Blythedale Children’s Hospital, in Westchester County, opened the doors of its new 86-bed, 56,000 square foot replacement inpatient hospital this past December. The building project – the first new addition to the Hospital in more than 40 years – addresses shifts in the Hospital’s patient population over the past several decades and dramatically strengthens the Hospital’s capacity to provide the most advanced care to medically fragile children in the New York metropolitan region.

“We at Blythedale Children’s Hospital have always prided ourselves on delivering the highest levels of quality healthcare and medical rehabilitation services to the most medically fragile patients,” said Blythedale President and CEO Larry Levine. “In this new building, with the latest in medical technology and enhanced amenities, we have the facilities to match the extraordinary level of expertise and care that our doctors, nurses and therapists have provided for so many years.”

New amenities include the most advanced wireless patient monitoring systems; larger, brighter inpatient rooms, with pull-out beds for family members; a spacious new entrance and lobby and additional space for clinical and family support services.

According to Chief Medical Officer Dr. Joelle Mast, the new inpatient building is custom-designed with the highest attention paid to the specific needs of medically fragile children and their families. “With more advanced technology in patient monitoring and medication dispensing, along with specialized services such as a dedicated TBI Unit, Blythedale helps patients achieve even better outcomes by allowing them to leave the ICU setting earlier to begin rehabilitation and recovery in an environment that optimizes patient care and comfort,” said Mast.

The new additions include:

- **Infant & Toddler Unit** - Blythedale’s 46-bed Infant & Toddler Unit is optimized for the care and treatment of the Hospital’s most medically complex patients, many requiring weaning from mechanical ventilation and transitioning from parenteral to oral feeding.
LETTER FROM THE CHIEF MEDICAL OFFICER

Dear Friends,

We are pleased to provide you with this inaugural issue of Pediatric Insight. This newsletter will be distributed twice a year, and will include timely articles authored by our clinical staff on patient care, research, teaching and training, and advocacy.

Our current issue highlights our magnificent new inpatient facility, which is a source of pride to all of us who work so hard for the patients and their families. The new hospital building provides 86 beds, including a new dedicated 10-bed TBI unit, large positive pressure isolation rooms, the latest technology in patient monitoring systems, and a Family Resource Center.

At Blythedale, we have students in diverse specialties: medicine, therapies, nursing and graduate students. The article on NMDA receptor encephalitis describes one condition that we have treated here, and about which we have taught our students from area medical centers and universities. Also in this inaugural issue, a Q&A details our newest outcome measure, Goal Attainment Scaling or GAS. This patient-centered measure will add a family-centered approach to our outcome assessments.

We look forward to your feedback and hope you enjoy this issue. And if you’ve not yet had the opportunity to see our new inpatient Hospital, we would be delighted to provide a tour!

Joelle Mast, Ph.D., M.D.
Chief Medical Officer
joellem@blythedale.org

New Dedicated TBI Unit Fills Critical Need in Tri-State Area

With the opening of a new 10-bed, dedicated Traumatic Brain Injury (TBI) Unit, Blythedale is meeting a high demand for these specialized services in the greater metropolitan region.

“Blythedale has been a longtime leader in the treatment of children recovering from brain injury,” said Dr. Jay Selman, co-director of Blythedale’s New York State certified TBI program. “But now, with the addition of the newest and most modern brain injury treatment unit in the state, treatment and recovery take on an even greater prominence.”

The specialized unit includes ten private sound and light-controlled rooms, optimized to meet the highly specific needs of children emerging from coma and recovering from TBI. The Unit features its own facility for physical, occupational and speech therapy, as well as the latest in neurophysiological monitoring equipment to monitor recovery from coma and detect subclinical seizures.

Blythedale’s interdisciplinary clinical team is specially trained in TBI management, maximizing patient goals with uniquely tailored treatment plans. Team members include Neurologists, a Neuropsychologist and Child Psychiatrist, Psychologists, Physiatrists (and other pediatric subspecialists, as needed), Nurses, Social Workers, Occupational, Physical and Speech Therapists (including feeding therapists), Pain Management, Child Life specialists, and a Registered Dietitian.

