

A newsletter for friends and supporters of UCSF Benioff Children's Hospitals

## Precision Public Health Summit: The First 1,000 Days



On June 6-7, 2016, UCSF hosted a Precision Public Health Summit in partnership with the White House and the Bill & Melinda Gates Foundation. The two-day event focused on improving the first 1,000 days of life, a critically important period in early childhood development.

Experts from around the country explored how big data can help ensure that all children have the best opportunity to survive and thrive, regardless of their circumstances.

"The brain is the single most complex physical object in the known universe," said Dr. W. Thomas Boyce, professor of developmental and behavioral health in the UCSF departments of Pediatrics and Psychiatry. "Those first 1,000 days determine how healthy and successful that individual will be for the rest of his or her life."

The summit also showcased UCSF Benioff Children's Hospitals' \$100 million global initiative to study the epidemic of premature birth—the leading cause of death for newborns and the second leading cause of death for children younger than 5. This research data will inform efforts to improve outcomes for mothers and the nearly one in 10 babies who are born preterm.

The event concluded with DJ Patil, chief data scientist of the US Office of Science and Technology Policy, pledging President Obama's full support.

"You have the commitment of the White House on this with you," he said. "You have the focus of the president on this, because this is one of his top priorities."

## An Amazing Recovery Ruth, Age 9

There are moments in your life when you wish you could turn back time, even for just five minutes.

For Emily Carpizo, one of those moments happened late on the afternoon of April 20, 2013. She had just gotten home from work. It was a warm day, so she had opened all the windows to let in fresh air. While she was making dinner, her 6-year-old daughter, Ruth, was running up and down the stairs, playing dress-up.

A few minutes after Ruth ran back upstairs to her third-floor bedroom, Emily heard pounding on her front door. She opened it to find her neighbor screaming, "Your daughter just fell out of her bedroom window!"

Emily raced outside. Ruth was moving slightly, and her eyes were open. "I remember thinking, 'She's alive, she's going to be OK!'" Emily says. "It had not yet clicked in my head how bad it was."

The neighbor had seen Ruth dancing on the window seat in her bedroom. When she leaned against the screen to wave to her friends outside, the screen gave way, sending Ruth tumbling 35 feet onto the concrete below.

The fall shattered the right side of Ruth's skull and her right elbow. An ambulance rushed her to UCSF Benioff Children's Hospital Oakland, where a team of neurosurgeons performed an emergency craniotomy, removing part of Ruth's skull to give her brain room to swell. She had a second craniotomy the next day and several additional surgeries over the following months.

Ruth's prognosis was grim. For two weeks, she remained in the hospital's pediatric intensive care unit, one of the most comprehensive Level 1 pediatric trauma centers in the Western United States.

Five days after the accident, a team of orthopaedic surgeons repaired Ruth's elbow. "That's when I knew there was hope," Emily says. "I asked the doctor, 'Does this mean she'll be okay?' And she said, 'We want her to have full use of everything when she gets out of here.'"

Today, Ruth has made a miraculous recovery. She can walk, run, and jump; speech is still difficult, but she's working on it. Emily credits Ruth's recovery in large part to her three-month stay in the hospital's pediatric rehabilitation clinic.

"It was as if Ruth was a newborn baby, and the therapists had to teach her everything all over again," says Emily. "Thanks to the incredible care the hospital's therapists provided, she got a great base of support on which she continues to build every day."



Nine-year-old Ruth, pictured with her brother, Zaiah, spent three months in the PICU on our Oakland campus following a traumatic fall out of her third-floor bedroom window.

Emily is sharing her family's story for one reason: "Ruth is a walking miracle. We cannot keep her story to ourselves. Her courage to overcome the obstacles she faces has inspired us to turn our pain into helping other kids at UCSF Benioff Children's Hospitals. They saved Ruth's life—and gave our family back our life, our hope, and our darling baby girl."

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Ruth's courage to overcome the obstacles she faces has inspired us to turn our pain into helping other kids at UCSF Benioff Children's Hospitals.

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—Emily Carpizo

Life can take a terrible turn when you least expect it. UCSF Benioff Children's Hospitals are here to care for every child in need. No matter how serious the injury or how rare the illness, kids just like Ruth inspire us to be our best every day.

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## When Music is the Best Medicine

For a sick child confined to a hospital, listening to music often brings a welcome sense of comfort and calm. But research shows that if the child participates in making the music, it can actually encourage healing.

This capacity to heal inspired the founding of the Jared Kurtin Music Therapy Program at UCSF Benioff Children's Hospital Oakland. Launched more than a decade ago, with early support from the Perloff Family Foundation, the program was the first established pediatric music therapy program in the Bay Area and continues to be an integral part of the hospitals' treatment plan.

