



# HOPE *and* HEALING

Breaking New Ground in Pediatric and Fetal Surgery

 The Children's Hospital  
of Philadelphia®

DIVISION OF GENERAL,  
THORACIC & FETAL SURGERY

 CENTER FOR FETAL  
DIAGNOSIS & TREATMENT

[GIFTofCHILDHOOD.org](http://GIFTofCHILDHOOD.org)



N. Scott Adzick, M.D., pictured with Mallen, whose name means “little strong warrior.” Mallen was diagnosed *in utero* with a life-threatening congenital cystic adenomatoid malformation, which Dr. Adzick surgically removed two weeks after he was born.

On Cover: Josephine, pictured at 6 months old, was diagnosed *in utero* with a sacrococcygeal teratoma. She underwent surgery to remove the tumor at The Children’s Hospital of Philadelphia immediately after birth and now enjoys a healthy childhood.

Dear Friends,

For years, the Division of General, Thoracic and Fetal Surgery at The Children’s Hospital of Philadelphia has made the extraordinary into the routine, bettering the lives of so many children and families.

At CHOP, we often say that children are not simply small adults. Pediatric surgery requires different knowledge, techniques and research. Many diseases of childhood are never seen in adults, and as science advances, we are finding new ways to save children who in decades past would have been considered untreatable.

Nowhere is this more evident than at the Center for Fetal Diagnosis and Treatment, an international leader in treating families with children prenatally diagnosed with devastating birth defects. We recently celebrated our 1,000th delivery in the Garbose Family Special Delivery Unit. In addition to expert clinical care, our family-centered care provides the best experience possible, supporting the entire family through what is often an emotional journey.

Minimally invasive surgery is an area of intense focus for this division because it provides better outcomes, faster recovery times and less scarring. To teach the next generation of surgeons increasingly complicated techniques, the division is opening the William Maul Measey Pediatric Surgical Training Laboratory, which is home to our new surgical practice facility.

We are grateful to the community of dedicated supporters who have contributed to our success. Private philanthropy is vital to the division’s continued preeminence, and everyone who works here — surgeons, nurses, support staff — is keenly aware of what you mean to the children in our care. If you are interested in learning more about how to help, please contact Becky Rohtbart, director of development, at 267-426-6529 or [rohtbart@email.chop.edu](mailto:rohtbart@email.chop.edu).

Thank you for all you have done and for all the work we will continue to do together.

Sincerely,

N. Scott Adzick, M.D.  
Surgeon-in-Chief  
Chief, Division of General, Thoracic and Fetal Surgery  
Director, Center for Fetal Diagnosis and Treatment  
C. Everett Koop Endowed Chair in Pediatric Surgery



## A Gift to Training

### PEDESTAL Opens in a New, State-of-the-Art Space

It was a vision that surgeon Thane Blinman, M.D., had been developing for years: a laboratory where he and his experienced colleagues could give surgical residents a place to practice their craft and hone their techniques. It would have laparoscopic surgery practice stations where young surgeons could practice delicate minimally invasive techniques. It needed “hacker space,” where they could learn the inner workings of surgical instruments and maybe even invent some of their own. It would have advanced technology to measure a surgeon’s movements. And all of it should be adjacent to the operating room complex so that it would be convenient for the surgical staff to stop by throughout the course of their day.

◀ *Thane Blinman, M.D., pictured opposite right, who leads the surgical practice laboratory, instructs a surgical resident.*

It was a big dream, and Blinman is amazed at how quickly it came true.


Last summer, the Measey Foundation made a \$1 million investment in the Pediatric Endoscopic Surgical Training and Advancement Laboratory (PEDESTAL) at CHOP. In recognition of that extraordinary gift, the newly built space was named the William Maul Measey Pediatric Surgical Training Laboratory.

“The Measey Foundation’s gift was nothing short of transformational for PEDESTAL,” says Surgeon-in-Chief N. Scott Adzick, M.D. “It has allowed us to buy the state-of-the-art technology that our residents and fellows will use to become even better minimally invasive surgeons. From the day the Measey Lab opened, it was instantly the premier pediatric surgical training lab in the nation.”

