24 HOURS of Critical Care
A photographic journey

When Little HEARTS FAIL
Life-sustaining circulatory support devices

The Impact of Childhood Vaccines
Past, present and future
Texas Children’s is a dynamic organization. We opened our doors with a modest three-story, 106-bed facility 59 years ago, and today we have grown to become a comprehensive health care system reaching all corners of the community, region and globe.

Our mission then was simple — to be a source of health and hope for children in our community. While our reach and depth of services have broadened, our mission remains the same.

We have built one of the nation’s largest pediatric-OB/GYN networks, with four health centers, two hospital campuses, the nation’s largest hospital-owned pediatric primary care network and a maternal fetal medicine program housed in Texas Children’s Pavilion for Women. Our network also includes the nation’s first pediatric health insurance plan, which today insures more than 350,000 children who might otherwise be without coverage.

More than 8,500 children and women are seen here every single day. They provide the inspiration around which our story revolves. We understand their complex medical challenges and know their struggles. It is our responsibility to improve their quality of life — and to ensure the best possible outcomes.

The Journal of Texas Children’s Hospital, our new publication, is our opportunity to explore relevant issues that face the populations we and our health care peers serve. The Journal is a place to share the fruits of our collaborative efforts with our colleagues, here and abroad.

Most importantly, The Journal is about telling our patients’ stories and how they drive our work to deliver the best in patient care, education and research. Stories like that of Leanny, whose Berlin Heart implantation at just 3 months old gave her a fighting chance to be the vibrant 4-year-old she is today; and Dr. David Gordon, an inspiring Texas Children’s Global Health Corps doctor who spent two life-changing years in Ethiopia; or the Martins, a couple with fertility challenges who had almost given up hope before conceiving their quadruplets.

These are just a few among many who fill our daily journal, illuminating the need for our abiding efforts. Welcome to our premier issue of The Journal of Texas Children’s Hospital.

Mark A. Wallace
President and Chief Executive Officer
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Hospital granted Magnet® status for third consecutive time

Texas Children’s Hospital for the third consecutive time has been granted Magnet® status, a national designation from the American Nurses Credentialing Center (ANCC) that recognizes health care organizations for quality patient care, nursing excellence and innovations in professional nursing practice.

First recognized in 2003 and again in 2007, Texas Children’s is one of only six freestanding children’s hospitals in the nation to earn Magnet status and is one of fewer than 7 percent of United States health care organizations to hold this designation.

“This designation reflects our dedication to supporting our nursing staff with the resources and tools they need to deliver the highest level of care to our patients and their families and to continuously demonstrate leadership in initiatives that improve patient outcomes,” said Lori Armstrong, MSN, RN, senior vice president and chief nursing officer at Texas Children’s Hospital.

The Magnet Recognition Program® has become the gold standard for nursing excellence. It is achieved through a rigorous application and review process that demands widespread participation from leadership and staff and includes a site visit by Magnet appraisers. Hospitals must reapply for Magnet status every four years.

Unprecedented study demonstrates Berlin Heart device as lifesaving “bridge” for young children

A tiny heart pump that maintains blood flow in babies and small children with serious heart failure proved effective and lifesaving in a pioneering study involving 17 institutions led by Texas Children’s Hospital and Baylor College of Medicine (BCM). A report on this study appeared in the August issue of the New England Journal of Medicine.

The study looked at the safety and probable benefit of the Berlin Heart EXCOR® Pediatric Ventricular Assist Device (VAD), the only VAD available for babies and children. Patients who received the Berlin Heart lived longer on the device and were more likely to receive a transplant or recover heart function than children who were maintained on more traditional support using extracorporeal membrane oxygenation (ECMO), according to the study’s results.

“This study is now the gold standard for VAD therapies in children. Everything going forward will be compared to this,” said Charles D. Fraser, Jr., M.D., Texas Children’s surgeon-in-chief and chief of congenital heart surgery and Baylor College of Medicine professor of surgery.

Fraser and his colleagues in the United States and Canada compared the outcomes for 48 children (infants to 16 years) who received the device between 2007 and 2010 to matched patients in a national registry of patients supported by ECMO. They divided the patients who received the German-manufactured heart assist device into two groups based on their body size.

The new center will become the leading site for the development of new diagnostic and therapeutic approaches for the treatment of childhood lymphoma and the focal point for childhood lymphoma research. Advances made at the center will impact patients at Texas Children’s Cancer Center, as well as children throughout the U.S. and around the world.

Multidisciplinary effort to save babies’ hearts before birth brings families hope

The Berlin Heart EXCOR® Pediatric VAD was approved by the U.S. Food and Drug Administration (FDA) for use in children in 2011. FDA approval allows the device to be used as a bridge to transplantation. The Berlin Heart has been used in approximately 1,000 children worldwide.

Cancer Center opens world’s first pediatric lymphoma research center

Texas Children’s Cancer Center recently opened the Faye Sarofim Lymphoma Center, the first and only center in the world dedicated specifically to the research, care and treatment of children with lymphoma. This innovative research center was made possible by a generous gift of $10 million to Texas Children’s Hospital.

Cancer remains the leading cause of non-accidental death in children, and lymphomas are the third most common malignancy in childhood. Modern therapies to treat children with lymphomas primarily involve chemotherapy, which is occasionally supplemented with radiation treatment.

Although the outlook for children with lymphoma has generally improved in recent years, substantial challenges still exist. The launch of the new center addresses those challenges. There, researchers will conduct breakthrough laboratory investigations on the biology of lymphomas, use the information gained from laboratory and basic research to develop new diagnostic approaches, and identify novel therapeutic targets and new approaches to therapy.

“Our researchers have already developed effective cell-based therapies that have demonstrated extremely exciting clinical results, and we are also evaluating new chemotherapeutic agents with significant clinical promise,” said Catherine Bollard, MBE, M.D., Faye Sarofim Lymphoma Center director and Baylor College of Medicine associate professor for cell and gene therapy.

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“Previously, patients had limited options for their babies when they received an early diagnosis of HLHS during a routine ultrasound,” said Michael A. Belfort, M.D., Texas Children’s OB/GYN-in-chief and Baylor College of Medicine Department of Obstetrics and Gynecology chair.

“From this moment on, through the collaborative work of the Fetal and Heart Centers at Texas Children’s, we can offer more options to families who otherwise would have little hope.”

HLHS occurs in approximately 1 in 6,000 live births, when the left side of the fetus’s heart does not develop normally. Because most of the structures on the left side of the heart are too small and underdeveloped (hypoplastic), it is difficult for the heart to provide enough red blood flow for the body’s needs.

All children with HLHS will undergo at least three surgeries within the first three years of life. However, if diagnosed early using a fetal ultrasound, some fetuses may be a candidate for the new in utero catheterization procedure that will help treat HLHS and allow them to be more stable at birth before having to undergo their first heart surgery.

