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

Sami, Age 6 Starting From Square One

It seemed so obvious. Six-year-old Samantha Corley — Sami to her friends and family — just had the flu. No big deal, right?

Wrong. Sami’s case of the flu turned out instead to be a serious autoimmune disorder that required a team of dedicated specialists at UCSF Benioff Children’s Hospital San Francisco to determine the underlying culprit and ultimately cure her illness.

As her parents, Brian and Zephra, recall, in mid-August, after Sami had run a high fever for a few days, they took her to their pediatrician. The doctor tried several different types of antibiotics over a few weeks, but nothing worked.

Within 24 hours, Sami’s fever spiked, and she developed a lump the size of a golf ball in her neck. This time, she was admitted to her local hospital, where she underwent tests for all kinds of infectious diseases, but doctors could not locate the source of the problem. And rather than helping with the symptoms, the antibiotics were causing debilitating side effects. Sami was not eating, her skin was turning gray, and a terrible rash had spread all over her body. That’s when she was transferred to UCSF Benioff Children’s Hospital San Francisco.

“I remember seeing a video of a UCSF researcher saying, ‘When doctors are dealing with unknown medical mysteries, patients find themselves on a diagnostic odyssey.’ That’s exactly what happened to us — until we came here,” says Brian.

As soon as Sami was admitted, a team of specialists went right to work, essentially starting from square one. “They knew how confused and terrified we were,” says Brian. “We put our full trust in them when they said, ‘We will find out what’s wrong with Sami, and we will treat it.’”

“We knew the key wasn’t more blood tests,” says pediatrician Tim Kelly, MD. “Instead we used a process that involves removing the enlarged lymph node in her neck and studying the tissue.”

This delicate surgery led the team to discover that a rare autoimmune disorder called Kikuchi-Fujimoto disease had attacked Sami’s lymph nodes. “Once we removed the lymph node and stopped the antibiotics, which were causing a severe rash and other problems, she made a full recovery,” notes Dr. Kelly.

At UCSF Benioff Children’s Hospitals, we are often the last hope for children like Sami, who end up on that terrifying diagnostic odyssey that takes them from doctor to doctor, clinic to clinic, test after test, with no conclusive results.

“We get diagnostic dilemmas all the time,” says Dr. Kelly. “Our researchers constantly seek to discover new information in order to unravel the complex puzzles in health. They have a passion for figuring things out, and they will absolutely never give up.”
Ringing in Hope for the Future

Tula Mouroufas was born in a small village overlooking Sparta in southern Greece. The youngest of six siblings, she moved to America at age 11, settling first with her mother in New York, and then venturing west to California as a young bride. She has remained deeply connected to her Greek roots.

A love of travel landed Tula in a public relations position at Alitalia and later, at United Airlines. While at United, she met her husband, Chris, a prominent political fundraiser.

Over the years, Tula and Chris made frequent trips abroad to Greece. On one such trip, they adopted Angela, a beautiful, 3-month-old girl. Angela grew to be an active child who loved soccer, swimming, and skiing. No one, least of all her parents, ever suspected that she had a serious health issue. But at age 15, Angela died suddenly from an undiagnosed heart arrhythmia.

Tula and Chris returned to Greece six months later, this time bringing their young nephew, also named Chris, back to the States, where he has remained ever since.

"Chris was a wonderful addition to our family at a very difficult time," Tula says. "We adopted him, and he is now a talented, up-and-coming artist in San Francisco!"

When her husband passed away from prostate cancer in 1995, Tula reflected on a meaningful way to celebrate the lives of Chris and their daughter. Maxine Papadakis, MD, a close friend and former associate dean for student affairs in the School of Medicine, introduced her to UCSF. While touring UCSF Benioff Children’s Hospital San Francisco, Tula was moved by the sight of a young cancer patient ringing a bell near the nurses’ station. The brass clanging joyfully signaled the end of the girl’s chemotherapy.

"My heart was so touched when I saw the pure happiness on her face as the bell was ringing," Tula recounts. "Children are very dear to my heart. I’ve always wanted to do something to ease their suffering. I knew then what I wanted to do."

