

Navigating Challenges in the Healthcare System

Our sprawling, ever-evolving healthcare system offers unique challenges for clinicians who treat patients with neuromuscular diseases. Pediatric neurologist Aravindhan Veerapandiyan, MD, director of the Comprehensive Neuromuscular Program at Arkansas Children's Hospital and associate professor of pediatrics at the University of Arkansas for Medical Sciences School of Medicine points out three of the most common challenges providers face in working with this patient population.

1. Getting payor approvals for medically necessary treatments

Most physicians have had an insurance company deny coverage for an expensive treatment. Physicians who advocate for their patients are more likely to get those medically necessary treatments approved.

When working with insurance companies, Dr. Veerapandiyan recommends taking a proactive approach and following the process all the way to the final step.

To that end, he doesn't wait for follow-up calls but proactively reaches out to payors. "Be open to having conversations with leadership on the payor side, such as medical directors and pharmacy directors," he says.

Appealing decisions requires time and understanding of how the process works, but it's invaluable to patients. If you follow through consistently, payors notice and often respond with positive changes.

2. Transitioning pediatric patients to adult providers

When patients age out of seeing pediatric providers, they may have difficulty finding physicians to assume their specialized care.

"Finding adult providers familiar with neuromuscular diseases and willing to treat these patients is a challenge," Dr. Veerapandiyan says. This is especially true in rural and underserved areas.

Pediatric providers in the neuromuscular field can help by raising awareness in their communities, spreading the word about resources provided by MDA and other advocacy organizations, and helping to educate adult providers about neuromuscular diseases.

For example, having adult providers shadow in a pediatric neuromuscular multidisciplinary clinic can be helpful. In addition, Dr. Veerapandiyan would like to see aspects of neuromuscular disease management, advances, and research incorporated into the training in medical school, residency, and fellowship programs.

3. Providing equal access

Diversity and inclusion in clinical trials have been in the spotlight recently. This is important so patients from all communities can access scientific advancements. Dr. Veerapandiyan urges research sponsors to pursue strategies to include patients from diverse communities and backgrounds. But research isn't the only area where there are challenges to equal access.

"The same neuromuscular disease can be experienced differently based on race, ethnicity, sex, sexual orientation, education, and living conditions," Dr. Veerapandiyan says. "We as a medical community need to access those inaccessible patients and families. They are facing far more social challenges and bigger problems than their disease, treatment, and participation in research."

For many families, getting to a clinic for regular visits is a barrier to receiving care. In his practice, Dr. Veerapandiyan has found that sometimes, the only way to understand these patients' challenges and give them the care they need is by reaching them in their homes. His team uses strategies such as virtual visits to remove barriers to care.

"Everyone deserves equal care," Dr. Veerapandiyan says.

Resources for Providers:

- Explore MDA's [Medical Education programs](#) to help you navigate some of the complexities of neuromuscular disease care.
- Help young patients and their families prepare to move to adult care with the [MDA Transition Guide: Pediatric to Adult Care](#).
- See actively recruiting clinical trials in the neuromuscular disease space [here](#).