Hello,

I came here today and talk to you about something called Fragile X Syndrome. It is the most common cause of inherited mental impairment in the whole world. In fact, there are thousands of boys and girls everywhere in the world that have Fragile X. To tell you the truth, I had never even heard of Fragile X until many years ago. Then a doctor told us that our son Mitchell had Fragile X Syndrome. I know that some of you already know who Mitchell is, because you have been in his class, or from daycare. I’m here to tell you a little about Mitchell, Fragile X, and how it affects our family.

When someone has Fragile X, it means that before they were born, a tiny part inside their brain didn’t operate the same way that most people’s do. Their brain is the same shape and size as everyone else’s, there is just a little, tiny part inside the brain that is different. That tiny part makes them act differently and makes them learn differently. Have you ever been in class and the teacher is explaining something, it might be science or math or spelling, and you just don’t get it? You are trying to under-stand and you just can’t? Put up your hand if that’s ever happened to you. I know that it used to happen to me too. You know what I would do? I would ask someone else to explain it to me, a friend or another teacher or my mom or dad. When that new person explained it to me, I would “get it”. I’ll bet that you know what I mean. The reason that you “get it” is because the other person explained it in a different way, and another part of your brain understood.

People with Fragile X can have a really hard time learning things in the classroom. Sometimes they have to learn the same thing over and over, explained to them in lots of different ways before they “get it”. When we were teaching Mitchell what a dog was, we had a book with a picture of a dog and we’d point to it and say “dog”. After a while, Mitchell knew that picture was a dog. Then, one day we were at the store and there was a dog tied up outside. I pointed to it and said “dog”. Well, Mitchell looked at me like I was CRAZY. I knew that he thought that “dog” meant the picture in the book. This dog was brown, the one in the book was black and white, this dog said “woof” and the one in the book didn’t say anything, this dog moved and wagged his tail, and the one in the book always stayed in the same spot. We decided that we had better try something else with the picture in the book. Next time, when we looked at the book, we said “woof”. Then Mitchell learned that dogs make a noise. Every time we saw a real dog, we said “woof” and one day Mitchell said “dog”. He finally got it. It took Mitchell a long time to learn about dogs, and we had to figure out a way to explain it to him so he could “get it”. Now he knows and understands all about dogs, and lots of other animals. Some things he learns things faster, some slower, just like all of you.

Fragile X makes people act differently too. Their brain lets in too much inform-ation all at the same time and they can get upset. I’ll try to tell you what I mean. Put up your hand if you like to watch t.v. Have you ever been watching t.v. all alone, when all the sudden your brother or sister starts talking to you, then your mom tells you to do something, then your dad starts up the lawn mower outside, then the phone rings and ALL you want to do is just watch t.v.? How does that make you feel? Pretty upset? Kind of mad? Does it make you want to yell at everything? You know what? People with Fragile X feel that way a LOT of the time.

Right now I know that you are all sitting here and listening to me. If you have Fragile X, your brain has trouble focusing on one thing. Right now, they might be smelling the floor cleaner, watching someone fidget, feeling the tag in the back of their shirt and trying to pay attention to me all at the same time, and that makes them feel the way you do when you get upset, trying to watch t.v. They can be trying so hard to figure out how to handle all that stuff happening to them, that they forget how to act appropriately, or the way that they should. They might flap their hands like this (demo), stand up when they should be sitting, or yell out something when they should be quiet. It is their way of dealing with the way they are feeling. Sometimes it can make them feel better, and then sometimes it can make them more upset. Sometimes Mitchell even gets upset about something that happened to him a little while ago, but it’s just sinking in now. That is part of the mystery of living with Mitchell. We have to try to help him learn how to handle things that upset him, in a way that can help him feel better next time.

I know that some of you have asked me why Mitchell won’t say Hi to you if you see him outside of school, maybe in the Park at the end of our street or up at the plaza. There is a very good explanation for that. I want everyone to think of someone famous right now - your hero - maybe a sports hero, a movie or t.v. star, a singer... Now picture that tonight you are sitting having dinner with your family and the doorbell rings. You answer the door and there is a huge stretch limo parked outside and the person you were just thinking of is standing right in front of you, saying Hello! Chances are you would not say “Hi, come on in”. Your brain would be so busy thinking “Why are they here? How did they get here? OH MY GOODNESS!” The person would still be standing in front of you and you are still not saying anything. Well, to Mitchell, all of you are HIS heroes. When he sees you outside of school, he’s not expecting it and so it throws him a curve. Kind of like seeing your teacher at the grocery store - you might be feel weird and awkward. What you don’t know is that a minute after you say Hi to Mitchell, he usually says Hi back to you, but you miss it. That’s why his dad or I say Hi for him. We know he really wants to, he is just overwhelmed at that moment.

The last thing I want to talk to you about is YOU! Mitchell’s Dad and I want to tell you that we feel really lucky that Mitchell goes to a school where so many of you know him and try to help him. You are all the best teachers that Mitchell has. He will watch you, and see how you do things, then he will know how to do those same things. If Mitchell is doing some-thing that he shouldn’t be, or acting silly, you can all help him learn the right way to do it, or a better way to behave. He will listen to you. Even though Mitchell’s brain may not work in the same way as yours, his HEART does. He likes having lots of friends, to play and to laugh with, just like all of you. He likes to ride his bike and scooter, watch videos, and go to the park, just like all of you. He has his good days and his bad days, just like all of you. It’s nice to know that he has people here that care about him and help him through the bad days and laugh with him on the good days. Mitchell and everyone else who has Fragile X has special needs, but we know that as long as Mitchell has people like you around him, he will have a good life! Thank you.

*I would then ask the students if they had questions and would answer them as honestly as possible. I would also send a copy of this “speech” home with every student. I always had feedback from other parents about dinner conversations about Mitchell and Fragile X Syndrome every year after I visited the classroom.*