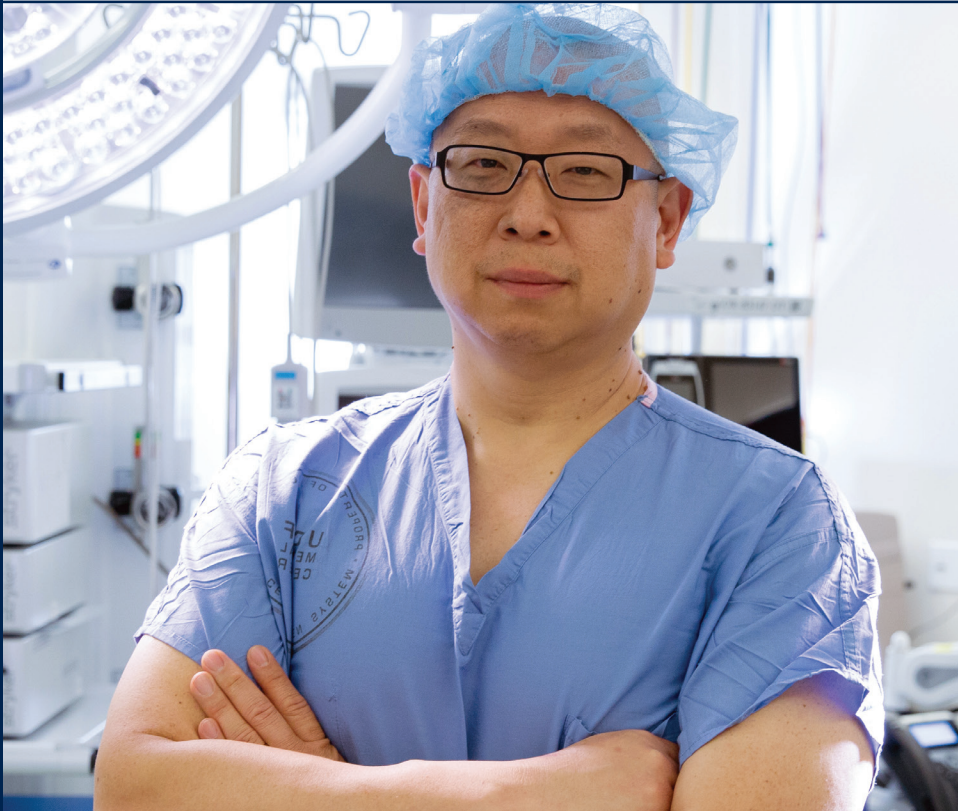




UCSF Benioff Children's Hospitals



Fetal Treatment Center





UCSF was first in the world to perform open fetal surgery.
Pictured: Michael Harrison, MD (left)



Fetal Treatment Center

The Fetal Treatment Center is proud of its 40-year legacy in fetal evaluation and treatment. Since its founding in 1981, the center has expanded its vision to incorporate dynamic new methods for diagnosis and treatment based on the emerging fields of maternal-fetal genetics and precision medicine.

Coordinated care in a children's hospital: Our Fetal Treatment Center is located in a children's hospital, which facilitates our ability to offer comprehensive, family-centered care from diagnosis and prenatal management through postnatal care and long-term follow-up.

Advanced diagnostics and intervention: Our multidisciplinary approach incorporates the knowledge and expertise of numerous specialists to ensure patients have access to the most advanced diagnostics and interventions available.

Experience that helps us provide the best possible care: Our large patient volume and the diversity of cases we see give us a depth and breadth of experience that help us provide the best care possible.

Nationally ranked pediatric specialties: UCSF Benioff Children's Hospitals are ranked among the best in the nation and among the top 10 in the nation for neonatology according to U.S. News & World Report's 2023-24 Best Children's Hospitals rankings. Babies delivered here have immediate access to more than 150 pediatric experts in 50 specialties.

UCSF is a world leader in diagnosing and treating birth defects before delivery.



Michael Harrison, MD



Hanmin Lee, MD

The birthplace of fetal surgery

Overview

The Fetal Treatment Center at UCSF Benioff Children's Hospitals is a world leader in diagnosing and treating birth defects before delivery. Since the first-ever fetal surgery took place at UCSF in 1981, the center has pioneered significant breakthroughs in fetal genetics, precision medicine and related research.