Blinman has developed a curriculum that teaches both technique and technology, everything from how to arrange the patient’s body on the operating room bed to the internal mechanics of each instrument. And his colleagues in Urology, Orthopaedic Surgery and Otolaryngology are also designing curriculums to teach their surgical trainees in the Measey Lab. A coordinator will help everyone make the best use of the space.

“The Measey Foundation believes that simulation programs are the cornerstone of future medical training and patient safety initiatives,” says Clyde F. Barker, M.D., president of the Measey Board. “We are proud to support the fine work being done at CHOP.”

In addition to receiving the generous Measey Foundation gift, PEDESTAL also received a gift from the CHOP Women’s Committee to purchase biometric equipment that will measure a surgeon’s every move, helping Blinman and other researchers to quantify the best surgical behaviors, from posture and stance to the movement of eyes and hands.

“Educating the next generation of pediatric specialists is one of CHOP’s key missions,” says Blinman, who is also the program director for the CHOP Pediatric Surgery Fellowship. “PEDESTAL’s new facilities in the Measey Laboratory will give everyone from first-year residents to the most senior surgeons a place to learn new techniques, invent new surgical tools and become confident and expert at new facets of pediatric surgery.” 

“From the day the Measey Lab opened, it was instantly the premier pediatric surgical training lab in the nation.”

– N. Scott Adzick, M.D.

# Carousel Ball

Carousel Ball  
2011

On Nov. 5, 2011, 600 of our most committed donors, trustees, physicians and grateful families gathered for the 39th biennial Carousel Ball, a black-tie gala that this year benefitted the Center for Simulation, Advanced Education and Innovation and the Pediatric Endoscopic Surgical Training and Advancement Laboratory (PEDESTAL). More than \$1.4 million was raised for these worthy initiatives, which enable the Hospital to continue to lead the world in pediatric care, education and research.





## Medicine in the Making

### First-of-its-kind Research Explores Complex Twin Condition

Adam and Laura Epstein were excited to learn that Laura was carrying identical twin girls. But at a routine ultrasound, the northern, N.J., couple also learned the pregnancy was complicated by a life-threatening condition.

Twin-twin transfusion syndrome (TTTS), in which there are abnormal blood vessel connections between the twins in their shared placenta, affects roughly 10 to 15 percent of identical twin pregnancies. One twin gets too much blood and the majority of oxygen and nutrients, while the other twin doesn't get enough. Left untreated, it results in the death of one or both fetuses in 70 to 80 percent of cases.

The obstetrician who made the diagnosis recognized that the twins' lives were in danger and referred the Epsteins to CHOP's Center for Fetal Diagnosis and Treatment, one of the few medical centers in the world able to provide comprehensive care for both mother and babies with this complex condition.

◀ *Rose Beatrice and Madeline Aliyah, diagnosed with a life-threatening twin condition before birth, were treated at CHOP in utero and born healthy.*

The center serves more than 200 families with twin pregnancies each year and performs more than 50 fetoscopic laser surgeries annually. In this type of fetal surgery, a laser beam is used to close abnormal blood vessel connections between the twins. CHOP has one of the highest volumes of prenatal laser surgeries in the nation, with survival rates that rank among the best in the world.

“Going to CHOP gave them the best chance for a healthy childhood,” says Laura.

Three days after a comprehensive evaluation at the center, fetal surgeons successfully operated on the twins *in utero*. The Epsteins returned home, and a few months later, Rose Beatrice and Madeline Aliyah were born healthy and full term.

Yet many questions remain about the long-term prognosis of children like Rose and Madeline. For example, some fetuses affected by TTTS develop heart disease.


“There has been research done on TTTS, but it's all focused on surviving the pregnancy,” says Adam. “There's nothing out there about what it will mean for them down the road, if they survive. There's nothing that tells you as a parent what you need to be prepared for.”

To address that need, the Epsteins and the Conway Family Foundation, a philanthropic organization run by the twins' grandparents, have funded a multiyear study at CHOP to look at the neurocognitive and cardiovascular effects of TTTS in twins through age 2. The study aims to provide families more accurate information on what to expect both before and after birth and to identify any additional long-term consequences.

