

Neuromuscular disorders affect approximately 1 in 3000 individuals throughout the world. Neuromuscular disorders for all ages include diagnoses involving the muscle, nerve and/or the neuromuscular junction. This may include the following common neuromuscular disorders:

- Duchenne muscular dystrophy
- Becker muscular dystrophy
- Limb-girdle muscular dystrophy
- Congenital muscular dystrophy
- Facioscapulohumeral dystrophy
- Spinal muscular atrophy
- Hereditary motor and sensory neuropathies
- Congenital myopathies
- Myasthenia gravis
- Hypotonia and weakness
- Arthrogryposis
- Friedreichs ataxia

The Iowa Neuromuscular and Related Genetics Disease Program provides comprehensive health services, including diagnosis and case management for individuals and families with a variety of neuromuscular and related disorders. Additionally, this program provides educational services for families, healthcare providers, educators, and others throughout the state of Iowa. Clinic services are currently available in the following cities.

- Des Moines
- Mason City
- Dubuque
- Iowa City
- Sioux City
- Waterloo

Program Services

Diagnostic Evaluation includes:

- Detailed neuromuscular examinations
- Review of family history and medical records
- Diagnostic testing: biochemical, genetic, neuropathological

Management of neuromuscular healthcare concerns includes:

- Physical therapy: Instruction for home programs
- Recommendations for bracing, orthotics and equipment (wheelchairs, scooters, lifts)
- Ongoing monitoring and management of pulmonary, cardiac and orthopedic manifestations of neuromuscular disorders; referrals to other specialists, as needed

- Recommendations on management of activities of daily living (transfers, mobility, home adaptations, vehicle modifications, etc) and assistance with identifying funding sources
- Medical management to slow progression of disease, control pain, treat symptoms

Patient and Family Education includes:

- Written and verbal information specific to disease process, treatment and management
- Genetic counseling for patient and families
- Anticipatory guidance regarding prognosis and level of disability
- Information about advance directives & living wills, as appropriate
- Education of school personnel, employers, childcare providers and others involved

Supportive Patient and Family Services include:

- Phone triage and assistance with daily management of emotional and physical aspects of the disorder
- Advocacy in communicating with educators, employers, health insurers, and others
- Referrals to the Muscular Dystrophy Association and other organizations
- Assistance in identifying social services and financial services
- Referrals to home health care, respite, and hospice services
- Referrals to patient and family support groups
- Access to research opportunities, as desired

How to request an appointment or more information about these services

Referrals are accepted from physicians, nurses, social workers, teachers, family members, and others. To arrange an appointment for neuromuscular services or inquire about educational presentations, call 319-356-1851.

Neuromuscular Program Personnel

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Funding

The Neuromuscular and Related Disease Program was officially established with the Iowa Department of Public Health in 1984. The NM Program is legislated under the Iowa Administrative Code 641IAC4.1 (136A). With IDPH funding, the University of Iowa Hospitals and Clinics provides these services to the State of Iowa, including Iowa City and the Outreach clinic sites.