



ALL CHILDREN NEED

Children's Hospitals



NACHRI

National Association of
Children's Hospitals
and Related Institutions

www.childrenshospitals.net

clinical care
research
education
advocacy



ALL CHILDREN NEED HOSPITALS

focused

SOLELY ON THEIR UNIQUE NEEDS.

**You've heard the saying countless times:
Children are not small adults. Children are unique
individuals with their own specialized needs.**

This is never more apparent than when a child needs health care, whether it's a highly specialized surgical procedure, a simple treatment for an early childhood infection, an immunization or such preventive care as nutritional counseling.

Children are different. And they need different health care that focuses on their unique needs, involves their parents from start to finish and is provided in places designed to be kid-sized and child friendly. Because they're growing and developing, children's health care needs are constantly changing. They require extra time, extra monitoring, specialized medications, and caregivers with the skills and compassion to understand the needs of children. For example, hospitalized children under age 2 require 45 percent more routine nursing care.

That's why all children need children's hospitals. Whether freestanding acute care hospitals, freestanding specialty and rehabilitation hospitals, or hospitals organized within larger medical centers, children's hospitals provide quality medical care, every day, to children all over the country. They are the backbone of the nation's pediatric health care infrastructure. Children's hospitals represent less than 5 percent of all hospitals in the United States, but they are critical resources to shaping the health of all of the nation's children. By combining compassionate, personalized care with the world's most innovative technology, children's hospitals devote themselves to making sick children healthy and transforming health care for all children for the better.

More than half of our children live in low income or poor families, and nearly 38 percent rely on publicly financed health coverage or are uninsured.

Children's hospitals are regional centers for children's health, meeting the health care needs of children from distant rural areas to the streets of suburban America and inner city neighborhoods. Because they draw children from all over the region, children's hospitals treat the majority of children with chronic conditions or congenital abnormalities present from birth, such as heart disease.

Children's hospitals are also vital centers of education in pediatric medicine, training the next generation of pediatricians and family practice physicians, nurses, social workers, dentists and others who will care for tomorrow's children. And as centers of cutting-edge research in children's health, these unique hospitals are responsible for lifesaving discoveries such as vaccines, gene therapies and specialized surgical techniques that not only benefit children, but adults as well.

We don't like to think that children in America are vulnerable, but they are. They represent the largest segment of the population living in poverty. They are medically and economically vulnerable and vulnerable to loss of insurance. More than half of our children live in low income or poor families, and nearly 38 percent rely on publicly financed health coverage or are uninsured. And because they represent less than 11 percent of all personal health care spending, they have little clout in the marketplace compared to adults.

Children's hospitals protect this unique population. They are dedicated to ensuring that every child has access to high quality, cost effective, primary, preventive and specialty care services tailored to fit their needs. Although few in number, they provide a disproportionately large share of the nation's clinical care, health professions training and research aimed at producing the best possible medical outcomes — and that benefits all children.

This report provides a snapshot of how children's hospitals together with their national trade association the National Association of Children's Hospitals and Related Institutions achieve their four-fold mission of clinical care, education, research and advocacy. It also highlights critical challenges facing children's hospitals today — challenges that NACHRI is striving to address and that should be of concern to everyone who wants to make sure children's hospitals are there for their children and for all children.



PHOTO BY BRIAN DALBALCON, MARY BRIDGE CHILDREN'S HOSPITAL & HEALTH CENTER, TACOMA, WA

Child life specialists and a bubble wand entertain Sarah, age 5, while the 24-hour video EEG monitoring equipment identifies where her seizures originate.

clinical care

CHILDREN'S HOSPITALS ARE indispensable TO THE HEALTH CARE OF ALL OF AMERICA'S CHILDREN.

Children's hospitals treat 98 percent of all children needing heart or lung transplants, 93 percent of children requiring cardiac surgery and 86 percent of all children with malignant neoplasm.

In 2001, 25-year-old Lynn Gerking was happily expecting her first child. She and her husband Jeremy were thrilled at the prospect of becoming parents and had decided to find out whether their new baby would be a girl or a boy. The sonogram revealed that their baby girl had CCAM (congenital cystic adenomatoid malformation), a condition so rare that the physician had to confirm her diagnosis with a medical text.

In CCAM, abnormal tissue grows in one lobe of the lung. Most dissipate or can be removed at birth. But by Lynn's 27th week of pregnancy, the cyst had grown so large the doctor recommended she call the Fetal Treatment Center at the UCSF Children's Hospital (University of California, San Francisco).

After meeting with the center's multidisciplinary team, Lynn and Jeremy made the decision to proceed with surgery. Michael Harrison, M.D. and his colleagues at the Fetal Treatment Center team at UCSF Children's Hospital are fetal surgery pioneers. Harrison performed the first fetal surgery more than two decades ago, developed the techniques used internationally and trained many of the surgeons practicing in the handful of U.S. hospitals with fetal surgery programs.

Today 5-year-old Rae Gerking is a bundle of energy. She's a dynamo on the soccer field and loves gymnastics and her new, healthy baby brother Owen. Now, the only visible sign of Rae's extraordinary beginning is a small scar on her shoulder.

Fetal surgery is still very rare — just 3 percent of children are born with birth defects and a smaller number of these have problems that would warrant fetal surgery. Yet children's hospitals have invested in finding and

While children’s hospitals represent less than 5 percent of all hospitals, they account for more than 40 percent of inpatient days and 50 percent of costs for all children hospitalized in the United States — \$10 billion worth of care every year.

testing new techniques, including non-invasive interventions, to save these very sick babies. As a result, many children’s hospitals now perform fetal interventions that don’t require open surgery, including techniques developed at UCSF, such as fetal image-guided surgery, a non-invasive technique in which real-time images help surgeons guide needles to deliver medications or place shunts to drain fluid from the fetus; and Fetendo, an endoscopic procedure much like adult laparoscopy that allows surgeons to manipulate very small instruments guided by a fetoscopic image viewed on a TV monitor.

