Schumer Pledges to Fight Medicaid Cuts

In the rotunda of Blythedale Children’s Hospital this past May, U.S. Senate Minority Leader Charles E. Schumer was surrounded by a large crowd of children and their families, Hospital trustees and staff, as he announced a... continued on page 3

Previously Conjoined Twins Jadon and Anias Take the Next Step... Home!

The milestones have been plentiful for two-year-old previously conjoined twins, Jadon and Anias McDonald, and on September 2, they added a new one to their growing list... going home.

Admitted to Blythedale’s Infant and Toddler Unit for nearly nine months, the boys were all smiles as parents Nicole and Christian buckled them into separate car seats for the ride to their new... continued on page 6

Pictured at left: Senior Physical Therapists Mara Abrams and Maureen Carroll help stabilize Jadon and Anias while mom, Nicole, and CNN Chief Medical Correspondent Sanjay Gupta cheer them on.

Photo by Mark Kauzlanich
Letter from the CEO

Dear friends,

This time of year, along with the change of seasons, always brings a time of reflection here at Blythedale. It’s great to look back on all we’ve accomplished in the past year, but far more important is keeping an eye on what we can and should be doing, going forward, to serve more medically complex children.

This year we have fought hard against proposed cuts to Medicaid. Senator Schumer’s visit was a very public recognition of the effort, but every day we are working tirelessly, behind the scenes, to ensure that the ongoing policy debate taking place in Washington doesn’t materialize in the form of healthcare cuts for children that are nothing short of inhumane.

We are also proud to share news of the Blythedale-Burke Pediatric Neuroscience Research Collaboration. This important partnership - the first of its kind - will lead to improved treatments for kids with a variety of neurological impairments.

So what’s on the horizon? Our newest dream is to become a national center for assistive technology. We have the clinical expertise, and the need is significant, but turning dreams such as this into reality takes hard work and philanthropy. That is why we are so grateful to our generous and dedicated supporters, who have already made many dreams come true for our patients and their families. Stay tuned for more news on this exciting initiative, and I hope you enjoy this issue of Inspiration!

Sincerely,

Larry Levine
President & CEO

Blythedale and BMRI Announce Landmark Research Partnership

The Burke Medical Research Institute (BMRI) and Blythedale Children’s Hospital have entered into a research collaboration to translate advances in basic neuroscience at the BMRI labs into new and improved treatments for children with neurological impairments at Blythedale and beyond. The collaboration seeks to improve movement, vision, and cognition impaired by stroke, traumatic brain injury, cerebral palsy, and birth defects, among other neurological conditions.

The Blythedale-Burke Pediatric Neuroscience Research Collaboration is the first partnership between a research institute and a children’s specialty hospital to study and treat the developing nervous system. According to the Child Neurology Foundation, one in six children have a neurological condition that limits function. These conditions diminish quality of life for affected children, yet few treatments are currently available. This collaboration will tackle this challenge through teamwork; scientists and clinicians will work together to apply innovative research techniques to important clinical problems.

“This isn’t just a marriage, it’s a marriage made in heaven,” said Blythedale Board Chair David Pedowitz. “With BMRI’s expertise in brain repair, and Blythedale’s expertise in the care of medically-fragile children, we are poised to make great advances in science and clinical care.”

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“We don’t know enough about

Blythedale Launches New TBI Program

Will my child recover? Will my child ever walk or talk again?

Those are just some of the questions parents pose when given the life-changing news that their child has suffered a traumatic brain injury (TBI). The diagnosis is the #1 cause of disability and death among children in the United States. And, with medical uncertainty surrounding outcomes for many TBI patients, their futures are dependent on understanding how the brain reacts to trauma and the subsequent therapies.

With a mission to delve deeper into the unknowns of traumatic brain injuries, the Burke-Blythedale Pediatric Neuroscience Research Collaboration has developed a new system to help those affected children. It utilizes cognitive neurorehabilitation and is spearheaded by the TBI Core Team, comprised of members from both medical institutions. The ambitious initiative would test

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Learn more about what’s happening at Blythedale... visit

www.newsroom.blythedale.org
major initiative to protect two-and-a-half million children in New York State. Schumer’s visit symbolized the nationwide effort to publicize critical programs that were gutted in the House of Representatives’ health care plan and the President’s budget.

According to the Senator, the Administration’s proposed budget would hurt more than 26,000 children in Westchester and Rockland Counties, and the cuts would mean that thousands of Hudson Valley children would lose access to affordable health care that working families rely on.

