Hebron Family Receives The Gift Of A Lifetime

April 2 promised to be a special day for the Mackay family of Hebron, Conn. This was the day that Jack Mackay would turn 9-years-old. And while it didn’t turn out quite the way it was planned, it certainly turned out to be a day the family would never forget.

Several hours before a scheduled birthday party featuring cake, presents and laser tag, Jack was playing golf with some friends in a neighbor’s yard. What seemed like a good opportunity to burn off some energy before the party took an unexpected turn for Jack’s parents, Andy and Beth, when they received a call with the following news: “Jack’s been hurt really bad and he’s bleeding everywhere!”

Jack had inadvertently been struck in the head with a golf club, resulting in a 1-½ inch gash on the side of his forehead. Once the bleeding slowed, Jack appeared to be fine and was answering questions coherently. To be safe, Andy took Jack to a local walk-in clinic to be examined.

“The first thing that went through my mind was the Natasha Richardson tragedy which had occurred just a few weeks before,” said Andy. “I recalled all the news stories saying that you should have every head injury, especially those of a child, examined immediately.”

At the local clinic, Jack was examined and Andy was relieved to learn that he would just need a few stitches. But before Andy could even share the news with the rest of the family, the situation quickly escalated – Jack’s eyes rolled back and he began shaking violently at the onset of an acute seizure.

Without any hesitation, Andy and Beth were told that Jack was going to be flown to Connecticut Children’s Level I Pediatric Trauma Center where they would be met by members of the Medical Center’s neurosurgery team.

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Education Plus Research Equal Cutting-Edge Clinical Care At The Center for Motion Analysis

With its 30th anniversary just a year away, the Center for Motion Analysis at Connecticut Children’s Medical Center continues to be a valuable asset not only within Connecticut but to patients, caregivers, and researchers across the globe as well.

Since the Center opened in 1980 at the former Newington Children’s Hospital, more than 9,000 children have benefited from the information that has been collected about their walking difficulties.

“Our orthopaedic surgeons use the motion data to precisely address each child’s needs through orthopaedic surgery and other interventions, and then to measure treatment outcomes objectively by comparing motion data collected before and after treatment,” said kinesiologist Sylvia Öunpuu, MSc, Director of the Center.

The Center for Motion Analysis provides comprehensive motion analysis services for treatment decision-making and evaluation for a variety of gait issues including neuromuscular disorders such as cerebral palsy and traumatic brain injury in addition to general orthopaedic deformities such as club feet, Blount’s disease and torsional deformities of the legs. Formally known as the Gait Lab, the Center for Motion Analysis relocated in 2007 to Connecticut Children’s major specialty center in Farmington.

During the late 1970s, orthopaedic surgeon James R. Gage, MD, decided that there must be a better way of understanding the complex movement abnormalities in children with cerebral palsy other than the standard clinical tools. In a unique partnership, Dr. Gage and United Technologies developed an automated method of documenting motion in three dimensions so that the underlying causes of walking problems in children could be identified more reliably.

“When I got the first fully automated gait lab in the world, I felt like a glider pilot in the

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As the number of visits to Connecticut Children’s continues to grow each year, the amount of traffic on our website has increased as well. Recognizing that Connecticut Children’s is the region’s only academic medical center devoted exclusively to children, many people turn to our website to learn about a wide variety of pediatric issues, ranging from the illnesses and conditions we care for at the Medical Center to the research we are conducting to discover cures for future generations.

To help meet the expanding needs of our patients, families and health care partners, Connecticut Children’s has redesigned our website to make it more efficient and easier to use. We encourage you to take a look at www.connecticutchildrens.org.

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CONNECTICUT CHILDREN’S IN THE NEWS

Connecticut Children's Nurses Receive Nightingale Honor

Five nurses from Connecticut Children’s Medical Center are the recipients of this year’s Nightingale Award for Excellence in Nursing.

In honor of National Nurses Week in May, VNA Health Care Inc., and hospitals throughout Greater Hartford established the Nightingale Award in order to provide a unique opportunity to inspire future nurses and to focus public attention on the nursing profession. The five recipients from Connecticut Children’s as well as winners from other Connecticut hospitals were honored at an April 30 reception at the Hartford Marriott Downtown.