The Fetal Center at Texas Children’s Pavilion for Women is one of only a few centers in the world capable of performing this complex fetal intervention, as it involves a coordinated effort among a large, multidisciplinary team of fetal cardiologists, OB/GYNs, interventional cardiologists, congenital heart surgeons, fetal imaging experts, maternal and fetal anesthesiologists, and other clinical specialists.

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Multidisciplinary effort to save babies’ hearts before birth brings families hope

The team at Texas Children’s Fetal Center, a national leader for treating fetal anomalies, has successfully completed two in utero fetal cardiac interventions to treat hypoplastic left heart syndrome (HLHS), a congenital heart defect that is one of the most complex heart defects to treat.

The first center in the Southwest to create a program to treat this defect in utero, Texas Children’s Fetal Center and Heart Center can offer this procedure to future parents looking for hope for their unborn babies with HLHS.

Fraser and his colleagues in the United States and Canada compared the outcomes for 48 children (infants to 16 years) who received the device between 2007 and 2010 to matched patients in a national registry of patients supported by ECMO. They divided the patients who received the German-manufactured heart assist device into two groups based on their body size.

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Texas Children’s Pavilion for Women commences labor and delivery services at premier facility for women’s, fetal and newborn care

Last spring, Texas Children’s Hospital announced the start of labor and delivery services at its landmark new facility, Texas Children’s Pavilion for Women. With the opening of the new hospital, Texas Children’s has fully expanded into obstetrical and gynecological care. The 15-story, $575-million state-of-the-art hospital is staffed, designed and equipped to be among the nation’s premier centers for women’s, fetal and newborn health. The hospital can accommodate 7,000 births annually and specializes in multiple births and high-risk pregnancies.

“The Pavilion for Women provides unprecedented access to leading experts offering the latest treatments and most advanced technologies in obstetrics, gynecology, maternal fetal medicine, fetal surgery and neonatal medicine,” said Michael A. Belfort, M.D., Texas Children’s OB/GYN-in-Chief and Baylor College of Medicine Department of Obstetrics and Gynecology chair. “This is a new paradigm for children’s hospitals, but one that is sure to become a model for care across the country.”

The Pavilion is designed to facilitate the practice of family-centered maternity care, an evidenced-based care model that involves the family throughout the birthing and postpartum care process and promotes better outcomes.

Outpatient and inpatient services for women and babies at the 1.3-million-square-foot Pavilion encompass the full continuum of care, including gynecology, fertility, obstetrics, maternal fetal medicine, fetal diagnostics and imaging, minimally invasive and open fetal surgery, women’s behavioral health, labor and delivery, and newborn care. As part of Texas Children’s, the Pavilion provides patients access to pediatric subspecialists in 40 specialty areas.

Three new physicians complement pediatric surgery team, expand depth and breadth of care

The Texas Children’s Hospital division of pediatric plastic surgery recently expanded its team with three new members, making it one of the nation’s largest full-time pediatric plastic surgery teams.

Cranio-maxillofacial surgeons David Khechoyan, M.D., and Laura Monson, M.D., and craniofacial orthodontist John Wirthlin, M.D., round out the Texas Children’s team, which provides sub-specialized, multidisciplinary and individualized care of all aspects of cleft lip and palate, orthognathic surgery, craniosynostosis, craniofacial microsomia, facial clefts, resonance disorders, and pediatric facial trauma.

Khechoyan’s clinical interests include all aspects of cleft lip and palate care, craniosynostosis, craniofacial microsomia and pediatric facial trauma, and his research involves critical examination and novel 3-D imaging analysis methods of surgical outcomes in craniosynostosis surgery. Monson’s clinical interests are craniosynostosis, comprehensive cleft care, vascular anomalies and ear reconstruction, and her research focus is on improving clinical outcomes in the cleft lip and palate population. Wirthlin’s specialty areas are pre-surgical infant orthodontics, craniofacial growth patterns of patients with cleft lip and palate, distraction osteogenesis, and combined orthodontic and orthognathic treatment planning.

The three complement a team that cares for thousands of patients each year who require specialized medical and surgical treatment for a diverse set of congenital and acquired craniofacial anomalies. In addition, the team offers special expertise in the treatment of congenital nevi, vascular anomalies and general pediatric plastic surgery.

IN BRIEF

Three new physicians complement pediatric surgery team, expand depth and breadth of care

Texas Children’s Pavilion for Women commences labor and delivery services at premier facility for women’s, fetal and newborn care

Photo: Allen Kramer

Summer and Brandon Franks were proud new parents after delivering daughter Autumn, one of the first babies born at Texas Children’s Pavilion for Women.
Dr. David Gordon, a California native and Peace Corps veteran, made a 9,000-mile commitment to practice medicine at the University of Gondar in Ethiopia, training local health care professionals in the essentials of neonatal and pediatric care.
Not every baby is born breathing. Sometimes, it’s up to the physicians and nurses present at delivery to coax the baby to take his first gulps of air. When David Gordon, M.D., began his work at the University of Gondar Hospital in northwest Ethiopia, he was startled to learn that not all of the hospital staff knew this basic step.

As part of Texas Children’s Hospital Global Health Corps program, he was at the beginning of a two-year assignment as a teaching physician at the hospital, with his time divided between direct patient care and training local physicians and students.

“It was heartbreaking, because we lost so many babies when there was no need for that to happen,” Gordon said. “I helped develop a resuscitation course so staff would know how to care for these children — that the best way to resuscitate a newborn is to warm his back by rubbing him and tickling his feet.”

Many mothers arrived at the hospital with previously untreated conditions that led to complications in delivery. In the neonatal intensive care unit, where Gordon worked as an attending physician, the joy of successful births often coincided with the pain of loss.

“Sometimes, despite heroic efforts, it was a matter of good care received much too late.

Gordon said. “It was one of the most heartbreaking rotations I’ve ever been a part of.”

Despite his team’s greatest efforts, about four babies died each week. But Gordon began each day anew, he said, with the same hope and the same determination to change a life — or to save one. And when he wasn’t caring for patients, he was still working to improve their care. He developed training materials for emergency pediatrics, he helped to establish outreach programs, and he developed curricula designed to extend medical training beyond the term of his assignment in Gondar.

DRIVEN TO CARE

How did Gordon — a native of Walnut Creek, California — end up teaching the basics of neonatal medicine to physicians and nurses in the mountains of Ethiopia? His journey began with a single trip he took as a high school sophomore to a remote village in Ecuador. After spending six weeks building latrines for a community of 1,000 villagers, Gordon, then 16, returned to California.

“It sounded like such an adventure at the time,” Gordon said. “But I took home a lifetime desire to do what I could to alleviate poverty.”