The Gerking family understands that without her lifesaving surgery at a children’s hospital Rae would surely have died. They also know that the hospital’s advanced surgical techniques and family centered care were critical to a happy ending.

Pediatric care, especially highly complex care, is concentrated in children’s hospitals and major general teaching hospitals. While children’s hospitals represent less than 5 percent of all hospitals, they account for more than 40 percent of inpatient days and 50 percent of costs for all children hospitalized in the United States — \$10 billion worth of care every year.

Freestanding, acute care children’s hospitals and children’s hospitals located in larger hospital systems, such as UCSF Children’s Hospital, treat 98 percent of all children needing heart or lung transplants, 93 percent of children requiring cardiac surgery and 86 percent of all children with malignant neoplasm.

Because they serve so many children with complex and chronic conditions, children’s hospitals must provide the most technologically advanced, compassionate, child-centered care available. But that’s not all they do. The children’s hospital in your community is really three hospitals in one: a hospital that specializes in treating children with complex, chronic or congenital conditions; a community hospital for all area children providing preventive and primary and acute care; and a safety net hospital for uninsured or underinsured or publicly covered children. The specialized knowledge, highly trained staff and unique medical equipment found in children’s hospitals are indispensable to all children needing health care, not just the seriously ill.

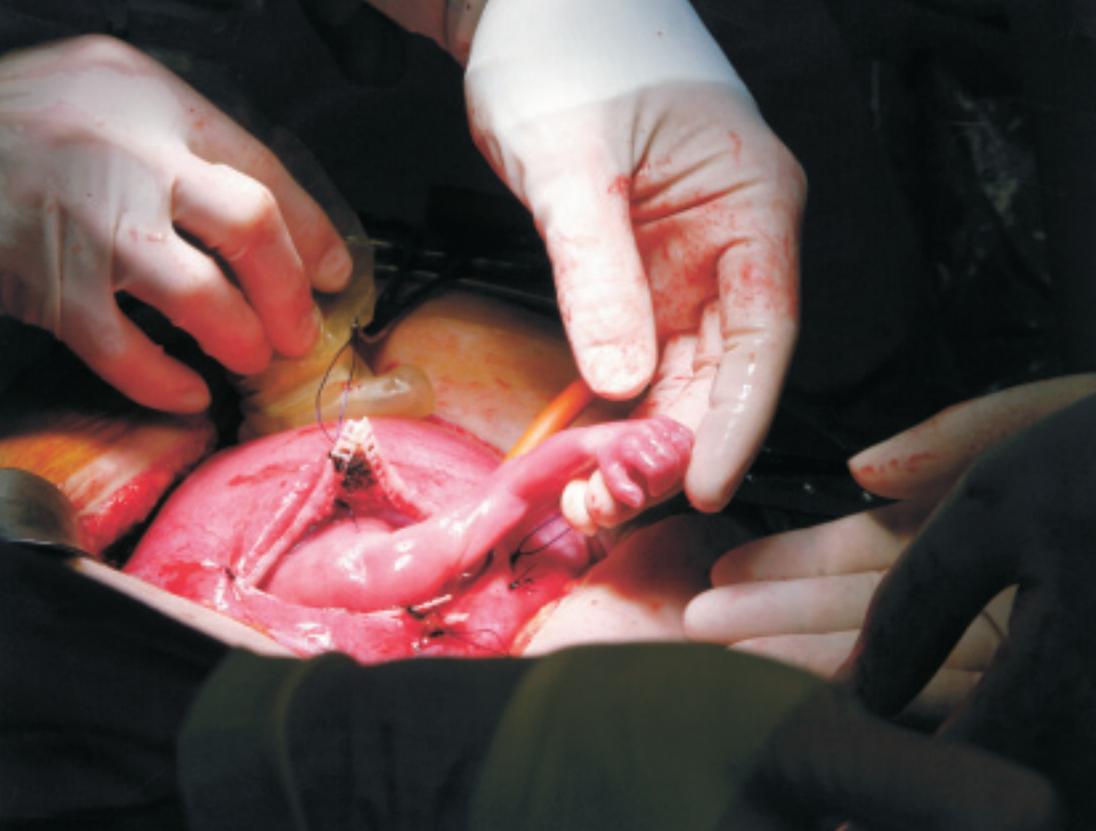


PHOTO BY ALLEN S. KRAMER, TEXAS CHILDREN'S HOSPITAL, HOUSTON, TX

In a rare surgery to correct a life-threatening birth defect, fetal surgeons partially extract an unborn baby from the mother's womb.

Driven by their commitment to all children, children's hospitals work hard to meet children's primary and preventive health care needs, as well as their needs for acute, specialty and rehabilitative care. The average freestanding acute care children's hospital provides care in 296,801 primary and specialty care visits to ambulatory clinics, 54,298 emergency department visits and 9,135 outpatient surgeries annually. Across the nation, about 2.3 million emergency department visits and 13 million outpatient visits are made to children's hospitals every year. And although children's hospitals are magnets for child health care throughout their regions, the care they provide doesn't stop at the hospital doors. They operate satellite clinics and health centers right in your neighborhoods and in your schools. Subspecialists from Cook Children's Medical Center, in Fort Worth, TX, hold specialty clinics in seven different communities of north and west Texas, as far away as Midland and up to Lubbock. These clinics, many serving isolated rural areas, care for the specific needs of communities that can't support a full-time pediatric subspecialist.

This regular access to quality preventive and wellness care, as well as acute specialty care, makes an enormous difference in children's health and in their lives, including how well they learn in school. Asthma, for example, is the leading cause of school absenteeism due to a chronic health condition. The devotion of children's hospitals to primary care and care for chronic conditions helps keep kids in school, enabling them to learn more effectively and preparing them for successful, productive lives.

