

# Leading the Way with MDA

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## Legislative Advocacy & MDA's Advocacy Program



# Agenda



- Why does MDA mean by Advocacy?
- Why does MDA advocate?
- Program Overview
- Notable Victories
- 2023 Legislative Goals
- Grassroots Volunteer Activities
- Join us!
- Thank you!

**MDA**<sup>®</sup>



**ADVOCACY**

# Legislative Advocacy: What is it?



## Ensuring public policies further MDA's mission

- Passing legislation
- Stopping legislation
- Executive orders
- Agency rules & regulations
- Corporate advocacy



# Why does MDA lead advocacy efforts?



MDA's mission is to empower the people we serve to live longer, more independent lives.

# MDA Advocacy Pillars

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**Access to Care**



**Accelerating Therapeutic  
Development**



**Empowerment  
& Independence**

# Recent Victories

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## Access to Care

- Expanded and invested in Newborn Screening
- Prescription drug affordability
- Telehealth flexibilities
- Investment in key government programs
- LGMD diagnostic codes
- Seat Elevation Systems

## Accelerating Therapeutic Development

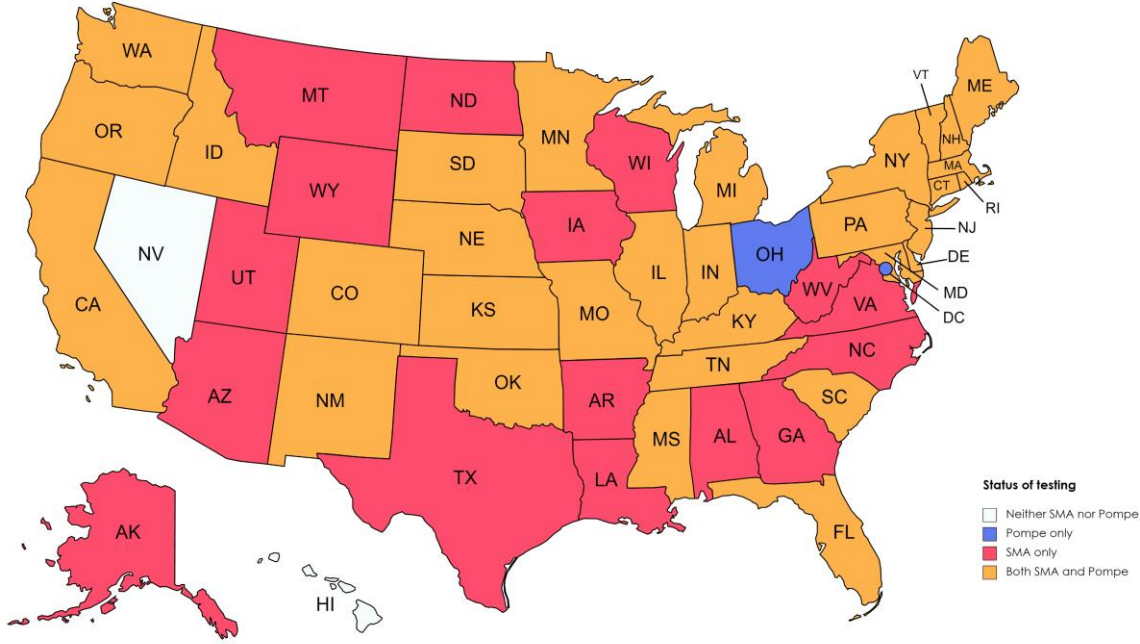
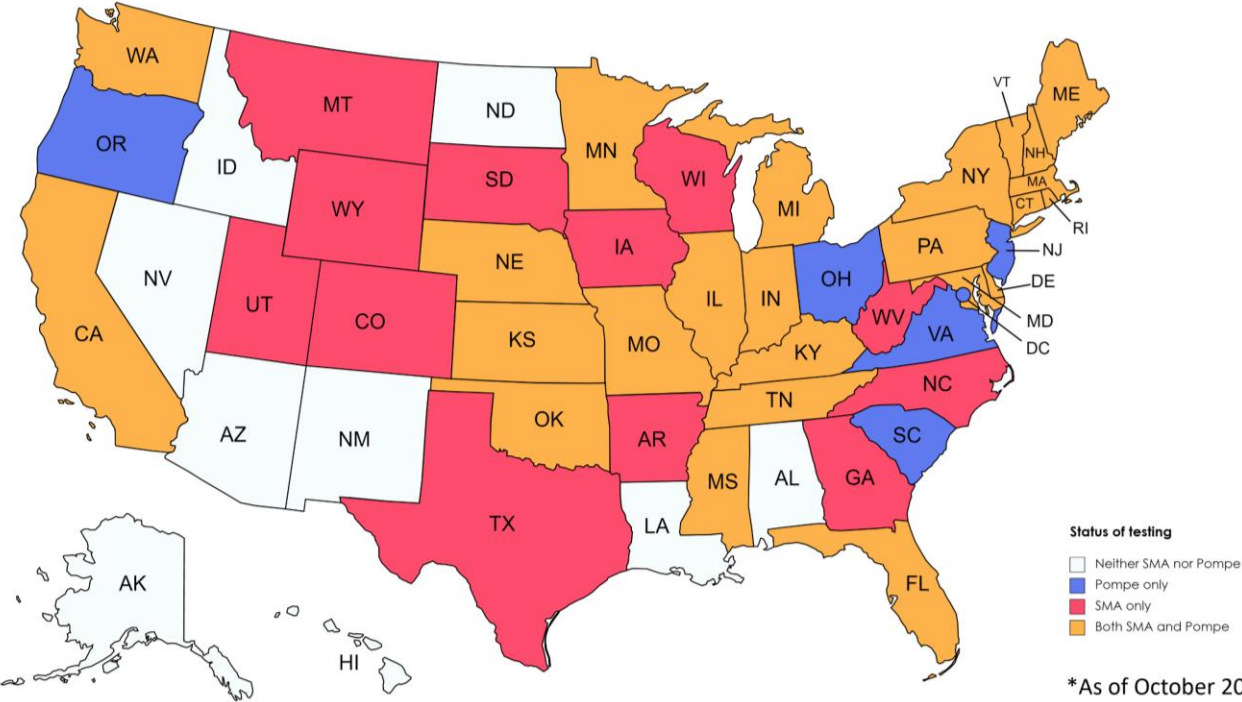
- FDA & clinical trial reforms
- ACT for ALS implementation
- Research funding and investments

