

MDA national ambassadors named



Assistant to the President
Geneva Kubal



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Faith
Fortenberry

Faith represents a new generation of MDA children who are now benefitting from the FDA-approved drug Spinraza, which has been heavily supported over the years by MDA funding. In Faith’s case, Spinraza already is having a tremendous impact on her life. “It has been a game-changer,” said her mother, Leeann. “She can now lift things, hold a glass and brush her own teeth, which she was not able to do before. More importantly, she is able to breathe better.”

Spinraza has helped Faith stay out of the hospital, which has not only enabled her to take on a busy travel schedule as a national ambassador, but also might very well have saved her life. “Her lungs were so weak before that, whenever she had sniffles, she had to go to the ICU,” Leeann said. “Now she’s breathing deeper and longer. She’s coughing now—she never was able to cough, or even sneeze. It’s been huge for her.”

Over the years, the Fortenberrys have been active participants in MDA events in the Waco area. “Any time there’s anything MDA-related, such as a dinner or a fundraiser, we like to go and show everyone that they are helping real people and not just an organization,” Leeann said.

With her confident, bubbly personality and a desire for advocacy instilled in her by her family, Faith is ready to spread messages of hope and perseverance to others.

Justin Moy of Concord, MA, has congenital muscular dystrophy. “I want to become a biochemist,” Justin said. “I want to go into academic research or work for a pharmaceutical company so that I can help find a cure for my disease.”

Justin is currently a 17-year-old senior in high school, where he enjoys science and participating in the school choir. Next year, he will be going to college, where he hopes to major in biochemistry so he could one day become a muscular dystrophy researcher. Justin uses a power wheelchair and has always been intensely focused on what is possible rather than dwelling on limitations. It is an at-

Each year, an MDA national ambassador is chosen to represent the thousands of people living with neuromuscular disease and to inspire the community through their personal stories. This year, two ambassadors—Faith and Justin—will be traveling the country and sharing our important mission with MDA partners, sponsors and supporters.

Faith Fortenberry of Waco, TX, has spinal muscular atrophy. “It’s OK to be in a wheelchair, and it’s OK to be who you are,” Faith said. “You can do anything, whether or not you are in a wheelchair. If you want to play sports or just hang out with your friends, you can do it all.” She is an energetic 6-year old who loves to dance, cheer and play softball.

titude instilled in him at a young age by his parents. The oldest child of Prow Sarnsethsiri and Chris Moy, Justin has always dreamed big and focused on the open doors in life.

He has been living with the effects of congenital muscular dystrophy since birth, although he was officially diagnosed at 6 months old. Since his diagnosis, MDA has played a major role in Justin’s life, providing services and opportunities that have enabled him to thrive. One of Justin’s fondest memories was his time at MDA Summer Camp, where he was able to befriend other kids like him.

Justin’s mother, Prow, is grateful for all that MDA has done. “MDA has given Justin so many opportunities, such as summer camp and participating in races, that make his life normal,” she said. “They are experiences that can’t be put into words.”

As Justin travels the country, meeting with MDA sponsors and partners, he is excited to embody MDA’s “Live Unlimited” motto. “We need to be outgoing, and not afraid to do things that are uncomfortable,” he said. “If you let fear hold you back, or you just don’t want to do something, you are missing an opportunity to enjoy life. There are so many doors you can open that will lead to a fulfilling life.”



Justin Moy

History of the Ambassadors Program

Beginning in the early 1950s, when public awareness and understanding of muscular dystrophy and related diseases were almost non-existent, MDA put a human face on its mission by calling on young people affected by these diseases to serve as national goodwill ambassadors, telling their personal stories and inspiring support of MDA.

To date, the program has had 40 such ambassadors. These young people, along with their families, have traveled the nation to meet with sponsors, supporters and luminaries, including U.S. presidents such as John F. Kennedy and Ronald Reagan. They’ve also appeared on MDA’s telethons—often with longtime telethon host Jerry Lewis—and other forums such as “Larry King Live,” “Oprah,” “Today” and “Good Morning America.” Ambassadors have graced more than 15 covers of *Parade* magazine and served as guests of honor at Walt Disney World, Disneyland and the Rose Parade.

Today, MDA ambassadors continue to play an essential role in motivating millions to help MDA through donations or volunteer action. Former ambassadors have grown up to achieve distinction, transitioning into adulthood while earning advanced degrees and making their marks as authors, educators, bloggers, musicians, artists and successful business professionals. Their distinctive voices continue to ring out, advocating with great passion and intelligence to raise standards of independence, research and care for all members of the MDA family and for the disability community in general.

Note: In the 2017 MDA Honor Roll printed in the April Postal Record, there was a formatting error for the state of New Hampshire. We apologize for the error.