Preserving the Hearts, Brains and Lungs of Premature Infants

Relatively early in his career, internationally renowned neonatal heart surgeon V. Mohan Reddy, MD, received a call from a pediatric cardiologist working at a nearby community hospital. A mother had just delivered a 640-gram (about 1.4-pound) premature infant, suffering from total anomalous pulmonary venous return with obstruction. Reddy’s clinical research had established that operating on such newborns is both possible and better for the long-term health and viability of these infants. In this case, without an operation, the child, a girl, would die. She arrived by ambulance about an hour later.

“As we rolled her into surgery, a lot of my colleagues thought I was insane,” says Reddy.

Yet he successfully completed the operation on the newborn – who had been born after a gestational period of only 26 weeks – connecting the pulmonary veins to the left atrium and closing the defect between the right and left atria. The child was on a respirator for a month and ultimately required another heart surgery, but says Reddy, “Last time we spoke, she was doing fine.”

Rare Experience and Expertise

Reddy recently returned to UCSF as chief of the Division of Pediatric Cardiothoracic Surgery and co-director of the Pediatric Heart Center at UCSF Benioff Children’s Hospital San Francisco. He is one of the few surgeons in the world capable of completing these complex operations, which require surgeons to handle the extremely delicate tissue of premature infants and work with hearts that are approximately the size of a grape.

Since 1998, for infants under 1,500 grams (about 3.3 pounds), Reddy has performed more than 40 of these procedures and has had a better than 80 percent survival rate.

(CONTINUED ON PAGE 7)
Perspective

One of the biggest challenges – and biggest responsibilities – that individuals or institutions face is how to respond effectively to relentless change. In health care, this means continually adapting to, among other things, new conditions, scientific discoveries, societal pressures, technology advances and regulatory demands. In this issue, we highlight some of the ways we are responding.

To address our growing understanding of the physical and cognitive challenges of premature infants with congenital heart disease, surgeon V. Mohan Reddy, MD, is doing groundbreaking work that gives these children and their families options that prior generations could never have imagined.

We are using advances in telehealth technology to create innovative partnerships that efficiently extend our subspecialty care to patients and health systems that do not have a way to access such care locally.

In response to federal and state regulations and concerns about the dangers of antibiotic use, particularly in children, we have created a Pediatric Antimicrobial Stewardship Program.

Our Pediatric Neuromuscular Clinic – the only one of its kind in San Francisco – offers children and their families comprehensive care as well as access to the latest clinical trials and emerging treatments.

Finally, we are increasing the number of providers in our Child and Adolescent Gender Center Clinic – which now sees patients in both San Francisco and Oakland – in order to respond to the unique health care needs of gender-expansive youth.

Yet in a deeply interconnected health care universe, we cannot respond effectively to change without our continued collaborations with all of you, for which we – and our shared patients – are enormously grateful.

Donna Ferriero, MD, MS
Physician in Chief
UCSF Benioff Children’s Hospital
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Telehealth Expands Access to Subspecialty Care

Since opening a new hospital at Mission Bay in February 2015, UCSF Benioff Children’s Hospitals have been successfully managing their own dramatic growth, in part by helping community providers bring their patients the highest-quality subspecialty care close to home.

In doing so, they are demonstrating the power of telehealth. Diverse telehealth implementations are playing an important role in:

- An expanding partnership with Community Regional Medical Center (CRMC) in Fresno.
- A long-standing partnership with Washington Hospital in Fremont.
- Close collaborations with affiliated clinics and individual patients throughout California and beyond.

Inpatient and Outpatient Care in Fresno and Fremont

For inpatients at CRMC, UCSF experts have secure access to medical records, labs and imaging while consulting by phone or videoconference with CRMC physicians about their patients.

“At this point, pediatric specialty consultations include critical care, hospital medicine, neonatology, cardiology, emergency medicine and dermatology,” says Linda Branagan, PhD, director of Telehealth Programs for UCSF Medical Center.