Inspired by her visit, Tula made a generous gift to name the waiting room on the first floor of the hospital in memory of her husband and daughter. In addition, she committed to leave a bequest to establish the Tula Mouroufas Endowed Professorship in Pediatrics.

"UCSF has a wonderful reputation for being number-one in research and clinical care," she says. "I never had a moment of hesitation in having my family’s legacy associated with UCSF Benioff Children’s Hospital San Francisco, because our children deserve the very best. If one child can be saved as a result of my giving, then I’ve done my job."

The Healing Power of Poetry

Engage the imagination powerfully enough to absorb a child completely for 20 minutes. Provocatively, gently, to stimulate a memory or a detail from the child’s past or present that will inspire a special word or two, an image, a name. And from that comes a poem.

It’s magical watching Sally Doyle and Kathy Evans set this process in motion. Both published poets from California Poets in the Schools – one of the largest literary artists-in-residence programs in the nation – they visit our young patients every week to pull them out of their illnesses and into the powerful world of poetry.

Sally and Kathy are part of the UCSF Benioff Children’s Hospitals poetry program, an offering through our Child Life department that helps patients put their experiences into words and give voice to their emotions. The program started on our San Francisco campus in 2010 with support from Ken Haas, a local poet and benefactor who wanted to see poetry brought to children suffering from serious injuries or life-threatening illness.

"At first, everyone I spoke with thought poetry writing in a children’s hospital setting was a great idea, though each had 10 reasons why it was impossible," says Ken. "But with perseverance, vision, and a willing ear on the part of UCSF, the idea won out."

Five years later, the program expanded to our Oakland campus, allowing us to bring the power of poetry to more than 500 young patients and their families on both sides of the Bay.

"I’ve taught poetry at juvenile hall, in colleges, and in senior homes," says Kathy. "But the hospital has been the most meaningful place to me. I’m stunned by some of the things these kids come up with."

Sometimes patients will use their poems to look squarely at their illness, treatment, things they miss about home. For others, a poem will offer the opportunity to explore new feelings, fears, and dreams.

Following the writing sessions, students have something to take home and share with family and friends. If there’s time, they have a chance to read their poems aloud to the rest of the class, which stimulates conversation and builds confidence.

"One of the most important battles we face as human beings is the war against disease," says Ken. "Children fighting for their health are on the front lines of that war and are therefore our greatest heroes in our greatest battle. Now more than ever, the world needs to hear their voices. When they write, they write for all of us."

Flying Potion

Start with a cup
Clip two eagle feathers
Add a handful of pixie dust
A pinch of blue sky,
Fill cup with upside down rain water,
Add two telescope eyes,
Toss everything into a cup
Decorate cup with a glitter cape,
Drink up and Wallaaa
You can fly!

– Diego, Age 6
Autism Researchers Discover Genetic ‘Rosetta Stone’

New findings by UCSF autism researchers could unlock fundamental mysteries about how events early in brain development lead to autism.

The study found that distinct sets of genetic defects in a specific gene, known as SCN2A, can lead either to infantile epilepsy or to autism spectrum disorders (ASDs), depending on how the mutations impact the gene’s function. The study also solidified SCN2A’s status as the single human gene with the strongest evidence for a causal role in driving autism.

“The genetics of neuropsychiatric disease are often complicated, but here we have a single gene in which specific mutations can cause either infantile seizures or autism in a consistent and predictable manner,” says study co-author Stephan Sanders, PhD, assistant professor of psychiatry at UCSF. “This gives us an opportunity to understand what these disorders have in common and what makes them different.”

The link between autism and the SCN2A gene was first discovered by Matthew State, MD, PhD, who chairs the Department of Psychiatry at UCSF.

“In autism research, understanding why mutations in a single gene can lead not only to ASDs but also to a wide range of other neurodevelopment disorders has emerged as a central question for the field,” says Dr. State, who was not directly involved with the new study. “This new work provides crucial clues that could serve as a molecular ‘Rosetta stone’ to illuminate autism pathology.”

