

At MDA summer camps, enrichment for kids of all ages



Assistant to the President
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One of the most rewarding experiences I have had since President Rolando appointed me to be our MDA liaison is volunteering at summer camp. I visited three camps this year with several NALC brothers and sisters from the areas where the camps were located. We had a great time, and all of us who had this privilege were enriched by the children and their counselors. The interaction we had with the campers was priceless and a learning experience for all of us. Through our activities together, we learned about geography, trivia, postal tidbits, letter writing and, most importantly, we

learned that personal challenges or struggles do not hinder having fun.

Camp might be the best motivational tool to help inspire you or your branch members to support MDA not only with money, but time. When you see firsthand the need and then the impact of this benevolence, it is hard not to do just a little something. If you need help getting started, give me a call so we can start planning ahead for next year's camp season. We have simple, fun ideas, and all you need is a minimal amount of money and some time. It might be one of the best times you have all summer. I am hoping that we can have an NALC presence at every MDA camp by the year 2020. I am counting on you to make that happen.

The impact of our fundraising

Although breakthroughs don't happen overnight, our fundraising efforts help MDA bankroll research that focuses on collaboration, supporting the world's best scientists and projects across all MD diseases. Our endeavors helped provide more than \$17 million in new research just this year alone. Since September, we have helped fund 22 research grants and two developmental grants. MDA funds only the highest-rated, most promising projects. All applications are reviewed and scored by a team of 40 of the world's leading clinicians and scientists who specialize in neuromuscular disease and serve in volunteer roles for MDA.

Some may ask why a cure has not been found. MDA states, "There are many neuromuscular diseases, and for some diseases there are even different types. Because there are so many, we will have to find many cures—not just one. We're going to have to treat the different diseases and disease types in many different ways. We can always use more funding to speed the search for cures, as it will allow us to fund more people to work on the various problems. But funding isn't everything. We also are limited by the speed at which science advances and how our knowledge about the different diseases moves forward."



President Rolando (second from r) with the lucky winner of a mini postal truck during an MDA Honor Roll trip in Milwaukee

But there has been much success to build upon. MDA has been involved in research into basic muscle and nerve biology since 1950, when virtually nothing was known about how muscles were formed or functioned, even in non-diseased tissues. Since then, thousands of scientific papers have been published explaining how the tissues work and what goes wrong in neuromuscular disease. MDA funding supported the research that led to the discovery of the genetic causes of dozens of diseases, starting with the discovery of the dystrophin gene in 1986. Without this knowledge, there was no hope for curing diseases.

MDA's research program has been so successful over the years that it started the translational research program in 2004 to help accelerate therapy development based on these results. This program attracted so much interest that it was expanded in 2009 with the formation of MDA Venture Philanthropy (MVP), which operates with more of a venture capital approach. MVP focuses exclusively on the funding and commercialization of treatments and cures for neuromuscular diseases and hopes to increase the speed of moving drugs through clinical development.

MDA's fingerprints are on nearly every major advance in neuromuscular disease research, with MDA-sponsored research having resulted in treatment breakthroughs and in increasing survival and quality of life.

This note from a camper named John says, in part, "Thank you for everything you do to support MDA summer camp. I am having a great time!" And in big letters, "Children grow with love!" The postscript is a request to "send bacon."

