**Sudden death of daughter Elysa has Rojas Family on a mission to help others**

*Parents carry out Elysa's legacy by educating families about myocarditis*

**An Angel on a Mission**

For her second birthday, Elysa Louise Rojas got a doctor's kit as a present. It was the one toy she played with nearly every single day.

With her stethoscope dangling from her neck, Elysa would give her teddy bear, Rosy, checkups. She would check Rosy's knee reflexes and blood pressure, and wrap athletic tape around any 'owie’ - just like her father would to an athlete or her mother to another child. After each exam, Elysa would give Rosy stickers for getting through the exam, all the while singing her 'checkup' song in her joyful and sweet voice.

As the first-born daughter of Colorado Rapids head athletic trainer, Jaime Rojas, and Jana Rojas, a children's physical therapist, Elysa - whose favorite show was Doc McStuffins on the Disney Channel - was born to help others in pain.

But on the day the Rapids left for their first preseason trip of the 2013 season, the Rojas family was blindsided by the sudden death of their little sweetheart. Two weeks before her third birthday, Elysa passed away on January 28 as a result of a viral myocarditis - a rare disease that inflamed and damaged her heart muscle.

After months of questions, studying, and reflection, Jana and Jaime want to ensure Elysa's memory lives on. They are ready to share the story of their tragedy, so that despite her passing Elysa can still play doctor and help others prevent the same from happening again.

"We were astounded that something this horrible could happen without anybody knowing what was going on," Jaime told ColoradoRapids.com. "We both wanted to know why this happened to our little girl and what could be done to keep this from happening to anybody else. Now that we've become aware of this, we feel this need, this purpose of doing something with this."

"We can't keep Elysa's three years to ourselves," Jana said, fighting back tears. "She was a very, very bright girl with amazing potential. And now that she's not physically here to carry that out, we need to do that for her. It was God's plan for her to act as an angel to our family, but we wanted to make sure that we honored her and continue showing others her potential."

With the support and assistance of the Rapids Sidekicks, the Colorado Rapids will hold an Open Closets, Open Hearts sidewalk sale on September 14 when the Rapids host FC Dallas at Dick's Sporting Goods Park. Fans will have the opportunity to buy gently used soccer gear and personal items donated by the Rapids players, with all proceeds going to the Myocarditis Foundation.

There will also be information booths with representatives from the Myocarditis Foundation, Rocky Mountain Hospital for Children, the American Heart Association and an AED distributor on hand to provide information and answer any questions that parents, youth coaches, or teachers may have about sudden cardiac arrest symptoms and first response management.

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Jaime and Jana met in Chicago in 2003 when they were both working for the same physical therapy clinic. They married in 2007 and moved to Colorado in 2009 when Jaime became the club's Head Athletic Trainer. At the time, Jana took three different jobs in Denver as a physical therapist.

Elysa was born on February 10, 2010. Her little sister, Isla, was born on November 18, 2011.

"Our lives changed drastically," Jana said of Elysa's birth. "I couldn't bear to be away from her, so we changed things up and figured out a budget. It was incredible. Watching your own child grow is just amazing. You see every little step of the way, and all the changes that they make, and the influence that you can have on your kid's personality and development, and how they interact with people."

While Jaime continued with the Rapids, Jana cut back her work load. She took a position as a part-time physical therapist at the Children's Hospital on weekends, helping kids overcome major accidents and recoveries. On those days, Jaime would bring the girls to the stadium with him.

"I'm very grateful for the job I have, it was awesome having my girls here (at the stadium) all the time," Jaime said. "Elysa liked being around the guys. It's one of my favorite parts of having this type of job, where I can bring my girls in and give my wife a little bit of a break."

On Wednesday, January 23, Elysa woke up with a fever. On the surface it appeared similar to any other virus kids pick up. Over the phone, the doctor gave Jana and Jaime instructions on how to manage Elysa's fever. The next morning it was gone. She acted like her regular self, playing with her doctors kit, teddy bear and little sister all day.

Feeling well, Elysa on Friday attended preschool, a once-a-week program that she had started going to a few months earlier. After class, Elysa's teacher told Jana and Jaime that although Elysa sat down a little more than usual, she still played and did all her art projects. When she got home, Elysa played outside with her family, showing signs that she was overcoming her virus.

It was the same on Saturday morning. A little weary, but no fever. When she woke up from her afternoon nap, her eyes were puffy – something that had happened previously when she had a cold or flu. The parents thought that perhaps Elysa picked up a new virus Friday at school, or maybe that she wasn't fully over the one that kept her home earlier in the week.

Elysa went to bed a little earlier than usual on Saturday night but slept well.

Sunday morning, Jaime gave his girls a kiss before heading for Dick's Sporting Goods Park. The team was departing for Phoenix that day for a week of preseason matches.

To comfort her, mommy had promised Elysa chocolate-chip Mickey Mouse pancakes and her favorite juice. After breakfast, Elysa spent much of the day on the couch. She was the same even after her midday nap, however it was her cold hands and feet that alarmed Jana.

"Something didn't feel quite right," Jana said. "I called the doctor and he said that if Elysa's not running a fever, she should be fine. And even though her eyes were puffy, that it was probably just a virus and to bring her in in the morning if she's still not feeling well."

Call it mother’s intuition, or something else, but Jana knew something was wrong.

At around 8:30 p.m. Elysa asked her mom if she could sleep with her. They were laying together when Elysa began vomiting and became "floppy."

