



BRAVE YOUNG FIGHTER – Bellmawr’s A.J. Gonzales, left, enjoys a special moment with his father, Rico, and UFC fighter, Chris Weidman.

Bellmawr’s A.J. Gonzales Is World’s New Superhero

By Anne Forline
Gloucester City News

Some superheroes have super human strength or possess superior intellect.

While others are highly trained martial artists and are masters of disguise.

A select few are capable of manipulating the weather or accessing the speed force.

Bellmawr’s four-year-old A.J. Gonzales is a fan of all things superhero.

One of his favorites is Superman because of his unique power to melt objects with heat vision.

A.J. would prove to be a worthy opponent against Superman, or any superhero, because of his own innate ability to melt hearts with just a flash of his bashful smile.

A.J. holds superhero sta-

tus because of his daily battle with fibrodysplasia ossificans progressiva (FOP) or “Stone Man Syndrome.”

In everyday terms, FOP is a rare and baffling genetic condition that causes bone to form in muscles, tendons, ligaments and other connective tissues, according to the International FOP Association (IFOPA).

IFOPA further notes that FOP progressively restricts movement and a second skeleton eventually imprisons the body in bone.

FOP is unique in that there are no other known medical examples of one normal organ system turning into another.

A.J.’s father, Rico, speaks of the rarity FOP and says there are 287 known cases of FOP in the U.S. and his son is number 286.

Kristi recounts A.J.’s journey with FOP and states: “He’s been through so much in such a short amount of time.”

She calls her pregnancy as “normal” up until the 20th week.

“That’s when they diagnosed me with varix (white mass) of the umbilical cord. At 35 weeks, A.J. lacked oxygen to the brain and they took him by emergency C-section,” she explained.

When he was born on October 14, 2010, he weighed a hearty 7 pounds 13 ounces, and measured 21 inches long.

However, she added: “He was born with crooked pinkies and malformed toes, which are the prime

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A.J. GONZALES A SUPERHERO

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genetic markers for FOP, but at the time we didn't know that."

Besides his pinkies and toes, he thrived in the hospital and did not need the NICU (neonatal intensive care unit) or anything, Kristi said.

To put their minds at ease and because Kristi had failed the initial screening for Down Syndrome, she said: "They did our chromosomes while we were in the hospital and they told us A.J. had a higher chance of having Down Syndrome, but those tests showed he didn't have it."

When A.J. was brought home from the hospital, his parents noticed he clenched his fists and as he started to grow, he was not meeting developmental milestones.

"He couldn't sit up unattended. When he crawled, he drug his right side and he walked late," Kristi said.

When A.J. turned one, that was when the Gonzaleses started to consult with specialists for answers.

Kristi said: "It was right after his first birthday when he saw an ENT. They noticed his ear canals weren't formed properly."

As for his crooked toes, A.J. was taken for orthopedic consults and in June, 2012 A.J. underwent reconstructive surgery for the extra bone growth on his left foot.

Looking back on that time Kristi recalls: "It is amazing because crooked toes are the main marker for FOP and they missed it. It is because nobody knows enough about it and you can't even be upset about it because no one knows enough."

Realizing that surgical intervention could have worsened or advanced A.J.'s condition, Kristi said: "We are very lucky. Other kids have had biopsies and their incision sites turned to bone. A.J. didn't have that. We've been blessed to have passed that."

A.J. also saw neurology for more tests, which included undergoing two MRIs.

The MRI results revealed periventricular leukomalacia, or white matter on the brain.

At that point, A.J. was

referred to Children's Hospital of Pennsylvania (CHOP) and he consulted with neurogenetics there.

"They were the ones who caught FOP," Kristi said.

She learned: "One of A.J.'s chromosomes is out of whack. He has a mutation of the ACVR 1 gene."

Once the Gonzaleses received A.J.'s diagnosis of FOP, Kristi remembers the doctors telling them: "We almost wish we could tell you it was cancer because at least there are treatments and medicine for that. With FOP, there is no medicine. There is no cure. There is nothing. We only have hope."

Kristi said that A.J. also sees doctors at the University of Pennsylvania and that "they are doing research constantly for a cure."

She says that they are involved with other families of FOP and calls them her "other family." Recently, the Gonzaleses travelled to Allentown, PA to participate in a bingo fundraiser for another child who also has FOP.

Kristi says, "We want A.J. to see and know there is no disability."

As for his day-to-day life, A.J. attends Tiny Little Pieces in Bellmawr, a learning center for both typical and atypical children.