This year’s recipients, who were nominated by their nurse managers and fellow staff members, include: Deb Civello, RN, of the Emergency Department; Linda Groom, RN, of the Operating Room; Debbie Hallbach, RN, BSN, of the Post Anesthesia Care Unit; Marie Lemay, RN, BSN, of the Neonatal Intensive Care Unit; and Joanne Walczak, RN, BSN, CPON, of Hematology/Oncology.

A NOTE FROM OUR WEBSITE:

Our 5-year-old son Holden broke his arm – badly – on June 1st. We just wanted to thank everyone at Connecticut Children’s for your care of our son. Paula, our family specialist, was WONDERFUL! She explained everything to our son in such a kid-friendly way that he was able to get an I.V. inserted without a tear. She also went above and beyond by putting shoes on and going into the operating room to stay with him until he fell asleep.

Dr. Mark Lee has been superb. Holden had such a terrible break and his arm – a week later – is pain-free and looked just about perfect on the x-ray this week.

Rabin in the casting room this week for our follow-up was unbelievably patient with our son, who was very upset, anticipating pain that he later admitted never occurred. Robin had a wonderful sense of humor and an incredible bedside manner. He took the time to explain the details and procedures to Holden to try and calm him down.

I wish I could name all of the nurses and staff members on 6/1 and then for our follow-up on 6/9 who were so incredibly kind to our son and us, and who were clearly born to work with children.

Thank you!!!!!!!!!!!

Peter & Carrie Conroy and our son Holden
Glastonbury, CT

Benefit Raises Funds For Connecticut Children’s Pediatric IBD Center

The Hartford Club was the location in early April for an elegant dinner and auction to raise funds and awareness for the vital mission of The Center for Pediatric Inflammatory Bowel Disease (IBD) at Connecticut Children’s Medical Center. The event, “For the Children... New Frontiers in IBD Research,” raised more than $75,000 after expenses. The proceeds from the event will help advance a cutting-edge research agenda dedicated to finding new therapies and ultimately searching for a cure for pediatric inflammatory bowel disease.

Attendees at the event enjoyed a cocktail reception, silent auction, entertainment and dinner. Students from the Music Department at Hall High School in West Hartford, CT performed at the cocktail hour and during dinner. Guests also learned more about the latest research underway at The Center for Pediatric IBD.

Joanne Millette, one of the committee members who helped to organize the event, shared a personal experience from the night of the dinner with Chris Pates from the Connecticut Children’s Medical Center Foundation. She said, “Of the many memories of the event, one stands out in my mind. I had just finished talking with a couple of fellow committee members about the wonderful turnout and a strange thought occurred to me. I looked around the room and realized that for the first and only time in the ten years since my daughter became ill, I was surrounded by HUNDREDS of people who not only knew what IBD is, but were somehow committed to a child with the disease. And all these people were celebrating the work of our Center and its importance to our kids. There was a joy, energy and sense of hope in that room that I wanted to bottle and preserve. Hopefully, it will stay with us all and keep us moving forward.”

Connecticut Children’s is home to the Center for Pediatric Inflammatory Bowel Disease, which is the largest clinical program for children with IBD in Connecticut, Rhode Island and Western Massachusetts. The Center provides treatment to children diagnosed with Crohn’s disease and ulcerative colitis and access to the latest clinical therapies including promising national trials of new biologic therapies. Jeffrey S. Hyams, MD, Head, Division of Digestive Diseases, Hepatology and Nutrition, directs the Center and is recognized as a pioneer and national leader in the field. Research interests include National clinical trials for Crohn’s disease and ulcerative colitis, inflammatory bowel diseases and its effect on bone density, mucosal immunology and allergy, interactions between microorganisms and epithelial surfaces, natural history of IBD and nutrition support.

In attendance at the benefit included (from left): Jeffrey Hyams, MD, head of Connecticut Children’s Division of Digestive Diseases, Hepatology and Nutrition; event committee co-chair Carol Goldberg; and event emcee Joelyn Maminta, news anchor and reporter for WTNH News Channel 8.

In Connecticut, Rhode Island, and Massachusetts, the Center for Pediatric Inflammatory Bowel Disease is the largest clinical program for children with IBD.

