

MDA looks back at 2024

It hardly seems possible, but 2024 is no more and the new year has arrived. It is a time for looking back at our accomplishments and for 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 Disaster Relief Foundation, national food drive on the second Saturday in May, or the heroes we honor, we show up and make a difference in cities and towns across the United States.

Below is a letter from MDA CEO and President Dr. Donald Wood that reflects on 2024:

As we approach the close of 2024, it's a moment for all of us at the Muscular Dystrophy Association (MDA) to reflect on the profound impact we've made together with our partners, supporters, and families. This year has been marked by extraordinary progress in our mission, strengthened through connection and collaboration. From groundbreaking treatments and significant legislative victories to inspiring annual initiatives like MDA Summer Camp, we have made strides in advancing care and treatment for neuromuscular diseases.

A year of major achievements—In 2024, we achieved several remarkable milestones that underscore the strength of our collective efforts.

Notably Advocacy and legislative impact:

- One of the standout accomplishments was the inclusion of essential accessibility provisions in the FAA Reauthorization, which is a significant step in advancing the rights and access for individuals with neuromuscular diseases.
- Additionally, MDA's Access the Vote campaign empowered voters to understand and exercise their rights during a pivotal election year, ensuring that the voices of those impacted by neuromuscular diseases were heard.

Clinical and scientific advancements:

- This year's MDA Clinical and Scientific Conference saw an inspiring address by Brooke Eby, who shared an urgent call for continued progress in research.
- Furthermore, we saw the introduction of new treatments for myasthenia gravis and Duchenne muscular dystrophy, reflecting our ongoing commitment to advancing research and treatment.

Community support:

- MDA celebrated the launch of its first college scholarship program, which aims to connect a new generation of advocates and supporters to the cause.

These milestones are a testament to the power of teamwork, determination, and vision. They lay the groundwork for what promises to be an extraordinary 75th anniversary year in 2025.

Investing in research and treatment: A central pillar of our mission is advancing research to find effective treatments and cures for neuromuscular diseases. This year, MDA demonstrated its continued commitment through key investments and partnerships:

- **ALS research:** MDA awarded a \$500,000 grant to Dr. Sabrina Paganoni of Massachusetts General Hospital, supporting the HEALEY ALS Platform Trial. This pioneering ini-

tiative tests multiple therapies simultaneously to identify promising treatments for ALS, one of the most challenging neurodegenerative diseases. Dr. Paganoni highlighted the importance of collaborations like these to expedite breakthroughs that offer hope to patients and families.

- **Gene therapy innovations:** MDA's Kickstart Program reached key milestones, receiving FDA designations for its gene therapy project aimed at treating congenital myasthenic syndrome caused by CHAT gene mutations. This partnership with UC Davis and Forge Biologics brings us closer to providing life-changing therapies for ultra-rare neuromuscular diseases.

Honoring advocacy and leadership—This year also saw a celebration of the outstanding advocacy and leadership within the neuromuscular community:

- MDA advocate and Major League Baseball player Rhys Hoskins was honored with the 2024 Marvin Miller Man of the Year Award and the inaugural Most Valuable Philanthropist Award by his peers. These awards recognize his leadership on and off the field and his longstanding commitment to MDA's mission. In honor of Hoskins' advocacy, The Players Trust awarded MDA a \$50,000 grant to support our efforts.
- We are also thrilled to welcome Barry J. Byrne to the MDA Board of Directors. A renowned pediatric cardiologist and geneticist, Dr. Byrne's contributions to gene therapy and neuromuscular research will play a pivotal role in shaping our future strategies.
- This year, MDA introduced Ira Walker as the organization's new adult National Ambassador, bringing fresh perspectives and insight to our advocacy efforts. Ira's addition symbolizes the growth of our reach and the diverse voices that are now a part of our mission.

Looking ahead to 2025: 75 years of impact

As we approach MDA's 75th anniversary in 2025, we reflect on the profound legacy we've built and the momentum we've generated in our work. The upcoming 2025 MDA Clinical & Scientific Conference in Dallas promises to be a landmark event, highlighting transformative therapies for conditions such as ALS, Duchenne muscular dystrophy, and spinal muscular atrophy. This event will bring together researchers, clinicians, patients, and advocates to share knowledge and accelerate progress.

