



CHARITIES Committee

Ralph Orleck, Chairman



The RISAA Charities Committee exists to lend a helping hand to others in need, and is a way of giving back to our community.

THIS MONTH'S CONTRIBUTION

Muscular Dystrophy Association

Report by
**JEFF
INGBER**



I am smarter today than I was yesterday after having the privilege of delivering a check to this month's recipient to the Rhode Island and Southeastern Massachusetts office of the Muscular Dystrophy Association.

Families are at the heart of MDA's mission. A caring and concerned group of families started MDA in 1950, and they continue to relentlessly pursue a promise to free families (approximately 1,900 individuals and families here in RI and South Eastern MA) from the life-threatening effects of muscular dystrophy and muscle-debilitating diseases.

MDA is built on 3 core missions: Research, Care and Empowering families.

Research MDA is the nation's largest nonprofit supporter of research on over 45, yes 45 different neuromuscular diseases. Categories of neuromuscular disease include: Muscular Dystrophies, Myopathies, Motor neuron diseases, Ion channel diseases, Mitochondrial diseases, Neuromuscular junction diseases, Peripheral nerve diseases and more.

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 sponsored research has resulted in breakthroughs in treating Pompe disease and Duchenne muscular dystrophy (DMD).

CARE Care Center Network offers tens of thousands of appointments each year for individuals living with muscular

dystrophy, ALS and other neuromuscular diseases to access expert multidisciplinary care, clinical trials, and to connect with MDA and the neuromuscular community.

Care and Clinical Services Specialists are available to answer questions, provide educational materials, coordinate any services you may need and assist with community resource referrals.

Upon diagnosis, a number of medical management measures may be recommended by the MDA Care Center team, including: Periodic re-evaluations, speciality consultations, physical, occupational, respiratory and speech therapy, social services, cooperation with personal physician, genetic counseling.

Empowering Families While Research and care are clearly the pathway to curing the more than 45 diseases under the MDA umbrella, I learned that empowering individuals and families of individuals living with one of these diseases is where the boots hit the ground. Literally!

MDA sponsors thousands of educational seminars annually to empower individuals and families with knowledge and resources. Information will be shared by experts in the field and individuals living with neuromuscular disease and will also provide an opportunity for families to connect socially.

For more information, visit www.mda.org/office/rhode-island or you can contact the RI office at 401-732-1910. They are located at 931 Jefferson Blvd, Unit 1005, Warwick.



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