

## *No Visiting Policies Are Heartbreaking For Families*

When pediatric nursing homes instituted a No Visitor policy in mid-March to protect their medically fragile residents from the Coronavirus, families complied reluctantly.

The three month separation has been heart-wrenching.

"Normally, I hang out with Kaida every day after work," said Heather, mother of Kaida, 9, a non-verbal, non-ambulatory resident at New England Pediatric Care (NEPC) for the past three years.

Until the pandemic mother and child spent most weekends and holidays together at home.

"She loves the feeling of wind in her hair when she's riding on a swing or we drive with the windows down," Heather recalls wistfully. "Being apart is so hard."

That is why their video chats with are so important.

"I want her to know I love her," Heather said.

NEPC staff members schedule weekly Zoom or Facetime visits to keep families connected during the pandemic. Like many residents Kaida is visually impaired, but if a smartphone or tablet is held close she focuses intently on the screen and smiles at her mom's voice.

Heather typically attends all of Kaida's medical appointments, so NEPC also included her in a recent tele-medicine visit.

"It may not sound like much, but it is reassuring to 'see' that Kaida is doing well each week."

Colleen, mother of 32-year-old Brian, usually visits two or three



*Families miss visiting Kaida, top, and Brian, below, because of pandemic restrictions.*



nights a week after work.

Brian was diagnosed at birth with moderate to severe spastic quadriplegic cerebral palsy. He is legally blind, fed by g-tube, and wheelchair bound.

"It has always been our goal to give Brian a loving home environment; his quality of life is important to us. We cared for him at home for 22 years, until we could no longer

manage," said Colleen. "Not visiting Brian has been a huge loss, but if I see him sit up in his chair and looks around, it is the highlight of my week."

She keeps video visits short because of Brian's limited cognition level and to avoid burdening the staff.

"I just hope he doesn't feel we have abandoned him!"





## ***Pediatric Homes Are Managing The Crisis***

**H**.A.L.O. informally polled three pediatric homes to learn how the Covid-19 pandemic is affecting care of the medically fragile children we champion.

**New England Pediatric Care and Seven Hills Pediatric Center** in Massachusetts and **Cedarcrest Center for Children with Disabilities** in New Hampshire all reported voluntary, proactive measures taken early in March, prior to state requests.

As of June 1st, no children at the three homes had been infected.

"As a facility that cares for medically fragile children, we always plan strategically. We have the expertise and experience to go into crisis mode if we need to," said Ellen O'Gorman, Executive Director at NEPC.

"Number one, we instituted a strict **NO VISITORS** policy in the building. This means no family members, volunteers, delivery people, or even people donating staff meals or equipment," said Ellen.

All three homes require every employee to wear a mask while in the building and request they limit exposure to others outside work. If they or family members become exposed to the virus, or sick, the employee is asked to self-quarantine

### *Founder's Message*

## **Pandemic Measures Protect H.A.L.O.'s Little Ones**

**D**ear Friends,

*Whether or not we have lost dear ones, we all have been touched by the worldwide effort to contain the deadly Covid-19 virus.*

*Thank you to the doctors and nurses caring for the infected, to the researchers seeking a vaccine, to the farmers, grocery shoppers, ambulance drivers, police officers and hundreds of thousands of essential workers enabling the rest of us to isolate at home to halt the spread.*

*Children with neurological impairment are extremely vulnerable to because of their many frailties. This newsletter reports how some of their families, caregivers, teachers and communities are supporting them during this pandemic.*

*Rather than focus on dark stories of death, unemployment, political upheaval and protests for justice, I hope the exemplary compassion, courage and selflessness shown by many will inspire your own kind acts.*

*To that end, I share a link to a short video about a military program that embraces young people with disabilities. <https://youtu.be/RiyXQUS1dfc>. If you have a few minutes, it's uplifting message may bring a tear to your eye and hope for meaningful inclusion of all individuals in our society.*

*I regret to inform you of the passing of Dr. Ralph Aserkoff, a renowned obstetrician/gynecologist, friend, and a righteous man. He gave our foundation its name. May his memory be a blessing.*

*Sincerely,*

and be tested for the virus before returning to work. When possible, staff is working remotely, to limit the number of people inside buildings.

