



Myles, the son of Maddie Levy, plays with his new drum set at their Lehigh Acres home on Monday. Myles just turned 1 and is one of 500 kids with Down syndrome being featured in the National Down Syndrome Society 2020 Times Square Video. AMANDA INSCORE/THE NEWS-PRESS USA TODAY NETWORK - FLORIDA

Lehigh Acres toddler on big Times Square screen

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Myles Levy is as adorable a kid as you'd ever want to see.

His natural cuteness, bright eyes and ubiquitous smile will be on full display Saturday when his photo and those of more than 500 other children with Down syndrome flash across the Jumbotron in Times Square in New York City as part of Down Syndrome Awareness Month.

The Lehigh Acres 1-year-old, the son of single mom Maddie Levy, 21, was among more than 2,000 submissions to the National Down Syndrome Society vying to be part of the organization's Times Square Video.

"Overall, we've been super lucky," said Myles' grandmother, Lisa Levy, "He's just the sweetest thing."

The Times Square Video presentation at 9:30 a.m. Saturday kicks off Down Syndrome Awareness Month during the NDSS New York City Buddy Walk.

Sara Goldberg, a society representative, said the featured photographs highlight children, teens and adults with Down syndrome working, playing and learning alongside friends and family. The collective images promote acceptance and inclusion, which is the foundation of NDSS and the National Buddy Walk Program.

"The Times Square Video presentation is part of our annual New York City Buddy Walk (this year

taking place virtually), which is one of hundreds of Buddy Walk events that take place across the country," Goldberg said.

As yet, there is no such event in Southwest Florida, something Myles' mom would like to change. A similar event, sponsored by Best Buddies, is planning its third Friendship Walk planned for April 17.

That Myles is loved and nurtured to the max is no secret at the Levy household. Maddie and her parents have the little boy in their focus day and night.

"Myles brought us all closer and made us better," Lisa Levy said.

For every step he makes progress on, such as sleeping through

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Myles

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the night or hitting age-appropriate functions, his mom makes a note. She calls those advances his "Mylestones."

"He's doing great," Maddie Levy added. "He's sitting. He can't crawl yet but you put him down and he gets around. He rolls and scoots backwards. He's very chill."

Myles goes to several therapies twice a week and takes part in a water safety lesson.

"He loves the pool," his mom said. "He doesn't necessarily love the lessons."

Maddie Levy's introduction to her son was not something she feels the mother of a child with Down syndrome should have to experience and hopes creating a local nonprofit — she's calling it "Myles Message" — will provide resources and help for parents like her.

"I want to do something for other moms," she said, "so they have a shoulder to lean on."

Maddie Levy was on her first day on the job at the daycare center in HealthPark Medical Center when she got a call about her pregnancy.

"They told me he was a boy and he had Trisomy 21, at the same time," she said. "I had no idea what that was."

Her mother added: "She called me in tears."

Maddie Levy said she knew absolutely nothing about Trisomy 21, which is one of three versions of the chromosome-based Down syndrome.

"I never had anything in life that would connect me to that. It was just the fear of the unknown. 'Oh, my gosh, what is wrong with my baby,'" she said. "I really thought they were calling me with a death sentence."

Her mom said her daughter was made to feel as if something was wrong. Maddie Levy said she was constantly asked if she wanted to terminate her pregnancy.

"It was never an issue. There's nothing that was going to change my mind," she stresses. "Just because our babies have an extra chromosome doesn't



Maddie Levy plays with her son Myles, 1, at their Lehigh Acres home. Myles is one of 500 kids with Down syndrome being featured in the National Down Syndrome Society 2020 Times Square Video. His photo will be live streamed online alongside more than 500 other individuals with Down syndrome on Sept. 12.

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mean their lives aren't worth living."

Maddie Levy said her experience at first was very negative and it's that mindset she would like change. She hopes creating Myles Message will be the venue.

She is grateful for the dedication of her own pediatrician, Dr. Angela d'Alessandro, who is now Myles' doctor.

"She was very supportive," Lisa Levy said, adding that Dr. d'Alessandro gave her daughter the right words of encouragement during the pregnancy.

Maddie Levy sees Myles Message as helping form a community around families with a child who has Down syn-

drome, change the delivery diagnosis from doctors and caregivers, provide realistic expectations of raising a child with Down syndromes and offer accurate resources.