“Medicaid and other programs that provide healthcare to kids need to be strengthened, not cut,” said Senator Schumer. “When it comes to something as important as healthcare, we cannot allow a situation to arise in which children cannot get the checkup or prescription they need because their family cannot afford the payments or insurance.”

The Senator was welcomed to Blythedale by Hospital President & CEO Larry Levine, who, in his opening remarks, noted the unfortunate circumstances of the visit, given the “draconian health policy debate going on in Washington” which has created widespread concern amongst the pediatric healthcare community.

He expressed his vigorous opposition to the proposed cuts to Medicaid and CHIP, remarking that both programs cover 40 million children in the United States, including two-and-a-half million in New York State. At Blythedale, 73% of the children the Hospital treats are covered by Medicaid and CHIP.

“No matter what your view on the role and size of government, I hope we can all agree that preserving the health of children is an important societal goal,” said Larry Levine. “We are looking at around $800 billion in Medicaid and CHIP cuts over the next 10 years. This would cause unspeakable hardships for families already devastated by their child’s illness. And, it would cut reimbursement to safety net children’s hospitals such as ours, where families and children rely on us to provide the highest level of quality care. As a nation we are better than this.”

Attendees at the press conference also heard from Renee Saltzman, whose daughter, Emilie, sustained a severe traumatic brain injury in October 2015, after falling from a horse. She spent four months as an inpatient at Blythedale, relearning how to speak, eat and walk.

“Our family found ourselves in this place that we never thought that we would be, having a child with a traumatic brain injury, a disability, and not having medical coverage to carry her through her recovery,” said Renee Saltzman. “Medicaid made it possible for Emilie to stay at Blythedale as an inpatient and to continue her care as an outpatient, and she continues to receive Medicaid for her needed therapies.”

Stephanie Doyle, whose daughter Isla has a rare genetic disorder and receives care at Blythedale, also spoke out against the proposed cuts.

“Every time I listen to the radio or I hear the news, and I hear politicians talk about families “having more skin in the game” when it comes to healthcare, I want them to know that my body is raw raising a child with a serious medical condition and when I think about the financial ruin and how it would affect her healthcare without the extra support of Medicaid, I am bleeding,” she said. “So please don’t take this away from our family and families like ours, because I don’t know what I would do. And don’t insult me by asking me to have more skin in the game, because it’s all there.”
Clockwise from above: Blythedale medical staff members Lori Robinson, N.P., Dr. Mary Didie, and Dr. Ruth Alejandro celebrate Barbara, who was featured in a video shown at the event; Blythedale President & CEO Larry Levine and Board Chair David Pedowitz both spoke at the gala; Donny Deutsch emceed the event honoring Blythedale Trustee Jordana Holovach, pictured with her daughters, Hailey and Remi; Blythedale Advisory Council members enjoy the view during cocktail hour; and Charity Auctioneer Charles Antin inspires attendees to donate.

A Memorable Celebration of Blythedale

This year we were delighted to honor Blythedale Trustee, grateful parent and founder of Jacob’s Cure, Jordana Holovach at A Celebration of Blythedale at Tribeca Rooftop in Manhattan.

The event, emceed by Donny Deutsch, recognized Jordana for her advocacy on behalf of children with complex medical needs and raised nearly $600,000 for Blythedale’s Assistive Technology Program.

Attendees watched a short video on the services the Assistive Technology Program offers, through the lens of grateful families whose lives were changed by the program. Charity Auctioneer Charles Antin led the successful “Mission Moment“, which resulted in more than $200,000 pledged by guests in less than ten minutes.

For more information about Blythedale events, please contact Christina Caras, at (914) 831-2512 or ccaras@blythedale.org.

Blythedale was excited to participate in The Corporate FunRun Westchester 5K for the fourth time this past July. The event, which took place at SUNY Purchase, provided a perfect setting for Blythedale staff and their families to celebrate their completion of the three-mile course.
The Stuart H. Dix Memorial Golf Outing Raises More than $350,000

The Stuart H. Dix Memorial Golf Outing and Dinner - co-hosted by Michael Brown, Blythedale Trustee Farrel Starker, and her husband, Steven - raised more than $350,000 to help support Blythedale.

More than 112 golfers participated in the outing held in June at The Stanwich Club in Greenwich, CT, while a group of the Starker’s family members and friends spent the afternoon volunteering at Blythedale.