Gordon ultimately enrolled at Dartmouth College to study international development and political economics. After graduation, he signed up for the Peace Corps and landed in the heavily Muslim nation of Turkmenistan, which borders Iran and the Caspian Sea. Like his time in Ecuador, Gordon’s experience in the Peace Corps was transformative.

“Unfortunately, a lot of the time it was people in Washington who made decisions for volunteers on the ground,” Gordon said. “I — a Western male — was supposed to teach conservative Muslim women how to breastfeed. Since that wasn’t going to happen, I put together a health education class for kindergartners instead.” In fact, whenever he had any free time at all, Gordon spent it with children, and he admired people who dedicated their time to improving children’s health and well-being. This lifelong interest ultimately led Gordon to enroll in medical school at the University of Vermont in 2003, specializing in pediatrics.

RETURNING OVERSEAS

As he completed his training, Gordon’s attention returned to international medicine. While he was completing his pediatric residency at the University of California at San Francisco, he decided to apply to the Baylor International Pediatric AIDS Initiative (BIPAI), parent organization of the Global Health Corps. Gordon had heard about BIPAI from another physician, who told him about the program that places doctors in one of 13 “centers of excellence” in Africa and eastern Europe.

With his heart set on joining the Global Health Corps for a full, two-year program, Gordon applied in late 2009. But it was not to be. By the time he submitted his application — well before the entrance into the program is not a requirement. Competition remains steep, and the deadline — the program was already submitted his application — well before the program, Gordon applied in late 2009.

But it was not to be. By the time he submitted his application — well before the deadline — the program was already full. Competition remains steep, and the program is not a given for even the best candidates. But in February 2010, a new opportunity arose when the program’s former administrator told Gordon about a new program in Ethiopia. It was a chance to train physicians in Africa, and it was what he’d wanted to do since his trip to Ecuador at 16.

Gordon successfully applied, and he arrived in Ethiopia in August, 2010. For almost two years, he divided his time at the University of Gondar Hospital between physician education, clinical care and improving hospital systems.

UNRIVALED EXPERIENCE

For physicians who join either the Corps or BIPAI, the comforts of Western civilization give way to basic furnishings, huge patient volumes, and a salary that is one-fourth what colleagues might earn in private practice. But the payoffs are as numerous as the trade-offs.

“You’re getting hands-on experience you wouldn’t get anywhere else,” Gordon said. “Plus, you’re living in a third-world country for literally only dollars a day. But the biggest reason people do it is because they absolutely love making a difference in these communities.”

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The need is significant.

“We have a shortage of medical experts, because while our country is indeed producing doctors, they’re leaving to practice in the United States and other countries.”
States or England, “said Mehretie Kokeb, M.D., an assistant professor of pediatrics and child health at the University of Gondar. “And, unfortunately, the ones who do stay aren’t always very committed because we don’t have the resources to compensate them.”

These challenges, however, were the reason for Gordon’s participation. Despite the difficulties of his work there, he treasures the experience.

“I’m sure my job in Ethiopia is the best job I’ll ever have,” Gordon said. “It was everything I’d ever dreamed about.”

THE RETURN

Gordon returned to the United States in May 2012. He joined the staff at San Francisco General Hospital and also began moonlighting with a medical service that provides care to underprivileged children living in the Bay Area and his hometown of Walnut Creek.

But on a recent night in a San Francisco restaurant, the earthy smell of onions and garlic transported Gordon back to the verdant hills of Ethiopia. He couldn’t stop talking about the people he had met and the children he had treated some 9,000 miles away.

“I can honestly say that I’ve never felt so stimulated and excited by my work as a physician as when I was in the Global Health Corps,” said Gordon. “Anyone who has ever worked in a third-world country comes away with the realization that the world is not supposed to work that way. Life is not supposed to be so hard for the people — and especially the children — who live there.”

His work as part of the Global Health Corps didn’t go unnoticed.

“When I think of Dr. Gordon I could literally cry because he was so good for this program,” Kokeb said. “Most telling of all — his shoes were never clean when he was here in Gondar. He was working much too hard for that.”

ABOUT TEXAS CHILDREN’S HOSPITAL GLOBAL HEALTH CORPS

The World Health Organization (WHO) estimates that 7.6 million children under age five died in 2010 around the globe. Many of the diseases they succumbed to are largely preventable — illnesses such as malaria, diarrhea, pneumonia and tuberculosis.

To combat this grim statistic, Texas Children’s Hospital launched the Global Health Corps in 2011. The Corps is part of the Baylor International Pediatric AIDS Initiative (BIPAI). While BIPAI debuted in 1996 to treat children with HIV/AIDS, the Corps addresses other illnesses that affect children in underdeveloped nations.

The doctors who serve with Texas Children’s Global Health Corps care for children and their families in Ethiopia, Malawi, Tanzania, Botswana and Swaziland, and they train local doctors and nurses in those countries. There are plans to expand the program to Asia and Latin America.

For more information about BIPAI and the Global Health Corps, visit bipai.org.

The Journal of Texas Children’s Hospital

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Leanny Rodriguez was born seemingly healthy on July 1, 2008. Within three months, however, her heart was failing. She was on the list to receive a heart transplant, but she was rapidly running out of time.

Texas Children’s Heart Center specialists recommended that Leanny have a Berlin Heart implanted. This device — a ventricular assist device, or VAD — connects to the heart from outside the body and helps the patient’s heart circulate blood. The Berlin Heart didn’t just buy Leanny more time, it improved her circulation and helped her grow stronger each day. She learned to crawl and stand up, and by the time she received a donor heart four months later, she was a better candidate for transplant surgery.

But the most remarkable part of Leanny’s story isn’t that she was able to thrive on a heart device. It’s that this option didn’t even exist a few years ago.

A PRESSING NEED FOR NEW EXPERTISE
When Charles D. Fraser, Jr., M.D., arrived at Texas Children’s Hospital in 1995 to take up his new position as chief of congenital heart surgery, he didn’t intend to become a leader in the use of pediatric VADs. He planned to build a surgical team that would provide the finest heart surgery for children with the best long-term outcomes.

“It’s a completely new day as compared to when I came to Texas Children’s,” said Fraser, now Texas Children’s surgeon-in-chief and chief of congenital heart surgery and Baylor College of Medicine professor of surgery.

“At that time, we did everything we could to avoid putting in a mechanical device, because with the only device option we had then, the patient had to be in the intensive care unit, oftentimes with the chest open on a ventilator. It was a desperate operation to try and buy a few days, maybe on rare occasions a week or two.

“It was a terrible situation because everybody knew that once you started down this road of connecting the patient to a temporary machine, it was usually a matter of time before some fatal complication occurred. It felt like there was an anvil over your head the entire time.”

BY EDEN McCLESKEY
The device was implanted into a 6-year-old girl, who was supported for 11 days before she died.

