All of us at UC Davis Children’s Hospital are enormously proud that we’ve had another outstanding year and that our talented faculty members and providers are drawing more national recognition as they lead the way in patient care, research and quality improvement initiatives. Recognition is important to our mission, but what we are most proud of is the extraordinary care and comfort we continue to provide to children and their families throughout the region.

A hallmark of our children’s hospital is that our leading-edge technology and groundbreaking research are just the start of our care. We have a culture of compassion woven through everything we do, and an awareness that children need care that is patient-centered and personalized to their needs.

Here are some of the reasons our care resonates nationally.

Children’s Surgery Center by the American College of Surgeons, a standard that was re-verified this year. And once again, we were ranked nationally in five pediatric specialties and among the Best Children’s Hospitals in America by U.S. News & World Report.

In addition, our hospital received the 2019 International Board Certified Lactation Consultants Care Award, as recognized by the International Board of Lactation Consultant Examiners and the International Lactation Consultant Association. This year, we also created a Pediatric Aerodigestive Center to provide a specialized team approach for children with complex airway, pulmonary, upper digestive tract, sleep and feeding disorders — health issues that are often complex and interrelated.

We unveiled a new pre-operative clinic to further improve quality and safety, and reduce surgery delays and cancellations. We are expanding our telemedicine network to provide pediatric subspecialty coverage to Federally Qualified Health Centers in rural and remote areas of Northern California.

As inland Northern California’s only nationally ranked, comprehensive pediatric hospital we offer world-class care for virtually every health condition for infants, children, adolescents and young adults. Just as importantly, we offer kindness and respect to every one of our patients — some of them very tiny — and to their families. We understand that beyond needing very special equipment, children need a very special touch from their caregivers. This understanding along with the experience and skills to offer that special touch are what we remain most proud of this year, and every year.

Satyan Lakshminrusimha, M.D.
Pediatrician-in-Chief,
UC Davis Children’s Hospital

Welcome
This past year we were re-verified as a level I Children’s Surgery Center by the American College of Surgeons (ACS), the world standard bearer for surgical quality. Our state-of-the-art surgery center coupled with our world-class expertise helps us remain the only hospital in California with this verification.

Our pediatric surgical patient volume has grown. Since we opened our new Children’s Surgery Center in fall 2018, we have seen a strong increase in the number of children and families we have been able to serve, particularly in pediatric heart and neurosurgery cases as well as medically complex cases.

In February 2019, the UC Davis Pediatric and Cardiac Intensive Care Unit (PICU) received the Silver-Level Beacon Award for Excellence from the American Association of Critical Care Nurses (AACN). It is an honor that involves a rigorous certification process, ensuring institutions have a commitment to nursing excellence, building strong relationships between patients, and improving outcomes and overall patient care satisfaction.

In fall 2019, we opened our new Pediatric Aerodigestive Center, exclusively designed to provide the best patient-centered care for ear, nose and throat patients throughout the region.

Three photographs of patients and caregivers at UC Davis Children’s Hospital were selected in the biennial Children’s Hospitals Photo Exhibit — the result of a national competition administered by the Children’s Hospital Association (CHA).

Our program to honor organ donors and their families with a staff-led honor guard procession expanded hospital wide.

UC Davis NICU nurse Christa Bedford-Mu was named National Magnet Nurse of the Year for New Knowledge, Innovation and Improvement at the 2019 American Nurses Credentialing Center National Magnet Conference. Created in 2010, the recognition is given to five nurses annually for their outstanding contributions in innovation, consultation, leadership and professional risk-taking.

UC Davis Children’s Hospital hosted a Social Determinants of Health in the 2019 Children’s Hospital Seminar. It explored ways that health care professionals can provide support to patients and families in crisis.
Surgery

Re-verified as a level I Children’s Surgery Center

In fall 2019 UC Davis Children’s Hospital was re-verified as a level I Children’s Surgery Center by the American College of Surgeons (ACS), the world standard bearer for surgical quality. We remain the first hospital on the West Coast, and one of only a dozen in the nation, to have earned this designation. Level I centers have children’s surgeons in every discipline, with pediatric anesthesiologists and dedicated operating rooms for children available 24 hours a day. They also train future leaders in education and research and participate in community outreach.

