

Talking with Students
about
Fragile X Syndrome

With Holly Usrey-Roos

A little about me



What we will cover today

- ✗ Why you should do this.
- What age/grade you should start.
- ✗ What you should expect.
- What you need to know up front.
- ✗ How to make it happen.
- Adding more information each year.

Getting Started

- ✘ Why did I start doing this? The story of Josh.
- Why should you start doing this?
- ✘ When should you start? What age?

My Warning

This is my very honest, very much needed warning to you.

This WILL be the hardest thing you ever do.
You will most likely

- Cry
- Debate leaving before you start
- Think you can't do it.

My PROMISE

This is my very honest, very much needed
PROMISE to you.

*And I don't make promises unless I really believe
in them*

You will:

- ✓ Survive
- ✓ Be extremely happy you did this
- ✓ Change the lives of everyone you meet that day
- ✓ Thank me 😊

How I know...



Things I *always* do

No matter how many times I've talked to a class there is one thing I always do – REMIND THEM of how alike they are!

- This is for EVERYONE
- Get them involved
- Make those lists!
- Put the “power” in their hands!

Start Simple

Kindergarten – 1st Grade

- o Please remember the attention span is
SHORT!
- o Visuals!
- o Don't anticipate that they have noticed a lot
 - o Keep it BASIC!

2nd – 3rd Grade

- o Be visual when possible
- o Encourage them to participate, they may need prompting!
- o Don't underestimate how much biology/FX 101 they will really understand. Simplify it but don't under do it.

4th – 5th Grade

- o Expect a lot. They are doing things we cannot imagine because our children may not be doing them.
- o Keep them engaged and participating
- o Emphasize the importance of their role
 - o Talk about the future.

- o Middle School 6th – 8th Grade
 - o Challenge them
- o Be specific with how FX works, they know biology better than we think!
- o Remember this is a hard age for everyone – remind them of that & the difference a good friend makes.
 - o Talk about research

Every time...

Here is what you will get from me.

Every time I do this there are a few things I cover – every time. No matter how many years in a row I have talked to a group, there are some things I find it important to repeat, build on, and see what they remember.

Plus – there are often new students and teachers – review is always good, even if minimal.

Introduction

- o I am Parker's mom. 😊 You will be amazed at the emotion that one sentence brings.
 - o Who knows Parker?
 - o Who, in the group, is Parker's Friend?

Why I am here.

**I want to tell you about
Fragile X Syndrome.**

No matter how many times we have said this to hundreds of people, saying it to your child's peers brings on a whole new meaning and level of emotion.

What is Fragile X?

- o Everyone – “Fragile X is the leading cause of inherited mental impairment and the leading known genetic cause of autism.”

Break it down – or give it more depending on the age

K – 1st What is FX?

- o FX is....
- o What does that mean?
- o It means that there are things about Parker, in his brain and body, that work different than the way your brain and body do.

Ex. It's hard for him to talk, think, stand in line, hold a pencil, jump, sit in his chair, be around loud noises, etc.

2nd – 3rd What is FX?

- o FX is
- o What does that mean?
- o It means Parker's brain and body work differently. (Give examples)
- o Tell them WHY. It works differently because there is a protein missing.

4th grade and up - What is FX?

- o Fx is....
- o What does that mean for Parker? - Give ways he's affected.

I stop here because they understand it. I go more in depth with them in other areas.

Lists

- o I do the lists each time because it is very important that from the start they see how very much Parker is just like them.
- o It gets them involved in the presentation.
- o It allows me to use their examples instead of guessing what kids their age might enjoy.
- o I get to bring home the point that everyone wants friends.

How do you get FX?

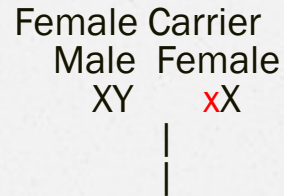
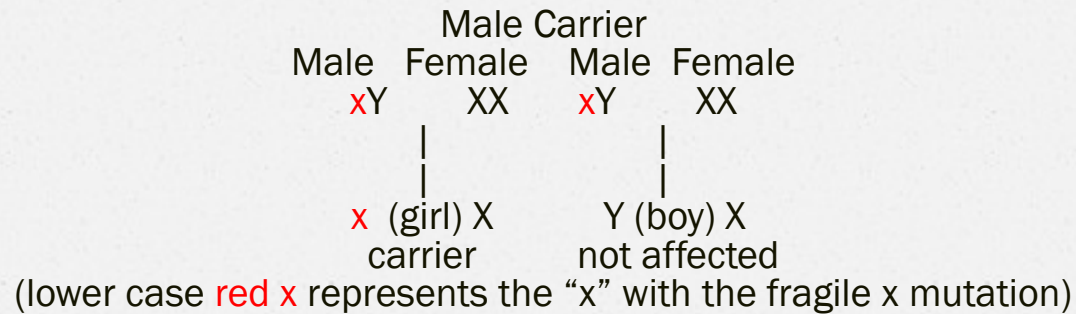
Detail varies on age. I always tell them that he has it because he was born that way. You can not catch it from playing with him or being his friend. FX is something you are born with. He was born that way because I have a little bit of Fragile X too and I gave it to him.

I also tell them that Parker's sister has Fragile X.

And that thousands of other people in the world have it too.

How is it passed?

From 2nd grade on we talk about the X chromosome and how it's passed.



50/50 chance for EACH child that the female will pass the affected **X** chromosome

How can they help?

One of the many important things I want to pass onto my children's classmates is a sense of importance and ability to help and make a difference.

I want them to understand peer modeling and the importance of being a good role model.

So I say.....

Who is the most important person in this room?

Clearly, it's the teacher, right?

I ask the teacher to please not pay attention for a bit so I can talk just to the kids.

I tell them, for all of YOU, Mrs. X IS the most important person in this room, she teaches you and that is how you learn. However, that is not how Parker learns. Guess who Parker learns from watching?

YOU.

Give them RESPONSIBILITY

Let them see how much they can help –

Ex. Parker really needs to work on social skills,
how can you help?

Everytime you see Parker, you tell him “Hi”

Parker needs to work on counting, spelling,
sight words, etc – when he watches you do it
out loud, he will do it too.

RESPECT

- o I always tell the kids “It’s ok to notice Parker is different. It’s always ok to ask me or the teacher questions anytime. It’s ok to not always understand Parker. What’s NOT ok is to make fun of him. It’s NEVER ok to make fun of anyone with or without a disability.”
- o One of the most important things to me is for the kids to understand the lessons I teach them about acceptance and understanding isn’t just about Parker. There are a lot of people in our community just like Parker – or different, maybe they are in a wheelchair, or walk different, maybe they can talk, or can’t at all...

Take Questions!

- o Always leave more time for questions than you think you will need.
- o Be prepared for anything!! And I mean anything from “does your child like hamburgers?” To “how does your child talk to you?”
 - o Stay on their level!
 - o Be there friend!

If you need me...

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