



# Pediatric Matters

A PUBLICATION OF CONNECTICUT CHILDREN'S MEDICAL CENTER



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## A Rare Disease Caught Just in Time



Daniela Ciriello of Southington was born with a chronic and deadly blood disease called Beta Thalassemia Intermedia. "If not for the thoroughness of Dr. Sayej and his team at Connecticut Children's, we might have lost Daniela," reflected father Dan Ciriello.

Daniela Ciriello's start in this world wasn't an easy one. Daniela lost her twin sister in the womb and had a tough start in life, suffering from what her parents first thought was colic and abdominal problems. Little did they know things would only get worse for their little girl before they got better.

"I remember Daniela always being fussy from day one," said Dan Ciriello of Southington. "We mistakenly believed it to be GI related. She was on a ton of different medicines to battle constipation and eating issues."

But what appeared to be a GI issue, was actually something much different. Daniela had a life-threatening condition that was caught in the nick of time.

"We ended up at Connecticut Children's through a referral by our birth-to-three consultant. Our pediatrician completely missed the symptoms and diagnosis," said Ciriello. "Daniela was seen by Dr. Sayej who was so compassionate and caring. He requested a full blood panel on Daniela and several other tests. That same night we got a call telling us to take Daniela to the Emergency Department immediately! The doctors couldn't even believe she was conscious because we found out her hemoglobin was so low."

"She was close to heart failure and we didn't even know it. Her spleen and liver were completely swollen and enlarged. If not for Dr. Sayej's thoroughness we may have lost Daniela that night," recalled Ciriello.

"I will never forget the day Daniela showed up in my exam room. When I first saw her she looked ill. Her parents were rightfully anxious and concerned about their daughter," said Wael Sayej, MD, Gastroenterologist at Connecticut Children's. "When I got her blood results back that night I became even more worried. I knew we needed to be aggressive with the management of her illness."

Turns out, Daniela was born with a chronic and deadly blood disease called Beta Thalassemia Intermedia. Although the condition is manageable, it is life changing and will require numerous doctors' visits, blood transfusions and therapies throughout her life.

"It obviously hurts and scares us all, but it also brings everyone closer. She's at Connecticut Children's several times a week, so it really affects our schedules, time and finances, but the entire staff has been amazing," Ciriello said.

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## Expanded Primary Care in a New State-of-the-Art Facility

It's going to be a big Spring for Connecticut Children's Primary Care division. Not only are they now operating in a brand new state-of-the-art building, but Primary Care is no longer affiliated with the Charter Oak Health Center.

"This change in operations will benefit many children and families in our community," said Martin J. Gavin, President and CEO of Connecticut Children's Medical Center. "In addition to better meeting the primary care needs of local children, we will now be able to offer greater access to our many health and wellness programs designed specifically for them."

Since opening in 1996, primary care services have been provided at Connecticut Children's main building at 282 Washington Street in Hartford. For the past several years, those services were provided through a partnership with Charter Oak Health Center. Now, primary care services will be solely operated by the Connecticut Children's Specialty Group. And, the transition took place with no interruption of care to patients.

In April, Connecticut Children's primary care clinic moved into their new location at 76 New Britain Avenue in Hartford. The new primary care center can accommodate up to 36,000 patient visits per year; 12,000 more than its previous location. The new center has immediate proximity to bus lines, offers free on-site parking and on-site laboratory facilities which will make visiting Connecticut Children's easier for patients and families.

Our board certified primary care pediatricians offer complete health care services in English and Spanish for infants, children and adolescents, from birth to 18 years of age.

In addition to the primary care services that will be provided at the new center, the primary care team will also be available to discuss preventative health care and wellness issues that may be of concern to children and families. Topics that fall into this category include behavior, development, discipline, education, nutrition, safety, and family relationships. Preventive health care also includes immunizations (shots) children need to prevent serious illnesses such as hepatitis, whooping cough and measles.



Connecticut Children's is the largest primary care provider between Boston and New York. To provide more access and enhance its clinical capacity, a new Primary care Center is now open at 76 New Britain Avenue in Hartford.



The state-of-the-art facility, which can accommodate up to 36,000 visits yearly, features a modern design, free parking and is located in immediate proximity to bus lines.

## Watch for These Coming Events

### Serata di Cibo

Monday, June 2, 6 p.m. – 9 p.m.