Children's hospitals are also essential "safety net" providers of care so that children who don't have health insurance or who don't have adequate coverage won't slip through the cracks. On average, more than 55 percent of the inpatient care and 48 percent of outpatient care at freestanding, acute care children's hospitals is covered by Medicaid. That's particularly vital because children are still the largest segment of our society living in poverty. Nearly 38 percent of all children are uninsured or depend on Medicaid and other public sources for their insurance. Consider the Dark family who lives in Chicago. Lenzie Dark first visited La Rabida Children's Hospital due to the onset of lupus. Unfortunately, this visit happened during the time when her family was switching from one health insurance company to another. She was hospitalized and diagnosed with lupus during the gap in coverage and the new insurance carrier refused to cover her health care costs because it

Getting to walk the hall with Dad and all the medical equipment in tow.

PHOTO BY NANCY LEVINE, CHILDREN'S HOSPITAL & REGIONAL MEDICAL CENTER, SEATTLE, WA



considered her condition pre-existing. La Rabida Children's Hospital, which devotes more than 83 percent of its care to children assisted by Medicaid, was able to get Lenzie on the fast track for All Kids, the state of Illinois insurance program for children. Lenzie received the care she needed during her first difficult months with lupus.

Freestanding acute care children's hospitals provide more than 10 times as much patient care to low income children assisted by Medicaid or uninsured as do all community hospitals. For example, on average, these children's hospitals provide more than 23,000 days of inpatient care to low income children per year compared to community hospitals, which provide, on average, less than 1,500 days of care per year.

And for all these children, doctors and other health professionals at children's hospitals take a family centered approach to health care. When your child receives care at a children's hospital, whether for the flu or for a broken arm or for something more serious, you're involved every step of the way. In colorful, welcoming exam rooms designed and equipped for children and their families, doctors, nurses, child life subspecialists and other health professionals at children's hospitals treat parents as their partners. They know that parents are experts at caring for their children. The staff at children's hospitals also knows that being in a hospital is one of the scarier things that can happen to a child, so they wear bright-colored scrubs, not doctors whites. They're experts in using toys and games to put kids at ease. And they make sure children feel comforted and safe — feelings reinforced by in-room accommodations for parents and age-appropriate playrooms. Some hospitals even have "training apartments" for families transitioning out of the hospital after extended stays.

Partnering to Improve Asthma Care

Just over three years ago, the physician-hospital organization at Cincinnati Children's Hospital Medical Center took aim at asthma, enlisting the help of 44 pediatric practices in close-by communities. The quality improvement project is very ambitious, but has already yielded significant improvements in care.

Keith Mandel, M.D., vice president of medical affairs for the physician-hospital organization, is leading the effort to improve the health of the nearly 14,000 children with asthma served by these community practices. These children represent nearly one-third of the region's pediatric asthma population.

Children’s hospitals treat a disproportionate 90 percent or more of all children needing heart or lung transplants or cardiac surgery.

“We launched this large-scale initiative to help practices, not only improve asthma care, but to build sustainable systems to support future improvement efforts,” Mandel says. Nearly 170 physicians are working together to improve the care of their patients with asthma, the most common chronic childhood illness in the United States.

Asthma affects more than 6 million children in this country and countless others not yet diagnosed. It accounts for an estimated 14 million lost school days every year and millions of lost workdays by parents. It’s the third most common reason why children are admitted to hospitals and results in more than 650,000 emergency room visits every year. Asthma is a perfect test case for orchestrating a quality improvement program that brings together community practices, hospital and community-based specialists and improvement experts.

The first priority? Identify all children with asthma within each practice and create a registry. Then develop interventions to better control asthma and to improve the ability of patients and parents to manage the condition.

For many practices, the simple act of engaging patients and parents in information gathering was a critical first step to improving outcomes. One-on-one conversations have given physicians a clearer understanding of how each patient is faring, and have sometimes uncovered surprising information, including just how frequently parents feel unsure of and confused by their children’s medications. But these revelations helped practices get a handle on patients’ symptoms and degree of control of their condition, and instigated more intense efforts to identify patient and parent concerns. As a result, the practices are making great strides in improving care.

Each practice now enters data directly into a Web-based registry that provides access to real-time, actionable reports. The data is “transparent” — each practice’s outcomes are available for everyone within the network to view and to use as a tool to gauge how well they are doing, as well as to promote shared learning and the spread of successful interventions.

The quality improvement journey was accelerated when the area’s largest health insurer agreed to support a “pay for performance” program designed by the physician-hospital organization, with rewards based on data from the registry. Practices were rewarded for participating in the improvement initiative, achieving network and practice-level performance thresholds and building improvement capability.

“Improvement in processes and systems comes first,” Mandel says. “Then we see the downstream effect as patient outcomes begin to improve.” That downstream effect has already made a difference for children and their parents. “We are seeing phenomenal improvements across the network in terms of key components of asthma care, as well as outcomes, such as hospital admissions, emergency department and urgent care visits, school days missed workdays missed, and patient and parent confidence in managing asthma.”

Improving the Quality of Pediatric Care

For people caring for children, good simply isn't good enough. And the best available care today may not meet tomorrow's highest standards. Pediatric health care is in a state of constant transformation as children's hospitals routinely question, probe and improve the way they deliver care.

In 1994 and every year since, NACHRI has brought together professionals from children's hospitals in collaboratives called FOCUS Groups to roll up their sleeves and share experiences in a heartfelt desire to improve clinical practice. During these meetings and multiple teleconferences, they tackle tough issues aimed at transforming children's health to be the best it can be and at making it more efficient, more effective and less expensive.

"In the early days," explains Lynne Lostocco, NACHRI director for the initiative, "we asked each other 'what do you do, what works best for you?' It was simple benchmarking of best practices that produced positive patient outcomes. But we soon learned that we needed to move beyond sharing 'what we think works' toward 'what we know works,' and then to creating real change in care."