The advent of genome sequencing in recent years has allowed researchers to make significant progress in identifying genetic risk factors for autism.

“In the past four years, we’ve gone from not really knowing how to find autism genes to having a long list of mutations linked to the disorder,” says Dr. Sanders, who led the new study with neurophysiologist Kevin Bender, PhD, an assistant professor of neurology at UCSF.

The next step will involve learning whether the severity of autism and developmental delay can be predicted by a specific SCN2A gene mutation.

Opting Outdoors with the REI Foundation

When Nooshin Razani, MD, was in fifth grade, her elementary school took a week-long trip to Yosemite National Park. She still remembers that week with startling clarity, comparing the experience to falling in love. Decades later, her appreciation of the natural world remains as strong as ever.

Dr. Razani is now director of the Center for Nature and Health at UCSF Benioff Children’s Hospital Oakland, which promotes access to nature as part of patients’ care and overall well-being. Dr. Razani is thrilled that “prescribing nature” has become an integral part of clinical treatment. Prescriptions include enrolling patients and families in a monthly nature shuttle to visit local parks, trails, and open spaces to improve their health.

The parks prescription program was designed in collaboration with the East Bay Regional Parks District and made possible through the support of dedicated partners such as the East Bay Regional Parks District Foundation, the National Recreation Parks Administration, and most recently, the REI Foundation, which awarded the Center for Nature and Health a grant of $200,000.

“One of the REI Foundation’s primary focuses is to get more young people – especially youth from underserved populations – into the outdoors,” says Laura Swapp, vice president of the REI Foundation. “By supporting the Center for Nature and Health, we’ll help families discover the benefits of outdoor experiences and ideally inspire other organizations and hospitals to follow UCSF Benioff Oakland’s lead.”

Studies show the trend toward sedentary, indoor life parallels the increase in heart disease, obesity, and type 2 diabetes. But these conditions also are preventable, and organizations like UCSF Benioff Oakland and the REI Foundation are actively exploring the role of outdoor activity as part of the solution.
A Night of Glamour for Teen Patients

It’s prom season, but some high school students never make it to the big party because they’re battling critical illnesses or recovering from serious injuries.

On April 21, UCSF Benioff Children’s Hospitals will bring this rite of passage to our patients with a special prom for those who may be forced to miss the event. From dancing to posing for pictures, every teen will have the chance to experience the whole nine yards.

This year, for the first time, we are hosting prom events concurrently on both hospital campuses. The masquerade-themed parties will include a photo booth, a dance floor, a DJ playing the latest hits, face painting and commemorative giveaways.

To top it off, NFL players from the San Francisco 49ers and Oakland Raiders will escort prom attendees down a red carpet and pose for photos.

For patients like Sana, who attended last year’s prom, the event was a welcome opportunity to unwind and feel like a typical teen, even if for only a night. “The prom was an unforgettable experience! I made lasting memories that will hold a special place in my heart forever,” she said.

We would like to extend a special thank you to our generous event supporters: Children’s Health Guild, Costco, Jeff Cable Photography, Denon & Doyle Entertainment, Girl Scout Troup 30647, Head Royce Fine Arts Dance Ensemble, the Milani family, the Novogradac family, the Oakland Raiders, Okutake Designs, Salesforce, the San Francisco 49ers, Sound on Stage, Elisa and Marc Stad, Style Bee, and Swinteron Builders.

“Many of our teens can miss out on important parts of their adolescence because of hospitalization or medical treatments,” said Katie Craft, child life specialist at UCSF Benioff Oakland. “It is incredibly moving to be able to help give them this special night.”

President’s Close Shave

Our new President, Mike Anderson, MD, has made a drastic change in his appearance in the name of cancer research: He shaved his head for the cause at the 10th annual St. Baldrick’s Brave the Shave event held on March 11.

Dr. Anderson was joined by a team of dedicated Children’s doctors, nurses, researchers, and staff who took to the barber chair to raise funds to support research in pediatric cancer. More than 160 participants took part in the hospital’s signature head-shaving event, raising over $160,000 to find the best treatments for kids with cancer.