### UC**DAVIS**HEALTH

The quarterly newsletter of **UC Davis Children's Hospital** 

# CHILDREN'S HOSPITAL PEdiatric Press

**FALL 2023** 

#### **Preparing for winter**

Winter is coming and we have been making plans to ensure that we are ready to receive more patients during the respiratory surge. A "tripledemic" of flu, COVID and RSV is likely to hit health systems across our country again this year and we are thankful for the cooperation and planning efforts made by so many on our team.

We have had a busy fall, with site surveyors from the American College of Surgeons visiting our Children's Surgery Center for a Level I children's surgery reverification site visit. A big thank you to Rajvinder Dhamrait, Karen Semkiw, Trudee Murray and Jennifer Prevatt (our Children's Surgery Program team), who worked extremely hard to make this visit go smoothly.

We hosted a Celebration of Life, the first one since 2019, to honor more than 300 children who passed away at UC Davis Children's Hospital from 2019 to 2022. The event was organized by the UC Davis Children's Hospital Bereavement Committee.

We also have our new mobile clinic van on the road, able to provide checkups, vaccines and clinical assessments within our Sacramento community. It is another way that we will be able to provide world-class health care that meets our community where they are. We are looking forward to sharing more about this and other developments in our next issue!



#### UC Davis first in the state to offer life-changing therapy for Duchenne Muscular Dystrophy



#### Newly approved gene therapy treatment looks promising for halting progression of genetic disorder

A 5-year-old boy named Andrew Rodriguez received an infusion of the first-ever gene therapy for treating Duchenne muscular dystrophy (DMD) for pediatric patients at UC Davis Children's Hospital.

Andrew made history as the first child in California to receive the groundbreaking, potentially lifesaving infusion treatment that was only recently approved by the U.S. Food and Drug Administration (FDA). He was the fourth child in the nation to receive the treatment outside clinical trials.

The treatment, years in the making, brings hope to as many as 12,000 people in the U.S., mostly males, who live with DMD, one of the most severe types of muscular dystrophy.

DMD is a genetic disorder that leads to heart and breathing problems. Until the new treatment came along, families had little hope of a cure.

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#### Let's get her to the OR now.' Infant's RSV exposes life-threatening heart defect

#### Pediatric nurse expresses gratitude after his co-workers save his daughter's life

When Mathew Hipwell's 3-year-old son, Everett, caught RSV (respiratory syncytial virus) — a common respiratory virus that can be dangerous for some infants and young children — in October of 2021, Hipwell urged him to steer clear of baby sister, Ellie. As a pediatric nurse at UC Davis Children's Surgery Center, Hipwell knew his daughter was especially susceptible. Soon she was coughing, too.



Since it happened to be time for Ellie's 2-month-old checkup, her mom, Bethany, took her to the UC Davis Health pediatrics clinic in Roseville. The staff determined Ellie had RSV, was too sick to get her immunizations and gave her a breathing treatment instead. Soon, she was on her way to UC Davis Children's Hospital.

"The next thing I knew, my wife was calling me from the back of an ambulance," Mathew Hipwell said. "I figured they would treat her for a few days, and we'd be good."

That wasn't the case. READ MORE »

### UC Davis Health and Kennedy Krieger Institute work to predict mental health issues after concussion



Researchers at <u>UC Davis Health</u> and the <u>Kennedy Krieger Institute</u> have received a five-year, \$2.5 million grant from the <u>Centers for Disease Control and Prevention</u> to study mental health and head injuries in youth. The health care teams will develop and validate a clinical tool to predict mental health concerns in adolescents following a concussion or traumatic brain injury.

Concussions are a growing public health concern — especially for children and teens who play sports. Increasing evidence suggests that concussed patients are at an increased risk of depression and mental health issues.

Poor mental health can negatively impact recovery from a concussion. Since <u>one in</u> <u>five teens report having been diagnosed with at least one concussion</u>, properly identifying mental health concerns is critical to getting adolescents back on track.

