# Embracing the C4RCD

## In memory of 'warrior' son, Laffoon family seeks to help others


Photo courtesy of the Laffoon family

When TGen announced the formation of the C4RCD, Steven and Shannon Laffoon were ready to help.

The Scottsdale couple had spent the past three years caring for their only child, Wylder James Laffoon, pursuing whatever treatments might be possible for his diagnosis of Niemann-Pick Type A, an extremely rare and fatal disease characterized by an inability to metabolize fats.

Following TGen's announcement of the C4RCD in October 2012, the Laffoon's now want to help other families of children with rare disorders.

"The C4RCD is everything we wanted to do. We want to provide options for people who don't have options," said Steven.

While the Laffoon's had a definitive diagnosis, what they didn't have was a captain, a champion, a go-to person willing to steer Wylder's treatment.

"We were alone; frustrated. We were the driving force," said Steven, who with Shannon spent years initiating and building relationships with doctors, scientists, biotech and pharmaceutical companies — even negotiating with the U.S. Food and Drug Administration for approval of an experimental drug trial.

"We're pretty self-sufficient. We can make things happen. But we also got chewed up and spit out by the medical system," Steven said. "If this is complicated for us, it's just got to be so hard for other families."

With Shannon providing intensive day-to-day care for Wylder, and Steven pursing a relentless Internet search for treatments, the Laffoon's navigated their son through 27 blood transfusions and 15 medical procedures, including 5 brain surgeries.

"There are families dealing with the same things we dealt with," Steven said. "They're getting diagnoses, but then getting essentially the same feedback from doctors that we did: 'There is nothing we can do. Go home and enjoy what time you have left with your child.' But we couldn't just sit there and watch his disease progress and be OK with it. For us, it was hard to fathom that we didn't have even one option."

Steeped in the culture of Hawaii, the Laffoon's described Wylder as their "warrior," fighting to survive while teaching his parents, and everyone who came in contact with him, what it means to care, to love, to live in the moment and never give up hope — how each of us are on a journey that teaches appreciation, patience, compassion, kindness and wisdom.

Though he could never speak, Wylder communicated to his parents when it was time to stop. In July 2012, he passed away — his ashes scattered with 6,000 flowers and an Aloha spirit across a shining bay in Maui, a bay now visited by a young humpback whale called Wylder.

Even before their son was gone, the Laffoon's started focusing on how their experience might help others. They are in the process of setting up a foundation, Warrior Nation, and Shannon even wrote a children's book, *Warrior Baby*.

"Since Wylder has passed, the thing that gives us the most peace is doing things for him, in his honor," said Shannon. "And long-term, to help parents have an easier journey, because we know how complex and difficult it is."

You can learn more about Wylder at wylderjames.com.

Genome in a day sequencer released

**2012**

**January**
- TGen begins planning the Center for Rare Childhood Disorders (C4RCD)

**May**
- TGen begins series of projects focused on rare childhood disorders, including Aicardi syndrome project

**August**
- First meeting of National Advisory Panel
- TGen completes 10th genome for the C4RCD

**October**
- TGen completes 30th Genome for the C4RCD
- Media launch of the C4RCD

**October**
- 10-family *Understand Your Genome* event with Illumina

**November**
- Second meeting of National Advisory Panel
- TGen acquires genome-in-a-day HiSeq2500