“My first patient, we were all just heartbroken when she didn’t survive,” said Texas Children’s Heart Center study coordinator and case manager Karol Arrington. “It was scary. You think, ‘Well, that can’t be the right thing to do’ if we lost this patient.”

“But you have to have courage as a surgeon, as someone who wants to make things better for patients. Thankfully, this little girl’s family had the courage to allow us to try it, and we learned so very much and advanced so much as a program.”

As it turned out, the next big breakthrough for the program — and the start of a new era — was actually just months away.

THE BERLIN HEART BREAKTHROUGH

In Germany, engineers at the Berlin Heart Institute had developed an experimental pediatric ventricular assist device for older children, which they first used in 1990. By 1994, they offered a scaled-down version for infants. Over the years, the pump was used successfully in Germany and other parts of Europe but was not FDA approved for use in the United States.

Early evidence suggested the Berlin Heart VAD could provide stable circulatory support for up to 421 days in children as small as 3 kilograms (6.6 pounds). Furthermore, the experience indicated that many subjects could be weaned from mechanical ventilation, discontinue sedation/paralysis and even become ambulatory — clinical benefits that help improve suitability for transplantation, but were generally considered unfeasible with other mechanical devices in children.

When between 2000 and 2004, two U.S. hospitals used the scaled-down heart pump in infants under the FDA’s Humanitarian Device Exemption (HDE) program for a “compassionate use.” The news of these uses piqued interest among pediatric heart surgeons around the country.

In 2005, Fraser implanted the Berlin Heart into a 3-month-old baby who had been born with a failing heart. The baby did well after the surgery and soon went on to receive a donor heart. Encouraged by the successful implantation, Fraser accompanied Berlin Heart representatives to Washington, D.C., requesting that the FDA allow an investigational device exemption (IDE) study.

In January 2008, Texas Children’s Heart Center announced that Texas Children’s had been chosen to serve as the national lead center of a first-ever, prospective multicenter North American clinical trial on what is officially known as the Berlin Heart EXCOR® Pediatric Ventricular Assist Device. Fraser was chosen as the National Principal Investigator who would coordinate the multicenter IDE study on the safety and efficacy of the Berlin Heart VAD as a bridge to cardiac transplantation. Once the study began, investigators around the country were able to enroll patients, implant the device and keep children alive while they waited for heart transplantation.

At the end of the clinical trial, Fraser and his study colleagues took the Berlin Heart results before a 22-member FDA advisory panel comprising pediatric and adult heart surgeons, device experts. At the end of a challenging round of questions about the study evidence, the panel...
members voted unanimously to recommend to the FDA that they grant approval. On December 16, 2011, the EXCOR® device received FDA approval for use in U.S. children as a bridge to heart transplantation.

“One of the most exciting things to come out of the trial — other than, of course, the approval of the only device that can help infants and small children — is that device companies have taken notice of our work, and there will definitely be other big clinical trials in our future,” said Arrington, who acted as study coordinator for the Berlin Heart trial. For Arrington and her colleagues at the Heart Center, it’s not about making a big name for themselves, it’s about contributing to a growing body of knowledge.

“I always say we’ve learned so much, and we’re so much better than we were when we started out,” she said. “We’ve made a difference by doing what we’ve done here because we can share that information with other centers. So they’re starting out where we are now, not where we were 10 years ago.”

**SIX DEVICES, ONE COMMON GOAL**

Today, Texas Children’s Heart Center leads the country in the use of VADs with pediatric patients whose hearts are failing. The Heart Center uses six different devices — more than any other pediatric hospital in the country.

This breadth of activity is helping make Texas Children’s a center for the use and investigation of new artificial heart technologies. And this critical mass of experience, insight and scientific rigor will help Texas Children’s advance the science of mechanical circulatory support in pediatric patients.

In the meantime, however, the success stories are adding up, as Leanny Rodriguez and her family can attest. Today, Leanny is a healthy, energetic 4-year-old with a strong heart and an encouraging future.

See Leanny’s progress at texaschildrens.org/LeannyStory.
Hope overtakes fear as families gain strength from their children’s courage.

Rounds take place at the bedside of patient Maria Sanchez. Texas Children’s Pediatric Intensive Care Unit (PICU) is staffed around the clock with an intensivist and three attending critical care physicians, while fewer than half of the hospitals in the country have even one critical care attending on staff at any given time.

Kangaroo Crew personnel transport a new patient into the PICU.

Katie and Eddie Wood check on their son, Reid Wilson, in the PICU.

Dr. Harish Bangalore (fellow) and Dr. Renan Orellana (attending) consult over an x-ray.
A nurse tends to PICU patient Hector Melecio. With more than 60 critical care nurses and 21 nurse practitioners and physician assistants on staff in critical care, Texas Children’s PICU is one of the safest in the nation, having achieved a remarkable 310 days without a central line infection.

Alexis Pigozzi climbs into bed to comfort her daughter Ami.

Attending PICU physician Dr. Jorge Coss Bu consults with Texas Children’s Cancer Center physician Dr. Kathryn Leung.

Cardiology fellow Dr. Benjamin Frischhertz consults with Amy Bundard about her son Tyler as her sister Anny Knight looks on.
Pediatric neurology specialist Dr. Angus Wilfong (second from right) consults on a case. 

Eddie and Katie Wood listen as their son’s progress is being discussed during morning rounds.

Pediatric intensive care unit (PICU) patient Karmine is comforted by his mother Manda Hurt. Texas Children’s PICU has the highest number of admissions and the shortest length of stay in the country, and consistently outperforms in predicted mortality and morbidity rates.
MultiPlYiNg tHe CHaNCEs

Ashley Martin gave birth to quadruplets Abby, Allie, Corbin and Carson after almost giving up following months of expensive fertility treatments.

Advances in Care Lead to More Multiples

BY Hasti Taghi
PHOTOS BY Allen Kramer

A TINY HEART MONITOR BEEPED INCESSANTLY. Cradling baby Carson, Ashley Martin looked up from her rocking chair. Corbin’s monitor was the one going off this time. In another crib, little Abby was getting fussy. And in the adjoining crib, Allie was beginning to open her eyes from an afternoon nap.

Martin didn’t seem alarmed as she waited for the monitor to quiet. The two nurses in the room tended to the other babies as she continued to feed Carson his bottle.

“At first, I freaked out every time I heard the monitors make a noise,” Martin said. “Now I’m used to it. I know they’re okay.”

This was a typical afternoon in room 825 of Texas Children’s Hospital Neonatal Intensive Care Unit (NICU), where the Martin quadruplets were being cared for as they gained the weight and strength to go home.

BABY STEPS

The journey that brought the Martins to the NICU began more than a year ago. Martin and her husband Larry already had one child — 3-year-old Ella — but they had difficulty conceiving another.
After almost a year of trying, the couple was advised by their doctors in their hometown of Mont Belvieu, Texas, to try fertility treatments. With the help of their physician, they considered their options, eventually settling on intrauterine insemination, or IUI, along with fertility medication. In this procedure, fertility medication was used for ovulation induction, followed by IUI, where the sperm are placed inside the woman’s uterus to promote fertilization.