Connecticut Children’s Foundation Events website at www.connecticutchildrensevents.org

To comment on any articles appearing in this publication, please visit our website at www.connecticutchildrens.org. If you have a change of address or do not wish to receive future issues of Pediatric Matters, please call (860) 610-5700.
Medical Staff Member Creates $1 Million Legacy

A member of the Medical Staff at Connecticut Children’s has made a legacy gift of $1 million to establish an endowment to further advance clinical and research programs in neuroscience at the Medical Center and to enable investment in breakthrough technologies that improve treatment and care. This gift, which is part of the donor’s estate plan, is among a handful of extraordinary legacy commitments that Connecticut Children’s has received, or knows it will receive, since opening its doors in 1996.

In making this gift, the donor shared some personal feelings on why it was so important to include Connecticut Children’s as part of their family’s long-term estate plans. “It is a pleasure to enhance the further development of Connecticut Children’s Medical Center as the premier neuroscience program for children in our state.”

“It is difficult for me to express in words how grateful the entire Connecticut Children’s community is for this extremely generous and thoughtful commitment,” said Martin J. Gavin, Connecticut Children’s President and Chief Executive Officer. “As a result of this donor’s careful planning and willingness to share the details, Connecticut Children’s knows that we will be far better able to ensure our ability to care for the region’s children and families for generations to come.”

“Though the donor has chosen to remain anonymous, this story is being shared with their approval because of an express desire to inspire and encourage others to create similar legacies, or to let the Medical Center leadership know if you already have created one.

Philanthropic investments like this are central to being able to make miracles happen every day at the Medical Center, and to investing in the programs, research and innovations that improve the cures and treatments available for children.

Education Plus Research Equal Cutting-Edge Clinical Care
At The Center for Motion Analysis

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cockpit of an F-14. The computers provided data tracking in minutes that used to take days using traditional movie film,” said Dr. Gage.

The facility was the first gait analysis lab of its kind to fully automate and synchronize videotaping, infrared motion cameras, force plates and electromyographic data to record and measure the three-dimensional biomechanics and muscle contractions of walking in order to improve medical treatment.

Former UTC chairman Harry Gray provided more than $200,000 in funding and technical assistance to help open the Gait Lab. Engineers from the UTC Research Center helped develop technology that tracked how a walker’s body moves in three-dimensional space, how the foot impacts the floor and how all this data is captured and integrated by a computer.

Connecticut Children’s Director of Orthopaedics Jeffrey Thomson, MD, said after the Gait Lab opened the benefit of gait analysis for children with cerebral palsy quickly became apparent.

“Instead of children undergoing repeat surgeries every year, information from gait analysis enabled orthopaedic surgeons to do the corrective surgery all at once,” Dr. Thomson said. “The Gait Lab also provides objective data that can be reviewed one year, five years and even 10 years after surgical intervention.”

Throughout its history, the Center’s research capabilities have not only helped thousands of children, but also have had a broad impact on medicine. Its studies – conducted through the collaboration of orthopaedic surgeons and experts in biomechanics, kinesiology, physics, biomedical engineering and physiotherapy – have generated an enormous data resource describing the biomechanics of normal gait as well as the characteristics of gait and movement in a variety of neuromuscular and general orthopaedic disorders.

“The Lab has really been a phenomenal research tool from the beginning,” Dr. Nissen said. “The research has profoundly changed the medical community’s understanding of gait pathomechanics for multiple conditions resulting in better treatment decisions and improved outcomes.”

In addition to research on children with cerebral palsy, myelomeningocele and spinal deformities, one of the Center’s other notable studies took place in 2000 when the Center collaborated with the Stride Rite Children’s Group to study how babies learn to walk.

The end result revolutionized the design of the Stride Rite baby shoe. It also helped the Center’s clinical staff better understand the development of typical gait, an important step for understanding pathological gait.

And more recently, the Center has gained national attention for its research into the causes of injuries to young baseball pitchers.

Since 2001, the Center has been collaborating with orthopaedic surgeon Carl Nissen, MD, Director of Connecticut Children’s sports medicine program, Elite Sports Medicine, to study the epidemic of elbow injuries that affect young little league pitchers.