The first clinical multi-institutional collaborative research study was in 2002 and examined one critical and common aspect of pediatric intensive care: the use of invasive respiratory support with an endotracheal tube. A child's illness, his limited understanding of the procedure and the small size of the airway can make it a risky procedure, requiring the expertise of the specially trained intensive care experts found in children's hospitals. Despite skill and experience, the procedure sometimes fails. This first-of-its-kind investigation was organized to determine how often, why and with what consequences. The result was an unprecedented evaluation of risk factors and outcomes — information that has helped reduce complications.

Since that time, NACHRI has spearheaded multiple collaboratives, which have tackled everything from ways to streamline care in ambulatory care centers to preventing serious skin ulcers during hospitalization. And each year, FOCUS Groups document their outcomes to share with the entire NACHRI membership of 200 plus institutions in the United States, Canada and abroad.

"The children's hospital community does come together more than most. We know that collaboration produces better results. And we all share a common goal to improve the health care we provide to children," Lostocco adds.

challenges

Adequate Reimbursement and Investment

Because they open their doors to all children, children's hospitals take on a greater burden in under-compensated and uncompensated care. On average, children's hospitals devote more than half their patient care to children reliant on Medicaid and these children are more resource intensive than non-Medicaid patients. As inpatients they are sicker and require longer hospital stays. Children's hospitals receive, on average, 78 percent of the cost of the care provided to Medicaid patients. Therefore, Medicaid reimbursement is a major challenge to children's hospitals and their ability to serve all children.

At the national level, Medicaid reform remains a hotly debated topic but is rarely viewed as the children's health program it really is. Created by Congress in 1965 to provide health insurance to low income Americans and the disabled, it now covers one in three — 28 million children — for part or all of a year. With the jointly administered state-federal program, the State Children's Health Insurance Program or SCHIP, it ensures that even more children receive preventive, primary and acute pediatric care to meet their needs. Yet, 9 million children in the United States remain uninsured.

Despite this crisis of the uninsured, year after year Medicaid coverage for children has been put at risk by proposals to reduce government health care spending to help balance the federal budget. While the future of Medicaid remains uncertain, what is certain is that the future of children's hospitals is tied to Medicaid. That's why the National Association of Children's Hospitals (N.A.C.H., the NACHRI public policy affiliate) aggressively advocates protection of Medicaid coverage for children and opposes changes that would diminish the ability of children's hospitals to care for all children.

On a brighter note, 10-year-old SCHIP is before Congress for reauthorization in 2007, and leading congressional proposals include funds to continue the program for five years, to enroll currently eligible children who are uninsured, to make more children eligible for the health coverage program and to fund pediatric quality improvement initiatives to improve care for kids. While it fully supports reauthorizing SCHIP, N.A.C.H. also champions passage of the "Children's Health Quality Act" introduced in April 2007. The bill would spur private sector development and testing of pediatric quality measures and would fund demonstrations of model programs in pediatric health information technology, pediatric disease management and evidence-based approaches to improve hospital care for children.

research



CHILDREN'S HOSPITALS ARE AT THE FOREFRONT OF
cutting-edge
HEALTH RESEARCH TO IMPROVE
CHILDREN'S HEALTH AND HEALTH CARE.

Research at children's hospitals has led to landmark discoveries, from imaginative surgical techniques and innovative cancer therapies to methods to prevent common childhood diseases.

At Children's Hospital Boston, pediatric surgical resident Jenna Garza, M.D., asked surgeon Mark Puder, M.D., for help when a young patient died of liver disease. She wanted Puder to supervise her research project to find a solution to a long recognized, but misunderstood problem. The lifesaving nutrition some tiny babies receive intravenously called parenteral nutrition (PN) can also cause serious liver damage even liver failure. This ironic medical twist of fate has never been fully explored. What clinicians did understand was that PN provides hope for children suffering from short bowel syndrome, in which a child's own intestines can't breakdown or absorb nutrients. For hundreds of children, PN is a critical lifeline.

Puder knew little about PN when this research began — a lucky circumstance he believes gave him a distinct advantage. "I had no idea what the conventional wisdom was so I could move forward with any notion I had," he says.

The research team included a member who did have some experience with PN: clinical pharmacist Kathleen Gura, M.D. It was Gura's previous work with a soy allergy patient that proved to be invaluable. What Gura and Puder believed and later proved was the opposite of standard practice. Through animal studies, they isolated the ingredient in the PN mix that caused the liver damage, and found another that did not. PN solutions contain a number of nutritional supplements including a plant-based fat made of soybean oil. Their research showed it to be the culprit when delivered intravenously, although it caused no harm when taken orally. Fat, they proved, was the critical component. They decided to replace the standard fat product with another — a purified form of omega 3 fatty-acid found in fish oil called Omegaven. The results were dramatic: Omegaven delivered intravenously through PN did not cause liver damage.

Children’s hospitals and pediatric departments of university medical centers account for 35 percent of all NIH-funded pediatric research.

For the parents of a little boy named Charlie, Puder’s and Gura’s discovery was the answer to their prayers. Charles Rolfe was born with a condition called gastroschisis, an opening in the abdominal wall that caused the intestines to develop outside the body. Surgery at birth saved his bowels, but after the procedure, Charlie was put on PN. By five months, he was facing liver failure and would need a transplant to survive. But there was little chance of finding a donor liver.

That’s when Puder was asked to intervene. Neither he nor Gura knew if Omegaven would help, but decided to present the option to Charlie’s parents. “We just kept hoping it would work because it had to,” Charlie’s mom Alyson Rolfe says.

It was a huge leap of faith for both parents and physicians. Omegaven isn’t yet approved for use in the United States, so the Federal Drug Administration (FDA) had to give its approval for Charlie in a gesture called “compassionate use.” Everyone knew it might be the little boy’s last chance.

After the first 12-hour infusion of Omegaven, Charlie was just fine. The Omegaven did not appear to cause any harm, so treatment continued. Charlie’s yellow skin, a result of his impaired liver, is now a rosy pink. Two years later, the active happy 3 year old continues to receive Omegaven while his bowel grows and adapts to absorb adequate oral nutrition. In the past, babies like Charlie would have died within a year of diagnosis of liver disease without a transplant.