"While a substantial number of children experience ongoing or worsening mental health concerns in the first three months after a concussion or traumatic brain injury, there are currently no validated prognostic tools to assess risk of ongoing or worsening mental health concerns in these patients," said <a href="Daniel Nishijima">Daniel Nishijima</a>, professor of <a href="Emergency medicine">emergency medicine</a> at UC Davis Health and co-principal investigator of the study.

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#### New study spotlights radiation exposure from medical imaging for children with Down syndrome

Children with <u>Down syndrome</u> often undergo extensive medical tests, including imaging, that may use ionizing radiation. At the same time, genetic disorders like Down syndrome have an established increased risk of certain cancers, making exposure to radiation early in life less than ideal. Until recently, little research had been done to measure typical imaging radiation exposure rates for children with Down syndrome.

A recent study by UC Davis Health researchers quantifies those rates of exposure. The paper is based on the work of <u>Emily C. Marlow</u>, a former epidemiology doctoral student at <u>UC Davis</u> and current postdoctoral fellow at the <u>American Cancer Society</u>. The <u>PLOS ONE</u> journal article, "<u>Medical Imaging Utilization and Associated Radiation</u>



Exposure in Children with Down Syndrome," details her research team's analysis of a decade's worth of data from over 4 million children's medical records at six U.S. health care systems. They found that children with Down syndrome experienced almost 10 times as many medical imaging examinations as other children, with implications for their lifetime cancer risks.

<u>Diana Miglioretti</u>, cancer center researcher and professor and division chief of biostatistics at the <u>UC Davis School</u> <u>of Medicine</u> is the study's senior author. She said that this is the first study of its kind to utilize a large, comprehensive data set to measure radiation exposure from medical imaging in children with Down syndrome.

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#### Pediatric GI telehealth for COVID-19 pandemic and beyond



#### New review looks at the current landscape and identifies future challenges

How is telehealth currently being used within pediatric GI and what does the future hold? This is the question asked in a <a href="new review">new review</a> by UC Davis pediatric gastroenterologist <a href="Daphne Say">Daphne Say</a>, which was published in the <a href="Journal of Pediatric Gastroenterology and Nutrition">Journal of Pediatric Gastroenterology and Nutrition</a>.

"As communities emerge from the COVID-19 public health emergency, telehealth has evolved into an important tool for pediatric specialists. This technology improves access to care for

"This technology improves access to care for medically complex and underserved patient populations"

UC Davis pediatric gastroenterologist Daphne Say

medically complex and underserved patient populations," explained Say, lead author of the study. "Though traditional in-person care has resumed as physical distancing restrictions relaxed, telehealth for pediatric GI seems to be here to stay."

In the review, Say and her co-authors aim to assess the current pediatric gastroenter-ology telehealth landscape. They examine challenges that inhibit successful telehealth implementation and sustainability and propose strategies by which telehealth can evolve to meet the needs of pediatric GI physicians and their patients.

## This postpartum contraception is more effective than condoms or birth control pills

### New study shows few people know lactational amenorrhea method

When it comes to postpartum contraception methods, many people consider condoms or birth control pills, but there's another option that's more effective than either of those: the lactational amenor-rhea method (LAM), which is <u>at least 98%</u> effective.

A new <u>UC Davis Health study</u> published in <u>Breastfeeding Medicine</u> found that many women in the U.S. are misinformed about or lack understanding of lactational

amenorrhea. It's the period of temporary infertility that accompanies exclusive breastfeeding, which is marked by the absence of monthly periods. The study concluded that nearly half of women surveyed by the researchers were unaware that exclusive breastfeeding would significantly reduce their risk of pregnancy until their monthly periods resumed.