Capitol Hill advocacy—Our grassroots advocacy continues to drive real change. In September, MDA on the Hill brought together 95 advocates for impactful meetings with lawmakers, advocating for critical bills that support the neuromuscular community. With over 97 meetings held, we worked tirelessly to promote bills such as the SSI Savings Penalty Elimination Act and the Accelerating Kids Access to Care Act, which will improve financial independence, rare disease treatment development and access to care for children.

Gratitude and reflection—As we step into the 75th year of our mission, I offer my deepest gratitude to each of you for the focus, creativity, and dedication you bring to MDA's work. Your commitment has made possible incredible milestones and created lasting change for families affected by neuromuscular diseases.

(continues on next page)

(continued from previous page)

Before we ring in the new year, I encourage you to reflect on what this anniversary means to you, your team, and the families we serve. Together, we are stronger, and together, we will continue to make a difference.

Wishing you and your loved ones a holiday season filled with joy, peace and a renewed sense of connection and purpose for the year ahead.

Together, we bring forward the spirit, the vision, and the commitment that define MDA.

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 2025? 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 NALC know well in advance. We can use the "Deliver the Cure" Facebook page to help promote the event.

—Christina Vela Davidson

Contract Talk

by the Contract Administration Unit

Route inspections, Part 5 (continued)

(continued from page 41)

abbreviated regardless of who carried the route, according to Section 221.11, because if there is no delivery or if delivery is abbreviated on a Saturday it is not to be included pursuant to Section 221.11 of the *M-39 Handbook*. That section is clear that for one-trip routes with an abbreviated or no delivery on Saturday, the count of mail must be for five consecutive delivery days, exclusive of Saturday. Section 241.33 of the *M-39 Handbook* does not obviate the requirement to comply with Section 221.11 of the *M-39 Handbook*.

This case had several other violations, but for the violation of this rule in particular, the arbitrator ordered USPS to cease and desist from future violations and awarded:

For the eight routes identified with abbreviated Saturday delivery, the Postal Service is directed to reinspect and adjust those routes without consideration of the Saturday delivery times in accordance with Section 221.11 of the *M-39 Handbook*. This shall be accomplished within 90 days of the date of this Award.

Route inspection teams come into an office for a week, do everything they can to build overburdened routes, and head to the next town, leaving both the letter carriers and local managers to deal with the mess they created. The Operations arm of the USPS has historically failed to grasp the concept that a square peg does not fit into a round hole. Letter carriers and union representatives alike should familiarize themselves with the route count and inspection process outlined in Chapter 2, *Handbook M-39* and Chapter 9, *Handbook M-41*. The more educated we are in the inspection and adjustment of routes, the more prepared we will be when management brings that square peg to our offices.

The NALC offers many resources to assist letter carriers and shop stewards with obtaining fairly adjusted routes. Two free publications/resources that every branch in the

country should arm themselves with are:

1. **The NALC Route Inspection Pocket Handbook**—This booklet fits in your shirt pocket and is specifically designed to assist letter carriers during the week of route inspection. Every letter carrier who goes through the route inspection process should be provided with a copy of this booklet in advance of the week of mail count and inspection. If your branch does not already have a supply, *NALC Route Inspection Pocket Handbooks* are available at no charge through the NALC Supply Department. Contact your national business agent's office to obtain copies. Note: The pocket handbook is not available online.
2. **The 2018 NALC Guide to Route Inspections**—This book is specifically designed to assist shop stewards before, during and after the week of route inspection. This resource also contains a section that thoroughly explains how to read, and the purpose of, all the route inspection forms USPS uses to evaluate and adjust routes. Once you understand how to read these forms and what to look for, the task of investigating route inspection grievances becomes much easier. It is highly recommended that every shop steward study and become familiar with this guide when USPS announces that an office you are responsible for will be inspected. The guide is available at nalc.org/workplace-issues/city-delivery/route-adjustments.

There are more resources related to route inspections and adjustments available on the NALC website at nalc.org/workplace-issues/city-delivery/route-adjustments. Past Contract Talk articles pertaining to these issues are also available on the NALC website at nalc.org/workplace-issues/resources/nalc-publications.