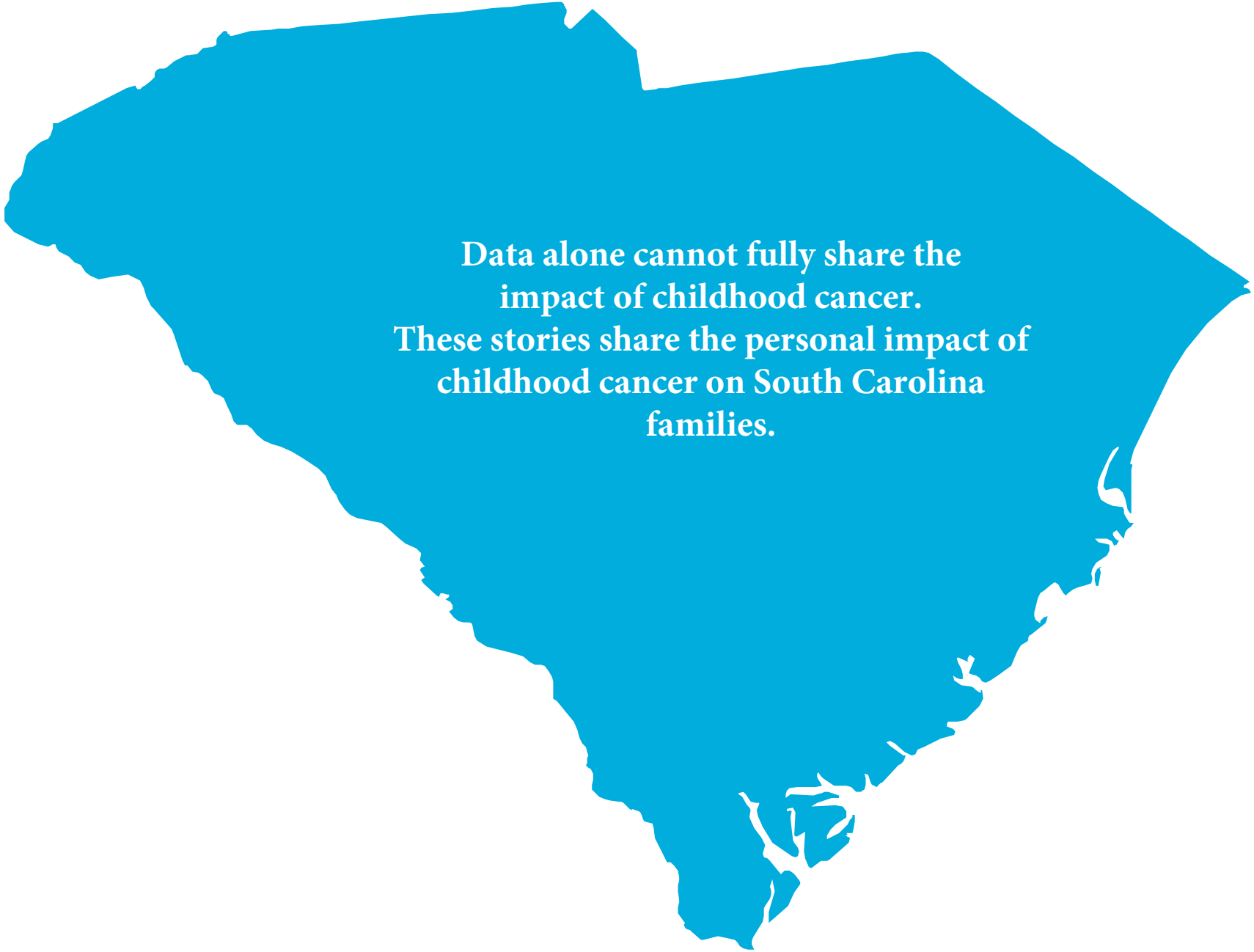
Patient and Parent Voices



Patient and Parent Voices

Leilani is now 10 years old having successfully been treated for neuroblastoma as a young child. At the time of her cancer diagnosis her little brother was an infant and her father was working nights. Her family reflects on the tremendous community support they received along the way in addition to the support of their doctors and nurses.

Leilani was diagnosed with metastatic neuroblastoma at 21 months of age. She is now 10 years old and has been in remission since August of 2018. At the time of her diagnosis, her mother was 6 months pregnant, and her father had just accepted a new job working the night shift which allowed him to be in the hospital with Lelani during the day. Lelani's treatments lasted for approximately two and a half years including chemotherapy, radiation, surgery and traveling for a vaccine clinical trial in New York.

Her mother reflects upon having a new infant and going back and forth between Leilani's hospital room and the Ronald McDonald House as well as traveling for additional treatments sharing, "It may seem crazy but during her treatment, hospital visits were the best times for our family because this is when we were all together. Even though Lei was getting chemotherapy, we were together as a family."