"This study is important as there is very limited information regarding use of lactational amenorrhea as a planned contraceptive in pregnant women here in the United States," said Adrienne Hoyt-Austin,



first author of the study. "Comprehensive education about postpartum contraceptive options is important to prevent unplanned pregnancies. To improve awareness of LAM, pregnant and postpartum individuals should be counseled on all forms of postpartum contraception, including LAM."

An estimated 1.5 million women world-wide use LAM inappropriately, potentially leading to unplanned pregnancy.

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### Best practices for children with prominent ears

Children with protruding ears can face bullying, anxiety and other issues. One solution is otoplasty, a safe and common procedure to change ear shape and size. In an <u>article</u> published in the journal <u>Facial Plastic Surgery Clinics of North America</u>, UC Davis Health's <u>Travis Tollefson</u>, a professor in the <u>Department of Otolaryngology</u>, and colleagues, outline several best practices for surgeons approaching otoplasty.

For Tollefson, who also directs the <u>Division of Facial Plastic</u> <u>and Reconstructive Surgery</u>, the process begins with in-depth conversations with families. Ideally, the child is old enough to participate in these talks and help make any decisions. He encourages all participants to consider the physical and psychological aspects of craniofacial differences when approaching these procedures.

"We want the families to know that there's no such thing as a normal child or a child that's not normal," Tollefson said. "They're all just children with differences in how their ears look, how their nose looks, how their lips look. It's important not to stigmatize these kids."

Tollefson notes that some parents may have sensitivity over their own ears and may transfer those concerns to their child. He encourages physicians to discuss the parents' experiences, as well as the child's, to better reach consensus among family members. He says in some cases, the best solution is doing nothing at all.

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#### **GIVING BACK:**

## Local Jersey Mike's Subs locations raise \$104,003 for Children's Miracle Network at UC Davis



Greater Sacramento area Jersey Mike's
Subs locations raised \$104,003.25 during the 13<sup>th</sup> annual Day of Giving in March.
A check was recently presented to
Children's Miracle

<u>Network</u> (CMN) at <u>UC Davis Children's Hospital</u>. This brings the sandwich chain's total donation to almost \$300,000 since 2016.

Jersey Mike's Subs locations nationwide accepted donations throughout the month, leading to the Day of Giving on March 29, 2023, when 2,500 restaurants donated 100 percent of sales to local charities including hospitals, youth organizations, food banks and more.

"Our local Jersey Mike's Subs restaurants really rallied this year and we could not be more grateful," said Michelle Tafoya, program director of Children's Miracle Network. "This company is all about making a difference and what they do for local sick and injured kids proves it."

This year's fundraising total of \$21 million exceeds the \$20 million raised during the 2022 campaign. Since Month of Giving began in 2011, Jersey Mike's Subs has raised more than \$88 million for local charities.

#### Diana Farmer, first UC Davis Health faculty member appointed to a leadership role with the National Academy of Medicine



#### Department of Surgery professor and chair recognized for contributions to health and medicine

<u>Diana Farmer</u>, chair of the <u>Department of Surgery</u>, has been appointed to a

prestigious leadership position within the **National Academy of Medicine** (NAM). She is the first **UC Davis Health** faculty member to be assigned to a leadership position with the academy.

Farmer was appointed to the NAM membership committee and will also serve as the Vice Chair of Section 6, which is one of 12 membership sections in the organization's structure. The section Farmer will help oversee encompasses

surgery, anesthesiology, ophthalmology, and radiology.

"It is both an honor and a tremendous responsibility to accept this leadership position within the National Academy of Medicine," Farmer said. "I am deeply grateful for the opportunity to contribute to the advancement of health and medicine on a national level. Together, we will continue to push the boundaries of medical science, inspire future generations, and shape a healthier, more equitable world."

The NAM is dedicated to advancing science, health, and medicine and

inspiring positive change across sectors. As part of its mission, the organization annually recognizes remarkable professionals who have made significant contributions to their respective fields and have displayed an unwavering commitment to service.