Since that first compassionate use of Omegaven, more than 45 other children have received it with remarkable results. Now Puder and Gura are beginning a two-year clinical trial and hope to enroll 30 more patients and finally prove once and for all the value of a simple fish oil to save children’s lives.

All over the United States — and all over the world — children like Charlie spend their days going to school and playing games instead of worrying about surgeries, radiation therapy and extended hospital stays thanks to cutting-edge research advances developed at children’s hospitals. Research at children’s hospitals has led to landmark discoveries, from imaginative surgical techniques and innovative cancer therapies to methods to prevent common childhood diseases. A physician at the Children’s Hospital of New Jersey in Newark was the first to identify AIDS in children. The polio vaccine was first tested at Children’s Hospital of Pittsburgh. Children’s hospitals have led the way in fetal surgery, treatment of compromised immune systems, bone marrow transplants and treatment of birth defects, such as spina bifida and congenital heart anomalies.



PHOTO BY KELLEY COOPER, ARKANSAS CHILDREN'S HOSPITAL, LITTLE ROCK, AR

Sharkesha Sims and a hospital volunteer rejoice in a task well done during therapy in the hospital pool.

Children's hospitals and pediatric departments of university medical centers account for 35 percent of all NIH-funded pediatric research. At these cutting-edge institutions, the distance from the research bench to patient bedside is so short that the clinical care improvements can move rapidly, unlike in community hospitals that do not have research capacity. New discoveries are converted into more effective treatment, enabling children's hospitals to transform more and more children's lives for the better. And the discoveries made at children's hospitals benefit not only children, but adults as well, because many of the costly and painful health problems that affect adults, such as osteoporosis, diabetes, and obesity, often begin in childhood.

Information Technology Empowers Innovative Care

Children's hospitals are harnessing the power of the information technology revolution to transform data into quality outcomes.

The virtual pediatric intensive care unit performance system, VPS, LLC for short, is a global, online network formed by NACHRI, Children's Hospital Los Angeles and Children's Hospital of Wisconsin to develop standardized clinical data collection and analysis — the electronic brainpower helping children's hospitals improve intensive care.

Today, researchers and clinicians mine data in hopes of discovering ways to measure and improve patient care. VPS, LLC was originally built to support one children's hospital's quality improvement process and now provides data analysis to 65 participating hospitals.

“While information collection in the hospitals' intensive care units begins on paper, it quickly becomes electronic,” explains Rick Moore, NACHRI director for hospital/health informatics. Then the system uses computer informatics to breathe life into numbers, converting complex data into meaningful and useful results.

Children’s hospitals have slashed catheter-associated, blood stream infection rates by close to 70 percent by applying rigorous measures shown to prevent infection.

“When the program first developed, we needed to create a standardized way to collect and input data. That was the first important step to understanding the delivery of care and outcomes in PICUs throughout the country,” Moore explains. “Now, all the participating hospitals are using a common language, so when we analyze information from 40-plus intensive care units in every region of the country, we are comparing apples to apples.”

That’s critical when you have dozens of people sending information through cyberspace to the VPS, LLC. Participating hospitals receive monthly confidential reports from “data harvested every 90 days.” These reports offer valuable insight into day-to-day care and outcomes — information that is helping intensive care practitioners improve overall care.

But real-time data collection and analysis are becoming increasingly crucial. And the VPS, LLC is using that feature of the Internet to help identify some very important quality care results. A project now underway is helping to eliminate blood stream infections associated with catheters, a complication from the insertion of central lines that deliver medications and nutrients directly into the bloodstream. Hospital-acquired infections are a serious problem and can strike as many as 16 percent of children in pediatric units and increase risk of death by up to 20 percent.

Catheter-associated blood stream infections (CA-BSI) have been a major problem in both adult and pediatric intensive care units. While new guidelines have helped to eliminate the dangerous infection in adult patients, few efforts have focused on reducing their occurrence in children.

Teams from 28 children’s hospitals in every region of the country are participating in the first phase of a three-year, NACHRI CA-BSI research project to reduce these infections. In the first six months hospitals in the project have slashed infection rates by close to 70 percent by applying rigorous measures shown to prevent infection.

The study design will no doubt become the model for future projects. As technology and the field of bioinformatics grows, so will the ability of children’s hospitals grow to evaluate and produce more effective health care interventions, not just for the sickest children, but for each child who comes through their doors.

challenges

Adequate, Public, Private Support

A major challenge to pediatric research programs is the need for public and private support to compensate for the limited commercial advantage of investment in research focused on children's needs.

Because they represent less than 30 percent of the population and less than 11 percent of personal health care spending, children use a disproportionately small share of the health care dollar. Therefore, the marketplace does not have strong financial incentives to invest in children's health care. In fact, in the 1990s, there was so little financial incentive for manufacturers to study the effectiveness and safety of new drugs for children's use that only about 20 percent of all pharmaceutical products were labeled with the results of safety and effectiveness tests. In response, in 1997 Congress enacted market incentives to test products under patent for pediatric use, and in 2002, Congress also added a regulatory requirement to expand such testing.

These laws, however, did not affect medical devices for children. There are many reasons why medical device manufacturers should design and/or improve medical devices for children, chief among them unmet needs. Children need smaller devices, appropriately sized, and there are other physiological and biochemical differences that impact design. When FDA clearance/approval requires clinical data, trials to measure long-term outcomes, especially in younger children, are limited.

In response, in March 2007, the Pediatric Medical Device Safety and Improvement Act was introduced in Congress to help break down barriers and encourage the development of life-saving pediatric devices. Championed by the American Academy of Pediatrics and supported by N.A.C.H., the legislation would offer incentives to manufacturers to create medical devices designed specifically for children. It would also give the FDA the authority to require post-market studies of approved pediatric devices to ensure their continued efficacy and safety.

education



CHILDREN'S HOSPITALS
train
PEDIATRICIANS AND SUBSPECIALISTS
WHO CARE FOR ALL CHILDREN.

