



## Renewing our commitment to a worthy cause—part 2

**L**ast month I wrote about the decision NALC made over 50 years ago to stay with the Muscular Dystrophy Association until a cure was found for a family of diseases that attacked children and adults. These illnesses cause premature death in those who bear the genetic marker for one of the 40-plus diseases, and untold suffering for them and their families.

Few of us will ever know the pain a parent feels when a child is diagnosed with an incurable disease. I have spoken with many of these parents. They remember all too well the day they were informed that their child would not walk, or that their son or daughter would most likely live a shorter life. As a parent, I always have dreaded the possibility I would outlive one of my children. For the families who get this terrible news, it is a reality they must face every day.

My own family has had to deal with the awful realities of a genetic disease. I know what happens when people find out they are marked with a defective gene. It can destroy individuals and families who feel there is no place they can turn for help.

MDA provides a place for these families. That is why I am involved and I know it is the reason all of you work so hard to fight for a cure. MDA is our national charity and NALC has decided to redouble its commitment to support the MDA's worthy goals.

**I am happy to report that the Muscular Dystrophy Association continues to be a good organization, with a proven record of integrity and effectiveness. Here are some of the MDA's more noteworthy achievements:**

- MDA is funded almost entirely by individual contributors and national sponsors like the NALC.
- In 2006, MDA allocated 77.25 percent of every dollar directly to research health care, support services and public and professional education.
- MDA maintains some 225 hospital-affiliated clinics across the U.S., staffed by top medical professionals skilled in the diagnosis and medical management of muscle-wasting diseases.
- MDA operates 37 ALS (Lou Gehrig's disease) clinics around the country, featuring programs of ALS research and medical management.
- MDA sponsors over 90 summer camps across America, serving more than 4,200 children from 9-21 years old. More than 5,000 volunteers staff these camps. To get involved in a camp in your area call 800-572-1717.

- One minute of research costs MDA \$65. We are making real progress, and each year there are new treatments that save lives.
- In 2006, MDA helped buy nearly 3,400 wheelchairs for people affected by muscle-wasting diseases. In addition, MDA loan closets gave out over 5,000 pieces of equipment, such as lifts and hospital beds. MDA loan closets gladly accept donations of used equipment. To donate call 800-572-1717 or visit [www.mda.org](http://www.mda.org).
- Information is power, and MDA's professional and public health information is second to none. MDA hosts scientific and medical conferences where information is shared with other organizations so that each can learn from the other. MDA publications keep families and sponsors informed of the latest breakthroughs so that all can be encouraged and have hope. The information on the MDA website, [www.mda.org](http://www.mda.org), is available to all.
- When you can't cough, there's no such thing as "a simple case of the flu." Influenza is life-threatening to people with weak respiratory muscles, such as those with spinal muscular atrophy or Lou Gehrig's disease. To prevent this problem, each fall the MDA offers free flu shots to people with any of the 40-plus neuromuscular diseases in its program.
- In an exciting development made possible by state-of-the-art technology, in 2006 researchers funded by the MDA identified more than 50 suspicious genetic abnormalities in people with ALS. Some of the abnormal genes had never before been suspected of playing a role in ALS. This is a huge boost for research seeking treatments and a cure for this devastating disease.
- In a major step toward human clinical trials, investigators supported by MDA used non-embryonic stem cells in 2006 to treat dogs with a disease similar to Duchenne muscular dystrophy. Dogs that received the healthy donor cells continued to walk long after untreated dogs had stopped due to weakness.

Finally, President Young and I met with all the key staff at MDA headquarters in Tucson, Arizona earlier this year. I was impressed with the quality and caliber of all those we met. A more dedicated group of individuals I have met in only one other organization and that is the union we all know and love, the NALC. Let's meet the pledge we made so long ago. Let's deliver the cure. ☒