Baylor College of Medicine Department of Pediatrics **2016 Annual Report**

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2016 Annual Report

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Welcome

Dear Colleagues,

The world today is as complex as it is massive. In medicine, the days of the "all-knowing" independent clinician, researcher or educator have passed. Many of the challenges we face as physicians, scientists and medical leaders are so large and so complex that they require the contributions of entire multidisciplinary teams. We need absolutely everyone.

In the pursuit of excellence, diversity is a necessity.

Today, our Department of Pediatrics is more inclusive and more diverse than ever before, closely resembling the wonderfully diverse city in which we live and work. We embrace and celebrate diversity in its broadest sense. In fact, it is our view that diversity will be one of the key drivers of our march to preeminence in pediatric medicine. No program or hospital can attract the greatest talent if its culture is exclusive or unwelcoming of segments of our community.

In a very real sense, our Department of Pediatrics is itself a community. We all share a passion for improving the health and lives of children and families, but we bring to that passion diverse and complementary backgrounds, experiences and areas of focus. Each of us brings to each discussion our own unique perspectives, and the conversations are very rich. The children, families and broader community we serve all benefit.

I'm thrilled that our department is not filled with people from identical backgrounds. Such a program could not possibly match the capabilities and potential of the amazingly diverse faculty and trainees you will see profiled in the pages of this annual report. I hope you find our story informative and inspiring.

Sincerely,

Mark W. Kline

Mark W. Kline, MD
Physician-in-Chief
Texas Children's Hospital

J.S. Abercrombie Professor and Chairman
Ralph D. Feigin Chair
Department of Pediatrics
Baylor College of Medicine

The Department of Pediatrics is more diverse than ever before, closely resembling the diverse city in which we live and work.

Patient Care

Changing the Milieu of Childhood Adversity

Reading to young children is a good way to build close relationships while increasing the quantity and quality of language. The Section of Public Health Pediatrics uses this strategy to relieve parental stress and improve children's outcomes.

Section blends approaches to prevent, intervene and heal

Imagine you are standing by a river, seeing children float by. You pluck them out of the river to rescue them, but you need to go upstream to find out how, why and where they're falling into the water.

Going upstream to find and correct the causes of problems is the model of public health.

"We have been spending all of our time scooping kids out of the river, and now we're developing a program, a strategy, to start going upstream," said Christopher Greeley, MD, MS, chief of the Section of Public Health Pediatrics at Texas Children's Hospital and professor of pediatrics at Baylor College of Medicine. "What are the reasons these kids are ending up at our door? We will always take care of these kids, but part of what our team does is to focus on things that place kids and families at risk."

The first public health section in a department of pediatrics in the United States grew out of the department's Child Abuse Pediatrics program, which was established in 1978. Greeley, who is one of five board-certified child abuse pediatricians in the section, is president-elect of the Ray E. Helfer Society, the international society of child abuse physicians. He served for four years as board chair of Prevent Child Abuse America, with Texas Children's Senior Vice President Angelo P. Giardino, MD, PhD, serving as vice chair.

Greeley and Giardino met while both were early in their pediatric careers. Two factors influenced Giardino to become a board-certified child abuse pediatrician. One was inspiration from the commitment of his residency's leaders to abused children. The other influence was more personal.

> ***A report of child abuse is made every 10 seconds in the United States, and four children die as a result of abuse every day.***
> ***– U.S. Centers for Disease Control and Prevention***

"At the end of my internship, I evaluated a healthy child at risk for child abuse, and I made a recommendation that he needed to be removed from his family to be kept safe," Giardino said. "The next year, I learned that this beautiful little boy had been killed. I asked what had happened. Because of a paperwork glitch, he was not removed from his family. This incident seared in my mind that these systems to protect children have to be held accountable."

A report of child abuse is made every 10 seconds in the United States, and four children die as a result of abuse or neglect every day, according to the U.S. Centers for Disease Control and Prevention (CDC).

More time on prevention

As child abuse physicians, Giardino and Greeley kept seeing children after they were harmed. It would be a great day if no one were hurt. And the only way for that to happen would be for the health care team to spend more time on prevention, they agreed.

Meanwhile, at Texas Children's and Baylor, Physician-In-Chief and Department Chair Mark W. Kline, MD, thought that increasingly, the lines between the disciplines of pediatrics and public health have blurred.

"Medicine has focused on the individual patient, and public health focuses on populations," Kline said. "You're only doing half the job if you focus on the patient to the exclusion of community and population health. Likewise, you're only half of a public health practitioner if you focus on populations and you never consider the impact you're making on the individuals.

"It really came together when I was recruiting Dr. Greeley to be chief of our Child Abuse Pediatrics program. His principal strength is understanding the milieu in which children are injured, the family dynamic that culminates in violence, injury and abuse of children, and understanding strategies to prevent that abuse from occurring.

"As I was thinking about how broadly I wanted to define child abuse pediatrics in recruiting a chief, I thought this is the perfect place to launch this public health pediatrics program," Kline said. And Greeley agreed.

Launched in October 2015, the Public Health Pediatrics section has two major domains. One is child abuse pediatrics, and the other is the Center for the Study of Childhood Adversity and Resilience (CARE), which focuses on research to help prevent adverse childhood experiences such as poverty, violence, inequality and lack of adequate resources and care.

Child abuse pediatrics

The child abuse pediatrics program has four main components:

The Child Abuse Pediatrics program interdisciplinary team members provide training and awareness sessions for civic groups, church groups and YMCAs.

- Excellence in clinical care: Identifying and caring for abused and neglected children and adolescents, testifying in court and working with Child Protective Services. Approximately 2,500 suspected victims of abuse and neglect are evaluated annually at Texas Children's and the Children's Assessment Center in Houston. Care is provided at Texas Children's Main Campus and planned for the new Texas Children's Hospital The Woodlands campus. Consultative services are available for Texas Children's Hospital West Campus. The program provides medical support to the Children's Assessment Centers in both Houston and Brazoria County. Because children in the foster care system are at risk of abuse, Texas Children's also is developing a foster care clinic.

- Training and education: Baylor and Texas Children's have three physicians in training in an accredited fellowship in child abuse pediatrics, one of the largest such programs in the country. In addition to education for medical students and the greater Houston medical community, a training program is being developed for post-doctoral public health practitioners. An outreach program trains members of the community on signs and symptoms and what to do if they recognize child abuse.

- Scholarship and new knowledge: Clinical research varies from early recognition of abuse to improving mental health services for children in foster care.

- Community presence: The program's interdisciplinary team of physicians, nurses, social workers and public health practitioners help primary care physicians and nonprofits who care for abused and neglected children and are available to provide training and awareness sessions for civic groups, church groups and YMCAs.

CARE

The primary focus of CARE is community-level research to identify, promote and implement strategies to prevent adverse childhood experiences (ACE), such as poverty, violence, inequality, homelessness, and a lack of health care and mental health resources, education and nutrition. A CDC study in the 1990s demonstrated a clear correlation between ACE and increased sickness and early death in adults.

CARE runs the following four ACE Workgroups, in coordination with partners from the Texas Medical Center, the greater Houston nonprofit community, and city and county agencies:

- Postpartum depression: If mothers are depressed or unable to care for their babies, that can affect the babies' lifelong trajectory. Workgroup members develop collaborations with pediatricians, primary care physicians and others in the community who are screening for postpartum depression and linking families to services.

- Intimate partner violence: Historically called domestic violence or violence in the household, this problem may manifest in a mother being unable to provide care for her children, or the children themselves may be victims of violence. True to the public health model, the goal is to develop partnerships and strategies to reach all families who need it, even those who never come to Texas Children's for care.

- Food insecurity in Houston: Food insecurity has a significant impact on a child's life and ability to go to school and pay attention. Food and nutrition are such basic functions that if food insecurity is a problem, it often clusters with other problems families may have, such as violence, transportation issues, lack of utilities, poverty and safety in the neighborhood. Texas Children's partners with city and county governments, nonprofits, businesses and school systems to determine how they can collaborate and how they can help.

- Parenting stress: Having a young child is difficult, and often young babies are at greater risk of harm due to parental fatigue or frustration. Funded by a grant from the Department of Family and Protective Services, a collaboration between Baylor/Texas Children's and The University of Texas System conducts research into strategies that can be deployed in pediatric offices to identify stressors, link parents with resources, and give families some evidence-based skills to help them cope with the stress.

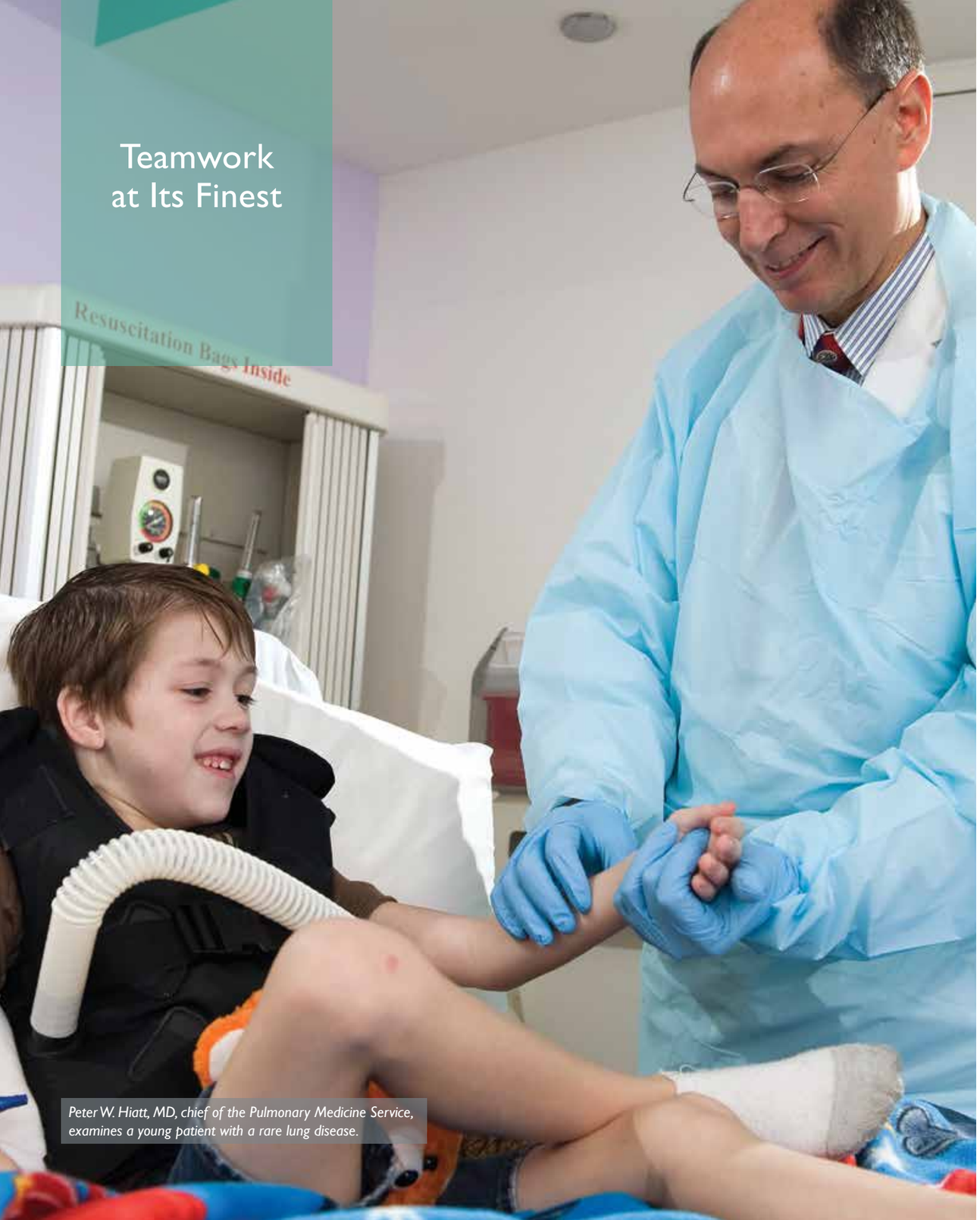
Grants from the State of Texas and the LENA Research Foundation support work on one promising strategy to relieve parental stress and improve children's outcomes. Called upWORDS, the strategy involves teaching parents how to improve the quantity and quality of language spoken with their child. By the time they're 4 years old, children who grow up in poor households have been exposed to 30 million fewer words than children in more affluent households, according to research at the University of Kansas. Early education has been shown to have a long-term impact on the child's success in life.

"One of the biggest obstacles for us is our time horizon," said Greeley. "We can't show definitive results next year or next legislative session. We're not trying to fix a specific problem. We're trying to make the circumstances better. It took decades for these circumstances to occur; it's going to take decades for them to get better."

Improving the circumstances that cause adverse childhood experiences is a long-term, complex undertaking that must be adapted to fit each community. But the section of Public Health Pediatrics is ready to do whatever it takes to improve the lives of children.

Christopher Greeley, MD, MS, chief of the Section of Public Health Pediatrics, takes a long-range view of solving community health problems.

Teamwork at Its Finest



Peter W. Hiatt, MD, chief of the Pulmonary Medicine Service, examines a young patient with a rare lung disease.

Program focuses on rare lung diseases

Never heard of BOOP, NEHI or PIG, much less how to treat them? Not to worry. Manuel Silva-Carmona, MD, director of the Rare and Interstitial Lung Disease program at Texas Children's Hospital, can help.

The simplicity of acronyms such as BOOP, NEHI and PIG belies the complexity of interstitial lung diseases, a general diagnostic term for a group of rare respiratory disorders, some caused by genetics, others from acquired lung injury.

In addition to their obscurity, these conditions usually impact multiple organs, making diagnosis and treatment more complex. Rare lung diseases require multidisciplinary medical teamwork at its finest.

Case in point: Ethan Smith of Winnie, Texas, was born at 38 weeks, what doctors call early term but not premature. Just two weeks later, his parents noticed symptoms of RSV, respiratory syncytial virus, an infection that can lead to life-threatening respiratory problems.