Unique Fetal Care and Treatment Center

As inland Northern California’s first comprehensive multidisciplinary fetal diagnosis and therapy center, the UC Davis Fetal Care and Treatment Center offers advancements in fetal surgery and maternal-fetal medicine that allow multiple avenues of intervention, including in utero or in real time during the birthing process. We are currently our region’s only center for on-site fetal surgery, and are proud to be one of a limited number of U.S. hospitals to offer these services for families facing conditions such as twin-to-twin transfusion syndrome and spina bifida.

Cure for spina bifida gets a step closer

The Fetal Care and Treatment Center also includes an extensive research program: Diana Farmer, our Children’s Hospital surgeon-in-chief and chair of UC Davis Health’s Department of Surgery, has led a spina bifida initiative and extensive research program for over a decade. Her team has demonstrated that surgery combined with stem cells helps canine patients with the disorder to walk without noticeable disability. Now, with the support of a $6 million grant from the California Institute for Regenerative Medicine (CIRM), her new study involving fetal surgery and tissue engineered stem cell therapy holds the hope of providing what so many families are looking for — a cure.
Trauma and Emergency

On Dec. 23, 2018, we lost our daughter, Kaiden lost his mom and had life-threatening injuries from being hit by a drunk driver. The doctors, nurses and entire staff saved Kaiden’s life and cared for all his physical needs. However, it was the emotional care that the entire UC Davis staff gave to Kaiden and our entire family that I will never forget! I cannot express our gratitude for all that UC Davis Children’s Hospital has done and continues to do for Kaiden and our family!

DANA LUND, GRANDMOTHER OF KAIDEN, WHO MADE A REMARKABLE RECOVERY AFTER SPENDING 18 DAYS AT UC DAVIS CHILDREN’S HOSPITAL AFTER A NEAR-FATAL HEAD-ON CAR CRASH.

Level I Pediatric Trauma Center for 65,000 miles

In 2018 UC Davis Medical Center was re-verified as a level I trauma center, the highest level possible, by the American College of Surgeons — making it the only level I trauma center for both adults and children in inland Northern California, and one of only two in California.

Our hospital and trauma center serve a 33-county, 65,000-square-mile area with the help of the most comprehensive children’s critical-care transport team in Northern California. The program travels 24–7 by ambulance, helicopter or fixed-wing aircraft to carry in more than 800 children each year, some from hundreds of miles away. In all, we saw more than 15,000 pediatric emergency department visits in FY 18/19.

New ER protocol for infants with fever

A JAMA Pediatrics study this year led by Nathan Kuppermann, M.D., also derived and validated a new emergency department protocol that can determine which young infants with fevers are at low risk of significant bacterial infections. The research, which involved nearly 2,000 patients at 26 hospitals, has important implications for identifying the need for spinal taps or other invasive care.

New high-tech, child-friendly ambulance

Our young referral patients throughout the region can now benefit from our new and improved transport ambulance. The new ambulance includes a state-of-the-art transport isolette for vulnerable neonatal patients, a technologically advanced air conditioning and heater system, crew cab space for family members, and a DVD player for patients.
The region’s only NCI-designated center
UC Davis Comprehensive Cancer Center is the only National Cancer Institute-designated center serving the Central Valley and inland Northern California, a region of more than 6 million people. Our team includes experts such as chief of pediatric hematology and oncology Marcio Malogolowkin, M.D., an international leader in pediatric liver tumors and an authority on adolescent and young adult (AYA) cancers.

The world’s first-total body PET scanner
EXPLORER is the world’s first highest-sensitivity medical imaging scanner that can capture a 3-D picture of the whole human body at once. The brainchild of two UC Davis scientists, the total-body PET scanner provides higher-quality diagnostic PET scans than ever possible by scanning up to 40 times faster — in as little as 20 to 30 seconds — using radiation doses up to 40 times less than PET. The new technology will help improve diagnostics, track disease progression, and lead to new drug therapies.

We met everyone in the cath lab during his procedure, and the staff made us feel really comfortable. They inserted a thin wire into his groin, and there were no scars.

Improving detection of critical congenital heart defects
New UC Davis research led by Heather Siefkes, M.D., assistant professor of pediatric critical care at UC Davis Children’s Hospital, is working to improve standard screening tools to detect critical congenital heart disease (CCHD) in newborns. By measuring blood flow levels in addition to blood oxygen levels, Siefkes research will help establish a screening threshold by applying artificial intelligence techniques to identify the blood flow value that can predict CCHD.

