It's a long, costly road to a cure, but we've made some great strides

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Thanks to all the delegates who stopped by the Muscular Dystrophy Association (MDA) booth at the National Convention in Detroit this summer. We were able to answer some of your questions, update our branch MDA coordinator questions and raise awareness and funds for NALC's only national charity. Several branches and the NALC Auxiliary donated proceeds from sales, and Detroit Branch 1 had an evening event to benefit MDA. I would like to thank them for their efforts.

Congratulations to the winners of the travel vouchers: Kati Brock of Arvada, CO Branch 4405; Dan Wheeler of Massachusetts Northeast Merged Branch 25; and George Attwood of Gainesville, FL Branch 1025. Each secured one of three travel vouchers in the raffle. Thanks to all who did their part to make this fundraiser a huge success. Proceeds will be sent to MDA to help those with MD "Live Unlimited." MDA continues to provide care, search for cures and champion the cause to live with strength and independence.

Cost of neuromuscular diseases in the U.S.

A cost study has been completed for three common neuromuscular disorders. It is the first comprehensive study of its kind to be published in the United States. A cost-of-illness study establishes the annual costs associated with having a specific condition, both on an individual basis and to society as a whole. MDA's study was comprehensive, including both medical and nonmedical costs, as well as loss of income to families due to caregiving, loss of opportunities for education, etc. The data may affect drug development and social and economic policies.

MDA's study looked at amyotrophic lateral sclerosis (ALS), Duchenne muscular dystrophy (DMD), myotonic muscular dystrophy (MMD, or DM) and early- and late-onset spinal muscular atrophy (SMA). These diseases were selected for a number of reasons:

1. Therapy development is advanced in some of these fields.
2. Population sizes are large enough and uniform enough so that a statistically significant number can be calculated.
3. Conditions could be separated well enough by medical codes to get useful values for medical costs.

Unfortunately, the data for SMA did not prove to be useful due to the inability to distinguish between early- and late-onset disease, in which the costs are very different.

The per-patient annual costs for ALS, DMD and MMD are as follows:

Disorder	Medical Costs	Nonmedical Costs	Lost Income	Total
ALS	$31,121	$17,889	$14,628	$63,692
DMD	$22,533	$12,939	$15,481	$50,953
MMD (DM)	$17,451	$5,157	$9,628	$32,236

The annual costs for ALS, DMD and MMD for U.S. society as a whole, based on the best available statistics on prevalence of the diseases in the United States, are as follows:

Disorder	Total national cost
ALS	$256-$433 million
DMD	$362-$488 million
MMD (DM)	$448 million

The total estimated cost of illness to the nation for ALS, DMD and MMD combined is $1.07 to $1.37 billion per year. The authors note that this estimate is likely to be conservative.

Stakeholders will use this data in different ways. A family may be interested in seeing what the average cost is in comparison to the family's own experience. A researcher may use the number to justify why his or her research should be funded, relative to research into another disease. A drug development company might use it to justify why an insurance company should reimburse for a newly developed drug, and organizations like MDA will use it to lobby the government for allocation of more resources to alleviate the costs absorbed by individuals and families living with a particular condition.

Putting a number to the impact of a disease allows that impact to be compared to other diseases. This is extremely important in competing for limited resources, such as allocation of research dollars, allocation of disability support, etc. These numbers show that the cost of living with ALS, myotonic dystrophy and Duchenne muscular dystrophy are of a similar magnitude to such diseases as multiple sclerosis and Parkinson's disease, which often get more federal attention.

MDA will use this data to lobby for increased allocation of resources to our disease areas. The information will be shared with researchers and companies to help them make a case for further involvement. In addition, more detailed studies are expected to follow up on the data collected here.

The data come with a large number of caveats, which make the numbers less precise than we would like. However, every issue with the data detailed in the paper would make the true cost of these diseases higher than listed, so we see this as a minimal price. The study also cannot take into account non-financial costs (e.g., emotional impact, etc.).

What has MDA achieved with NALC's help?

Thanks to our partnership, MDA supports nearly 350 physicians and scientists each year, with a research commitment in about 40 different neuromuscular diseases. Through your fundraising efforts, NALC has assisted MDA with contributions to almost every development in muscle biology in the last 50 years.

MDA-sponsored research has resulted in treatment breakthroughs. For example, funded research helped Genzyme develop Myozyme, a therapy for Pompe disease that has saved the lives of many patients. Even where no cure is available yet, research has resulted in better treatments that increase survival and provide a better quality of life. In the past, boys with DMD died in their teens, but there are now some men in their 40s living with the disease.