“This is pioneering work that wouldn't have happened without philanthropy and stands to be transformational in the care of children with TTTS,” says Nahla Khalek, M.D., M.P.H., who is leading the study.

Rose and Madeline, now 2, are among more than 100 pairs of twins the study will enroll. They recently visited the center for their first study evaluation.

“I think about where we started and where we ended up,” says Laura. “We feel very lucky. I'm very relieved to know that the best doctors are going to be telling me whether or not there are any lasting repercussions from their experience.”

Adam adds, “It's great to support a first-class organization doing what we believe is incredibly important research.” 

“This is pioneering work that wouldn't have happened without philanthropy and stands to be transformational in the care of children with TTTS.”

– Nahla Khalek,  
M.D., M.P.H.



◀ *The Strickler family, pictured with N. Scott Adzick, M.D., at the Center for Fetal Diagnosis and Treatment's 2011 Fetal Family Reunion.*

Connected  
to the Cause

Pursuing  
a Cure for  
Congenital  
Diaphragmatic  
Hernia

For Kathleen and James Strickler, a white rose will forever have a special place in their hearts as a memory and symbol of their beloved daughter, Allisyn Grace.

Allisyn was diagnosed before birth with congenital diaphragmatic hernia (CDH), a condition in which the diaphragm fails to close completely, allowing abdominal organs to move into the chest and interfere with lung development. The survival rate for babies with CDH is only 50 percent, and unfortunately, Allisyn passed away just 10 hours after her birth in CHOP's Garbose Family Special Delivery Unit (SDU). It was an emotional roller coaster, as it was also a day to welcome Allisyn's healthy fraternal twin, Kathryn Julene.

Allisyn's condition was simply too severe for doctors to save her. Her lungs were too small due to compression by the intestines that had moved into her chest *in utero*. But the Stricklers are thankful to CHOP for giving them 10 beautiful hours together as a family.

While the SDU nurses cared for baby Kathryn, Allisyn spent precious time with her parents and each of her five older siblings. The whole family had also temporarily relocated from Utah to Philadelphia for the birth.

CHOP staff did everything they could to help the entire family create meaningful memories. Child Life specialists worked with the Strickler children to create memory boxes and fill them with heartfelt crafts. One of the Stricklers' sons placed a white-ribbon rose, provided by Child Life, in Allisyn's hand.

"That was a beautiful moment for our family," Kathleen says.


That white rose has become one of the family's most treasured possessions. Though the loss of Allisyn was heartbreaking, the family finds peace knowing they did everything they could to give her the best chance of survival.

"We really believe that we got the best care possible at CHOP," Kathleen says. "I've delivered seven children and the Special Delivery Unit was the best birthing experience I ever had. I was treated with respect and deep compassion every moment I was there."

The Stricklers are determined to do all they can to raise awareness of and find a cure for CDH. "Other than one little flaw, our daughter was a perfect little girl who should have lived and had a chance to grow up," James says. "I don't want any other families to feel that sorrow."

About a year after the twins' birth, the Stricklers worked with Utah's governor to establish a CDH Awareness Day. They coordinated an awareness campaign around the day, enlisting local media outlets to get the word out about the need for increased research. They held a fundraiser at a local restaurant in honor of Allisyn that supported CDH research at CHOP and set up a fundraising page on CHOP's GiftofChildhood.org website. The couple even recently traveled to Washington, D.C., to petition members of Congress to establish a National CDH Awareness Week. Their hope is that greater awareness of CDH will lead to increased funding to develop better treatments and a cure.

"If anybody is going to find the cure for CDH in our lifetime, it's going to be the doctors and researchers at CHOP," says Kathleen.

*"We want to turn our daughter's life to a positive. I can think of no better way to do it than by working toward a cure,"*  
James says. 

## On the Cutting Edge of Care

Even with the best care, CDH still proves fatal for too many children. But a complex procedure being studied at CHOP may brighten the outlook for children with severe CDH.

Called tracheal occlusion, it is a fetal surgery to insert and inflate a tiny balloon in the fetus' trachea (airway). Blocking the trachea creates pressure that is thought to expand the lungs and stimulate their growth. The hope is that the larger, stronger lungs will help push the abdominal organs back into place.