Across the Bay, a new gift has established the Peterson Family Foundation Music Therapy Program to bring the same healing powers of music to patient rooms at UCSF Benioff Children's Hospital San Francisco.

"Kids put up walls when they're in pain and when they're in the hospital," says music therapist Oliver Jacobson, who works with young patients on our San Francisco campus. "But there's a moment in our session when those walls come down, and I get to see them experience joy and happiness."

That joy is contagious. Jeff Peterson, president of the foundation, experienced it firsthand several years ago while visiting the hospital and watching Oliver at work.

"The music brought pure joy to the little ones," Jeff says. "My son, Kort, was with me that day, and after we left, he remarked on how happy I was. That's when I knew I had to get involved."



Music therapist Oliver Jacobson and a patient create a song from scratch in the All Stars Helping Kids Music Therapy Recording Studio at UCSF Benioff Children's Hospital San Francisco.

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The music brought pure joy to the little ones.  
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— Jeff Peterson, president of the Peterson Family Foundation

The Peterson family has been a staunch supporter of UCSF since 2003, funding research into cancer and pediatric diabetes, but Jeff says the music therapy program holds a special place in his heart.

Now, patients on both hospital campuses can benefit from the healing properties of music therapy. In a hospital setting, music has a greater purpose than simply entertainment; it helps achieve goals ranging from bringing family members together to improving patients' speech and mobility.

The Oakland music therapy program is named in memory of Jared Kurtin, a former patient and pianist who passed away in 2005. Jared's love of music and generous spirit inspired his family to establish the program. Ongoing support is also provided by Another Planet Entertainment, the Perloff Family Foundation, and Salesforce, among others.

## Acoustic-4-A-Cure Rocks the Fillmore



Bay Area rock legend Sammy Hagar (center) raised \$100,000 for pediatric cancer at this year's Acoustic-4-A-Cure benefit concert.

On May 15, an all-star lineup of musicians united at The Fillmore for the third annual Acoustic-4-A-Cure concert benefiting the pediatric cancer program at UCSF Benioff Children's Hospital San Francisco. Bay Area rock musician Sammy Hagar organizes the annual fundraiser.

The popular event raised \$100,000 with star-studded talent that included Metallica singer James Hetfield, singer/songwriters John Mayer and Melissa Etheridge, Mötley Crüe drummer Tommy Lee, Train lead vocalist Pat Monahan, and guitarist Joe Satriani. Singer Kris Kristofferson joined Sammy Hagar to close the show.

A longtime supporter of UCSF Benioff Children's Hospitals, Sammy told the *San Francisco Chronicle* that he enjoys giving fans a chance to experience something special.

"They get to see these people like they've never seen them," he said. "Who gets to see James Hetfield on an acoustic guitar singing 'In My Life' by the Beatles? I'm just going, 'Whoa, this is worth a hundred bucks right here!'"

"We're very grateful for Sammy's vision in creating Acoustic-4-A-Cure," said Jean Nakamura, MD, whose research receives funding from the concert.

## PLAYING IT SAFE

### Protecting Young Athletes

Oakland Raiders cornerback and Bay Area native TJ Carrie is no stranger to adversity.

During his freshman year of high school, TJ collapsed suddenly during fall football tryouts. He was rushed to the emergency department at UCSF Benioff Children's Hospital Oakland, where he was diagnosed with a coronary artery anomaly.

This birth defect, described by his doctors as a one-in-a-million case, caused the artery to constrict when his lungs expanded, decreasing oxygen circulation during physical activities.

His doctors presented TJ with two treatment options: Avoid physical activity and opt out of high-impact sports or undergo open-heart surgery. The thought of never again playing the game he loved proved too much, so TJ proceeded with the surgery and never looked back.

Not only did TJ continue playing football after the procedure, he earned awards for best football and track athlete his senior year and



TJ Carrie of the Oakland Raiders underwent open-heart surgery at UCSF Benioff Oakland when he was in high school.

was named First-Team All-Conference. He played college football at Ohio University and was drafted by the Raiders in 2014.

"Children's Hospital Oakland has been a cornerstone in my life," TJ said. "Their advanced technology provided vital details about my heart condition. Throughout my recovery from surgery, I received excellent care. The hospital staff treated every patient as if they were their only patient. Thanks to the excellent care, I was able to pursue my goal of becoming a professional athlete."

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The hospital staff treated every patient as if they were their only patient.  
”

— TJ Carrie, Oakland Raiders

Stories like TJ's inspired UCSF health care providers to establish PlaySafe, an outreach program that provides free physical exams for high school athletes. The goal is to detect underlying medical abnormalities and prevent sudden death.