Pediatric cardiology chief receives master Interventionalists designation
Frank Ing, M.D., chief of pediatric cardiology and co-director of the UC Davis Pediatric Heart Center, received a Master Interventionalists designation from the Society for Cardiovascular Angiography and Interventions (SCAI). The designation showcases excellence in invasive/interventional cardiology and a commitment to clinical care, innovation, publication and teaching. The society recognized Ing’s achievements in the development of transcatheter techniques, delivery systems and cardiovascular devices to treat congenital heart disease from the fetus to the elderly.

New pediatric heart mobility program
Last year, the UC Davis Pediatric and Cardiac Intensive Care Unit launched a new Pediatric A–F Bundle and Early Mobility Program for patients with congenital heart defects and other heart conditions. The approach, including early mobility and exercise, has been shown to help patients recover faster and decrease long-term effects of delirium. UC Davis Medical Center is the first in Northern California to have both a pediatric and adult early mobility program.
**Diabetes and Endocrinology**

**Nationally ranked**

**Spanish language support group offers positivity, education**
A new Spanish support group for pediatric endocrinology patients and their families provides an emotional and educational space to gain knowledge, share advice, and improve diabetes management. The group was created to support the need for culturally relevant support groups to help families and children continue positive conversations at home.

**Being treated at UC Davis Children's Hospital has been a life changing experience. Everyone who works with me is like family now. I have learned to be grateful despite the circumstances because of the care I have received.**

AMEIASH WILLIAMS, 15-YEAR-OLD PATIENT, ON HER TREATMENT AND CARE AT UC DAVIS CHILDREN'S HOSPITAL FOLLOWING HER DIABETES DIAGNOSIS.

**Home-based telemedicine project awarded at national conference**
In 2018, Stephanie Crossen, M.D., assistant professor of pediatrics and a Clinical and Translational Science Center scholar, received the Judges’ Award at the Society for Education and the Advancement of Research in Connected Health’s Telehealth Research Symposium for her research on the use of home-based telemedicine to improve care for pediatric patients with poorly controlled Type 1 diabetes. Her study — aimed to determine whether telehealth visits every four-to-eight weeks can ultimately help children reduce their A1C levels — is a pathway to improve diabetes care in children.

**New Pediatric Aerodigestive Center opened**
As the first and only center of its kind in inland Northern California, the Pediatric Aerodigestive Center provides a specialized multidisciplinary team approach including pediatric gastroenterologists, pediatric surgeons and pediatric otolaryngologists for children with complex airway, pulmonary, upper digestive tract, sleep and feeding disorders. The center will improve coordination of care, reduce patients’ number of procedures, imaging and anesthesia exposures, and allow more convenient appointments.

**Largest population-based study**

**Pediatric Colorectal Center**
Payam Saadai, M.D., and collaborators participated in several articles, case studies and presentations about pediatric GI and colorectal conditions at the American College of Surgeons Clinical Congress and other national meetings. Saadai also organized the REACH (Research Education and Awareness for Children with Hirschsprung Disease) annual meeting.

**Gastroenterology/GI Surgery**
Neonatology

Tackling necrotizing enterocolitis

Partnerships focused on neonatal care are also helping us advance health close to home. The NEC Society, a nonprofit organization aimed at eliminating necrotizing enterocolitis (NEC), received $250,000 from the Patient-Centered Outcomes Research Institute (PCORI) to build its research capacity on the leading cause of death in very premature infants. Working hand in hand with UC Davis Health’s Center for Healthcare Policy and Research, the society will create and train a dedicated leadership team, develop methods and strategies to identify and prioritize research, and establish a model framework that can be shared with and used by others.

Level IV NICU

The UC Davis Neonatal Intensive Care Unit (NICU) is a level IV-designated nursery (the highest possible rating) for the Sacramento region, providing clinical care for infants throughout Northern California and conducting research on health problems facing infants, including those who are born very prematurely, are extremely ill, or require surgery.

Nationally ranked


Customized breast milk for premature babies

Thanks to a new Miris human milk analyzer machine funded by Children’s Miracle Network Hospitals (CMN), premature babies in our level IV NICU will receive customized breast milk fortified with the nutrients they need to support their growth and wellness.