Leilani's family had many people supporting them throughout their journey including family members and school friends, however the biggest support came from the doctors and nurses at the hospital. She states, "I wouldn't trade anything for the nurses and the doctors that we had during her treatment. There were times when the nurses would even come and grab Leilani's brother and walk with him and love on him because he was essentially raised in the hospital. They really treat you like family which is so comforting and a huge load off. They show up in ways you didn't even know you needed; it's amazing."

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Skyla was treated for leukemia and reached a remission though subsequently developed treatment-related acute myeloid leukemia and died at 8 years of age. She was well known to her care team for her adventurous nature and pranks during hospital stays. Her parents founded the Skyla Strong Foundation to support other parents and children facing childhood cancer.

Skyla, well known for her pranks throughout her many hospital stays, was often seen hoverboarding into the pediatric cancer clinic in full protective gear for her appointments. She was treated for leukemia with approximately two and a half years of chemotherapy. After several months of remission, she developed a second type of leukemia, treatment-related acute myeloid leukemia. Despite the best treatments, this leukemia recurred.

Her parents Shannon and Brian reflect upon their conversation with Skyla regarding her cancer returning and the decision to go home with hospice care. They sought to never hold anything back from Skyla. They told her that there was one last treatment Skyla could try but it was very toxic. Brian told Skyla, "If we go home, your 9th birthday is going to be in heaven." He remembers that Skyla stroked her chin and said, "well I was planning on going to Carowinds for my birthday, but they probably have bigger roller coasters in heaven."

Skyla had a private conversation with her doctor and together, they made the "toughest decision anyone should never have to make" to go home with hospice care where they spent 15 weeks as a family making lots of memories. In recounting the night that Skyla passed away, Shannon brought her to the hospital as she "knew she wanted to be back with the people who had started this with us. I just felt so safe with all of them. We were a family. Brian and I both had our hands on her heart, and we felt her heartbeat for the last time and she took her last little breath. And went to heaven."

Her parents started the Skyla Strong Foundation to support other children and families impacted by childhood cancer. Brian states, "Through Skyla Strong, I get to engage with families. I wish the end to my story was different. It's been my healing to be there and help people on their walk that are going through what I've been through."

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Emma remains in a remission for childhood leukemia. Her mother describes the shock of the initial diagnosis and the isolation she has sometimes felt during the treatment journey. She is grateful Emma is feeling more like herself. Treatment for Emma's type of leukemia lasts for approximately 2.5 years.

Emma was diagnosed with leukemia at 7 years of age. Her mother remembers having a gut feeling something was wrong when Emma would no longer laugh because laughter caused her physical pain, and her ongoing leg pain caused her to avoid activities she typically loved. Her mom recalls, "I got on my knees and prayed for it to be anything but that - arthritis, a bone infection, anemia, anything - but in the pit of my stomach I knew." The doctors shared that her blood work was concerning for cancer which was confirmed with additional tests.

Her mother shares her thoughts during that first week of cancer treatment remembering, "Our world collapsed on top of us, but we are slowly processing this new world that will be our new life and our new normal for quite some time. I have gone through all 7 stages of grief since and reached acceptance… I am hopeful she will be cured."

Treatment for this type of childhood leukemia is long, lasting approximately two and a half years. Her treatment includes chemotherapy in the hospital and clinic and being sedated for additional chemotherapy being delivered through spinal taps. Her mom describes going through cancer treatment as "isolating at times even when you have a crowd of people in a room supporting you." During these times, she has relied on her faith, her oncology team, and the outpouring of love and support from their friends, family, and community.

Emma remains in remission from leukemia. Her mother describes her as a "rockstar" bringing joy to all in her presence.

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Collin was diagnosed with a brain tumor at age 2, facing multiple relapses over his life and passing away at age 15. Despite his long medical journey, his upbeat attitude was contagious when he would declare his plans to "wake up, kick butt, repeat!" His medical journey spanned more than a decade. His mother wished there was more support along the way for him to be around other children and do activities like art or yoga to help with his anxiety. She continues their fight as a clinical trials research nurse for pediatric cancer.

Collin was diagnosed with an ependymoma at 2 years of age. After being sick off and on for about 6 months, his mother had him admitted to the hospital for evaluation. She was working as a nurse at the time and recalls, "It just hit me. He has a brain tumor. [He was down getting a CT scan but] I already knew." Due to his age and the risks of radiation, Collin had specialized radiation therapy out of state. He returned home and his mother remembers, "I knew all about the cognitive effects [of radiation] and had him enrolled in early intervention and speech therapy. He was really thriving at that point."

When Collin was 7 years old, he relapsed. His mom describes that day, which was 5 years from the end of treatment. "He was supposed to be cancer free. I was six months pregnant at the time and they said it [his tumor] had come back in a different part of his brain, a distant metastasis." Collin underwent additional brain surgery and radiation therapy, and though he did experience some side effects from radiation including high frequency hearing loss, he was still able to do what he loved. His positive attitude was contagious, and he would declare, "I'm gonna wake up, kick cancer's butt and repeat!"