“There has been such an upswing in the number of elbow injuries in young pitchers that we have been examining the biomechanics of pitching in order to understand injury mechanisms based on technique and ultimately to prevent injuries,” Dr. Nissen said.

In addition to research, the Center for Motion Analysis has become known internationally for its educational programs, in particular its annual gait course; “Clinical Gait Analysis: A Focus on Interpretation.” The conference is a collaborative effort between Connecticut Children’s, Gillette Children’s Specialty Healthcare in St. Paul, Minn., and University Hospital Pellenberg in Belgium.

The three-day course takes place on a rotating basis every year at each site. Ounpuu said the course – which began in 1990 – attracts participants from as far away as Hong Kong, Germany, Japan and Australia and is limited to only 70 attendees.

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Sylvia Ounpuu, MSc, Director of the Center for Motion Analysis, said the Center’s research has changed the medical community’s understanding of many conditions affecting gait resulting in better treatment decisions and improved outcomes.

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As Pediatric Matters went to press we learned of the passing of Harry Gray. In addition to being one of the founding fathers of our Gait Lab, Mr. Gray has been a loyal supporter of the Medical Center since our days in Newington. Through his commitment and dedication, Mr. Gray has touched the lives of many children. We look forward to featuring a history of Mr. Gray’s contributions in an upcoming edition of Pediatric Matters. Our condolences go out to his wife Helen and the entire Gray family.

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Hebron Family Receives The Gift Of A Lifetime continued from page 1

neurosurgeon Jonathan Martin, MD, of Connecticut Children’s, informed them that Jack had not suffered any brain damage as a result of the accident. Jack, did however, have a fractured skull that was pressing against his brain, resulting in a sizable dent in his skull that would have to be elevated following the closing of the laceration on his head.

As Jack was wheeled into the operating room, Beth gave him a kiss and looked at her watch: 10:30 pm – exactly nine years ago to the minute that Jack was born. “I took that as a sign that we were exactly where we were meant to be and that we would have a happy ending,” said Beth.

“Jack had an acute fracture in which we drilled a hole and inserted titanium plates to level off his skull,” Dr. Martin said. “The procedure also carried some cosmetic significance due to the visibility of the fracture site on his forehead.”

Dr. Martin added that another reason for the procedure was to minimize any risk of infection to Jack. While closure of lacerations with underlying fractures can be accomplished in the Emergency Room, Jack’s age coupled with the above concerns made cleaning and closure in the operating room a better option for Jack both medically and emotionally.

“This surgery was the preferred option because we were able to comfort Jack’s parents and minimize pain or fears for him,” Dr. Martin said. “That’s the goal of any children’s hospital and something that was certainly accomplished with this successful outcome.”

After his operation, Jack spent one night in the Intensive Care Unit and one night in an inpatient room before being sent home and resuming school, just 96 hours after the accident.

“We can’t tell you how grateful we are to have this hospital nearby, how terrific Dr. Martin and everyone who cared for Jack was and what an impressive place Connecticut Children’s really is,” commented Andy several weeks after their ordeal.

As for Jack, while he wished it was under different circumstances, the ride on LifeStar and learning about the many different electronic devices he was hooked up to made it a birthday to remember, albeit with one small regret: “I only wish I could have stayed longer to play some of the Wii games,” said Jack with a smile.

Pediatrician Hopes Genetics Study Will Help Children Breathe A Little Easier

Improving the treatment of children with asthma through the study of genetics is a research goal of Christopher Carroll, MD, MS.

Dr. Carroll, a pediatric intensivist in the Division of Critical Care at Connecticut Children’s Medical Center, said asthma is the number one diagnosis for children admitted to the Pediatric Intensive Care Unit. Through his research, Dr. Carroll hopes to identify children who are at risk for severe asthma attacks, and examine if genetics affect how children respond to specific therapies.

“Children with mild baseline asthma can have severe attacks that require hospitalization or ICU admission,” said Dr. Carroll.

Through this research, Dr. Carroll wants to be able to target therapy to a specific child thus improving clinical care, shortening durations of illness and reducing side effects from ineffective therapies. Some of the preliminary data from his studies have been published in journals of the American Academy of Pediatrics and the American College of Chest Physicians.

