

MDA news and updates



Asst. to the President for the Contract Administration Unit Geneva Kubal



NALC President Fredric Rolando escorted representatives from the 11 highest fundraising NALC branches (announced in the April issue of *The Postal Record*) on an expense-paid trip to Dallas to participate in an MDA Muscle Walk. Team NALC raised more than \$9,000 at this event. Additionally, a few local branches joined and raised an additional \$9,000.

This \$18,000, when combined with the \$92,000 raised at the NALC biennial convention this past summer, adds more than \$100,000 to MDA's efforts just since August.

Speaking of which, I thank Los Angeles Branch 24 members for their efforts in hosting an MDA fundraiser at their branch office; their work and the participation raised more than \$18,000. I also thank all the delegates who generously donated at the national convention. You were great.

Efforts like these could not happen without all of the people who worked very hard. You know who you are, and your efforts have not gone unnoticed. These donations, along with what each local branch does throughout the year, help those with MD "live unlimited" while MDA continues to provide care, find a cure, and champion the cause to live with strength, independence and life.

Cost of illness for neuromuscular diseases in the United States

As I mentioned in my article last month, MDA performed a comprehensive cost study designed to explain the direct medical and non-medical costs, as well as the loss of income, associated with neuromuscular diseases—specifically amyotrophic lateral sclerosis (ALS), Duchenne muscular dystrophy (DMD), myotonic muscular dystrophy (MMD, or DM) and early- and late-onset spinal muscular atrophy (SMA).

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

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

Disorder	Medical costs	Non-medical 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 the U.S. as a whole, based on the best available statistics on prevalence of the diseases in the U.S., are as follows:



Members of Team NALC celebrate their finish at a recent MDA Muscle Walk in Dallas.

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

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

Different stakeholders will use this data in a myriad of ways. A family may be interested to see what the average cost is in comparison with its own experience. A researcher may use the number to justify why his or her research should be funded, relative to research on 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 effect of a disease allows that effect to be compared with other diseases. This is extremely important when competing for limited resources, such as allocation of research dollars or allocation of disability support. These numbers show that the cost of living with ALS, myotonic dystrophy and Duchenne muscular dystrophy are all of a similar magnitude in comparison with diseases such as multiple sclerosis and Parkinson's disease, which often get more federal attention.

MDA will use this data in various ways through its advocacy program to lobby for increased allocation of resources to our disease areas. MDA also will share the information with researchers and companies to help them make a case for further involvement in the area. In addition, more detailed studies are expected to follow up on the data collected.

This data has a large number of caveats associated with it, which make the numbers less precise than MDA would like. However, every issue with the data detailed in the paper would make the true cost of these diseases higher than listed, so MDA sees this as a minimal cost—with the true cost of these diseases being much higher. The study also cannot take into account non-financial costs (e.g., emotional impact).