"I immediately called the pediatrician back, and when I didn't get a call back in about two minutes I called the ambulance," Jana said. "I knew something was clearly wrong - normally she would be climbing on me, scared to death of all the strange people in our house. They did their evaluation and said everything looked fine."

Jana knelt down next to Elysa and could see that Elysa was looking straight through her. She convinced the paramedics to bring Elysa to the hospital.

At the nearby emergency room, doctors conducted several tests. Even though they couldn't find anything wrong, they, too, sensed something was not right, so they took Elysa by critical care ambulance to the pediatric intensive care unit at the Rocky Mountain Children's hospital.

On arrival around 3 a.m., Elysa's blood sugar was unusually high, giving doctors reasons to think it could be juvenile diabetes that had not been diagnosed, and that Elysa might be heading to a diabetic coma.

Jaime was awake all night in Tucson, having to wait until the morning for the first flight back to Denver.

"Initially I thought it was going to be something small, but something in me in Arizona made me decide to come home," Jaime said. "And getting the updates from Jana throughout the night, while I waited, things just kept getting worse and worse. It was such a helpless feeling."

At 5:30 a.m. Elysa was still agitated and had not slept, so Jana asked the doctors to allow her hold her daughter to provide comfort.

"I told Elysa, 'Papi and everyone's going to come and the doctors are giving you the medicine and they're going to help you feel better," Jana said.

Minutes later, Elysa stopped breathing. Jana was told Elysa's heart went into ventricular fibrillation, which is very hard to recover from.

For 40 minutes doctor tried to resuscitate Elysa. After calling her parents and Jaime, Jana knelt on the ICU floor, holding Elysa's teddy bear while praying.

When she realized the doctors were slowing down, Jana asked if she could talk to her little angel one more time.

"I went over and I told her that I was right there, and that I loved her and her Papi loves her - and went through our whole family and everyone that loves her," Jana said. "We'd say a night-night prayer every night, so I said her night-night prayer.

"It was 13 days before her birthday. I told her that her great-grandma was going to bake her a birthday cake in heaven and that it's going to be wonderful. I told her, 'you can dance your ballet and do twirls all day. I don't want you to go, but if Jesus is there waiting for you, you need to go and I'll understand. I'll talk to you every day and I just can't wait to see you again."

The doctors and nurses were all in shock and in tears. No one knew what had just happened.

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"I've talked with a half dozen cardiologists," Jana said of the past six months. "The doctors at the hospital were great. They sat down with us after we got her autopsy results and they discussed what they found and what had happened. Apparently it's very hard to detect heart failure in children, so they didn't know that was going on and treated it like they would 98 per cent of patients."

In short, for unknown reasons the virus had attacked Elysa's heart, instead of causing the more common upper respiratory infection or the stomach flu.

Elysa was laid to rest in Kansas City. Last week, when the Rapids played at Sporting KC, Jaime accompanied Jana and Isla to the cemetery for the first time since her burial.

"That was a very, very emotional day," Jaime said. "How much I miss my daughter is beyond words. My life has not been the same since. Your life does change when you have kids, but when you lose your daughter at three years old, your whole outlook on life is completely changed."

According to the Myocarditis Foundation's website, *"most cases of myocarditis have no symptoms and are only identified by an electrocardiogram or by blood tests that detect heart injury. Because myocarditis is rare, the best way to diagnose and treat the disease is not known, but research is being done."*

"It was very important for me to know what had happened, for multiple reasons," Jana said. "I don't want it to happen again - to anybody. So the more I can learn about it, the more I can educate other people - other parents, or health care providers. It's the worst thing you can imagine."

Both Jaime and Jana said it took months to get over the guilt of wondering if there was anything they could have done to prevent Elysa's death. Now at peace as they continue to heal, their mission is to help others.

"What I don't want to do is scare other parents," Jana said. "I think the main thing that other parents need to know, is that if you're not comfortable with the diagnoses, or something feels wrong to you, it's okay to pursue and keep asking questions."

Jana has begun working with the Myocarditis Foundation, which is *'dedicated to providing accurate and up-to-date information to medical professionals, patients and their families, and to the scientific advancement of both the diagnosis and treatment of the disease with the goal of saving more lives.'*

"If one person takes an information sheet to their doctor and their doctor then thinks, maybe I should order an EKG and they find something, then that's wonderful" Jana said. "The more people that learn about this, the more moms and dads who are aware of this and things to look for, and the more doctors who are aware that this is out there and that they should check for it, the better."

The two are also establishing the “For Elysa Foundation,” using their daughter's initials as the core mission.

**Elysa** - **E**ducation of health care providers and the community about myocarditis and other causes of sudden cardiac arrest in children

**Louise** - Bring **L**ight for those families affected by pediatric cardiac disease through goodwill projects, such as arts and crafts at the hospital.

**Rojas** - **R**esearch by supporting the work of the physicians and scientists at the Myocarditis Foundation.

"Just the idea of our little girl being a poster child for a horrible disease is hard for us," Jana finished. "I think it's important, but it took me six months to come to the point where I could actually do it. I've been learning as much as I can about the diagnosis, what's available, and what else needs to be done. And, trying to wrap my head around how I can be helpful without scaring people and how I can effectively try to help other people who have been through this or who could potentially go through this."

"Elysa seemed like she wanted to be a little doctor," Jaime said. "And maybe this is the way she's doing it. With what happened to her, with both Jana and I being medically educated, we're hoping that her little legacy is going to be that she's going to teach doctors and families that myocarditis is not as rare as people think. If we save one life through the education than we'd be beyond ecstatic."