## Empowerment & Independence

- ABLE Age Adjustment Act
- Accessible air travel



# Newborn Screening



Created with mapchart.net

# 2023 MDA Advocacy Priorities

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## Access to Care and Therapies

- Early detection and intervention via Newborn Screening
- Access to affordable, quality health care and coverage
- Telehealth
- Home & Community-Based Care
- Ending Diagnostic Odyssey



## Accelerating Therapeutic Development

- ACT for ALS implementation
- Innovating clinical trials & FDA reforms
- Increased investment in medical research



## Empowerment & Independence

- Accessible air travel
- End workplace discrimination
- Paid Leave
- Economic independence and security



# 2023 MDA Advocacy Priorities

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# Access to Care & Therapies



- Telehealth- building for the future
- Working on care for those with ALS
- Home and Community Based Care
- Newborn Screening
- Access to devices
- Defending public insurance programs

*MDA Advocacy  
Institute Presents:*



**Access to Care in the Home**

**Wednesday, April 6th  
7:00 p.m. ET**



# Increasing Access to Genetic Medicine



## Three Key Legislative Goals:

1. End the Diagnostic Odyssey by expanding access to whole genome sequencing under Medicaid.
2. Improve access to genetic counselors by advocating for their services to be covered under Medicaid
3. Streamline the process for patients to be seen by out of state providers under State Medicare and Medicaid plans.

*MDA Advocacy Institute Presents:*



*Unlocking Treatment Development*

*for Rare Neuromuscular Diseases*

**Thursday, February 24**

**7:00 p.m. ET**



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## Accelerating Therapeutic Development

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# Accelerating Therapeutic Development

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## Implementing enacted FDA and Clinical Trial Reforms:

- Expedited approval pathway reforms
- Cell and gene therapies
- Clinical trial endpoints in rare diseases
- Clinical trial diversity
- Decentralized clinical trials
- Patient-focused drug development
- And more!