Carbone's Kitchen, Bloomfield

Enjoy the culinary creativity and artistry of Carbone's Ristorante and Carbone's Kitchen along with selected wines and boutique beers, music and unique raffle items at this celebration of fine food and wine. Proceeds from this event will help fund a new Injury-Free Playground at the CCMC School in New Britain, an affiliate of Connecticut Children's. The CCMC School provides education for students, ages 5 through 21, with severe emotional disturbances, cognitive compromises, Autism Spectrum Disorders and other conditions.



### Concorso Ferrari & Friends

Sunday, June 29, 11 a.m. – 3 p.m.

West Hartford Center, West Hartford

More than 100 current and vintage Ferraris, Lamborghinis, Alfa Romeos, Maseratis, and other Italian cars will descend upon West Hartford June 29th for the 14th Annual Concorso Ferrari & Friends event. The morning begins with 40 Ferraris escorting patients from Connecticut Children's Specialty Care Center to West Hartford, where the cars will be on display for public viewing and a judged competition. Food, live entertainment and a silent auction will be among the festivities at this annual event that attracts more than 10,000 spectators and Ferrari participants from along the Eastern seaboard.

### Geno Auriemma's Fore the Kids Charity Golf Tournament

Monday, June 23

Hartford Golf Club, West Hartford

Geno Auriemma has been associated with this tournament for more than a decade and supports Connecticut Children's as a "roving golfer," driving around the course to interact with sponsors and players. This event will benefit the Department of Orthopedics and the new Cardiovascular Care Center at Connecticut Children's.

### LEGO Children's Charity Golf Tournament

Monday, July 28

TPC River Highlands, Cromwell

LEGO Systems, Inc. partners with the Travelers Championship to deliver a first-class golf experience for all participants. The Tournament is held on an award-winning championship golf course that also plays host to the annual PGA TOUR's Travelers Championship. Funds raised through this event will benefit the new Cardiovascular Care Center at Connecticut Children's.

## What Others Are Saying About Connecticut Children's

### ON FACEBOOK

"Just want to send a shout out to Nurse Emily on MS8 and Kyle from child life they were amazing yesterday during my daughters monthly infusion. Emily was right on top of things, kept it moving all while keeping Aliana comfortable and at ease. Kyle too as always was by her side doing what he does best and rooting her on!!!! Thank You Again:)" – **TINA FICHERA**

"Hi I went to your hospital when I got hit in the head with a golf club in 2009 I think you guys helped my a great amount and saved my life! Keep up the good work." – **OLIVIA LAUTIER**

### ON TWITTER

**CountMeInHartford @CountMeInHtfd:** Happy 18th birthday @ctchildrens! Thank you for all you do to make CT children the healthiest in the country.

**Make-A-Wish of CT @MakeAWishCT:** @ctchildrens Thank you for always supporting our wish kids and standing behind their dreams!

**D. Windham Vance @CTMSUDawg:**

"CT Children's has been so good to us and our sweet Lily. Thank you for the wonderful, personal care you all give! Anyone in need of pediatric care, we highly recommend! God bless all the nurses and doctors there!" – **MARY COLLAMARE KIRTON**

"This is the best hospital for kids. They have told me to stay strong during my surgeries when I was upset. Now thanks to the amazing people I want to be a nurse for this hospital. I hope too work for you guys one day." – **MEAGAN ZITO**

Home after brief stay at @ctchildrens my little man getting his arm operated on. What an amazing place and even more amazing staff.

## CONNECTICUT CHILDREN'S IN THE NEWS



### Pain & Palliative Medicine Team Earns Clinical Center of Excellence Award

Connecticut Children's Pain & Palliative Medicine group has a lot to smile about these days. Not only are they helping to reduce pain during typical medical treatments for our patients, they recently received the 2014 Clinical Centers of Excellence in Pain Management Award from The American Pain Society (APS). This prestigious distinction only recognizes the nation's most outstanding pain care centers.

"This distinction is an important one to us because it was determined by a group of our peers and that makes it very special," said William Zempsky, MD, Director of the Pain and Palliative Medicine Division. "This validates all that we do to make our program special and is a great reminder that we are doing great things for our patients and families."

APS established the Clinical Centers of Excellence in Pain Management program in 2006 to increase awareness about teams of health professionals who address critical, sometimes unmet, needs in pain management within their communities. The division will be honored at a reception during the APS Annual Scientific Conference in Tampa, Florida in May.

