For Dr. Milicent Mitchell, Chief of Pulmonology at Blythedale Children’s Hospital, the success of the Hospital’s nationally recognized Ventilator Weaning Program can be measured in many ways. In reviewing the highly impressive outcomes achieved over the last 15 years, several things stand out, including the fact that 80% of the children admitted to Blythedale for ventilator weaning are successfully weaned, 85% of our patients are discharged home, and, after six years, 97% of the children weaned remain ventilator free.

Impressive statistics for sure. But for Mitchell, who also serves as the Coordinating Physician for the 46-bed Infant and Toddler Unit, it’s the stack of holiday cards she receives every year from the “graduates” of the Program that remind her of the vital role Blythedale plays in giving families back their lives.

Blythedale is the only specialty children’s hospital in New York State that offers a comprehensive pediatric ventilator weaning program, and more than one-third of all children admitted to Blythedale are referred for ventilator weaning and respiratory care. To date, more than 1,500 medically fragile infants and children have been successfully weaned.

“Our high rate of success is the direct result of the committed efforts of a finely honed team, with many years of experience in all aspects of caring for infants and children with complex medical needs,” said Blythedale Chief Medical Officer Joelle Mast, Ph.D., M.D. “We are admitting patients with multi-system involvement, complex congenital anomalies, and complicated cardiac and pulmonary diseases. We are very proud of the superior outcomes we are achieving with these extraordinarily fragile patients.”

This intensive program is run by Blythedale’s pediatric pulmonologists and is complemented by a 24/7/365 in-house staff of board-certified pediatricians, 20 full-time pediatric respiratory therapists, and experienced nurses, many of whom have trained in NICUs and PICUs.

The interdisciplinary team also includes board certified rehabilitation physicians, child neurologists, child development specialists, pediatric physical, occupational, speech and feeding therapists, nutritionists, and social workers. A full-time discharge planning nurse coordinates equipment needs and home care.

The team approach is critical, says Dr. Mitchell. “Ventilator weaning requires a dedicated group effort, because weaning affects all aspects of care.”

The role of the dietitian, for example, is critical. A

Continued on page 3
LETTER FROM THE CHIEF MEDICAL OFFICER

Dear Friends,

This year we celebrate something very special at Blythedale Children’s Hospital - the 15th anniversary of our Ventilator Weaning Program. We are very proud of the program we have developed, and of the extraordinary outcomes we have achieved in helping this increasingly fragile population achieve independence from mechanical ventilation. This issue of Pediatric Insight highlights this unique program, and offers a glimpse of the vital role played by all the members of our interdisciplinary team.

In this issue, you will also find an article on the gait analysis research conducted by several of our physical therapists. Our team is evaluating the effectiveness of utilizing BalanceMaster technology as a way to improve gait velocity and speed in order to safely cross a busy street. It’s an example of yet another way we are using research to improve the delivery of care to children with complex medical needs.

I also encourage you to read our “Q&A” with Physical Therapist Mara Abrams, and learn a little more about our aquatic therapy program.

If you’ve not yet had the opportunity to visit our new inpatient Hospital, I encourage you to contact us and make an appointment for a tour!

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

Why Blythedale for Ventilator Weaning?

• Board Certified Pediatricians 24/7 and experienced nursing staff (many coming from NICUs and PICUs).
• 24/7 pulmonary and respiratory support (20 full-time pediatric respiratory therapists).
• State-of-the-art medical technology, monitoring equipment, and new Maquet Servo-i ventilators enable staff to respond to a patient’s rapidly changing condition.
• Largest hospital-based pediatric therapy department in New York State, with 85 full-time pediatric therapists (physical, occupational, and speech pathology). In addition, a therapeutic feeder (specially trained speech or occupational therapist) is assigned to each patient.
• 36% of all children are admitted for ventilator weaning and respiratory care.
• 80% weaned from the ventilator.
• 85% of our patients are discharged home.
• After six years, 97% of the children weaned remain ventilator free.
• High Flow Nasal Cannula, CPAP and BiPAP management and weaning.
• Extensive experience in enteral feeding, weaning infants and children from supplemental tube feeding (naso-gastric, gastrostomy, and jejunostomy), and decreasing dependence on tube feedings.
• Full-time child neurology and pediatric rehabilitation coverage.

In the News...

Blythedale’s Caregiver Training Program was prominently featured in the Wall Street Journal. The article can be accessed by visiting: www.blythedale.org/in-the-news
weaning infant frequently loses weight due to the energy expended during the weaning process, therefore caloric intake must be closely monitored and adjusted to meet his or her highly specific needs. Blythedale also has 49 therapeutic feeders (specially trained speech or occupational therapists) with extensive experience in enteral feeding, weaning infants and children from supplemental tube feeding, and decreasing dependence on tube feedings.

