

# 'This is who I am': Kids taunted him for having cerebral palsy. Then he found his talent.

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 [indystar.com/story/entertainment/arts/2019/04/25/kids-taunted-johnson-simon-his-cerebral-palsy-then-artist-](https://www.indystar.com/story/entertainment/arts/2019/04/25/kids-taunted-johnson-simon-his-cerebral-palsy-then-artist-)

Domenica Bongiovanni, Indianapolis Star Published 8:29 a.m. ET April 25, 2019 | Updated 3:07 p.m. ET June 28, 2019

In Johnson Simon's studio sits a painting of him clutching his throat. His left hand is sprawled around it, muscles tense, showing the frustration of communicating with cerebral palsy. It's how he feels when people ask, "Can you say that one more time?" It's how he feels when people, tired of trying to understand his speech, put their own words in his mouth.

Simon was born with the disability, which affects muscle control and posture. He has spent his 29 years navigating a world that sets up barriers. In overcoming the hurdles, Simon has developed a talent for painting deeply emotional works that capture his journey from Grand Turk Island to Indianapolis, including years trapped in special education classes he didn't need and walking the stage to a standing ovation after earning a master's degree in fine art.

Simon's painting talent has won him awards and been his sanity. It earned him a place as an artist-in-residence at the Stutz Business and Arts Center, where he'll show his work Friday and Saturday during the annual Stutz Artists Open House.

And painting is how he is finding his footing as a teacher. He currently instructs classes at Outside the Box, which provides training in art, employment and life skills for adults with developmental disabilities. He will co-teach a class at the Herron School of Art and Design, IUPUI, in the fall.

It's a journey a 5-year-old Simon hadn't yet dreamed of when he spent days at his grandmother's house in Haiti, waiting for his younger brother and cousin to come home from a school he couldn't attend.

## 'I'm not faking. This is who I am'

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Simon was born with the umbilical cord wrapped around his neck in a hospital on Grand Turk Island, about 600 miles southeast of Miami. His mother, Esperanta Pierre, told her son years later that the doctor said he would have been brain dead if the cord had squeezed just a few seconds longer.

The baby spent the first 16 days of his life in a coma. His mom was left to wait as she watched the hospital staff poke his feet to see if he would move.

*God, this is my first baby, Pierre prayed. Please don't let anything happen to him.*

Simon spent his first few years in his grandparents' home in the Haiti countryside while his parents, Pierre and Joel Simon, traveled to the U.S. to carve out a life for their family. A young Simon crawled for what felt like forever, unable to go to school because the resources weren't available to accommodate a boy who wasn't able to walk.

That changed when he was 5. Holding onto both hands of his grandmother's friend and then letting go, the little boy took his first steps with bare feet on the patio outside. He remembers feeling disbelief. His grandmother cried.

Later that year, Simon and his younger brother, Johnnie, moved to West Palm Beach, Florida, to be with their parents.

Once in the U.S., Johnson Simon could attend school. His learning capability was unencumbered by the cerebral palsy, which is caused by an injury to the brain during fetal development or birth. But because of the way it affected his physical movements, speech and handwriting, educators put him in special education classes when he was in fourth grade. His mom, who didn't speak much English, signed off on it, not understanding the implications, Simon said. The classes were too easy for him.

Although Simon made friends, other school peers taunted him and mimicked the way he walked. Johnnie Simon ended up punching some of them to defend his brother.

"Going to school and walking to my class, kids would come up to me (and ask), 'Why do you walk that way?' And say, 'You're faking! Why are you faking?' and push me down the hallway. And I'm like, 'I'm not faking, I'm not faking. This is who I am. This is who God made me to be.'

"But they'd be like, 'No, you're faking. Get up, get up.' It was hard, hard to convince them (that) this is how I really walk."

Many times, kids refused to see the brother that Johnnie Simon knew. The one who loved Dr Pepper and cheered for the Miami Dolphins and the Heat, no matter how they played. The one who rode his brother's skateboard, fell off, cut his head and laughed about it after their mom scolded him.

"I see myself as a free, capable person, and when I'm faced with tasks, I'm like, 'Oh, yeah, I do have a disability,'" Johnson Simon said.

As much as Simon fought his frustration and anger from the bullying, they seeped through in other ways. He talked back to his mom. He told his mentor, Michael Tischler, that he didn't see the point in living anymore.

## 'Never, never give up'

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Befriending Tischler proved to be a turning point. Simon, his brother and their sister, Stephanie, met him through their mom, who was Tischler's aide.

Tischler had juvenile rheumatoid arthritis that turned into arthritis throughout his body as an adult, his mom, Molly Tischler, said.

Pierre helped him cook and bathe. She didn't have a place to leave the kids after school while she worked, so she brought them with her.

Micheal Tischler, who didn't have kids of his own, became a father figure. He created art with them, helped them with schoolwork and talked about sports. He found a way for Johnson Simon to play golf with his brother since he couldn't join Johnnie Simon on the football field.

He told Simon to "never, never give up," a motto the artist still holds dear along with his Christian faith.

*You might have a disability, but don't make your disability who you are,* Tischler told him.

"One of the things that he did with Johnson, for years, was he had to entertain him, so he'd say, 'Hey, pick up the brush and put colors on the paper,' " Molly Tischler said. "It turned out that Michael realized that Johnson has a talent for painting."

A middle school teacher noticed 14-year-old Simon's skills after he began painting and encouraged him to enter a competition. He thought she was just being nice — until he won second prize.

He realized "this is my calling, and from that day on, I wanted to be a painter," Simon said.