The doctors and nurses at UC Davis Children’s Hospital are the best. Gonna love them forever.

MELISSA BAIKIE-RICK, ON HER SON’S NEONATAL CARE AFTER HE WAS BORN AT 25 WEEKS, WEIGHING 620 GRAMS. LOGAN RECOVERED FROM FIVE MAJOR SURGERIES AND MULTIPLE PROCEDURES AFTER SPENDING THE FIRST SEVEN MONTHS OF HIS LIFE IN THE NICU.

Nationally ranked

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Nephrology and kidney transplantation

Making transplants more accessible
We continue to acquire many difficult-to-transplant kidneys that other centers lack the expertise to use, and utilize them to save and extend lives. Transplant surgeon Christoph Troppmann, M.D., is currently working to increase our deceased donor program, which now also includes one of the largest pediatric donor programs nationally.

Nationally ranked

Unique dialysis service provides bridge to transplant
To better serve children waiting for a kidney, our program continues to be the region’s only outpatient peritoneal dialysis service for patients under 10 years of age.

Neurology and Neurosurgery

Seeking cure for rare neurological disorder
World renowned neurologist and new School of Medicine dean Allison Brashear, has been researching a cure for Rapid Onset Dystonia Parkinsonism and Alternating Hemiplegia of Childhood — both rare neurological disorders — for more than a decade. Through National Institutes of Health (NIH) grants, Brashear’s research aims to understand the basic science of the sodium potassium pump and what pathways in the brain are affected. Identifying these links may help find potential treatments and give experts more of an understanding of these rare mutations.

First in California to treat patient with postpartum depression drug
In October 2019, UC Davis Health became the first and only hospital in California to offer Zulresso (brexanolone), a new medication to treat mothers with postpartum depression. Developed by UC Davis neurologist Michael Rogawski, M.D., the intravenous drug rapidly brings insomnia, appetite loss and mood swings to remission. Zulresso was approved by the U.S. Food and Drug Administration in March, and currently only three other states offer this type of treatment.

Dr. Zwienenberg and all of the neurosurgeons are just amazing. We have had four craniotomies in this family and they have all gone smoothly. We completely trust them.

KEVIN ARREDONDO, WHOSE 11-YEAR-OLD DAUGHTER WAS TREATED FOR CAVERNOUS MALFORMATIONS BY UC DAVIS PEDIATRIC NEUROSURGEON MARKE ZWIENENBERG.
Orthopaedics

Nationally ranked
U.S. News & World Report ranked our pediatric orthopaedics program 8th in the nation in 2019–2020, in collaboration with Shriners Hospitals for Children – Northern California, our long-standing partner on orthopaedic disorders and spinal injuries.

Treating trauma and complex sports injuries
UC Davis pediatric orthopaedic surgeons perform a high volume of trauma surgeries and play an important role in our American College of Surgeons-verified level I pediatric trauma center. We also provide care and research for complex sports injuries and investigate brachial plexus birth palsy.

Pulmonology

Educating patients about e-cigarettes
After more than 2,000 cases of vaping-associated lung injuries were reported across the U.S. — including more than 170 in California — our expert pulmonologists have expanded the conversation outside of the clinic walls, and have continued to educate children, teens and their parents about the dangers of e-cigarettes and addiction.
New pediatric rheumatologist

Last year we secured the services of expert pediatric rheumatologist Angel Herrera Guerra, M.D. His specialties include helping children throughout the Sacramento region with rheumatologic conditions such as juvenile idiopathic arthritis, lupus, and juvenile dermatomyositis.

Our experience at UC Davis has been amazing. It is our home away from home. The team has been like family to us, from the doctors and nurses to the janitors. We love UC Davis.

SARAH ANNE MAITLAND ABOUT HER BROTHER FABIAN’S RHEUMATOLOGIC CARE

Urology

Nationally ranked

U.S. News & World Report consistently ranks the pediatric urology program at UC Davis Children’s Hospital among the best in the nation. In the 2019–2020 Best Children’s Hospital survey, our program ranked 20th nationally, in collaboration with Shriners Hospitals for Children – Northern California, our longstanding partner in caring for children with urological issues.