Frequent communication with referring physicians is critical, Mast emphasized, and extensive caregiver training is a “vital part of the protocol” (see accompanying sidebar on page 7).

The Hospital’s new $65.3 million, 56,000 square foot inpatient building, which opened last December, offers the latest in state-of-the-art medical technology, as well as a multitude of amenities for patient families.

According to Director of Respiratory Care Dawn VanSickle, the new building has played a significant role in facilitating the weaning protocol.

“The larger patient rooms offer great flexibility in terms of moving the vent and allowing multiple clinicians to be bedside at once,” she said. “And the spacious accommodations for parents allow them to be part of the process from day one.”

VanSickle says that while the numbers fluctuate to some degree based on the daily census, there are typically between 20 and 35 ventilators running daily, while staff can have as many as 20 infants and children undergoing weaning on any given day.

“We use an acute care ventilator designed for micro-preemies, born as early as 24 weeks gestation” she said. “They can’t tolerate a portable ventilator yet, but we are still able to admit them to Blythedale. We also have expertise in the use of High FlowNasal Cannula, CPAP and BiPAP, which are all non-invasive forms of ventilation. The use of these technologies is booming in the new inpatient hospital.”

With families every step of the way is a social worker, assigned upon admission. In addition to securing the resources needed to go home safely, Social Work also involves arranging for services such as medical care, therapy, and schooling, acquiring equipment and supplies as needed, and making connections with

**PROFESSIONAL PROFILES**

**Milicent A. Mitchell, M.D. and Agnes Banquet, M.D.**

Dr. Mitchell is Blythedale’s Chief of Pulmonology and the Coordinating Physician of the Hospital’s Infant & Toddler Unit.

She is Board Certified in Pediatrics and completed a residency in pediatrics and a pulmonary fellowship at the State University of New York Health Services Center/Kings County Hospital in New York.

Dr. Agnes Banquet is an Attending Pulmonologist at Blythedale Children’s Hospital. She is Board Certified in Pediatrics and Pediatric Pulmonology.
Robot-Assisted Therapy Research Turns to Anklebot

by Barbara Ladenheim, Ph.D., Director of Research

For the past several years, in collaboration with scientists from MIT, researchers at Blythedale Children’s Hospital have been involved in robot-assisted therapy research. Our studies will serve to enhance and better understand motor recovery after brain injury, and to assist in the development of new treatments that maximize this recovery.

We have been studying the efficacy of robot-assisted therapy in children with upper extremity spasticity. Now we have the opportunity to test a novel pediatric ankle robot (anklebot) designed to reduce motor impairments and improve gait in children with Cerebral Palsy and acquired brain injury. The anklebot has been used successfully with adult stroke patients and we are presently involved in “alpha” testing the apparatus with typically developing kids to fine tune the setup and to obtain some basic evaluation data. We will then study the effectiveness of therapy using the anklebot in children with lower extremity spasticity.

This technology has great potential for improving function in children with lower extremity impairment. We are very excited to continue to be involved in this research.

Researchers Study Role of BalanceMaster in Improving Gait Velocity

by Linda Fieback, P.T., Asst. Dir. of Physical Therapy

A team of physical therapists at Blythedale Children’s Hospital has embarked on an important research study to assess walking velocity, as it relates to crossing a city street. The study utilizes the Hospital’s BalanceMaster, an interactive technology which offers visual feedback to patients as they stand on different surfaces, challenging and strengthening components of their balance skills.

The purpose of the study is to determine if selected sequence training using the BalanceMaster, added to established physical therapy treatment programs, will increase gait velocity of ambulatory children receiving in- or outpatient rehabilitation in relation to their ability to cross an intersection within the confines of a community traffic signal (a gait speed of 120 cm per second is the typical constraint imposed by most city traffic lights). By devising a setting where children are challenged to safely navigate a virtual street, therapists are able to collect data related to optimal speed and velocity.

The BalanceMaster enables researchers to simulate the experience of crossing a city street by creating visual conflict, the sensation created by rough terrain or potholes, vestibular challenges, and a real world life experience.