Within two days, Ethan had been transported by Texas Children's Kangaroo Crew from his pediatrician's office in Galveston to the Pediatric Intensive Care Unit (PICU) at Texas Children's Hospital. Ethan was critically ill, and his respiratory system had failed. He had to be intubated, which exposed him to two more infections.

Cavalry arrived

"Every morning they'd do rounds, and other families would have maybe two or three doctors outside their room, but we'd have 20, some even from different hospitals, who were there to help Ethan," said his father, Steven Smith. "It felt like the cavalry had come."

In fact, for children like Ethan, it takes a cavalry of medical professionals to find a diagnosis and successful treatment. Initially, his parents wrote down the name of everybody who helped them, but after three-and-a-half months the list had "literally hundreds" of names, Steven said.

> ***"Part of our commitment is to work in collaboration with other pediatric specialists to better understand, diagnose and treat the rare lung diseases and improve outcomes for these patients."***
> ***– Manuel Silva-Carmona, MD***

Ethan ultimately spent three months in the PICU, with 20 days on ECMO (extracorporeal membrane oxygenation), as Silva-Carmona and a team of other physicians tried to decipher exactly what was wrong. ECMO uses a pump to circulate blood through an artificial lung back into the bloodstream, allowing the lungs to rest and heal.

With time, doctors diagnosed Ethan with a pulmonary growth abnormality. This disease results in lung underdevelopment and is more common in premature patients or patients with heart disease, making Ethan's case unusual.

"For these lung disease patients, it's great that our Pulmonology Medicine Service is rated number one by *U.S. News & World Report*. But these children also need our expertise in immunology, rheumatology, genetics, transplant medicine, diagnostic imaging and pathology," said Silva-Carmona, assistant professor of pediatric pulmonology and critical care medicine at Baylor College of Medicine. "The ability to provide some of the best diagnosis and care across multiple disciplines is what makes Texas Children's rare."

In search of answers

It's not unusual for these patients to be referred to Texas Children's because their local doctor can't figure out what is wrong. Like Ethan, what starts as a common infection like RSV leads to a severe pneumonia. Or, it may be an infant or teen with recurrent bleeding in the lungs, lung collapse, or uncontrolled pulmonary hypertension combined with arthritis.

"Not enough is known about some of these diseases," Silva-Carmona said. "While we are more aware of these conditions compared to a few years ago, and we have become better at making timely diagnoses, there's much more work to be done."

Silva was recruited in 2016 to lead the Texas Children's Rare and Interstitial Lung Disease program due to his experience in both lung disease and intensive care. He inherits a program that was one of the first in the country, founded by Leland Fan, MD, in 1995 and nurtured by Tim Vece, MD, prior to Silva-Carmona's arrival.

Being trained and board certified in both pulmonary and intensivist care makes Silva-Carmona uniquely qualified to help these young patients. So many of them end up in hospital ICUs and have a disease that affects multiple organs.

His dual training also gives him experience working with multiple specialists to find the right treatment for very sick children.

"Part of our commitment is to work in collaboration with other pediatric specialists to better understand, diagnose and treat the rare lung diseases and improve outcomes for these patients," Silva-Carmona said.

To that end, Silva-Carmona is leading an effort to formalize the team's multidisciplinary collaboration with other subspecialties such as Immunology, Rheumatology and Bone Marrow Transplant, with the ultimate goal of improving patient care.

In addition to expert physician specialists, the team includes nurses, social workers, dietitians, pharmacists and physical and occupational therapists dedicated to the care of children with these complex and often severe diseases.

Refuge and resource

"It's not unusual for a pediatric pulmonologist in a smaller city or less populous state to see only one or two of these cases in a lifetime," said Peter W. Hiatt, MD, chief of the Pulmonary Medicine Service at Texas Children's and associate professor of pediatrics at Baylor. "There aren't many papers about these conditions, and there are virtually no randomized trials for these kids."

That's why the volume of patients seen in Texas Children's Rare and Interstitial Lung Disease program is an asset. The 100+ children followed by this program provide the volume needed to amass research data points that translate into better patient care, in the form of quicker diagnosis and changes in treatment to reduce the incidence of lung injury.

"Especially for the interstitial lung disease patient, a large referral program like ours helps generate the critical mass needed to conduct the research that leads to quicker diagnosis and better treatments," Silva-Carmona said.

Earlier diagnosis, better treatments

Much has been learned about many pediatric conditions, but some, like rare lung diseases, remain tantalizingly obscure. Texas Children's plans to change that.

While only in place for six months, Silva-Carmona has already begun the process of formalizing the collaboration that takes place for every Texas Children's patient with such conditions.

He's identified a core group of physicians in different pediatric subspecialties who are also interested in these complex patients. This early groundwork has resulted in more patients being referred to his program.

"Through this collaboration we streamline the very complex clinical care that these patients receive," Silva-Carmona said. "Thanks to our multidisciplinary approach, this collaboration also helps us improve our chances of recognizing diseases that might otherwise fly under the radar."

In addition to partnering with Immunology, Rheumatology, Genetics, Transplant Medicine, Diagnostic Imaging and Pathology, Silva's team also works closely with the Vascular Anomalies and Bone Marrow Transplant programs. Such cross-pollination of research into what works for these patients ultimately will help the team reach diagnoses more quickly and improve treatments.

A happy ending

At 3 months old, Ethan was released from Texas Children's. He weighed 8 pounds, was on oxygen 24 hours a day, and needed a feeding tube. He had little muscle tone after having spent so long attached to various pieces of medical equipment and being unable to move around like other babies.

"It was a big learning curve, dealing with all the equipment, giving him shots twice a day, and reinserting his nasogastric tube when he pulled it out," said Ethan's mother, Kellie Comeaux.

Today, Ethan has gained weight and is off oxygen, and he's busy getting into mischief with his siblings like other healthy, rambunctious 2-year-olds. He is followed closely by Silva-Carmona and his team, as they continue to search for a definitive diagnosis for Ethan and his parents.

Once Ethan is 6 years old, he will be able to take a pulmonary function test to determine the long-term damage to his lungs. They still keep oxygen and a pulse oximeter handy for the occasional respiratory infection.

"It's truly amazing because he was so sick but now there's nothing he can't do. He's a very driven kid," Steven said. "To have a child get that sick, to literally kiss death, and come out the other side. It's an amazing experience."

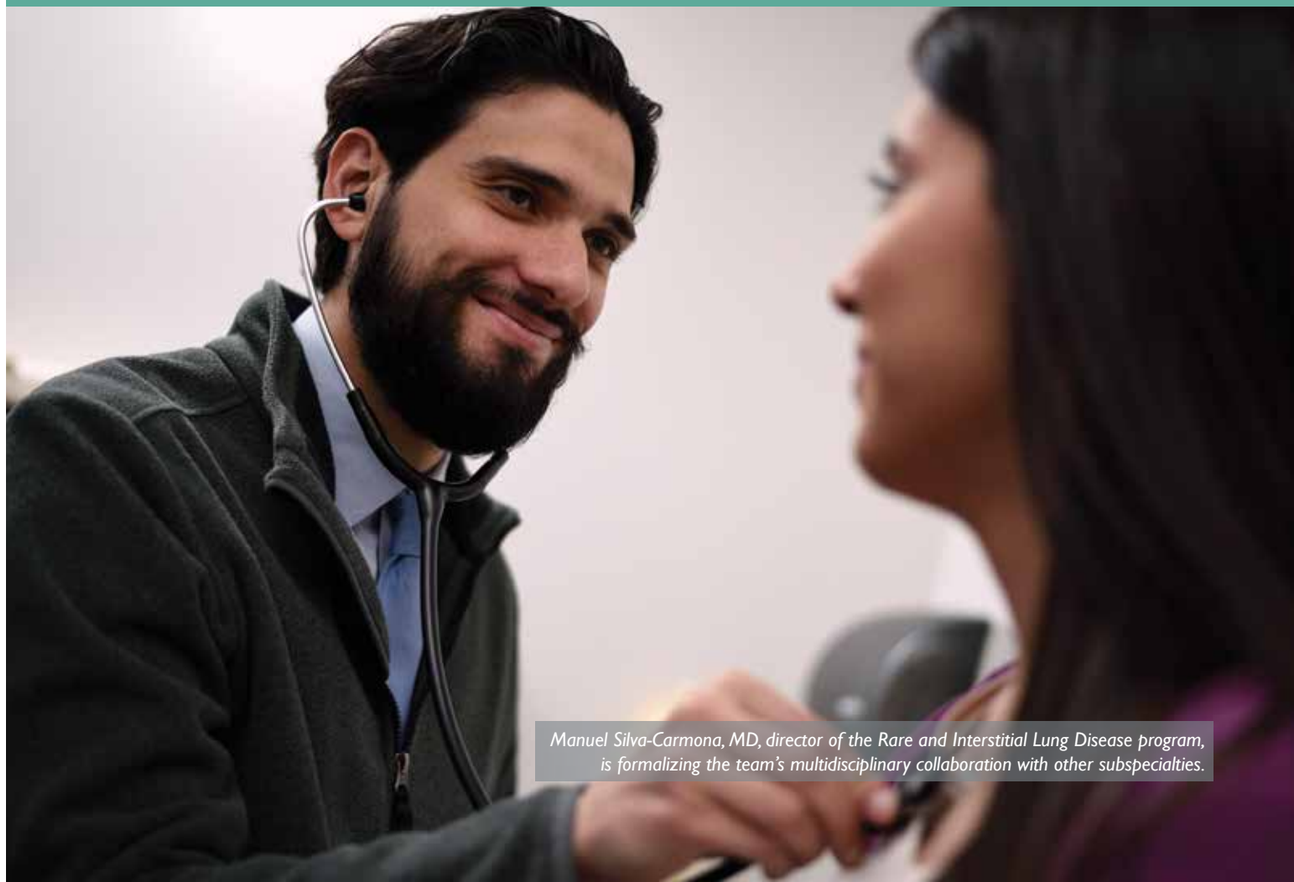
Types of rare lung disease

Typical symptoms in children referred to the program include diffuse lung disease visible in imaging, decreased oxygen levels and abnormal respiratory patterns such as fast or labored breathing.

Acquired lung disease may be caused by rheumatologic and immunologic disorders. In some cases, chemotherapy or radiation needed to treat cancer or prepare the body for transplant can contribute to the development of lung disease.

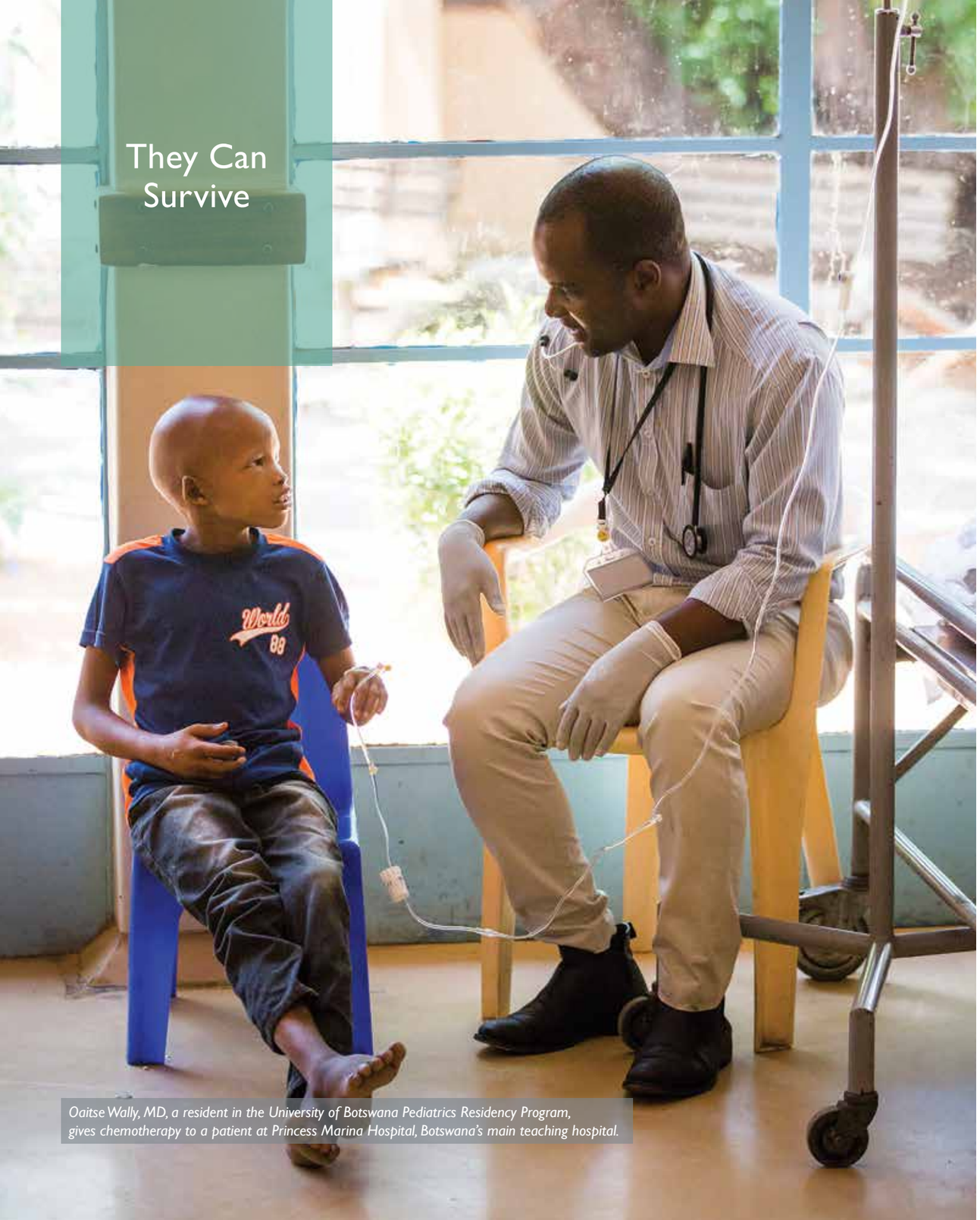
Rare lung disease diagnoses include:

- Acute interstitial pneumonia/pneumonitis
- Alveolar capillary dysplasia
- Alveolar hemorrhage syndromes
- Aspiration associated lung diseases
- Autoimmune or rheumatologic related lung disease
- Bone marrow transplant associated lung disease
- Cryptogenic organizing pneumonia formerly known as bronchiolitis obliterans organizing pneumonia (BOOP)
- DNA repair disorders
- Drug induced lung disease
- Eosinophilic pneumonia
- Follicular bronchiolitis
- Pulmonary growth abnormalities
- Hypersensitivity pneumonitis
- Hypereosinophilic disorders
- Immune-mediated lung disease
- Immunocompromised host associated lung disease
- Primary immunodeficiency associated lung disease
- Lymphocytic interstitial pneumonia
- Lysosomal storage disorders
- Neuroendocrine hyperplasia of infancy (NEHI)
- Nonspecific interstitial pneumonia
- Pulmonary interstitial glycogenosis (PIG)
- Pulmonary histiocytosis
- Pulmonary lymphangiectasia



Manuel Silva-Carmona, MD, director of the Rare and Interstitial Lung Disease program, is formalizing the team's multidisciplinary collaboration with other subspecialties.

