Stories of Hope

*These patients have shared their stories with us and with our governing Board. Hear first hand about their hopes for a cure, alongside updates from CIRM grantees who are working to make these patients’ hope a reality.*

The CIRM Stem Cell Four

At our 2016 CIRM December Board meeting, we invited four people to speak about their experience participating in CIRM-funded stem cell clinical trials. Their stories are inspiring and remind us that the ultimate goal of funding stem cell research is to find treatments that can cure patients with unmet medical needs. We hope that the voices of these individuals will inspire others who are suffering from diseases that have no cures.

*Read More*
Sickle Cell Disease

For Evie Junior, personal health and fitness have always been a top priority. During his childhood, he was active and played football, basketball, and baseball in the Bronx, New York. One would never guess that after playing these sports, some nights he experienced pain crises so severe that he was unable to walk. One would also be shocked to hear that he had to have his gallbladder and spleen removed as a child as well. The health issues that Evie has faced all of his life are related to his diagnosis of sickle cell disease (SCD), a genetic, blood related disorder.

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Lea la historia de Evie en Español

Diabetes

The last thing Maria Torres expected was to be diagnosed with type 2 diabetes. She exercised, ate well and kept her weight under control. There had to be some mistake. Maria asked her doctor to repeat the tests, but the results were the same. At 43, for reasons no one could fully explain, she had diabetes, and her life was going to change dramatically.

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Lea la historia de María en Español

Alzheimer’s Disease

Adele Miller knew what came next. She had lived it twice already: her father’s unraveling, due to Alzheimer’s disease, and, a few years later, her mother’s journey through the same erasure of mind and memory. So when doctors told her, at age 55, that she, too, had the disease, she remembered her parents’ difficult last years.

“She was ashamed,” her daughter, actress and writer Lauren Miller, recalls. “She was so embarrassed because there’s such a stigma.” And she worried about her family. How would they handle all this? “I asked her once if she was scared,” Lauren says. “She said she wasn’t afraid for herself. But she was afraid for me, and my dad, and my brother. She knew what she’d gone through with her parents.”

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Lea la historia de Lauren en Español
Stroke

Six months after surviving a stroke, Sonia Olea wanted to die. Her right leg was weak, her right arm useless. She had trouble speaking and even small tasks were challenging. Just making a phone call was virtually impossible. One morning, she woke up with her arm pinned in an awkward, painful position. After finally repositioning it, she wanted to call her fiancé, but knew she couldn’t get the words out. That’s when it hit her. “I thought, I’m only 32,” says Sonia. “How could this be happening to me?”

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Lea la historia de Sonia en Español

Spinal Cord Injury

In high school, Jake Javier played offensive line and was being recruited to continue to play football in college. His original plan was to play football for Cal Poly San Luis Obispo while studying mechanical engineering. Unfortunately, one day before his graduation from San Ramon Valley high school, Jake was paralyzed from the neck down in a freak accident after diving into a swimming pool.

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Lea la historia de Jake en Español

Leukemia

Stem cells create life. But if things go wrong, they can also threaten it. Theresa Blanda found that out the hard way. Fortunately for her, CIRM-funded research helped her fight this threat, and get her life back. In the first few days of human development embryonic stem cells are a blank slate; they don’t yet have a special, defined role, but have potential. The potential to turn into the cells that make up our kidneys, heart, brain, every other organ and every tissue in our body. Because of this flexibility, stem cells have shown great promise as a way to regenerate dead, diseased or injured tissue to treat many life-threatening or chronic conditions.

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Lea la historia de Theresa en Español

Multiple Myeloma
Byron Jenkins was every bit the Top Gun. As a Navy fighter pilot he flew F-14’s, the kind of plane featured in the movie Top Gun. An accomplished athlete in college Byron was the epitome of good health, until one day in June 2013 when he jumped into a swimming pool and almost died. He was rushed to the hospital and diagnosed with multiple myeloma, an incurable blood cancer.

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Retinitis Pigmentosa

Rosie Barrero was 26 years old and pregnant with twins when she was diagnosed with Retinitis Pigmentosa (RP) a rare degenerative disorder that attacks the light sensing cells in the eye. “It was absolutely devastating to know that I would be a mom, and that I would eventually go blind.”

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Bone Repair

It was just a little stumble. Or that’s what it seemed to Diana Souza when she fell while doing chores on her Northern California ranch. But her left arm was fragile and it snapped where an earlier break had healed crookedly. What came next was worse: three surgeries that didn’t work, an orthopedic surgeon proposing a fourth, and an arm bone riddled with holes.

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Autism

One of the most complex aspects of autism is that it is not one disease—but many. Known more accurately as the autism spectrum disorder, or ASD, experts have long been trying to tease apart the various ways in which the condition appears in children, with limited success.

But now a new kind of stem cell is helping unlock some of the secrets behind ASD and offer clues as to potential new treatments. And it’s all thanks University of California at San Diego researcher, Dr. Alysson Muotri, and the Tooth Fairy.

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Heart Failure

It was grandpa to the rescue when Fred Lesikar’s granddaughter tried to put on a pair of jeans several sizes too small. The toddler was stuck. She could not pull them up, and she could not pull them off. Lesikar, then 59, stood on the cuffs of the jeans and began to lift her out of the pants.

But it hurt. Pain radiated across his back and around his chest. It ran through his biceps and up under his chin.

He should have called 911. He will tell you that now. Instead, he asked his stepdaughter to drive him to the hospital.

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Macular Degeneration

Anna Kuehl was in her mid-30’s when she was diagnosed with an early form of macular degeneration (AMD), a condition that results in the loss of central vision and is the leading cause of vision loss in the US.

Over the next few years her eyesight deteriorated to the point where she wasn’t able to hike on her favorite nature trails. “I couldn’t read the trail names on the posts anymore,” said Kuehl. “I always had to take so many things with me — my magnifying glass, my reading glasses — and I always printed out a big map.”

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ALS (Lou Gehrig’s Disease)

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease, is a particularly nasty degenerative disease where motor neurons, the brain nerve cells that control movement, are damaged and stop working properly. As those motor neurons die the muscles they control stop working. Once ALS starts it almost always progresses. Patients lose the ability to do things for themselves: to walk, to speak and even to swallow. Eventually, the muscles that control breathing fail—the cause of most ALS deaths. There is no cure and treatments are limited. CIRM has funded two clinical trials targeting ALS.

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HIV/AIDS

It was perhaps the biggest moment of Loring Leeds' life, but as he lay waiting for doctors to return his stem cells to his body, Leeds realized it was a signature moment for the crowd in the room as well.

It was 1998, and surrounding him were the doctors and scientists who had developed a treatment for non-Hodgkin lymphoma in AIDS patients—something most of the medical community at the time considered pointless and hopeless. But Leeds' stem cell treatment was even more dramatic, because some of his cells were genetically modified to express an enzyme researchers hoped would short-circuit AIDS.

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Parkinson's Disease

For Bruce Wisnicki and other Parkinson's patients, the benefit of most Parkinson's medications might be summed up with the bromide: "This too shall pass."

Because of the degenerative nature of the disease that depletes the dopamine producing brain cells, medications to control symptoms eventually lose their punch.

"I'm one of the lucky ones," Wisnicki says.

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