



## MDA and NALC go to the desert

**R**ecently, President Rolando, along with the 2011 NALC branch category winners, visited Tucson, AZ. The purpose was to reward the winning branches that diligently worked to raise money for the Muscular Dystrophy Association. MDA has been NALC's official charity for more than 60 years.

Pam Donato, assistant to the president for community services, and I accompanied the delegation and for two days, and we were presented information about the diseases MDA supports. While Las Vegas and the national telethon previously had been our destination, the telethon, as we knew it, is no more and has been replaced by a shorter, taped show on Labor Day.

As a result, President Rolando decided that our representatives would be better served by visiting the national headquarters of the Muscular Dystrophy Association. MDA put together a fun and educational time that included a visit to a local MDA clinic, presentations concerning the changing role of MDA with adults and research updates.

Our first stop was at the local clinic in Tucson. We met with a number of MDA representatives and had many questions answered about the services MDA provides. The mission of MDA is to provide help and hope to those afflicted with these diseases. Every MDA clinic has an important person who is responsible for helping the families cope with the decisions they need to make. The MDA health care service coordinator (HCSC) is a central figure at clinic visits. He or she usually is present on clinic days to answer questions, distribute MDA educational materials, coordinate any MDA services that are required and assist with community resource referrals.

Jennifer Hall, the HCSC at the Tucson clinic, met with us and explained how clinic days work and how vital these services are to each family. MDA clinics use a multidisciplinary team approach, meaning that individuals can see knowledgeable health care specialists from a variety of disciplines all at one location and on the same day. This means that persons who have MD do not need to take multiple days off to see their physicians. Remember, an individual suffering from a disease might need to see a cardiologist, neurologist, pulmonologist or one of many other specialists, depending on the need of the patient.

Not the least benefit, though, is the familiar friendly face of an MDA representative. Jennifer bonds with the families and patients very deeply and is a great resource to them. HCSCs are a vital part of the help and hope MDA provides.

The next day was full as we heard what is happening with the latest research and additional services MDA is working to supply. One of the intended consequences of the ongoing research is that many children are living much longer lives. While that is a great thing, young adults have different needs than a child does. MDA is transitioning its services to include how a young person enters adulthood. How does he or she become self sufficient to the full extent of their abilities? How about work or school? Those are just some of the questions MDA will be wrestling with for the foreseeable future.

Finally, we heard from MDA's research department about the many drugs that are being developed to combat muscular diseases. It is mind-boggling how expensive it is to develop a drug that works. Just one drug can cost upwards of \$3 billion from start to finish. As a result, MDA chooses to fund multiple tracks of drug development at the initial levels until major drug companies can see a reason to take on the trials necessary to get the Food and Drug Administration (FDA) to approve the drug. That is where your money goes and breakthroughs are on the horizon. Human trials on some incredible treatments are going on now.

All in all, it was a great trip and we learned a lot about MDA and the future.

**On a separate note, next month is the time we designate to focus on the National Bowlathon.** While we know that many branches have bowlathons at other times of the year, this emphasis next month is to try to get branches that do not take part to attempt this money-making venture for MDA. We are targeting the second Sunday of January for each year.

**As we look to this holiday season, please join with me and remember those who are less fortunate.** That certainly includes families suffering from muscular dystrophies. God bless you all!