They Can Survive



Oaitse Wally, MD, a resident in the University of Botswana Pediatrics Residency Program, gives chemotherapy to a patient at Princess Marina Hospital, Botswana's main teaching hospital.

Global initiative changes outcomes of cancer and blood disorders in Africa

In the United States, 80 percent of children with cancer survive. In sub-Saharan Africa, the overwhelming majority of pediatric patients do not survive. The mortality rate is estimated to be as high as 90 percent, meaning that thousands of children die from cancer across Africa each year.

The high mortality rate is in large part due to an inadequate health care infrastructure and a significant lack of expert physicians and other health care workers trained to treat children with cancer.

Now there's hope in the form of a comprehensive initiative called Global HOPE – Heal the Children (Hematology-Oncology Pediatric Excellence), which will build long-term capacity to treat and dramatically improve the prognosis of thousands of children with cancer and blood disorders in southern and eastern Africa.

In February 2017, the Bristol-Myers Squibb Foundation, Texas Children's Cancer and Hematology Centers and Baylor International Pediatric AIDS Initiative at Texas Children's Hospital (BIPAI), through public-private partnerships with the governments of Botswana, Uganda and Malawi, announced a $100 million initiative to create an innovative pediatric hematology-oncology treatment network in southern and eastern Africa.

Global HOPE will partner with local governments and ministries of health to build medical capacity to diagnose and treat pediatric blood disorders and cancer in Botswana, Malawi and Uganda. The initiative also will create significant clinical, educational and research capabilities. Doctors, nurses and ancillary professionals will be recruited from around the world to provide training to local health care professionals and to continue treating children with blood disorders and cancer.

> ***"We believe in these countries there are more than 11,000 new cases annually of pediatric cancer and 40,000 new cases of serious, life-threatening blood disorders such as sickle cell disease and hemophilia, many of which are currently going undiagnosed."***
> ***– David G. Poplack, MD***

Solid foundation

"This project is building on a solid foundation for pediatric cancer treatment in Botswana that began over a decade ago with pediatric oncologists from Texas Children's Cancer and Hematology Centers," said His Excellency the President Lieutenant General Dr. Seretse Khama Ian Khama of the Republic of Botswana. "The Global HOPE program will bring to Botswana the latest biomedical technologies and the potential to work with local institutions such as the Botswana Innovation Hub and University of Botswana to quickly increase the survival of children with cancer and life-threatening blood disorders in Botswana and the region."

Texas Children's Cancer Center's presence in Africa began in 2006, when Parth Mehta, MD, MPH, went to Botswana as a member of BIPAI's Pediatric AIDS Corps. As the first pediatric oncologist in the country, he recognized the need there and stayed for three and a half years. In that time, he increased the overall number of cancer diagnoses threefold, and increased cancer survival two and a half-fold in Princess Marina Hospital, the nation's leading teaching hospital, where he practiced.

Since then, Texas Children's has had a pediatric oncologist continuously located at that site. Mehta now is associate director of Global Oncology and the Malawi Program at Texas Children's and assistant professor of pediatrics at Baylor College of Medicine.

Through Global HOPE, the Bristol-Myers Squibb Foundation is committing $50 million over five years to fund the training of local health care providers as well as clinical infrastructure and operations. BIPAI/Texas Children's will raise an additional $50 million for the initiative.

"We are eager to get started on this critical initiative to help children with blood disorders and cancer. Working with our partners and drawing on our expertise of building sustainable health systems in underserved countries, we will help make a significant difference in the outcomes for children while creating a blueprint for other countries to follow," said Giovanni Caforio, MD, chairman of the board of the Bristol-Myers Squibb Foundation and chief executive officer, Bristol-Myers Squibb Company. "This initiative builds on 18 years of success of the Foundation's SECURE THE FUTURE program and will offer new hope to families impacted by pediatric blood disorders and cancer."

As public-private partnerships, the various governments each will play an important role in developing the pediatric hematology-oncology network, assisting with the training, technology, logistics and resources to support Global HOPE.

Not enough experts

"With only five pediatric oncologists currently in the countries of Botswana, Malawi and Uganda combined, there are simply not enough expert doctors to treat all the children diagnosed with blood disorders and cancer," said David G. Poplack, MD, director of Texas Children's Cancer and Hematology Centers and professor of pediatric oncology at Baylor.

"We believe in these countries there are more than 11,000 new cases annually of pediatric cancer and 40,000 new cases of serious, life-threatening blood disorders such as sickle cell disease and hemophilia, many of which are currently going undiagnosed," Poplack said. "Because of these staggering numbers, more health care providers with special expertise are urgently needed. Global HOPE will help build capacity in the region to diagnose and care for children with blood disorders and cancer, offering the potential for transformational change in survivorship for these children."

The new East Africa Pediatric Hematology and Oncology Fellowship Program in Uganda already has enrolled four Ugandan pediatricians as the first trainees. They will graduate in two years as the first pediatric hematologists-oncologists fully trained in sub-Saharan Africa (outside of South Africa). A similar program will be established in Botswana to train additional pediatric hematologists-oncologists for southern Africa.

Global HOPE also is providing comprehensive multidisciplinary training programs for all levels of health care workers needed to provide excellent pediatric hematology-oncology care.

"They say that pediatric oncology is the rising tide that floats all boats. To take excellent care of children with cancer, you have to partner with many different disciplines," Poplack said.

Excellent pediatric cancer care requires pediatric specialists including oncologists, cancer surgeons, radiotherapists, pathologists, intensivists, infectious disease experts, pharmacists, specialized nurses and social workers. This effort will improve the care not just for children with cancer and hematology, but for all pediatric patients in major cities where these programs are located.

Botswana President Ian Khama, center, participates in the groundbreaking for the Botswana Children's Cancer and Hematology Center of Excellence, in February 2017 in Gaborone, Botswana. Pictured, from left, are Phillip Makgalemele, assistant minister of health and wellness; John Damonti, president of the Bristol-Myers Squibb Foundation; Emmanuel Blin, chief strategy officer and senior vice-president at Bristol-Myers Squibb; Dorcas Makgato, minister of health and wellness; Khama; Cris Daskevich, senior vice president, Texas Children's Hospital; David Poplack, MD, medical director of Texas Children's Cancer Center; Michael Mizwa, COO of BIPAI and director of Texas Children's Global Health.

Building on the success of the BIPAI model

The Global HOPE initiative will be modeled on the work of the Bristol-Myers Squibb Foundation, BIPAI and the governments of Botswana, Uganda and Malawi, which created the largest pediatric HIV treatment network in the world, leveraging existing experience, infrastructure and public/private partnerships.

Since 2003, the Bristol-Myers Squibb Foundation and BIPAI have trained 52,000 health care professionals and currently provide care for nearly 300,000 children with HIV and their families in sub-Saharan Africa, lowering the mortality rate for these children from nearly 100 percent to 1.2 percent.

"The success we've had in radically changing the course of pediatric HIV/AIDS in sub-Saharan Africa is due in large part to the tremendous support provided by the country governments, health care providers on the ground and donors who have made our work possible," said Mark W. Kline, MD, president and founder of BIPAI, physician-in-chief of Texas Children's and chair of the Department of Pediatrics at Baylor.

The Global HOPE initiative will train an estimated 4,800 health care professionals from Botswana, Uganda, Malawi and other African countries. The program estimates that more than 5,000 children will receive care in the first five years.

"We look forward to helping patients and their families by embarking on this uncharted area of cancer care in Africa," said Mark W. Kline, MD, president and founder of BIPAI, physician-in-chief of Texas Children's and chair of the Department of Pediatrics at Baylor. "Working with our partners, we aim to build a self-sustaining infrastructure that changes the tide of these childhood diseases in sub-Saharan Africa."

Future holds new promise

Global HOPE is expected eventually to expand and create a Center of Excellence for pediatric hematology and oncology at each of the seven current BIPAI sites. The initiative is developing a template for effective expansion as needed, using innovative solutions for temporary facilities while long-term facilities are under construction. Standardized facilities that are sturdy, easy to maintain and transportable can be used for several years as doctors' offices, pharmacies and laboratories and then shipped to the next location.

In addition to growing the physical presence of the Centers of Excellence and the medical knowledge, Global HOPE will reach out to communities to grow the cultural knowledge base.

"Churches, communities and families need to begin thinking of pediatric cancer as something that they can beat, and that it's an important investment," said Kristi Wilson-Lewis, MSSW, director, Administration and Planning for Texas Children's Cancer and Hematology Centers. "Engaging the local community is important in building cancer awareness and the recognition that we can save lives and give these children back their lives."

The five-year Global HOPE initiative is envisioned as the first phase of a long-term project. Although it will take many years to accomplish, the eventual goal is to bring the cancer and blood disease care in these countries to the point that excellent outcomes, equivalent to those in the U.S., will be achieved at all of the sub-Saharan sites.

Parth Mehta, MD, MPH, visits with a cancer patient during a follow-up visit at Princess Marina Hospital in Gaborone, Botswana. Mehta was the first pediatric oncologist to practice in Botswana as a member of the Pediatric AIDS Corps.

Wherever They Are

Members of the Houston Fire Department's Emergency Medical Services take part in a Texas Children's Hospital Pediatric Simulation Center training to be better prepared for treating children.

Emergency Medicine leads programs for improving children's outcomes

Geography – perhaps even more than the severity of illness or injury – makes a big difference in your survival from an emergency. Depending on where you are at the time and where you go for treatment, your outcome could be very different, according to multiple reports by the Institute of Medicine (IOM) over the past two decades.

Children face even more challenges to survival in an emergency due to a lack of specialty training and equipment for pediatric care. More than 27 million children in the U.S. visit emergency centers each year, with almost 2 million of those arriving to the hospital by Emergency Medical Services (EMS), also known as prehospital care. Not all hospitals have the special equipment, facilities and personnel needed for optimal care of children, and a 2007 IOM report identified significant knowledge and training gaps among first responders in pediatric emergency care.

Texas Children's Hospital and Baylor College of Medicine have taken the lead in developing programs that are improving emergency care for children across the U.S. and the world. They are using:

- Simulation to train prehospital emergency providers.
- Quality improvement to develop protocols for optimum pediatric treatment.
- Partnerships to share improvements and innovations so that children can receive the best emergency care, wherever they are.

Training providers

It started with an everyday activity, a 3-year-old boy having a snack of starfruit at home. Somehow a piece of fruit became stuck in his throat, and the child began to choke. Then he stopped breathing. And then his heart stopped.

His frantic parents called 911. A Houston Fire Department team of prehospital providers arrived at the boy's home to find him in cardiac arrest – the first time the team had dealt with a child in that condition. It was not, however, the first time that they had rehearsed for just such an event.

Like airline pilots who train over and over again to prepare for unusual events, this crew had trained as well. They had recently participated in Pediatric Simulation Training for Emergency Prehospital Providers (PediSTEPPs), initially funded by the Cullen Trust for Health Care and developed by a multidisciplinary team of paramedics, EMS medical directors, pediatric emergency medicine physicians, and simulation specialists from Texas Children's, Baylor and the Houston Fire Department.

With the cooperation of a nearby high school, Pediatric Emergency Medicine conducts a mass disaster training for members of the Houston police and fire departments.

Within seconds of arriving at the little boy's home, the team removed the starfruit and performed cardiopulmonary resuscitation (CPR), following an established protocol. By the time the child reached the Texas Children's Emergency Center, he was awake, breathing on his own and responding to spoken words. The emergency responders credited their PediSTEPPs training for helping them save the child's life.

Nationally, only about 10 percent of calls to EMS involve children, according to the IOM report *Emergency Care for Children: Growing Pains*. Many emergency care providers rarely encounter pediatric patients, making it difficult for them to maintain pediatric skills.

"Finding a way to train 5,000 providers to give consistently good care to pediatric patients is not an easy task," said Paul Sirbaugh, DO, MBA, chief of Emergency Medicine at Texas Children's and associate professor of pediatrics at Baylor. In addition, he serves as pediatric medical director for the City of Houston Fire Department EMS, on call for tough cases that call for experienced judgment beyond the protocols.

As the fourth largest city in the country, Houston has one of the busiest EMS systems.

"We looked at the guidelines and training for prehospital providers, and we looked at the most recent evidence — what are the best pediatric practices for everything from cardiac arrest to seizure to drowning," Sirbaugh said. "Then all the amazing experts in this institution worked with us to develop written protocols."

Making a list and checking it twice

Research in the last decade has proven that check-off lists improve care and safety, even with expert medical staffs. Written protocols improve upon check-off lists because they are based on evidence from research.

"I tell my medics as I educate, 'You guys are 18, 20, 25 years old, and you are actually treating patients in some of the same ways we treat them in our ER,'" Sirbaugh said. "It's not just trying to make them feel good; it's true. They're actually very well trained folks that are constantly educated and tested."