“See one, do one, teach one” is the mantra of medical education.

During 72 harrowing hours as nature ripped apart New Orleans, Leron Finger, M.D., led four pediatric residents through the toughest test of their lives to deliver very young and very sick patients on their way to safety.

As the floodgates of New Orleans opened in the wake of Hurricane Katrina in August 2005, Finger's steady hand on a telephone arranged the transport of 20 pediatric patients — those dependent on technology and who had not yet been evacuated from Tulane Hospital for Children. He charged his residents with an even more critical task of tending to the care of patients and their families. “I told them to stay with the kids,” Finger says. “They were basically in charge of pediatrics while I took care of evacuation.”

Finger was completing the circle, teaching what he had learned while a resident and fellow at Rainbow Babies and Children's Hospital in Cleveland, OH. “See one, do one, teach one” is the mantra of medical education. And nowhere has this philosophy proven more critical than during three days following the powerful force of Katrina.

Finger is no stranger to disaster — natural or man-made — but the product of the Global Child Health Track for residents at Rainbow Babies, where he completed his residency and a fellowship in pediatric intensive care. The 20-year-old program gives physicians-in-training extraordinary experiences with an indelible mark, as they take care of children in global crises from war torn Kosovo to the tragic consequence of genocide in Rwanda; from the South Asian tsunami to earthquakes in Pakistan.

Finger studied under Anna Mandalakas, M.D., who was trained by program founder Karen Olness, M.D. “When I was a resident,” Mandalakas says, “I went to Rwanda and the experience absolutely shaped my ideas about pediatric medicine.” The skills Mandalakas cultivated changed her perspective about public health in this country, and today infuses her work as the medical director of the Cuyahoga Ohio County Board of Health.

But Mandalakas is also a teacher who is passing on her knowledge to young physicians who will soon staff community pediatric practices, public health facilities and children's hospitals across the country.

Children’s teaching hospitals train 35 percent of all pediatricians and nearly 50 percent of pediatric subspecialists.

When Finger marshaled his four residents during those critical hours in New Orleans, he was fulfilling the long-held tradition of pediatric training. For pediatric resident Sonia Kamboj, M.D., those days at Tulane were life altering.

“I had to write discharge orders for my patients, trying to imagine what their needs would be over several days and anticipate what medication they would require. And I had to contact the parents to tell them that their babies were being evacuated to one of several children’s hospitals including Arkansas Children’s and Texas Children’s. I didn’t know which.”

Kamboj eventually found her way to Texas Children’s Hospital in Houston, where she stayed for 10 months to complete her training with her three colleagues from Tulane. She discovered that some of her patients were in Texas Children’s neonatal intensive care unit, and many of the patients she would treat in the hospital’s emergency room were like her New Orleans refugees.

Ultimately, Kamboj landed in the nation’s capital, where she is completing her residency at Children’s National Medical Center. For Kamboj, the Katrina experience didn’t end in New Orleans. It taught her to think on her feet, anticipate patients’ needs, and think ahead about what might happen and what the appropriate next step for patients’ care should be. Now children in the Washington metro area are benefiting from her training and experience.

If you have children, they’ve probably been cared for by pediatricians or family practice physicians who trained at a children’s hospital at some point in their career. Independent children’s teaching hospitals train 35 percent of all pediatricians and nearly 50 percent of pediatric subspecialists and a majority of the nation’s pediatric surgeons and researchers. Factor in pediatric departments of major teaching hospitals, and children’s hospitals train the large majority of pediatricians and nearly all pediatric subspecialists. The majority of the pediatricians trained at many children’s hospitals stay in the area to practice. So the young doctors learning about compassionate, quality, cutting-edge care at your local children’s hospital today will be the doctors treating your child tomorrow.

Not only do children’s hospitals train physicians, they also train nurses, occupational therapists, social workers, dentists and other health professionals who dedicate their careers to working with children in the family centered, child friendly halls of children’s hospitals.



PHOTO BY ANN-MARGARET HEDGES, ST. JUDE CHILDREN'S RESEARCH HOSPITAL, MEMPHIS, TN

While riding her bike through the halls,
Grace stops to talk with her doctor.

Across the nation, about 2.3 million emergency department visits and 13 million outpatient visits are made to children’s hospitals annually.

Families as Teachers

Family expertise and perspective are like no other, and children’s hospitals across the country have incorporated patients and their families into training programs for pediatric residents, nurses and other health care professionals.

Founded in 1996 by Children’s Hospital & Regional Medical Center in Seattle, WA, Families as Teachers is a well-established, home-based training experience for residents during their developmental pediatric rotation. In this situation, residents are the students and families of children with special needs are the teachers. Families represent a wide variety of diagnoses, ages, lifestyles and health care experiences.

During home visits which typically last 3-4 hours each, residents get a feel for the family’s day-to-day reality — to “walk in their shoes.” Because residents have no clinical responsibilities attached to the visit, it is the perfect setting for open conversations about what works and doesn’t work in partnering with health care professionals. The result is an enhanced sense of mutual respect for one another’s roles and responsibilities, and a better understanding of the special challenges each faces.

“We’ve been doing this program for over 10 years and it’s still going strong. It continues to be a highly valued, relevant component of resident rotation,” says Lyn Kratz, program coordinator at Children’s. “It’s a win-win — families get a chance to talk about their experiences and what has made a difference. Residents get to ask questions that time and role in other settings wouldn’t allow. Together they can dialogue about issues that are important to all.”

challenges

Reliable, Equitable Support

A major challenge to children's hospitals' education programs is securing reliable, equitable support for a service that is not, in most cases, funded by the federal government the way education programs of adult hospitals are.

Teaching great physicians takes time and involves substantial costs. A teaching hospital incurs additional costs to train medical residents while also delivering care to patients. Residents, unlike medical students, don't pay for their training; the teaching hospital pays them for their hard work with an annual salary and benefits. And extra time must be taken by all hospital staff to work with the residents and make sure they're learning to be the best physicians they can be. That means more costs to the hospital for the time of the physicians who supervise and the nurses who work with residents.