The surgery requires precision and speed. The incision in the mother's uterus is smaller than a keyhole, the balloon no bigger than seven millimeters.

The Center for Fetal Diagnosis and Treatment has honed this procedure and is now poised to launch a clinical trial of its effectiveness. If successful, fetal tracheal occlusion could become a standard of care for severe CDH.

Progress is aided by grateful patient families who support CHOP's CDH research. Among them are Dustin and Debbie Laricks, who have organized Peyton's Promise, an annual 5K run and 2K walk in Sea Isle City, N.J. The event, named after their daughter Peyton, who was born with CDH, has raised more than \$100,000 since it began four years ago.

"We're so grateful for Children's Hospital," Debbie says. "Supporting this research is our way to give back and help prevent others from going through what Peyton went through."

# Board of Visitors

## Division of General, Thoracic and Fetal Surgery Establishes a Board of Visitors

In September of 2011, The Children's Hospital of Philadelphia took a transformative step by establishing a Board of Visitors for the Division of General, Thoracic and Fetal Surgery. The group is an appointed board of community leaders who believe in the mission of Children's Hospital and are committed to advancing CHOP's excellence in pediatric and fetal surgery. By promoting philanthropic support, raising public awareness and providing volunteer leadership, the Board of Visitors is enabling the Division to further push the frontiers of surgery and care for children of all ages, from before birth through young adulthood.



*Jaidyn, 6 months, diagnosed in utero with spina bifida, benefitted from nearly two decades of research and innovation at CHOP and was treated before birth.*

THE FOUNDING MEMBERS OF THE BOARD OF VISITORS, LISTED BELOW, ACT AS PUBLIC AMBASSADORS, PARTICIPATING IN AND LEADING EFFORTS TO RAISE FUNDS AND AWARENESS FOR THE DIVISION OF GENERAL, THORACIC AND FETAL SURGERY.

JAMI AND JOEL FRIEDMAN  
*(Co-Chairs)*

LAURA AND ADAM EPSTEIN  
ARIELE AND STEVE GORDON

JESSE JANTZEN  
MARY AND JED KELLY  
NORA AND JEFFREY NAZZARO



*Alexa, 4, had minimally invasive abdominal surgery as an infant to treat a rare inherited condition.*



## Delivering Comfort

## Embracing Families with Emotional Support

As excited new parents head to their ultrasound at 18 to 20 weeks, their biggest question is often, “Boy or girl?” But for some, this routine ultrasound is the first time they hear devastating news: Something isn’t right. In an instant, their whole world falls apart.

Thoughts about names or nursery colors shift to the most basic concerns: “Will my baby survive? What will his or her life be like? What does this mean for our family?”

With the normal anxieties of pregnancy suddenly magnified a hundredfold, couples may not know what to do next for their baby, or even whether anything can be done. Birth defects like congenital diaphragmatic hernia or spina bifida are beyond the expertise of most obstetricians and local hospitals.

That is what brings families to the Center for Fetal Diagnosis and Treatment (CFDT) at CHOP. Families come to the CFDT for the world’s top experts in treating birth defects, but they find the experience is so much more than the best medical care. The CFDT also addresses the psychosocial needs of the entire family, giving expectant parents and older siblings emotional support through this difficult time.

◀ *CFDT Social Worker Marty Hudson, M.S.W., L.S.W., is one of a team of staff members that supports families throughout their care at CHOP, often remaining involved with the family well after discharge.*

“We take care of these families in a special way,” says Lori Howell, R.N., M.S., executive director of the CFDT. “They are incredibly stressed and asked to make the most monumental decisions of their lives that will impact them forever. Our job is to guide them and help them in any way possible during this difficult time with the team of nurses, social workers and other staff, many of whom we wouldn’t have without philanthropic support.”

From the moment the family contacts CHOP, a care coordinator works with them to arrange a visit, often as soon as the next day, and remains a constant presence and guide throughout the whole process.

At other institutions, a typical evaluation might require visiting lots of different specialists in many different locations — a tiring and frustrating process. At CHOP, patients make a single visit to the CFDT and each specialist needed to evaluate the pregnancy comes to them. That same consideration for families also prompted CHOP Trustee Lynne Garbose and her husband, Bill, to help create the Garbose Family Special Delivery Unit (SDU). It is the world’s first delivery unit devoted to mothers carrying babies with prenatally diagnosed birth defects. Since 2008, more than 1,000 mothers have delivered there, enabling families to stay together with their fragile newborns.