SARAH ANNE MAITLAND ABOUT HER BROTHER FABIAN’S UROLOGIC CARE
Nursing

Nation’s highest recognition for nursing excellence

UC Davis Medical Center has long been identified as a U.S. center of nursing excellence devoted to optimal, collaborative and evidence-based care. We are privileged to have been granted Magnet® recognition status by the American Nurses Credentialing Center again in 2018. Only about 8 percent of U.S. hospitals carry Magnet® designation, and UC Davis is currently the only medical center in Sacramento to earn the recognition.

PICU honored with Silver Beacon Award for Excellence

In 2019, the Pediatric and Cardiac Intensive Care Unit (PICU) received the Silver-Level Beacon Award for Excellence from the American Association of Critical Care Nurses (AACN). Recognized units have met AACN’s rigorous certification process that ensures a commitment to nursing excellence, building strong relationships between patients, and improving outcomes and overall patient care satisfaction. Each unit has shown dedication to teamwork, high morale in the work environment and supportive environments of professionalism among colleagues and leaders.

National Magnet Nurse of the Year

NICU nurse Christa Bedford-Mu, M.S.N., R.N., CNS-BC, was named National Magnet Nurse of the Year for New Knowledge, Innovation and Improvement at the American Nurses Credentialing Center National Magnet Conference. The recognition is given to five nurses annually for outstanding contributions in innovation, consultation, leadership, and professional risk-taking.

Bedford-Mu is a board-certified neonatal clinical nurse specialist and a key participant in innovative telehealth programs at UC Davis Children’s Hospital. She is a lead contributor to a tele-visit and telehealth project aimed at improving the transition from the NICU to home, which has allowed for earlier discharge, increased parental and provider satisfaction, and reduced readmission rates.

Community classrooms served by Operation Backpack

During the eighth year of Operation Backpack, nurses collected a total of 323 backpacks filled with supplies to serve classrooms throughout the region. The program aims to help ensure that all children from pre-school to high school are prepared in order to improve their chances for success.
As a Federally Qualified Health Center (FQHC), CMC provides high-quality primary, dental and behavioral health services to nearly 90,000 patients each year.

program provides physical therapy, occupational therapy, and durable medical equipment to children with neurological or musculoskeletal disorders at designated school-based Medical Therapy Units.

Bringing advanced heart care to Mexico
UC Davis Children’s Hospital cardiothoracic surgeons are extending their expertise beyond our borders by helping Heart to Heart Global Cardiac Care establish the first pediatric congenital heart disease treatment program in northern Mexico. Partnering with local cardiologists from Hospital Universitario, the team has provided diagnoses, surgical procedures and post-operative treatment for newborns and teens.
Neonatologist receives national award
Kristin Hoffman, M.D., received a Children’s Miracle Network (CMN) Achievement Award for her development of a NICU webcam program that enables parents to see their infants remotely when they are unable to be at the bedside. The national honor — awarded to a caregiver, team or unit that has specifically been impacted by Children’s Miracle Network Hospitals’ funds — showcases her significant impact to elevate care, expand access, and improve the connections and bonding between families.

Empowering foster parents
Our Trauma Prevention and Outreach Program was established in 1996 to help decrease preventable death and injuries through education, research and outreach. A new component of the program focuses on training foster parents in areas of drowning prevention, car seat safety, and infant-safe sleeping.

Genetic testing for critically ill newborns
In January 2019, UC Davis Children’s Hospital became the fifth hospital statewide to join Project Baby Bear, the first California state-funded program to offer rapid whole genome sequencing for critically ill newborns. The $2 million Medi-Cal pilot program provides genome testing for babies who are hospitalized in intensive care and suspected of having a genetic disorder.

Patients express themselves through film
Pediatric patients have an outlet to express their imaginations by becoming directors, actors, and heroes of their own stories. In partnership with BayKids Studios, the Bay Area nonprofit helps normalize the hospital environment by allowing children to be creative, learn new skills, and create unique stories through filmmaking.
Cleats for a cause
Sacramento Republic FC midfielder (and childhood cancer survivor) Ray Saari and 11-year-old UC Davis patient Gianna Arredondo partnered to brainstorm design ideas for a special pair of one-of-a-kind soccer cleats. The Sacramento-based soccer team commissioned local artist Kevin Lee to design the cleats, then auctioned them off to support UC Davis Children’s Hospital — and to help tell the stories of patients like Arredondo, treated here for a genetic brain condition. In 2013, UC Davis Health was the founding kit sponsor and continues to be the kit sponsor of the Sacramento Republic FC — a second division professional team recently awarded a franchise in the top division of professional soccer in the U.S., Major League Soccer. The team and health system have partnered on multiple community initiatives, such as street soccer in underserved neighborhoods.

