



## Never Forgotten: Micah Kester and Trevor Wildberger

*CHILD homepage summary: Not all patients treated with immunotherapy can be saved. Those we have lost made a tremendous impact during their short lives. We remember four such patients in this two-part series.*

Seattle Children's cancer immunotherapy clinical trials have saved the lives of children and young adults who had no other treatment options. But not all patients are cured.

*InHouse* wants to recognize some of the young people who could not be saved. Their participation in research is a gift to the patients who came after them. Their time at Children's changed the lives of those who cared for them.

Please take a moment to meet, or remember, Micah Kester and Trevor Wildberger.



Micah Kester (left) and Trevor Wildberger.

### Micah Kester



You can't help but smile when you listen to Denice and Greg Kester talk about their son, Micah. Their pride is palpable as they describe their funny, happy, sweet boy who was also stubborn and lacked appreciation for the word "no."

"He was fearless," Greg says. "He was the one we had to watch closely at the park because he was always jumping off the highest thing."

Micah loved to put puzzles together and spent many days dressed up as a Ninja Turtle, even though his mask barely fit over his sizeable head. He was athletic and enjoyed playing soccer. But most of all, Micah was enamored with his big brother, Declan. Whatever Declan liked, Micah liked too.

Micah (left) with his brother Declan. Declan was 5 years old when his little brother was diagnosed with leukemia. “It was very confusing for Declan,” Denice says. “His world was suddenly flipped upside down.”

Micah was diagnosed with acute lymphoblastic leukemia in the fall of 2018 when he was 3 years old. Denice had taken him to his pediatrician, believing he was struggling with seasonal allergies. Later, though, it became clear something else was wrong when Micah came home from daycare pale and lethargic.

The family returned to their pediatrician, who detected a heart murmur and sent them to the Emergency Department (ED) of their local hospital — St. Luke’s in Boise.

Denice waited with Micah for hours at the hospital while providers ran blood tests. The results shocked her: Micah’s white blood cell count was extremely high. He had leukemia.

The oncologist called Micah’s condition an “oncologic emergency.” If they hadn’t brought him to the ED, Micah likely wouldn’t have woken up the next day.

“We were terrified,” Greg says. “Denice and I went into survival mode, focusing on the things we could control. You just want to do something helpful, but there’s not much you can do.”

“Neither of us thought anything was seriously wrong with Micah, so I stayed home with our older son when Denice took him to the ED.

“I was already asleep when she called and told me Micah had leukemia. It felt like I was dreaming. **I still feel like I’m dreaming, today.**”

—Greg Kester



“Micah had a world to explore and a big brother to keep up with,” says Heidi Ullom, care coordinator for Children’s immunotherapy program. “His laughter was like a little chiming bell that made us all smile.”

Micah quickly started a standard chemotherapy regimen at St. Luke’s.

After 35 days of treatment, his cancer cells had decreased, but not as much as oncologists hoped. Denice and Greg decided to enroll Micah in the [PLAT-O2 immunotherapy clinical trial](#) at Children’s.

“The idea of traveling to another state with Micah was overwhelming,” Denice says. “But it was our only option.”

Micah easily charmed Children’s providers.

“You never would have guessed he had relapsed leukemia,” says **Dr. Adam Lamble**, one of Micah’s oncologists. “He looked and acted like a normal toddler, bouncing around the room. He showed remarkable bravery.”

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Micah was administered chimeric antigen receptor (CAR) T cells on March 6, 2018. His body's reaction to the treatment seemed typical at first, but on March 14 he lost consciousness. Surgeons tried to relieve pressure in his brain, but Micah could not be saved. He died on March 15 with his mother and father at his bedside.

Today, Denice and Greg focus on helping Declan, who is now 7 years old, cope with the loss of his brother.

Occasionally, the family brings gifts to the oncology unit at St. Luke's.

"I like to remind people that we were just another family, like theirs," Greg says. "When I'm driving down the road and I see the hospital, I always say a prayer for the kids up there, for the people who are fighting for their lives just on the other side of those walls."

Looking back, Denice and Greg don't regret enrolling their son in the PLAT-02 trial. They see Micah's contribution to the ongoing research as his legacy.