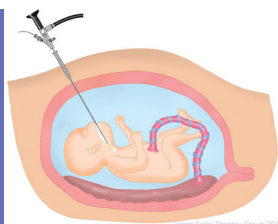
- The center has campuses in Oakland and San Francisco.
- The San Francisco location is in a children's hospital, which enables both mother and child to be cared for in the same location post-delivery.
- Many of the fetal conditions we treat are rare, but our team has the knowledge and experience to provide unparalleled service to all families.

The University of California (UC) Fetal Consortium brings together clinicians, researchers and educators from the five UC medical centers (at Davis, Irvine, Los Angeles, San Diego and San Francisco) to improve maternal, fetal and neonatal care.

A history of firsts

- Performed the first open fetal surgery in 1981
- Designed and were the first to use a uterine stapling device for fetal surgery
- Enrolled the first patient in an FDA-approved fetal stem cell transplantation clinical trial for alpha thalassemia major
- Developed anesthesia techniques for pregnant women and fetuses undergoing open fetal surgery
- Performed the first successful open fetal surgery for fetuses with congenital diaphragmatic hernia (CDH), urinary tract obstruction and life-threatening tumors
- Was the first to successfully describe and treat congenital high airway obstruction syndrome
- Was the first to use radio-frequency ablation (RFA) for twin reversed arterial perfusion (TRAP) sequence
- Was among the first to use tracheal balloon occlusion for treating CDH
- Pioneered the use of steroids for the treatment of congenital pulmonary airway malformations (CPAMs)
- Performed the first successful resuscitation of a fetus during open surgery

For a more complete list of the conditions we treat, visit ucsfbenioffchildrens.org/fetaltreatment.



UCSF was among the first to perform fetoscopic tracheal occlusion to treat severe congenital diaphragmatic hernia.



Jameson Saved His Mother's Life

The road to Jameson Alcorn's birth was a bumpy one, presenting one challenge after another. But in the end, a surprising hero emerged.

During a routine ultrasound at 13 weeks into her pregnancy, Shannon Alcorn's doctor discovered that the baby's chest was filled with fluid, which was pushing his heart to the side and collapsing his lungs.

Shannon and her husband, Mitch, sought help at the UCSF Fetal Treatment Center, where their baby was diagnosed with pleural effusion that was compromising his heart and lungs. Without surgery, the team did not believe the baby would make it to birth.

After some difficult conversations with the fetal treatment team, Shannon and Mitch decided to go ahead with the surgery that would

place a shunt into the baby's chest to drain the fluid from it.

Shannon recalls feeling that "this was our best option if we had any hope of bringing this baby into the world."

It took two attempts and two surgeries to successfully place the shunt in Jameson's chest. His fetal age was 19 weeks at that point.

But in a follow-up ultrasound after the first surgery, the Alcorns received more bad news: A mass located in Shannon's lower abdomen was identified as stage 1 kidney cancer.

"At that point, our whole world felt like it was crumbling," says Mitch. "Why me? Why her? Why us?"

"We're in the major leagues here, so we see curveballs all the time," noted Hanmin Lee, MD, director of the Fetal Treatment Center. "But

suddenly we were in a situation where Shannon needed the entirety of adult medicine expertise, and Jameson needed the entirety of neonatal medical expertise. That combination doesn't exist outside of UCSF."

Because kidney cancer usually progresses with no symptoms, by the time it's diagnosed in most people, it's too late to treat or cure. But Shannon's ultrasounds revealed the cancer at such an early stage that it was treatable. She had surgery to remove the tumor three months after Jameson's birth.

Two years later, Jameson is a healthy preschooler and Shannon's cancer is in remission. "Without Jameson, we would never have found that mass," says Shannon. "Jameson saved my life."

Continuum of care

Expertise across the continuum of maternal and fetal care

Maternal-fetal medicine and clinical genetics specialists provide care to both mother and fetus from gestation through delivery – and beyond. Working together, this team pursues both traditional and novel diagnostic approaches and interventional therapies to ensure that patient outcomes are the best they can be.