The appointment is considered one of the highest honors in health and medicine.

## UC Davis Health pediatric surgery nurse receives national award

UC Davis pediatric surgery nurse
Andrea Reich is honored for going
above and beyond. The American
Pediatric Surgical Nurses Association
(APSNA) awarded her the 2023
Spotlight Award. APSNA is a national
organization that shapes pediatric surgical nursing through advocacy, collaboration, mentorship and leadership.

The Spotlight Award recognizes an APSNA member who demonstrates involvement in pediatric surgery exceeding the usual job expectations.

"Andi effortlessly connects with our patients and their families, easing their anxieties and creating an atmosphere of trust," said Amy Powne, Fetal Care and Treatment Center and pediatric surgery nurse practice manager. "Her compassionate care, clinical excellence and unwavering dedication serve as an inspiration to all, reminding us of the transformative power of nursing and the limitless capacity to make a difference."

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## Safe Kids Greater Sacramento at UC Davis Health honored with national award



Safe Kids Worldwide recently honored Safe Kids Greater Sacramento at UC Davis Health with the Herta Feely Communications and Advocacy Award for outstanding work in communications, awareness and advocacy.

The award was one of 16 Safe Kids Awards presented at the Safe Kids Childhood Injury Prevention Convention (PrevCon). The event is a three-day gathering of more than 500 safety professionals who come together to network, learn and collaborate on efforts to enhance children's safety.

"I was honored to accept this award on behalf of our Safe Kids Greater

Sacramento members, its advisory board, and the staff here at UC Davis Children's Hospital," said Jennifer Rubin, Safe Kids Greater Sacramento coalition coordinator. "Injury prevention initiatives like ours can go unnoticed because the best outcome of our work is nothing! No injuries, no school days missed, and no bad news to share. Communicating safety messages to families in a way that inspires them to follow our safety advice is hard work, and we appreciate the recognition."

## UC Davis Health launches volunteer doula program

When pregnant patients go into active labor at <u>UC Davis Medical Center</u>, they can now receive support from a trained doula.

<u>Doulas</u> are trained individuals who provide emotional and physical support during one's pregnancy and childbirth. Assistance from a <u>doula is shown to promote better</u> <u>birth outcomes</u>, especially for socially disadvantaged mothers at risk for adverse birth outcomes.



The new volunteer doula program launched in August. The hospital currently has a group of 15 volunteer doulas and plans to double that by the end of 2023. Patients can request a doula upon admission, based on first-come, first-served availability. Doulas are currently available during the day, but as the program expands, the hospital aims to have doula availability seven days a week, night and day.

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### Early pregnancy access center opens at UC Davis Health



UC Davis Health has recently launched an early pregnancy access center, offering specialized expertise for patients in the beginning stages of pregnancy.

"This new clinic will provide specialized care for patients who are experiencing complications and want to be seen ASAP," said Anne Flynn, OB-GYN physician in family planning. "Our clinic will provide expedited and compassionate care

to patients during early pregnancy. These may be patients diagnosed with pregnancies that need management, such as miscarriage or ectopic pregnancy. Or these may be patients experiencing symptoms of bleeding and cramping early in pregnancy."

Eight OB-GYN physicians with subspecialty training in complex family planning will work in this clinic, along with support from OB-GYN fellows and residents.

The Early Pregnancy Access Center will provide care for patients with:

- Miscarriage/early pregnancy loss, including diagnosis and management (procedural or medical management)
- Pregnancy of unknown location, in which a positive pregnancy test occurs but ultrasound does not show intrauterine or ectopic gestation (including workup and management)
- Ectopic pregnancies, including cesarean scar ectopic and cervical ectopic pregnancies
- Complications of early pregnancy, such as bleeding and cramping
- Medication or procedural management of undesired pregnancy
- Pregnancy verification for patients not previously seen by a provider and who cannot be scheduled with a new OB provider for some time

Patients who would like to schedule an appointment can call 916-734-6900.