"We are committed to being even better next year," said Zempsky. "We are currently developing our 5-year plan and I can tell you great things are ahead for the division and our patients."

The Pain & Palliative Medicine Team was recently recognized by The American Pain Society (APS).



HuskyTHON participants danced for 18 hours straight to raise funds for Connecticut Children's new Cardiovascular Care Center.

### HuskyTHON Raises a Record-Setting \$457,581 for Connecticut Children's

Dancing made all the difference at the University of Connecticut's 15th Annual HuskyTHON! Students, patients and families moved and grooved for 18 consecutive hours during the highly anticipated dance marathon, which raised \$457,581 for Connecticut Children's. This marked a record-setting year for the event, which raised \$343,416 in 2013.

The annual student-run dance marathon was held from Saturday, February 15 at 6:00 p.m. until February 16 at 12:00 p.m. at the Hugh S. Greer Field House on the UConn campus. During the marathon, students were able to meet and interact with more than 45 patients and families from the Medical Center, who attended the

event in support of the participants. All funds raised through HuskyTHON registration fees, pledges and sponsorships will support the Medical Center's new Cardiovascular Care Center through Children's Miracle Network Hospitals. More than \$1,300,000 has been raised from HuskyTHON since its inception. For more information, visit <http://www.huskython.uconn.edu/>.

### Connecticut Children's Medical Center Recognized for Commitment to Energy Efficiency

Connecticut Children's was recognized by Connecticut Light & Power (CL&P) and the Connecticut Energy Efficiency Board for the installation of new energy efficient equipment.

Connecticut Children's officials received a special plaque during a ceremony, held at the hospital's Hartford campus, celebrating completion of the energy-saving upgrades.

Connecticut Children's worked with energy experts from CL&P to complete the \$1.4 million project, which will save the hospital more than \$150,000 in annual energy costs, more than 800,000 kilowatt hours of electricity and 37,000 CCF (one CCF equals 100 cubic feet) of natural gas each year. These savings are equivalent to the amount of electricity 75 homes would typically consume in one year, and result in avoided emissions of approximately 609 tons of CO<sub>2</sub>, which is the equivalent of taking 106 cars off the road for a year.

Connecticut Children's received an Energize Connecticut program incentive of \$500,000 to help with costs of the project, which included upgrades to the hospital's energy infrastructure. Old, inefficient lighting was replaced with energy-efficient LED bulbs, and weather stripping and pipe insulation was installed, making Connecticut Children's an even brighter place for children and families.

*Connecticut Children's is grateful for the dedication provided by many individuals, clubs and organizations who host events to support and promote the mission of Connecticut Children's. If you are interested in learning more about events that support the Medical Center or hosting an event, please visit the Connecticut Children's Foundation website at [www.connecticutchildrensfoundation.org](http://www.connecticutchildrensfoundation.org)*

To comment on any articles appearing in this publication, please visit our website at [www.connecticutchildrens.org](http://www.connecticutchildrens.org). If you have a change of address or do not wish to receive future issues of Pediatric Matters, please call (860) 837-5700.

# Sleep and Neurodiagnostic Center Expands and Relocates to Farmington

As part of its growth initiatives to provide greater access to children and families, Connecticut Children's has expanded and relocated its Sleep and Neurodiagnostic Lab Services to Farmington, CT. The new office is located in Connecticut Children's new Surgery Center at 505 Farmington Avenue, just one mile off I-84.

This new facility is owned by Connecticut Children's and provides sleep studies, EEGs and EMGs on an outpatient basis. This expands Connecticut Children's capacity from two rooms to five. Additionally, accommodations are now available for up to four overnight sleep studies as well as day-time accommodations for three patients for EEGs, one for EMG, and one for day time sleep studies such as multiple sleep latency tests.

All rooms are decorated in a nature theme with one room specifically designed for bariatric patients. The space allows parents to room-in and includes amenities such as iPad docking stations, flat-screen TVs, DVD players, private bathrooms and

locking closets.

For monitoring purposes, the rooms are equipped with high definition cameras operated from a staffed control room.

Craig Schramm, MD, Head of the Connecticut Children's Pulmonary Division, is the Interim Medical Director of the Sleep Center while a national search for a permanent director is underway.