- The Fetal Treatment Center consults with more than 500 families every year and performs more than 50 fetal procedures annually.
- Since its founding, the center has cared for more than 10,000 expectant parents from all 50 states and dozens of countries.

Experts from numerous subspecialties at UCSF Benioff Children's Hospitals have input on the care plan for each patient; these pediatric subspecialties may include the following:

- Anesthesiology
- Cardiology
- Cardiothoracic surgery
- Craniofacial surgery
- Endocrinology
- Genetics and genetic counseling
- Neonatology
- Nephrology
- Neurology
- Neuroradiology
- Neurosurgery
- Nursing
- Orthopaedic surgery
- Otolaryngology
- Palliative care
- Perinatology
- Radiology
- Social work
- Surgery

CONDITIONS MANAGED

- Agenesis of the corpus callosum
- Alpha thalassemia major
- Amniotic band syndrome
- Bowel obstruction
- Comprehensive early anatomic evaluation
- Congenital diaphragmatic hernia (CDH)
- Congenital heart disease
- Congenital high airway obstruction syndrome (CHAOS)
- Congenital pulmonary airway malformation (CPAM)
- Fetal anemia and thrombocytopenia
- Gastroschisis
- Hydrops fetalis
- Monochorionic twins
- Multiple anomalies
- Omphalocele
- Pulmonary sequestration
- Sacrococcygeal teratoma (SCT)
- Spina bifida
- Stem cell treatments
- Twin-to-twin transfusion syndrome (TTTS)
- Twin pregnancy complication
- Twin reversed arterial perfusion (TRAP) sequence
- Unequal placental sharing
- Urinary tract obstruction
- Ventriculomegaly
- And many others



From left: Janice Scudmore, MSN, FNP-BC; Rachel Perry, RN; and Hanmin Lee, MD



Teresa Sparks, MD

We are dedicated to working toward a world where all children are born healthy.



Tippi MacKenzie, MD



Mary Norton, MD

Emerging therapies in maternal-fetal precision medicine

Our history at UCSF as the birthplace of fetal surgery drives our vision for the future: to use targeted prenatal diagnostic approaches, including state-of-the-art genomic techniques, to understand, manage and treat fetal diseases before delivery. The UCSF Center for Maternal-Fetal Precision Medicine is on the leading edge of this new frontier.

Maternal-fetal precision medicine is an expanding field with opportunities to implement the newest techniques for prenatal diagnosis and to develop novel in utero treatments for pregnancies with fetal diseases and congenital disorders. Next-generation sequencing approaches such as genome sequencing allow diagnosis of single-gene disorders that are not identified by standard genetic testing. It is essential to make these genetic diagnoses as early as possible to optimally manage the pregnancy, plan for neonatal needs and, ultimately, develop targeted in utero treatments for each specific diagnosis.

We focus on several areas of prenatal diagnosis and emerging in utero therapies:

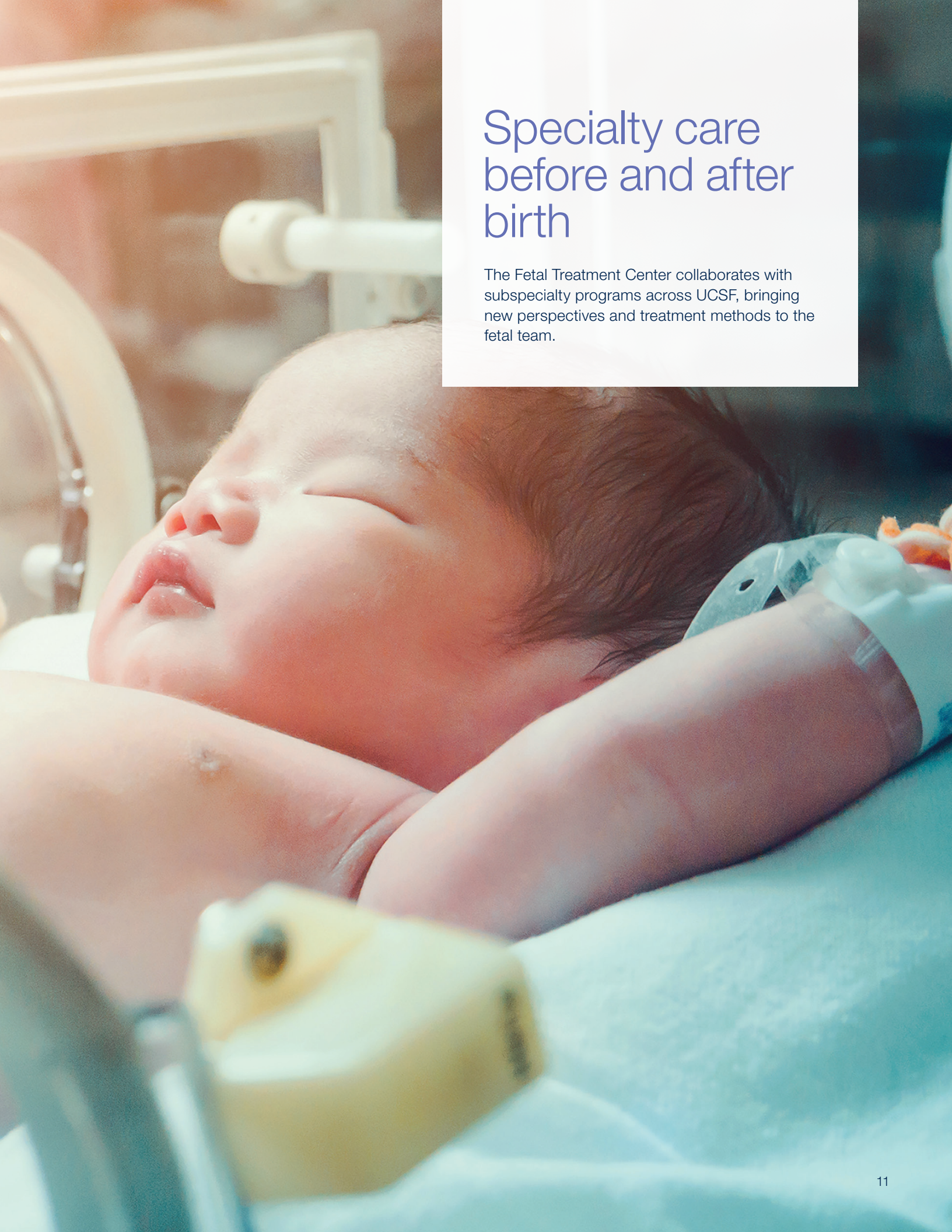
- **Genome sequencing.** Next-generation sequencing has demonstrated great benefits for the diagnosis and management of congenital anomalies, suspected genetic disorders and other fetal and neonatal complications.
- **Hydrops fetalis.** A wide variety of genetic diseases can underlie nonimmune hydrops fetalis. Next-generation sequencing has demonstrated a particularly high yield for establishing a diagnosis in these cases. Many of these underlying genetic diseases may be amenable to novel in utero therapies.
- **In utero enzyme replacement.** Our research suggests that starting enzyme replacement therapy before birth in fetuses with lysosomal storage disorders has multiple advantages and may improve outcomes after birth.
- **Stem cell transplantation for alpha thalassemia major (ATM).** We are conducting the world's first clinical trial of in utero stem cell transplantation to treat fetuses with this severe blood disorder and improve outcomes after birth.



Next-generation sequencing (NGS) is one area of precision medicine that holds promise for the diagnosis of congenital anomalies, genetic disorders and other complications of pregnancy. This technology allows UCSF clinicians and researchers to make precise genetic diagnoses that can guide treatment of fetal conditions. The UCSF Center for Maternal-Fetal Precision Medicine is leading new advances in gene-based interventions for fetal care.



UCSF has experience performing and interpreting fetal magnetic resonance imaging (MRI) to better define anomalies, especially fetal brain abnormalities, for more accurate detection and diagnosis.



Specialty care before and after birth

The Fetal Treatment Center collaborates with subspecialty programs across UCSF, bringing new perspectives and treatment methods to the fetal team.

