Finding the Right Match: Leukemia, a Stem Cell Donor and Charlie's Law

When Charlie Huang almost lost the chance at a lifesaving stem cell transplant to treat his acute myeloid leukemia, he vowed to help others find a donor match.

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A cancer diagnosis is hard enough to deal with under normal life circumstances, but it became a major ordeal for thousands of Americans during the height of the COVID-19 pandemic. Getting a diagnosis, scheduling medical appointments and receiving treatment—never simple tasks to begin with—were burdened with extra difficulties. What's more, to avoid possible exposure to the virus, people with cancer in many cases could not be surrounded by their loved ones; instead, they had to face these challenges alone.

Charlie Huang knows the struggles well. His cancer battle has spanned the years of the pandemic. In August 2019, he was a 44-year-old criminal prosecutor in Santa Clara County, California, engrossed in the middle of a domestic violence murder trial, working long, intense hours, when he caught a cold from one of his three daughters, ages 12, 9 and 3 at the time. "I could not shake it. I just got worse and worse," he recalls. His back went out, his stomach acted up and his muscles cramped, making climbing stairs difficult. And every day, he got terrible headaches.

Charlie Huang and his wife, DorisPaul Sakuma

Finally, in November, after the trial ended, Huang saw his doctor, who told him he was stressed and needed physical therapy to address his slouch. “My head was so heavy, I couldn’t keep it upright,” he says. But after two weeks of relaxation, he was no better. So the doctor recommended blood work. When the results came back, the lab tech crew requested another test because they thought their equipment was broken. But the retest showed the issue was his blood: His white cell count was off the charts. The likely reason, he discovered, was chronic leukemia.

It took another three weeks for Huang to connect with a specialist, who was certain that Huang had acute leukemia and that as a chronic leukemia specialist he could do nothing for him. But the doctor was also adamant that Huang go to the emergency room at Stanford Hospital right away. He arranged for a bone marrow biopsy at 6:15 a.m. the next morning, a Saturday, which confirmed the diagnosis—acute myeloid leukemia (AML), an aggressive blood cancer. After a weekend at home, Huang was admitted to the hospital on Monday, December 5, 2019. He was so ill, he recalls, “the doctors told me if I had waited three more days before going in, I would not be around anymore.”

Remission—and Relapse

During his hospital stay, Huang was given four rounds of “superstrength chemo to basically do a reset of my bone marrow,” he explains. His last round of chemo was in April 2020. He had spent more than four months alone in the hospital as COVID raged across the country.

Huang returned to work in November 2020, hopeful that he was cured of AML. He resumed his old routine, avoiding COVID and getting bone marrow biopsies and blood draws “every so often.” So far, so good. Then he caught a minor cold in February 2021. “I thought it was allergies, but by the time April rolled around, my headache had come back,” he says. “That’s when I knew it was bad news.” This time, the doctors told him that “the only way to kind of stay around was a bone marrow transplant [also called a stem cell transplant].” But there were several hurdles to surmount first. Huang would need to be back in remission. And an appropriate match would have to be found.

Remission Again—and Charlie’s Law

In May, Huang returned to the hospital and underwent a month of “consolidation” chemo that put him back into remission. Meanwhile, Stanford Hospital staff searched the local, national and global databases for a donor. “They came back and told me, ‘We’ve searched, and you don’t have a single match in the entire world,’” he says.

That’s not uncommon for minorities (Huang identifies as Asian American), especially those with no siblings (siblings offer the greatest chance for a match). While white patients have a 79% chance of finding a match, the odds drop to 48% for Latinos, 47% for Asians and Pacific Islanders and 29% for Black Americans. COVID was also making the odds more difficult, with international travel bans, border closings and a drop in stem cell collections.

“I felt so much despair,” Huang recounts. “I worked so hard, and I was so lucky to be in remission, but it didn’t even matter. All the suffering through chemo didn’t matter because there was no light at the end of the tunnel for me.

“My girls and my family—they’re the center of my universe,” he continues. “To feel that they would grow up without a father, no one to teach them to drive, to scare their boyfriends away. I just remember crying in the hospital room by myself and thinking, This is the worst feeling. I do not ever want anyone to feel the way I am feeling, with so much despair and hopelessness.”

Huang’s emotional anguish planted the seed of an idea. If Californians could sign up to be organ donors when getting their driver’s licenses, he reasoned, why couldn’t they sign up to be stem cell and bone marrow donors? He immediately started drafting legislation in his hospital bed (see “Charlie’s Law: How It Will Help,” below).

