



GNE Myopathy Specialty Clinic at UC Irvine Health

GNE Myopathy

GNE Myopathy (also known as HIBM, DMRV, Nonaka Distal Myopathy, and Quadricep Sparing Myopathy) is an inherited muscle condition that leads to weakness and wasting of muscles in legs and arms. The weakness progresses slowly, causing weakness of proximal muscles, hands and shoulder muscles, which can eventually lead to disability and loss of ability to ambulate and independently sustain activities of daily living (ADLs).

Because the care of a person with GNEM can be multi-faceted, a multidisciplinary approach can help to address the varied issues a person may be facing.

GNEM Multidisciplinary Clinical Team

- **Physician (Fellow and Attending Neurologists)**
 - Assesses extent of neurological involvement and disability from it. Confirms the genetic diagnosis. Leads the team in your evaluation and management plan.
- **Physical Therapist**
 - Evaluates mobility and overall function for patients and makes suggestions to improve mobility and safety and optimize function.
- **Occupational Therapist**
 - Evaluates difficulties conducting daily activities. Helps patients adapt to upper limb weakness and maintain the highest level of independence in activities of daily living (ADLs).
- **Genetic Counselor**
 - Helps confirm the genetic diagnosis and provides genetic counseling to patients and families.
- **Clinic Nurse Coordinator and Medical Assistants**
 - Works closely with physicians to assist with providing care to patients during clinic and in between visits. They are the primary team member to contact regarding health concerns, medication questions and refills.
 - Available Monday-Friday 8am-5pm (PST) 714-456-2332 option 4 or via MyChart Patient Portal.
- **Social Worker (available on referral basis)**
 - Helps patients and their families locate and utilize community resources, discusses health care benefits and concerns related to work and financial matters, and provide resources for psychosocial support.

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The GNE Myopathy Specialty Clinic is held within UCI's Neuromuscular Center and will specifically serve individuals who are affected by GNE Myopathy. The Neuromuscular Disease Foundation (NDF) is supporting this clinic and one visit per year for GNE myopathy related neurological visit, visits to physical therapist and occupational therapist and consultation with genetic counselor is paid for by NDF. Furthermore, the purpose of this clinic is to provide updated information to the patients and caregivers about current standard of care and about the research that is happening in GNEM. The GNEM specific clinic affords us an opportunity to collect research-related information about the natural history of GNEM, validate outcome measures for use in future research studies, and collect research-related biospecimens (blood, saliva, urine and skin biopsy) for related projects and to create a GNEM biorepository for use by GNEM researchers from around the world.

What to expect during a visit

Since the GNE Myopathy Clinic utilizes a multidisciplinary team approach, visits may vary between 1-2 hours to allow for patients to meet with each specialist. The clinic will be held in a hybrid model, with some of the visits in-person and others through tele-video visits. At each visit the patient will meet with the neurologist (and the trainee fellow/resident), as well as the physical therapist, occupational therapist, and the social worker. At the first visit and then based on the unique situation, the genetic counsellor will also meet with the patient. The nurse manager and the medical assistant will help coordinate the care and provide follow up and help complete any paperwork required for DMV applications, disability, medical insurances, etc.

GNE Patient Registration/Appointments

To make an appointment, please call UC Irvine's ALS and Neuromuscular Center at 714-456-2332 option 4 (Monday-Friday, 8am-5pm PST) to speak with a clinic scheduler.

UC Irvine Health ALS and Neuromuscular Center

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