Families come from all over the country and the world for the CFDT’s specialized care, but travel, lodging and related expenses can be an enormous financial burden. Charitable gifts by many families to the Hope for Fetal Families Fund have eased this burden, supporting hundreds of families with expenses not covered by


insurance. Inspired by their personal experience with their daughter, Jed and Mary Kelly took this fund to a whole new level in 2010 by making a generous donation to establish the Addison’s Hope for Fetal Families Fund. Thanks to their leadership, the CFDT has been able to provide even greater support and access to care.

“We have a seamless multidisciplinary approach, addressing every medical and psychosocial need a family could have,” Howell says.

This spirit extends to even the smallest details: SDU mothers get fluffy pink bathrobes, cards and customized gift baskets. Thanks to funds generously donated by Macy’s, gift baskets are stocked with amenities such as ingredients to prepare their first meal at home after the birth.

“Many moms cry out of gratitude for the thoughtfulness behind the baskets,” says Joanna Horst, R.N.C., M.S.N., nurse manager of the SDU.

Center staff are fully committed to doing anything and everything they can for the entire family. The CFDT recently added a dedicated psychologist to provide ongoing emotional support for families going through some of the hardest times they will ever face. It is thought that rates of postpartum depression and even post-traumatic stress disorder are higher in families of babies with birth defects, a subject the new psychologist will study.

“In our modern medical culture, the burden is often on the family to assemble and coordinate all the pieces of their care,” Howell says. “At the Center for Fetal Diagnosis and Treatment, it doesn’t work like that. The way we wrap our arms around a family is unique.” 



# Fetal Reunion

## 15th Annual Fetal Family Reunion

In 2011, the Center for Fetal Diagnosis and Treatment held its 15th annual Fetal Family Reunion, sponsored by the Lynn Saligman League. Hundreds of former patients and their families attended the event, reuniting with the men and women who made such a difference in their lives. A group photo from the event aired in Times Square in celebration of the 15-year milestone.

The 2012 reunion will be held Sunday, June 24th. For more information, visit [fetalsurgery.chop.edu/reunion](http://fetalsurgery.chop.edu/reunion).





*Kim Smith-Whitley, M.D., director of CHOP's Sickle Cell Center, Alan Flake, M.D., surgeon and director of CHOP's Center for Fetal Research, the Johnsons (patient family), and Ann C. Bonham, M.D., chief scientific officer of the American Association of Medical Colleges, all traveled to Washington, D.C., to advocate for additional NIH funding for sickle cell research.*

## Hope on the Horizon


## Sickle Cell Disease Research Takes National Stage

Groundbreaking sickle cell disease research, nearly 30 years in the making, is now reaching the halls of Congress in an effort to raise awareness of this common blood disorder and the possibility of a cure.

On Feb. 29, fetal surgeon Alan Flake, M.D., director of the Center for Fetal Research at CHOP, presented his research at a briefing on Capitol Hill hosted by Chaka Fattah (D-PA). Dr. Flake spoke on the use of *in utero* bone marrow transplantation to treat sickle cell disease before the child is even born. The procedure transplants cells from the mother's bone marrow into her growing fetus at a time when the child's immune system has not fully formed and will accept the cells as his or her own. A second transplant after birth would ensure that the child never develops symptoms of the disease.

Dr. Flake was joined by Kim Smith-Whitley, M.D., director of the Comprehensive Sickle

Cell Center at CHOP, and Ann Bonham, chief scientific officer of the American Association of Medical Colleges, to emphasize the vital role played by the National Institutes of Health in funding this and other critical research, and the Johnson family, whose twins both have sickle cell disease.


Following the briefing, Flake shared his work at a private reception for members of the Congressional Black Caucus and other African-American leaders from the business, civic and educational communities. The evening was hosted by Alfred C. Liggins III, CEO, president and treasurer of Radio One. 