“Basically what we’re finding is that if a child is not responding to one medication we should just try another,” Dr. Carroll said.

Dr. Carroll said asthma is most prevalent in the fall and spring, fall, because of back to school infections, and spring, because of the high number of allergens such as pollen. The average length of stay for children with asthma in the PICU is three to four days and the current fatality rate is zero. Since the study began data has been collected from more than 100 children thanks to the cooperation of their parents.

“Although the data we collect will not immediately benefit their children, the parents I’ve spoken to are very eager to enroll their child in this study because they know our findings will help children in the future,” Dr. Carroll said.

There are two phases to Dr. Carroll’s study. Phase 1 – which is beginning to wind down – involves the collection and processing of the data; and Phase 2 – which includes extending the study outside of the PICU and adjusting the therapies being administered to the patients.

There are several reasons why Dr. Carroll chose to research the role that genetic markers play in children with asthma. Some of them include the dozens of children admitted to the PICU with asthma as well as the lack of studies available. But he has personal reasons as well.

“I have a son with asthma and as a physician, I just simply want to improve the care for every child suffering from asthma,” he said.
Helping Children Find the Programs and Services They Need – When They Need Them

Connecting children with developmental or behavioral issues to appropriate, existing services and programs is an ongoing and complex problem. A problem that Dr. Paul Dworkin, Physician-in-Chief at Connecticut Children’s, has been making steady progress against for many years. “Children with developmental and behavioral problems are too often eluding early detection. Quality programs exist to help them, but we need to remove barriers that keep kids from connecting with the resources they need. In a nutshell, that is the idea behind the Help Me Grow model.” The program addresses these issues so well that it has grown from a Hartford based program, to a Connecticut wide program, to an eight-state model — and growing. And yes, there is international interest as well.

While the Help Me Grow model is gaining momentum across the country, it has its roots here in Hartford and in the passion of Dr. Dworkin. “I practiced primary care medicine within the University of Connecticut’s system for a number of years, and I was one of the earliest group of pediatricians who were trained in what would become Developmental and Behavioral Pediatrics. My interest has always been centered in promoting children’s optimal healthy development through the delivery of exemplary child health services. That has really been the theme of my training and clinical work for the last thirty years.” Cooperation and coordination has always been the root of successfully delivering early intervention programs for children with developmental and behavioral issues.

The Help Me Grow model.

Training – Targeted at child health providers to enhance the practice of developmental surveillance and screening (early detection). Grand rounds presentations are delivered through hospital based pediatric departments and large pediatric clinics across Connecticut. Trainees visit community-based pediatric practices and present guides and protocols for developmental screening and referrals to Child Development Infoline. Training is done by Child Health and Development Institute via a module in the Educating Practices in the Community (EPC) curriculum.

Single, confidential telephone access point – The Child Development Infoline (CDI), a specialized call center of the United Way 2-1-1, links families with young children to existing services and supports. When calling this number, families may choose to participate in the Ages and Stages Questionnaire which helps parents and providers monitor a child’s development. Infoline is staffed with trained child development coordinators who work directly with the family. It takes an average of seven contacts with a family to make the correct referral.

Current inventory of community-based programs – Infoline can only be effective if its information and referrals are accurate and timely. Information is kept current and referrals are accurate and only be effective if its information is kept current.

Results-based accountability – Annual outcome evaluation is conducted by the University of Hartford’s Center for Social Research. The review tests the programs effectiveness in matching family needs with program services, tracks the nature of incoming calls, and assesses Help Me Grow’s progress toward established goals. For instance, Help Me Grow received 2,522 calls during the fiscal 2007-2008 year. Most of the calls were from parents or guardians, however there was a substantial increase in calls from pediatricians (up 14%).

This increase is a direct consequence of increased pediatric outreach and training. While Help Me Grow is in its infancy, it has already emerged as a model program of national significance. Many states have some of the necessary components for a comprehensive, coordinated system. However, few have been able to create a model that is integrated, comprehensive, and effectively connects families with the most appropriate services. Based on the success of the Connecticut program, there’s been growing interest in other states and communities. Help Me Grow has been successfully replicated in Polk County, Iowa, and Orange County, California. With support from The Commonwealth Fund of New York City, the program is now being developed in Kentucky, New York, Oregon, South Carolina and Colorado.

