

Winter Park / Maitland Observer: MD Muscle Walk comes to Maitland

<http://www.wpmobserver.com/news/2012/mar/21/md-muscle-walk-comes-maitland/>



- By [Brittni Johnson](#)
- March 21, 2012 4:03 p.m.

Jace Pitre is probably one of the sweetest 2-year-olds you'll ever meet. No matter what he's doing, be it curiously going after a bit of paper his mom has left in his reach, petting his puppies or holding on to his favorite little yellow Frisbee, if he catches your eye the one thing you can count on him doing is offering up the biggest smile he can.

For Jace, who has an undiagnosed muscle disease, this is the best way he can communicate and interact with the world around him. While he is 2 years old, his muscles aren't strong enough to let him jet around the house, hop on a swing in the park or work on a finger painting. His mouth can't form words yet.

If you ask his mom how he's like any other kid his age, she'll tell you frankly that he isn't. His movement is limited to wiggling on the floor — but he will use a new skill he's learned and mischievously and happily roll to whatever he wants to examine — and his speaking skills are mostly coos. Physically and mentally, he seems more like a baby than a toddler.

His parents, Courtney Gavares and her boyfriend, James Pitre, experienced a completely normal pregnancy. But one month after Jace was born, they noticed he was developmentally delayed. He was favoring his left side and his head became flattened because of that. He was diagnosed with torticollis, which is shortening of the neck muscles, and hypotonia, a lack of muscle tone. He's gone for test after test, but nothing has come up positive, and the family doesn't have a diagnosis. His symptoms are like muscular dystrophy, but he doesn't have that disease.

It wasn't easy at first, but Gavares and Pitre have learned to cope and move forward so they can help Jace be the best he can be.

“I never thought this would happen, but it’s a road that we’re traveling and I don’t have a problem traveling down it,” Pitre said. “I see a light at the end of the tunnel.”

“Two years ago we looked at our son and our life and we said, ‘Oh my God how are we going to do this?’” Gavares said. “You want perfect, everybody wants perfect ... and now I look at my son two years later and I realized he is perfect; if anything he’s opened up our eyes to what a real problem is and to what real true kindness is.”



Jace Pitre, 2, with parents James Pitre and Courtney Gavares, has an undiagnosed muscular disorder.

Seeing kindness

Gavares and Pitre have seen the kindness of strangers. People they’ve never met have sent supplies and money to help Jace only because the family expressed need.

Now the Altamonte Springs family is participating in the MDA Muscle Walk, which will be held at Lake Lily in Maitland. At first they did it to give just a little back, but Gavares said she never knew how big her role would get. Team Jace and the Jollyhoppers are in first place of teams raising money, with \$3,921 as of March 20. For their family, this experience has been one that has changed their lives. It’s put a little control back in their hands to make a difference, and to help Jace and others like him.

“It brought motivation to our family and to our lives,” Gavares said.

All the money raised will go to local families in need — MDA has 1,300 members in Central Florida. It will buy wheelchairs and send kids to a special camp. While Jace probably won’t benefit from this money now, Gavares said she can’t wait for the time Jace can go to a summer camp made for him.

Walk organizer Brandi Rice said Team Jace has inspired others to work harder.

“It means everything to these families,” Rice said.

Help from students

Jace has also received help from some college students. Liani Steenekamp, Jace’s occupational therapist and Keiser University instructor, has had her students create a piece of equipment to help him get in the crawling position so he can learn to do it. He’s grown out of it, but Steenekamp plans to have her students build more learning and therapy tools for Jace.

Steenekamp is also his occupational therapist and has helped him learn to hold his head up and gain strength in his core. She said Jace works so hard at therapy with her — his face will get red and his breathing will shorten and he'll make noises because of his efforts. Gavares said this helps her keep hope for her son.

“That want to do things makes all of the difference,” she said. “He tries so hard to please you.”

And even though it may not seem like much, the progress Jace has made is a serious achievement.

“A little step is actually a big thing for him,” Steenekamp said.

And all this help couldn't be more important to their family. Jace only gets about four hours of therapy a week — a far cry from what he needs and many kids get. But they just don't have the money, and insurance only pays so much.

“This is the battle that we fight,” Gavares said.

She lives her life for Jace, but she hopes for a time when he can get better, and she doesn't have to think and move and worry for him every moment of his life, when she can go back to school to be a nurse. She gets sad sometimes, but when she looks at Jace, it changes everything.

“If he is this happy, I don't have a right to be sad.”