

New drugs and new hope for MDA families—your fundraising is making a difference



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MDA takes a big-picture approach to uncovering breakthroughs for treatments and cures across muscle-debilitating disease types. They can often apply what they've learned from one disease to others to bring urgently needed answers to MDA families. Within the last year alone, two new, life-saving drugs have been granted FDA approval—and they are already making a profound impact on kids and adults in towns across America.



Spinraza: Helping kids walk, play and dance—In December, the FDA granted approval for Spinraza, the first

disease-modifying drug to treat spinal muscular atrophy (SMA). The achievement was historic for the entire SMA community—including 4-year-old Lexi from Colorado, who, thanks to this promising new drug, is now learning how to walk. When Lexi first began the clinical drug trial two years ago, she was only able to stand for a second or two. About six months later, Lexi was able to take 12 steps all by herself. She's now taking more than 30 steps at a time—a far cry from where she was when she was diagnosed with SMA more than two years ago. "It would be great to see her, one day, not need her walker or walking sticks at all," said Lexi's mom, Tammy. For now, Lexi's family is grateful that the drug is working. And Lexi is happy to have some mobility and a little independence. "She's already in dance class," Tammy said, "and she loves it."

Exondys 51: A pioneering treatment for DMD—Last September, FDA approved Exondys 51 as the first disease-modifying drug to treat certain forms of Duchenne muscular dystrophy (DMD). Since then, it's been helping kids find strength and independence in the face of muscle degeneration and weakness. For 13-year-old Alejandro, this new treatment is a precious source of hope as he fights to live longer and grow stronger. Since the diagnosis, Alejandro's parents have dedicated themselves to helping their son get the treatment he needs to not only survive but thrive. Now, with Exondys 51, Alejandro is closer than ever to living life the way he's always dreamed—unlimited.

Letter carriers help fund the development and/or purchase of devices that promote mobility and independence. In addition, letter carriers continue to champion progress by partnering with MDA to communicate information; to fund care facilities, which support more than 100,000 individuals; and to fund MDA Summer Camp.

It doesn't stop there. Letter carriers and their families have volunteered time at MDA summer camps. The camp experience is "like a vacation from the disease. You feel like you can do anything," said Payton, age 14. For letter carrier volunteers, it gives you a small glimpse into why we have been raising money for MDA since 1952. If you have not volunteered for an

MDA camp experience, I highly recommend it.

The representatives from the winning branches from the 2017 NALC MDA Honor Roll participated in an MDA summer camp this year. At MDA camp, kids with neuromuscular disease discover a world created specifically for them and meet many other kids sharing the same needs and experiences. MDA campers dream about summer camp all year and often say it's better than Christmas; some even say it's changed their lives. Almost all campers agree that it's the best week of the year.

MDA camp offers a fun and safe outdoor experience, along with opportunities to engage in a variety of activities such as horseback riding, swimming, adaptive sports, arts and crafts, camp dances and much more. In addition to all of the fun and friendship it offers, MDA camp enables campers to stretch their comfort zones and grow in independence as they spend a week away from home, permit someone other than their parents to provide personal care and make new friends.

Sure, there's an abundance of fun and games at MDA camp, but if you talk to MDA campers, they'll tell you the real benefits come in a much subtler form—the lifelong friendships, the increased self-esteem and confidence, and the chance to spend at least one week of the year in a place where physical disabilities are the norm rather than the exception.

For parents and guardians, MDA camp provides a brief break from their roles as caregivers for children with neuromuscular disease. It's a place where parents know they can send their children for a week of summer fun and, at the same time, be assured that their children's medical and physical needs will be met by a team of dedicated health professionals and trained camp volunteers. MDA staff and volunteers assume all camper care, including physical and emotional support, allowing parents much-needed time to attend to their own needs and, in some cases, spend some special time with the camper's siblings.

For NALC, camp provides our volunteers a rare opportunity to connect in ways we might not be able to do at any other time in the year. If you have not attended a VIP day at a camp, please try to do so in the future. It is a blast and you will walk away changed.



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