

INTHENews

ONEVoice Survey Garner Valuable Insights

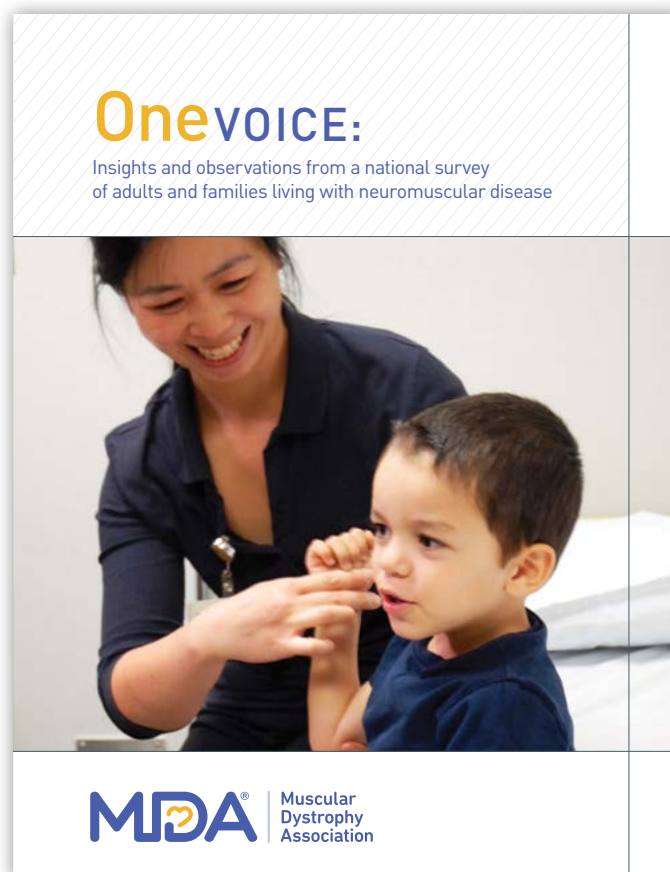
Lynn O'Connor Vos | President and CEO, MDA

MDA commissioned Edge Research, an established research firm with extensive expertise working with patient advocacy organizations, to conduct an objective and thorough study among the neuromuscular disease community. Goals were to identify both key areas of concern among individuals with neuromuscular disease and their caregivers/families and opportunities to address these concerns.

The responses of the more than 3,000 individuals who completed the survey are gathered in a report, "ONEVoice: Insights and Observations from a National Survey of Adults and Families Living with Neuromuscular Disease," the full text of which is available here.

The survey gave us some important information about the day-to-day needs and challenges of patients and caregivers. Here are a few highlights:

- Genetic testing is underutilized. Nearly a third of adult patients say they have not had their diagnosis confirmed through genetic testing.
- Three-quarters of surveyed neuromuscular patients have never participated in a clinical trial, but the interest is high. Nearly 8 in 10 survey respondents say they are interested in finding a clinical trial for which they may be eligible.
- More than 3 in 4 respondents have concerns about access to health care and/or health care professionals with expertise in neuromuscular disease.
- Independence and mobility are major concerns for 64 percent of the neuromuscular community and were the top concerns of those surveyed.



- The neuromuscular disease community is eager for information and counts on MDA to fill this need. Three out of 4 survey respondents say they use MDA for information on issues related to neuromuscular disease.

This study is only the beginning of a continued commitment to listening to the community and doing our utmost to transform the lives of neuromuscular patients and their families.

Read the full ONEVoice survey report online [here](#).