# Accelerating Therapeutic Development



## Orphan Drug Act (ODA):

- Celebrating the 40<sup>th</sup> anniversary
- RARE Act
  - Clarify original intent of the law
- Defend ODA in Congress

## Accelerating Gene Therapies

## Investments in biomedical research:

- Further funding gene and cell-based therapy research and therapeutic development



Credit: EveryLife Foundation for Rare Diseases

# 2023 MDA Advocacy Priorities

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# Empowerment & Independence

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- Increasing employment opportunities for people with disabilities
- Improving access to higher education opportunities
- Reforming Supplemental Security Income by eliminating punitive rules and penalties for getting married or saving money
- Ending discrimination in federally-funded healthcare programs

*MDA Advocacy Institute Presents*

## Ending Disability Discrimination in Healthcare

**Tuesday, April 25**

7:00 p.m. ET



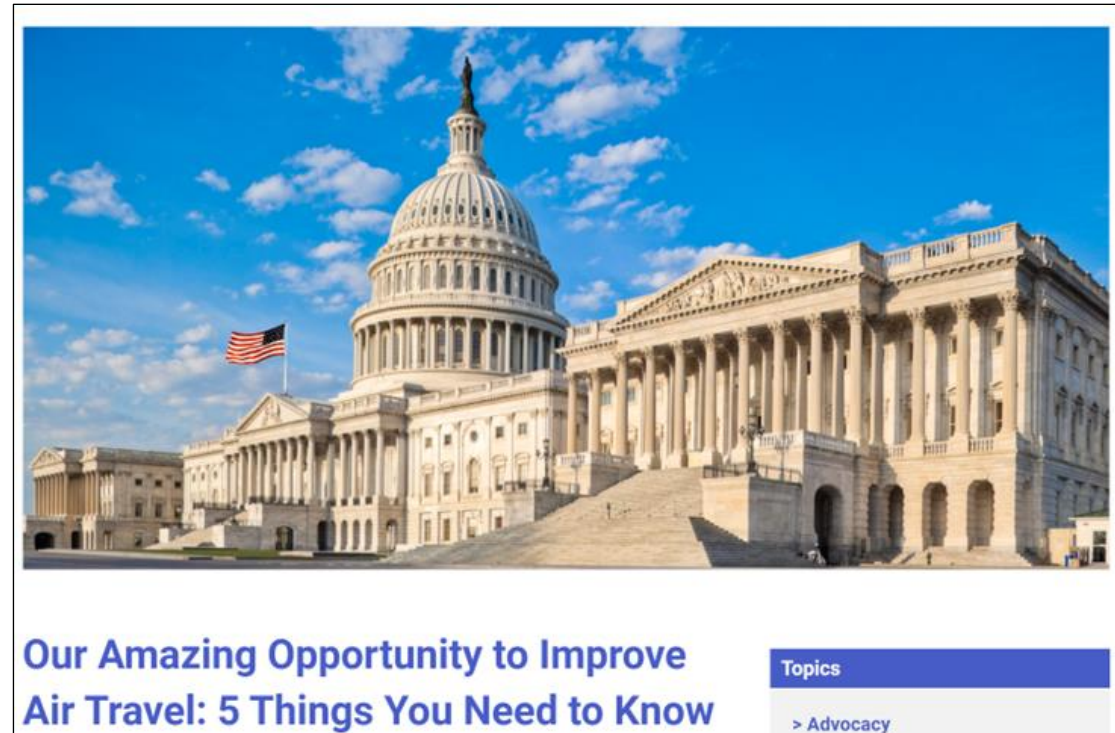


# Deep Dive: Improving Air Travel



## 2023 Federal Aviation Act (FAA) Reauthorization: What's the big deal?

- The Federal Aviation Act governs nearly everything related to air travel
- Congress updates the Act every five years
- They are updating the FAA reauthorization this year with a due date of October 1st
- This is our best chance to make air travel more accessible!

