

Father Shares Perspective On 'Every Parent's Worst Nightmare'

On December 15, 2020 Michael and Sasha learned that their healthy 10-year-old daughter complained of a headache, vomited, then became unconscious at school.

They spent the next six weeks with Marina at Children's Hospital in Boston not knowing if she would ever wake up from multiple strokes caused by a ruptured arteriovenous malformation (AVM) in her brain.

"It was every parent's worst nightmare," Michael said.

Marina endured three surgeries in the next two days to relieve pressure on her brain and remove the AVM. However, the bleeding and increased pressure caused damage so severe, doctors initially doubted she would ever wake up, he said. Somehow she beat the odds and was sent to Spaulding Rehabilitation Hospital.

When Marina returned home in April 2021 she had awakened but could not walk, speak, or swallow; she received nourishment via a G-tube.

But here is the story the family wants to share.

"Children's brains are still developing, they have plasticity, and with constant stimulation they might re-wire around these injuries," Michael



Marina hugs her service dog, Savvy.

explained. Determined to utilize all available resources to help Marina recover, the family arranged for intensive rehabilitation at home.

(Continued on page 2)

Covid Then and Now: How Have Things Changed?

When did the pandemic start? When does it end? It's tricky, according to Harvard Medical School.

With thousands of Covid infections and hundreds of related deaths still reported daily, pediatric nursing homes are still under strict regulation to safeguard residents, many of whom are vulnerable to viral infections.

Each state mandates its own health policies; medical and nursing directors implement them. H.A.L.O. spoke with Patty Farmer at Cedarcrest Center For Children With Disabilities in Keene, NH to get a sense of how Covid has changed operations since March 2020.

"Our whole purpose is to be here for children and families who need us. The pandemic changed us, but the deep-rooted foundation did not change. We continue to strive to provide the highest level of normalcy possible for our residents."

"Our medical and nursing directors stay updated on Covid via the National Center for Disease Control, Dartmouth-Hitchcock Medical Center (a regional resource), the state Department of Health and Human Services, and Medicaid. Procedures are relaxed only when changes are deemed be safe for the center's population."

Masks continue to be required for all staff, family and visitors, but daily Covid testing has been

(Continued on page 4)

Founder's Message

As H.A.L.O. Evolves “Little Ones” Remain Our Priority

Dear Friends,

This December our daughter Sarah, will be 34 years old – another remarkable milestone considering her poor prognosis in 1991 after complications of meningitis.

Sarah has thrived for the past 30 years due to her resilience, the excellent care she receives at New England Pediatric Care, and the medical and technological innovations that have emerged.

The Help A Little One Foundation has also thrived through your benevolence. Our gifts to individuals and programs enrich the lives of hundreds of children with neurological afflictions.

Birthdays remind us that time moves on for all of us. Cognizant of that, I want to assure our families and “Little Ones” that we are exploring how best to fulfill our mission in the future. We hope to share concrete plans with you next year.

Presently H.A.L.O. is in the process of making our annual bequests to pediatric nursing facilities, enabling them to select gifts appropriate for each of their residents. In October we once again supported the seasonal hayride featured on page 3, and throughout the year we continue to make gifts to individuals in need.

We are all about quality of life, and as Julian's face (above right) demonstrates, even small gifts can help a child feel embraced by the larger community. Julian's mother says: “The bike was a blessing! Julian LLLLOOOOOVVVVES to go biking. Aside from being home, his second favorite hobby is biking.”

Thank you for your continued interest in and support of our “Little Ones.”

Sincerely,



Julian

‘You Will Have Bad Days and Worse Days’ So Take One Day At A Time

(Continued from page 1)

Lesson #1: Health insurance is set up for the adult stroke model and does not necessarily fund additional therapies beneficial to children. The family set up a Go Fund Me to help cover therapy and reached out to other resources for help.

Lesson #2: Devastating illness is isolating. Everyone wants to help at first. Friends essentially took care of Marina's older brother for the four months Marina was in hospitals. A coalition of colleagues, community, friends, and synagogue set up a food train. But as the saga continued some people stepped back, perhaps because they did not know what else to

say or do; they were not having the same shared experience. Michael and Sasha found emotional support when the hospital connected them to a Facebook group and to other families thrust into similar journeys. Their clergyman suggested they contact H.A.L.O.

“H.A.L.O. helped us with some of the uninsured expenses and made it possible to obtain Savvy, a service dog, who assists Marina as she relearns how to walk,” applauded Michael.

Marina has now progressed to eating whole food, including her favorite bacon and cheeseburgers. She attends school two hours a day, is relearning how to

speak, read and write, and walks around a local lake with Savvy and her family.

“Her words may be hard to understand, but she has made it clear that she hopes to snowboard again, Michael laughs.

Lesson #3: Take one day at a time.

“Marina has a long way to go. We don't know if she will ever be able to live independently,” Michael admits.

“This is hard work, every day. You will have bad days and worse days. You know you're doing better when the bad days outnumber the worse days. This is a work in progress. Help each other and take one day at a time,” Michael said.