"I find hope in believing he won't be forgotten," Greg says. "I believe this will be the frontline treatment for kids in the future. I'm proud he was a part of it."



From left: Micah, Greg, Declan and Denice.

## Trevor Wildberger



Children's gave Trevor and his family tickets to a Seattle Sounder's match while they were in Seattle. "He was so happy," Tammy remembers.

Trevor Wildberger was an inspiration long before he was diagnosed with neuroblastoma.

His engaging personality and positivity allowed him to connect with others easily. His determination was something to be admired.

"He was a charismatic, life-of-the-party kid," says Tammy Wildberger, Trevor's mom. "If you met Trevor, you were an instant friend. He had a talent for working his way into your heart!"

Trevor had a passion for soccer since he started playing at age 5. He was a goal keeper on his high school team and in a competitive league. He trained intensely, often playing baseball and soccer at the same time, determined to earn his place on a college team.

At the start of his junior year, Trevor's perseverance paid off: He was offered a scholarship to play for Montana State University in Billings (MSUB).

"He was in the prime of his life," Tammy says.

Trevor's life changed dramatically after he injured his jaw during a soccer match. Tammy took him to a pediatrician, who ordered X-rays of Trevor's jaw and spine. They were concerned Trevor might have scoliosis.

The images revealed something far worse: Trevor had a tumor on his adrenal gland.

"That was the beginning of the end," Tammy says. After an 11-hour surgery to remove the tumor and 12 affected lymph nodes, Trevor was diagnosed with stage-four neuroblastoma. His bone marrow was 80% malignant.

Doctors said they'd never met a patient as healthy and fit as Trevor with this disease.



Trevor's father, Jon, quit his job of 25 years the day his son was diagnosed. He was with Trevor every day after that, spending more than 150 nights in various hospitals.

“We were shocked,” Tammy says. “He didn’t have any symptoms. We wondered, how can someone without any symptoms have such advanced cancer?”



### A Lasting Impression

Trevor was diagnosed with neuroblastoma the day before he was supposed to sign a letter-of-intent to play soccer for MSUB.

“I think Trevor was scared he was going to lose his spot,” says former MSUB coach Alex Balog. “But I told him we were committed to him, no matter what. His position would be waiting for him when he was ready.”

Between treatments, Trevor visited MSUB to meet his future teammates and share his story.

“Trevor was only on campus for 48 hours, but he left a profound impression on the team,” Alex remembers. “Even though he was sick, Trevor’s incredible lust for life inspired us all.”

Trevor’s teammates each signed an MSUB jersey that he kept in the hospital with him. Some even had Trevor’s initials tattooed on them.

Trevor was first treated with a standard chemotherapy regimen for neuroblastoma. When that failed to cure him, he enrolled in two clinical trials at University of California San Francisco Medical Center. Unfortunately, those treatments were also unsuccessful.

“Trevor was an extremely intelligent, engaging, lovely young man.

“During clinic visits, the first item addressed was soccer. I’ll never forget his consent conference — he would only agree to receive CAR T cells if we guaranteed he would be back to school in time for soccer practice at MSUB.”

– Heidi Ullom, care coordinator nurse, Immunotherapy

That’s when Trevor decided to enroll in Children’s [ENCIT-01 T-cell Immunotherapy trial](#).

Tammy and Jon can still picture the day Trevor, then 18, signed the ENCIT-01 consent forms.

“He said, ‘Mom, I want to do this clinical trial because I want to help people, just like all the people who did clinical trials before me.’”

Immunotherapy was not effective for Trevor, so he decided to go to Lucile Packard Children’s Hospital for a stem cell transplant.

The transplant was initially successful, but six weeks later Trevor developed a serious infection in the hospital. He spent 15 days in the intensive care unit before he died on Aug. 25, 2015.

Living without Trevor is a constant challenge for Tammy and Jon. But their son inspires them to never give up.

“Trevor taught people how to live during their happiest times and when faced with adversity,” Jon says. “Despite everything he was dealing with, he carried himself in a positive and optimistic manner. Our lives are brighter because of the lessons he taught us.”

The family created the [Trevor Wildberger Foundation](#), which has donated exclusively to Children’s immunotherapy program.