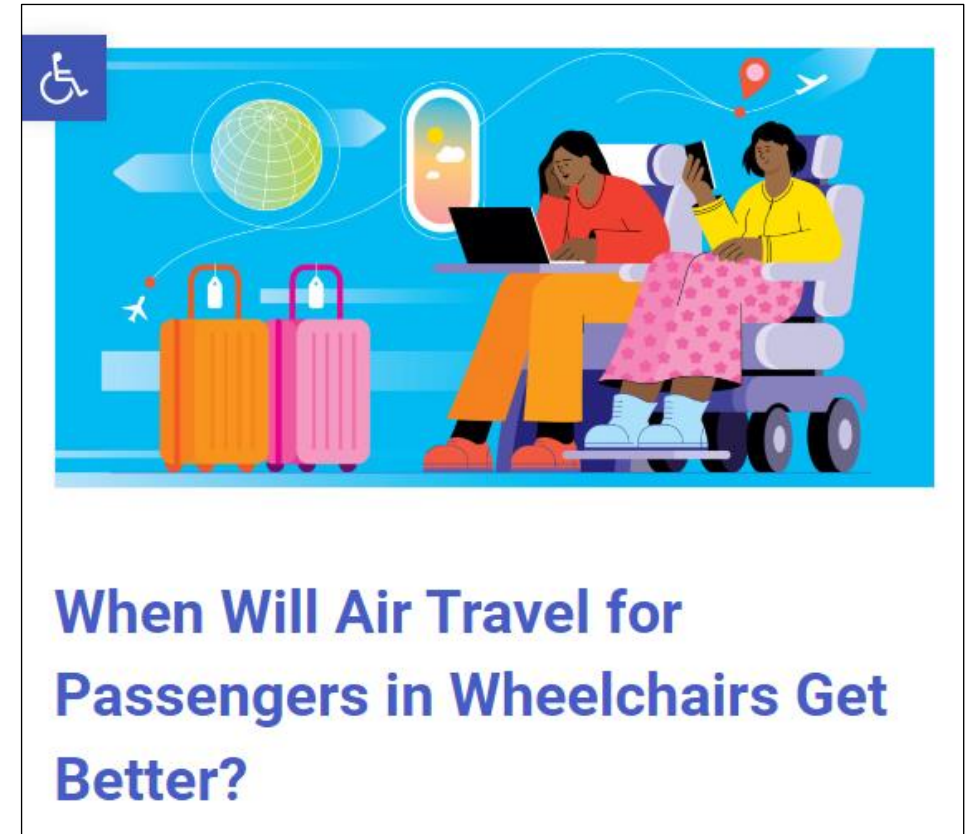


# Deep Dive: Improving Air Travel



## Our 5 Goals for FAA Reauthorization

1. Make Airplanes More Accessible
2. Ensure the Safety of Air Travelers with Disabilities:
3. Minimize Damage to Wheelchairs and Other Mobility Devices:
4. Hold Airlines Accountable for Broken, Damaged, or Lost Wheelchairs and Violations of Passenger Rights
5. Give the Disability Community a Seat at the Table





**How can you help?**

# The Role of the Grassroots Volunteer



- **Online Opportunities**

- Receive timely email updates
- Email and tweet to members of Congress
- Take action on government agency regulations
- Educational webinars & trainings
- Share your story

- **Offline Opportunities**

- Visit members of Congress' offices
- Call members of Congress
- Write blogs and other pieces
- Organize in the community



[www.mda.org/advocacy](http://www.mda.org/advocacy)  
Text MDAUSA to 50457

# The Power of Your Story



## ADVOCACY

### Reporting Back on MDA's First-Ever Virtual Hill Day

MDA STAFF | 09/01/2020

*When the COVID-19 pandemic made meeting in person impossible, MDA's Advocacy program needed to shift from in-person to virtual meetings with lawmakers. In early August, volunteers met with their lawmakers virtually — for the first time — to urge elected officials in Washington, DC, to end the process of surprise medical billing, which can be devastating for patients, including those in the neuromuscular disease community.*