Jennifer Arnold, MD, MSc, former medical director of Texas Children's Pediatric Simulation Center; Manish Shah, MD, MS, prehospital domain lead for the National EMS for Children Innovation and Improvement Center, director of the EMS for Children State Partnership in Texas and associate professor of pediatrics at Baylor; and Cara Doughty, MD, MEd, associate professor of pediatrics at Baylor, were the Texas Children's physicians who collaborated with the Houston Fire Department to create the nine-hour PediSTEPPs curriculum.

Beginning in 2012, simulation-trained Pediatric Emergency Medicine faculty and educators from Texas Children's Simulation Center and Houston Fire Department conducted two courses per month to train teams of 12 to 14 Basic Life Support (BLS) and Advanced Life Support (ALS) providers. When tested, both BLS and ALS providers showed an immediate, significant increase in knowledge and self-confidence.

By 2017, the training has reached 1,600 providers from Houston, and has been adapted to reach other providers in the U.S. and Botswana.

Written treatment protocols in the Pediatric Emergency Center are based on evidence from research.

Improving hospital quality

Many of the protocols that start in an ambulance eventually progress through the entire hospital system, from Texas Children's Emergency Center (EC) to critical, inpatient and outpatient care. In addition, guidelines for a particular department often have an EC component.

For example, Texas Children's Cancer and Hematology Centers have specific guidelines for children who come into the EC with fever. Because the children are at high risk of developing infections, faculty created guidelines that call for quick evaluation, lab tests, antibiotics and collaboration with the Cancer Center to help provide the best care for patients.

"We are more than 95 percent effective at meeting our goal of antibiotics within one hour, which means we're doing a very good job of making sure we take care of some of our sickest patients," said Binita Patel, MD, chief of Quality and Safety for Emergency Medicine at Texas Children's and associate professor of pediatrics at Baylor.

The Emergency Medicine Quality Improvement team is heavily involved in evidence-based guideline creation for Texas Children's, working with other Texas Children's providers and Baylor faculty content experts through the Evidence-Based Outcomes Center at Texas Children's.

Sepsis was the topic of one of the higher impact protocols created for the whole hospital. Sepsis, an overwhelming infection that can affect all the organ systems of the body, is one of the leading causes of death worldwide and one of the highest cost illnesses for a hospital.

"Guidelines had been in place for years, but when you really looked at Texas Children's process, we weren't actually doing those things," Patel said. "It's not that it was bad people; it was a bad system that was causing delays and preventing the best care possible."

To develop an effective protocol, Emergency Medicine partnered with Critical Care, Infectious Disease and high-risk subspecialties like Hematology-Oncology and Transplant. The multidisciplinary approach also included nurses, respiratory therapists, pharmacists and information systems (IS).

> ***"Finding a way to train 5,000 EMT providers to give consistently good care to pediatric patients is not an easy task."***
> ***– Paul Sirbaugh, DO, MBA***

"We had support from the bottom up, including executive leadership," Patel said. "It had to be something that the hospital valued. Leadership was vested in it, and said that we want to make this happen. Through months of planning and stakeholder meetings, figuring out what wasn't working and what we should be doing, we were able to create a protocol to treat these kids faster."

When implementation of the sepsis quality improvement project began at Texas Children's in 2009, mortality from septic shock was 8 to 12 percent. Now the 30-day mortality is consistently 2 to 4 percent.

Collaboration goes national

"We were one of the first hospitals to have this protocol for pediatric septic shock care," Patel said. As the American Academy of Pediatrics was launching a quality improvement collaborative for sepsis under the leadership of faculty at Baylor, three papers about the local sepsis work were published by the Texas Children's improvement team.

Eventually, 44 hospitals across the nation joined the collaborative to learn and use shared information. The resulting improvements are being analyzed. That collaborative has transitioned into an even larger and more broadly scoped initiative, IPSO (Improving Pediatric Sepsis Outcomes) through the Children's Hospital Association of America. Co-chaired by Baylor associate professor of pediatrics Charles Macias, MD, MPH, IPSO looks at sepsis care not just in the EC, but through an entire hospital system.

"Sepsis is a great example of addressing a problem through teamwork and collaboration, rather than finger pointing and blame," Patel said. "It was one of the key elements that helped bridge a gap between nurses and physicians, where we started working together on projects."

Shared leadership in quality improvement

As so often is true in a hospital, the frontline nurses are key to improving processes and implementing protocols and guidelines. EC nurses not only participate in quality improvement projects but also are empowered to suggest and lead improvement opportunities.

Emergency Medical Services train to give better care to children through simulations of trauma and disasters.

At Texas Children's, Daniel Christopher, RN, became a quality improvement specialist in the EC to help increase patient safety and improve the overall experience for both patients and their families. Through collaborative work, he has helped define flow processes within the EC and through the continuum of care into inpatient units.

The EC has defined a more efficient, timely and patient-centered model of flow through the department. Projects have involved the creation of an onsite Urgent Care unit to help with low acuity patients, using physicians in triage, and rapid placement of patients into rooms.

The EC has also partnered with inpatient units to improve flow. One example of this is the EC-to-inpatient patient transport process allowing nurses a face-to-face report in the inpatient unit.

"When we rolled out the patient transport process, I went upstairs to interview families and see what they thought of it," said Christopher, who received one of the hospital's highly valued Catalyst Leadership Awards for 2017. "The very first person we interviewed turned out to be a nurse who worked at an adult hospital somewhere else. She said, 'I wish we did this where I work.'"

Efforts have led to improvement in the EC "Left without being seen" rates and in patient satisfaction over the last three years.

Spreading the word through partnerships

Decreasing mortality and morbidity for children in emergencies by ensuring they receive the highest quality care is a goal of the Emergency Medical Services for Children (EMSC) program, funded by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services.

In 2016, EMSC created the EMSC Innovation and Improvement Center (EIIC) to increase comprehensive, rapid uptake of quality improvement strategies that reduce mortality and morbidity among children in urgent and emergency care settings, no matter where they live or travel in the United States.

"We realized that what was going to drive innovation and improvement was going to be a stakeholder group that had quality improvement skills and also content expert knowledge," said Macias, who is executive director of the EIIC.

The EIIC focuses on the critical domains in emergency medicine:

- disaster planning
- trauma
- prehospital care
- hospital-based care
- research

Matrixed into that activity are core domains in quality improvement:

- advocacy
- education
- collaboratives
- measurement
- evidence-based practice
- patient safety

Teams at Texas Children's and Baylor collaborate with partners at the American Academy of Pediatrics, American College of Emergency Physicians, Emergency Nurses Association and National Association of State EMS Officials, and work cooperatively with their federal partners at HRSA.

"There's a lot of great work going on in silos all across the nation, so we want to connect the dots and empower the best of the best to be able to drive some of these strategies," Macias said. "A lot of the things that began as innovations here at Baylor and Texas Children's we've been able to expand and disseminate throughout the rest of the country."

One of the partners in broad sharing of innovations has been the Center for Collaborative and Interactive Technologies, led by C. Michael Fordis Jr., MD, senior associate dean for continuing medical education at Baylor. The center uses enhanced technology to communicate research findings and the best science in a variety of materials and technology platforms that can be used by physicians, patients and policymakers.

Getting ready for kids

"One of the challenges that we have recognized is that fewer than roughly 85 percent of children with emergency conditions are treated in pediatric facilities," Macias said. "How do we reach out to the rest of the community to make other medical institutions more capable of handling pediatric emergencies?"

The EIIC collaborates with 14 states on a quality improvement collaborative to recognize facilities that are ready to manage children. In Texas, the EIIC has worked with the Governor's EMS Trauma Advisory Committee to endorse a facility recognition program, so that both individuals and EMS providers will know where to go for the best care for specific types of illness or injuries in children. It also will help all institutions become more prepared to manage children.

The EIIC is getting ready to launch a reassessment for the National Pediatric Readiness Project (NPRP) in 2018. The NPRP was built by consensus with multiple stakeholder organizations to identify the characteristics of pediatric readiness.

"In two national surveys of more than 4,000 hospitals, we've seen some improvement in pediatric readiness scores across the country," Macias said. "But the scores also have demonstrated huge gaps for many hospitals in becoming pediatric ready."

The NPRP is designed not only to make repeated assessments but also to provide tools to help institutions understand how to identify and bridge their gaps.

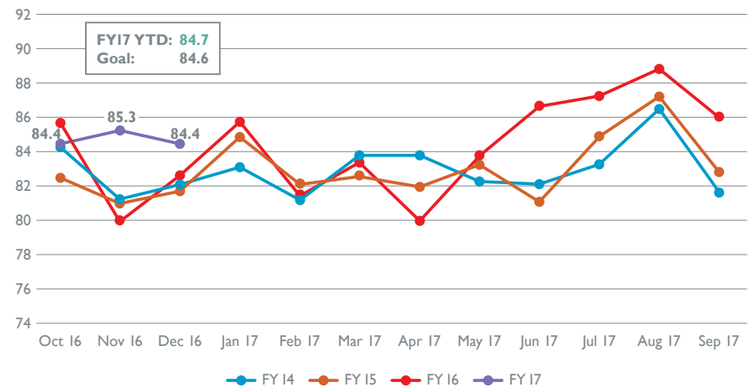
"The intensity of our work has grown tremendously," Macias said. "The more we learn about what's successful, the more we can provide for others to learn, adopt and improve their outcomes."

The EIIC partners with other organizations to drive data analytics to create greater transparency in outcomes of performance measurement across 58 states and territories through the network of EMSC State Partnerships. Using quality improvement strategies to bridge gaps in high quality care delivery, the EIIC is working with its national partners and federal collaborators to drive improvements in disaster preparedness, trauma, prehospital care and research across the country, and is expanding some of those partnerships across the globe.

"The bottom line is we're doing a lot to improve the outcomes of the children that we treat," Macias said. "We never lose sight of that. That is what we're here for."

Improving children's outcomes is the ultimate goal.

Texas Children's Main Campus Patient Satisfaction Rates



Multiple quality improvement efforts in the Texas Children's Emergency Center over the past three years have improved processes so that patients can be seen more quickly and efficiently. As a result, patient satisfaction rates have gone up.

Navigating Complex Systems

Jill Ann Jarrell, MD, MPH, who has dual appointments in palliative care and complex care, directs the new Pediatric Palliative Care Fellowship program, one of only 11 accredited programs in the U.S.

Palliative Care team helps families and children with serious illness

When a patient's mother needed it most, she found an incredible resource and sense of relief in the form of Texas Children's Palliative Care team. Her teenage son with developmental delays had just been hospitalized for the fifth time that year with pulmonary problems, and the Palliative Care team came by for a visit.

"I've never had the chance before to sit and talk to a team of people – from the physician to the social worker to the chaplain – about what my concerns are for his future, what it's like to manage a special needs child in a home by yourself as a single parent, how to manage two other children, or how to manage expectations of extended family members and what they think you should be doing with a child with special needs," the mother said.

Helping parents verbalize their challenges and focus on what they want to accomplish with their seriously ill child are among the goals of the new system-wide Palliative Care program at Texas Children's Hospital.

"What we have tried to promote is the understanding that palliative care is about maximizing quality of life, and improving care and support for children and families with serious illness, regardless of prognosis," said Tammy Kang, MD, section chief of Palliative Care at Texas Children's and associate professor of pediatrics at Baylor College of Medicine.

Kang, who also holds a clinical epidemiology degree, was recruited from the prestigious Children's Hospital of Philadelphia, where she started a palliative care team and managed it for the past 15 years. She launched the program at Texas Children's in October 2016.

Clearing up misunderstanding

"Many people have the idea that palliative care is hospice care or end-of-life care," Kang said. "We certainly partner with hospice agencies in the community to provide those kinds of services, if that's what the patient is facing and that's the family's choice. But the vast majority of children served by pediatric palliative care providers are not in hospice care and are not terminal. Instead, these are children with complex, serious illness who require additional support and services for managing distressing symptoms. It's for helping families understand the medical processes and interventions, for providing psychosocial, spiritual and emotional support for patients, their families and their siblings. And it's just helping families navigate this very complicated health care system."

To provide that support takes an interdisciplinary team of physicians, nurses, social workers, child life specialists, chaplains and other support specialists.

"Many of the kids have issues with multiple organ systems, where they have 20 or 30 medical problems that you'd expect from someone in their 70s or 80s," said Daniel Mahoney, MD, palliative care physician at Texas Children's and assistant professor at Baylor.

Sometimes the course of treatment, such as chemotherapy or bone marrow transplants, may cause problems in the heart or kidneys. A problem in the genetic code can affect every organ system in the body – the brain, heart, lungs, kidneys and liver.

Tammy Kang, MD, leads the Palliative Care section at Texas Children's Hospital to help children with serious illness and their families.

"Often kids have multiple specialists who try to coordinate care," Mahoney said.

Long-term attitude

Although the formal, system-wide Palliative Care program is new at Texas Children's, individual palliative care programs existed in several service lines. And, of course, working as a team to provide the best care for very sick children is not a new concept at Texas Children's.

A landmark report published in 2000 by the Institute of Medicine, *When Children Die: Improving Palliative and End of Life Care for Children and Their Families*, stimulated work across the country to improve palliative care programs for children.

In the years since then, Texas Children's has:

- taught twice a year the End-of-Life Nursing Curriculum, developed from a national Robert Wood Johnson Foundation project
- started a perinatal palliative care service for pregnant women facing difficult fetal diagnoses
- supported clinicians to attend the Palliative Care and Practice Educational course at Harvard and a retreat presented by the Initiative for Pediatric Palliative Care
- started a palliative care service for Texas Children's Cancer and Hematology Center patients

Under the leadership of Mark W. Kline, MD, physician-in-chief of Texas Children's and chair of the Department of Pediatrics, and with the efforts of Susan Blaney, MD, deputy director of the Texas Children's Cancer and Hematology Centers and executive vice chair of the Department of Pediatrics, and Perry Ann Reed, director of Ethics and Palliative Care at Texas Children's, the organizational umbrella opened in 2016 with support from the Department of Pediatrics and Texas Children's Hospital.