## Gift Supports Creation of Fetal Diagnosis Resource Library

Fetal therapy is one of the most rapidly evolving fields in medicine. Discoveries in genetics advance every year, just as more effective diagnostic and treatment techniques develop at a lightning pace.

As the largest prenatal diagnosis and treatment program in the world, CHOP's Center for Fetal Diagnosis and Treatment receives more than 1,000 referrals each year. Staying on the cutting edge of this advancing field enables the center to continually deliver the best care to patients with even the rarest, most complex conditions.


A newly established resource library, established thanks to a gift from Bruce and Judi Goodman, now makes it easier for clinicians to access the most current information on prenatal diagnosis, genetics and obstetric care in one centralized location. The library, which has both printed and online components, is regularly consulted by staff before counseling families.

"Up-to-date Web-based databases have become essential tools used here at the center daily to aid in prenatal diagnosis and counseling," says Nahla Khalek, M.D., M.P.H., attending obstetrician at the center who oversees the library. "Thanks to support from the Goodmans, the resource library allows us to provide our families with the most comprehensive assessment of prenatal findings." 

## One Year, Many Happy Birthdays

It has been a busy year since a study co-led by CHOP established fetal surgery as a standard of care for myelomeningocele (MMC), the most severe form of spina bifida. Now able to offer the surgery widely, CHOP has received more than 200 fetal MMC referrals from all over the world and performed more than 100 evaluations and nearly 30 prenatal surgeries. The team at CHOP, one of the most experienced in the world at fetal MMC repair, now performs about three of the surgeries every month.

"The increase in referrals we're now seeing suggests this important information is finding its way into the medical community," says Mark P. Johnson, M.D., director of Obstetrics at the CFDT. "As a result, more patients are now being offered this as a validated clinical option, and more babies may benefit from this innovative therapy in the future."


To build on this pioneering care, the Center for Fetal Research is developing a minimally invasive technique for prenatal spina bifida repair using engineered tissue. In the future, the procedure could require only a short stay at CHOP and allow mothers to give birth at their local hospitals. In addition to significantly reducing the burden on the mother, the fetus would be expected to have even better outcomes since the procedure could take place several weeks earlier in gestation, when the spinal cord is less likely to have sustained damage. 

## New Textbook by Peter Mattei, M.D., Offers Expert Techniques in Pediatric Surgery

Surgeons seeking a comprehensive reference book on the latest and most advanced techniques in pediatric surgery have a new resource: *Fundamentals of Pediatric Surgery*, edited by Peter Mattei, M.D., an attending general pediatric surgeon at CHOP.

Published last spring, the textbook has more than 140 contributors from dozens of children's hospitals and other institutions.

"This textbook is aimed at practicing surgeons — both surgeons specializing in pediatric surgery and general surgeons who want current information on the specific needs and special considerations surrounding surgical care of children," says Mattei.

The textbook covers trauma, critical care, pediatric surgical oncology and organ transplantation as well as specialized issues such as fetal surgery and conjoined twins. Divided into 15 sections spanning 921 pages, each chapter presents up-to-date, pertinent information written by an experienced surgeon or clinician. 

The stories of hope, innovation and progress within this report are possible thanks to the support of generous families. To learn about how you can help, contact **Becky Rohtbart**, director of development, at **267-426-6529** or **rohtbartr@email.chop.edu**, or visit **GiftofChildhood.org**.



The Division of General, Thoracic and Fetal Surgery at The Children's Hospital of Philadelphia was established by C. Everett Koop, M.D., in 1946 as the first pediatric surgical program in the city of Philadelphia, and the second in North America. Throughout its long history, the Division has provided some of the finest, most compassionate multidisciplinary care in the nation, and has continued to pioneer advancements to improve the lives of children for generations to come. The Center for Fetal Diagnosis and Treatment, founded in 1995 by N. Scott Adzick, M.D., allows us to dedicate these unparalleled resources to the care of babies even before birth.



*The Children's Hospital of Philadelphia shares the No. 1 spot on the prestigious U.S. News & World Report Best Children's Hospitals Honor Roll for 2011-12.*

**CH** The Children's Hospital  
of Philadelphia®

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THORACIC & FETAL SURGERY**

**CENTER FOR FETAL  
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Keep the connection.