Short term respite care and day school operations were suspended at all the pediatric facilities, also. (See related stories on impact.)

Isolation beds/zones have been readied at each as a precaution to treat any resident who might contract the highly contagious virus.

"It's a scary time for everyone, so we have emphasized communication and are very explicit about procedural changes and expectations," reported Patty Farmer, Director of Development and Communication at Cedarcrest.

"We recognize our employees as superheroes. They are consistently positive and making a strong, fortified

effort to keep the virus out," she said.

Personal Protective Equipment (PPE) is now readily available to all the homes either from state public health stocks, donations or direct purchases from suppliers, but there were some supply chain shortages along the way. (See related community support story.)

"We have frequent team meetings to brainstorm solutions to challenges," said Monica Kleeman, Director of Education and Activities at Seven Hills Pediatric Center. From the custodians to the kitchen staff, teachers, therapists, nurses, their assistants and the office staff, everyone has been creative and dedicated to staying ahead of the crisis," she said.

Cedarcrest's Patty Farmer summed it up: "Parents are counting on us. It is a huge responsibility."



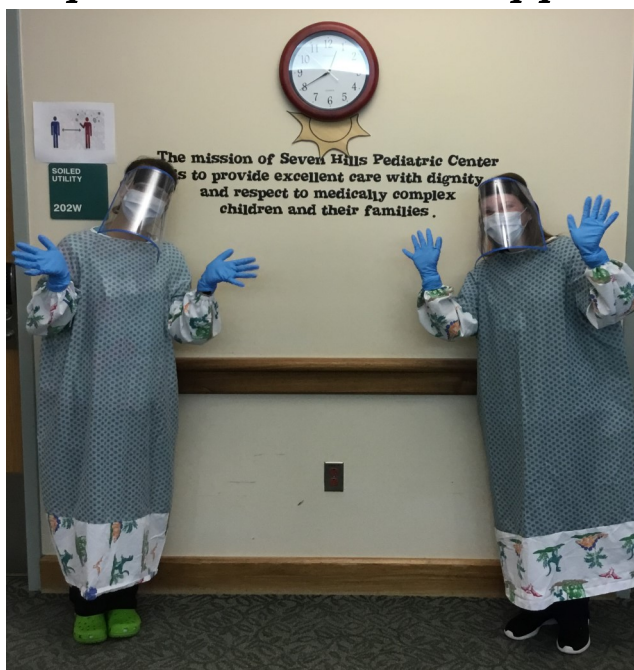
## Communities Step Up To Provide PPE Supplies, Boost Morale

**M**aking the best of what you have to work with is the “new normal” at Seven Hills Pediatric Center in Massachusetts.

In the early days of the Covid-19 pandemic, the staff had a shortage of the N95 masks used to limit contagion. Executive Director Holly Jarek posted a plea on a local Facebook group for area residents to search their garages and closets for painter’s and landscaping masks. Almost immediately neighbors in Townsend and Groton were dropping packages of masks at the front door.

“Since we have had no face to face contact, we have barely been able to say thank you. We don’t even know the people helping us” said Monica Kleeman, Director of Education and Activities, who serves as community liaison.

When the center’s supply of disposable paper gowns was running short, she said the staff switched to cloth “johnnies” –



*Seven Hills staff model johnnies and face shields used as PPE.*

those short gowns that fasten in the back. But the johnnies had short sleeves, so another appeal went out for sheets and pillowcases. An army of home sewers produced 600 long-sleeved gowns in less than two weeks.

Local knitters also crocheted “mask

mates” to cushion the ears when wearing a snug mask all day.

Sterlite, a local manufacturer, donated dozens of plastic storage bins to store PPE, and donut shops, restaurants, and residents’ families donated soup and snacks and cooked meals daily so the staff could focus on all the extra precautions.

The Seven Hills in-house team brainstormed innovative solutions to problems. For instance, they used clear page protector sheets as inserts in homemade face shields.

“It just kicks you back on your heels, when so many people pull together and pitch in to help,” Monica said.

“Our communities have always been very supportive and involved with our population, but it feels like everyone wants to contribute.”