Dr. Schramm commented, "This expansion of the Sleep Medicine Center, along with the transition to sole ownership and operation by Connecticut Children's, is obviously a boost to our capacity, but that also translates into us being able to see children and make diagnosis sooner, which means better outcomes for our patients."

The Connecticut Children's Neurology Division will also be relocating to 505 Farmington Avenue in the fall, just upstairs from the EEG Lab. "Since neurology physicians are the ones who read EEGs, it's especially beneficial to have

everyone working in one place," said Jennifer Madan Cohen, MD, director of Connecticut Children's Epilepsy Center.

She also notes that the expanded EEG lab is part of Connecticut Children's growing Epilepsy

Center, which includes the Epilepsy Monitoring Unit, comprehensive care for patients with epilepsy, the state's only Ketogenic Diet program and collaboration with Neurosurgery on potentially curative surgery for epilepsy.



(L-R) Sleep Technologist Cyril Marshall and Manager Alex Rivera review a patient's sleep study results. The new Sleep Lab will provide expanded sleep studies, EEGs and EMGs on an outpatient basis.

# MyChart Allows Easier Access for Patients and Families

Connecticut Children's Medical Center and Connecticut Children's Specialty Group ("Connecticut Children's") is in the process of implementing an electronic health record (EHR) program called Care Navigator across their inpatient and outpatient areas. Implementation began in 2012 and is expected to be complete in 2015. This means patient records will be created electronically and paper records will be phased out. Existing paper records will be maintained for a mandated number of years, as is the current requirement. A number of areas have already begun using Care Navigator, so you may have experienced this new documentation process if you have visited Connecticut Children's recently.

Electronic health records will improve the sharing of pertinent patient information among primary care providers and other healthcare providers within Connecticut Children's as well as outside, such as specialists and pharmacies. This also allows for patients and families to have online access to portions of their own health records through an application called MyChart.

MyChart gives parents convenient online access to portions of their child's electronic health record (EHR) where their doctor stores the child's

health information. Certain lab results, appointment information, medications, immunizations, and more are all securely stored for quick retrieval. MyChart also provides parents new, convenient methods of communication with a doctor's office, such as sending messages, and requesting appointments – all online. **It should be noted that for emergencies and urgent issues, parents should not use MyChart as a way to communicate with the provider.**

Connecticut Children's expects to launch the secure MyChart portal in June of this year for those departments that are currently using Care Navigator. When new departments begin using Care Navigator, MyChart will be available as well.

As MyChart becomes available, patients and families will be invited to sign up and obtain electronic access to the child's health record.

MyChart is offered as a convenience to allow patients and their families' access to portions of their health records. As always, a full medical record will be maintained by Connecticut Children's and can be formally requested by a patient if needed.

 Connecticut Children's  
Care Navigator



# Blood Donations are the Key to Daniela's Success

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Currently, Daniela receives blood transfusions every 3 weeks and will likely need a splenectomy by age 6. Even so, she handles every procedure like a trooper and is feeling so much better these days.

"It's like we have a new kid. She's gained weight and is walking and talking and eating like she should have been all along," said Ciriello. "She has basically caught back up to other kids her age even though she has this condition."

"Even though Dr. Michael Isakoff is Daniela's physician, I have continued to follow her case and have worked with dietitians to increase Daniela's caloric intake to help her gain weight," said Dr. Sayej. "She has done very well since her diagnosis and her weight is now normal for her age and size."

"The bottom line is when a child does not look well, we have to trust our clinical judgment and trust parental instincts," Dr. Sayej continued. "Doing the most basic test led to getting Daniela the proper care she needed. I try to treat every child that I see as my own."

The Ciriello's recently created "Daniela's Dream for a Cure," a non-profit foundation to raise awareness and funds for her treatments. Not only that, they are also Blood Drive Coordinators and have held many successful blood drives since September 2013.

"Blood donors are truly heroes and save lives, like Daniela's," concludes Ciriello. "We will do anything to get more people to donate. Daniela has such a way of touching people and reaching them, it never ceases to amaze us."



"I remember this hug. Daniela's mom asked if she could take a picture of me holding her little girl. It's hard to resist taking a picture with such an adorable toddler," said Dr. Wael Sayej.

