

## Preparing Emotionally for the 11<sup>th</sup> International Fragile X Conference

If this is your first National Fragile X Foundation (NFXF) conference or you are newly diagnosed here are some words of wisdom from one who has been there. Actually, even if this is not your first conference, it is good information to think about before and as you go through the next few days.

1. Don't take every word as gospel. You may hear "You should do this..." "Make sure you..." "Do everything you can to..." In reality, what you are hearing are good ideas, and while the information is based on research and practice, you need to find what works for you, your child, and your family. You cannot do everything, nor should you be expected to—make sure you always take time to be a mom or dad and just enjoy your children.

2. Many of the lectures highlight extreme cases and may not describe your child perfectly. Keep in mind that children with fragile X have a huge variability in how they are affected. Some are toilet trained at 2, others at 12. Some have significant behavior issues, others have none. If the session accurately describes your child—great, otherwise, look at it as broadening your knowledge of Fragile X.

3. Know that you will hear the words "mental retardation"; they are medical and clinical in nature and may be used in the scientific sessions. It is not intended to be offensive or derogatory, because everywhere else, you should hear child (or person) with a developmental disability. Know that everyone here—gets it. We see people who have *different* abilities, and that applies to all of us.

4. Don't feel like you have to go to every session to qualify as a good parent. The reality is that you cannot go to every session because there are so many of them, and they will not all pertain to you anyway. Pick a few topics that you want to learn more about and focus on those.

5. Use the conference to take the time to go for walk, have a cup of coffee, exercise, or just sit and do nothing for an hour or two. They are all okay. It allows you the time to be introspective; look at all you have done, and while there is more to do, there always will be. Pat yourself on the back and then set a couple of goals for yourself.

6. Have fun with all the people you meet. There is something to having so many "carriers" around you. You have that instant bond with them, and you will feel like you have known these people forever. You "understand" and it is pretty amazing! Oh but, don't forget to include the "non-carriers" in your conversation.

7. You will have a chance to meet *famous* doctors and researchers from all over the world. This is a very unique aspect about the NFXF conference. However, do not expect them to address your individual concerns. They will be able to give you general information, but use the time to put a face to a name and plan to contact them after the conference.

8. After the conference, where you have just found a new family and others who understand fragile X, it may take a bit of time for "re-entry" into your home life and community. If possible take an extra day or two after the conference to digest all the new information and internalize it as it pertains to your child and your life. Then it is time, as some have described, to put your armor back on for the real world.

All in all you are going to learn so much about how to better your life and that of your loved one. I am confident that you will find the National Fragile X Foundation's Conference extremely worthwhile. Take the time to not only to learn, but to meet other families and professionals.

Enjoy!