"One of the things that already existed here is this commitment from the leadership on down to the clinical providers to really provide the best possible care for every patient, for every family, regardless of where they came from, what their diagnosis was, or their prognosis," Kang said. "What also exists here is this great collaborative energy between the medical teams, the department, the hospital and the hospital administration that's needed for our integrated way of caring for children."

"It's not high tech, but high touch is really important."
– Joy Hesselgrave, RN

The Palliative Care team sees patients across the hospital and its many clinics. In the first 60 days, the team exceeded their estimated patient volume by about 200 percent.

"We've heard from families that they really appreciate this consultant team helping them identify the goals of care," said Joy Hesselgrave, a longtime nursing staff member in Hematology-Oncology, who is now assistant clinical director of Palliative Care. "The team listens to what the family thinks they want for their child, listens to the clinical medical team who manages the medical care and who says what's possible, and then communicates with both sides to help with the decision-making process.

"I think a lot of families have ideas about what they think, but they haven't articulated them. They haven't made any plans or contingencies. Just offering them a space in which to communicate and to clarify is very helpful. It's not high tech, but high touch is really important."

Available 24 hours a day

It may not be clear in the first visit how the team can be helpful, but it becomes clear as they get to know the family and build a long-term relationship. The team provides a cell phone number to parents, staff and referring physicians for a phone that is answered 24 hours a day, seven days a week by a physician from the team.

One of the team's goals is a home visit program, in which psychosocial providers can go to the homes to check on patients, as well as provide support for caregivers and siblings.

"We know that siblings of children with serious illness are at risk for increased health issues, increased learning issues, and increased behavioral and psychological issues," Kang said. "These children are often going through a lot of difficulties because their parents are at the hospital, and there is a lot of emotional and financial stress in the household. Being able to provide some support for these children in the home is a future goal."

While physician visits are billed as medical visits, families are not billed for any of the other services.

"We really rely upon philanthropy to allow us to think about how to grow and to provide the best care and the best support both in the hospital and in the community," Kang said. "I perceive our outcomes as being successful if we are doing our very best for every patient and every family that walks through the door."

Significant support for staff

In addition to caring for patients and families, the team helps support staff.

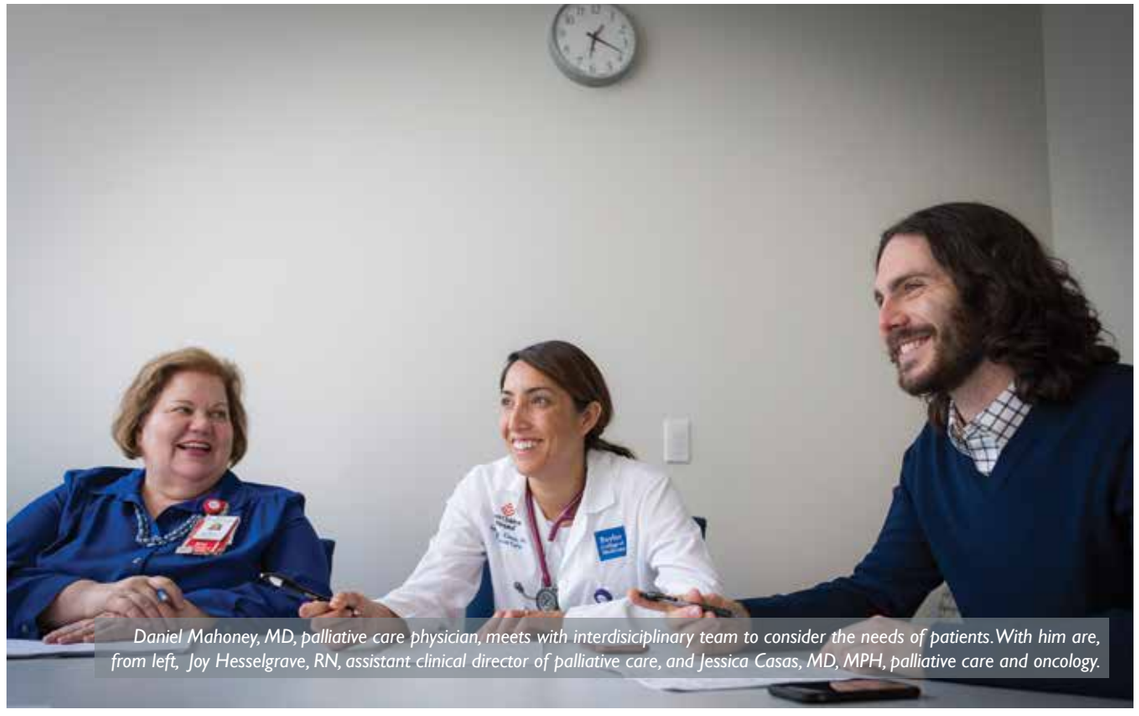
"We didn't really anticipate support for staff as being so significant," Hesselgrave said. "To take care of and be the witness and the caregiver for children who are very sick or dying is very emotionally, physically and mentally exhausting. It's very helpful to have members of our team there walking the journey with them."

Besides emotionally supporting the staff, the team provides education about palliative care to staff at Main Campus, The Woodlands and West Campus. Beginning next year, team members will be working with and helping to educate a fellow, who will become a board-certified palliative care physician. They anticipate broadening their reach to areas of the hospital that haven't yet started referring patients and to community physicians, educating them on the benefits of palliative care.

"We are committed to developing a research and outcomes platform as well," Kang said. "We are well poised at Texas Children's, because it is the largest academic pediatric program in the country, to help move the palliative care field forward through actively engaging in educational and research opportunities. A number of researchers across this institution right now have research interests relevant to palliative care, where I think important questions could be answered here relatively quickly."

Putting its large, diverse patient population to good use for research, Texas Children's is a member of the Pediatric Palliative Care Research Network, a research group of children's hospitals in the U.S. and Canada.

In the complex world of medicine, the Palliative Care team leads families and staff through the thicket today and uses research to clear the way for tomorrow.



Daniel Mahoney, MD, palliative care physician, meets with interdisiciplinary team to consider the needs of patients. With him are, from left, Joy Hesselgrave, RN, assistant clinical director of palliative care, and Jessica Casas, MD, MPH, palliative care and oncology.

Education

Diversity Enriches Experience

Janaki Paskaradevan and Henry Shiau, both third-year pediatric residents, typify the diverse backgrounds at Texas Children's Hospital. Paskaradevan, a native of Sri Lanka, plans to specialize in pulmonary medicine, and Shiau, whose parents are from Taiwan, plans to specialize in gastroenterology.

Residents bring varied backgrounds to patient care

On a given day at Texas Children's Hospital, pediatric residents care for lots of little Texans, who represent the ethnic diversity of Houston, one of the most diverse cities in the United States.

Houston has no ethnic majority and a breakdown of 37% Hispanic, 37% Anglo, 17% Black, and 8% Asian, according to the U.S. Bureau of the Census 2015 American Community Survey.

"Houston's diversity affords us both the opportunity and the mandate to reflect that diversity among our house staff," said Mark W. Kline, MD, physician-in-chief of Texas Children's and chair of the Baylor College of Medicine Department of Pediatrics. "I tell candidates for the residency program that they will interface with children and families from every imaginable background. Living in Houston, they have an opportunity to include in their circle of contacts people from all over the globe."

Thanks to efforts of the Department of Pediatrics, the pediatric residents are more and more likely to come from equally diverse backgrounds.

"We really want our patients to be able to interact with health care professionals who look like them and who may share some of their experiences because of a common background," said Susan Gillespie, MD, PhD, associate program director for the Pediatric Residency Program and associate professor of pediatrics at Baylor. "Patients are more satisfied and tend to do better when their health care professionals are able to relate more fully to them."

Second Look begins

Efforts to ramp up recruitment of under-represented minority applicants started in 2013 with the Second Look program, an opportunity to bring talented under-represented minority applicants back after the interview season is over.

"It's not intended to be a second interview, it's a second chance for them to look at us and all that we have to offer," Gillespie said.

Susan Gillespie, MD, PhD

The visit includes a welcome dinner, a special grand rounds presentation, meetings with Kline and Mark A. Ward, MD, director of the Pediatric Residency Program and associate professor of pediatrics, time to interact with fellows and faculty in their area of interest, and a no-holds barred lunch with current residents.

The program has been very successful. Three applicants participated the first year, and all three matched to Baylor. This year, of 13 Second Look participants, six matched to the categorical pediatrics program, and two matched to the new Primary Care LEAD and ACQUIRE program.

Diversity Council supports

In addition, a Diversity Council was recently established to support the residents through recruitment, mentorship and outreach.

In 2015, Gillespie sent an email to see who was interested in a group focused on diversity. Within one hour, she had 75 people signed up, and today there are 120 members.

The council is developing a mentorship program that will help establish a support system for residents without adding another formal activity to their already busy schedules. Members participate in Baylor activities such as Doctors Day Out (visiting local schools to inspire minority students to become doctors) and Saturday Morning Science (high school students visit the medical school for lectures and activities).

"Dr. Kline has really been a champion of our efforts to create a culture of inclusion and diversity," Gillespie said. "This is a big commitment, a big investment of our resources, and it takes this kind of top-down support to make it work."

As evidence of its effectiveness, the Residency Training program is twice as diverse today as it was five years ago.

"Diversity in every sense – ethnicity, socioeconomic background, geography, gender, age and sexual orientation – is essential to everything that we hope to accomplish as a department and as a hospital," Kline said. "You can't exclude part of your talent pool or make them feel unwelcome in some way. If you want to be the best, you have to pull from the deepest pool."

New track trains future leaders

A new pediatric residency track at Baylor College of Medicine and Texas Children's Hospital is training primary care physician leaders committed to serving underserved and vulnerable populations.

Called LEAD and ACQUIRE (**LEAD**ership in **A**dvocacy/**C**ommunity collaborations/**QU**ality **I**mprovement in primary care **R**esidency **E**ducation), the track has obtained a grant from the State of Texas to train four residents beginning July 1, 2017. For the first year, 147 graduates of U.S. medical schools applied to this track, of which 54 (or 37 percent) were under-represented minorities.

"This program attracts individuals who want to give back to their communities, people who have the heart of service," said Teri L. Turner, MD, MPH, MEd, associate professor and vice chair of educational affairs in the Baylor Department of Pediatrics. "We need to develop skills for someone who would lead a clinic in an underserved area, who can figure out how to provide the best and highest quality of care with a limited amount of resources."

The residents will learn to collaborate with their communities and partner with other organizations to solve problems and to advocate, not just for individual patients, but for changes on a broader scale.

Leading the residency track are Teresa Kay Duryea, MD, and Lanessa Bass, MD, MEd, co-program directors and associate professors of pediatrics; Julieana Nichols, MD, MPH, associate director and assistant professor of pediatrics; and Jill Roth, MD, assistant director and assistant professor of pediatrics.

For more information, please contact Holly.Hummel@bcm.edu.

Voices of Diversity

Alex Alali, second-year, plans on specializing in cardiology

Hometown: Victoria, TX

College: Houston Community College, University of Houston and Baylor University

Medical School: The University of Texas (UT) Medical Branch at Galveston

Background: My dad is Iraqi, and my mom is Colombian, and they met in college in England. They were chemical engineers, and that caused them to travel a lot. They had my sister in England, my brother in New York and me in Sydney, Australia. When I was 10, my parents divorced, and my mother and brother and I moved to Houston, and then Victoria.

Experiences that shaped me: I got kicked out of high school right after I turned 18, and I wound up leaving home, working in fast food, and sleeping in different places every night. I needed stability, so I decided to join the Army. I had to get my GED first, and then I was in the Airborne Infantry for almost four years.

I knew I wanted to be a doctor when: I was in high school biology class and we learned about the heart. Even though I wasn't the most motivated student at the time, I knew I wanted to become a heart doctor. The whole time I was in the Army, my goal was to go to college and become a doctor. While I was an undergrad, I supported myself as an EMT, because I wanted to be gaining some useful experience in the medical field. I've been narrowly focused on this goal for a very long time now, and I'm finally applying for my pediatric cardiology fellowship. It's exciting.

You might overhear me say: "I want to be able to look back on my life and see that it had meaning." I haven't worked this hard to do something meaningless with my life. There's nothing more rewarding than taking care of the sickest children.

Voices of Diversity

Vathsala Ariyaratna, third-year, joining a pediatric practice after graduation

Hometown: Kingwood, TX

College: University of Houston

Medical School: Baylor College of Medicine

Background: My family is originally from Sri Lanka. My parents left to seek a better life and greater educational opportunities. They first moved to South Africa, which is where my brother was born. They then moved to the United States right before I was born so my father could complete his master's at Texas Tech. My father is a professor of mathematics, and my mother is a family physician.

Experiences that shaped me: After visiting Sri Lanka in high school, I truly understood the hardships my parents faced growing up and how fortunate I am to live in the United States. I realized how much I take for granted – such as electricity 24 hours a day – and became more grateful for the life that my parents have worked so hard to give me.

What I like about the program: The people I get to work with every day are some of the most amazing, smart, funny and compassionate people I've met in my entire life. Our residency class is so diverse, and being Sri Lankan hasn't made me feel isolated, only unique. I've met people from so many unique cultures and backgrounds, and understanding and learning about them has made me a more well-rounded person. For example, one of my closest friends is from Eritrea, a country in Africa I didn't even know existed until I met her! I attended her wedding, which incorporated traditional Eritrean customs, and I enjoyed learning so much about her beautiful culture.

You might overhear me say: "Speak up!" As a woman I think sometimes we forget to be assertive because we were raised to be demure and polite. My intern year I received feedback from a female attending that because I spoke so softly to other physicians, they were zoning out during my presentations. Throughout my training I've worked with so many strong women that have taught me to be confident in who I am and what I can do. Now as a supervisor, I always advise my female interns to let their voice be heard!