It was a long journey for their family spanning more than a decade. Collin had anxiety from all he had experienced, and his therapist recommended a support group. "Ok – where do I find that?" his mother shares, "We live in a rural area." His mother wished there had been more support along the way, more chances to be around other children facing the same thing. When Collin suffered further relapses a clinical trial gave him two additional good years. He ultimately passed away at 15 years of age after treatments had stopped working. His mother shares, "I told him he could rest, and I would continue to fight." Collin's mother works in childhood cancer clinical trials. Collin would have turned 19 years old this year.

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Kaycen was diagnosed with neuroblastoma at age 8 and completed over 2 years of treatment. He is now 11 years old and thriving as a straight A student who loves playing baseball. His mother remembers the challenges of frequent travel to and from the oncology clinic and the long hospital stays made more challenging during the COVID-19 pandemic. She acknowledges her faith and his medical team for getting her family through the scariest time of their lives.

Kaycen was diagnosed with high-risk neuroblastoma at 8 years of age. His mother remembers the day of his cancer diagnosis sharing, "During our diagnosis we were numb. Hearing your child has cancer is one of the worse feelings ever. From that point, our lives changed forever." For his cancer, Kaycen required over 2 years of treatment that included chemotherapy, surgery to remove his tumor, immunotherapy, two stem cell transplants and radiation. It was a challenging time for their family as his mother recalls, "Countless days and nights in the hospital and days without seeing our younger son [Kaycen's brother] and family back home about 73 miles away! We would travel back and forth [to the hospital] sometimes 3-4 times a week to get blood work and to check on Kaycen because chemotherapy would make him so sick." Kaycen underwent treatment during the beginning of the COVID-19 pandemic and the strict visitation policy didn't allow extended family members to visit, however, "The staff quickly became family and they will always hold a special spot in our hearts!"

Kaycen remains in remission and is now 11 years old having completed his treatment. As a childhood cancer survivor, his mom feels he is thriving. He is a straight A student in school and loves playing baseball. She wonders how her family was able to get through such a long and intensive treatment saying, "Sometimes we look back and wonder how did we get through all of it! Faith, prayer, and our love for God is our how! It was one of the scariest times of our lives but we are forever thankful for today's medicine and our oncology family!"

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Ellie is a childhood cancer survivor, now 12 years old who was treated for a germ cell tumor at 2 years of age. Her mother remarks how cancer will always be part of their lives and story. Ellie has side effects of her childhood cancer treatments and required a hip replacement as a result. Ellie uses her creative strengths to raise awareness about childhood cancer and plans to be a child life specialist to help other children when she grows up.

Ellie was diagnosed with a germ cell tumor of her mediastinum at 2 years of age. Her initial cancer was cured though she relapsed at 6 years of age requiring additional treatments. In total she received two rounds of chemotherapy as well as radiation and a bone marrow transplant. She is currently 12 years old and in remission.

Ellie speaks about being a childhood cancer survivor. She is most proud of "being able to come back better and stronger as well as still be who I am." Her mother acknowledged that this diagnosis will never disappear completely from their lives sharing, "Yes, Ellie beat cancer, but cancer will unfortunately always be a part of our lives. We wonder if it will come back again. Ellie still deals with the after effects of her treatments including alopecia from her radiation as well as leg length discrepancy [from] when the chemotherapy stunted her growth in her left leg. She had hip reconstruction surgery two years ago for this. I do not think many people are aware of everything that goes into a diagnosis of [childhood] cancer."

Ellie uses her artistic talents to inform others about childhood cancer. Last summer she drew pictures of cartoon characters with gold ribbons beside them (representing childhood cancer awareness month) and sold them around her neighborhood to raise awareness. Due to her experience with childhood cancer, Ellie plans to be a child life specialist when she grows up.

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Tori was treated for osteosarcoma at age 16, completing treatment at 21 years of age which included chemotherapy, surgery and two clinical trials. She is now 26 years old and a childhood cancer survivor. She remembers the financial stress of her years in cancer treatment. She was able to endure her long journey by focusing on one day at a time.

Now 26, Tori is a childhood cancer survivor diagnosed at 16 years of age with osteosarcoma, a type of bone tumor. She was an athlete accustomed to pain but when persistent discomfort remained in her arm, a bone scan confirmed the diagnosis of cancer. She completed nine months of treatment and when unsuccessful, she underwent additional surgery and participated in two clinical trials, completing treatment at 21 years of age.

Tori shared that her insurance did not cover medical expenses until there was a diagnosis. That uncertainty added to the financial hardship while undergoing cancer treatments which included out-of-pocket costs like parking, travel, lodging and meals – costs that she shared lasted for years.

She stressed the importance of taking the punches as they come because there are no guarantees and every patient's situation is different. During her cancer treatment journey, she checked off the days of her treatment roadmap, which helped her stay focused and endure the long journey.