The Martins’ insurance covered the treatments, but co-pays along with the medication and parking in the Texas Medical Center added up to about $2,000 a month. It took the Martins three months to conceive.

“The last month we tried was the final month we were going to do it,” Martin said. “We just couldn’t afford it, and my body couldn’t handle any more. We were going to do one last push, and then if it didn’t work, we would wait a while and try again later.”

The third month was the charm. During their five-week ultrasound, the Martins’ doctor immediately saw there was more than one embryo. While there was an obvious multiples boom at the Pavilion, Gandhi said it’s not necessarily a forecast of what’s to come nationwide.

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“The Texas Children’s program for Multiples (PFM) has provided prenatal support to the parents of multiples, helping them come to grips with the challenges and responsibilities of a multiple pregnancy. Texas Children’s PFM specialists see each patient for a half-day visit, which includes an ultrasound to determine the kind of multiples the mother is having; genetic counseling; advice from a dietician about her dietary needs; and a visit with a maternal-fetal-medicine specialist to clarify the pregnancy risks.

“First, there were three sacs grouped together, then he found a fourth,” Martin said. “After that, I don’t remember much. I was in absolute shock.”

There was another week of waiting until the next appointment, during which they heard four tiny heartbeats, confirming they were expecting quadruplets. The Martins had been warned of the possibility of multiples due to fertility treatments, but they had never envisioned four babies.

“We got our money’s worth, that’s for sure!” Martin said.

MULTIPLYING MULTIPLES

The Martins are part of a national trend toward increased numbers of multiple births. The most recent report on multiple births from the U.S. Department of Health and Human Services (dated 2010) shows that out of nearly four million births in the U.S., more than 132,000 were twins, about 5,500 were triplets, 313 quadruplets, and only 37 were higher-order multiples of more than five. On average, there is one set of sextuplets born in the U.S. each year.

Manisha Gandhi, M.D., is chief of the Maternal Fetal Medicine Clinic, director of the Program for Multiples at Texas Children’s Pavilion for Women, a Baylor College of Medicine assistant professor of obstetrics and gynecology, and an associate residency program director. Gandhi said the increase in multiple births in recent years is due in part to the increased effectiveness of fertility treatments, and in part to increased maternal age at time of conception. As women decide for a variety of reasons to wait longer before having kids, their statistical chance of having multiples increases.

Adding to that are fertility treatments and their increased potency. Gandhi said the highest recurrence is twins, and most higher-order multiples are a product of ovarian stimulation rather than in vitro fertilization, or IVF.

“These are the ones where the woman gets hormones to stimulate her ovaries and then she ovulates,” Gandhi said. “Sometimes she ovulates multiple ova, and that’s leading to the higher-order multiples. It’s very rare these days to get higher-order multiples from IVF because (physicians specializing in reproductive endocrinology and infertility) are rarely doing three, four, five embryo transfers anymore.”

This change has come about because physicians have become more confident in their ability to fertilize just one or two eggs along with the fact that higher-order multiple pregnancies are associated with significantly increased maternal and neonatal risks. Physicians consider each case separately when deciding which method to use.

A LOCAL BOOM

On March 26, 2012, Texas Children’s Pavilion for Women opened its doors for inpatient services and began delivering babies. Within two months, the Martins’ quadruplets were born. Among them were 14 sets of twins, three sets of quadruplets, including the Martins, and a sextuplet pregnancy — the “Perkins Pack” of three girls and three boys. Born at the Pavilion on April 23, the Perkins sextuplets received a surge of local and national media attention. By the end of October, 81 sets of multiples had been delivered at Texas Children’s Pavilion for Women.

“The last month we tried was the final month we were going to do it,” Martin said. “We just couldn’t afford it, and my body couldn’t handle any more. We were going to do one last push, and then if it didn’t work, we would wait a while and try again later.”

While there was an obvious multiples boom at the Pavilion, Gandhi said it’s not necessarily a forecast of what’s to come nationwide.

“Texas Children’s is a premier facility, so we can get a skewed view because this is where people come with higher-order multiples for both the maternal and neonatal care. So, we’re not seeing a general population.”

PREPARING FOR MULTIPLE ARRIVALS

A multiple pregnancy can be daunting for the parents-to-be. Since 2010, the Texas Children’s Program for Multiples (PFM) has provided prenatal support to the parents of multiples, helping them come to grips with the challenges and responsibilities of a multiple pregnancy.

Texas Children’s PFM specialists see each patient for a half-day visit, which includes an ultrasound to determine the kind of multiples the mother is having; genetic counseling; advice from a dietician about her dietary needs; and a visit with a maternal-fetal-medicine specialist to clarify the pregnancy risks.

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“There was more pain, swelling and discomfort, but worse than anything was the fear that comes with carrying multiples,” Martin said. “The pregnancy was the hardest part. Just not knowing whether they would all make it and be healthy when they were born.”

A SUCCESSFUL OUTCOME

The Martin quads stayed in a room in the neonatal intensive care unit in four side-by-side cribs. They were
It was worth every second of the worry. It was worth all of the pain knowing they’re healthy and how loved they make me feel. It was all worth it.

Martin checks in on 7-week-old Abby, who shares a state-of-the-art private room at the neonatal intensive care unit in Texas Children’s Pavilion for Women. Born at 28 weeks and five days gestation, weighing less than 3 pounds each. Abby was the smallest at 2 pounds, 6 ounces. Carson came in weighing 2 pounds, 11 ounces. Corbin and Allie were the biggest at 2 pounds, 13 ounces each.

On her afternoon visits, Ashley sat with her newborns, enjoying the occasional squeak from one of the babies. Two nurses tended to them, and the NICU was bustling with activity. Asked if she felt calm, Martin admitted that she wasn’t quite calm yet and that she definitely wasn’t calm when she found out she was having quads. But, sitting in her babies’ room counting down the days until they go home with her, Martin said she couldn’t think of having it any other way. “It was worth every second of the worry,” she said. “It was worth all of the pain. Knowing they’re healthy and how loved they make me feel. It was all worth it.”

For every couple in America that simply “gets pregnant,” there are five more who dream, pray, wish, medicate and — quite literally — do whatever it takes to have a baby. Thanks to advances in reproductive medicine, couples hoping to conceive now have even more options that multiply their chances.

Intrauterine insemination

Intrauterine insemination (IUI) involves the placement of spermatozoa into a woman’s uterus around the time of ovulation. The sperm are usually obtained from the man and are usually concentrated and “washed” before being transferred. The goal of IUI is to increase the chances of pregnancy by allowing the sperm to bypass the cervix and Fallopian tubes and have more direct access to the oocyte (egg). IUI is often used as a first-line treatment for couples trying to conceive who have normal semen parameters and normal findings on fertility testing.

