



HOW TO FIND A MG-EXPERT NEUROLOGIST IN YOUR AREA

There are a number of organizations across the country that will provide help in finding a MG-expert neurologist for those living with MG in their area. Some organizations are affiliated with the national organization, *The Myasthenia Gravis Foundation of America in NYC*, and others are not. Our association provides information and support for those who live in Kansas and Missouri, but we hope that our website will help those living in other areas as well.

If you live outside of Kansas & Missouri, you can go to the Myasthenia Gravis Foundation's website at myasthenia.org and check to see if there's an association affiliated with them in your state. If you don't see an association listed for your state, it doesn't mean that one doesn't exist, it just means that they are not affiliated. In that case, you can Google your state along with the words "Myasthenia Gravis" and see what is referenced. For instance, there may not be an association, but you may find a support group or a local MG blog or chat room that would be of benefit.

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 a booklet that's available from the Myasthenia Gravis Foundation. It's a professional manual for physicians that's available for \$12. 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.

Our association has a limited list of referral neurologists in KS & MO that includes the names of physicians that our members have confidence in. As an association, we cannot recommend these doctors, but if there are neurologists in your area on our referral list, we're happy to offer you their contact information.

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. Good luck.