UCSF clinicians will also support CRMC outpatient visits as needed. “For example, if a CRMC clinic doesn’t have a neurologist on-site, we can arrange an outpatient visit via videoconference, so
a clinically appropriate patient doesn’t have to drive several hours to see us,” says UCSF pediatric neurologist Kendall Nash, MD.

For Washington Hospital, the telehealth focus to date has been on pediatric cardiology collaboration. To supplement UCSF’s weekly, full-service pediatric cardiology clinic at Washington, UCSF also provides 24/7 telehealth support for Washington’s pediatric echocardiography program.

“If a patient needs an EKG [electrocardiogram] or echocardiogram, hospital technicians at Washington do the study and call a UCSF cardiologist, who is available 24/7 to read the study via telemedicine, complete a report and transmit relevant clinical information to the primary physician,” says UCSF pediatric cardiologist Phillip Moore, MD.

### Working with Outpatients in Local and Far-Flung Locales

In addition to the affiliations with these two medical centers, UCSF is expanding its use of telehealth in many other ways. Among them:

- UCSF pediatric neurologists conduct follow-up telemedicine visits with clinically appropriate pediatric headache, epilepsy and neurovascular patients around California. “Our subspecialists use a WebEx interface with the patient at home, so they don’t need to go to a busy clinic or drive long distances, which can be especially difficult for these patients,” says Nash.

- Nash also sees pediatric neurology patients via videoconference in Butte, Montana, where Nash is licensed and credentialed. “Since there are limited pediatric neurologists in the state, and none near Butte, I’m able to offer a needed resource for local pediatricians and children with certain neurologic conditions appropriate for an initial telemedicine evaluation. If there is a need to travel, at least we’ve made that initial connection,” she says.

- UCSF has also instituted video-enabled discharge planning for complex patients, which involves patients, families, their home physicians and UCSF specialists. “It’s interactive, collaborative and more useful than a discharge note,” says Branagan.

“We believe telehealth will become an increasingly important way for many hospitals and communities to improve access to needed subspecialty expertise,” says Nash.

For more information, contact Linda Branagan at 415-353-3678.
Protecting Children Through Antimicrobial Stewardship

The Pediatric Antimicrobial Stewardship Program at UCSF Benioff Children’s Hospital San Francisco recognizes that all health systems must constantly refine their efforts to reduce the adverse consequences of antibiotic use.

Led by pediatric infectious disease experts Rachel Wattier, MD, MHS, and Jonathan Faldasz, PharmD, the program brings together Pharmaceutical Services, Microbiology, Hospital Epidemiology and Infection Control, Information Technology and clinical services.

“Antibiotic therapy is often life-saving for children with serious infections, but the kinds of infections children get are different than adults,” says Wattier. “Our goal is to promote the optimal antibiotic drug, dose, duration and route to avoid resistance, adverse drug reactions and secondary infections.”

Daily Antibiotic Reviews and Recommendations

The program is multifaceted, but its central component involves daily review of antibiotic prescriptions and, where appropriate, working with prescribing providers to refine prescriptions.

“It’s a collaborative discussion,” says Wattier. “We’re looking to see if there’s an opportunity to improve the regimen or de-escalate, but we understand that frontline providers know things about their specific patients that we may not know.”

Nevertheless, a complicated antibiotic formulary and emerging knowledge about age-specific guidelines and certain antibiotics being contraindicated in younger children means that frontline providers often welcome the help.

“We have about 70 different agents in common use, and it’s a lot to expect that every provider be very familiar with all of them,” says Wattier. “We bring new evidence and reassure providers that an alternative choice of therapy can be equally good.”

The success of this approach is evident even in its early days. Frontline providers accept the program’s recommendations 85 percent of the time. Since July 2015, there’s also been a 14 percent reduction in antibiotics most closely associated with Clostridium difficile infection, which has become all too common in hospitals throughout the region and has been a specific target for the stewardship team.