She has an Instagram page, Myles_Message19, with 3,000 followers, and a Facebook page, through which she is trying to build up support for the nonprofit group.

For the time being Maddie Levy has had to step back from her HealthPark daycare job due to a low-white-blood-cell count issue with Myles.

"I didn't want to put him at risk," she said. She has hopes to go back to the job eventually.

She also recently graduated with an associates degree from Florida Southwestern University and plans to get an education degree, possibly special education, at FGCU.

But, for now, Myles is Maddie Levy's world and she plans to make sure his walk through it isn't fraught with problems.

"The moment Myles was born and they put him on my chest I felt like I could take a deep breath and he was mine and nobody could tell me anything else," she said.

Sitting at their home, Myles is a busy little boy, playing with a small, electronic drum set, focusing on anything new and intriguing around him and generally acting as, well, a 1-year-old baby boy — snips and snails and puppy-dog tails.

What is Down syndrome?

In every cell in the human body there

is a nucleus, where genetic material is stored in genes. Genes carry the codes responsible for all of our inherited traits and are grouped along rod-like structures called chromosomes. Typically, the nucleus of each cell contains 23 pairs of chromosomes, half of which are inherited from each parent. Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21.

This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome. A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm — although each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all.

What causes Down syndrome?

Regardless of the type of Down syndrome a person may have (there are three main types), all people with Down syndrome have an extra, critical portion of chromosome 21 present in all or some of their cells. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.

Connect with breaking news reporter Michael Braun: MichaelBraunNP (Facebook), @MichaelBraunNP (Twitter) or mbraun@news-press.com.

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 **Florida Lottery**
Results are for tickets sold only in Florida

FLORIDA LOTTO

SATURDAY, SEPT. 56-10-21-28-40-44 (x4)
6 of 6: \$1.5M (0). Wednesday's jackpot \$2M
5 of 6: \$3,712 (21). 4 of 6: \$63 (877).
3 of 6: \$5 (16,839).
2 (with XTRA): Free ticket (52,259).

POWERBALL

SATURDAY, SEPT. 515-21-22-27-47 PB: 7 (x2)
5+PB: \$66 million (0). Wednesday's jackpot \$75M
5 of 5: \$1 million (0).
4+PB: \$50,000 (0). 4 of 5: \$100 (23).
3+PB: \$100 (67). 3 of 5: \$7 (1,511).
2+PB: \$7 (1,548). 1+PB: \$4 (10,468). PB: \$4 (22,984).

MEGA MILLIONS

FRIDAY, SEPT. 419-22-24-28-53 MB: 25 (x3)
5+MB: \$88M (0). Tuesday's jackpot \$97M.
5 of 5: \$1 million (0). 4+MB: \$10,000 (1).
4 of 5: \$500 (18). 3+MB: \$200 (42).
3 of 5: \$10 (1,078). 2+MB: \$10 (837).
1+MR: \$4 (6,272). MR: \$2 (15,202).

JACKPOT TRIPLE PLAY

FRIDAY, SEPT. 41-10-12-34-41-42
6 of 6: \$525,000 (0). 5 of 6: \$310.50 (36).
4 of 6: \$23 (1,167). 3 of 6: \$1 (19,550).
Combo10+: \$10,000 (0). Combo9: \$500 (8).
Combo8: \$50 (91). Combo7: \$20 (532).
Combo6: \$10 (2,922) Combos: \$5 (10,646).
Combo4: Free ticket (29,084).

FANTASY 5

MONDAY, SEPT. 79-12-16-19-27
5 of 5: \$172,223.29 (1). 4 of 5: \$90 (307).
3 of 5: \$8.50 (8,880). 2 of 5: Free ticket (80,733).

PICK 2, 3, 4, 5

TUESDAY, SEPT. 8 MIDDAY
4-50-8-96-7-8-02-2-4-4-2

MONDAY, SEPT. 7 EVENING

5-70-8-07-2-3-81-4-5-0-3

CASH4LIFE

MONDAY, SEPT. 71-2-20-37-56 CB: 3
No winners of \$1,000 a day or week for life.
4 of 5+CB: \$2,500 (1). 4 of 5: \$500 (1).
3 of 5+CB: \$100 (48). 3 of 5: \$25 (146).
2 of 5+CB: \$10 (1,084). 2 of 5: \$4 (12,219).