

# Collaborative care against cancer

## Camaya's story

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Camaya is a ticklish 1-year-old with big, brown eyes who loves cuddling in her blanket and laughing with her family. The youngest of three identical triplets, born at 31 weeks in August 2022, Camaya was the first of her sisters to master milestone skills like rolling over. But at 7 months, this round-cheeked kiddo appeared to suddenly regress in comparison, acting listless and less social.

"It seemed like she wasn't feeling good," remembered her mom, Carney Meade. "We could tell she just wasn't herself."

## The journey begins

When Camaya's eyes began to cross, Carney took her to her pediatrician, who sent her to the ER where she could be tested quickly late on a Friday afternoon. They found Camaya's head had grown an unusual amount since her six-month checkup. A head ultrasound showed fluid buildup (hydrocephalus) and a concerning mass. Her doctors sent her straight to Children's Mercy.

After further evaluation with an MRI, Christian B. Kaufman, MD, FAANS, Chief of Neurosurgery, drained the fluid on Camaya's brain and biopsied the mass. Four days later, the family had a diagnosis: an atypical teratoid rhabdoid tumor (ATRT), malignant and aggressive. ATRT is only found in 3% of pediatric brain tumor patients. Overall, it is more common in children under 3, where it makes up around 20% of tumors.

## A triple threat?

"Up to 30% of ATRT patients could have an underlying gene mutation that puts them at risk for developing that tumor," said Kevin Ginn, MD, neuro-oncologist and Director of the Pediatric Brain Tumor Program. "If Camaya was at risk, then her identical siblings were, too."

While they waited for genetic testing to come back, the other triplets had head and kidney ultrasounds, which fortunately came back clear. Eventually, Camaya's tests came back negative for the mutation as well.

"I don't think I really realized what the conversations were about at the time," remembered Carney. "Looking back, now I realize they were all very concerned I was about to have three babies lined up down there on the oncology floor. But your body takes over and protects you from some of those fears."

"I had never come across a monozygotic twin or triplet situation where I was concerned about three kids having this potential risk," said Dr. Ginn.

Another first for Dr. Ginn was reversing the usual order of ATRT treatment. Because of the size of Camaya's tumor, and how bloody it was, Drs. Ginn and Kaufman decided it would be safer to wait on resection surgery. "We opted instead to start chemotherapy with the goal of shrinking the tumor first and then taking her to a delayed surgical resection," said Dr. Ginn.

## It takes a village

Camaya's community rallied as she started two cycles of induction chemotherapy. Carney's parents traded shifts with her, so between the three of them, there was always someone at the hospital with Camaya and always someone at home with the remaining two triplets and their older sister, still a toddler. Friends signed up for feeding shifts and brought meals for the adults.

"I had tons and tons of support at home," Carney said. "I don't know how I would have done it, otherwise. It allowed me to be there for those big days for Camaya."

One of those big days was Camaya's post-chemo resection surgery. "We went into the day prepared for a much more invasive and dangerous surgery than it ended up being because of how well she responded to the chemo," said Carney. Camaya's golf-ball-sized tumor had shrunk to the size of a pea. Carney and her parents were waiting in the chapel when they got the news that Dr. Kaufman had been able to remove the tumor more easily than expected.



Camaya, the youngest of three identical triplets, was diagnosed with ATRT, a malignant and aggressive brain tumor.



Dr. Kevin Ginn examines Camaya during one of her visits to CM.

Next, Camaya began three cycles of consolidation chemotherapy — compressed, high-dose rounds of treatment combined with stem-cell rescue. Earlier, the transplant team had collected Camaya’s own stem cells, so they could be given back to her to replace those killed by the strong cancer drugs.

“The idea is to get rid of the microscopic disease and make the radiation-targetable disease as small as possible,” said Doug Myers, MD, Section Chief of Blood and Marrow Transplantation.

The consolidation phase took a little longer than usual because Camaya experienced more toxicity during the second cycle and also caught a viral infection. The team waited until she was healthier to start her third and final round, which she completed in early September.

## Proton therapy

This fall, Camaya underwent five and a half weeks of daily proton radiation therapy to eradicate any remaining tumor tissue.

“**Proton therapy** is a major technological advancement that delivers the radiation in a much more focused, precise manner,” explained Ronny Rotondo, MDCM, FRCPC, Director of the Pediatric Radiotherapy Program and Medical Director of Proton Therapy at The University of Kansas Health System. “We’re able to maximize the radiation dose in the target and minimize radiation dose to normal, healthy tissues. This is especially important for children who are particularly sensitive to the effects of radiation. Ultimately, proton therapy allows for significantly reduced acute and long-term effects and an overall improved quality of life.”



Camaya receiving a proton therapy radiation treatment at the University of Kansas Cancer Center's Proton Therapy Center.

After proton therapy, Camaya’s care team will assess her progress and make a plan for the future — collaborating all the way.

“There was such a massive coordination of care between my team, the transplant team, and the proton radiation team to get her through all the treatment she needs,” said Dr. Ginn.

Carney and her parents continue to express gratitude for the care they’ve gotten at Children’s Mercy and the help they’ve had at home.

“The experience of love that I’ve gotten from family to friends to complete strangers has been life-changing,” said Carney. “I’ll never forget how so many people took us into their arms and did whatever they possibly could.”

*Learn more about the state-of-the-art clinical care and translational research being done at Children’s Mercy for pediatric central nervous system tumor patients in our [2022-23 Cancer Care Annual Report](#).*

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Mom Carney beams with pride at daughter Camaya.



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