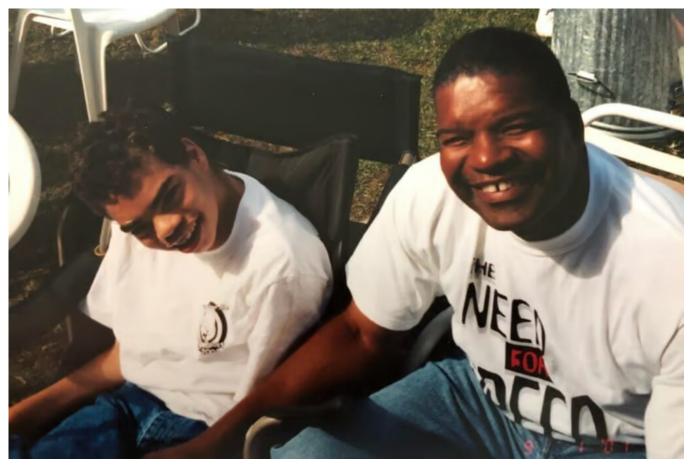
C Culture

Dave Henderson's legacy lives on through foundation aiming to cure Angelman Syndrome



By Melissa Lockard 3h ago

For a 10-year period between the mid-1980s and the mid-90s, there was no smile more recognizable in baseball than the huge, gap-toothed grin of center fielder Dave Henderson. Henderson died of a heart attack in 2015 at age 57, but his smile can still be seen on the face of his eldest son, Chase.

The legacy of that smile, and the joy and kindness behind it, has been carried forward through the Always Having Fun Foundation (AHFF). Founded by Dave "Hendu" Henderson's family in 2017,

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<u>roughly 500,000 people worldwide</u> — can experience seizures, deal with motor skills issues, are frequently non-verbal, and most require lifelong care. Chase, 37, was diagnosed with the disorder in 1989. Hendu was devoted to caring for his son.

When Dave retired as an active player after the 1994 season, he and Chase became inseparable.

"They were best buds," Trent, Hendu's youngest son, said. "He was always taking care of Chase, going on the road together, golfing together, that kind of stuff."

One of the ways Hendu cared for his son was by raising money for organizations within the Angelman Syndrome community. The family hosted a golf tournament for more than a decade. Initially, the money raised went to an organization that provided care and support for families impacted by the disorder, according to Trent, but as finding a cure became more of a possibility, the Henderson family began to support the Foundation for Angelman Syndrome Therapeutics (FAST), which helps to fund and raise awareness of research for a cure. When the Henderson family founded AHFF, the foundation revived the golf tournament — Hendu's Golf Classic — to support FAST.

"We wanted to continue to raise money for research for Angelman Syndrome and try to continue what he was doing," Trent, 35, said. "From everything we've heard from FAST, they are making such huge strides in actually curing this thing. A lot of times you're providing funds for therapy or

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One of the biggest challenges for those searching for cures for rare disorders or diseases is a lack of funding and resources. That's where FAST looks to fill the gap. Last December, <u>FAST gave \$5 million to Rush University in Chicago</u> to establish a center for new clinical trial and translational research efforts for rare neurodevelopmental disorders. There are currently three clinical trials underway for potential cures for Angelman Syndrome, and several more in the pipeline. The new center at Rush is able to manage research that is rapidly widening in scope.

"Effectively, we got to a place where the challenge now wasn't actually whether or not we had treatments to administer, but whether or not we had the people and the institutions that had the capacity to do this kind of therapy at a scale that we're getting to," Alana Newhouse, president of FAST, said, adding that the work being done at Rush to administer therapies to treat Angelman Syndrome can be applied towards administering treatments for other neuro-genetic disorders, as well.

Newhouse says the biggest challenge for FAST is raising awareness of the disorder and also getting the message out to those not directly impacted about why they should care about treating it.

"There is an aspect in rare disease of 'rising tides lift all boats," she said. "If you're not touched by rare disease, you might not realize that, and so being able to transmit that message to people,

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Dave Henderson hit <u>one of the most dramatic home runs in postseason history</u> when he homered for the Boston Red Sox in the ninth inning of Game 5 of the 1986 ALCS with the California Angels one strike away from clinching the pennant. He was one of the top postseason performers of his era, appearing in 36 playoff games for the Red Sox and Oakland A's, homering seven times and posting a .946 OPS. He played 14 years in the big leagues — the majority with the A's and the Seattle Mariners — and was an All-Star in 1990. He was a fan favorite wherever he played, but is most remembered on the field for his time in Oakland when he patrolled center field, which was nicknamed "Henduland" by the bleacher fans at the Oakland Coliseum.



Henderson makes a catch in 1991 in front of the "Henduland" sign at the Coliseum. (Richard Mackson / Sports Illustrated via Getty Images)

"If you asked my dad what he would have wanted his legacy to be, he would say he just wanted to be remembered as a good human being," Trent said. "I think that's something that he tried to spread to everybody that he interacted with, that he was just a nice guy that you could have any kind of conversation with, have a beer with, and it's all good."

Like his dad, Chase loves the lighter side of life, like funny movies — "That's something that makes him laugh and smile. Jim Carrey. Eddie Murphy, movies where people fall down. He loves that kind of stuff," Trent says — and treats. When Hendu lived in Alki Beach in Seattle, he and Chase were fixtures at the local ice cream shop. Chase also enjoys riding in the car, which was one of the activities he shared with his dad. They would frequently go on road trips together. Chase was often by Hendu's side at Mariners home games. Hendu was a popular color commentator on Mariners' broadcasts from 1997-2006 and again in 2011-12. Trent says even now, when he takes his brother to a game, the T-Mobile Park stadium staff will come up and greet him.