Voices of Diversity

Peace Dike, second-year, plans on specializing in gastroenterology

Hometown: Katy, TX

College: UT-Austin

Medical School: UT Medical Branch at Galveston

Background: My parents are from Nigeria. They came to Texas through a lottery in 1982 and have been here ever since. They left because there was a general lack of opportunity for them in Nigeria. Even though they had degrees, there was no guarantee they'd get a job. And if they did get a job, there was no guarantee they'd get paid for it. It was that lack of stability that they wanted to escape, to have a better life for their children.

Experiences that shaped me: Coming from a family of immigrants, seeing my parents struggle and work so hard and take jobs that they wouldn't have taken if they'd had better opportunities really instilled in me a strong work ethic and has been my driving force to succeed. I got here (to being a doctor) about as quickly as I could – no wandering off that path!

I wanted to become a doctor: Partly because of my father. He always wanted to be a doctor, but when he came here he had to start from scratch. He had mouths to feed, so he became a psychologist because it was quicker than medical school and residency. My mother is also in a health field; she's a substance abuse counselor.

Why gastroenterology: I like it because there are so many different pathways you can take with it. I'm really interested in the way the body processes food – how important it is, how it works in our bodies, how it can be harmful or healing. I want to be a clinician because I love interacting with patients and helping them feel better.

Why Baylor/Texas Children's: This was one of my last interviews, and probably because I'm from Houston and I wanted more excitement, it wasn't really high on my list. Then I came here and met the program director, and my whole list was immediately turned upside down. It's hard to describe the feeling; there's a certain energy that is created because of all the different types of residents they pick. It makes this place feel like home. And not just the residents, the faculty. You're rubbing elbows with some of the smartest people you'll ever meet, but there's a humbleness and a lack of pretention that is really hard to find elsewhere.

Voices of Diversity

Josh Hilliard, second-year, plans on specializing in sports medicine and primary care

Hometown: Houston

College: Johns Hopkins University

Medical School: UT Southwestern at Dallas

Background: I was raised by a single mom who was a social worker. I grew up in Greenspoint, considered one of the roughest neighborhoods in Houston. I also have an older sister who is 13 years older than me who was like a second mom. We moved out to the suburbs right before I went to high school.

Experiences that shaped me: When I was in the fifth grade, my mom gave me a children's version of pediatric neurosurgeon Dr. Ben Carson's autobiography. His story really influenced me. I found similarities in our lives, and I thought, "Oh, I could do that too." There aren't many people from my neighborhood – or even in my family – who get a full-ride scholarship to a place like Johns Hopkins. My mom valuing education, seeing my potential and giving me that book – that really set me off on this path.

Why pediatrics: I love working with children. Medicine is a really tough job. It's nice to have a cute face to look at while you're doing it. Also, children are very resilient.

Why Baylor/Texas Children's: My girlfriend and I co-matched here. At first we thought we wanted to go outside of Texas, but then she interviewed here and said, "It's amazing. If we get in, we have to go." And of course she was right. Also, I'm interested in pursuing medicine in underserved communities, and we put a huge focus on that, whether it's here or abroad. One of our health centers is in Greenspoint. I like the idea of going back and helping out in the community I came from.

What I like about the program: They give us a lot of freedom to pursue our own interests. I'm on a diversity council to help the school attract even more diverse faculty and residents. I also like the people in my program and the dumb little things we do together, like go to bouncy houses once a month. All 50 of us are really different, but as a whole we get along great. I don't know how they picked us, but it just works really well.

Voices of Diversity

Flora Nuñez Gallegos, second-year, plans on specializing in cardiology and public health

Hometown: Los Angeles, CA

College: UCLA

Medical School: Stanford University

Background: I was born in a small village in El Salvador and raised primarily by my grandmother after my mom went to the U.S. during the civil war. When I was around 5, my 60-year-old grandma decided it was safer for us to leave as well. After a long journey, we crossed the border into the U.S. and reunited with my mother. My mother quickly instilled in me the notion of making the best of each opportunity. Particularly when it came to my education.

Experiences that shaped me: I vividly remember going to immigration offices, standing in line all day for an update on our case, meeting so many other families going through the same thing. My mother worked as a nanny and made sure that I had whatever I needed for my education. My mother would tell me that "When that day comes, you have to be ready." That gave me a strong sense of self and a desire to make something out of my life and give back to my community.

Fortunately, my green card was approved when I was a junior in high school. I got a scholarship to UCLA. And then I went to Stanford Medical School, where I concentrated on community health. I also went to Harvard to get a master's in public health so I could become an advocate for underserved communities. I've always pushed myself because I am acutely aware of the opportunity I have in this country and the sacrifice it took from my family so that I might be in this position.

When I meet with my patients today, I tell them my story, and how, through education, everything is possible. I start conversations with "Where are you going to college?" not "Are you" or "If you." Because education is one of the most powerful ways to break the cycle many immigrants find themselves in.

Why Baylor/Texas Children's: My decision to come here was an easy one. I am surrounded by brilliant physicians, there is a center for advocacy and policy, and I have the possibility to impact one of the most diverse communities in the country.

Voices of Diversity

Janaki Paskaradevan, third-year, plans on specializing in pulmonary medicine

Hometown: Newport, Minnesota

College: University of Minnesota

Medical School: Johns Hopkins

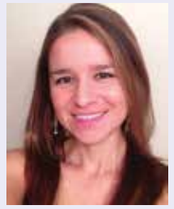
Background: My parents are from northern Sri Lanka. My two older siblings and I were born in Sri Lanka. But, when a civil war in Sri Lanka escalated in 1988, my parents decided to leave the country. My older siblings tell me that while my mom was pregnant with me, they had to take shelter in temples during night raids and bombings. This clearly wasn't the environment my parents wanted for their children. Shortly after I was born, my dad was able to get a visa to Canada and our family moved to Calgary, Alberta. We lived there for about 10 years before my dad took a job in Minnesota. My parents still happily live in Minnesota.

Experiences that shaped me: Seeing and hearing about the risk my parents took to move my family from Sri Lanka to Canada has shaped me a lot. My dad is a mechanical engineer by training and gave up a successful career in Sri Lanka to take a chance in a new country. My parents struggled for many years, with my dad initially working at fast food restaurants to make ends meet before he was able to go back to school for a degree in information technology. Seeing how much they sacrificed for the success of their children has always influenced me, showing me the importance of hard work and resilience.

Why Houston: I wanted to be in a big, diverse city that had a variety of things to offer (sports, theater, museums). I also wanted to work in a city where I could care for populations that are typically more underserved. Houston seemed a city that was both ethnically and socioeconomically diverse, without success being directly correlated to ethnicity.

Why Texas Children's: When I came to visit, I was so impressed by the size and scope of Texas Children's. Before starting residency I didn't know if I wanted to be a general pediatrician or a specialist and wanted to be somewhere that I could be exposed to most aspects of pediatrics. TCH was perfect for this. I also appreciated the diversity of faculty members and seeing women in leadership roles. It's always nice to see a diverse residency program, but having a diverse faculty gives you a wider group from which to find mentors and also shows you the opportunities for advancement.

Voices of Diversity



Dani Roberts, first-year at Children's Hospital of San Antonio

Hometown: Katy, TX

College: Trinity University

Medical School: Texas A&M University in Temple

Background: My dad is this huge, redheaded English man, an executive at AIG, and my mother is a tiny 4'11" Chilean woman, who is a pre-kindergarten teacher.

Experiences that shaped me: I was born in England and lived there for my first seven years. Then we moved to Buenos Aires for seven years, and I had to learn Spanish. And then we moved to Katy. That was really hard. Fourteen is a difficult age anyway, and being new and different, and going from a tiny private school to an enormous Texas high school, that was a big adjustment. Thankfully, it got easier, and I made friends. Now, as a doctor in San Antonio, I find my past experiences to be really helpful. There are a lot of children here who speak only Spanish and live in communities that feel like Latin America, but of course they live in the U.S., and they're Americans. It creates a bit of a culture clash or identity crisis. Because I know what it's like to feel like an outsider and like people don't understand me (literally and figuratively), I can better connect to that struggle.

Why Baylor/Children's Hospital of San Antonio: This is only the second year of our residency program. That presents some challenges, yes, but it's also a huge opportunity. For many of us, this was our first choice because we wanted to be a leader and we wanted to have a real impact. The things we do now, the programs we shape or create, those things really matter. They'll help define this hospital from here on out. It's a responsibility we all take seriously.

What I like about the program: Because there are only 10 residents in our year, we get to know each other really well, and our personalities and diversity come out that much more. We have residents from other states and other countries, like Puerto Rico and Syria, and we really value diversity and promote it. In a new program like this, it's important to have a good attitude and be prepared to roll up your sleeves and get stuff done. If you can do that, you're in. That's what I love about it.

Research

Quicker Diagnosis For Liver Disease

Researchers recommend a heel-prick screening for the liver disease biliary atresia as a standard of care for all newborns.

Researchers uncover hope for biliary atresia patients

Sanjiv Harpavat, MD, a pediatric gastroenterologist at Texas Children's Hospital and Baylor College of Medicine, is dedicated to improving outcomes for children with gastrointestinal disorders. But one particularly devastating liver disease has become the centerpiece of his research activities.

Affecting approximately one in 10,000- 18,000 births in the United States, biliary atresia is a rare but deadly liver disease and the No. 1 reason for pediatric liver transplants worldwide. As a result of a blocked bile duct that connects the liver to the small intestine, the buildup of bile in the liver scars tissue so rapidly that most newborns need a liver transplant to survive.

"Infants with biliary atresia develop a tremendous amount of liver scarring in the first few months of life, comparable to that seen in adults with chronic liver diseases such as hepatitis C," Harpavat said. "The best way to improve their outcomes is by detecting and treating the disease early before symptoms appear."

The only proven treatment strategy for biliary atresia is the Kasai portoenterostomy, a procedure in which the surgeon replaces the damaged bile ducts with a piece of the infant's intestine. The procedure has variable success in preventing or delaying the need for transplantation.

"Preliminary data suggest infants who undergo Kasai before 30 days of life have a better outcome and may have a lesser chance of needing a liver transplant," said Texas Children's pediatric surgeon and Baylor professor of surgery Mary Brandt, MD, who is a national leader in performing this procedure. "Waiting until there is significant scarring in the liver increases the chance of needing a liver transplant."

One major challenge in achieving early treatments is that infants with biliary atresia may appear normal in the first few weeks of life. Because of this, they are difficult to identify and are diagnosed and treated after 60 days of life on average.

> ***"The best way to improve outcomes is by detecting and treating the disease before symptoms appear."***
> ***– Sanjiv Harpavat, MD***

Acknowledging these delays, the American Academy of Pediatrics published a position paper recommending studies that explore screening strategies for biliary atresia. Currently no standard screen exists in the United States, and pediatricians generally do not suspect the disease until considerable liver damage has already occurred.

Just like a hearing screen is standard for all newborns in the United States, the Texas Children's Hospital team hopes to someday implement a newborn screening program nationwide for biliary atresia. To do this, the group has initiated a clinical research program with provocative early results.

Closer look at numbers

In a retrospective study published in the December 2011 issue of the journal *Pediatrics*, Harpavat and his colleagues including Texas Children's Department of Pathology Chairman Emeritus Milton Finegold, MD, examined lab records of 61 children with biliary atresia referred from their birth hospitals to Texas Children's Hospital for care. They discovered that all newborns with biliary atresia had persistently high direct or conjugated bilirubin measurements in their blood, indicating a problem with liver function that could be detected in the newborn period.

Currently, many pediatricians already draw bilirubin levels on newborns. They are looking for high unconjugated bilirubin levels to assess severity of jaundice prior to administering phototherapy. Often during this testing, the direct or conjugated bilirubin levels also are measured. Currently, pediatricians have no guidelines to follow on how to manage patients with abnormal levels of direct or conjugated bilirubin. Now, however, they are starting to pay more attention to the values.

"We're realizing that any abnormality in conjugated bilirubin is potentially an important value that may need to be examined if we are to detect biliary atresia at its earliest, most treatable stage," Harpavat said.

Texas Children's neonatologist Joseph Garcia-Prats, MD, helped implement a biliary atresia screening initiative at Ben Taub General Hospital and later at Texas Children's Newborn Center following Harpavat's retrospective findings. Garcia-Prats said biliary atresia screening should be a standard of care for all newborns.

"Unlike a stool color card test, which detects biliary atresia after symptoms appear, Dr. Harpavat is testing a newborn screening tool that has demonstrated great potential in diagnosing biliary atresia earlier," said Garcia-Prats, who also is a professor of pediatrics at Baylor.

Novel tool put to the test

To determine whether such a screening program could work at diverse hospitals such as those found throughout the country, Harpavat and his colleagues, including Benjamin Shneider, MD, professor of pediatrics and George Peterkin Endowed Chair at Baylor and chief of the Gastroenterology, Hepatology and Nutrition Service at Texas Children's, designed a study to test a simple way to screen infants for biliary atresia in the first two to three weeks of life. Their research appeared in the August 2016 issue of the *New England Journal of Medicine*.

The population-screening study included all infants born in four hospitals around Houston during a 15-month period. The research now has been expanded to 10 hospitals in Houston and South Texas. The screening they developed is based on newborn direct or conjugated bilirubin measurements.

All of the infants in the study were screened, and those identified as having direct or conjugated bilirubin concentration exceeding the 95th percentile were rescreened at or before their first well-child visit. A total of 11 infants retested positive at the median age of 14 days.

"This new study presents preliminary data on a novel method for screening for biliary atresia in newborns, and shows that the test is very accurate," Shneider said. "If confirmed in larger studies, this screening method might be used to screen every infant born in the United States for biliary atresia, similar to the way newborns are routinely screened for other diseases."

While data is still being collected, one unique aspect of Harpavat's ongoing research study is that newborn patients are receiving immediate benefits from the blood screen test.

"Hospitals outside our study have used our preliminary data and are paying closer attention to the conjugated bilirubin measurements," Harpavat said. "They're calling us about their results, so we're picking up biliary atresia cases in a non-studied way as well."