## UnitedHealthcare Provides \$1 Million Dollar Grant

It's a partnership that's bringing Connecticut Children's one step closer to making our kids the healthiest in the nation! Recently, UnitedHealthcare provided a \$1 million grant for the Office for Community Child Health (OCCH) at Connecticut Children's to help enhance healthcare delivery and address several critical public health issues for children. More specifically, the collaboration will fund development and expansion of community-based children's health care programs.

"These are dollars that will immediately start improving the health of children in our communities," said Paul Dworkin, MD, Director of OCCH.

Connecticut Children's OCCH is a first-of-its-kind model for providing community-based coordinated care for children with an emphasis on healthy child development, wellness, and disease and injury prevention. OCCH is developing and testing health service delivery models that address community, state and health system needs. Many new programs will be piloted in Hartford with the goal of seeing them replicated on state and national levels.

The UnitedHealthcare grant will help create a Maintenance of Certification program to train primary

care pediatricians in managing diseases such as asthma and obesity. The UnitedHealthcare Innovation Fund will also be established to help OCCH quickly bring new programs from design to implementation, and ultimately, to evaluation and replication.

In addition, OCCH will provide 600 primary care doctors at more than 170 practices in Connecticut with training to enhance children's health care quality.

"We are proud to partner with UnitedHealthcare to support pediatricians' lifelong learning and professional development," said Dr. Dworkin. "Together, we will enhance the quality and capacity of pediatric care to address an array of critical health issues, and help promote the healthy development of children in Connecticut and nationwide."

"We look forward to working with Connecticut Children's Office for Community Child Health and pediatricians throughout Connecticut to enhance the coordination, delivery and quality of children's health care," said Stephen J. Farrell, CEO, UnitedHealthcare of New England.

To date, OCCH has partnered with 10 local, state and regional programs to help community and primary care providers coordinate quality, cost-

effective care for children under one roof. The programs include Easy Breathing, Educating Practices in their Communities (EPIC), the Hartford Childhood Wellness Alliance, Help Me Grow, Injury Prevention Center, Lead Action for Medicaid Primary Prevention (LAMPP), Resident Education in Advocacy and Community Health (REACH), and the Special Kids Support Center (SKSC).

"Our office is a better place for primary care because of the OCCH and its programs. Looking ahead, there is

an opportunity for OCCH to have a dramatic impact on Connecticut's childhood obesity epidemic by helping identify key indicators and community resources for patients and families dealing with the disease," said Barbara Ziogas, M.D., a primary care physician at Farmington Pediatrics. "Obesity is a significant health issue in our country, and the OCCH provides us with the resources to access community care and intervene now."



A \$1 million grant from UnitedHealthcare will help address several critical public health issues and enhance health care delivery to children. Pictured above, Stephen Farrell, CEO, UnitedHealthcare, presents the gift to (l-r), Paul Dworkin, MD, Director of Connecticut Children's Office for Community Child Health and Martin J. Gavin, Connecticut Children's President and CEO.

## Connecticut Children's is Making Price Transparency A Priority

One of the hottest topics in healthcare is pricing transparency. In a fairly rapid sequence of events, launched by the Attorney General, pricing transparency is fast becoming a new standard of care at hospitals across Connecticut.

Because of the Attorney General's interest in hospital billing procedures, Connecticut Children's has taken the lead to make this often complicated process as simple as possible for our patients and families. We recently rolled out a new brochure notifying patients and families about our fees

and the different providers that could be caring for their child.

"Price transparency is more important than ever because a growing number of consumers face greater out-of-pocket expenses with high-deductible health plans," said Kim Garvey, Director of Compliance for Connecticut Children's. "This is not a change in how we do things, rather an extra effort to make it as clear as possible to our patients."

The brochure clearly explains that patients could receive services from

our Specialty Group, the Medical Center and/or other service providers in just one visit. Receiving all of these different services in the same visit means that the family may receive several bills for the appointment.

"These high-deductible health plans are placing a great financial burden on individuals and families," said Garvey. "The cost of every health care service matters to them because it's often coming out of their own pockets."

In addition to the brochure, new flyers and posters have been posted

around the Medical Center explaining billing procedures. There's another valuable tool on our website as well. Patients and families can find a chart clearly estimating their financial liability for a variety of different services.

Our patients and families are also encouraged to contact their insurance companies for information about their health insurance coverage or one of Connecticut Children's financial counselors to learn more about their bill or financial assistance.

