

Finding an MG Expert

The following document was prepared by the Myasthenia Gravis Association.

HOW TO FIND A MG-EXPERT NEUROLOGIST IN YOUR AREA

If you live in Kansas or Missouri, call us at the **Myasthenia Gravis Association of Missouri and Kansas** at 816-256-4100 and we'll check our list of MG knowledgeable neurologists recommended by our members to see if we refer you to someone in your area.

The next place to check for a MG knowledgeable neurologist in your area is the **Myasthenia Gravis Foundation of America**, where you'll find a "Physician Referral List". Also on their site is a list of support groups – if you find one in your area, call the group leader for a referral. You can also call the MGFA's Patient Service Line at 800-541-5454.

You can check for **other Myasthenia Gravis organizations** in the US by browsing on the internet for 'myasthenia gravis' and your state. If you find a local organization, support group, blog, etc., ask them for a referral.

The **American Academy of Neurology** has a "Find a Neurologist" search engine at patients.aan.com/findaneurologist. Enter "myasthenia gravis" as the subspecialty.

The **Muscular Dystrophy Association** has clinics around the country that serve those with myasthenia gravis. Go to mda.org/HelpThroughServices/YourMDACareCenter and fill in your location.

Look in your area for **teaching hospitals** with a Neurology specialty, preferably with a neuromuscular subspecialty.

If you don't live near an urban area where there is a neurological practice or if limited transportation necessitates that you will only have access to a primary physician to manage your myasthenia gravis, you may have to work with your local physician to insure that he or she obtains the most recent information regarding MG treatment. Don't assume that your doctor will do the research necessary. If you look on our website under "Member Services" and drop down to "Educational", you'll see the "Manual for the Health Care Provider" that's available from the Myasthenia Gravis Foundation. It can be read online or purchased in print (\$12) or on CD (\$3). It would be worth it to purchase it for your doctor.

For others.....it's important to know that just because you are seeing a neurologist, it doesn't mean that they are current with treatment practices. Again, you need to do your homework and ask questions of your physician and if need be, even provide information and resources

But here is what you can do for yourself. Let's say you were just newly diagnosed or you've just moved from a different area and you need to become a patient of an MG expert neurologist.

- Make notes of what you will need to say in a phone conversation, in order to be brief and to be clear about your needs. In a busy doctor's office, there is no time to hear a long story.
- Remember that the person who answers the phone is the least informed and least educated of everyone in the office and they may never have heard of myasthenia gravis, so you need to ask the right questions of that person in order to get to the informed staff person.
- Contact the closest hospital, especially teaching hospital and ask to speak to the neurology department.
- You might get a recording that will lead you through numbers to push. You could start with the prompt for "make an appointment". When you reach an appointment setter, you could tell them that "you'd like to speak to a nurse associated with one of the neurologiststo inquire if any of the doctors are specialists in myasthenia gravis". If you're put through to a nurse, you will most likely get a recording. Be ready with your message: "My name is _____(spell)_____ and my number is _____(slowly)_____. I have myasthenia gravis and I'm interested to know if any of the neurologists in this practice are knowledgeable in the treatment of MG. I would appreciate a call back as soon as possible as I have symptoms that need attention. Thank you."
- So now you get your call back: If the nurse says that yes, a particular doctor is familiar with MG...you could ask if he/she has current MG patients. If you're satisfied with the information that you get regarding a doctor's experience in treating MG, you could ask the nurse what to say to the appointment-setter so that you could make a new patient appointment as soon as possible, since you need medication to control symptoms. If you're clear and to the point, most staff members will be happy to make suggestions.
- If the nurse says that there is not a doctor in this practice who has knowledge about MG, ask her if she has heard of a neurologist in the area that does treat MG patients.
- Do not procrastinate in finding an appropriate doctor to treat your MG. It can take a few months to get a new patient appointment. You don't want your symptoms to get out of control so that you have to use the ER.
- Becoming your own Health Care Advocate is a job and you're worth the effort. Take care

Becoming your own health care advocate can be a challenging task, but it is always worth the time. There is nothing more important than your health and it's up to you to become proactive to get the best care you can!