

Planting Seeds



(Left to right) Ruvy and sons Jordan and Dominick

Photo courtesy of Hawaii Music Live

by Megan Long

Life tends to unfold in unexpected ways. For better or worse, we must learn to find strength and believe in ourselves to adjust and carry on. California native Ruvy De Guzman had to learn how to do just that.

On February 9, 1989, Ruvy gave birth to her first-born child, Jordan Barcelona. Going through labor and becoming a parent is a scary thing for most, so when Ruvy found out that her son would have to have a below-knee amputation, it was devastating to her entire family.

“I was in total shock and actually went into premature labor. They admitted me to the hospital and I woke up the next morning with four doctors in my room,” Ruvy says. “My heart

sank as they explained to me that my baby had amniotic band syndrome.”

Amniotic band syndrome occurs when a limb gets entangled in fibrous bands, causing abnormalities. This condition affects 1 in 10,000 babies. Amputation, however, is not a very common solution.

“I had never heard of it. My world crashed. It was like a nightmare,” Ruvy says.

After having a natural childbirth and bonding with Jordan for a “hot second,” he was whisked away and his foot was amputated immediately. “There was no way to save the foot. It was hanging like a twisted balloon with no formation,” Ruvi says.

“It’s hard enough raising a family and being a career woman. When you are raising a child with a disability, it is tenfold,” Ruvi says.

Two months later, Jordan’s bone was protruding through his leg. It had grown faster than the skin, requiring doctors to “shave” it. The orthopedic surgeon told Ruvi that Jordan would probably need surgery about every 2 years. Fortunately, he only needed two surgeries rather than the 10 Ruvi had anticipated. As he grew, he would also need a new fitting for his prosthesis every 2 months. Ruvi often had to take off work to accompany Jordan to get his prosthesis refitted or to undergo surgery.

Through it all, Ruvi has remained optimistic and strong. “You can’t wallow in your sorrows forever,” she says. “You have to learn to count your blessings. It’s a mind-shift.”

Over the years, Ruvi has raised three kids (Jordan, 20, Dominick, 16, and Ciara, 8), maintained a full-time job, owned a business, taught classes, volunteered as a mentor, gone on leadership retreats and organized charity events.

“I have always been a multitasker and very involved. I learned how to carve my time wisely,” she says. “I have learned to eliminate time-wasters and hone in on what should take priority.”

Ruvi sees herself as a visionary. “I believe that this has happened to me for a purpose. I feel as if I am designed to be a mentor and a warrior.”

Ruvi felt the call to become a mentor after realizing how helpful she could be to someone going through the same thing she experienced. She, after all, didn’t have anyone that could empathize with her when she was a new mother.

After doing some research, Ruvi called CARE Parent Network, a support group for families

of children with disabilities. “Something was telling me to be there,” she says. “I just wanted to hear their stories because I was sure I had already walked down that road.”

Ruvi became the first amputee mom to work with the organization. Little did she know what a difference she would make. One day, CARE Parent Network received a call from Children’s Hospital of Oakland,

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looking for a parent of an amputee. Tamika Southern-Mixon had just given birth to a baby girl whose case was very similar to Jordan’s. She needed to talk to someone who could understand. “We became fast friends,” Ruvi says. Coincidentally, Tamika only lived 15 minutes away from Ruvi.

Ruvi feels she is at a phase in her life where she has the desire to share her story with others. “It’s interesting how when you give out that energy and reach out, doors begin opening,” she explains. First 5, a nonprofit organization that funds the CARE Parent Mentoring Program, will feature Ruvi and Tamika as a successful mentor match for their annual report. The *Contra Costa Times* recently highlighted the women in a front-page article. “Something in my gut tells me something big is about to happen. Who knows? Maybe we’ll end up on *Oprah*,” she muses.

In September 2008, Ruvi put together a charity event to raise money for the Amputee Coalition of America. Her childhood friend Bobby Santos, and his wife Lori, were looking for a new cause they could support with their annual event that they held in their backyard garden. “Duh!” she said. “I can help you with that.” Ruvi visited many local merchants to

ask for donations. “Everyone was so generous. Restaurants even donated some food,” she says.

Ruvi also joined forces with Susie Kagami of Hawaii Music Live, who provides entertainment for charity and corporate events, to bring Grammy Award-winning ukulele player Daniel Ho and recording artist Herb Ohta, Jr., to the event to perform.

“I also befriended Howard Prosthetics, who was one of the sponsors for the event,” Ruvi says. “They brought an amputee there to speak at the event and Howard even did an educational piece.”

Ruvi spoke at the event on raising Jordan and the inspiration she has received from him. “I had a baby picture of Jordan along with his first prosthesis on display,” she says. At \$65 a head, the event turned out to be upscale and classy, with proceeds donated to the ACA.

Michelle Nichols, author and former sales columnist for BusinessWeek.com, also attended the event. “She is a dear friend of mine,” Ruvi

remarks. Nichols featured a piece written by Ruvy in her book *Hug Your Kids Today*, written for working parents of school-age children. "She kept telling me time and time again that I didn't realize that I was planting seeds and will help so many families with my story," Ruvy says.

Ruvy credits her enduring strength to her family, friends and faith. She doesn't see Jordan's limb difference as a disability. She believes it is a blessing in disguise. "Without my son, I would not have met such amazing people," Ruvy says. "I know God is using me. I can feel it. I know it in the depth of my soul. I know this is only the beginning."

Jordan currently works for Lafayette Safeway, a grocery store, and is preparing to start his first semester of college. He recently moved into an apartment on his own. "I went through months of feeling anxious, wondering if I was doing the right thing," she says. "My husband, Jordan's stepfather, felt he needed to gain integrity and have his own independence." Ruvy had a tough time letting him go. She stopped by his apartment one evening to drop off some groceries. "When I turned to leave and saw him standing there with his groceries, prosthesis exposed, I had an 'Ah ha' moment. Letting him go is part of the journey," Ruvy says.

Ruvy's other children, Dominick and Ciara, have learned a lot from having a sibling with a disability. "Jordan's siblings are more protective of him than he is of himself. There is a richness, understanding and compassion they have gained from having him in their lives," Ruvy says. "They have old souls because they see how I have handled this situation and know that I am a strong woman and mom."

Because Ruvy has experienced raising a child with a limb difference and has kept an upbeat and positive attitude, she can offer a lot of advice when it comes to raising a child with a disability. The first thing she advises is to get connected with someone who has been down the same road you are going through. "You need someone to hear you, someone to talk to," she says.

Secondly, Ruvy believes you should learn how to be an advocate for your child. "I tie everything into raising a child with a disability. I would bring prosthetics to Jordan's show-and-tell to educate the children."

Ruvy also advises that you should give yourself quiet time, a time to grieve. "There are emotions that an average person will not go through. Dealing with these emotions brings you to a deeper place. If you do not go to the depths of sorrow, you will not reach that level of understanding. It humbles you and teaches you humility."

Through Jordan, Ruvy has learned to focus on what one can do as opposed to what one cannot do. "Everyone brings their own strengths and weaknesses to the table," she explains.

Ruvy De Guzman is a truly inspirational person. She has turned grief into positivity and balanced out her life in order to achieve happiness and fulfillment. She hopes to one day travel to developing nations and speak to children and parents of children who cannot afford prosthetics. "I have a STRONG vision of this. I am in the right place," she says. ■