Specialty care before and after birth

Perinatology and Medical Genetics

Our perinatologists provide clinical and consultation services to patients and physicians in all aspects of maternal care and fetal disorders. They routinely manage fetal conditions such as multiple gestations, alloimmunization, growth disorders and all types of structural anomalies.

All patients have the opportunity to meet with a perinatologist to discuss the findings from various imaging modalities and review potential etiologies.

Genetic testing options, management strategies and possible therapeutic interventions are discussed. Our weekly multidisciplinary meeting allows a thorough discussion that incorporates input from various subspecialties.

When appropriate, our perinatologists assist in the coordination of delivery at UCSF as well as provide care to prenatal patients who require inpatient admission.



Teresa Sparks, MD

Advanced Fetal Diagnostic Testing

Our patients have access to:

- The full range of the most advanced fetal diagnostic testing available.
- An experienced team specially trained to identify and diagnose rare fetal anomalies. Many of these advanced diagnostic tools were pioneered at UCSF.
- High-level fetal ultrasound that can uncover additional findings to further clarify the fetal diagnosis and prognosis, and can be critical in guiding treatment options.
- Expertise in performing and interpreting fetal MRI to better define anomalies, especially fetal brain abnormalities, for more accurate detection and diagnosis.
- Urgent and elective fetal echocardiograms that can screen for structural, functional and rhythm-related fetal heart disease, from 12-14 weeks to term.



Vickie Feldstein, MD

SPECIALTY CARE BEFORE AND AFTER BIRTH (continued)

Fetal Cardiovascular Program

The Fetal Treatment Center works closely with the UCSF Fetal Cardiovascular Program to assess and manage fetal and pediatric heart disease.

- Sophisticated imaging technology helps to determine diagnoses as early as 12-14 weeks' gestation.
- Performing more than 3,000 fetal echocardiograms annually, we are one of the highest-volume fetal cardiovascular programs on the West Coast.
- We are the only center in California performing fetal interventions for evolving cardiac diseases such as hypoplastic left heart syndrome (HLHS).

- Fetal cardiologists are on call around the clock.
- Newborns are treated in the Pediatric Heart Center, an integrated program providing care from infancy through adolescence.

For postnatal surgery or catheterization, experts from the UCSF Pediatric Heart Center perform the procedures, while coordinating with local pediatricians and neonatal care providers.



Fetal Neurology Clinic

The UCSF Fetal Neurology Clinic is nested within the Fetal Treatment Center. Child neurologists with particular interest in neurological disorders of the fetus work closely with specialists in maternal-fetal medicine, pediatric neuroradiology and genetics to help diagnose neurologic conditions, as well as counsel patients and families about treatment options and potential outcomes.

The Fetal Neurology Clinic leverages close collaboration with the UCSF Neuro-Intensive Care Nursery and Pediatric Brain Center to ensure seamless transition from the fetal period to the neonatal period, and beyond, as needed.



Dawn Gano, MD



Elliott Sherr, MD, PhD



Bridget Ostrem, MD, PhD



Marisa Gardner, MD

SPECIALTY CARE BEFORE AND AFTER BIRTH (continued)

Birth Center

The Birth Center in UCSF Betty Irene Moore Women's Hospital provides patients with access to the highest level of neonatal care while preserving a comfortable, homelike atmosphere.

Each of our nine labor and delivery rooms is designed to promote a sense of calm for the intimate, anxious and joyful birthing experience. At the same time, it is a highly functional environment in which physicians and caregivers can safely and efficiently provide the highest-quality care.

The Birth Center is also where patients are admitted for procedures or monitoring during their pregnancies.

Our Birth Center rooms feature the following:

- Private rooms with a private bathroom
- Dedicated relaxation area for support person
- Foldout sofa for family member or support person's overnight stay (linens provided by UCSF)
- Spa-like bathtub designed with a seat to facilitate getting in and out
- Infant care area located next to the birthing bed

Antepartum and labor and delivery teams work closely with neonatologists to support coordination of care during complex deliveries.