Carlo’s Calming Station
Make-A-Wish recipient Carlo Sandoval has given back to the UC Davis MIND Institute after he opted to give his wish away to help children with autism. Thanks to his kindness, and support from wish sponsor Bristol-Myers Squibb, Inc., the MIND Institute has obtained a calming station, valued at more than $5,000. The calming station features durable, hospital-grade material and long-lasting, non-breakable mirrors that create interesting illusions, a bubble-producing tube that changes colors, 100 fiber-optic strands for braiding and other play, an aromatherapy diffuser, a projector that can display a variety of realistic and abstract scenes, and an MP3-compatible stereo. The sensory-friendly machine helps kids cope with difficult procedures like blood draws and is great for patients of all ages who have developmental disabilities.

California International Marathon partnership
We are the medical team sponsor and chief beneficiary of the CIM, a major qualifier for the Boston Marathon. More than 12,000 runners and teams participated in the main race at the 37th annual event in 2019 and an additional 2,000 children participated in the UC Davis Children’s Hospital MarA-FUN Run, a 5K fun run/walk. Meanwhile more than 100 faculty, staff and students reported for volunteer duty on the course and the finish-line medical tent, which included acute care and musculo-skeletal teams.

Children’s Miracle Network Hospitals and philanthropic support
Philanthropy plays a crucial role in the kind of advanced care and research at UC Davis Children’s Hospital, and we are incredibly thankful to have the support of many partners. UC Davis Children’s Hospital is a proud member of the Children’s Miracle Network Hospitals (CMN), an international nonprofit dedicated to raising funds for, and awareness of, children’s hospitals. Donations create miracles by funding medical care, research, equipment and education that saves and improves the lives of our children.

The CMN team is glad to help community members get to know our hospital and the variety of ways they can get involved. To learn more or give a gift, please visit us at give.ucdavis.edu/CHLD or contact Jacquelyn Mills, Executive Director of Development at 916-734-9192 or jrkaymills@ucdavis.edu. News and information is also available at children.ucdavis.edu/cmn.

Former Pediatric Intensive Care Unit patient Jackson Manning was named the 2019 Sacramento Children’s Miracle Network child champion for being an advocate for children’s hospitals just like UC Davis. Jackson, who suffered from undiagnosed Type I diabetes was in the PICU for 39 days after he was unable to walk or talk. He is now living a normal life, attending school, and managing his diabetes. Every year, 170 Children’s Miracle Network Hospitals identify a “champion” in each of their communities to serve as the face for children treated at their local children’s hospital.
The Central Valley’s only level I pediatric trauma center, with 117,473 clinic visits, 7,155 hospital admissions and 15,322 emergency department visits per year.

The West Coast’s first level I children’s surgery center as verified by the American College of Surgeons, with 4,575 children’s surgeries this year.

850 members of our all-R.N. nursing staff have been trained to care for children
- Granted Magnet® recognition status by the American Nurses Credentialing Center
- 88% of UC Davis nurses hold a B.S.N. degree or higher
- 12% hold advanced degrees
- 50% of UC Davis nurses have obtained a specialty certification through the American Nurses Credentialing Center

Designated children’s hospital beds
- Neonatal Intensive Care Unit (NICU) – 49
- Pediatric and Cardiac Intensive Care Unit (PICU) – 24
- General Pediatrics – 48
- Pediatric Emergency Department – 11
- Children’s Surgery Center – 6 operating rooms, 1 procedure room, 24 pre-op/post-op beds

Provides care for children in 33 counties, covering 65,000 square miles, with over 3,157 transfers accepted from referring institutions.

120 physicians across more than 30 subspecialties (the region’s greatest diversity of pediatric subspecialties)

If it weren’t for the high-quality care we received from the compassionate, kind and dedicated staff we would not have the blessed life we have with our beautiful daughters now.

Greg and Lucia Walker, parents of identical twins Sofia and Isabella Walker, who were born monozygotic monochorionic (MOMO) twins, a rare condition that affects 1 in 100 pregnancies