Developing Clinical Guidelines and Expanding to Outpatient Use

In addition to its daily review and recommendations, the program team is working on a number of other goals, which include:

• Development of evidence-based clinical guidelines for common conditions in UCSF’s specific patient population. “Microbiology can change from location to location and over time,” says Wattier, who notes that the team is in contact with other local hospitals and tracks the sensitivity of isolated bacterial strains to different antibiotics in an effort to maintain antibiotic susceptibility and avoid resistance.

• Creation of service-specific guidelines that support identified goals. “For example, we are supporting the Emergency Department’s efforts to reduce the time to administering antibiotics for children with fever during cancer therapy,” says Wattier.

• Moving this initiative to the outpatient space. “This is where the majority of antibiotics are prescribed, and we will work closely with outpatient providers to see what they need from our program,” says Wattier. ★

For more information, visit idmp.ucsf.edu.

Rachel Wattier, MD, MHS

Jonathan Faldasz, PharmD

Colored transmission electron micrograph of Clostridium difficile bacteria
Team-Based Care the Best Option for Children with Neuromuscular Disorders

“Children with peripheral nerve and muscle disorders – and their families – need specialized, team-based treatment,” says Jonathan Strober, MD, director of the Pediatric Neuromuscular Clinic at UCSF Benioff Children’s Hospitals. Sponsored by the Muscular Dystrophy Association and the only one of its kind in San Francisco specifically for children, the weekly clinic specializes in the diagnosis, treatment and research of disorders of the muscles, nerves and the connections between them.

At UCSF, the team includes:

• A pediatric neuromuscular specialist
• An orthopedic surgeon
• A pulmonologist
• A cardiologist
• A gastroenterologist and nutritionist
• A social worker
• A nurse case manager
• Respiratory, physical and occupational therapists

It Begins with Muscle Weakness

“Typically, primary care providers see some muscle weakness and refer patients to our clinic, where they can get all their needs met in one visit – which is especially helpful for families that need to travel,” says Strober.

When patients arrive, their workup typically includes a thorough history and physical, blood work and additional testing where appropriate, which might include:

• Electromyography and nerve conduction studies
• Muscle biopsies
• Genetic testing

Once the team has made a diagnosis, it develops a treatment and supportive care plan that, depending on the diagnosis, could include:

• Physical and occupational therapy.
• Equipment to aid in breathing or movement.
• Medication. “Steroids can slow progression in Duchenne muscular dystrophy, but we don’t prescribe them automatically, because we work with the families to weigh steroid use against potential side effects,” says Strober.

• Psychosocial support – including coordination with communities and schools – from a social worker and nurse case manager, who work with both patients and families.

In Search of the Latest Treatments and Innovations

Because of the shortened life expectancy associated with many of these conditions, Strober and his team are especially attuned to the urgency of finding new treatments. The clinic is involved in some of the latest clinical trials and other research to find new therapies.

“We’re also seeing a lot more autonomic instability, called postural tachycardia syndrome, or POTS,” says Strober about an autonomic dysfunction that tends to affect young adolescent females. “That’s why, as an offshoot of our neuromuscular clinic, we’ve opened a new autonomic instability clinic that brings together neurology, cardiology, GI and psychiatry to coordinate care for these young women.”

For more information, contact Dr. Strober at 415-353-7596.
Comprehensive Care for Gender-Expansive Children, Teens and Young Adults

As awareness of the unique health care needs of gender-expansive children, adolescents and young adults grows, health systems are seeking ways to respond.

The Child and Adolescent Gender Center (CAGC) – a collaboration between UCSF and community organizations – is one example. In addition to advocacy and legal support, the center offers comprehensive medical and psychological care through the CAGC Clinic at UCSF Benioff Children’s Hospitals.

A Deep Understanding of Gender-Expansive Youth and Adolescents

Vance, who recently completed his fellowship in adolescent and young adult medicine and joined the UCSF Division of Adolescent and Young Adult Medicine, notes that many experts now consider transgender a normal variation in gender identity.