The average age of infants undergoing Kasai portoenterostomy has dropped at Texas Children's since these studies began. A significant proportion of the change is the result of the educational activities that have occurred in the context of Harpavat's studies.

Push for universal screening

To mobilize statewide support for this lifesaving initiative, Harpavat has collaborated with longtime newborn screening advocate and Texas Children's neonatologist Charleta Guillory, MD, to begin introducing the research to leaders in the newborn screening field.

"The more compelling statistics we present in the state of Texas, the more credibility we'll have in pushing forth this newborn biliary atresia screening test on a national level," said Guillory, who is an associate professor of pediatrics at Baylor.

Harpavat has presented his research to the Texas Medical Association, the Texas Pediatric Society's Fetus and Newborn Committee, the March of Dimes and the State Newborn Screening Advisory Committee. He also is discussing his research findings at pediatric conferences across the country.

Harpavat's ultimate goal is to screen 100,000 to 150,000 newborns in this multicenter study before presenting his findings to national health screening panels, like the National Screening Advisory Committee, and eventually reaching out to policymakers for their support.

"Our mission is to improve outcomes in biliary atresia," Harpavat said. "We are evaluating an affordable, widely available, easily interpretable test that has the potential to hasten diagnosis for infants with this serious disease."

Shneider said Harpavat's exciting findings on biliary atresia screening already have changed the landscape of the early phase of this disease and other forms of neonatal cholestasis in Houston.

"This work is a marvelous example of the positive impact of clinical research on the well-being of children and exemplifies the rationale for clinical research being a major focus for programmatic development in pediatric gastroenterology, hepatology and nutrition at Texas Children's Hospital," Shneider said.

Book chronicles triumphant outcomes

On Dec. 16, 2008, Tara Fields and her husband, Troy, welcomed 6-pound fraternal twins Abigail and Memphis into their family.

While both twins appeared healthy at birth, it wasn't until the twins' two-week checkup that their pediatrician noticed Abigail hadn't grown as much as her brother. The difference in size between the two babies became increasingly obvious. At 6 weeks old, Abigail produced white stool, and subsequently her complexion changed and the corners of her eyes began to turn yellow.

When lab results revealed that Abigail's conjugated bilirubin levels were abnormal, her pediatrician immediately referred her to Texas Children's Hospital, where she underwent a battery of tests.

"Our emotions were raw," Tara recalled. "By the end of the week, our daughter was diagnosed with biliary atresia. She underwent the Kasai procedure on Feb. 23, 2009, and today she is a healthy, vivacious 8-year-old who loves to dance and perform gymnastics."

Abigail's triumphant story is one of eight inspiring patient outcomes featured in a book edited by then Baylor College of Medicine medical student Beverly Lee. Since the publication of *Biliary Atresia Patient Stories* in 2015, Lee has maintained a strong bond with many of the families, in some cases helping those undergoing liver transplantation write appreciation letters to donor families.

Beverly Lee, MD

The book is part of the packet of information that families receive from their liver team at Texas Children's when their child has been diagnosed with biliary atresia.

The idea for creating this book was conceived by a patient's mother, Ana Camacho. She expressed a desire to be connected with other parents who had gone through a similar diagnosis. Through this initial conversation Lee and Camacho began conceptualizing the book. Camacho's story about her daughter is featured in the book.

Prior to editing the publication, Lee collected stories written by patient families recounting their unique journeys with this disease. Each inspiring story contains the contact information for the featured patient family.

"I was privileged to collaborate with these biliary atresia families as they entrusted me with their most personal thoughts and stories," said Lee, MD, now a pediatrics resident at Baylor and Texas Children's. "The book has already helped families connect with each other and demonstrates the partnership that's possible between physicians and patient families."

The publication also contains a foreword from Texas Children's pediatric audiologist Ross Tonini, AuD, who underwent one of the country's earliest Kasai procedures to treat biliary atresia almost 60 years ago when he was just 6 weeks old.

(From left to right) Sanjiv Harpavat, MD, Charleta Guillory, MD, and Joseph Garcia-Prats, MD, discuss implementing a new screening tool for the liver disease biliary atresia.

The Language of Life

Huda Zoghbi, MD, leads a team of scientists in discovering the genetic causes of pediatric neurological disorders.

Neuroscientists chart paths toward viable therapies

In 1983, during her pediatric residency at Texas Children's Hospital, Huda Zoghbi, MD, saw her first patient with Rett syndrome, a nonverbal 5-year-old girl who couldn't stop wringing her hands. Mysteriously, the patient had been healthy until the age of 18 months, when she became withdrawn, avoided eye contact and eventually stopped talking. The encounter profoundly changed the young pediatrician and set her on course for a career uncovering the genetic causes of pediatric neurological conditions.

The remarkable discoveries emerging from the Jan and Dan Duncan Neurological Research Institute (NRI) at Texas Children's Hospital and Baylor College of Medicine offer hope for children and families facing rare and devastating neurological disorders like Rett syndrome.

Under Zoghbi's transformational leadership, the NRI is unlocking the genetic and molecular mysteries behind developmental and neurodegenerative brain disorders in both children and adults. Dedicated to improving the lives of patients facing these devastating neurological disorders, the NRI is a basic research institute committed to understanding the biological mechanisms that lead to neurological diseases in order to develop effective treatments.

A Howard Hughes Medical Institute investigator, Zoghbi is founding director of the NRI and holds the Ralph D. Feigin, MD, Endowed Chair in Pediatrics. Born and raised in Beirut, Lebanon, Zoghbi was a first-year medical student at the American University of Beirut when civil war broke out and forced her to immigrate to the United States. After finishing medical school, Zoghbi came to Houston for further training.

"Dr. Ralph Feigin recruited me to the pediatric residency program at Baylor College of Medicine and taught me clinical scholarship," she said. "Dr. Marvin Fishman, an exemplary clinician, then inspired me to become a pediatric neurologist, and I met the patients who changed the course of my career.

> ***"I turned to research for answers, and today, together with numerous collaborators and trainees, we are charting new paths toward viable therapies.'"***
>
> ***– Huda Zoghbi, MD***

"As a young physician, I found it heartbreaking to watch my patients, young and old, lose their lives to neurological diseases," Zoghbi said. "When I realized I needed to pursue basic research to truly help these patients, Dr. Arthur Beaudet, one of the finest geneticists in the country, took me into his lab and taught me how to be a scientist.

"I turned to research for answers, and today, together with numerous collaborators and trainees, we are charting new paths toward viable therapies. There is still a long way to go, but it is thrilling to see that we are beginning to understand the language of life and translate it to help mankind."

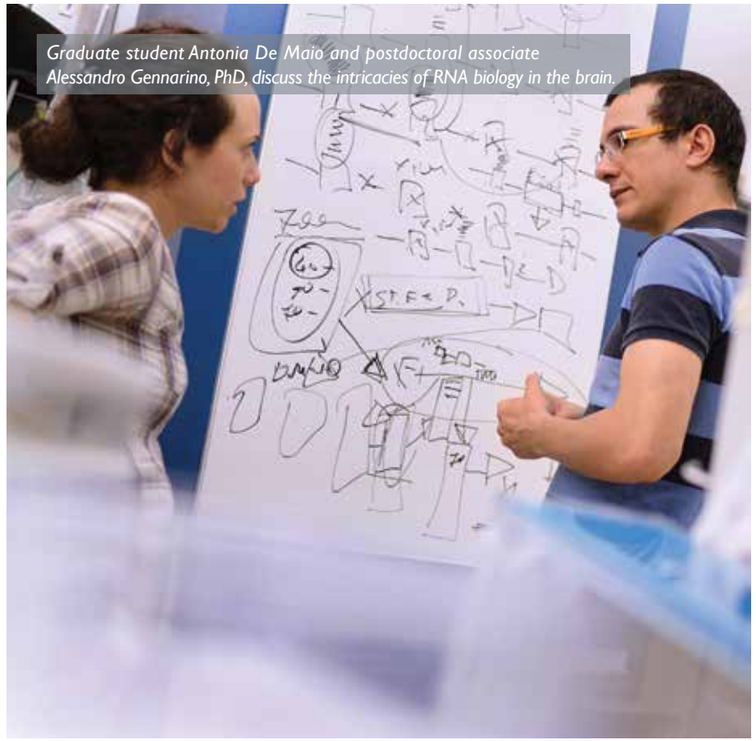
International recognition

Now an internationally recognized neurogeneticist, Zoghbi has received numerous honors for her pioneering work, including most recently the prestigious Breakthrough Prize in Life Sciences. Established by such Silicon Valley luminaries as Facebook co-founder Mark Zuckerberg, the Breakthrough Prize recognizes paradigm-shifting research, celebrating scientists and generating excitement about science as a career. Zoghbi was honored for her discoveries of the genetic causes and biochemical mechanisms of Rett syndrome, as well as spinocerebellar ataxia, which usually appears in adulthood, destroying brain cells that control balance and breathing, killing patients within 10-20 years of the first symptoms.

Zoghbi has donated most of the $3 million prize to advance genetic and neuroscience research and to inspire and support the next generation of investigators.

Since the nationally televised Breakthrough Prize awards presentation in December 2016, hosted by actor Morgan Freeman and featuring musical guest Alicia Keyes, Zoghbi has been flooded with an overwhelming response from a wide-ranging community extending far beyond her colleagues, family and friends.

"The messages I have received showed me how the Breakthrough Prize presentation ceremony humanized the process of science for so many young people, especially young girls," Zoghbi said. "Some said they are now excited about a career in science. Some messages were from parents who said the televised ceremony gave them the opportunity to sit down with their children and talk about a career in medicine or science."



Graduate student Antonia De Maio and postdoctoral associate Alessandro Gennarino, PhD, discuss the intricacies of RNA biology in the brain.

And it wasn't just the messages involving young people that touched Zoghbi.

"I have so many emails from immigrants who said how proud they were and how they related to my journey, not just in science, but in being a successful, valued part of this country. Since I am an immigrant myself, these really touched me."

Earlier in the year, Zoghbi was honored in Hong Kong with the international Shaw Prize in Life Science and Medicine, along with her Edinburgh colleague, Sir Adrian Bird, for their discovery of the genes and encoded proteins that recognize one chemical modification of the DNA of chromosomes that influences gene control as the basis of Rett syndrome.

The Shaw Prize was established by Sir Run Run Shaw, the media tycoon who helped bring Chinese martial arts films to an international audience. The prize honors individuals who have recently achieved significant breakthroughs in academic and scientific research and whose work has resulted in a positive and profound impact on mankind.

Building for the future

The investigators at the NRI are continuing to gain insight into the underlying causes of numerous neurological and neuropsychiatric disorders and are developing new therapeutic targets to treat them. So far, most genetic disorders can't be cured, but once the causes are discovered, treatments sometimes can prevent or manage the disorders caused by abnormal genes.

Many of the NRI investigators are physicians or physician-scientists, whose patients inspire the time-consuming basic research necessary to move forward toward more effective therapies. And discoveries in the pediatric arena now have led to breakthroughs in adult neurodegenerative and neuropsychiatric disorders, including Alzheimer, Parkinson, bipolar disorder and ALS.

The NRI brings together faculty with unique and complementary expertise representing a wide range of disciplines, all focused on solving previously intractable problems in neurological disorders and disease. Mathematicians, high-level statisticians and computer scientists work closely with geneticists, neuroscientists, neurologists, pathologists, neurophysiologists and neurosurgeons. The environment is open and generous, encouraging innovative collaborations between formerly isolated fields.

Through robust, multidisciplinary collaborations, the NRI is bridging the gap between initial gene discovery and clinical applications, with the ultimate goal of developing effective treatments for a broad range of disorders.

Cultivating the next generation

When Zoghbi started her career more than 30 years ago, she says it was much easier to pursue bold research ideas.

"It wasn't as hard to get funding, and we didn't feel the same pressures young scientists face today. I had no research experience when I decided to study genetics, but Dr. Beaudet took me into his lab anyway. That would be very hard to do today."

Zoghbi has therefore established a special fund at the NRI to support the next generation of scientists by giving them room to pursue creative ideas as they are beginning to launch their independent research careers.

"The transition to independence is the most difficult period in a young scientist's career," Zoghbi said. "This kind of funding gives them a measure of freedom and signals our faith in their abilities to carve out their own niche."