To learn more about Blythedale’s new TBI Unit, please contact Dr. Jay Selman at (914) 831-2480 or jays@blythedale.org.

The Brain Injury Team at Blythedale includes (l-r) Dr. Jay Selman, Nurse Manager MaryCris Nee, Social Worker Nicole Martini, Dr. Josephine Kuhl, Dr. Ruth Alejandro, and Dr. Christopher Rackley.

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• **Traumatic Brain Injury (TBI) Unit** – In the 10-bed dedicated TBI Unit, each room is private, sound- and light-controlled, and optimized for the specialized, multidisciplinary care that patients with TBI require. It also includes a therapy room, for a low-stimuli environment for treatment sessions.

• **Pediatric/Adolescent Inpatient Unit** – The 30-bed Pediatric/Adolescent Inpatient Unit is designed with older children and adolescents in mind, and is coordinated by an adolescent medicine physician. This Unit also includes a Teen Lounge.

• **Family Resource Center** – With a kitchen and dining area, TV and family room, medical library, computer access, Wi-Fi capabilities, and a playroom, the Family Resource Center is designed to accommodate the needs of parents and family members who must spend extended periods of time visiting patients at the Hospital.

• **Isolation Rooms** – Three positive pressure isolation rooms enable Blythedale to admit patients with compromised immune systems. A negative pressure room is available for patients with contagious airborne infections.

The new building officially opened its doors to patients on December 6, 2011, filling every available bed within just a few days.

Phase II of our historic building project is already underway, and includes renovation of the existing building to accommodate an expanded Day Hospital and Early Childhood Center, a new Center for Assistive Technology and a new Center for Speech and Audiology.

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**PROFESSIONAL PROFILE**

**Jay Selman, M.D.**

Dr. Jay Selman joined Blythedale Children’s Hospital in 2002, and became the Chief of Child Neurology and Co-Director of the Hospital’s Traumatic Brain Injury Unit in 2007. He has clinical expertise in Pediatric Neurology/traumatic brain injury, EEG interpretation, baclofen pump management, EMG/NCV, spasticity, and sleep disorders.

Dr. Selman received his medical degree from University of Texas Southwestern Medical School, and completed his Pediatrics and Neurology training at Jacobi Hospital – Albert Einstein College of Medicine Hospital. He has served on the faculties of Einstein, North Shore University Hospital, and New York Presbyterian Hospital. He was in private practice for more than 25 years in Mt. Kisco, NY, and also in New York City.

Dr. Selman is Board Certified in Pediatrics, Child Neurology, Neurodevelopmental Disabilities, and Sleep Medicine.
Blythedale’s Top Services

- Ventilator Weaning - Blythedale is widely recognized as a national center of excellence due to the Hospital’s extraordinary success in weaning fragile infants and children from the technology previously needed to sustain their lives.
- Traumatic and Acquired Brain Injury - Blythedale is a longtime leader in the treatment of brain injury, including Traumatic Brain Injury (TBI) and Acquired Brain Injury (ABI) from various conditions (such as meningitis, encephalitis, tumor, stroke) and post-infectious causes.
- Pre- and Post-Organ Transplants - Blythedale has cared for children pre- and post-organ transplant for many years. The new “positive pressure” isolation rooms allow us to care for children with compromised immune systems even sooner after treatment.
- High Tech Nutritional Support and Feeding Therapy - Blythedale has extensive experience in weaning infants and children from parenteral feeding or tube feeding, and decreasing dependence on tube feedings.
- Burn and Wound Care - Our specialized burn rehabilitation teams provide acute comprehensive inpatient burn rehabilitation and wound care to children who are admitted from regional tertiary care centers.
- Complicated Trauma/Post- Surgical Orthopedics - Blythedale is one of the nation’s leading providers of comprehensive pediatric rehabilitation services.
- Spinal Cord Disorders - Blythedale’s interdisciplinary team specializes in the management of acute spinal cord injury, acute and inflammatory polynuropathies, and other spinal cord disorders.
- Complicated Pain Syndromes - Blythedale’s interdisciplinary team helps children maximize function, minimize disability and improve coping skills.
- Childhood Cancers - Blythedale’s 24-hour staff of pediatric specialists support the medical and rehabilitative recovery of children with all types of cancer.
- Genetic and Neuromuscular Disorders - Each child’s team works collaboratively to identify goals to improve mobility, foster independence, and address the medical needs of children with rare and complex conditions.

