPads kicked off a facility-wide technology initiative earlier this year.

"Thanks in large part to H.A.L.O. we have now replaced our outdated school equipment with the latest tablets. Having Bluetooth wireless capability and hardware that doesn't freeze up all the time is epic," said Director of Education Amy Gagnon, M.Ed.

Why is this revolutionary? At work, home and school people utilize their devices for communication, information and entertainment. Students at NEPC are just as fascinated, but accessibility is more challenging, say Lily and Susan.

"Like everyone else, the kids love looking at the screens. The teachers use colors, pictures and sound to motivate students to participate in learning using highly sensitive switches," Lily explained.

Lily's background is in behavior. She is enthusiastic about the variety of applications the staff can now use. For instance, learning about cause and effect can open up a new world for kids: click on this color and the lights go on; click on that shape to play music.

"It's pretty exciting for these individuals to be able to affect their environment. They can express their opinion, or demonstrate creativity, or communicate their needs in real time," she said.

The technology can also reinforce positive behaviors, Lily added.

Virtually all students at NEPC have some visual impairment. In addition to her special education certification, Susan has



*Special educators Susan Lunt, left, and Lily Altshuler help Kelvin use an iPad.*

worked with blind and deaf students, and has Cortical Visual Impairment certification. CVI is brain-based impairment, not vision-based.

"People with CVI can receive visual input, but their brains can't interpret the information," explained Susan. "Now it may be possible to assess *how* students see using different apps. In some cases we may be able to use other apps to change how the brain responds to visual stimuli by creating different responses."

Education Director Amy Gagnon, said the new iPads also:

- Create a more inclusive environment—there are more ways for students to communicate
- Equalize interactions with siblings, who can use devices with residents
- Facilitate better experiences for short term/respite residents
- Help individuals achieve IEP (Individual Education Plan) objectives
- Are used to document IEP progress

NEPC utilizes a consultant model across the facility. This means that the teachers collaborate with the physical, occupational, speech and rehabilitation

therapists to find solutions that work across disciplines.

As part of the technology initiative, Lily and Susan network with other special educators via on-line communities to find the most appropriate "apps" for different cognition levels. They share information with their peers, and even make up "cheat sheets" to make things user friendly for those less tech-savvy.

For more information on how NEPC uses iPads and "apps" at the school, contact [agagnon@nepc.org](mailto:agagnon@nepc.org).

## *We Help Individuals, Too*



*Dayana's Special Tomato Jogger, a modified stroller, enables her to enjoy the outdoors.*



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with Neurological  
Impairment**

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## Music Therapist Energizes Sunday Respite Sessions

**A**n energetic new music therapist is adding zest to H.A.L.O.s' Sunday Swim & Sing program.

Madison Kronheim, MT-BC, NICU-MT., engages participants in an interactive session each week, using music to strengthen skills and self-esteem.

"It's always fun," says Madison, "but there is always an underlying structure, too. Music is so good for engaging people, they don't realize they are also practicing skills."

Music therapy is the clinical use of music interventions to accomplish individualized goals in a therapeutic setting. Because music has been proven to activate both sides of the brain, it can be especially useful for people with neurological impairment.

In each of the two 1.5 hour Sunday sessions, staffers pair up with eight mostly non-verbal, non-ambulatory individuals. Madison plays instruments or recorded music

she has selected for that week's theme, while the class taps out rhythms, hums, chortles and sometimes are spun around in their chairs.

Themes are organized around the seasons, holidays and cultural events.

"While the kids are experiencing music, we are working on fine and gross motor development, teaching self-regulation, start and stop skills and appropriate social behavior," Madison said. "The time we spend together also creates a sense of community."

Sometimes the therapist sparks interaction by asking questions about a photo of a singer; other times she delights participants with recordings of their own voices. Madison also plays favorite artists suggested by families, and provides tips and feedback to caregivers who ask.

"I always have a backup plan, in case the mood changes or a lesson is not working. I try to match the energy in the room.

In the end, I want everyone to feel good," Madison explained.

Each session climaxes with the raising and lowering of the parachute, a signal to ramp down the energy and relax.

"Madison puts a lot of effort into planning," noted Angela Waring, MS., Respite and Recreation Program Manager for Jewish Family & Children's Service, which operates the program for H.A.L.O. "Her sessions are consistently age-appropriate and well researched."

Madison said she discovered her calling to help others through music when she saw the impact her French horn performances had on senior citizens and other groups.

Sunday Swim and Sing is on vacation until the fall, but Madison has helped JF&CS assemble a music therapy binder for use over the summer. For more information about Sunday Swim and Sing, email Angela at [awaring@jfcsboston.org](mailto:awaring@jfcsboston.org).