



## Ryan House Shining Stars



### Donovan

An infectious laugh and love of music is what you'll encounter when you meet 5-year-old Donovan. You'd never know he was born at one pound, 11 ounces along with his identical twin, Darrius, who passed away at just 6-days-old. Diagnosed with Cerebral Palsy, Cortical Visual Impairment, severe mental retardation and prone to seizures, Donovan never learned to walk or crawl, and will never develop fine motor skills.

"The qualified staff at Ryan House not only provides respite and peace of mind, but they know me! I call three to four times a day and that is ok!" mom, Toya, said. Donovan loves the sensory room and hydrotherapy pool—things he doesn't get at home and his journal is FULL of loving notes from the staff. "Sometimes parents, especially a single parent, needs a break and may not even realize it until they have one," she said. "I don't know what I would do without Ryan House. I don't know how I did it without it."

### Trinity

Shortly after learning she was pregnant with triplets, Heather was told her three children, Sebastian, Trinity and Estellah, had only two placentas. At 28 weeks, Estellah passed away in utero and Trinity began having strokes and her kidneys stopped developing. While Sebastian was born healthy at 35 weeks, Trinity was diagnosed with Cerebral Palsy and terminal renal failure with a life expectancy of 15 months.

"The day I stepped into Ryan House is the day I became a woman again," Heather said. "When you have a child with special needs you not only become a nurse and caregiver but also an advocate, making all the hard decisions. Now a single mom, I don't have someone to talk to or share things with. Ryan House has given me the security and confidence to go forward. We are progressing every day, hopefully there will be no more cloudy days but if there are, well, it's ok."



### Mikaela

Not expected to live past six months, Mikaela is the bravest 2-year-old you'll ever meet. Born with a severe heart defect, pulmonary artesia and one kidney, she requires 24/7 care. Her family has tough decisions to make relating to Mikaela's quality of life.

"I thought respite was like hospice, but the first thing we noticed was Ryan House felt like home," mom, Melody said. "During our tour our jaws dropped, it was like a resort! I was never more nervous than the day we booked our first stay but within days we booked a second visit. Ryan House gives me time to rest and brother, Jovani, time to shine, he loves the Playstation and all the attention he receives and so desperately needs. Now when we need a break, I can just bring Mikaela here with all of her friends. Whoever thought of Ryan House is truly brilliant and we will be forever grateful."

## William

Born November 3, 2009, William George Leon weighed only two pounds, 14 ounces and just 14 inches long. He was born with an unknown genetic syndrome, with multiple congenital anomalies (birth defects) and was diagnosed with over eight rare medical conditions. Now 18-months-old and weighing 18 pounds, William has endured 15 hospitalizations, eight surgical procedures and has 14 core physicians following his medical care.

William is the sweetest boy, has a tiny little smile and laugh that would light up anyone's world. His big sister, Isabell, also has special needs and medical issues including a heart defect, hearing and visual impairments, as well as overall developmental delays. The family feels very fortunate to be able to take William to their beloved Ryan House especially when Isabell is at the hospital for another surgery. "Every night we are reminded of the gifts in our life," mom, Crystal, said. "Among them are Isabell, William and Ryan House."



## Esra

5-year-old Esra is friendly, happy and always ready to say "hi." She was born with severe Spina Bifida; neurological, orthopedic, cardiac, respiratory and genetic impairments; along with cognitive, motor and speech delays. Even with all these conditions, Esra is one of the friendliest children you'll ever meet and has a smile that can light up a room.

Referred by Phoenix Children's Hospital, the family was not sure what Ryan House was all about, but knew they needed respite. "The first minute we met the Ryan House staff I felt understood, appreciated, cared for and welcomed," mom, Peggy, said. For Esra, Ryan House means freedom and fun. "There is constant assurance when we're away she is happy and cared for," she said. "She is accepted and welcomed, uninhibited and free to be herself. It doesn't matter who walks in the door, Esra greets and hugs them! Ryan House is truly Esra's home away from home."



## Soliz & Camilia

Born 21 months apart, both Soliz and Camila have a rare chromosomal syndrome called Wolf-Hirschhorn Syndrome (4p-). They are both considered to be "deafblind"-being both visually and hearing impaired and require hearing aids and glasses. Both children are prone to seizures.

"Ryan house has become a huge factor for us, someone to count on," mom, Heather, said. "After our first weekend we felt renewed...we felt like we had been on a two week vacation. Ryan House allows us to rest and reconnect with each other. We are together a lot, but just physically.

I wish I could convey to other families how important total respite is, not just me as a mom but for Andre and I as a couple. If we don't take this break we can't give our family what they need and deserve."

"It's such a precious resource," dad, Andre, said. It's humbling that there is a community that donates its time and money to help us. I'm really grateful."







## Caroline

Jim and Karrie Pierson have been blessed with four wonderful children, Katherine, Joe, Caroline and Anna. Caroline and Anna were born with a rare, undiagnosed genetic disorder causing their brains to stop growing around 20 weeks gestation. "Our sweet Anna passed away at just 5-years-old and Caroline cannot walk, talk or eat orally and struggles with seizures, muscle spasms and visual impairment, but her smile is contagious!" Jim said.

"Jim and I joined the Ryan House Board so we can help others understand the importance of taking time to nurture yourself and care for every precious relationship in your life," Karrie said. "The Ryan House Care Team is the most knowledgeable in the country for pediatric palliative care and we are proud to be part of this amazing organization."

## Ryan

Jonathan and Holly Cottor learned their youngest son, Ryan, was not just a "late bloomer," but was born with Spinal Muscular Atrophy. There is no treatment or cure for SMA and they were told that 80% of children diagnosed before their first birthday would likely not survive to their second birthday. "We were told to take Ryan home and enjoy the time we had with him," said Jonathan. "We felt devastated, shocked, and anxious about what the days or months ahead would bring."

"We felt as though we'd hit a wall both physically and emotionally," Holly said. "Ryan House is not only a dream come true for our family, but for the over 4,000 children diagnosed with life-threatening conditions in Maricopa County. Ryan is not only the Ryan of Ryan House, but a frequent visitor who looks forward to his next stay so he can play games with friends, Cade and Colby, and be spoiled by every member of the Ryan House team!"



## Cade & Colby

Cade and Colby have Duchenne Muscular Dystrophy, a weakening and deterioration of the muscles. With your heart and respiratory system being a muscle and your spine requiring muscles to hold it up, the 11-year-old twins have bodies that just cannot keep up. Starting out as active kids, who crawled until they walked and walked until they ran, they have also witnessed their older brother, Ethan, endure and pass away from the same condition at 25-years-old. Shortly after his death, the twins found a message from Ethan giving them advice on how to get through this. Sadly each time they listen, things become clearer.

"Learning about Ryan House was a huge emotional release for me," mom, Amy, said. "Before Ryan House some days were dark and scary, but now I have a ray of hope. With just two days rest I know I can go on and do anything."

## Cloey

When you meet Cloey, the first thing you notice is her never-ending smile and her adorable sentences that always begin with "Guess what!?" Due to a rare genetic condition, the only documented case, Cloey was born with five vertebrae in her neck (compared to seven) along with several conditions that have damaged almost every major system of her body. With hospital bills mounting and days consumed with treatments both parents lost their jobs and went through bankruptcy. "While I'm trying to be positive, I realize this is the beginning of a downhill path," mom, Megan, said. "It's like having a newborn for 10 years."

Ryan House allows Cloey's parents to spend time with their two other children at the beach or camping places she can never experience because of her tracheostomy. "Knowing that Cloey is having the time of her life at her own little Disneyland gives us great joy and peace of mind," mom said.

