Taking Charge of Your Care

Taking charge of your dystonia treatment means being a proactive patient. Being a proactive patient means asking questions.

A proactive patient is one who has dedicated him/herself to living well with dystonia. You may have many questions regarding dystonia and your treatment. In order to get the most out of your medical appointments, prepare yourself for each health visit, establish a rapport with your medical team, and develop a system to take notes or identify a person to assist you in taking notes.

Your doctors and health care team work for you. Do not be intimidated or afraid to ask anything. You have a right to fully understand all of your treatment options and any potential side effects associated with your choices.

Be prepared. Do research or have a loved one do it for you. The more educated you are, the better questions you will be able to ask. Prepare a written list of questions for your doctor or nurse prior to each meeting. It can be difficult to remember each question when a lot of information is being exchanged during an office visit. Ask for clarification of any tests or procedures you do not understand.

Establish rapport. It is important from the beginning to establish a positive relationship with your physician and health care team. Keep in mind, good teams communicate well. As such, your doctor will have questions for you and likewise you will have questions for him/her too. This is part of a healthy rapport.

ARTICLE AT A GLANCE

- Taking charge of your dystonia treatment means asking questions.
- Prepare yourself for each medical appointment to make sure you get the most out of it.
- Keep your own copy of your medical record and history.
- Remember you have the right to choose your doctor, clinic, and treatment.

Focus your questions and start with the most important. Your doctor wants to answer your questions but will likely have time restraints and limitations due to many patients who require his/her time and attention. Take time to write down your questions in advance and take them with you.

Medical history. You will often be asked to recount your medical history. Write this down and always carry it with you. Information to be included: childhood illnesses, traumas and injuries, history of medication use and allergic reactions, family and medical history including cases of dystonia or other movement disorders, allergies, other medical conditions.

Build your own record. You are the center of your care team, and it only makes sense for you to have copies of your scans, x-rays, and test results. Your doctors may refer back to parts of your medical record or you may need them when seeking a second opinion. Consider keeping a health journal that includes observations about your symptoms and pain, the dates and duration of treatments, your response to treatments including side effects, and other information relevant to your dystonia and general health.

Have a record of all your medications with you. It is imperative that you keep detailed records of your medicines and complementary therapies including vitamins, supplements, and herbs.

Remember that you have choices. You have the right to choose your doctor, movement disorder center, and course of treatment.

Adapted from information from Mission Hospitals.
In spite of focal dystonia of the leg, Ben Beach of Bethesda, Maryland has competed in the Boston Marathon every spring since 1968. He holds the record for running the second most consecutive Boston Marathons. This year, at age 61, he completed the race in 4 hours – 33 minutes – 35 seconds, more than five minutes better than his time last year. Ben uses each marathon as an opportunity to promote dystonia awareness by sharing his story in the local media and The Washington Post.

Ben was previously featured in the Dystonia Dialogue in 2009 and continues to be going strong. “Aside from the dystonia, I’m pretty healthy,” he says. “I do exercises and stretches recommended by NIH [his physicians at the National Institutes of Health] and others to help my body deal with the weird gait I have. My dystonia is not painful, fortunately.”

Ben’s dystonia manifests as a mild limp that becomes more pronounced when he runs, limiting his training and making his dedication to running even more remarkable. “NIH has been experimenting with the injection sites and dosage of my Botox® since starting me on it in 2006. Finding the right formula is a challenge, as most of us have learned. I believe that the current formula is starting to pay off, and that made the marathon somewhat less difficult. Because I have so few training miles under my belt, I can count on cramping quads and a lack of energy during the second 13 miles, so I had to battle that.”

The DMRF congratulates Ben for this amazing accomplishment and for inspiring others in the dystonia community and beyond.