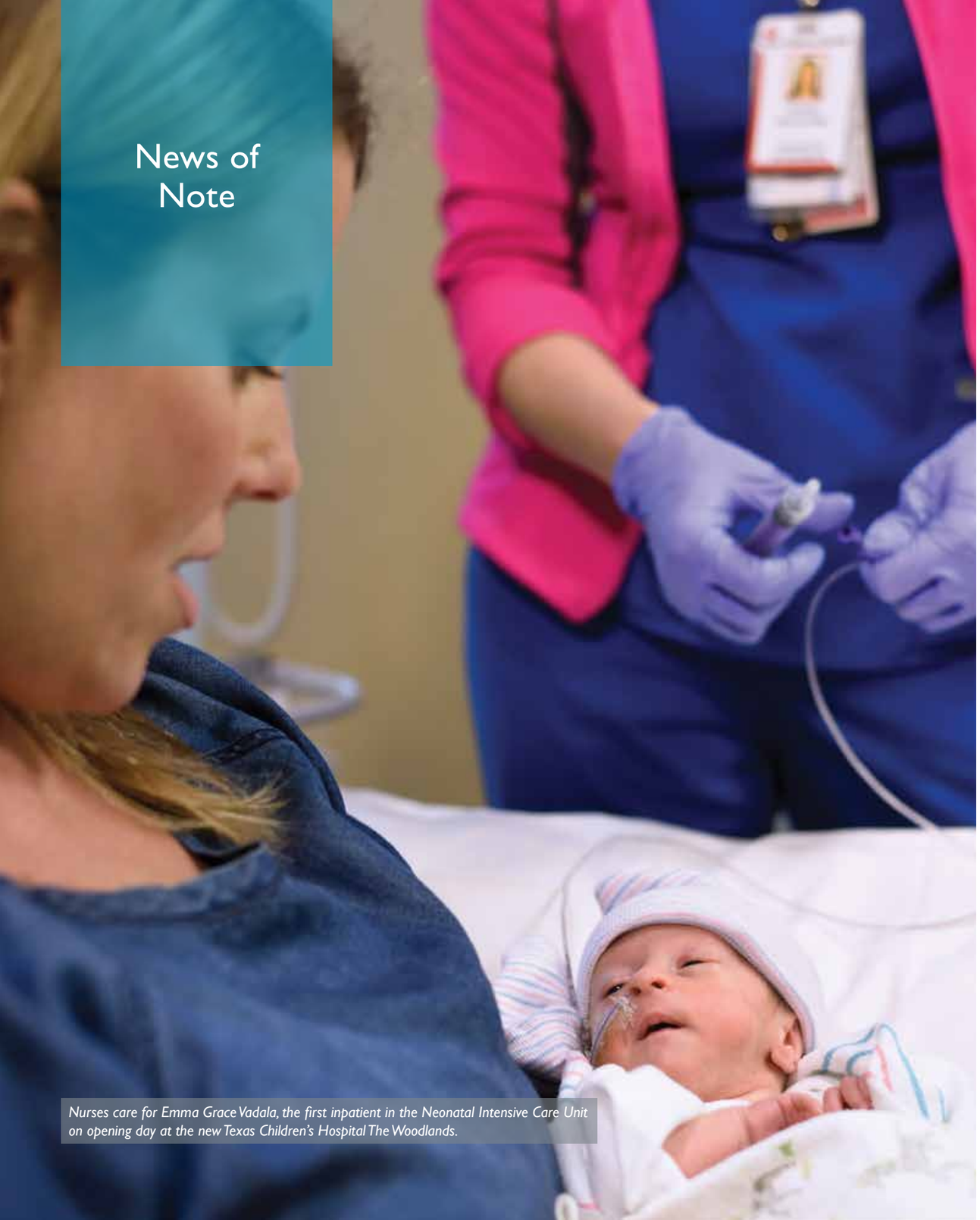
The NRI Mentorship Fund will provide one year of support to postdoctoral fellows who want to test bold hypotheses that would not be supported through conventional grants. Zoghbi started the fund when she received the Gruber Prize in Neuroscience, shortly after the NRI first opened in 2010.

With subsequent donations from additional prizes and awards, including the Shaw Prize and the Breakthrough Prize, she has grown the fund substantially. Zoghbi hopes that support from this fund, combined with hard work and protected space for intellectual freedom, will ensure the success of many young scientists poised to embark on their independent careers.

She hopes that, together, the young researchers and more experienced investigators will be able to provide answers and help for those with neurological disorders.

Postdoctoral associate Carlyn Adamski, PhD, purifies the ataxin1 protein to study its interactions with its protein partners.

News of Note



Nurses care for Emma Grace Vadala, the first inpatient in the Neonatal Intensive Care Unit on opening day at the new Texas Children's Hospital The Woodlands.

Baylor, Texas Children's lead site for largest autism study ever

Baylor College of Medicine and Texas Children's Hospital coordinate the Houston research site for an online autism research initiative, one of the largest studies on autism to be undertaken in the United States.

The Simons Foundation Powering Autism Research for Knowledge, or SPARK, study will collect information and DNA for genetic analysis from 50,000 individuals with autism and their families to advance the understanding of the causes of this condition and to promote the discovery of treatment and support.

The Houston site is one of 21 across the country collaborating in this effort. Robin Goin-Kochel, PhD, associate professor of pediatrics in the section of psychology at Baylor and associate director for research at the Autism Center at Texas Children's, leads the study locally. Approximately 200 individuals with autism and their family members will be recruited annually over the next three years to participate in the effort at Baylor/Texas Children's.

"The SPARK study will empower researchers to make new discoveries that may ultimately lead to the development of new supports and treatments to improve the lives of people with autism," said Goin-Kochel. "It is one of the most insightful research endeavors to date on this disease."

About 50 genes have been identified that are believed to play a role in autism, and scientists estimate that an additional 300 or more are involved.

To learn more about SPARK or to participate, visit **sparkforautism.org/texaschildrens** or call 832-824-3624.

Texas Children's Hospital The Woodlands opens

Texas Children's Hospital The Woodlands is now open and ready to serve children and families in The Woodlands, Kingwood, Conroe, Spring, Magnolia, Humble, Huntsville and beyond.

The 550,000-square-foot state-of-the-art inpatient facility opened its doors on April 11, 2017, serving more than 150 children on its first day.

Located off of I-45 in The Woodlands near CHI St. Luke's and Methodist hospitals, Texas Children's Hospital The Woodlands offers services in more than 20 areas of specialty care and is building on a decade's worth of relationships Texas Children's has built in the community through primary and subspecialty care at Texas Children's Pediatrics locations and the Texas Children's Health Center The Woodlands.

"Texas Children's Hospital The Woodlands is really a comprehensive, stand-alone children's hospital that's part of a larger system that provides care across the spectrum," said Charles Hankins, MD, chief medical officer at the new hospital.

Designed with a "spirit of the woods" theme to incorporate the lush, woodsy landscape that surrounds it, the hospital offers an open and inviting setting for patients, families and staff alike.

Just inside the main entrance is a grand staircase that simulates a tree house, giving the area a safe, central location for children and families visiting Texas Children's Hospital The Woodlands. As you travel throughout the campus, there are images of leaves on the ceiling, rivers on the floor, and trees and 1,700 pieces of art created by children in The Woodlands community on the walls.

"A lot of planning and thought went into the design of this facility," said Trent Johnson, director of business operations and support services in The Woodlands. "It's focused completely on our patients."

Nearly 600 guests gathered on the grounds of the new hospital for the Grand Opening Gala April 28. President of Texas Children's Hospital The Woodlands Michelle Riley-Brown welcomed everyone to the fête.

Co-chaired by Tracey and Sean O'Neal and Johnna and Ryan Edone, the gala raised nearly $900,000 for the new hospital. Guests bid on items during a live auction before a performance by singer-songwriter Jewel.

The following day Hankins showed Jewel around the new facility. The first stop on the tour was the audiology suite in the Outpatient Building to see the audiology booth, which was generously donated by Jewel.

The Grand Opening celebration continued with an Inaugural Family Fun Run April 29.

The hospital's outpatient facility opened in October 2016.

Collaborators develop immunotherapy for cancer treatment

Baylor College of Medicine announced in September 2016 the launch of a sponsored research collaboration representing a significant milestone in its efforts to develop a new class of lifesaving cancer therapy.

Baylor has provided biotech company Cell Medica an exclusive license to its proprietary Natural Killer T Cell immunotherapy platform, five product candidates and an option to license future product candidates.

Baylor and Cell Medica also entered into a co-development collaboration combining Baylor's expertise in the creation of modified immune cell technologies with Cell Medica's expertise in manufacturing and commercialization of cell therapy products. Together, the collaborators will develop a pipeline of next-generation cellular immunotherapy products for the treatment of cancer.

The collaboration will accelerate the pioneering work of Leonid Metelitsa, MD, PhD, professor of pediatrics – oncology at Baylor. While recent clinical successes in the use of chimeric antigen receptor (CAR) modified T cells to treat blood-related malignancies have generated considerable promise, results in solid tumors have been limited. The primary goal of this collaboration is to extend the use of CAR technology to natural killer T cells, which have biological properties that may allow effective targeting of solid tumors.

Metelitsa's research team is part of Texas Children's Cancer Center and the Center for Cell and Gene Therapy at Baylor and Texas Children's Hospital. Support from the Cancer Prevention and Research Institute of Texas (CPRIT) was instrumental in conducting the underlying research and in attracting Cell Medica to establish its U.S. headquarters in Houston.

Vaccine unit studies people with Zika virus

The National Institutes of Health selected the Vaccine Treatment and Evaluation Unit at Baylor College of Medicine as one of three sites in the nation to study people infected with Zika virus to better understand the infection and the immune responses following infection. The study will help inform diagnostic and infection control measures, as well as development of a Zika vaccine.

Pediatrics Chair Mark W. Kline, MD, reads about preventing Zika virus at a community education event.

Kristy Murray, DVM, PhD, associate professor of pediatrics-tropical medicine, leads the Baylor portion of the study that involves Zika virus detection in human subjects. Shital Patel, MD, Baylor assistant professor of medicine-infectious disease, is principal investigator of the entire study. Hana El Sahli, MD, associate professor of virology and microbiology, is responsible for enrollment and follow-up of study participants.

The other two sites are St. Louis University and Emory University schools of medicine.

Houston and Harris County are vulnerable to an outbreak of Zika virus because the two types of mosquitoes that transmit the virus are prevalent. Other risk factors are areas of standing water that help the mosquitoes thrive and large numbers of people traveling back and forth to Latin American countries that are reporting outbreaks.

The Centers for Disease Control and Prevention has concluded that Zika infection causes severe birth defects, including the abnormally small heads of microcephaly. The agency continues to recommend that pregnant women not travel to areas where Zika infection has been reported.

Teaching kitchen offers classes in Children's Hospital of San Antonio

The new Culinary Health Education for Families (CHEF) teaching kitchen at the Children's Hospital of San Antonio opened in January 2017, offering cooking demonstrations, instruction and hands-on classes for patients, families, associates and physicians of the hospital.

The CHEF team cosponsors events with organizations like the YMCA, San Antonio Botanical Gardens and the Boys and Girls Club of America to help teach children and families in the San Antonio community about the benefits of preparing healthy, home-cooked meals.

"Culinary medicine is all about delicious and satisfying food that happens to be good for you," said Julie La Barba, MD, medical director of CHEF and assistant professor of pediatrics at Baylor College of Medicine.

Funded by a grant from the Goldsbury Foundation and created in partnership with the Culinary Institute of America, CHEF drives healthy eating as a key ingredient for life-long health and wellness. Maria Palma, CHEF program director and Culinary Institute of America alumna, and Celina Parás, the CHEF registered dietitian, have developed evidence-based classes that bridge the art of cooking and the science of nutrition. Participants learn nutrition information and practical cooking skills that will help them address prevalent health issues, including obesity and type II diabetes.

In 2014 shortly after Children's Hospital of San Antonio opened, the CHEF program launched and construction began on the teaching kitchen.

Video game promotes eating fruit and vegetables

Getting children interested in eating healthy foods is a challenge almost every parent can relate to. Recent research at the U.S. Department of Agriculture/Agricultural Research Service (USDA/ARS) Children's Nutrition Research Center (CNRC) at Baylor College of Medicine and Texas Children's Hospital has uncovered an unlikely ally in this age old battle – video games.

When children created action or coping plans designed to help them meet goals while playing a video game promoting fruit and vegetable intake, the researchers found that the children increased their meal-specific fruit and vegetable intake.

"Few children eat enough servings of fruit and vegetables each day," said Karen Cullen, DrPH, RD, professor of pediatrics at Baylor and the CNRC and first author of the paper in the *Journal of Nutrition Education and Behavior*. "These foods are part of a healthy diet, and may reduce the risk of some chronic diseases including cardiovascular disease and certain cancers. So interventions to help children choose and eat more fruit and vegetables are important."

The 10-episode video game, Squire's Quest II: Saving the Kingdom of Fivealot, was designed to both entertain and promote behavior change.

Parents received a weekly newsletter and a link to a website with information on their child's weekly goals, suggestions for supporting achievement of goals and ways to overcome common barriers.

Researchers found that children in the action and coping plan groups reported higher vegetable intake at dinner, and all groups had significant increases in fruit intake at breakfast, lunch and snack time.

Funding for this study came from the USDA/ARS and the National Institute of Child Health and Human Development. Debbe I. Thompson, PhD, RD, a USDA scientist and associate professor of pediatrics-nutrition, was principal investigator and senior author of the paper.

Cancer patients make their mark

Colorful paintings on the walls at Houston airports welcome thousands of travelers to the city. The paintings are part of a larger exhibition of art and creative writing called "Making A Mark," presented by The Periwinkle Foundation. Most of the artwork is from patients and their siblings at Texas Children's Cancer and Hematology Centers.

"Making A Mark" is a traveling exhibit on display in Houston and around Texas. Viewers are encouraged to share feedback in the form of postcards. A drop-box is provided at most exhibition sites, and to date, more than 25,000 postcards have been sent back to Texas Children's artists.

The work will be on display this summer at the William P. Hobby Airport and the George Bush Intercontinental Airport in Houston.

Artwork by patients and siblings at Texas Children's Cancer and Hematology Centers is on display at Houston airports this summer.

Spotlight on the Department of Pediatrics

Texas Children's Hospital and Baylor College of Medicine attract highly trained physician-scientists from around the world to care for patients from all over.

By the Numbers 2016

Baylor College of Medicine* Department of Pediatrics

One of the largest, most diverse departments of pediatrics in the United States

#7 rank of pediatrics educational program for 2016 by *U.S. News & World Report*, up from #9 the previous year

100% of faculty reported high satisfaction with Department of Pediatrics in a survey by the Association of American Medical Colleges

1,499 full-time, part-time, secondary and voluntary faculty

178 residents

190 clinical postdoctoral fellows

93 research postdoctoral fellows

1,444 applicants for **46** slots in pediatric categorical residency program

3 books written or edited

435 chapters written or edited

1,224 journal articles

$66.6 million in federal research funding

$15.9 million in gifts and contributions from individuals and foundations
($14,002,602 from TCH and $1,922,420 at BCM)

Texas Children's Hospital**

#4 rank on *U.S. News & World Report* Best Children's Hospitals list

34,096 total patient admissions

226,950 census days

119,878 Emergency Center visits

3,569,163 patient encounters

Patients from nearly **60** countries

50 states in U.S. are home to patients

**Baylor College of Medicine = July 1, 2015 – June 30, 2016*

***Texas Children's Hospital = October 1, 2015 – September 30, 2016, including Main Campus, West Campus and Pavilion for Women*

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For a patient referral form, see **texaschildrens.org/refer**