### One-in-a-million pregnancy brings woman to UC Davis Health

Her newborn son died of a rare disorder. Brianna Thompson was going to do everything she could to save her next child.

For Brianna and Spencer Thompson of Auburn, the excitement was overwhelming. Brianna's pregnancy was a wonderfully normal experience. The couple was excited about their son's arrival.



"It was the cookie cutter, ideal pregnancy," Brianna Thompson remembers.

But at 33 weeks, Thompson noticed decreased movement in her belly. She sensed there was a problem. A visit to the hospital led to an emergency <u>C-section</u> where doctors discovered her son Finn had severe liver damage.

"It all happened so fast, but at the same time, it was slow motion in my mind," Thompson said. "I had no idea what was going on. It didn't feel real."

Finn was transferred to several different hospitals for increasingly critical care, but died five days later.

"It was traumatic," Thompson said. "We were living a nightmare and had no answers."

#### Pediatric GI, endocrine patients gain more access to mental health services

Coping with chronic illness can significantly impact a child's health, increasing rates of depression and anxiety for young people.

"Many gastroenterological (GI) conditions like Crohn's disease, irritable bowel syndrome, and celiac disease are what I would classify



Caroline Timmer and Salina Rodriguez

as invisible illnesses, with no outward signs or symptoms of disabilities," said **Daphne** Say, pediatric gastroenterologist at UC Davis Children's Hospital. "As such, these children

shoulder unique emotional baggage as others may not be able to understand what they're experiencing or how to help them. Some people may not believe that they have chronic medical conditions because they don't look sick."

Functional gastrointestinal disorders like irritable bowel syndrome have been linked to symptoms of depression and severe anxiety. Chronic GI symptoms can lead to increased pain and can be worsened by stress. Researchers have identified bidirectional communication pathways between the gut and the brain, noting that a person's mental health or early life trauma can impact their gut health.

Connecting patients to behavioral health services has provided needed support for Say's patients. The protocol is simple:

- Say and other pediatric GI physicians identify patients who might benefit from behavioral health services.
- A social worker refers the pediatric patient and their family to a mental health specialist from the **UC Davis CAARE Center**. Visits can be virtual or in-person, depending on the family's preference.

The service is part of a growing integrated care model at UC Davis Health.

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## laryngoscopy

**Pediatric pulmonary** 

team now offers

A new diagnostic tool is now available to pediatric patients experiencing pulmonary and sleep related challenges: flexible laryngoscopy.

This bedside procedure is now offered in the pediatric pulmonology and sleep clinics at UC Davis Health. The procedure is performed by passing a fiberoptic laryngoscope via nasal passage with mild local anesthetic. This procedure is not offered in other pediatric pulmonology clinics in the Sacramento area.

"The procedure provides useful information about the patient's upper airway anatomy and the possible reasons for upper airway obstruction such as enlarged tonsils, adenoid, nasal turbinate, lingual tonsils, laryngomalacia and more," said Kiran Nandalike, chief of pediatric pulmonology at UC Davis Children's Hospital. "The findings of this procedure can quide physicians and families on the best management strategies for their pulmonary and sleep-related conditions."

#### New CAARE Center web course teaches trauma-responsive knowledge to caregivers

The UC Davis CAARE Center has launched a free new web course for caregivers of youth experiencing sex trafficking and exploitation. This web course was funded by the California Department of Social Services and created by Dawn Blacker, interim co-director and training director at the UC Davis CAARE Center, and Brandi Liles, a trauma responsive care trainer at the UC Davis CAARE Center. Together, Blacker and Liles have 25 years of experience working with sexually exploited youth and their caregivers.