## An 'out-of-body experience'

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Sitting in the corner of hip hop, ballet and modern dance classes at Western Michigan University, Simon concocted the idea for his undergraduate independent study. He wanted to be a dancer, but he'd have to take a nontraditional route. So he sketched the way dancers leapt, kicked, twirled and glided.

"When I was drawing them, I could see myself also doing the same movement but without the physical limitations," Simon said. "I could feel it, too, an almost out-of-body experience."



Johnson Simon, an artist with cerebral palsy who just finished his Master's Degree, works out of the Stutz Building, is working on his career as a painter, and will be showing at the facility's upcoming open house. At the artist's studio, Thursday, April 11, 2019. Robert Scheer/IndyStar



Johnson Simon, an artist with cerebral palsy who just finished his Master's Degree, works out of the Stutz Building, is working on his career as a painter, and will be showing at the facility's upcoming open house. At the artist's studio, Thursday, April 11, 2019. Robert Scheer/IndyStar



Working with acrylic paints and an oil paint stick, Simon doesn't firmly plan what his pieces will become. Sometimes, like with his work "Reflex," he decides not to take the medication that calms his muscles to see if he can control them. He began to paint hands but had a spasm. Instead, he ended up with burgundy, teal and white abstracted movements. Now, he says, you can feel it, see it move in a way that it didn't before.

"He's not doing tightly drawn images with real sharp edges," said Marc Jacobson, a professor of painting at Herron who was Simon's thesis adviser. "If there's a splatter, he's deciding that's where that should be. If an edge kind of gets ragged, he's deciding to leave that the way it is or to work back into it."

Simon perfected his technique over the years with Michael Tischler, during an after-school art club and when he was finally admitted to a high school where he could learn.

Tischler became increasingly ill when Simon was in high school and, wanting to set up his young friend for success, he helped Simon get in to the [A.W. Dreyfoos School of the Arts](#) in West Palm Beach for his senior year. The school proved to be life-changing for the young artist, who received an aide, help with taking notes and lessons that challenged him.

"When he got in, which was for the August/September term, Michael felt that his job was done, and he knew that I was there and I would help (with) whatever needed to be done," Molly Tischler said.

Michael Tischler died the October after Simon transferred to Dreyfoos.

The Simon kids were close enough with Tischler's family that they called his parents "grandma and grandpa" and his sister, Bonnie Giacobelli, "auntie."

With help from Molly Tischler, her husband, Steve, Giacobelli and Sylvan Learning, Simon shored up his test scores enough to enter Western Michigan University, which had recruited his brother to play safety for the football team.

Before Simon went to college, Giacobelli ran what he called "Auntie's boot camp," where she helped him conquer the physical skills he'd need to eventually live by himself.

Simon graduated with a bachelor's in fine art. Then he was accepted to graduate school at Herron — a feat he originally thought impossible.

The art he could do. Simon painted people with ongoing or temporary disabilities, like claustrophobia, depression, having their tonsils removed and ALS to demonstrate how people have to adapt to the world.

But how could he write almost 20 pages of a thesis paper?

Haley Welch, a fellow student at Indiana University-Purdue University Indianapolis, helped Simon gel his ideas and type them. By the end of his master's degree, the two had strung together shorter essays into a full thesis.

## 'He just does not exclude anyone from knowing him deeply'

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Simon stands at the front of a classroom each Tuesday evening to teach a painting class at Outside the Box. It's the first time the studio art program has been able to offer such a course. Studio art coordinator Cait Renk said they didn't have a master painter on faculty until someone forwarded her an IUPUI video of Simon.

The teaching gig is a step on the way to Simon's dream: opening a nonprofit after-school art program with a gallery and civic center for everyone, including those with physical limitations. He'd like to teach there, invite speakers to give workshops and continue to develop his own painting.

Right now, he teaches five classes at Outside the Box. He creates pieces alongside the students and responds to their jokes, like when student Mary Lipp calls him "grandpa."

"Hi, grandma," Simon replies.

His quick wit comes from a natural ease with people. As a kid, he made friends by spinning wheelies in his wheelchair and letting others ride with him on his scooter. He and his best friend, James Pompey, who also has cerebral palsy, still laugh about the time their scooters became stuck in the snow during a Michigan winter.

And Simon's jokes — "Oh, you don't think I can do that because I'm handicapped?" — can surprise some. In college, a group of his brother's football teammates were stunned when Simon beat them in a Madden NFL 15 tournament. ("I told all my teammates how good he was on the game, and they didn't believe me," Johnnie Simon says.)

"He invites people into his life so readily. He just does not exclude anyone from knowing him deeply," Welch said.

How Johnson Simon lives with cerebral palsy makes a lasting impression on those who know him.

"When I have a bad day, even if I don't talk to Johnson, he's always in the back of my mind. 'What would Johnson say?' " Pompey said.

Simon says he focuses on what he can overcome and how he can pass along the support he has received.

"I see the reason why I was put on this Earth," he said, "to discover my art talent, to show someone that the outside doesn't describe who they are. It's what's on the inside."

## If you go

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**What:** Raymond James Stutz Artists Open House

**When:** 5:30-10:30 p.m. Friday and 2 p.m.-7 p.m. Saturday.

**Where:** Stutz Business and Arts Center, between 10th and 11th streets and Senate and Capitol avenues. Johnson Simon is in Building B, Studio 255a.

**Cost:** \$16 in advance, \$20 the week of. Free for kids 12 and under. [stutzartists.com](http://stutzartists.com)