



## Year in Review

### The pandemic situation further improved in 2022 — and MDA is geared up for 2023

As the world headed into 2022, there was still a great deal of uncertainty with the pandemic, but MDA kept pushing forward. Now, we look forward to the next year with optimism, and we carry forward the lessons we learned from a year that required creativity and the ability to adjust.

#### Meeting challenges

“Our neuromuscular disorder community had many challenges in 2022, including inflation rates and supply chain issues, that greatly impact their daily life and independence,” says Nora Capocci, vice president of healthcare services for MDA.

“It also affected clinicians and researchers in terms of recruiting for clinical trials,” says Sharon Hesterlee, PhD, chief research officer for MDA.

When it came to research grants, MDA adjusted. “We’ve been mindful with our grantees when they take longer than they typically would with their work,” Dr. Hesterlee says. “We don’t want to cut a grant short when it’s a supply chain issue, for example. As far as gene therapy challenges, we started a new invitation-only workshop and held it in January, featuring academic and industry immunologists.”

In 2022, MDA funded about 80 research grants for roughly \$19 million. “We also held an in-person conference in Nashville in March, and we launched a brand new initiative, the MDA Kickstart program, focusing on ultrarare disorders,” she says. “They just don’t get the same attention, so we are focused on developing gene therapy for this underfunded area.”

### Looking ahead

In 2023, MDA aims to offer a hybrid telehealth/in-person experience in MDA Care Centers to help expand access to high-quality neuromuscular disease care. MDA declared 2022 the Year of Independence, and we hope to continue building on that moving forward.

MDA is also looking at better ways to support patients without a genetic diagnosis for their symptoms. “For those with limb-girdle muscular dystrophy, as an example, it can be tough to get a diagnosis,” Dr. Hesterlee says. “In fact, a decent percentage of those with neuromuscular disorders don’t have a diagnosis. We are renewing efforts to change that.”

In the research space, MDA will make efforts to improve the diversity of grantees. “We looked at our current grantees and there wasn’t a proper reflection of the diversity in society,” Dr. Hesterlee says. “For this program, we will focus on undergraduates and do summer internships for diverse students to work in labs and get them well supported for their career.”

The work MDA did in 2022 is expected to lay the groundwork for changes to come in 2023. “It should be a year of important opportunities,” Dr. Hesterlee says.