Previous studies have shown that minimum velocity for crossing the street is seldom addressed or documented when assessing gait speed in patients, and that distances required for community independence were greater than those assessed in rehabilitation settings. Additionally, clients who are ambulatory within their rehabilitation environment often have a wheelchair or stroller for community maneuverability. One of the major criticisms of clinic/lab-based measures of gait speed is that relative performance may not be representative of independence within the community. Only one study evaluated gait speed in the clinical environment compared with the natural environment. This study...
showed poor agreement between clinically-tested ambulation speeds versus tests in natural surroundings. Finally, although pediatric standardized tests of motor skills evaluate walking performance as part of a multi-dimensional assessment, they don’t place these skills in the context of the environment in which the child must function. In addition to standard rehabilitation, sequence training using fundamental components of gait, such as weight shifting and dynamic mobility, may allow for a faster and greater improvement in gait velocity.1

Recognizing the importance of gait speed, as it relates to crossing streets, getting to class on time, and other important tasks of daily living, therapists developed a set of criteria by which participants would be selected for the study itself. To qualify for participation, children must be inpatients of Blythedale Children’s Hospital between the ages of five and 21, with an ability to ambulate independently with or without an assistive device and/or lower extremity orthoses; complete the functional assessment “Walk Across”; and possess the ability to follow and understand experimental procedures. In addition, they must not have a progressive disorder or visual field loss. To date, 44 children have participated in the study. Of the wide range of diagnoses represented, the most common are cerebral palsy, traumatic brain injury, acquired brain injury, remission from cancer, and Guillain-Barre syndrome. Because the patient population is so diverse, the team determined that a large number of subjects were required in order to achieve meaningful data.

The children were randomly assigned to one of two groups: a weekly BalanceMaster sequence training group (in addition to their regularly scheduled therapy sessions) or a group that continued their regularly scheduled therapy sessions over a six-week period. Both groups were tested at baseline and after six weeks for gait velocity and balance. Gait velocity was measured by “Walk Across” Functional Assessment using the BalanceMaster long force plate.

Early results indicate that specialized balance training (that highlights weight shifting and dynamic mobility) increased study participant’s gait velocity when compared to that of subjects in the standard group. While both groups demonstrated change in velocity the mean speed for the trained subjects was 108 cm/sec., approaching the goal of 120 cm/sec. Assessment of gait in a contextual environment may be conducted in rehabilitation settings in order to promote carryover of therapeutic training within the community. This study suggests that work on gait components such as weight shifting and mobility using a tool such as the BalanceMaster for enhanced feedback may improve efficiency of training.1

“Analysis of walking speed is especially important to patients who live in a city and need to cross busy streets with uneven surfaces,” said Blythedale Chief Medical Officer Dr. Joelle Mast. “While gait has been well studied in adult patients, less is known about the gait function in the pediatric population who have gait impairment. This study reflects the emphasis on assessing children’s impairments in real life activities.”

The team presented their findings to date at the annual meeting of the American Physical Therapy Association in Florida, in June. The team plans to evaluate seven more subjects for a complete study.

Oversight was given for use of participants by Blythedale’s IRB. The research team includes Linda Fieback PT., M.A., C-NDT; Nia Toomer-Mensah PT., D.P.T; Mark Felsenfeld PT., M.S.; and Teresa Smith PT., M.S., NCS, C-NDT

1 Fieback, Linda - An Intervention Providing Sequence Training to Improve a Child’s Ability to Cross a Community Traffic Signal in a Safe and Timely Manner Using the Balance Master™: A Randomized Control Trial (2256-R) PTJ, May ’12, Vol 92, Issue 5
What is Aquatic Therapy?
Aquatic therapy is physical therapy performed in the water by a physical therapist to benefit patients in ways that land-based physical therapy cannot.

For whom is aquatic therapy (or pool therapy) best suited, and why?
Here at Blythedale, many children with many different diagnoses benefit from aquatic therapy. We’ve worked with children who have cerebral palsy, brain tumors, spinal cord tumors, muscular dystrophy, Guillain-Barre, TBI, transverse myelitis, peripheral neuropathies, AVM, ADEM, and orthopedic injuries to name a few. Depending on the child’s love of the water and motivation, amazing gains have been made in the P.T. pool.

Why is Blythedale well-suited to provide this type of therapy?
Because we make it a fun and motivating environment. Our physical therapists are trained in aquatic therapy, which adds to their excellent land-based skills. The pool physical therapist coordinates the child’s plan of care with the child’s land-based physical therapist and physiatrist. Additionally, the pool physical therapist has the advantage of seeing the child on land as well as in the water. Because of this close contact, the pool therapist can determine how much carryover the child is achieving in the transition from water-based skills to land-based skills.