In vitro fertilization

In vitro fertilization (IVF) is a fertility treatment used to help couples conceive a baby. It involves removing eggs from a woman’s ovaries and combining them with sperm outside the body. The fertilized eggs are then placed into the woman’s uterus, where they can implant and develop. IVF is often used when a couple has fertility problems, such as male infertility, female factor infertility, or tubal infertility. IVF can also be used when a couple wants to use donor sperm or donor eggs.

Intracytoplasmic sperm injection

Intracytoplasmic sperm injection (ICSI) is a fertility treatment used to help couples conceive a baby. It involves inserting a single sperm into an egg, directly into the egg’s cytoplasm, to fertilize it. ICSI is often used when a couple has fertility problems, such as male infertility, female factor infertility, or tubal infertility. ICSI can also be used when a couple wants to use donor sperm or donor eggs.

Michelle Flippin

For every couple in America that simply “gets pregnant,” there are five more who dream, pray, wish, medicate and — quite literally — do whatever it takes to have a baby. Thanks to advances in reproductive medicine, couples hoping to conceive now have even more options that multiply their chances.

While fertility treatments increase the odds of conception, there are risks. Complications of fertility treatments can include bleeding and infection, as well as ovarian hyperstimulation syndrome, which can cause significant pain and discomfort.

In cases where fertility treatments result in multiple pregnancies, these mothers face much higher risks of postpartum diabetes, anemia and preeclampsia. Multiple pregnancies also raise the chances of premature birth and low birth weight — with premature birth in turn increasing the risk of further health and developmental problems.

Michelle Flippin
Many 30-somethings are focused on building a career, growing a family, or buying a first home. And for a handful, these milestones accompany early scientific and medical achievements that can help advance understanding and save lives for years to come.

For these gifted individuals, early professional success is the result of several factors: individual drive and ability; the opportunity to work within an institution that provides even young researchers with significant resources; and access to mentors who can teach, support and motivate them.

LIFE IS LIKE AN EXPERIMENT

Amy Courtney, Ph.D., a postdoctoral fellow with Texas Children’s Cancer Center, is one of these talented young scientists. Courtney, 30, is researching how natural killer T cell (NKT) antitumor activity may be used to fight neuroblastoma, a cancerous tumor that develops from nerve tissue.

She is the 2012 winner of the American Association of Immunologists Abstract Trainee Award and was the recipient of the Keystone Symposia Future of Science Scholarship. Courtney also has contributed to several peer-reviewed publications.

She balances her life-changing work with a growing young family — she and her husband had a baby girl, Amanda, in September. Some say she makes it look much too easy. She said she learned long ago to apply what the field of science forces you to learn: don’t stress.

“Life is just like an experiment — you have a plan, and some days things work out, and some days, with no explanation, they don’t,” she said. “All you can do is keep trying. When you’re young and want to achieve great things, it is easy to get stressed, but eventually you realize it isn’t going to benefit you.”

Her peer group also keeps her grounded and encourages her along the way.

“They are incredibly supportive of the fact that I am a scientist,” she said. “It’s nice to have people around you who are proud of the work you do.”

WHAT MATTERED MOST

Christian Schaaf, M.D., Ph.D., said he can identify with the struggle to balance. Schaaf is a physician-scientist at the Jan and Dan Duncan Neurological Research Institute (NRI) at Texas Children’s Hospital and assistant professor of molecular and human genetics at Baylor College of Medicine. His work at the NRI is focused on exploring how the brain is affected when genes are altered, deleted or duplicated.

Schaaf has already identified chromosomal differences in patients with schizophrenia, bipolar disorder and autism. He is the winner of the Doris Duke Clinical Scientist Development Award for his study of how the brain processes sensory stimuli that affect intellectual disability, autism and other neuropsychiatric problems. All this, and he’s only 33.

Schaaf admits that he never anticipated being where he is in his career so soon.

“I’m grateful that I decided to come to the kind of place where my age and enthusiasm have consistently...”
Physician-scientist Dr. Christian Schaaf, with wife Kathrin and son Felix, juggles the demands of a growing family and thriving career in research.

"I wouldn't mind if the treatment I discovered could be applied to 100 kids or 100,000 kids," he said. "Just knowing that my life's work helps sick children is what's important to me."

**BALANCING ACT**

Although he spends the majority of his time conducting research, Schaaf also remains dedicated to his responsibilities in the Texas Children's Hospital genetics clinic, where he sees patients with neuropsychiatric disorders.

"So much is going on at this point in most people's lives, professionally and personally, that a lot of young physician-scientists struggle with balancing life," Schaaf said. "That balance is important. I want to take the time to conduct great research and see my patients — and that's just one part of the balancing act. I also want to be more than my job. I want to have a great relationship with my wife, Kathrin, and my son, Felix." Schaaf and Kathrin had another son, Lukas, in October.

**RIGHT PLACE AT THE RIGHT TIME**

Courtney and Schaaf agree that one of the benefits to being so successful in science at such a young age is the opportunity to have great mentors.

Schaaf trained under Huda Y. Zoghbi, M.D., one of the world's leading neurogeneticists. Zoghbi is responsible for the co-discovery of a mutation in the gene known as ATAXN-1, which can lead to spinocerebellar ataxia type 1, a neurodegenerative disorder that causes a person to lose control of their motor function.

Zoghbi also discovered that mutations in the gene MECP2 cause Rett syndrome and that the same mutations can cause a variety of other neuropsychiatric disorders, ranging from learning deficits to early-onset schizophrenia.

"Having Dr. Zoghbi as a mentor is incredibly significant," Schaaf said. "As a young scientist especially, it's important to recognize what an incredible advantage that is. How many young researchers can say they've been trained by one of the best in the world? If you are in the right place at the right time, you will have people who want to teach you and help you be successful. I am extremely grateful for the opportunities that Dr. Zoghbi has given me."

Courtney also has had the opportunity to work as a postdoctoral fellow with mentors such as Leonid Metelitsa, M.D., Ph.D., a leading scientist with Texas Children’s Cancer Center. In Metelitsa’s lab, Courtney is conducting cutting-edge research on novel forms of immunotherapy for childhood cancer. She is also acquiring critical research skills from Metelitsa on how to plan research projects and apply for funding from organizations like the National Institutes of Health, which has a highly competitive peer-review process.

In addition to mentorship, funding — which has forever been critical to successful research — is sometimes available specifically for young investigators. Some funding organizations — such as the Gruber Foundation and the Thrasher Research Fund — provide grants and resources for researchers under a certain age or who are just beginning their journeys in research.