The Hospital extends its deepest gratitude to the family and friends of Stuart for their extraordinary support of Blythedale in his memory, as well as the outing’s Presenting Sponsor, Wheels Up, and the entire event committee: Rick Blank, Jr., Gary Dix, Lawrence Dix, Andrew Friedwald, Peter Hochfelder, Chip Kaye, Scott Musoff, Robert Sobel, Dean Starker and Ray Starker.

Clockwise from top: (l-r) Judy Dix, Farrel Starker, parent speaker Stephanie Doyle, Presenting Sponsor Wheels Up Co-Founder & EVP Gary Spitalnik, and Michael Brown and Steven Starker; Celebrity golfer and radio personality Scott Shannon (second from left) prepares to hit the links with Donald and Brett Lazar, and Avrom Doft; friends and family of Stuart Dix gather before the day’s festivities; Jenna and Jamie Musoff volunteered at Blythedale during the golf tournament.

Corporate Partners at Work

Blythedale’s Corporate Partners program continues to grow since its inception last spring with 13 companies now dedicated to making a difference in the lives of our young patients. This summer we welcomed Citrin Cooperman at the $5,000 Shooting Star Level and Turner Logistics and MBIA at the $2,500 Rising Star level. One of the highlights of our Corporate Partners program is the volunteer days when partners send employees to Blythedale to lend a helping hand. Pictured: Citrin Cooperman employees have fun sprucing up Blythedale’s Parent Housing.

Apple Store, The Westchester Citrin Cooperman DigiTech Empress Medical Services Magnakron MAM USA MBIA Neuberger Berman Regeneron Robert Half Team Success NY at Keller Williams Teladoc Turner Logistics
home in Orange County. “This day is bittersweet, because I will miss them,” said Dr. Dennis Davidson, Chief of the Infant and Toddler Unit. “I think you just have to look at the results here of this amazing journey that has occurred for both boys and recognize that it couldn’t have been done without the tremendous round-the-clock care here. It’s been a great team effort and I think the parents have learned a lot. We feel very comfortable now that they’ll be able to go home to a safe environment.”

The boys were admitted to Blythedale in December for comprehensive rehabilitation following the life-saving surgery to separate them at the Children’s Hospital at Montefiore last fall.

During their admission to Blythedale, the boys have been immersed in a daily regimen of physical, occupational, speech and feeding therapy. This, in addition to the complex post-surgical care they received.

For more information, or to view CNN’s in-depth coverage of their journey, please visit www.newsroom.blythedale.org.

Twins (cont.)
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Recovery Laboratory at BMRI and an Assistant Professor at Cornell, initiated a clinic for children with brain injuries at Blythedale in 2013. Since then, he has helped found the Collaboration with colleagues from BMRI and Cornell.

“We are thrilled to work with Blythedale to translate rehabilitation science to children with neurological impairments,” said Rajiv Ratan, M.D., Ph.D., Executive Director of BMRI. “The joint studies offer tremendous potential to yield new scientific insights and innovative therapies for patients.”

“While Blythedale patients make gains every day because of our superb clinical staff, we see the cutting-edge research at BMRI as critical to bringing the next generation of therapies to children with neurological disabilities,” said Blythedale President & CEO Larry Levine.

“Today, as scientists and doctors, we too often have to tell our patients and their families, ‘We cannot help you,’” said Dr. Carmel. “Through the discoveries and treatments we expect of this collaboration, we will be able to tell these same patients, ‘Yes, we can help you.’”

Research (cont.)
> continued from page 2

how injury affects the developing brain,” said BMRI Board Chair Robert Baldoni. “This partnership offers a unique opportunity to accelerate the scientific discoveries and clinical advances that these children desperately need.”

The Collaboration is directed by Jason Carmel, M.D., Ph.D., a pediatric neurologist and neuroscientist with expertise in electrical brain stimulation to improve movement. Dr. Carmel, who is also Director of the Motor Recovery Laboratory at BMRI and an Assistant Professor at Cornell, initiated a clinic for children with brain injuries at Blythedale in 2013. Since then, he has helped found the Collaboration with colleagues from BMRI and Cornell.

“We are thrilled to work with Blythedale to translate rehabilitation science to children with neurological impairments,” said Rajiv Ratan, M.D., Ph.D., Executive Director of BMRI.

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TBI Program (cont.)
> continued from page 2

and track young TBI patients from admission to discharge to collect structured assessments for every child admitted to Blythedale Children’s Hospital. “The long-term goal of this project is to predict how children will recover from brain injury and to understand the brain processes that support recovery,” said Dr. Sudhin A. Shah, Scientific Director of TBI/DOC (Disorders of Consciousness) Research Program at Blythedale Children’s Hospital.