Historically, teaching hospitals covered their education costs by charging more for patient care. But in today's price competitive health care marketplace, fewer and fewer payers — with the major exceptions of Medicare — are able to cover the extra costs required of teaching. That's a challenge to all teaching hospitals, especially children's hospitals, which do not receive Medicare reimbursement since they treat children, not the elderly. Therefore, N.A.C.H. and children's hospitals support long-term broad-based financing in which all payers contribute their fair share to financing of graduate medical education (GME).

Until that happens, children's hospitals and N.A.C.H. advocate annually for federal investment in the Children's Hospitals Graduate Medical Education (CHGME) program, now in its sixth year. Investment is authorized up to \$330 million per year, although Congress determines the exact amount when it decides how much funding to allot to discretionary, domestic programs, which include CHGME. Since the program began, 60 children's teaching hospitals have been able to expand their physician training programs instead of having to reduce them.

Notwithstanding the program's success, shortages of pediatric subspecialists still limit the ability of communities to meet children's medical needs and point to the need to maximize federal funding for CHGME, which has hovered just below \$300 million annually for the past few years. According to a 2007 NACHRI survey, children's hospitals report that many pediatric subspecialists in such fields as endocrinology and neurology are in short supply, with waiting lists of over 9 weeks for an appointment. For children waiting for child and adolescent psychiatric appointments, the wait can last more than 10 weeks. Shortages, in turn, delay medical visits and reduce levels of service. Clearly, challenges still exist.

advocacy

CHILDREN'S HOSPITALS
advocate
FOR THE HEALTH AND WELL-BEING OF
ALL CHILDREN IN THEIR COMMUNITIES.

Each year, children's hospitals advocate in their communities for the root causes of illness and injuries they see every day.

Every day, hundreds of pediatric emergency physicians witness the tragic results of the greatest threat to our nation's children — unintentional injuries. And while injury prevention programs have been ongoing since the 1980s, they have been fractured and not nearly as effective as everyone had hoped when they were conceived. Today, the battleground for the fight against the number one killer of children ages 1 to 14 years has logically shifted to children's hospitals.

“As pediatric physicians, our first job is to prevent morbidity and mortality,” says Michael Gittelman, M.D., spokesperson for the national Get on Board with Child Safety! campaign and an emergency department physician at Cincinnati Children's Hospital Medical Center. “Children's hospitals are the centralized location for pediatric health care in most communities where children and parents congregate. They are the logical place to mount an injury prevention program to put prevention tools in the hands of those who can make the most difference — parents.”

That is the mission of Get on Board with Child Safety!, a collaborative effort of NACHRI, Dorel Juvenile Group USA, manufacturers of Safety 1st child safety products, and children's hospitals. In 2006, the campaign undertook research to explore parental knowledge about injury prevention and confirmed what many pediatric physicians have long suspected. Parents and other caregivers are confused about situations that pose the greatest threat to children and about the appropriate tools to prevent them.

“The survey really served a valuable purpose,” says Gittelman. “It demonstrated that we need to keep giving parents access to information and products that can save their children's lives in their home and on the road.”

A Get on Board with Child Safety! partner hospital, Riley Hospital for Children Clarian Health Partners in Indianapolis launched a children's safety store in 2005 and now serves as the model for children's hospitals selected to replicate the store with the help of funding provided through the Get on Board campaign.

Karen Stroup, Ph.D., director of community education and child advocacy at Riley, says that the store's success is the result of tailoring inventory to the needs of the families the hospital treats. "We did our homework," Stroup says, "and collected data to identify the leading causes of injury we treat at Riley — motor vehicle accidents, falls, fires and pedestrian accidents." And because the hospital sees the largest number of autistic children in the state of Indiana, "the store now carries wristbands with a tracking device so caregivers will know if their children have wandered from home. It was a direct response to the tragic reality of several lost kids," Stroup adds.

Education at the point of sale about the proper use of the products and about injury prevention is key. "Children's hospitals are in a unique position to provide this type of instruction," says Gittelman. "And we have the resources to collect information, data to make our programs meaningful and to measure and evaluate results."

Get on Board with Child Safety! joins other nationally recognized injury prevention programs like Safe Kids World Wide, founded by Children's National Medical Center in Washington. By collaborating in innovative programs like these, children's hospitals focus community attention on children's health issues and improving child health through prevention, as well as on cutting-edge care.

Each year, children's hospitals advocate in their communities for remedies for the root causes of the illnesses and injuries they see every day. Through community outreach and partnerships with other community agencies, children's hospitals offer a vast range of health promotion activities, disease and injury prevention, public education programs, and school-based services.

Children's hospitals help to educate local, state and federal lawmakers and other officials about public health issues affecting kids and how small changes in laws and policies can make a big difference in protecting children's health and even saving their lives. As a result, representatives of children's hospitals are frequently invited to deliver expert witness testimony before legislative and regulatory panels.

Children's hospitals also work with other organizations in their communities to increase access to health care services for all children. Children's hospitals reach out through highly effective health care services based in the schools — immunization, injury prevention, school-based clinics and substance abuse prevention. Many children's hospitals run school-based health clinics and provide health education programs in partnership with schools in their communities.

the public-private partnership

When the government of the nation's capital was faced with a health care crisis of enormous proportion, the District of Columbia looked to Children's National Medical Center (CNMC) for help. CNMC was asked to assume responsibility for health care services in the city's public schools and to take over medical services for children in foster care.

The partnership between the city government and the nonprofit private hospital was the most ambitious community collaborative effort ever mounted for CNMC — and the District government. Despite the fact that the venture had not been figured into CNMC's strategic plan, the hospital agreed. "While it wasn't on our radar screen," says Joseph Wright, M.D., M.P.H. executive director, CNMC's Child Health Advocacy Institute, "providing a safety net for children needing health care is an important part of our mission."