What type of therapist provides this service, and is special training involved?
All of our physical therapists get the opportunity to rotate into the physical therapy pool. Physical therapists study and learn how to utilize the pool’s unique advantages. Here, our water temperature averages a balmy 92 degrees. This warm water temperature helps to relax muscles, improve range of motion and, in some cases, reduce pain. The physical therapist takes advantage of the property of water known as buoyancy. This can make a child feel lighter. Buoyancy can make it easier for the child to move. We also can use the water to make it harder for the child to move if we want to target certain muscle groups for strengthening. Our pool has two water depths. We use different depths for many reasons. One simple reason is so that children of varying heights can experience standing in the water and use their antigravity muscles with control. Sometimes we use everyday pool apparatus such as kickboards to gain control of stomach and gluteal muscles or lengthen hip flexors. Other times one can observe the pool physical therapist handling the child so that the trunk rotates. This can help provide stretch and if the child has the control, they can learn to use the muscles that rotate the trunk. Working on these deep postural muscles allows the children to perform more controlled movements of the arms and legs. The pool physical therapists learn to use the water to promote cardiovascular benefits. In a simple way, the children can gain an awareness of breath control through blowing bubbles. More challenges occur when the child is encouraged to move faster thus challenging the cardiovascular system even more.

What do you think are the greatest benefits of aquatic therapy?
P.T. pool therapy can restore function and mobility, improve independence, and foster fitness. As a child learns swimming skills they not only become safer but they learn a life-long skill that they can enjoy in their community when they are discharged from Blythedale.

Mara Abrams has been a physical therapist at Blythedale for more 20 years.
Empowering Parents to be Confident Caregivers

For the parent of a child with complex medical needs, bringing baby home requires more than a new car seat and a book on newborn care. Blythedale’s highly trained staff is well-versed in simplifying complicated technology, and ensuring that caregivers feel confident not only in their ability to care for their child, but stand fully prepared to respond to potential emergencies, should they arise.

Blythedale’s Respiratory Therapy staff includes 20 full-time registered respiratory therapists (RRT) who are PALS-certified and NPS-certified (or on track for completion). Working collaboratively with the Hospital’s staff of nurses, caregiver training begins at bedtime, upon admission.

“For many parents, this is the first time they are providing hands-on care for their child,” said Kimberly Everett, R.N., B.S., C.P.N., Senior Director of Nursing. “Many have never bathed their baby, or even changed a diaper. We start at the beginning and help them bond with their child. This immediately facilitates transition to the more complicated process of becoming comfortable with all the technology.”

In 2011, 89 caregivers were trained in areas including ventilator care (they are taught to break down and reassemble all the components, in order to familiarize themselves with the machine), ambu bag, suctioning, traechoestomy care, supplemental oxygen use, and more.

“The education is extensive,” said Dawn VanSickle, B.S., R.R.T.-NPS, Director of Respiratory Care. “At Blythedale, they are trained on all the equipment they will go home with, so they will be fully prepared to go home, travel to doctor’s visits, and handle an emergency.”

Ventilator Weaning

Continued from page 3

community agencies that can provide ongoing help. Discharge planning begins on admission and is a key part of the collaborative process.

The average length of stay at Blythedale is approximately 50 days, but varies according to each patient’s unique circumstances.

“Over the last 15 years there has been a drastic change in the acuity of our patients, said VanSickle. “Babies are saved earlier and at a much lower birthweight. They are truly beating all odds.”

“Our families come to us at the most uncertain time in their lives, and we are able to help their children reach their maximum potential,” said Dr. Mitchell. “It is enormously gratifying to hear from our ‘graduates’ and learn of all they have come to achieve following their discharge from Blythedale.”

For more information on Blythedale’s Ventilator Weaning Program, please contact Director of Clinical Outreach Theresa King at 914-831-2431, or email her at theresak@blythedale.org.
iPads for Babies?

For children like Mercedes, whose fragile medical condition may not allow for a more strenuous therapy regimen, Blythedale’s therapists are finding increasing benefits from portable tools such as the iPad.

According to Jean Marie Florkowski, Mercedes’ occupational therapist, there can be benefits for babies and toddlers in the pre-writing stage from the visual stimulation. For a baby with complex medical needs, the portability and ease of use offers an opportunity for “play” that can be provided at the crib.

In Mercedes’ case, multiple admissions and surgeries have left her in varying stages with respect to what she can handle therapeutically. According to her occupational therapist, while Mercedes’ strength is limited “it is less of an issue with the iPad as she can activate and receive feedback from her reaching and working through her simple touch of the screen versus some toys that you need to apply force or pressure that she is lacking currently”. In addition, she explains, “She loves the iPad so much that I can actually distract her and hold her in static developmental positions now while she is able to maintain her vitals and (respiratory) saturation levels”.

This also allows for great carryover to the home, as parents are given the ability to load the same “apps” for use upon discharge. The Hospital currently utilizes 13 iPads in the Speech Pathology and Audiology department, and seven in the Occupational Therapy department.

Pictured above: Mercedes celebrates her first birthday at Blythedale with her parents and other family members.