Dr. Jason Carmel, Director of Research at Blythedale Children’s Hospital and member of the TBI Core Team, explained that his team had their sights set high on this new endeavor. “Our goal is to be the first hospital in the U.S. to collect structured outcomes from every child with a brain injury,” he said.

And with respect to the optimism the new program brings? “Hope,” he said. “Hope is a feeling that there is a real possibility for a better life.”
Patient Family Education Team Presents at NYU

Blythedale’s Patient Family Education Team presented its pilot program, “Assessing the Need for a Multi-Disciplinary Patient and Family Education Initiative for the Medically Fragile Pediatric Patient in an Inpatient Pediatric Rehabilitation Setting”, at the 21st Annual NYU Nursing Research Conference in Manhattan. This marked the first time Blythedale has been showcased at the conference.

The Hospital’s initiative began in January with a comprehensive, multidisciplinary family-centered approach to teach patients and families how to care for their medically complex child. Education for parents, patients and other caregivers is tailored to meet the psychosocial needs and skill level of the learner. This preparation allows for everyone involved to become competent first responders in their child’s continued care. The learning experience would begin at admission to Blythedale and continue throughout their stay.

“We want families to feel confident in taking care of their child when they are getting ready for discharge,” said Melissa Shemek, Director of Nursing Education and Research at Blythedale Children’s Hospital and one of the co-presenters at the conference.

Helping Hands

For most children, summertime means no school, no classes and no teachers. But, for a small group of motivated youngsters at Blythedale, summer means something more. It means heading indoors, slipping on a special blue mitt and working hard to achieve new therapeutic goals as part of the Hospital’s Upper Extremity Summer Program.

Anthony (pictured at right) is one of 19 children who participated in this year’s six-week program, uniquely developed to help children with hemiplegia/hemiparesis as a result of either cerebral palsy, traumatic brain injury, stroke or other diagnosis. Blythedale’s expertly trained occupational therapists work with participants to increase motor function and strength in their weaker hands.

“During the constrained therapy part, we use a mitt on the stronger hand to facilitate more spontaneous use of the weaker hand,” said Ka Lai (Kelly) Au, Upper Extremity Summer Program Supervisor and Senior Occupational Therapist. “In the bimanual activities, we encourage them to use both hands together to complete tasks.”

In addition to the program helping and teaching new skills to the children, it’s also an important research project for the Burke-Blythedale Pediatric Neuroscience Research Collaboration. Julie Knitter, Director of Blythedale’s Occupational Therapy Department, praised the endeavor.

“We are fortunate to collaborate with our outstanding neuroscience researchers to analyze and share our results, as well as develop the scientific evidence to support and guide clinical practice.”

A typical day in the program includes activities like arts and crafts, sports and playground activities, sensory play, self-care activities and exercises to strengthen their weaker arm and improve range of motion. For Anthony, bowling a strike with his right hand was a highlight.

“Yes, I did it!” he said enthusiastically.

“It was always a struggle to work on his right arm,” said Anthony Pastore, Anthony’s father. “He was always smart enough to find another way to use just one hand,” said Anthony Pastore, Anthony’s dad. “As parents, it’s hard to get your kids to do things they don’t want to do, but the therapists here magically make him, and the other kids, do so much more.”
Inspiration is designed to inform our friends in the community about the programs and activities of Blythedale Children’s Hospital. If you know someone who would like to be on our mailing list, or if you have ideas for future issues, please let us know.

Call Connie Cornell at 914-831-2570 or email to ccornell@blythedale.org.

Visit us at our website
www.blythedale.org

Blythedale Welcomes Pfizer Volunteers

Blythedale recently hosted a group of senior-level executives from Pfizer’s Innovative Health business for a morning of hands-on volunteering with our patients. They helped toddlers with arts and crafts projects in an Early Childhood Center classroom; went bedside to read to and play with patients; assembled “family welcome baskets” stocked with toiletries and snack items; and presented soft and cuddly “no-sew” blankets to some of the children. “I was truly inspired by the incredible work that takes place at Blythedale Children’s Hospital,” said Albert Bourla, Group President, Pfizer Innovative Health. “Seeing first-hand their passion and dedication to change the lives of very sick children was very moving. I am so grateful for having been part of this experience, and I hope we made a positive difference in the lives of the children and families we met.”