“Trevor wanted to support the future of cancer treatment,” Tammy says. “Although his immunotherapy treatment didn’t have the outcome we were hoping for, we still believe this important work will help many others like him.”

*We will recognize two other patients, Lukas Wiliker and Matéo Lepetit, in part two of this article series.*

— Rose Ibarra



From left: Trevor, his brother Austen, Jon and Tammy.

- *Comment by Pamela Nelson* September 26, 2019  
In the midst of such a tragic article, I LOL at a little boy who "lacked appreciation for the word "no." What a gem he must have been. And what a wonderful article by Rose Ibarra about both of these boys and their families.
- *Comment by Channing Daniel* September 26, 2019  
So important. Thank you.
- *Comment by Jennifer Brailey* September 26, 2019  
This is a lovely tribute to these two special boys. Reading their stories is such a gift. Thank you.
- *Comment by Carol Rockhill* September 26, 2019  
Thank you for helping us remember and appreciate these wonderful people who left this world too soon. Their families must miss them terribly, and my heart aches for them. They and their families are inspirational.
- *Comment by Tammy Mitchel* September 26, 2019  
What beautiful and radiant individuals. Their legacy will live on through stories like these- thank you so much for sharing.
- *Comment by Gary Gooden* September 26, 2019  
Fantastic tributes
- *Comment by Kristina Spencer* September 26, 2019  
While these articles have me wiping my tears, I still enjoyed them so much. It's really important that we all never forget the LIVES that we are a part of. Thank you for this article.
- *Comment by Michelle Stewart* September 26, 2019

Thank you so much for the gift of sharing these wonderful boy's stories.

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- *Comment by Jennifer Enich* September 26, 2019

Wow. Hard to read, and think of the great loss these families live with every day. Thank you to their families for sharing their very meaningful stories. My heart goes out to them.

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- *Comment by Viola Basilio* September 27, 2019

I am touch with the story. I am very sorry for your loss.

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Thank you for sharing I donate for cancer research and hope we find a cure for all the decease.

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- *Comment by Jill Richmond* September 27, 2019

Thank you for sharing this beautiful, important tribute.

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- *Comment by Chelsie Gallagher* September 27, 2019

Thank you, thank you for sharing the stories of these two boys and their families. So important to keep those who have not survived close to our hearts.

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- *Comment by Jane Gregg* September 27, 2019

I appreciate hearing about these lives that continue to impact others, even in their absence. Reminds me to cherish the value of each and every person I encounter. Thanks all of you who cared for these folks and for the work you do to ensure more patients like these can survive.

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- *Comment by Jennifer Fisch* September 27, 2019

Thank you for sharing these moving tributes, and for giving us a glimpse of the impact they have had on their families, communities and providers.

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- *Comment by Javier Saenz* September 27, 2019

What a blessing, thanks for sharing.

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- *Comment by Araceli Aguirre* September 30, 2019

Thank you for sharing these lovely tributes, they were very touching, but made me smile. What an honor to be a part of such an amazing team.

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- *Comment by Julie Kirkham* October 01, 2019

So beautiful - thank you so much for sharing these stories. I'm so thankful to all of my colleagues who give love and care to each of our families who pass through our doors. And, it was an honor to read about these two amazing individuals - little Micah's story, especially, really hit my heart.

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- *Comment by Rachel VanDeMark* October 01, 2019

Thank you to the families of Micah, Trevor, Lukas and Matéo for sharing their stories, and to Rose for her beautiful writing. It is a deep privilege and an immense honor to bear witness to your love and loss.

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- *Comment by Pamela Rock* October 01, 2019

Beautiful stories of beautiful individuals and I am longing for the day where pediatric cancer is easily cured - very touching stories and a reminder of the very important work our teams are doing to develop those cures.

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- *Comment by Heather Cooper* October 02, 2019

Thank you for sharing these stories of courage and love.

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- *Comment by Natalie Pinkerton* October 03, 2019

I really loved reading these stories. Thank you for honoring these research participants and their families and giving us a glimpse into their lives. Reading things like this is part of why I feel so proud to work here at Children's.

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- *Comment by Marcus West* October 08, 2019

Beautiful tributes.

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