Practically overnight, CNMC was charged with taking care of the 2,500 children who at any given time are in the foster care system and more than 55,000 children who are enrolled in the city's public elementary, secondary and high schools. The hospital had some growing pains providing care so quickly to so many children, but soon refined and streamlined these services, which are now administratively housed within the Child Health Advocacy Institute that Wright directs.

Changes in the system came swiftly. Instead of a busy emergency department, health screenings for children entering and leaving the foster care system are now provided in a new community health center staffed by CNMC faculty and located in the heart of the city's 7th District — home to many of the children. "Often children have been taken from their homes in the middle of the night because of suspected abuse. They are very frightened and disoriented," Wright says. "The community health center is a welcoming and non-threatening environment that helps put them at ease at a very stressful time in their lives."

The nurses staffing the District public schools are now CNMC employees who benefit from continuing education and support from a team of pediatric subspecialists who are their colleagues. With more than 175,000 encounters with school children each year, the school nurses have become critical to identifying children who need health services and to connecting them to the right resources. This is just the beginning of a process that has an ambitious goal to create a "medical home" for children in public schools, as well as for children in foster care. Because CNMC now touches the lives of most of the city's children, the potential positive effect on the community's overall health is tremendous. Children who have never had routine preventive health services could ultimately have access to this vital care.

The success of this partnership is vividly demonstrated by its five-year-old immunization effort. "When we inherited the program," Wright says, "there was a serious problem with immunization compliance in DC city schools." Just 40 percent of students had been properly immunized against basic childhood diseases. "There was the potential that a 19th century health risk would be revisited in the 21st century."

A comprehensive campaign was launched. Today compliance has reached 97 percent — a level that has been sustained for two years. "This is what we do as a children's hospital," Wright says. "We look at problems and develop interventions to address them. In every aspect of this partnership with the DC government, we bring this important skill set to the table. We examine an issue, study the data and institute methods to improve outcomes."

More than 90 percent of children's hospitals offer child abuse services.

Children's hospitals take the lead in the critically important issue of patient safety, which poses special issues in pediatrics. Think, for example, about medication. Children usually require dosages based on age and size, and medications and formulations appropriate for pediatrics often are not available commercially. Since children's hospitals specialize in caring for these vulnerable patients, they have unique expertise in enhancing their safety and serving as the standard-bearers for everyone to follow. They display this strength in creating partnerships with patients and parents and through their role as guardians of the unique safety issues in pediatric health. Children's Hospitals and Clinics of Minnesota has developed a comprehensive patient safety campaign that includes hospital-wide "safety action teams" to identify improvements in high-risk processes such as prescribing, dispensing and administering medication. Utilizing frequent rounds by patient safety-dedicated volunteers, teams initiate conversations with parents and families about safety essentials, such as hand hygiene and patient identification. Patient safety reviews are also convened to focus on newly identified issues and have proven crucial to improving the overall safe delivery of care.



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challenges

Sustaining Programs that Benefit the Whole Community

A major challenge to children's hospitals is sustaining programs that focus on public health and benefit the whole community.

Every day it seems we are reminded about risks to the safety of our children — from Shaken Baby Syndrome to the need for protective equipment in using the latest recreational toys like wheeled shoes. Of course there are many important measures to prevent children from needing a hospital's care —immunizations, good nutrition and exercise, regular dental, hearing and eye examinations. Children's hospitals take on the responsibility of being expert in these needs to prevent a child from ever having to enter a children's hospital.

While medical expertise at children's hospitals is employed daily to benefit the greater public good, there is no better illustration than in the area of child abuse. Children's hospitals evaluate and treat the children who are suspected victims of abuse, even though these services come at a high cost that is largely absorbed by children's hospitals.

To better understand this challenge children's hospitals face, in 2005, NACHRI surveyed its member hospitals to measure the services hospitals provide to abused and neglected children and released the findings in the 2006 report *Defining the Children's Hospitals Role in Child Maltreatment*. More than 90 percent of all children's hospitals said they offer child abuse services. However, the traditional health care financing system does not reimburse hospitals for the range of services needed by child victims of abuse. Eighty-eight percent of children's hospitals report a negative bottom line for these services. Five hospitals report that they subsidize their child abuse programs in amounts between \$500,000 and \$800,000 annually. But for children's hospitals across the country, this important service in support of child advocacy and its benefit to the whole community are part of the mission.

The American Board of Pediatrics, with the support of physician experts in child abuse, has moved to establish child abuse pediatrics as a new subspecialty by 2009. This stands to be the greatest evolution in the field since 1962 when C. Henry Kempe, M.D. and his colleagues pioneered the identification and recognition of child abuse with their defining paper "The Battered Child Syndrome." The new subspecialty will advance the field in two significant ways: (1) the certification of individual physicians and (2) the accreditation of high quality fellowship training programs in child abuse pediatrics.

As educators of pediatricians and pediatric subspecialists, it will be the burden of opportunity for children's teaching hospitals to create, staff and fund the new infrastructure to train the future generations of child abuse pediatricians. This certification process will bring greater recognition of individual expertise, elevate the quality of care provided for children who have been abused, and bring an increased focus — and assumedly funding — to advance research in diagnosis, treatment and prevention of child abuse and neglect.



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NACHRI is a membership organization of children's hospitals with more than 210 members in the United States, Canada, Australia, China, Italy and the United Kingdom. NACHRI promotes the health and well-being of children and their families through support of children's hospitals and health systems that are committed to excellence in providing health care to children. It does so through education, research, health promotion and advocacy.

N.A.C.H. is the public policy affiliate of NACHRI. N.A.C.H. is a trade organization of more than 140 children's hospitals and supports children's hospitals in addressing public policy issues that affect their ability to fulfill their missions to serve children and their families. N.A.C.H. fulfills its mission and vision through federal advocacy, collaboration and communication designed to strengthen the ability of children's hospitals and health systems to influence public policy makers, understand federal and state policy issues, advance access and quality of health care for all children, and sustain financially their missions of clinical care, education, research and advocacy.