*Gabrielle Runyon participated in MDA's first-ever Virtual Hill Day, and we sat down to talk to her about her experience. Gabrielle, a college student from Louisville, Ky., is a veteran advocate who also participated in MDA's in-person Public Policy & Advocacy Conference last year in Washington, DC.*

#### Why was it important to you to participate in MDA's first Virtual Hill Day?

MDA has been a big part of my life for quite a while. My mother started taking me to an MDA Care Center to get flu shots when I was 5 or 6 years old because our insurance didn't cover them. I continued going to the Care Center, then at 7, I heard about MDA Summer Camp and I really wanted to go. My mom was afraid to let me go, so it took a year of convincing her. When I turned 8, she said I could attend. All of the paperwork was filled out and I was ready to head to camp, but then it got canceled because of the H1N1 influenza outbreak.

After that I started fundraising so I and other kids could go to camp. In 2016, I became a local MDA Ambassador for the Louisville area, and in 2018 I became one of the MDA State Ambassadors for Kentucky.

I love participating and advocating whenever I can to help out as much as MDA has helped me.


#### How did you prepare for the meetings?

We were given materials and information on what we were going




# Advocate Resources

## MDA.org/advocacy

ACTION CENTER


Sign-Up Current Issues Action Center Your Officials Advocacy Institute Advocacy Blog

📌 Campaigns ✍️ Surveys




### Urge Congress to Prohibit Ableism is Healthcare

Did you know that those living with a disability can face discrimination in accessing care and treatments solely because they have a disability? Unfortunately, that is the case through the use of a health measure called Quality-Adjusted Life Years or QALYs. QALYs can...




### Congress: Make Air Travel Accessible

Broken wheelchairs. Broken bones. Broken plans. For too many living with a disability, traveling by air is a nightmare and improving the system is long overdue. The good news is this year we have a unique opportunity to pass meaningful reforms that will make air travel more...



### MDA Advocacy Institute


We're excited to share MDA's new educational series, The MDA Advocacy Institute. These monthly webinars will provide advocates with grassroots skills, timely news on issues that are important to the neuromuscular community, and updates from Capitol Hill and Federal agencies...




### Tell us what you're interested in!

We know you get a lot of emails and only want to receive messages that you care about. Therefore, please let us know what you're interested in. Take our survey today.

### Recent Tweets


**MDA Advocacy**  
@MDA\_Advocacy · 13m

Thank you [@RepGwenMoore](#) for cosponsoring the Air Carrier Access Amendments Act, which would allow individuals with [#neuromuscular](#) disease to travel with fewer complications! [#AccessibleAirTravel](#)



### Accessible Travel

ALT

**MDA Advocacy**  
@MDA\_Advocacy · May 28

### Blog Posts

March 8, 2023


[MDA Calls for Widespread Insurance Coverage of FDA-Approved Neuromuscular Disease Treatments](#)

February 10, 2023

## Quest Media

## MDA's 2023 Advocacy Plan


## Advocacy Institutes



### MDA Advocacy Institute Presents

## 2023 Advocacy Kickoff

**Wednesday, January 25<sup>TH</sup>**  
7:00 p.m. ET



# All-Star Moments: 2022 Virtual Hill Day



- **Advocates Back After 3-Years**
  - In-depth training
  - Connect with fellow advocates
- **Key Issues**
  - Accessible Air Travel
  - Increase Access to Genetic Counselors
  - FDA and Clinical Trial Reforms
- **By the numbers**
  - 78 participants
  - 28 states represented
  - 100 Congressional meetings



# All-Star Moments: Air Travel Videos

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<https://youtu.be/9TLFCams5oU>



# All-Star Moments: 2023 Hill Day



# What can you do now?

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1. Sign-up
  - [MDA.org/Advocacy](https://www.mda.org/Advocacy)
  - Text MDAUSA to 50457
2. Urge Congress to improve air travel
  - [MDA.org/AirTravel](https://www.mda.org/AirTravel)
3. Follow us on Twitter
  - @MDA\_Advocacy





# Q&A