

## Inspirational stories that keep us on the road to a cure



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**I**t hardly seems possible, but 2018 is no more and the new year has arrived. For those of us who care deeply about community service, this is a time for looking back at our accomplishments and planning for the future. You should be proud of your union and the work we do to make our communities better. Whether it is our national food drive in May, disaster relief, Carrier Alert or the heroes we honor in fall, we show up and make a difference in cities and towns across the United States.

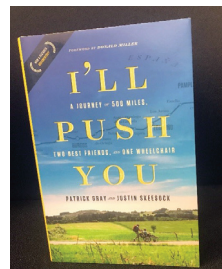
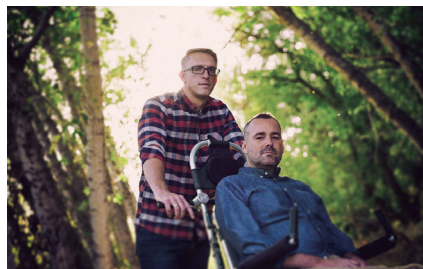
And for more than 66 years, we've been there for the Muscular Dystrophy Association (MDA). Each year, an MDA national ambassador is chosen to represent the thousands of people living with neuromuscular disease and to inspire the community with his or her personal story. This year two ambassadors were chosen, Faith and Justin. In November, I was able to meet them at an MDA Partner Summit.

**Faith Fortenberry, 7, is from Waco, TX, and has a diagnosis of Spinal Muscular Atrophy Type 2. Justin Moy, 18, is from Concord, MA, and has a diagnosis of Congenital Muscular Dystrophy.**

Since the early 1950s, when public awareness and understanding of muscular dystrophy and related diseases were almost nonexistent, MDA has 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. To date, the program has had 40 such ambassadors. These emissaries and their families have traveled the nation to meet with sponsors, supporters and luminaries including U.S. presidents John F. Kennedy and Ronald Reagan. Ambassadors have graced more than 15 covers of *Parade* magazine, visited daytime talk shows and served as guests of honor at Walt Disney World, Disneyland and for the Rose Parade. They also have graced our stages at NALC conventions.

Today, MDA ambassadors continue to play an essential role in motivating millions and galvanizing support. Former ambassadors have grown up to achieve distinction, 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 for raising standards of independence, research and care for all members of the MDA family and for the disability community in general.

**I also heard Justin Skeesuck and Patrick Gray speak.** Justin and Patrick have been friends all their lives. In June 2014, these two lifelong friends embarked on a nearly six-



***I'll Push You* is a book and documentary chronicling the journey of two lifelong friends, Justin Skeesuck and Patrick Gray, who traveled Spain's El Camino de Santiago. Justin has a rare neurological condition that requires him to use a wheelchair.**

week expedition to hike Spain's El Camino de Santiago. Their journey was complicated by the fact that Justin, who has a rare neurological disease, uses a wheelchair. Their 34-day journey, a 500-mile hike across mountains, deserts, hills and valleys, has been chronicled in a book and documentary, both titled *I'll Push You*.

The film, clips of which were shown at the summit, features perspectives from their families, friends and the strangers they met along the way, and explores the true meaning of friendship, generosity and vulnerability. Listening to the two and watching the film humbled me, and I got a little misty-eyed at some of the clips. I know I use the word "humble" a lot but that is my true feeling: I was humbled by their story. If you get a chance to read the book or watch the documentary, I strongly recommend it.

**MDA and NALC dream of a day when every child and adult diagnosed with muscular dystrophy will have access to treatment or even to a cure.** NALC's fundraising helps MDA with that promise as it builds on recent successes.

On that note: The beginning of the new year is a time when many people make resolutions to better themselves or those around them. Has your branch set any goals for community service for 2019? If not, I hope your executive board sits down soon to plan for the year and considers helping with MDA and the needs that are still there.

And if your branch is planning an activity, please let me know well in advance. We will use the "Deliver the Cure" Facebook page to promote the event, and once we know the exact date, NALC has MDA T-shirts and collector pins that we will make available.

Requests will be handled on a first-come, first-served basis until the supply is exhausted. Please call me at 202-662-2489 for details about this incentive.