

Neuromuscular and Related Genetic Disease Program

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, based on population distribution and geographic coverage of the state:

Des Moines	Mason City
Dubuque	Iowa City
Sioux City	Waterloo

Neuromuscular Program Services

Diagnostic Evaluation

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

Management of neuromuscular healthcare concerns

- Physical therapy: Instruction for home programs
- Recommendations for bracing, orthotics & 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 ADL's (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

- Written and verbal information specific to disease process, treatment & 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 & Family Services

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

Who Qualifies for Neuromuscular Services?

Neuromuscular disorders affect approximately 1 in 3000 individuals.

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 & sensory neuropathies
- Congenital myopathies
- Myasthenia gravis
- Hypotonia & weakness
- Arthrogryposis
- Friedreichs ataxia

Referrals

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.

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 Rules and Regulations, Chapter 4:641-4.1 (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

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