The three-hour web course, entitled "Increasing Trauma-Responsive Knowledge and Practical Skills: A Web Course for Caregivers of Youth Experiencing Sex Trafficking and Exploitation," includes three modules about:

- Information about sex trafficking
- Meeting the needs of youth with practical parenting strategies
- Secondary traumatic stress and self-care strategies



### Pediatric and adult heart specialists perform life-saving procedure on 15-year-old boy

Fresno teenager Orlando Gayles was a picture of health and never dreamed he would have a heart attack at 15. He



was an athlete and had played football for years. He had no known preexisting heart conditions.

But one evening last November, something wasn't right.

His first symptom was repeated vomiting. When he started having trouble breathing, his grandma called 911. An ambulance took him to a nearby children's hospital.

"I felt like my chest was closing. I knew something was wrong," Gayles said.

After an assessment, the hospital team determined they were not equipped to handle his case. Due to his age and size,

they felt he needed a team of adult cardiac specialists to help. But the adult teams at other hospitals would not take him because he was a child.

Thankfully for Gayles, <u>UC Davis Medical</u>
<u>Center</u> in Sacramento offered a combination of adult and pediatric cardiologists who could collaborate and perform the <u>cardiac catheterization</u> he needed.

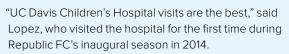
"We have the benefit of being a children's hospital within an adult hospital, so we can collaborate with our adult cardiologist colleagues on a case like this," said <a href="Frank Ing">Frank Ing</a>, chief of pediatric cardiology and director of the UC Davis Pediatric Heart Center. Ing performed the procedure with adult interventional cardiologists <a href="Manoj">Manoj</a> <a href="Manoj">Mesarwani</a> and <a href="Jeff Southard">Jeff Southard</a>. <a href="READ MORE">READ MORE</a> »

#### Sacramento Republic FC players visit pediatric patients

<u>Sacramento Republic FC</u> scored its goal of making hospitalized children happy during their recent visit to <u>UC Davis Children's Hospital</u>.

Five players — forwards Russell Cicerone and Rodrigo "Roro" Lopez, defenders Johnny Fenwick and Jared Timmer and goalkeeper Danny Vitiello — spent the afternoon, visiting with pediatric patients and their families in the pediatrics playroom. For patients who weren't well enough to go to the playroom, the players visited bedside, bringing cheer

and signing autographs.



Player visits take place monthly during the season and are made possible by the <u>Child Life and Creative Arts</u> <u>Therapy Department</u> and Hospital Administration.

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#### Sickle cell patient rings the bell to celebrate milestone

Equipped with bubble blowers and noise makers, doctors, nurses and staff members lined both sides of the patient walkway in the UC Davis Pediatric Infusion Center recently. They were there to cheer on 10-year-old sickle cell patient Cameron Bowers Woods as he walked to the brass bell.

Cameron gave high fives and big grins to the team members that have become like family.

For cancer patients, ringing the bell is a tradition that marks the end of treatment. It is a celebration for the patient, their family and their care team. But a sickle cell patient had never rung the bell before. Until now.

Cameron became the first sickle cell patient to ring the brass bell in UC Davis Comprehensive Cancer Center history. It signified a monumental milestone in Cameron's patient journey at <u>UC Davis Health</u>. The bell ringing commemorated Cameron's recent accomplishment of taking his medication orally, every day without fail, meaning fewer clinic visits. His port-a-cath, an implantable port that provides direct access to his central line, was removed since he no longer needs to receive his medicine through the port.

WATCH VIDEO » READ MORE »



The public is invited to support hospitalized babies and their families by donating board books through the Amazon wish list. NICU families receive the books to keep and take home. Due to infection control policies, all books must be brand new.

"Reading to babies promotes the development of language skills, supports bonding between baby and caregiver, and can help establish a routine and promote normalization of the hospital environment," said Cleo Lacey, NICU child life specialist at UC Davis Children's Hospital. "Thank you in advance for supporting our NICU families."

View the wish list:

ucdavis.health/NICUboardbooks

