

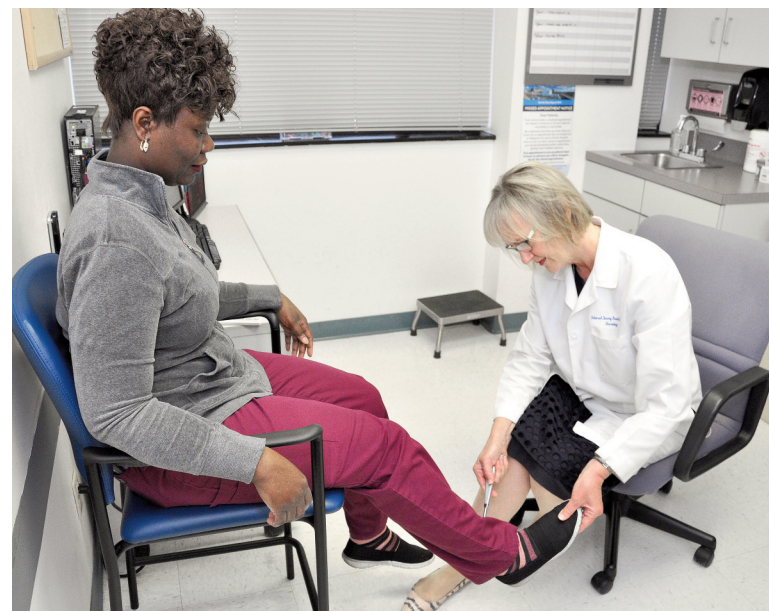


The MDA Care Center is located on the 4th floor of the Upstate Health Care Center, 90 Presidential Plaza, Syracuse.

Office Hours
Monday - Friday 8 AM - 4:30 PM

To Make an Appointment call:
(315) 464-4243

For more information, contact:
Tess Oliver
MDA Health Care Specialist
(315) 451-8269 or (607) 767-3463
Email: toliver@mdausa.org



MUSCULAR DYSTROPHY ASSOCIATION CARE CENTER

The Muscular Dystrophy Association (MDA) Care Center utilizes a multidisciplinary team approach. Patients 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 Care Center?

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 Care Center 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) 464-7328, Attention: MDA Care Specialist.

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, to speak with your Care Specialist. 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 1 month of referral. Patients 17 and younger are scheduled within approximately 4 to 6 weeks. If the referring physician believes that the referral is urgent, he or she can request an urgent appointment.



Muscular Dystrophy Association Care Center

90 Presidential Plaza | Syracuse, NY 13210
315-464-4243 | www.upstate.edu/neurology

IN PARTNERSHIP WITH



www.upstate.edu/neurology

MUSCULAR DYSTROPHY ASSOCIATION CARE CENTER

What do I need to bring with me to a new appointment?

- A completed New Patient Questionnaire, which will be mailed to you prior to your 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; ie: twice daily, or at bedtime.
- 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 Care Center 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 2 hours.

You may want to bring a snack with you to your appointment.

Will they give me my medications at my appointment?

No. If you need to take medications during your appointment time, you need to bring those with you.

Will they give me my prescriptions at my appointment?

Prescriptions that the provider feels are needed will be prescribed electronically to your preferred pharmacy.

Who will I see at my appointment?

At MDA Care Center, you will first be seen by one of our Medical Office Assistants, followed by our MDA nurse.

At the MDA Care Center, you will be seen by a resident or fellow (MD who is training in a specialty related to muscular dystrophy). Then you will be seen by one of our physicians.



The MDA Family Care Specialist (FCS), Tess Oliver, 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.

Depending on your (or your child's) condition, you may also see our physical therapist, or occupational therapist.

If needed, a social worker or a nutritionalist will be called into the appointment. Our MDA care specialist is also available to assist our specialists with your needs and questions.

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:

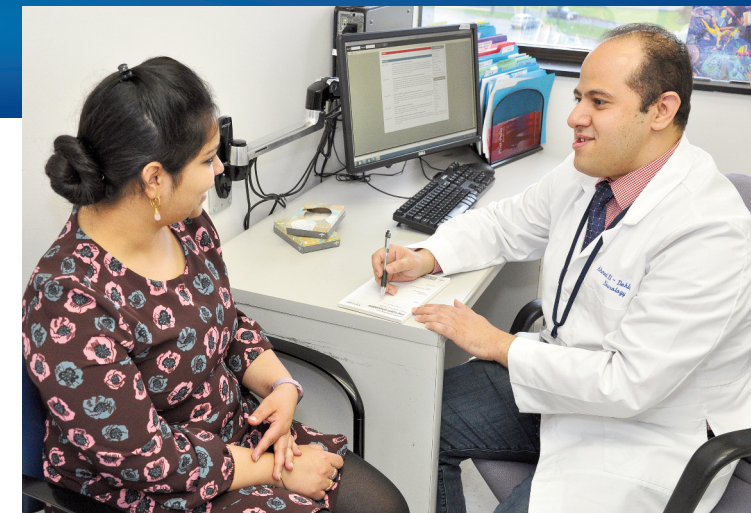
- Cardiology (Heart specialist)
- Pulmonology (Breathing/lung specialist)
- Endocrinology (for diabetes, thyroid or osteoporosis)
- Sleep Medicine

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.

Appointments can usually be scheduled on the same day as the MDA Care Center appointment.

Can I get a flu shot at my appointment?

Yes flu and pneumonia vaccines are available in clinic at the time of the appointment.



Is there a wheelchair clinic during the appointment?

No, but there is a wheelchair clinic connected to the MDA Care Center 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 Care Center?

Yes, if you have medical insurance (Fidelis, MVP, BCI85, Medicare, Medicaid, etc.) your insurance will be expected to pay clinic costs. You may receive bills for your care from Upstate University Hospital and/or your provider groups, depending on your insurance. The MDA 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.