



## Changes in latitudes, changes in attitudes

**W**ith all due respect to Jimmy Buffett, not all changes are the result of a change in attitude. The researchers at the Muscular Dystrophy Association are involved in new and exciting plans to change the way research is done in the scientific community. And those plans are based on hard work and solid scientific efforts.

MDA has always led the way in breakthroughs in genetic research. Many people are unaware that MDA shares its knowledge with all those who are working to find cures and treatments for genetic diseases. Due to those MDA-funded efforts, many people afflicted with these diseases have hope and help in their struggles. For more than 50 years, MDA has been working toward this end.

But that is not the whole story. Many say to me and oth-

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ers, “Where is the cure?” What has happened to give us hope? Just a few weeks ago, Executive Vice President Fred Rolando and I went to MDA headquarters in Tucson, Arizona, to film a new MDA DVD for our branches to use to inform the membership of the continued need to raise funds for these families. While we were there, we received an update on MDA’s research developments. It was time well spent.

What we learned was that the MDA’s work has laid a strong foundation. All the money we have raised over the years has funded the back-breaking work that has brought us to this exciting time. We are on the cusp of achievements that were not even dreamed of just a few years ago. The expansion of knowledge combined with the human testing now being done gives us hope that

cures and treatments are around the corner, and NALC has played a key role by keeping faith with the commitments we made more than 50 years ago.

**Recently, I had the great joy of touching base with a family** with whom I have a real attachment. The readers of this column may remember the Murphy family of Troy, New York. I wrote about their efforts to deal with the diagnosis of their son, Derek, with Duchene’s muscular dystrophy when he was 2½ years old.

Now Derek is 8 and still deals every day with his disease. He is a very bright young man and has reached that age when he questions why this has happened to him. His parents, John and Sue Ellen, told me that he wonders why he can’t run as fast as his friends or jump as high. Now, I can tell you that they did not share this to cause anyone to feel sorry for them. In fact, John told me that Derek’s questions have allowed them to stress the qualities he has that others may not. As I wrote, he is a very intelligent young guy. But you need to know why you work as hard as you do for these kids.

Most of us don’t worry about answering these types of questions. We don’t have to deal with the fact that each year brings a worsening of the symptoms. Little Derek has difficulty climbing stairs, so the family installed a device that allows him to ride up the stairs. Most days he tries to walk up and not take the easy way. He wants to do it on his own. I asked John and Sue Ellen what they have learned this past year in the face of all this, especially when it gets tough. Their answer is simple but powerful. John said, “We look at Derek and know that if he can do it, so can we.”

Why do we keep working for these kids? It’s the least we can do. 