For Alexander Berbey, a high school junior preparing for the fall football season, the PlaySafe physical may have saved his life.

Alexander's EKG revealed a rare congenital heart condition known as Wolff-Parkinson-White Syndrome. "We will always be thankful for the PlaySafe program," said Alexander's mother, Rhoda. "Even the most responsible parents are sometimes unaware of the unique opportunities to keep their kids safer. The test was a lifesaver."

## Life After Cancer

Fifty years ago, only a fraction of children diagnosed with cancer lived to see their next birthday. Today, thanks to advancements in therapies and surgery, kids with cancer have a nearly 80 percent survival rate. That translates to one in every 570 adults between the ages of 20 and 34 being a survivor of childhood cancer.

This is a tremendous success, but the treatments that save so many lives also have a downside: They often damage healthy cells and tissue as well. As a result, children who survive pediatric cancer face an increased risk of “late effects”—health problems including organ dysfunction, reproductive issues, secondary cancers, and psychosocial challenges that surface years or even decades after treatment.

In 2016, UCSF Benioff Children’s Hospitals in Oakland and San Francisco launched a joint Cancer Survivorship Program that brings together the existing programs on both campuses to meet the long-term needs of the Bay Area survivor population.

Co-directed by Drs. Robert Goldsby and James Feusner—both recognized leaders in the field of pediatric oncology—the multidisciplinary program helps survivors achieve optimal health through research-driven clinical care and education for patients and families. As a key component, the program includes a research center focused on investigating late effects of cancer and its treatments.

The Cancer Survivorship Program is made possible in part by a generous gift from Camilla



Shahan and Camilla Soghikian are generously supporting the hospitals’ new joint Cancer Survivorship Program.

and Shahan Soghikian. In his role as a member of the UCSF Benioff Children’s Hospitals Board of Directors, Shahan frequently hears pediatric cancer success stories. But he also understands the potential challenges that face survivors down the road.

As parents of a young cancer survivor, Shahan and Camilla appreciate firsthand the importance of this program in helping survivors navigate life after treatment. They feel fortunate to have benefited from the years of research and dedicated professionals that culminated in the successful treatment of their son, who is now in medical school.

“When Drs. Goldsby and Feusner approached us with the idea of supporting an effort to create a sustainable program built around survivors, we were thrilled to become a part of it,” says Shahan.

Support from the Soghikians will help fund crucial services not covered by health insurance. “Dedicated donors like Shahan and Camilla play a key role in meeting the many needs of our cancer survivors,” Dr. Feusner says. “This gracious donation will allow us to collaborate to an extent not possible before.”

## Teddy Bear Clinic Helps Kids Cope



Hundreds of pint-size doctors and nurses filled the courtyard of UCSF Benioff Children’s Hospital Oakland during the hospital’s free Teddy Bear Clinic on June 4.

Kids brought their favorite teddy bears, stuffed animals, or dolls through a mock hospital. Medical staff and volunteers performed various procedures on the toys, including X-rays, lab tests, and surgery. The interactive event helps familiarize young children with clinical settings and medical procedures.

Festivities also included games, crafts, face painting, and live entertainment by “Tiny Rock,” the Peter Pan Foundation, and children’s author Elisa Kleven.

Reading and singing activities were presented as part of “Talking is Teaching: Talk, Read, Sing,” a national campaign that encourages parents to engage in language-rich activities with their young children starting at birth. The campaign underscores how simple actions can significantly improve a child’s ability to learn new words and concepts.

## LEAVING A LEGACY CLOSE TO HOME

It used to be the family home of Elsie and John McElrath and their 11 children. Now it’s a place that seriously ill and injured kids call home when they receive care for life-threatening conditions.

In 1912, nurse Bertha Wright and social worker Mabel Weed, along with a group of charitable Bay Area women, raised \$12,500 to purchase the acre-plus grounds of the McElrath family estate at 51st and Dover streets in Oakland. The mansion’s stables were cleaned out, and on September 6, 1914, the building officially opened as the Baby Hospital, today known as UCSF Benioff Children’s Hospital Oakland.

As the only pediatric hospital in the Bay Area at the time, the hospital’s growth coincided with growing awareness that children required specialized care. In 1948, as the Baby Boom swept the country, the hospital added a new wing to increase patient capacity. Today, the Oakland campus continues to grow with the addition of our new Outpatient Center, scheduled to open in fall 2017.

Though the family estate was sold before he was born, Alden “Mac” McElrath Jr. maintained a special connection to this historical locale where his father had grown up. He went on to serve as chair of the hospital’s facilities planning



The McElrath family estate officially opened on September 6, 1914, as the Baby Hospital with 38 beds.

committee, a leadership role that complemented his historical ties to the organization.