He also says that many gender-expansive youth and adolescents feel a strong conflict between their inner sense of who they are and their physical sex characteristics, which helps explain the array of services the CAGC Clinic offers:

- **Medical management**, which includes:
  - Carefully monitored and fully reversible puberty-blocking medication, which delays what can be confusing physical changes while young people come to grips with their feelings.
  - Cross-gender sex hormones when the clinic’s patients are old enough and emotionally prepared to make a decision about their gender identity.
  - Expertise in primary care and adolescent medicine to complement the pediatric endocrinology services and expertise highlighted above.

- **Psychosocial support.** “It is not uncommon for our patients to have to simultaneously cope with the confusing changes of adolescence, difficult interactions at school and sometimes complex psychiatric issues,” says Vance, who assesses patients for everything from depression, substance abuse and eating disorders through emerging gender identity and sexuality. “It’s important to have a provider with experience managing these concerns, especially because adolescent development is a moving target.”

Providers at the clinic also coordinate care with outside primary care doctors, mental health providers and schools. “We always send a letter about what our evaluation shows, educate fellow providers where necessary and work closely with outside mental health professionals to arrange necessary mental health services,” says Vance. ★

For more information, call the Child and Adolescent Gender Center Clinic at 415-353-7337.

Services Expand in East and South Bay

“In response to growing needs, our clinic has expanded its services,” says its medical director, Stephen Rosenthal, MD. He points to the addition of adolescent and young adult specialist Stanley Vance, MD, in San Francisco and pediatric endocrinologist Ivy Aslan, MD, in Oakland, who join a team that in San Francisco already includes a nurse practitioner, psychologist, pediatric endocrinologist, education/advocacy expert, social worker and attorney.

Moreover, last year’s affiliation with UCSF Benioff Children’s Hospital Oakland and full integration of the UCSF Division of Pediatric Endocrinology have led to the opening of a monthly Oakland clinic that will bring together the San Francisco team with Oakland-based clinicians, including Aslan, psychiatrist Herbert Schreier, MD, and another nurse practitioner. Beginning July 1, 2016, the San Francisco team will also expand existing services at its satellite clinic in San Mateo.
“We’ve shown that if these infants are in heart failure, on a ventilator or dependent on drugs to maintain circulation, it’s better to operate as soon as possible after birth because if we wait, there are more complications. Lungs and other systems become damaged,” he says.

A Team Approach Is Crucial
Addressing the challenge of working with premature infants with congenital heart disease demands a lot more than a skilled surgeon, says Reddy. It’s equally important to have an expert team with experience caring for these newborns from delivery through preoperative and postoperative care and beyond. The team at UCSF, for example, includes:

- Pediatric anesthesiologists
- Critical care physicians
- Pediatric cardiologists
- Expert nurses throughout the perioperative process
- Respiratory therapists

One of the reasons expert care throughout the process is so crucial is because infants undergoing surgical intervention for congenital heart disease are at risk for neurodevelopmental abnormalities, especially those infants who are delivered early.

Thus, one aspect of Reddy’s clinical research program focuses on ways to better protect the brain during the surgeries he performs – and postoperative attention to brain development is a strong focus of UCSF’s pioneering Neuro-Intensive Care Nursery.

For more information, contact Dr. Reddy at 415-476-3501.
UCSF Benioff Children’s Hospital News

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UCSF Benioff Children’s Hospitals, with campuses in San Francisco and Oakland, is among the nation’s premier children’s hospitals in all 10 pediatric specialties, according to the 2016-2017 Best Children’s Hospital rankings conducted by U.S. News & World Report.

The 10 recognized specialties for UCSF Benioff Children’s Hospitals are:

- Cancer (Best in Bay Area)
- Cardiology & Heart Surgery
- Diabetes & Endocrinology (Best in Bay Area)
- Gastroenterology & GI Surgery (Best in Bay Area)
- Neonatology
- Nephrology
- Neurology & Neurosurgery (Best in Bay Area)
- Orthopedics
- Pulmonology
- Urology (Best in Bay Area)