

The wind beneath the wings of MDA patients and their families



Christina Vela Davidson



The mission of NALC and the Muscular Dystrophy Association (MDA) is to free individuals from muscle-debilitating diseases and to be a source of comfort and hope to patients and their families.

Every day, people go to amazing lengths to advance this mission, including a variety of dedicated medical specialists involved in patient care and treatment. Below is a list of some of the specialists you are likely to find at an MDA Care Center:

- **Neurologist or physiatrist**—Most MDA Care Centers are directed by a neurologist or physiatrist. A neurologist specializes in diseases of the nervous system; a physiatrist concentrates on physical functioning and rehabilitation.
- **Social workers**—Social workers help families cope with diagnosis and disease progression and assist with the practical aspects of illness and disability—insurance reimbursement, financial aid, equipment and housing needs, transportation, home care, community resources, etc.
- **Physical therapists**—Physical therapists identify muscle weakness and joint tightness and develop treatment plans to maintain and improve muscle strength and range of motion. They also may recommend suitable adaptive equipment.
- **Care Center coordinators**—These may include nurses, nurse practitioners, genetic counselors and more. They offer families support and information and can connect them to community resources that offer additional assistance.
- **Cardiologists**—Cardiologists specialize in the heart and cardiovascular system. They monitor heart health and function and treat cardiac conditions that arise as a result of neuromuscular disease.
- **MDA family care specialists**—MDA's family care specialists attend MDA Care Center sessions to represent MDA and serve as a resource to the families receiving care at these facilities.
- **Occupational therapists**—Occupational therapists provide strategies and tools to help patients with daily activities at home and at work.
- **Pulmonologists**—Pulmonologists specialize in disorders of the lungs and respiratory system. They typically work with respiratory therapists to monitor lung health and recommend breathing exercises and aids when needed.

MDA is funded almost entirely by individual private contributions, generous organizations and corporate



Neurologist Scott McWilliams, co-director of the MDA Care Center at New York's St. Charles Hospital, tests a patient's strength.

sponsors. The association uses the money wisely; 74 cents of every dollar goes to research, services and education. The remaining funds help support the staff and events that make the work they do for families possible.

A last thought, from Jimmy Williams, retired executive vice president and MDA coordinator for NALC: "Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next."

End-of-year fundraising reminder

End-of-year reporting and Honor Roll money should be turned in to the local MDA office within two days of the conclusion of a fundraiser. A copy of the NALC Activity Report should be included with the check or money order.

All funds must be mailed by Dec. 14 to be counted toward the calendar year and to be included in the Honor Roll. Pledge money that has not yet been received cannot count toward your year-end total. MDA can provide a receipt, called the SE-14 Income Verification Form, for all cash or checks upon request.

Mail a copy of any receipts for all cash or checks, along with the NALC Activity Report, to NALC Headquarters, 100 Indiana Ave. NW, Washington, DC 20001-2144.

Please reach out if you have questions about special circumstances or events that conclude after the Dec. 14 deadline. If you wish to know where your branch stands on donations for this year to ensure proper credit, contact me at 202-662-2489 or mda@nalc.org well before the end of the year. This will allow the time needed to research any concerns.