NMDAR Encephalitis

by Laura J. Mirkinson, M.D., F.A.A.P., Chief of Pediatrics

Encephalitis, an inflammation of the brain, is a rare condition, most commonly caused by viruses and occasionally caused by bacteria or non-infectious conditions. Historically, encephalitis was frequently caused by infectious illnesses such as measles, mumps, rubella, tuberculosis and syphilis. West Nile and Lyme disease are also well known etiologies of encephalitis. In 2008, the first study documenting a large group of patients with NMDAR or N-methyl D-aspartate receptor encephalitis was reported (Dalmau 2008). This unique condition is closely associated with a newly discovered antibody, produced by the immune system against non-brain tissues such as teratomas. Although the antibody is produced against tissues outside of the brain, they bind to specific and important receptors in the brain, including the NMDA receptor, resulting in encephalitis. Ultimately, synaptic transmission and nerve excitability is affected (Lancaster 2011).

In the first large group of adult patients described with NMDAR encephalitis (Dalmau 2008), the patients were overwhelmingly female and presented acutely with apparent psychiatric symptoms such as psychosis and memory loss, confusing the initial diagnosis. However, within 2 to 3 weeks, seizures, involuntary movement disorders and often critically severe neurological deterioration requiring intensive care emerged. Forty percent had tumors, most commonly ovarian teratomas. In that study, patients with identified tumors who received early treatment had better outcomes than those with late or no tumor treatment or those who never had a tumor identified. In time, a clinical profile of characteristic signs and symptoms have become apparent, including acute psychiatric symptoms, movement disorders, speech disorders, dysautonomia, seizures, altered level of consciousness and respiratory depression (Maramattom 2011, Luca 2011, Goldberg 2011, Gataullina 2011, Schimmel 2009). Impairment of executive function has been reported as the primary ongoing deficit in children with NMDAR encephalitis (ladiesernia 2012).

NMDAR has become an essential consideration in the diagnosis of acute encephalitis in females and males in all age groups. It is confirmed by the
presence of anti-NMDAR antibodies in the serum and cerebrospinal fluid. In some patients, antibody levels may correlate with the clinical severity of the disease (Irani 2011). For many patients, substantial recovery can be expected if the disease is treated early with immunotherapy and multidisciplinary therapeutic interventions.

Acute treatment includes a combination of intensive care and immunosuppressive therapies including intravenous immunoglobulin, plasmapheresis, high dose steroids, and Rituximab® a monoclonal antibody used in the treatment of autoimmune diseases. Of course, if there is an identified tumor, it is removed. If not, close surveillance is required, because the risk for development of a tumor remains extremely high. The youngest patients are less likely to have tumors. However, it is important to note that in younger children, ovarian tumors can be extremely small and difficult to detect on abdominal CT or pelvic MRI (Frawley 2012). Relapses are known to occur months or years after the initial diagnosis and rates as high as 24% have been reported (Gabilondo 2011).

Five patients have been admitted to Blythedale since August of 2011 with antibody confirmed NMDAR encephalitis (see Table). These patients are admitted to our TBI Unit, where the quiet and low-stimulation atmosphere provides the appropriate environment for recovery. A designated team of specialists headed by our Chief of Neurology and supported by Pediatrics, Psychiatry, Physiatry, Social Work, Nutrition and all the therapeutic modalities (Physical, Occupational, Speech and Feeding Therapy) develop a multidisciplinary plan of care. Team rounds and ongoing conversations regarding