“Those women did a remarkable thing,” Mac said while serving on the committee, “not just in starting the hospital but also in keeping it going.”

From 1988 to 2006, Mac served on the hospital’s board of directors. During this time he saw the hospital’s research arm, Children’s Hospital Oakland Research Institute (CHORI), grow from a core of five researchers in 1958 to a staff of more than 200. He was a visionary friend of CHORI, providing generous support for the Center for Immunobiology and Vaccine Development.

“Those women did a remarkable thing, not just in starting the hospital but also in keeping it going.”

— Alden “Mac” McElrath

Mac McElrath passed away in 2011, but his family’s legacy will remain strong at UCSF Benioff Children’s Hospital Oakland for generations to come. His wife, Barbara, has included a bequest to the hospital in her estate plan. Her support will help ensure that the hospital her late husband was so passionate about will continue to provide top-quality pediatric health care to Bay Area children well into the future.

A planned gift to UCSF Benioff Children’s Hospitals can provide hope and healing for the area’s most vulnerable children.

For more information, please contact Tina Hurley at (510) 428-3834 or Tina.Hurley@ucsf.edu.



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**UPCOMING EVENTS**

**17**  
September

**An Evening in the Meadow**  
**Private Sonoma residence**  
The inaugural fundraiser for the Ambassadors auxiliary group.

**1**  
October

**Swim Across America**  
**Little Marina Green**  
Make waves to fight cancer at this unbeatable swim under the Golden Gate Bridge.

**5**  
November

**Extra Life Gaming Marathon**  
**Virtual campaign**  
Sign up for the biggest gaming charity event of the year and help support our patients.

**19**  
September

**Score Fore Kids**  
**Blackhawk Country Club**  
Tee off and Score Fore Kids this fall at one of the East Bay's premier golf tournaments.

**5**  
October

**The Concert for UCSF Benioff Children's Hospitals**  
For tickets and more information, go to: [theconcertforkids.com](http://theconcertforkids.com).

For more information please visit [give.ucsfbenioffchildrens.org](http://give.ucsfbenioffchildrens.org) or contact us at [events@mail.cho.org](mailto:events@mail.cho.org).

**CONNECTIONS**  
FALL 2016

**Nationally Ranked in 10 Specialties by U.S. News & World Report**

UCSF Benioff Children's Hospitals rank among the best in the nation in all 10 specialties, and the best in the Bay Area in five practices—cancer, diabetes and endocrinology, neonatology, neurology and neurosurgery, and urology—according to *U.S. News & World Report's* 2016-2017 Best Children's Hospitals survey.

"We are delighted that once again UCSF Benioff Children's Hospitals are among the most highly acclaimed hospitals in the country," said Mark Laret, president and CEO of UCSF Health. "Our physicians, nurses, other patient care workers—all of us—take the care of the children and

**10 fingers toes awards**



families we serve very seriously. They drive our aspirations for excellence in care and research in the pediatric field."

*U.S. News & World Report* introduced the Best Children's Hospitals rankings in 2007 to help families find the best medical care available. The rankings—which are based on annual surveys in which physicians are asked to name hospitals they consider the best in their specialty for difficult cases—open the door to an array of information about each hospital's performance.

"The outstanding patient care and treatments at UCSF Benioff Children's Hospitals are supported by the hospitals' world-class research and the education of residents," said Bert Lubin, MD, CEO of UCSF Benioff Children's Hospital Oakland. "Our rankings demonstrate the value of the services we provide to all children in our community, as well as nationally and globally."

The full report is available at [health.usnews.com/best-hospitals/pediatric-rankings](http://health.usnews.com/best-hospitals/pediatric-rankings).

**Getting Your Kids Involved in Giving**

With the back-to-school season in full swing, this is a great time to teach students about the importance of charitable giving.

A community fundraiser is a meaningful way for young people to give back by supporting a group to which they can most easily relate—other kids.

From bake sales to walk-a-thons, students can take part in planning, promoting, and executing fundraising events that touch the lives of the children and families who rely on UCSF Benioff Children's Hospitals every day.

To learn more about hosting a community fundraiser for UCSF Benioff Children's Hospitals, contact the foundation at (415) 502-0382 or [meghan.mcmurray@ucsf.edu](mailto:meghan.mcmurray@ucsf.edu).



Grateful patient Sarah Banholzer (center) has raised over \$41,000 for our Oakland campus through her annual Be Strong and Give Back Happiness Swimathon.

Photo credit: © 2016 Jon Poling