The MDA Clinic utilizes a multidisciplinary team approach which allows patients to receive comprehensive care from a variety of knowledgeable health care specialists during their visit.

How can I or my family member obtain an appointment with the MDA Clinic?

The patient must have confirmed or suspected neuromuscular disease covered by MDA. (contact MDA at 315-451-8269 or visit mda.org to determine if your diagnosis is one of MDA’s 43 diseases).

If the patient has not been seen in an MDA Clinic before or if the patient has not been seen for three years or more, a referral from the primary care doctor or specialist is needed. The referral and all relevant clinical notes, EMG reports, muscle biopsy reports, genetic testing results, MRI reports and other pertinent labs (especially serum CPK) should be faxed to (315) 464-5350, Attention Heather Robenolt, MDA Clinic Coordinator.

If your insurance company requires an authorization to be seen by an MDA doctor, this is a separate process and must also be completed by your primary care physician.

How do I know if my diagnosis is covered?

Contact your MDA office at 315-451-8269, speak with Donna Schilt your Health Care Services Coordinator. Or go to www.mda.org and look under the heading Diseases.

What if I don’t know what my diagnosis is?

Your referring doctor should know what the diagnosis or suspected diagnosis is. Talk to your doctor.
How long will I have to wait for an appointment?
Currently, patients 18 and older are scheduled within 3 months of referral. Patients 17 and younger are scheduled within 1 month. If the referring physician believes that the referral is urgent he or she can request an urgent appointment.

What do I need to bring with me to a new appointment?
Any medication that you must take during the appointment time.
A complete list of medications you are now taking, including the size (mg) and how often you take it; i.e: twice daily, at bedtime and so on.
Any equipment such as wheelchair, walker or cane that you use so that our therapists can see you using them and determine if they meet your needs.

How long will the appointment take?
This varies with your diagnosis and condition. However, MDA clinic visits are longer than typical doctor visits, because you will be seen by several members of the MDA team.
A new patient appointment takes 2-3 hours.
A follow up appointment takes 45 minutes to 1 1/2 hours.
You may want to bring a snack with you to your appointment.

Who will I see at my appointment?
At adult MDA clinic you will first be seen by a resident or fellow (MD who is training in a specialty related to muscular dystrophy).
Then you will be seen by Dr. Deborah Bradshaw or Dr. Eufrosina Young, Co-directors for the MDA Clinic.
At Pediatric MDA clinic you will be seen by Dr. Klaus Werner, the Pediatric Neurology MDA doctor. He will see and examine the child during the visit.
The MDA Health Care Service Coordinator (HCSC) is a central figure at clinic visits. She is usually present on clinic days to answer questions, distribute MDA educational materials, coordinate any MDA services you may require and assist with community resource referrals.
Our MDA HCSC is Donna Schitt.
Depending on your (child’s) condition, you may also see our:
Physical therapist, Denali Remonda
Occupational therapist Chris Lighthuep
If needed, a social worker and a nutritionist will be called into the appointment

Will I need to see other specialists too?
Many patients with neuromuscular disease develop complications in other body systems. Referrals to other specialists who know how to prevent and treat these complications are frequently needed. Common referrals include:
Cardiology (Heart specialist): Dr. Robert Carhart at Upstate Medical University is our official MDA cardiologist. We encourage patients to see Dr. Carhart if a cardiologist is needed. It is easy to share medical information with him, because he is in the same system. In addition, he has developed expertise in the heart problems associated with muscular dystrophy. Appointments with Dr. Carhart can be scheduled on the same day as the MDA clinic appointment.
Pulmonology (Breathing/lung specialist), Endocrinology (for diabetes, thyroid or osteoporosis) and Sleep Medicine referrals are often necessary. While there are not MDA-specific lung, endocrine or sleep doctors, it is helpful if all specialists are in the Upstate system so that your doctors can share medical information easily.

Can I get a flu shot at my appointment?
Yes flu and pneumonia shots are available in clinic at the time of the appointment.

Will they give me my medications at my appointment?
Prescriptions that the provider feels are needed will be prescribed electronically to your preferred pharmacy.

Is there a wheelchair clinic during the appointment?
No, but there is a wheelchair clinic connected to the Muscular Dystrophy clinic that you might be referred to. This is a separate appointment and is set up by the clinic team.

Is there a cost to be seen at the MDA Clinic?
Yes, if you have medical insurance (Fidelis, MVP, BC/BS, Medicare, Medicaid, etc) your insurance will be expected to pay clinic costs. You may receive bills for your care from University Hospital and/or your provider groups, depending on your insurance. The Muscular Dystrophy Association provides some monies through a grant to assist MDA patients with uncovered medical costs. However, NYS insurance regulations do not allow the grant to cover insurance co-pays and deductibles. You will be responsible for paying these. If you do not have any insurance at all, the MDA grant may be able to pay for some services.