# A Change in Perspective Could Make a Big Difference for Children with Crohn's Disease

Jeffrey Hyams, MD, Division Head of Gastroenterology, Digestive Diseases, Hepatology and Nutrition at Connecticut Children's, and Professor of Pediatrics at the University of Connecticut School of Medicine, has authored a study that could change the way children with Crohn's disease are treated. This research provides a new perspective on existing treatments that will help kids with moderate to severe Crohn's reach remission sooner than ever before.

Dr. Hyams explains, "There are many therapies available for children with a wide range of symptoms and severity of disease progression. Much of our current research is directed toward improving our understanding of predictors of disease response and progression, but the bottom line is that it is still impossible at disease diagnosis for us to know with certainty who will respond to a particular therapy. Our current therapies offer high hope of good disease control but each therapy is associated with its own benefits and risks. And of course, for the parents and child, and for me too, that one child's remission is the most important thing in the world. The overarching goal of new research is to find genetic and other markers that will help us provide truly customized care with the best possible, individual outcome. As we've looked for those individualized markers, we discovered something else. The therapy we've traditionally reserved as a second tier or step-up option, might just be the best place to start for some children."

For patients newly diagnosed with Crohn's disease, historical standard therapy has included initial treatment with corticosteroids followed by treatment with immunomodulators. Use of biologics, such as anti-tumor necrosis factor (TNF), has traditionally been reserved for patients who failed to achieve satisfactory clinical remission through immunomodulators. "We postulated that children would benefit from earlier introduction of

anti-TNF therapy and we designed a study to test that theory. It didn't make sense to us to wait to use the most effective treatment currently available. The side effects of the treatment are equivalent to those of the traditional first regimens and the long-term risks are also equivalent. In my view, the most risky treatment choice of all is inadequately treating chronic, progressive conditions like Crohn's disease," said Dr. Hyams.

"Anti-TNF has been studied and proven effective in adults for years. Especially for patients judged to be at risk for serious and chronically active disease, early introduction of anti-TNF has had promising results. This is not a new therapy," explains Dr. Hyams. "But despite the widely recognized superior efficacy of anti-TNF therapy in adults as an initial therapy for moderate to severe disease, it had yet to be demonstrated in a large study for pediatric patients. We needed to see and demonstrate whether the traditional 'step up' to anti-TNF is more or less effective than early introduction of the therapy. Specifically, we wanted to see if introduction of anti-TNF therapy in the first three months after diagnosis improved the one-year clinical and growth outcomes."

The RISK observational study, funded by the Crohn's & Colitis Foundation of America, included 28 pediatric gastroenterology centers in North America. Newly diagnosed children, age 17 and under, were eligible to enroll in the study conducted between 2008 and 2012. At the time of diagnosis and subsequently, key clinical information was recorded. Simultaneously, select biospecimens including serum, DNA, rectal biopsy tissue and stool was collected for translational studies. Within a larger study we were then able to perform clinical effectiveness using an advanced statistical methodology called propensity analysis. In contrast to a controlled clinical trial where there are often many arbitrary limitations on trial design, clinical effectiveness studies are designed



Jeffrey Hyams, MD, Division Head of Gastroenterology, Digestive Diseases, Hepatology and Nutrition, pictured here with a Gastroenterology patient, authored a study that could change the way children with Crohn's disease are treated.

to see how well a therapy performs in a typical patient in real-world scenarios. In this study all patients were managed according to the dictates of their physicians, not a standardized protocol. A total of 552 children participated in the study in North America.

The study carefully cross-matched comparably sick children by age, sex and other disease-specific factors and then looked at comparative outcomes of similar patients at one year treated either

will eventually necessitate surgery – sometimes multiple surgeries. Immunomodulator based therapies have been successful in relieving symptoms, but it's not clear that the natural history of the disease is improved. With early introduction of biologics, we may be actually stopping the progression of the disease."