| TABLE 1: Patients Admitted to Blythedale with a diagnosis of NMDAR Encephalitis |
|-----------------------------------------------|-----------------------------------------------|
| **Initial Presenting Symptoms** | **Acute Course and Progress at Blythedale Children’s Hospital** |
| Female Adolescent |  |
| Awoke one morning confused, unable to dress herself, hallucinations | Acute course: deterioration in neurologic and respiratory function; PICU admission, immunosuppressive therapy, (+) anti-NMDA antibodies. Progress at Blythedale: improved cognition and strength, ability to ambulate, negotiate stairs, jump, catch a ball and perform all ADLs. Barriers to full recovery continue to be inattention, poor cooperation, agitation and perseverative behaviors. Slow but steady progress is being observed. |
| Female Adolescent 1-2d Headaches and agitation |  |
| Acute course: admission to a psychiatric unit, fever and seizures, admission to PICU. Onset status epilepticus and respiratory decompensation; mechanical ventilation and a tracheostomy. Ovarian teratoma was identified and removed. Immunosuppressive therapy, (+) anti-NMDA antibodies. Progress at Blythedale: weaned entirely from the ventilator and decannulated. Steady progress in all therapies and transfer to Day Hospital program. Inattentiveness noted to be interfering with her progress, methylphenidate initiated with good results. |
| Female Adolescent 5 |  |
| Sudden onset left facial numbness and slurred speech | Acute course: L hand weakness, slurred speech, facial twitching, agitation, progressive autonomic dysfunction, dystonia/movement disorder and temporal slowing on EEG; immunotherapy, (+) anti-NMDA antibodies. Progress at Blythedale: initially the patient was unable to follow commands, was nonverbal, and had decreased truncal tone. Within two weeks he showed a marked decrease in the involuntary movements and improved sleep. Now starting to ambulate, increased eye gaze, smiling and vocalizing vowel sounds. |
| Male Child |  |
| Fever, headache, seizure | Acute course: repetitive right arm movements, right eye deviation and drooling; treated for acute seizures and discharged to home. Developed involuntary movements and a general loss of function, episodes of asystole (requiring the placement of a pacemaker), respiratory failure and severe dysautonomia. (+) anti-NMDA antibodies; immunosuppressive therapy. Progress at Blythedale: Weaned from the ventilator to a tracheostomy collar. Continues to require significant medical support for the neurologic complications, severe cognitive and motor deficits. |
| Male Toddler |  |
| Tantrums and changes in behavior | Acute course: initial changes in behavior, then developmental regression, involuntary movements, L hemiparesis, agitation, insomnia, aggressive and self-mutilating behaviors. (+) anti-NMDA antibodies; immunosuppressive therapy. Progress at Blythedale: within two weeks, left hemiparesis was reduced to a right handed preference, noted improvements in speech, gait and sleep. |

The recognition of the acute presenting signs of NMDAR encephalitis is essential for clinicians in the acute care arena. Neuropsychiatric findings are prominent and early immunotherapy is associated with the best prognosis for these patients, although relapses requiring re-treatment do occur. In the subacute and chronic phases, the course of recovery can differ in its speed, but the necessity for multidisciplinary intervention is clear and the need to provide sufficient time for treatment to be effective is paramount. NMDAR encephalitis dramatically changes the capabilities of previously normal children and the requirement for family support cannot be overstated. At Blythedale, we are proud to treat and respect the family as a whole as we support and guide our patients on the road to recovery.

Additional information, footnotes and charts can be found on our website at www.blythedale.org
**What is GAS?**

Goal Attainment Scaling (GAS) is a family-centered outcome measure. But it is different from traditional outcome measures in that, upon admission, patients and families are asked to select their most important goals. The clinical team then works with the family to set expected outcomes for these goals. Common functional outcome measures are insensitive to many goals that are important to patients and their families. In addition, many of our patients are admitted for comprehensive medical issues not addressed by functional scales. GAS is flexible. It is a measure of how closely a child met expected outcomes set by the treating team with the family and child.

**How is it implemented?**

For implementation, a patient and family are asked what their top two or three goals are for a particular hospitalization, or intervention. The multidisciplinary team along with the family and the patient then negotiate what outcomes can be expected following treatment. A goal can be as simple as being able to open and close the Velcro on his shoes or as complicated as learning to operate a motorized wheelchair. Goals must be SMART (specific, measurable, achievable, realistic and time-sensitive). Once goals are set, they can be weighted by the patient and family in terms of how important they are and how difficult they will be to achieve.