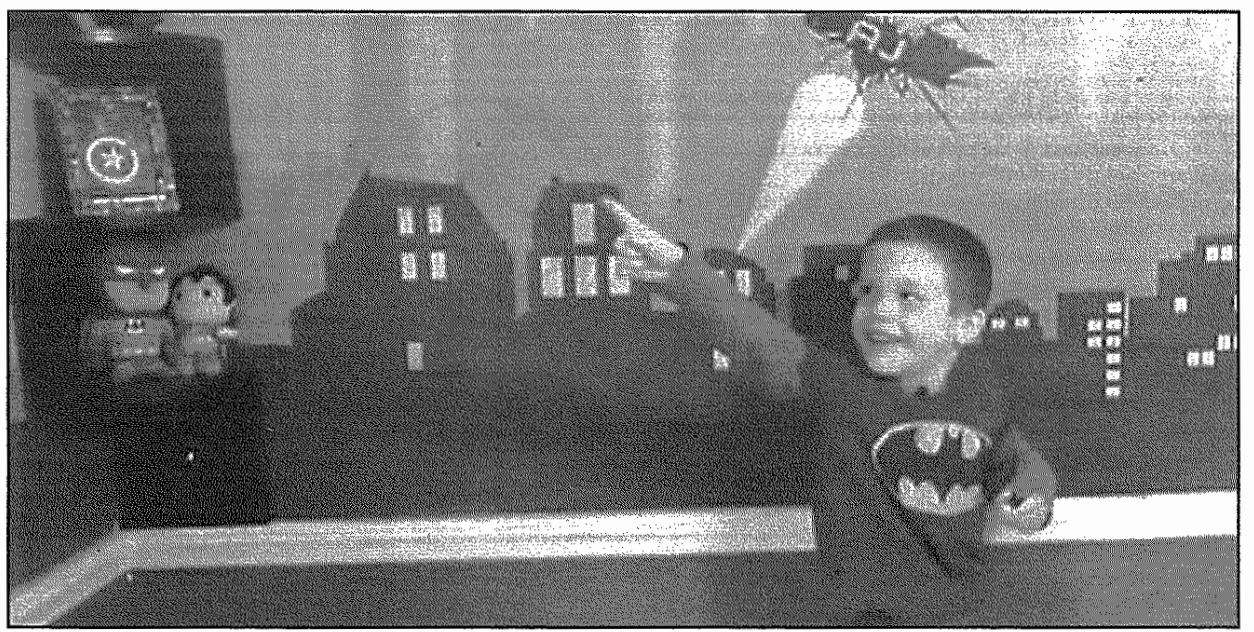
A.J. also has two older sisters, Lilly, 12, and Lexi, 16. Kristi and Rico are also very involved in their daughters' activities. Lexi and Lilly both dance while Lexi also cheers and Lilly takes karate.

When Lilly played soccer, Rico coached her team. He would hold A.J. in his arms while shouting instructions to his team from the sidelines.

Rico explains that FOP limits how A.J. interacts with other children. He explained: "A.J. is involved with other kids, but we have to be very careful. He can't roughhouse and he'll never take gym."

Kristi adds: "We can't take him to Bounce-U. He can't do those things because he can't be in that type of environment. We're preserving his bones for as long as we can."

Because A.J. has physical limitations, one thing he enjoys is playing video games. One of his favorites is Mario Kart.



SUPERHERO UNVEILED – A.J. Gonzales reacts happily to the recent, surprise makeover of his bedroom. A.J. has been diagnosed with FOP (fibrodysplasia ossificans progressiva). A.J. loves everything about superheroes and his parents tell him every day he is a superhero because he has extra bones in his body.

Warning: if you ever have the opportunity to play against him, you will lose and you will lose badly.

But A.J. is such a good sport, he will give you multiple attempts to play him over and over, no matter how many times your car careens off a bridge or it crashes into a wall. He'll just tell you: "Good try. You'll do better next time" as he presses "Next Round" to start another game.

He also loves to do puzzles and play with his superheroes. His dog Ace, an affectionate Cavachon, is never far from his side.

While A.J. was showing me his vast collection of action figures, he cautioned me to "be careful" with one of them because the leg was loose and it wiggles off.

I told him I didn't want to break it and I reached for another one to play with. Instead, he placed the action figure back in my hand and said: "No, it's ok. If the leg comes off, just give it back to me and I'll fix it for you."

Superheroes are such an integral part of his life, it is only fitting that A.J. has a bedroom, or a special place of his own, completely dedicated to that theme.

Back in the fall, A.J. received a bedroom renovation from the Delaware-New Jersey-Pennsylvania chapter of "Special Spaces," a nonprofit organization that creates dream bedrooms for children with life challenging illnesses.

Kristi said of the room: "It's absolutely amazing. Every superhero is repre-

sented: Batman, Superman, Captain America, all of his favorites."

"Special Spaces did not overlook a single detail. They completely re-did his entire room. They did the paint, brought the decorations, installed a ceiling fan and put in a closet organizer," she said.

One special item that surprised them was the gift of an orthopedic mattress.

"It helps contour A.J.'s body and it's just wonderful for him," she said.

Rico joked: "Now, if A.J. can't fall asleep, we'll both argue over who gets to lay down in bed with him."

A.J.'s room unveiling was filmed by Fox-29 news and the family was interviewed by on-air personality, Dawn Timoney.

A.J. smiled and nodded when asked if he liked being on TV and said the best part was having the "little box" (the microphone pack) strapped on him so everyone "could hear my noises."

The family was also treated to a Disney vacation from the Make-A-Wish Foundation from November 17-23 and Kristi has just been "blown away" by the kindness and generosity shown to her family and son.

Kristi notes there is such a lack of awareness about FOP and she hopes with the attention that has been showered on A.J., the light will shine on FOP so others can learn about the condition.

"Always check for crooked pinkies and toes,"

she advised.

Kristi said she and her family vow to "remain positive," even though she admits that there have been times of sadness, but "we won't stay there."

"We have to keep hope that in A.J.'s lifetime that they will find some medicine or a cure so he, and others with FOP, can have somewhat of a normal life," she said.

Despite everything that A.J. has been through, Kristi said her son still "smiles all the time and has a heart of gold."

She said: "He has taught us so much. We do not take anything for granted and we appreciate everything. We just do things a little bit differently. He has changed our lives so much and he changed us for the better."