"Everywhere that my dad was going, Chase was going with him, and everybody recognizes him," Trent said.

Trent says caring for Chase gave his father a strong purpose for his life. He recalled a time when he and his father were driving home from a poker tournament and Hendu began explaining how his close relationship with Chase and his desire to be there to care for his son kept him on a good

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"That was kind of his motive for making sure that he was available for Chase because Chase can't take care of himself," Trent said.

Trent has taken up the mantle of supporting his brother since his father's passing. His death was unexpected, coming just a few weeks after he had successful kidney transplant surgery. Trent was in Montana celebrating Christmas with his wife's family when he received the call in the middle of the night that his father had collapsed. By the time he arrived back in Washington, his dad was gone. Trent believes his father's death — a heart attack that was likely caused by a blood clot — could have been avoidable. Hendu had complained of leg pain in the days leading up to his death. Trent hopes his father's story serves as a reminder that if something doesn't feel right, people should go see a doctor.

"Don't be the tough guy," he said. "We'd rather have you go there (to the doctor) and it be nothing than have it be something and you missed out. That's something that's definitely stuck with me.

"I'm sad he didn't get to meet my son (who was born in 2018). I know they would have been really close,"Trent added, noting that his wife viewed Dave as a father figure as well. "It's just a really significant loss for our family."

Trent says his father wasn't scared of the kidney procedure but did make him promise he would look after his older brother should anything ever happen to him. When Hendu died, it became

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"Since my dad passed, it's always been a concept in me that I had to take care of Chase," Trent said



Trent (back) and his son Carter and Chase at the ceremony to induct Dave Henderson into the African American Franchise Six. (Courtesy of Trent Henderson)

Chase lives with his mom, Loni, in New Castle, Wash., a few miles away from Trent and his family, who reside in Maple Valley. Chase's care is a full-time job, and at the moment, Loni handles the day-to-day mostly on her own. Loni is now 65, so the family has had discussions about how to care for Chase in the future. Trent says his brother has developed some separation

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from home. A poor night's sleep can trigger seizures the next day. Chase walked when he was younger, but as he grew and his seizures continued, it became more dangerous. He has used a wheelchair since he was a teenager.

Today, families who are given a diagnosis of Angelman Syndrome for a loved one can connect with other caregivers around the world through the internet and social media, something that didn't exist when the Henderson family learned of Chase's diagnosis. Through FAST, Trent and his mom have met with several other families with children of varying ages who have Angelman Syndrome.

"That was really eye-opening for me and my mom to see these other families and talk about the experiences together,"Trent said.

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From left to right: Chase, Dave, Trent and Loni at an A's game. (Courtesy of Trent Henderson)

Newhouse calls the Angelman Syndrome community "the best community you never wanted to be a part of." The community has helped raise awareness of the disorder and answer questions from those who are newly dealing with a diagnosis. For example, Easton Bryant, a Council Member of FAST and parent to a daughter living with the disorder, hosts a YouTube series called "FAST facts" that brings more awareness and understanding of the disorder. When asked what she would want most for people outside of the community to understand about Angelman Syndrome, Newhouse said it was that there is so much hope for a cure.

"One of the most magical things about being part of the FAST community, in particular, is that we get to see how quickly and how robustly the science is moving," she said. "And it's magic to watch."

FAST supports a community fundraising campaign called "Cure Angelman Now" or CAN, which raised close to \$1 million last year. Their goal is to exceed the million dollar mark this year, says Meghan Edberg, director of Community Engagement of FAST.

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community on."

"I almost think about the parents in this community is that they are our seed investors," said Newhouse, whose 9-year-old son, Elijah, was given an Angelman Syndrome diagnosis roughly a year ago. "They're the foundational support for everything that we do, not only because of their engagement and their fundraising and their activism but also because it's going to be caregivers who are going to enroll their loved ones in these trials and help us start to answer some of the questions."



Trent (left) and Chase Henderson at an A's game. (Courtesy Trent Henderson)

The Henderson family is committed to being part of that effort. On Saturday, AHFF hosted its sixth annual Hendu's Golf Classic, with the proceeds from the event going to the FAST

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currently the foundation's only fundraising event, though supporters can make donations at any time through <u>their website</u>.

"My wife and I, we knew we wanted to take over some of that responsibility or at least try to support Angelman research in the future," Trent said. "We thought this was an appropriate way to continue that legacy."

Trent has been contemplating hosting an event in the Bay Area, where his father remains a beloved figure. The Last Dive Bar's "Henduland" T-shirts remain a common sight at the Coliseum. Trent is also active with "Rick's Toys for Kids," a charity that his father was involved with alongside his Mariners' broadcast partner, Rick Rizzs. He says he's learned a lot from that work about how to grow the AHFF. He knows that his father's joy resonated with a lot of people and he hopes AHFF can honor that legacy.

"People always said that he was the nicest guy, always had a smile on his face," Trent said. "It's definitely left a mark on us, and just to know that life is too short to be upset about the day-to-day stuff. We're all in this together and we're trying to coexist together, and why not have fun doing it."

(Top photo courtesy of the Always Having Fun Foundation)

Melissa Lockard is a senior editor and writer for The Athletic. She edits MLB content and focuses her writing on MLB prospects and draft coverage, with a particular focus on the Oakland A's and San Francisco Giants. Before joining The Athletic, she covered baseball for a variety of outlets, including Scout.com, 2080baseball.com and FoxSports. She is the founder of OaklandClubhouse.com. Follow Melissa on Twitter @melissalockard

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