



NALC and MDA: We are making a difference

It can't be sorted by ZIP code or package size, and it won't fit in a mail truck. But it's delivered all the same. "It" is research, and the Muscular Dystrophy Association (MDA), with help from the NALC, is working hard to deliver it to the doorsteps of the millions of individuals and families across the country affected by muscle-wasting diseases like Duchenne muscular dystrophy, spinal muscular atrophy and ALS (Lou Gehrig's disease).

Last month, I wrote about the great strides in research Executive Vice President Fred Rolando and I learned about in our visit to national Muscular Dystrophy Association headquarters. We were there to take part in the filming for a new DVD from MDA, which will be sent to all registered branches in April. Branches can use this material to present the MDA story to our members in the coming months.

This month, I'd like to follow up on the progress we're making together with MDA. For nearly 60 years, NALC branches have participated in bowlathons, raffles, walks and letter-writing campaigns in support of MDA, a voluntary health organization seeking treatments and cures for muscular dystrophy and related muscle-wasting diseases.

Thanks to such generous support, MDA-supported researchers continue to make significant and exciting progress on a number of research fronts.

Meanwhile, children with these diseases are living longer, more comfortable and more independent lives, and families affected by these diseases have the hope of knowing cures are close at hand.

Recent MDA-funded research advances include:

- **The identification of flaws in a gene on the X chromosome** responsible for a rare, severe form of spinal muscular atrophy
- **Development of iron-binding drugs as a means of treating Friedreich's ataxia**, which causes severe nerve and heart problems
- **Clinical testing of Iplex in myotonic muscular dystrophy**, a disease characterized by muscle-wasting, loss of endurance, weakness, cognitive impairment, eye abnormalities, gastrointestinal problems and hormonal changes

- **Preclinical development of exon skipping**, a method of blocking error-containing parts of a gene, as a way to treat Duchenne muscular dystrophy
- **The creation of muscle-controlling nerve cells (motor neurons)** from the skin cells of a person with ALS. Scientists expect this development will provide insight into the disease process as well as therapeutic applications

Turning research into drugs

In order to actually deliver therapies and cures to the people who need them, the association has intensified its focus on speeding the most promising research through the drug development process. To fund this extremely expensive stage of development, MDA has launched a new research initiative: MDA Venture Philanthropy, or MVP.

Begun in January 2009, the 501(c)(3) nonprofit MVP seeks major gifts (greater than \$500,000) from philanthropists, corporations and organizations, which it uses to help fund the completion of the early stages of drug development (moving compounds from the lab to clinical trials). MVP also seeks collaborations with pharmaceutical and biotech companies for completion of the final stages required to bring a drug to market.

MVP is the result of the advanced status of several projects in MDA's research pipeline, and the decision by the association to employ novel means to expand its fund-raising reach.

Through creative and energetic approaches to funding research—and thanks in large part to committed partners like the NALC—MDA is confident it can continue to deliver the research that one day will lead to treatments and cures.

For more information about MDA's lifesaving, worldwide research program, visit mda.org; for information on MVP, see mdavp.org.

Next month, I plan to publish the names of the winners who will accompany me to Las Vegas during Labor Day weekend to present the monies we have collected in 2008 and pledge our total for 2009. My hope is that we continue to increase our total and make MDA families our first priority. Thanks for all you've done and will do. ☒