

Steps to Finding a Movement Disorder Specialist

By Beka Serdans, RN, MSN

Your First Task is to:

Get names and phone numbers. Try an Internet search. Several websites list physicians across the country. Scroll to the physician referral link on major medical center/facility websites in your area. An example is:

University of Maryland Department of Neurology

<http://www.umm.edu/neurohome/>

Maryland Parkinson's disease and Movement Disorders Center

<http://www.umm.edu/parkinsons/index.html>

Post inquiries on the multiple tremor and dystonia Message Boards that exist online today. Many of these Boards have extensive lists of "Who is Who in Tremor and Dystonia." You may need to email others directly to inquire about available medical care in your area.

Ask family, friends, and co-workers for help. Contact your local support tremor or dystonia group or State and County medical societies, Hospital referral services, other doctors or nurses and word of mouth (relatives, neighbors, co-workers). Don't be shy in asking or learning "Who is Who in Movement Disorders."

Ask yourself "How far can I travel?" Patients with complex conditions will travel any distance to see a good doctor, if they can. Realistically, driving is very hard on some and impossible for others. Think about what you can consistently manage.

Does my insurance restrict who I can see or where? It is easier to work within your insurance guidelines than outside of the network, but consider all possible doctors, regardless of insurance.

Call to set up an appointment. Call more than one number, if possible. Is there a fee for an interview with a doctor? Generally there is not a fee for so called no-cost interviews.

Share your goals and expectations with the staff after arriving. Sometimes meeting others in the waiting room can clue you in on the office and the quality of care being provided to patients. Tell the receptionist what type of care you expect.

Ask the following Questions:

Is the Physician "Board-certified" in Neurology? Do they specialize in movement disorders? In tremor? In dystonia? Where did he/she complete their medical training? Did they complete a "Fellowship" in movement disorders? What are their credentials? Is the physician affiliated with medical center(s) that are approved by the Joint Commission on Accreditation of Healthcare Organizations?

You can find this information on the American Board of Medical Specialties website (ABMS): www.abms.org and Specialty licensing boards: www.abms.org/member.asp.

How many patients with tremor or dystonia does he/she treat on a weekly-monthly basis? How frequently are patients with tremor or dystonia seen?

Is the physician familiar with botulinum toxin therapy? Dosing guidelines? If so, who gives the toxin in the office/clinic (i.e. medical students or the neurologist/attending)?

Does the physician work with a coordinated team? Is there a neurosurgeon for deep brain stimulation for tremor-dystonia available? If there is no team approach available, are these individuals (dietician, genetics counselor, social worker etc.) easily accessible by referral?

What is the waiting time to get an appointment? Weeks? Months? What is the usual waiting time in the office before you actually see the physician? Are family members allowed to attend appointments? Is there someone on 24-hour emergency call? How easily can you contact them?

Does the office/center carry patient education material about tremor or dystonia? Is the Patient's Bill of Rights posted and visible in the

office/center?

Does the physician accept your medical insurance policy? Are there any out-of-pocket expenses?

Will you have access to your medical records including CT Scans, MRIs? Are prescriptions updated on a consistent basis?

Ask as many questions as you need. Ask to speak with another patient who is being currently treated for tremor or dystonia.

Evaluate the office/center-staff:

Was the receptionist/office-center staff courteous and helpful? Was the office/center clean or cluttered? Are OSHA policies in effect?

If paperwork needs to be completed, how difficult was it? Are forms in Spanish or other language available?

Was the waiting room comfortable? Is the office-center handicapped-accessible?

Is there possible assistance with transportation to/from appointments? Is there a 24-hour appointment cancellation policy?

Make your Choice:

If you're satisfied with the Answers, go for it! But, remember "it's your time."

Use your intuition when coming to a decision. If you "feel uncomfortable" with the physician or the office/center, they most likely are not the "right" movement disorder physician for you. One basic element to remember is that **"Not all Neurologists are Movement Disorder Specialists; but ALL Movement Disorder Specialists are Neurologists."** Reread this sentence again. We often don't realize the meaning or importance of this basic element. Bear in mind to trust your gut feeling. Your main goal is to interact with each doctor, checking for a comfortable fit and ability to work

together as a team.

Your final task is to begin writing all of your symptoms and questions in a diary/log or in a note pad. Questions can easily be forgotten when visiting a physician. This "diary" becomes your own personal medical record of tremor and dystonia. And it may prove to be of great value to both you and your chosen healthcare provider.

Good Luck!

Useful Websites:

American Medical Association Online Doctor Finder:

www.ama-assn.org/aps/amahq.htm

WebMD: <http://www.my.webmd.com>

Doctor Directory: <http://www.doctordirectory.com>

Web Guide: <http://www.docguide.com>

Interactive website: <http://www.findadoc.com>

About the Author

Beka Serdans, RN, MSN, is a strong patient advocate and founder of Care4Dystonia, Inc. She has written about her experiences with dystonia in I'M Moving Two and I'm Moving On...Are U??. Learn more about Beka by reading online blogs pertaining to DBS in her forthcoming book: Walk a Mile in My Shoes at www.care4dystonia.org/narrativeDBS.htm