“We have a six-member team that now assists in the selection of states to replicate the Help Me Grow model. The team builds on existing systems to create efficiencies and promote collaboration among agencies and state government,” explains Dr. Dworkin. “The political side of this has been fascinating to me. But we have found a genuine interest among lawmakers, state and private agencies, to build more cooperative and integrated systems to link children with optimal services. We are very optimistic about the future of the program and its impact on the health and well-being of at risk children everywhere.”
Spring Activities At Connecticut Children’s

Local Children Learn About Animal Bite Safety (above) About 140 pupils from Metacomet Elementary School in Bloomfield took part in this year’s Connecticut Safe Kids Day event which took place April 30 on the front lawn of Connecticut Children’s Medical Center. The event, which takes place every year in conjunction with National Safe Kids Week, included a 20-station course that includes presentations on this year’s safety theme of animal bite safety “Ask Before You Pet Me.” Safe Kids Connecticut is a program of Connecticut Children’s that is supported by the Connecticut Elks and Kohl’s department stores.

Champion Child Meets President (above, right) Rebecca Redman, Connecticut Children’s 2009 Champion Child, had the opportunity, along with children’s hospital representatives from all 50 states, to meet President Obama in Washington, D.C., earlier this spring. The meeting was part of the Children’s Miracle Network Champion’s Across America Program presented by Wal Mart. (Rebecca is pictured wearing pink tights.)

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Connecticut Children’s Staff Help Judge Citywide Science Fair Clinical Education Specialist Sally Strange, PhD(c), RN, of Connecticut Children’s Medical Center, watches a scientific demonstration as part of her role as a judge in the Hartford Public Schools 18th Annual Citywide Science Fair. Strange was one of 16 Connecticut Children’s employees who volunteered their time to be a judge in the science fair, which took place on May 12 at the Sports and Medical Sciences Academy.

Connecticut Children’s Recognizes Volunteers Connecticut Children’s Medical Center Senior Vice President and Chief Operating Officer Wendy Warring greets volunteers Louis DeMaio (left) and Chuck Schuberth at the Medical Center’s annual volunteer recognition dinner on April 29 as part of National Volunteer Week which took place April 27 through May 3. Connecticut Children’s has approximately 250 volunteers who generously donate more than 20,000 hours a year. DeMaio volunteers in the Department of Hematology/Oncology while Schuberth volunteers in the Medical Center’s surgical lounge.

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Kohl’s Ensures A Safe Summer For Local Children (above) As part of the University of Hartford’s annual Community Day in April and Kohl’s Tween Safe Program, staff from Connecticut Children’s Medical Center’s Injury Prevention Program gave away dozens of free bicycle helmets during a bike rodeo safety event. Children in attendance also had the opportunity to enter a drawing to win one of four bicycles that were donated by Kohl’s. The timing of the event coincided with the beginning of trauma season which results annually in a significant increase in the number of bicycle-related injuries at the Medical Center. Kohl’s has generously supported Connecticut Children’s since 2004, and presented a $178,568 check to fund the Kohl’s TweenSafe Program which will deliver safety messages for children ages 8- to 12-years old. The check presentation included (from left): Garry Lapidus, MPH, PA-C, Director of the Injury Prevention Center; Kevin Borrup, JD, Director of the Violence Prevention Program; Janet Gangaway, DPT, faculty advisor of the University of Hartford’s Physical Therapy Student Association, and Todd Johnsky, store manager of the Plainville Kohl’s store.

Leaving a Legacy Of Caring For Children

Please consider your own legacy by including the Medical Center in your estate plans. If you already have, please let us know so we can welcome you as a valued member of the Legacy Society. From charitable gift annuities, to charitable trusts, to bequests, there are many ways to incorporate giving into estate planning. Please call the Foundation office at 860-610-5735 to learn more about how you can make a difference in the life of a child.

LEgACY SOCIETY AT CONNECTICUT CHILDREN’S MEDICAL CENTER

860-610-5735