**START EARLY**

Metelitsa and Zoghbi remember what it was like to be at the onset of a budding research career. They relate to Courtney’s and Schaaf’s ambition and their passion for new discoveries.

"I owe my career to my clinical and research mentors," Zoghbi said. "Recognizing what a difference they have made in my work as a physician-scientist, I feel strongly that it is my duty to pass on what they have taught me."

Zoghbi said mentors to young researchers need to advise, nurture and support by sharing what they learned from their successes and mistakes, by encouraging when the road to discovery seems impossible, and by providing input on research ideas, experiments and grants.

"Last but not least, mentors need to be a source of support and advice when issues of managing a career and life come up," Zoghbi said.

Metelitsa was just 20 years old when he began scientific research in medical school. He recalls being groomed by brilliant minds who stepped back and allowed him to form and express his own ideas. From those experiences, he learned never to micromanage and has always worked under the belief that students should be given as much independence as they can handle.

"Being a young researcher can be a challenge, but when it comes to science, it is best to start early," Metelitsa said. "In fact, it is critical that scientists start as early as possible to reach their fullest potential."
In 15 years of training and practicing in the Texas Medical Center, I’ve been able to treat a huge variety of diseases, from middle ear infections to childhood cancer. Thankfully, there are some diseases I have never encountered and hopefully never will.

Every day, I work alongside a practitioner who has vivid memories of caring for children with polio and measles. I’ve heard terrifying tales of clinicians’ limited abilities to prevent the morbidity that these illnesses would cause — involving in one case the physician’s contracting measles, causing his wife to fear for his life.

Recently, I was fortunate enough to hear a lecture from Dr. Carol Baker, director of Texas Children’s Center for Vaccine Awareness and Research and one of the most qualified people in the world to discuss the science and history of vaccines. She explained that people have been questioning the safety and efficacy of vaccines for almost 300 years.

Benjamin Franklin, initially a skeptic about the practice of self-inoculation against smallpox under the skin, became an advocate after the death of his 4-year-old son from smallpox, or as he called it, the distemper. During the Revolutionary War, George Washington inoculated his soldiers because smallpox was more lethal to his men than the English Redcoats. Later, in 1796, Edward Jenner created an oral vaccine that was at the time harshly scrutinized as unsafe. Now, thanks to his contributions, smallpox has been eradicated and no longer poses a threat to public health.

Although we mostly hear it in harmless pop-culture references, the phrase “going viral” has very serious origins — the lightning-fast spread seen by some viruses, like the measles. An outbreak of illness can sometimes be an international flight away.

Dr. Baker has co-written a remarkable book entitled Vaccine-Preventable Disease: The Forgotten Story. I recommend this book to anyone wanting to learn more about the devastating impact under-vaccinating can have on individuals and families.

In 2011, the United States suffered a massive spike of measles cases (222), including that of an 11-month-old at Texas Children’s Hospital. The national spread of the disease was traced back to 22 countries. Of those hospitalized, 97 percent were under-vaccinated against measles.

Never vaccines have greatly impacted how we practice pediatric medicine. One vaccine called Prevenar has greatly reduced the frequency of infections from Streptococcus pneumoniae, otherwise known as pneumococcus. This bacterium is the predominant cause of bacterial meningitis, severe pneumonia and other types of serious infections. With the adoption of Prevenar, the number of pneumococcal infections has fallen precipitously.

In the past, present and future, the impact of childhood vaccines has fallen precipitously. The American Academy of Pediatrics’ Advisory Committee on Immunization Practices, chaired by Dr. Baker, recommends a revised vaccine schedule directed at 20 vaccine-preventable diseases every new calendar year. According to research, vaccines are the second-most cost-effective way to prevent disease, behind only the purification of one’s water supply. Immunizations, if provided to children as recommended, also provide “herd immunity” to those unable to receive certain vaccines. Unfortunately, of late, the protection that high vaccination rates provide has been diminishing here and abroad, exposing more of those at risk to vaccine-preventable disease.

In 1995, the Advisory Committee on Immunization Practices recommended a revised vaccine schedule that included the meningococcal C vaccine. In 2006, ACIP recommended the first dose of Menactra between ages 11 and 12 with the goal of protecting teens from meningococcal for approximately 10 years. Recent research indicated that immunity from the dose at this age is not sufficient for long-term protection through college age. Therefore, a new vaccine requirement was introduced.

It states that teens must receive a meningitis vaccine at age 16 or later. The current recommendation of vaccinating at 11 to 12 years has been maintained, as this is the age where meningococcal risk increases. Even if they received the first dose at an early age, they are still required to get another vaccine at age 16 or later.

I am concerned about the HPV vaccine from what I have heard in the news. And if my teen will not be sexually active for years, why is my doctor encouraging it?

Two HPV vaccines have been developed, and the one our clinic provides is Gardasil. Although it has been a political lightning rod ever since its introduction in 2006, Gardasil is the first vaccine introduced to actually prevent the development of cancer. The vaccine targets the four strains of HPV that cause the vast majority of cervical cancer. Imagine a breast or brain cancer vaccine that would prevent 70 percent of the cancer risk throughout a woman’s lifetime simply by getting three injections at the age of 11.

A day after discussing Gardasil during a Republican primary debate, Representative Michelle Bachman infamously linked the vaccine with “mental retardation” on national television. The vaccine has never been scientifically linked to such a claim, harming her credibility with the national and scientific media. The vast majority of the vaccine’s adverse effects are related to headache or dizziness, which resolve in minutes. We observe patients for 15 minutes following the administration of this vaccine to monitor for any such effects.

Additionally, there is no known evidence that receiving a shot at the doctor somehow makes a preteen or teenager more likely to have unprotected sex, as claimed by some. In fact, delaying vaccination until teenage years may in some cases lead to reduced vaccine effectiveness. As of 2009, statistics indicate over 50 percent of ninth graders were sexually active in the state of Texas — regardless of race, gender or religion. The bottom line is that as a teen or an adult, most people will eventually be exposed to HPV, and the potential cost of under-vaccination is what your pediatrician is trying to prevent.

I heard there was a new vaccine requirement in Texas. What is it, and when does my child need it?

Teens have been encouraged to get the meningitis vaccine prior to going to college since the drug’s advent. However, several changes have been made recently to the recommendations regarding this important vaccine. When first released, Menactra was a vaccine offered to college- or military-bound seniors. In 2006, ACIP recommended the first dose of Menactra between ages 11 and 12 with the goal of protecting teens from meningococcal for approximately 10 years. Recent research indicated that immunity from the dose at this age is not sufficient for long-term protection through college age. Therefore, a new vaccine requirement was introduced.

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Huffington Foundation Focuses on Parkinson’s Research

MICHELLE FLIPPIN

A $2.5 million gift from the Huffington Foundation in September 2011 is providing an unprecedented opportunity for researchers at the Jan and Dan Duncan Neurological Research Institute at Texas Children’s Hospital in Houston to advance research and treatment for Parkinson’s disease and other complex neurological illnesses.

