

A tribute to Jerry Lewis— What happened to ‘Jerry’s Kids’?



Assistant to the President
Geneva Kubal



Jerry Lewis became associated with the Muscular Dystrophy Association about the same time NALC did. Lewis was as tireless in his humanitarian efforts as NALC. As host of the MDA Labor Day Telethon for 45 years, he helped NALC raise \$100 million for MDA and the children it supports, known as “Jerry’s Kids.” Although a cure has not been found, the efforts of Lewis and NALC have made an impact not only for the families, but also for the research that has helped those with MD in everyday life. We have gone from “Jerry’s Kids” to “MDA families.”

The impact letter carriers make can be directly tied to the quality of life that individuals who live with MD experience. For example: Chase Miller (with Becker muscular dystrophy, or BMD) works as a fundraising coordinator for MDA. Kushal Parikh (with BMD) works as a social worker in Chicago. Victoria Haire (with limb-girdle muscular dystrophy, or LGMD) landed an internship in a care facility. MDA offers young adult employment services to help those looking for work.

Cindi Reamer (diagnosed with LGMD as a child) has been working for her orthopedist since age 20. She has held this job for more than 30 years. Justin Skeesuck was able to conquer the Carmino de Santiago trail in Spain. Katrina Gossett found love and married after she chose to no longer hide her disease from potential suiters. Karen Condron (with amyotrophic lateral sclerosis, or ALS) lost her ability to speak, but now expresses herself through her paintings that are sold online at karencondron.com. Take a peak at her work and you may find something you need to place in your home or office.

Individuals with MD understand there are joys and challenges in everyday life. They are just like letter carriers who regularly make the best of their workday or life in general. That’s one reason why NALC continues to support MDA. MDA funds the world’s best scientists who are working on the most promising, most innovative, most cutting-edge science out there. With research investments totaling more than \$1 billion over the last six decades, MDA has fingerprints on many major advances in neuromuscular disease research, and with these latest awards, it is continuing to fund the science that will lead to the next medical and scientific breakthroughs poised to change lives.

MDA has announced more than \$3 million in funding for 13 new research projects. These new grants join the 29 research and development grants already announced earlier this year. NALC’s fundraising efforts support MDA’s quest to end muscular dystrophy, ALS and related life-threatening diseases:

- **For all neuromuscular diseases:** Researchers in Houston are working to enhance the discovery of new disease genes and advance molecular diagnostics for people with neuromuscular disease.
- **For facioscapulohumeral muscular dystrophy (FSHD):** Scientists in Boston are studying genes that minimize or exacerbate disease symptoms to determine whether they could explain why some individuals with FSHD-causing gene defects appear to be “resistant” to the disease.
- **For spinal-bulbar muscular atrophy (SBMA):** Researchers in Ann Arbor, MI, are testing a modified antisense therapy to treat SBMA.

Over the last six decades, NALC has helped MDA invest more than \$1 billion in research focused on finding treatments and cures for diseases that take away physical strength, independence and life.

“We’ve seen a tremendous amount of progress in the last few years with the approval of several new drugs to treat neuromuscular diseases,” MDA Senior Vice President and Scientific Director Grace Pavlath said. “Those recent successes don’t give us license to scale back on our efforts, however. Our families are counting on us, and that’s why we continue to support the most innovative, cutting-edge science out there.”

As an organization that covers dozens of neuromuscular diseases, MDA is leveraging the power of a big-picture approach in the search to find treatments and cures, with most, if not all, the research projects having the potential to further knowledge that can make an impact across all muscular diseases. Additionally, MDA supports families in their quest to “Live Unlimited.” With 13 new projects, the work continues to change lives. Progress is MDA’s promise.

NALC’s fundraising helps MDA with that promise as it builds on recent successes. Over the last two years, four drugs that can trace their origins to MDA research grants have received FDA approval. In 2015, the FDA approved Keveyis for the treatment of periodic paralysis. In 2016, the agency approved Exondys 51 for the treatment of some forms of DMD, and Spinraza was approved to treat individuals with spinal muscular atrophy (SMA). And last February, FDA approved Emflaza to treat Duchenne muscular dystrophy (DMD), regardless of the genetic mutation underlying the disease. Making progress, like MDA has with these new drugs, is the reason MDA is optimistic about this new round of funding. Every new grant has the potential to catalyze the next medical or scientific advance for MDA families.

So as more and more of Jerry’s Kids are growing up and having families of their own, let’s continue to do what we can to help. NALC is committed to “Deliver the Cure.” With your help, we will deliver on that promise.