Dr. Hyams continued, "We are keenly aware that everything comes with a cost. Treatment with biologics is more expensive than

***"The therapy we've traditionally reserved as second or a step-up option, might just be the best place to start for some children."***

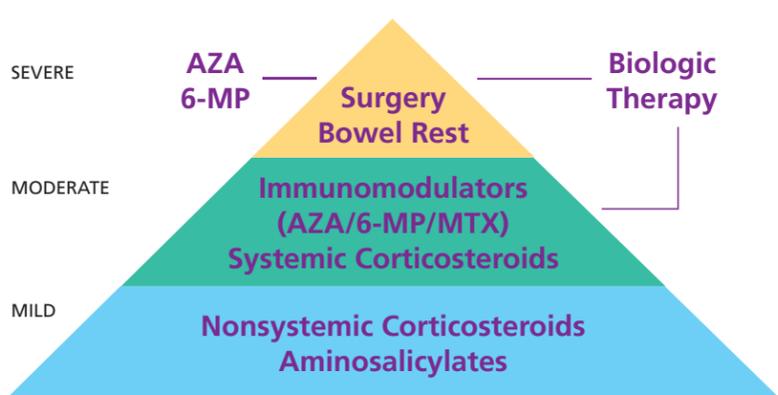
– Dr. Jeffrey Hyams

with early anti-TNF only, early immunomodulator only, or neither within the first three months following diagnosis. A dramatic improvement in rates of steroid free remission and normalization of growth was found in the anti-TNF group compared to the two other treatment groups. Even those children on early immunomodulators who were treated with anti-TNF after 3 months did not do as well as those children receiving anti-TNF therapy in the first three months. Dr. Hyams added, "There are several important things to consider here. First, since we are treating children, a rapid return to normal growth and development provides lasting, long-term benefits. Second, Crohn's disease is a progressive disease. While it is possible to relieve symptoms, the disease still progresses and there are ongoing and injurious changes which can occur in the bowel that

immunological therapies. But the numbers are showing that solving the problem early and avoiding treatment and surgery down the road, is not only obviously better for the patient, but is also proving to be less expensive overall.

"This is really about the evolution in our thinking about how we best triage treatment strategies for Crohn's disease. Medical protocols need proof and time to evolve because the stakes are so high. That single child I mentioned earlier? His or her parents come to us looking for answers. Recent studies like ours are giving medical professionals better paths to the best possible outcomes. While we spend much of our time in direct clinical care we also lead and participate in pioneering research studies that play a large role in helping us advance care for these children."

## IBD: Traditional "Step Up" Treatment Pyramid



This traditional paradigm is now being questioned with emerging research.



# Happenings at Connecticut Children's



Patient Benjamin Dylewski, from Windsor, received a big surprise this past March when U.S. Paralympic snowboarder, Evan Strong, paid the Medical Center a very special visit following his gold medal win in Sochi. Evan posed for pictures, signed autographs and shared his inspirational story with patients, families and staff.



Morgan Platt, of Avon, received a standing ovation from the crowd during an on-court plaque presentation at the American Athletic Conference Women's Basketball Championship at the Mohegan Sun Arena. Connecticut Children's President and CEO Marty Gavin presented Morgan (the face of the "ROAR" video on YouTube) with the plaque for inspiring all kids with cancer to keep fighting. Pictured above, Morgan receives her plaque, joined by her parents Kathy and Scott and her brother Kyle.



Connecticut Children's Nurse Manager and CT ENA President, Colleen Desai, recently joined Governor Dannel P. Malloy, Attorney General George Jepson, Travelers Insurance executives, local students and other teen safety driving advocates to help select the Top 10 student-made video submissions and 5 overall winners of the 2014 DMV-Travelers Teen Safe Driving Video Contest.



Virtus Investment Partners of Hartford presented Connecticut Children's with a \$250,000 donation in support of our new Cardiovascular Care Center. This generous contribution will fund the Virtus Investment Partners Family Consultation room in the new Cardiovascular Care Center, which will provide a comforting, private space where treatment options and outcomes can be discussed between families and caregivers. Pictured above are leaders from both organizations at the gift presentation.



The University of Hartford men's basketball team, led by Head Coach John Gallagher, continued their annual of taking a break during their season to visit the Medical Center. Above, patient Tyrell Brady of Meriden spends some time with Hawk players Nate Sikma, Mark Nwakamma, Evan Cooper, Yolonzo Moore and Oren Faulk.



Fourteen year old Aida Flores of Oakdale was all smiles when the UConn men's basketball team visited the Medical Center just prior to winning their 4th national championship. Joining Aida above are Head Coach Kevin Ollie, senior Lasan Kromah and senior, co-captain and All-American Shabazz Napier.