Parkinson’s disease (PD) is the second most common neurodegenerative disease in aging populations, affecting some 10 million people worldwide — 1 million of them in the United States. Common symptoms include shaking (tremors) and difficulty with walking, movement and coordination.

The gift from the Huffington Foundation is enabling established and up-and-coming scientists to pursue three novel approaches to understanding the pathogenesis of PD. Andrea Ballabio, M.D., and Carmine Settembre, Ph.D., aim to modulate lysosomal activity to promote cellular clearance and prevent, or even reverse, neurodegeneration in PD. Hugo Bellen, D.V.M, and Hector Sandoval, Ph.D., hope to delineate the role of particular genes in mitochondrial dysfunction, which plays a critical role in the disease. Juan Botas, Ph.D., and Thomas Westbrook, Ph.D., and the Institute’s director, Huda Y. Zoghbi, M.D., will use systematic genome-scale screening to identify genetic modifiers and targets suitable for therapeutic interventions.

“We so appreciate the generous support from the Huffington Foundation to allow us to launch this collaborative research program in Parkinson’s disease,” Zoghbi said. “Philanthropy like this enhances the breadth, depth and diversity of research we conduct every day.”

A portion of the Huffington Foundation gift also will enable the Institute to recruit another top researcher in the field of PD. Drs. Settembre, Sandoval and Park will be groomed to develop independent and expanded PD research programs. Collaborations within each team and among the three teams will help speed the process of discovery and development of new treatments for PD.

“My parents turned their attention to the needs of Houston’s elderly years ago when they established the Roy M. and Phyllis Gough Huffington Center on Aging at Baylor College of Medicine,” Terry Huffington said. “This investment at the Institute for research related to PD has the potential to impact not only the lives of elderly people in our community, but also people everywhere — young and old — with neurological diseases.”

W.M. Keck Foundation Funds Research into Neurodevelopmental Disorders

MICHELLE FLIPPIN

Girls with Rett syndrome — one in 10,000 — begin to experience loss of speech and purposeful hand movement and other symptoms within the first six to 18 months of their lives.

One of every 12,000 to 20,000 children born has Angelman syndrome, causing developmental delays, loss of movement or balance, speech impairments, and unique behaviors like frequent laughing.

While genetic defects have been linked to both, much remains to be discovered about each syndrome’s distinctive origin and development.

Last year, the W.M. Keck Foundation invested $1,000,000 in a study at the Jan and Dan Duncan Neurological Research Institute (NRI) at Texas Children’s Hospital designed to push the frontiers of medical understanding of these diseases.

NRI Director Huda Y. Zoghbi, M.D., is working with Daoyun Ji, Ph.D., Jianrong Tang, Ph.D., Yuri Dabaghian, Ph.D., and Akash Patel, M.D., to analyze neural network activity in mouse models of Rett and Angelman syndromes. Theirs is the first study to use in vivo models of specific neurodevelopmental disorders to characterize disease-causing alterations in the neural network and to explore deep brain stimulation as a novel method for restoring normal function.

The multidisciplinary study at the NRI builds on a recent discovery in Zoghbi’s laboratory that highlighted the importance of inhibitory neurons for normal behavior and function in a model of Rett syndrome.

Characterizing the neural network activity in genetic models of these two disorders — which are considered prototypes for intellectual disabilities and autism spectrum disorders (IDs/ASDs) — could reveal changes that underlie shared phenotypes (genetic traits). The preliminary data collected in this study of Rett and Angelman syndromes will allow the scientists involved to successfully compete for National Institutes of Health funding, and the understanding gained in these studies could eventually lead to treatments for multiple IDs/ASDs.

“The W.M. Keck Foundation’s gift helps us at the Institute move more quickly toward our ultimate goal of developing new interventions and treatments for individuals with IDs/ASDs,” Zoghbi said. 

Stories of Giving

Dr. Gary Clark with patient Kevin Sharp.

W.M. Keck Foundation Funds Research into Neurodevelopmental Disorders

Dr. Daniel Glaze with patient Rachael Seiler.
**Disco Legends Set a Single-Night Fundraising Record**

**ANGELA DOLDER**

In his book, *You Gotta Dance Like No One’s Watching*, Lester Smith shared six words that sum up his motto for life: “Anything worth doing is worth overdoing,” he wrote.

In 2012, Smith and his wife Sue lived up to this motto as chairs of the highest-earning, single-night gala in the history of Texas Children’s Hospital — An Evening with Disco Legends benefiting Texas Children’s Cancer Center.

These iconic Houston philanthropists (and champion ballroom dancers) not only underwrote all expenses for the evening but also matched each gift to the event through The Lester and Sue Smith Foundation, allowing every penny of the more than $30 million raised to support the Cancer Center.

“This transformational gift will accelerate pediatric cancer research initiatives here, including those that use genomic technologies to analyze samples and identify the specific genetic mutations responsible for the development and growth of tumors in pediatric cancer patients,” said David G. Poplack, M.D., director of Texas Children’s Cancer Center.

“My thoughts led me to all the things I would never get to do,” he said. “I’d never win another ballroom dance competition, climb Mt. Everest or chair a record-breaking gala. If anything, my cancer diagnosis spurred me on to crank up the heat and go for the gold. After more than eight years of hard work and fun, we made it to the top of our dance Mt. Everest.”

The Smiths were the 2002 and 2003 United States Grand Senior Latin Dance Champions.

“As chairs for Disco Legends, I hope that we transformed the shadow of cancer into a bright light of hope shining on the Cancer Center’s youngest warriors fighting the disease,” Sue said. “We knew that many children would be helped thanks to the tireless efforts of everyone involved with the magical evening that was Disco Legends.”

A standout moment at Disco Legends was hearing Gloria Gaynor’s ode to empowerment — “I Will Survive.”

“I have a pacemaker and defibrillator, a device that corrects abnormal rhythms of my heart and gives my heart an electrical shock if it needs it,” Hailey said. In a gesture of thanks to Texas Children’s Hospital, Juneau has loved playing basketball. Last year, she was the starting point guard on her school’s team when she came down with a mysterious and aggressive cardiac condition caused by a virus that attacked her heart.

She required risky open-heart surgery, and the team that had one shot to save her was at Texas Children’s Hospital.

“Had she not received the expert care that this hospital provides, Hailey would not be here today,” said her father, Brad Juneau. “Without a doubt, Texas Children’s saved my daughter’s life.”

The surgeries included the installation of appliances that help Hailey’s heart maintain a normal rhythm.

For as long as she can remember, 14-year-old Hailey Juneau has loved playing basketball. Last year, she was the starting point guard on her school’s team when she came down with a mysterious and aggressive cardiac condition caused by a virus that attacked her heart.

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