

# Kamakoia Dela Cruz: A 'Brave Warrior'

Leslie Lang

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The first time I met 9-year-old Ethan "Kamakoia" Dela Cruz, it was a beautiful fall afternoon. He greeted me with a hand slap, and then leaned in to give me a friendly hug and kiss.

We were at a park near his Kohala home, along with his Full Life Hawaii direct support worker Katherine Belleci. "Aunty Kat" has worked with Kamakoia for about a year, focusing on four areas that are challenging for the third grader who was born with Down syndrome: socializing, words, physical activity and personal hygiene.

The day before, she'd taken Kamakoia for a therapeutic horseback riding lesson, and I asked him if he liked riding horses. "Yeah," he said, touching my arm. "How about you?"

That, Kat tells me later, is exactly what they've been working on – having conversations that go beyond just saying, "Hi."



“He can’t say some sounds well and it’s hard to understand him, so we work on speech patterns,” she says. “When he says a word I don’t understand, we talk about it. We figure out what it is, we say all the sounds, and we say a whole sentence with the word. It’s going great. He’s voluntarily using whole sentences on his own now. And his speech patterns are so much clearer. After a year, we’re actually having real conversations now.”

While Kat and I talked at a picnic bench, Kamakoa got up and started walking off. Kat watched for a moment and then gently followed. She told him he could be on his own but he needed to stay nearby. He did a little happy dance – “He loves having his freedom,” she told me – and then sat down on the grass not far from us. After awhile, he was lying on his stomach and arms, comfortably resting.

When his mother Malia Dela Cruz was pregnant, she had an ultrasound and then, at the doctor’s recommendation, an amniocentesis test. It was April Fool’s Day when they got a phone call saying their baby had Down syndrome, and at first Malia and her husband thought it was a bad joke. But it wasn’t.

“We were pretty devastated,” she says. “Just kind of grieving, in shock – not knowing how to deal with it.”

“Now, though, we don’t know what our life would be without him,” she says. “We feel blessed.”

The baby was born prematurely, and at two weeks old, he had heart surgery for a hole in his heart. He was in Kapi’olani Hospital’s NICU for five weeks. Before he went home, nurses trained his parents to administer oxygen and use his feeding tube.

Malia and her husband Eugene named the baby “Kamakoa” – Brave Warrior, or Child Warrior – because they wanted him to have a strong name. Malia says it ended up being very appropriate.

“When we got him home,” she says, “he really thrived. After maybe a month, he pulled out his feeding tube. And he didn’t need oxygen anymore. He was just this trooper.”

“He had health issues that whole first year, and he overcame every one. It was hard, and we didn’t know what we were doing as parents, but he just showed us, every step of the way. He was such a happy baby. It made it so much easier.”

To this day, she says, “He’s all about joy.”

She’s not only very happy with his progress this past year since they started with Full Life Hawaii, but also with his schooling. Kamakoa spends part of each school day in a third grade classroom, with an aide, and the rest in a special ed class. Malia says he loves school – the social interaction, and being included with the rest of his classmates.

“The majority of the morning, he’s one-on-one with language arts and math,” she says, “and when it comes time for science and social studies, they have him in inclusion. It’s a nice balance for him.”

Kat adds that the school is also working with him physically. “The physical therapist said he needs to strengthen his core, so his arms and everything else will get stronger, and they’re emphasizing this at school with floor exercises and the jungle gym. They just started with dodgeball the other day. They’re getting him running and dodging the ball. He loves that.”

When school’s in session, Kat and Kamakoa spend four afternoons a week together, and they have more time together when it’s not.

They play basketball, swim, or climb on the park’s playground equipment. When other kids show up, Kamakoa introduces himself. It’s another area he and Kat are working on – getting someone’s attention appropriately, and issues of personal boundaries.

Malia talks about how good Kat is with Kamakoa. “She is just so perceptive, and whatever goals we have for him, she really strives for them,” she says. “She is very professional about how she approaches everything.”

And she appreciates that Kat doesn't baby him. "She said she wants to be his ally, someone he can depend on – but not like a mom. She's just been a rock star for our family. We are so pleased to have her."



#### Kat and Kamakoa

Kat's happy, too. She says, simply, "I love Kamakoa. We became best friends within the first couple months. The closer we get, the easier it is to teach him the things he wants to know and needs help with. Having that kind of rapport, I think, really benefits our goals."

She calls it "a sweet job. It's really sweet working with him and seeing his excitement. I get really excited seeing him take steps on his own."

Kamakoa's parents' goals for him, which Kat and Full Life are helping him work toward, are that one day he will graduate from high school and be able to live independently. "Whether he wants to be in his own apartment, or in a group living situation," says Malia. "We just hope he will become a successful citizen; and somehow contribute to his community, wherever he ends up."

She says she can see him doing it. "We just have to be patient and get him there. I am so pleased with how it is going."

When Kat considers Kamakoa's future, she says, "He's smart. He's going to do something great. That's all I know."

After a few more games of thumb wrestling at the park, it was time to say goodbye. Kamakoa put his arm around me as we walked together to the parking lot. "I'll help you with your door," he said. He opened my car door, I got in and he closed it. I mimed an exaggerated "Bye!" through the window and got a huge grin in return.