- Labor and delivery teams include OB-GYNs, maternal-fetal medicine specialists, midwives and nurse practitioners, all skilled in both low- and high-risk deliveries.
- Our operating suite includes a neonatal resuscitation area that supports emergent clinical procedures.
- Each of our children's hospitals in San Francisco and Oakland has a Level IV Regional Neonatal Intensive Care Unit (RNICU); see page 17.



Neonatal Intensive Care Nursery

In the intensive care nursery, critically ill infants and all who need advanced care are treated by a neonatologist, in consultation with maternal-fetal medicine specialists, obstetricians and other specialists as needed. Expert multidisciplinary neonatal care is provided, with a team of experienced nurse practitioners, nurses, respiratory therapists, pharmacists, dietitians, feeding specialists and physical therapists.

- Our intensive care nurseries in both San Francisco and Oakland are designated Level IV Regional Neonatal Intensive Care Units (RNICUs) by the state of California. This means that the hospital and NICU can provide the highest level of care that a newborn might need, beyond what can be provided in a general pediatric unit or community hospital.
- In San Francisco, obstetrical services are adjacent to the intensive care nursery, so mother and baby are cared for under the same roof. Newborns get their care from a dedicated NICU team at the time of birth, with direct admission to the NICU after initial stabilization, if needed. These inpatient services are provided at the same location as the Fetal Treatment Center and surgical and other subspecialty follow-up clinics.

- The NICUs at UCSF Benioff Children's Hospitals in Oakland and San Francisco are staffed by board-certified pediatric and surgical subspecialists who provide comprehensive medical and surgical care for infants with a wide range of neonatal conditions, including the following:
 - » Congenital heart disease
 - » Lung and airway abnormalities
 - » Neurological conditions
 - » Disorders and anomalies of the gastrointestinal tract
 - » Kidney and urological abnormalities
 - » Complex ear, nose or throat conditions
 - » Other major and minor birth defects



Arthur D'Harlingue, MD



Debra Hummel, NP

SPECIALTY CARE BEFORE AND AFTER BIRTH (continued)

Neuro-Intensive Care Nursery

The Neuro-Intensive Care Nursery (NICN) at UCSF Benioff Children's Hospital San Francisco is a specialized neurocritical care unit serving infants in the San Francisco Bay Area and Northern California who are born with, or are at risk for, neurologic conditions. In addition to providing the highest level of care, the mission of the NICN is to continuously improve the lives of children and families at risk for long-term disabilities. Investigators at UCSF's Neuro-Intensive Care Nursery have discovered many of the therapies and treatments now considered standard care for critically ill infants. Newborns with a neurologic condition identified in the fetal period are evaluated after birth by a neurologist from the NICN. These consultations can be obtained

whether a baby is rooming-in with the mother or has been admitted to the Neuro-Intensive Care Nursery. The NICN will coordinate and interpret any neuromonitoring and neuroimaging that may be needed, including continuous video electroencephalography (EEG) and MRI. The NICN will also expedite other neurologic investigations that may be required, such as electromyography (EMG) and nerve conduction studies, as well as consultations with other specialists, such as pediatric geneticists and pediatric ophthalmologists. Outpatient follow-up with the Pediatric Brain Center and referrals for early intervention services are coordinated by the NICN.



Pediatric Brain Center

The Pediatric Brain Center brings together world-class experts from every specialty related to children's neurologic health, from migraines to brain tumors, from muscular dystrophy to stroke. Experts from this center provide insights into the treatment of birth defects of the brain and spine, including stroke and cerebrovascular disease, brain injuries, brain tumors, birth defects, epilepsy, hydrocephalus, movement disorders, development and behavior issues, neuromuscular disorders, headache, spina bifida, and sleep disorders.



Nalin Gupta, MD, PhD

SPECIALTY CARE BEFORE AND AFTER BIRTH (continued)

Pulmonary Hypertension Program

The Pulmonary Hypertension Program at UCSF Benioff Children's Hospital San Francisco provides diagnosis and the latest treatment options for neonates, infants and children with pulmonary hypertension (PH).

- We are one of only two medical centers on the West Coast accredited as a Pulmonary Hypertension Center of Comprehensive Care by the Pulmonary Hypertension Association.
- Online second opinions are available for patients throughout the United States and around the world.
- We are pioneers in the “treat and repair” strategy for patients with pulmonary vascular disease and complex congenital heart disease.