‘Typical’ Activities Stimulate The Senses, Light Up Their Faces



Imagine a crisp, fall day. A van pulls up to the barn at Jest-A-Bit Farm and three young people from Seven Hills Pediatric Center in Groton, MA, emerge. The support staff pushing their wheelchairs might be just as excited as the residents are to be on this adventure. (Photos at top.)

The unfamiliar aroma of hay and horses arouses the curiosity of the young people; they lift their heads at the sound of unexpected whinnies and snorts. Some vocalize when a gentle giant gives them a little nuzzle.

Those with adequate trunk stability are belted securely on a trained horse while a hippotherapist from Clover Physical Therapy guides them around the ring.

Other residents are wheeled alongside with a lead in hand or feed the animals from buckets. Some enjoy brushing the horses' coats or petting cackling hens.

"It's incredible to see their smiles, to see residents who don't often have a lot of movement reach out and touch them," says Connie Williams, Director of Therapy.

"Their faces just light up."



H.A.L.O. is a long time supporter of the annual autumn hayride at New England Pediatric Center in Billerica, MA.

Always a festive event, residents enjoy music, pumpkin crafts and other activities in the sensory art room before and after their rides and receive lots of one on one attention. (Photos on left)

"There's lots of engagement throughout the day," says Ashley Richard, Director of Social Services. "We try to provide experiences that any typical child could have not living at a facility and we are rewarded with very happy faces."

Grochmal Farms of Tewksbury has supplied the open air-wagon with lift for many years. The drivers are well-versed in the residents special needs and assist with loading the wheelchairs. This year they brought along one of the farm dogs, which delighted residents.

Logistics for the hayride are challenging. Everyone at NEPC gets to ride, so school, therapy, and medical appointments need to be coordinated. This year three nurses, three recreational staffers and most teachers and nursing assistants helped facilitate the activities.

"We arrange special events at least once a month, but this is an especially amazing day for all of us," Ashley said.



In August Cedarcrest Center in Keene, NH marked its 75th year with a “Back to the Hive” event. Former staff and families were invited to celebrate the organization which was founded in a farmhouse in 1947 by a nurse and physical therapist to provide residential care for children with complex medical and developmental needs. You can view a video chronicling how Cedarcrest has evolved at <https://youtu.be/iNgdfs8cOY8>

The Cloud Is Lifting; Pre-Covid Activities Resume

(Continued from page 1)

replaced by “surveillance” – periodic — testing of staff and residents to catch asymptomatic cases. Only last month Cedarcrest was allowed to end temperature screening as people enter the building.

During the first year of the pandemic children were isolated from even their closest family members; visitations resumed slowly.

“We continue to ask families to let us know when they want to visit with their children,” Patty said. “This was especially important when transmission was very high; now it is more about logistics.”

Because some residents are not eligible for vaccination, Cedarcrest limits visits in the home (bedroom) area to one adult per resident to reduce potential infection. The facility wants to ensure there is space available for private family time, Patty explained. Outdoor spaces are also utilized, weather permitting.

Social activities were paused the first year of the pandemic. Socialization has always been important because interaction with the larger community broadens the residents’ experiences.

“That cloud is lifting. We held our ‘prom’

this year, we celebrated Cedarcrest’s 75th anniversary, and reinstated the Walk & Roll walkathon, which draws great participation from the greater Keene community,” reported Patty. Volunteers are once again welcomed to spend time with residents, also.

“Our first steps opening the doors were cautious; after each community event we waited for the shoe to drop, but it didn’t. We are excited to relearn how to be social and feel ok about it,” she noted.

While there are workforce shortages in general, Cedarcrest maintained high levels of nursing and education staffing during the pandemic. The center expanded its recruitment strategies to include more automated job boards to get greater exposure for available positions.

“Nursing homes typically operate with a small administrative staff. Recently we’ve partnered with a company to streamline work processes and to handle payroll and benefits,” Patty said.

“This pandemic has been a devastating historical event. We were fortunate to have experienced a limited number of cases at Cedarcrest. Perhaps the rural nature of New Hampshire changed the dynamic, but we are all the wiser today and we will continue to be vigilant.”

VOLUME 29, ISSUE 1
FALL 2022



A Foundation for Children with Neurological Impairment

OFFICERS

Alan Pinshaw, M.D.
Founder and President

Julius Levin
Vice President

Ronald Marcus, M.D.
Vice President

Scott P. Gladstone, Esq.
Treasurer

Michael Alper, M.D.
Clerk

Ian L. Katz, M.D.
Secretary

BOARD OF DIRECTORS

Rebecca Dalpe, Esq.

Sigal Klipstein, M.D.

Susan Treisman Mirageas

Gayle Pinshaw

Julia Anne Wicoff

ADVISORS

Harvey Levy, M.D.

Peter Mowschenson, M.D.,

Ellen O’Gorman, MA, NHA

Michael Ronthal, M.D.

Rabbi Donald M. Splansky,
Ph.D., D.D., D.Hum.

Harry Webster, M.D.

CERTIFIED PUBLIC ACCOUNTANTS

Abrams, Little-Gill, Loberfeld, P.C.

H.A.L.O. Foundation
1330 Boylston Street
Chestnut Hill, MA. 02467
WWW.HALO.ORG