The Perfect Match

Ironically, Huang knew of a perfect match: Denny, his only sibling. Denny had been tested when Huang first became ill, but he was a brain cancer survivor, which made him an unsuitable match. However, with no other eligible donors, Huang’s doctors decided to put Denny through two weeks of comprehensive testing to determine whether donating his stem cells would be safe for both brothers. They made the highly unusual decision to harvest Denny’s stem cells, a process that

takes time but isn’t painful.

Charlie Huang, left, with his brother, DennyCourtesy of Charlie Huang

The stem cell transplant was done in July 2021. The first 100 days posttransplant required 24-hour care, which Huang's wife, Doris, and his mother-in-law took on. "Your immune system is completely wiped out, so there's no eating out, no salads, no eating anything raw. Everything had to be exactly the right way," he says. His doctors predicted it would take a year to regain his strength, which Huang feels was accurate.

There are two big risks posttransplant, he says. The first is graft versus host disease (GVHD), which can be acute or chronic. The acute version, when the donor stem cells start to attack the host's organs as foreign, can happen within days to a year after a stem cell transplant and can be fatal. ("Knock on wood, I'm out of the window for the acute," Huang says.) The chronic version, which occurs more than three months posttransplant, leads to symptoms like dry eyes, dry mouth, fatigue, joint pain and rashes and can last a lifetime.

The second big risk is relapse, which means that, although the donor stem cells are doing their job in the host's body, "the transplant didn't work; the cancer is still too strong or overwhelming," he says. "The doctors tell me it's a three-year window—if I can make it past three years, then statistically the odds are really good." This summer marks year two.

Huang is not taking immunosuppressant drugs, which could lower his odds of getting GVHD, because they increase his risk for relapse. "I told my medical team that I'd rather live with graft versus host disease than not be around for my kids," Huang says.

Life, Reimagined

Huang is back at the Santa Clara County prosecutor's office but no longer overseeing murder trials, which are stressful and consume months of high-pressure work. And he takes a lot more time off to be with his family.

"We try really hard to have dinner together every night and talk about our day," Huang says. "We enjoy traveling as much as possible, and we're always making more memories and trying out new experiences every time we take a trip." Since the transplant, the family has been to three different islands in Hawaii in addition to New York City; Philadelphia; Washington, DC; Vancouver; Washington state; and, over spring break, Japan, where they visited Tokyo's famous cat and pig cafés to cuddle the animals.

"My goal is to do as many things with my kids as possible," he says. "Whatever happens in the future, I want them to remember that they did things with their dad—hanging out at the resort pool, deep-sea fishing, snorkeling, taking golf lessons together. I'm also trying to squeeze in as many parenting duties as possible—like picking my kids up and dropping them off at school. And my wife and I hold hands and watch Netflix together a lot more often now and enjoy our time together.

“I spent many nights alone in the hospital being so sad as I recalled my life. I thought I was doing the right thing, dedicating my time and energy to public safety, but it was at the expense of watching my kids grow up. And not to say my job isn’t important—it is very important. But anyone can do my job, but not anyone can be a father to my three daughters.”

Sidestory

Charlie’s Law: How It Will Help

As a criminal prosecutor and community activist, Charlie Huang is well connected. He has met many lawyers and legislators through the nonprofit he started, the National Asian Pacific Islander Prosecutors Association (NAPIPA), which now has seven regional chapters across the United States. And those connections helped him turn a dream into reality.

Spurred by his own challenges in finding a donor for a lifesaving stem cell transplant, Huang wanted to help others—especially those in underrepresented communities—find a matching donor. His idea was simple: Californians ages 18 to 40 who are applying for or renewing a driver’s license (or ID card) can sign up for the National Marrow Donor Program’s registry as a bone marrow or blood stem cell donor by checking a box. Potential donors will receive a kit in the mail for them to swab the inside of their cheek for DNA. When it is returned to Be The Match, that genetic information will be stored in a secure national database, and cancer doctors who need to find a match for their patients will have access to it.

Sponsored by Evan Low, a California assembly member, the bill failed in the appropriations committee when it was first introduced in 2021. Undeterred, Low reintroduced it in 2022. This time, Huang, the Leukemia & Lymphoma Society, Be The Match, Stanford Health, the University of California health care system and numerous volunteers formed a powerful coalition to get Assembly Bill 1800—aka Charlie’s Law—across the finish line. And on September 30, 2022, Governor Newsom signed it. The law takes effect in 2027.

Since the legislation was introduced, advocates in New York, Louisiana and North Carolina have reached out to Huang for his help in passing laws to increase bone marrow donors in those states too.