Some of the conditions we treat:

- Idiopathic (primary) pulmonary hypertension
- Pulmonary hypertension of the newborn
 - » Pediatric pulmonary hypertension related to:
 - Congenital heart disease
 - Congenital diaphragmatic hernia
 - Chronic lung disease and bronchopulmonary dysplasia (BPD)
 - Genetic predisposition



Roberta Keller, MD

Long-term Infant-to-adult Follow-up and Evaluation (LIFE) Program

The Long-term Infant-to-adult Follow-up and Evaluation (LIFE) Program provides expert medical care to children with complex birth defects. Our goal is to foster the development of healthy, well-adjusted and independent adults.

- Our team of specialists includes gastroenterologists, neonatologists, pulmonologists, dietitians, social workers, occupational therapists and pediatric development specialists, led by the pediatric surgery service.
 - The clinic serves children who received either prenatal or postnatal treatment for congenital anomalies. Patients range in age from infants to teenagers.
 - These patients may be at risk for medical conditions such as reactive airway disease, feeding difficulties or developmental delay.
- By controlling or preventing these problems, we help our patients live more comfortably, stay healthier and enjoy a better quality of life.
 - Some of the conditions we treat include:
 - » Anorectal malformations (imperforate anus, cloacal malformations)
 - » Anterior abdominal wall defects (omphalocele, gastroschisis)
 - » Biliary anomalies (choledochal cyst and biliary atresia)
 - » Congenital diaphragmatic hernia
 - » Congenital lung masses (congenital pulmonary airway malformation, bronchopulmonary sequestration)
 - » Esophageal atresia, with or without tracheo-esophageal fistula
 - » Hirschsprung's disease
 - » Sacrococcygeal teratoma



Lan Vu, MD (right)



Elianna Makes History

Five blood transfusions and a bone marrow transplant may sound daunting. But consider this: The patient hadn't even been born yet.

That was the experimental treatment doctors offered to parents Nichelle Obar and Chris Constantino when they found out that the baby Nichelle was carrying had a potentially lethal genetic blood disorder: alpha thalassemia major (ATM).

Currently, children with ATM face a lifetime of blood transfusions. For some newborns, a stem cell transplant with a matched donor can be a cure, but the procedure comes with a risk of rejection and serious side effects from immunosuppressive drugs.

A transplant directly to the fetus in the womb, before birth, takes advantage of the fetus's own immune

system. The mother serves as an ideal donor as the fetus is naturally exposed to cells from the mother during pregnancy, and does not recognize them as foreign. The fetus doesn't reject its mother's stem cells and avoids toxic immunosuppressive drugs. The hope is that with access to its mother's healthy cells, a fetus has all it needs to produce blood cells of its own.

