



# The Doctor is in...

## Getting the Most From Your Physician

By Janet Lin, MD



I am the parent of a son with fragile X syndrome. I am also a neurologist. As a parent, I don't always know what to do for my son. But as a doctor, I do know what I need from my patients to better serve them and meet their needs. Here are a few simple suggestions that will help you get the most out of your doctor.

First, prearrange the type of visit that you need. Most routine office visits are scheduled for fifteen minutes or less. For a new patient, doctors usually allow thirty to ninety minutes. If you arrive distraught about a significant issue and with a million questions, the likelihood of you having a calming information-filled visit in only fifteen minutes is not high. If the waiting room is full of screaming kids and the doctor is already forty minutes late, you will not get what you want or need.

Advise your doctor why you're coming in so that enough time can be prearranged. "My child was recently diagnosed with fragile X syndrome. I have many questions and want to make sure we have enough time." In this way you can hopefully avoid an extended time in the waiting room and assure that you'll have enough time to address all of the issues that are important to you.

Even if you are seeing a doctor that you have seen before, if it's not for a routine visit, make sure the doctor knows ahead of time what the problem is. This kind of "heads up" will allow your doctor to do a better job solving the problem. The operative words here are, "Please tell Dr. Smith". If you are taking the time to provide advance information, you want to be sure that the office staff relays that information to the doctor ahead of time.

Second, keep your own set of medical records from other providers and bring them with you. Mailed records don't always arrive where they're supposed to. It is very helpful to me when parents have records with them. Sometimes I need that information right away and it allows me to make decisions that, without the records, would have to be delayed.

Third, bring a list of the things you need to accomplish in the visit. Obviously if your child has a total body rash and can't stop scratching you won't need a reminder, but for most other things I find that if I don't write my issues down I invariably forget one or two. If it's a long list, prioritize. The doctor may not have time to

deal with everything. In my practice, I always feel bad when I spend twenty of a twenty-five minute visit talking about one issue only to hear of a much more serious second problem when my hand is on the doorknob. Sometimes it is reasonable to put aside some issues for the next visit in order to deal with an acute need.

Fourth, don't assume. Don't assume that the doctor knows everything and don't assume that she knows nothing. Also, just because she seems unfamiliar with fragile X don't assume she can't help. Be assertive, educate! Tell the doctor about The National Fragile X Foundation. Share the information you have and your sources for information. Even without being an expert, she probably knows great occupational therapists, can refer you to the psychologist who has the most patience, and can help you navigate insurance company mazes. Most should be able to refer you to a geneticist and if necessary discuss alternatives to routine pregnancy for female carriers. If a real expert is needed there are excellent fragile X centers in different parts of the country. If that's an alternative you pursue make sure that your regular doctor receives a copy of all records. Even if you consult with an expert you'll still need a physician close by that is there for the serious and not so serious daily stuff.

Lastly, if for whatever reason, the relationship with your doctor is not working, don't just accept the situation. Find a new doctor who appreciates your knowledge, sees you as a partner, and has the ability to learn from his or her patients.

### ONLINE DONATIONS

Did you know that you can now support the efforts of the National Fragile X Foundation through online donations? Just visit [www.FragileX.org](http://www.FragileX.org) and click on "Donate". Our secure server will process your contribution.