**How is it scored?**

Scoring is on a five point scale from -2 to +2 with 0 representing achievement of a goal. A +1 is a little better than expected, and a -1 is falling slightly short of expected outcomes. Scores are converted to “T-scores” so that group results can be assessed. In this way, we can see how we are performing as a hospital for all patients and for particular groups of patients.

**What do the clinicians think?**

The initial reaction of the physicians using the scales has been very positive. According to one of our physicians, she feels it has brought her closer to the patients and their families. And others agree. We hope that GAS will be one more way in which Blythedale is a patient-centered, family-focused hospital.

Joelle Mast, Ph.D., M.D. is the Chief Medical Officer and Barbara Ladenheim, Ph.D. is the Director of Research at Blythedale Children’s Hospital.
Blythedale has a long tradition of providing graduate medical education for residents and fellows. Teaching is an important part of our mission and we believe it benefits both the student and the teacher. We currently are part of the training program for physiatry residents at New York Presbyterian-Columbia/Cornell, New York Medical College, orthopedic residents from Montefiore/Albert Einstein, and the fellowship program in pediatric rehabilitation at Montefiore/Albert Einstein. In addition, fellows in pediatric pulmonology and child psychiatry come to Blythedale from Westchester Medical Center/NY Medical College.

We have expanded our graduate medical education to include rotations that are selected by residents as part of their elective time in training. These selectives can range from one week to one month. Blythedale offers a very important learning opportunity that cannot be duplicated anywhere else in New York State. Our resident selective includes time on the inpatient units (infant and toddler, pediatric/adolescent, TBI), Day Hospital and the outpatient department. Our selective includes shadowing not only pediatricians but also medical specialists in physiatry, psychiatry/psychology, pulmonology and neurology as well as physical, occupational and speech/feeding therapists. Specialized services that are important to patients but not part of a traditional pediatric residency program include brace and equipment clinics with the opportunity to learn about splinting and orthotics and other equipment.

Residents can see the progress made after discharge from the Intensive Care Unit to Blythedale. A true understanding of interdisciplinary care and the role various specialists play is gained by attendance at our interdisciplinary care plan meetings at Blythedale.

Observation in our Day Hospital Program further expands training along the continuum of care. The Day Hospital for children with need for daily medical and/or therapy is focused on meeting functional goals so that the child can be discharged to the community with therapy, medical and educational needs in place. For pediatric residents who plan to go into practice, understanding the needs of children with complex medical problems, and how various services can be coordinated is invaluable.

Presentation of our selective program has received support from training programs in the area and we look forward to residents taking advantage of this unique and rewarding experience.

What our residents have to say:
“This rotation is an invaluable experience in our training.”
“I now am much more comfortable in caring for patients with such highly unique conditions.”
“A wonderful experience.”
“Every patient interaction was a valuable lesson.”
Recognized as a regional authority in pediatric rehabilitative therapies in the New York metropolitan region, Blythedale is pleased to again offer an intensive upper extremity (UE) therapeutic summer program to children (ages five through 10) with hemiplegia or hemiparesis.

The six-week “Two-Hand All-Stars” occupational therapy treatment program promotes improvement in two-handed skills for children with upper extremity limitations (commonly due to cerebral palsy, TBI and stroke). Each day will consist of a dynamic interplay of fun, educational, social and therapeutic activities aimed at optimizing bimanual skills.

This program utilizes a removeable constraint mitten on the unaffected hand, with a decrease in use as the program continues. Individual therapy and group activities will be provided through a structured schedule to work on different motor and sensory components, and functional skills that promote use of the affected hand when the mitten is on. Bimanual functional activities will be designed to facilitate bimanual skills when the mitten is off. OT evaluations are ongoing throughout the session, and communication with parents is paramount in order to ensure skills are carried over at home.

For additional information, please contact Director of Occupational Therapy Julie Knitter at (914) 831-2503 or email to juliek@blthedale.org.