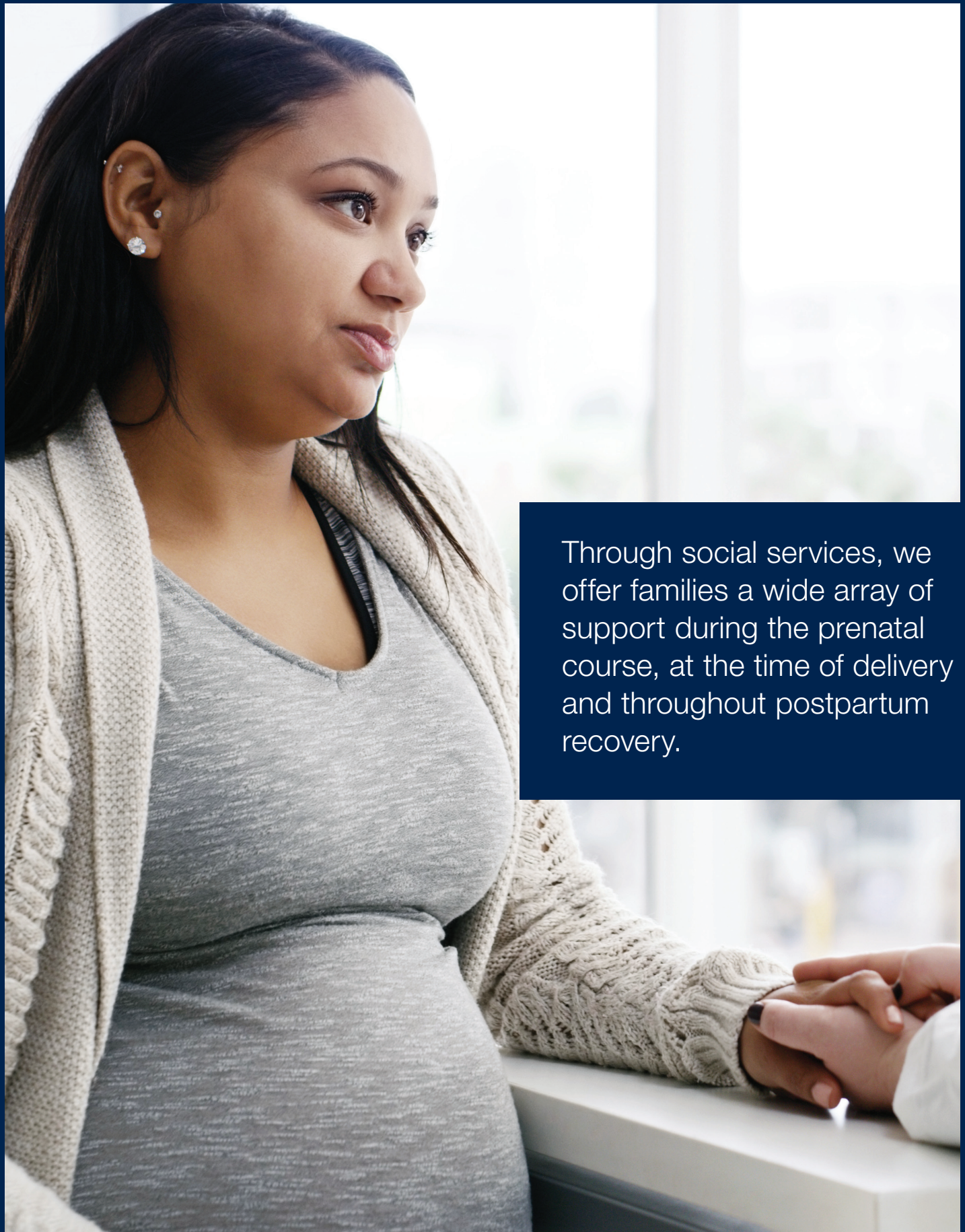
"When we heard there was another option for us, there was hope, and I held onto that hope," recalls Nichelle.

In an attempt to stop a disease before it starts—in the womb—Tippi MacKenzie, MD, transplanted stem cells from Nichelle's own bone marrow to her growing fetus. With or without the treatment, the baby stood a high chance of dying. But with it, and the subsequent blood

transfusions, doctors gave the infant a fighting chance.

Baby Elianna was diagnosed with ATM during the second trimester of pregnancy. Her parents weren't aware that they both carried the gene for the disease, which was passed on to their daughter. Elianna was the first patient enrolled in the UCSF "In Utero Stem Cell Transplantation for Fetal Alpha Thalassemia Major" clinical trial.

Elianna and her family are now back home in Hawaii. She still requires further blood transfusions, and the family is considering another stem cell transplantation as a potential cure for their daughter. Elianna celebrated her sixth birthday in 2024.



Through social services, we offer families a wide array of support during the prenatal course, at the time of delivery and throughout postpartum recovery.



Refer a Patient

For patient referrals or evaluations, please contact either of our Fetal Treatment Center campuses. We work closely with referring physicians to coordinate and co-manage pregnancies, regardless of whether fetal intervention is required.

UCSF Benioff Children's Hospital San Francisco

Phone: (800) 793-3887 (800-RX-FETUS)

Fax: (415) 502-0660

UCSF Benioff Children's Hospital Oakland

Phone: (510) 428-3156

Fax: (510) 450-5670

ucsfbenioffchildrens.org/fetaltreatment

