

How to Prepare for Your/Your Loved One's Next Doctor's Visit! (Items to consider a week or two before your visit)

***Please note that this document is "For the Patients and By the Patients". This means that Mito Action cannot fully endorse any of the below recommendations or comments. These items were created by a close knit of people who are our MitoChampions. This document is to be used as a source of encouragement.*

Get Your Questions Ready

- **Begin writing a list of questions several weeks before your appointment.** This will give you time to remember and reflect on what questions you have, and prioritize the most important ones! Create your list in the most accessible location (ie. phone, computer, or post-it note on your refrigerator!)
- **Email questions to your doctor and yourself ahead of time.** This will provide extra time for your clinician to think about your most complicated questions and feel more prepared for your visit.
- **Bring your questions to your doctor's visit** (even if you previously sent the list to your doctor), so you both can stay focused on what is most important to you during your visit. Prioritize your questions, so you can make sure that you get to the questions that are most important.
 - Ask the most important questions first. Try to think of your extra questions as the "candy" or dessert of your appointments.
 - At the beginning of your appointment, share, "I have 3 main things I would like to talk about today." Prioritize the top 2-3 questions and have realistic expectations of what can be answered during your appointment.
- **Always bring an extra pen and paper/notecards to your visit.** It is normal to have questions come to mind at the last minute that you may want to jot down, and it is nice to have a space to write some of your clinician's answers down. Decide ahead of time, "Do I prefer to take notes on my phone, in a notebook, or on notebook paper?"
- **Bring questions from your referring doctor.** If you were referred for this visit, ask your referring doctor if they have any specific questions or updates that they would like you to relay during your appointment.

Prepare Your Documents

- **Get clarification from your referring doctor** as to why you are seeing a particular specialist.
- **Consider bringing backup paperwork explaining the purpose of your visit** in case you are struggling to explain, on the day of your visit, why you are there.
- **Bring a short summary of your medical condition/genetics report and health summary.**

This "cheat sheet" may include:

- Name
- DOB
- Medical diagnosis(es)
- List of current doctor(s) and their address(es)/ phone number(s), and fax(es)
- Medical timeline
- Description of specific acute event
- List of current medications

Consider working with your primary care or specialist doctor to create a "Medical Passport." This is a one to two page document that you can carry with you, that gives new clinicians a brief

summary of your diagnosis, treatment, and medical events that are important for them to note. Your health summary and diagnosis cheat sheet may be two different documents. Ask your referring doctor to put this on their letterhead.

- **Update your medical binder and/or your “My Mito App”:** Many Mito patients have a medical binder that they bring to appointments with their most important medical paperwork. The “My Mito App” allows for documents and symptoms to be easily stored on your phone! Decide for yourself if you prefer to have one or both of these items with you on the day of your appointment.

*****As you think through your questions and prepare your documents, it is important to know your doctor’s style and how/when they prefer to receive information. This takes time and it may help to ask your doctor directly to clarify this!***

Prepare for Your/Your Loved One’s Needs

- **Ask a family member or close friend to attend your doctor visit with you**
 - This can help you remember what is said during your appointment, especially when you are struggling with brain fog.
 - It is easy to get overwhelmed with information. Having an extra set of ears during an appointment will give you someone to reflect with afterwards and provide emotional support.
- **Consider if you need a “healthcare representative”** or outside agency available at your appointment.
- **Ask your doctor if you can record the meeting or certain information** they are sharing, if this will help you remember particular items (ie. Some patients use the “abridge app”)

Prepare for the visit to take longer than what you expect

- Bring extra snacks and meals
- Fluid (water and gatorade)
- Phone charger and headset
- Back-up Meds
- Bring items for your service dog (print off ADA website what is a service dog and where they are allowed)
- Bring a “fun bag” for your children (or yourself!). This may include games, books, coloring books and small toys!

****Consider creating a dedicated back-pack that you keep packed and change every 6 months to conserve energy around your doctor visit preparations.***

Emotional Preparation

- Remind yourself that doctor visits use both emotional and physical energy. To better prepare emotionally for your visit see: “Caring for yourself before, during, and after your doctor visits”.