*NOTE: NEPC and Cedarcrest Center also praised their local businesses, families, and religious institutions for their donations and help during the public health threat.*

## H.A.L.O.’s Family Support Programs Ease Social Isolation

**Z**oom at Noon is the pandemic version of Sibshops, a free support group for kids ages 8-14 who have siblings with special needs.

Seven to 13 children regularly sign in for the now weekly sessions, which offer activities, games and conversation opportunities.

“I knew it was going to be really challenging for our Sibs to be isolated at home with their sibling with complex disabilities,” said Angela Waring, Director of Social and Behavioral Supports, at Jewish Family & Children’s Service. She manages *H.A.L.O.’s Sunday Swim and Sing* activity and *SibShops*, which H.A.L.O. supports in part.

“We moved both programs to Zoom (a popular video conferencing application)



*A SibShop participant “zooms” at home.*

on March 15th with very positive feedback from families,” Angela reported.

“In *SibShops* the goal is to help the kids laugh and enjoy a special time just for them. Often families need to focus on the sibling

with special needs. It’s a safe place to express emotions.”

One recent exercise asked siblings: *How are you feeling right now?*

A nine-year-old said he felt “brown” — all the colors that represented happy times were getting mixed up with dark feelings like sadness and confusion. Angela sends home sample activities to help families “unpack” these kind of feelings.

The *Sunday Swim and Sing program* is thriving on-line on Sundays and Thursdays for young people who usually participate in the therapeutic sessions. There’s no swimming and no real respite for the families, but utilizing Zoom, music therapist Joanna Kennedy encourages participants to “dance” in their wheelchairs, echo sounds, and reproduce rhythms with family members’ help.

# School Is Never Out For Kids With Special Needs

**T**he pandemic may have closed school buildings, but special education continues for children who attend the school at New England Pediatric Care in Massachusetts.

"Every child and young adult in the facility is seen daily in their rooms by a teacher, instructor or recreational specialist," according to Amy Gagnon, Director of Education. "Teaching one to one is intensive, but health is our number one priority."

Lessons and activities are planned for each individual's cognitive ability to keep them engaged and working toward individualized goals. Teachers have reorganized case loads so that teams are assigned to one wing only, limiting



*Richie enjoys sensory play.*

exposure to different people. Visits are coordinated with the direct care, rehabilitation, and recreation teams who are also continuing to provide individualized therapeutic services to all residents. Although children are not participating in the typical classroom model, the one to one activities, communication with families, and learning in their home environment.

"We adhere to the protocols strictly," assured Amy. Everyone is masked, temperatures are taken daily, hands are sanitized frequently and then the teachers' carts are loaded with sensory and instructional materials to prepare for their day.

NEPC provides frequent updates to families on each child's progress using multiple modes of communication.

Teachers are designing creative ways to deliver distance learning lessons to students who live in the community and cannot enter the school during the pandemic. They regularly send instructional materials to the home, record lessons and work with families via video conferencing."

## Teletherapy Helps Children Stretch, Stay Limber

**M**any neurological conditions cause spasticity – muscle stiffness. Physical therapy relieves pain, improves movement and maintains flexibility, and builds strength that most people take for granted: the ability to hold up your head, sit, stand, or even to breathe. When schools closed down due to the coronavirus, children living in pediatric homes continued treatment in their rooms, but children in the community lost access to their on-site treatment. At Cedarcrest Center for Children With Disabilities in Keene, NH, therapist Karen Wallace has been coaching

their families how to do exercises and how to manage daily logistics and equipment at home. She sends them video demonstrations and written instructions and also connects weekly with them using a HIPPA-compliant video conferencing program. "Remote work is challenging in such a hands-on profession, but there have been some silver linings," she said. As she coaches families they have revealed challenges they did not realize could be addressed. For instance Karen recently arranged installation of a handheld

shower to make bathing of a non-ambulatory child easier. She helped obtain a new Hoyer lift for another child who had outgrown his equipment. "For me, remote PT has underscored the importance of home visits to optimize a child's living conditions," Karen said. "Families need to learn new ways to help their children, such as how to transfer them to their chair or car, as they grow up, and a visit will make this easier." "Moving forward I will make sure I do more home assessments for our day students."

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