

*Talking With
Students About
Fragile X Syndrome*

Holly Roos

About me



Getting Started

- It's important to remember this is going to be one of the hardest talks you will ever give – because it is so personal – it is your child's peers – his/her friends.

It is also important to remember – this will be one of the most influential talks you ever give –this is your chance to help children understand and move forward in a positive

Kindergarten – 1st grade

- It's important to remember in Kindergarten & 1st grade, the attention span is short!
- Using visuals will help! - example – toy truck
- Talking about how we are similar
- Talking about how we are different
- In the end – we are all the same! Feelings, wants, needs!
- How they can help!

2nd – 3rd grade

- Building on the current knowledge
- Adding more information but keeping it visual and simple. Move from toy to chalkboard.
- Talk about ways they have helped and how to build on that!



4th – 5th grade

- Adding detail on how the gene is passed.
- Explaining hyperarousal with Tracy and Mouse's hands on exercise
- Giving more credit to the peers for help
- Reminding them of their role and it's importance.

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- When should I go?
- Should my child be present?
- How do I set this up?
- Should I send home information to the parents, and if so, what?
- What if there is a question I can't answer?

Remember your reason!



Let's do it!

- *Introduce yourself & why you are there – Ex. “Hi, my name is Holly (or Mrs. Roos) and I am Parker’s mom. Some of you already know me and some of us have never met. I’m here today to talk to you about Parker and Fragile X Syndrome...”

Ask and let THEM answer...

“What are things you like” and “What are things you like about school”?

Write all of the answers on the black board or somewhere in view.

Things I like....	Things I like about school...
Riding my bike	Recess
Playing with friends	Lunch
Playing video games	Being with my friends
Going swimming	Math
Going to the movies	PE
Playing on the computer	Music
Going to football games	Reading
Going out to eat	Teachers
Watching TV	Art

Go over everything listed, circle what your child likes and cross out what they don't.

ASK THEM – do you think Parker likes... (riding his bike?)

If they answer is Yes feel free to say if the child likes it a lot of a little.

If the answer is "NO" explain why

Things I like....	Things I like about school...
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What's different?

Sometimes this takes encouragement to get them to answer

Parker.....	
Jumps a lot	Lays on the floor when mad
Flaps his hands	Bites his hand
Doesn't talk much	Carries his backpack everywhere
Can't read	
Makes funny noises	
Can't write	
Eats in the classroom	

Bottom line- you're a lot more alike
than different!



Why? – because they are more alike than different!

- Go over each item, talk about how much fun the things they all like are – like riding a bike or recess and also why your child may not like some of the things.
- Ex – Parker doesn't like lunch because the cafeteria is so loud and because of all the smells.
- The biggest thing is to point out that there are WAY more things they have in common and like than don't!

So... WHY is Parker different?

- Kindergarten & 1st grade –

Take a toy – like a firetruck that can work with and without sound.

Show them how much fun it is to play with with the sound on, then play with it with the sound off. Still, just as fun but different.

Connect the sound missing – to the protein missing in fragile x.

*Bottom Line – just because it's different doesn't mean it's not fun!

Parker also has strengths that make him different – he sees and remembers EVERY detail! Kinda like a superhero – he remembers what's on the walls, what everyone wore, all the details!

Thanks Sharla Davis, Washington, IL for this idea!

- 2nd – 3rd grade – “Remember the firetruck?”

Instead of bringing the firetruck, ask who was there in previous years. Then move it up a level but using the blackboard to explain fragile x/protein.

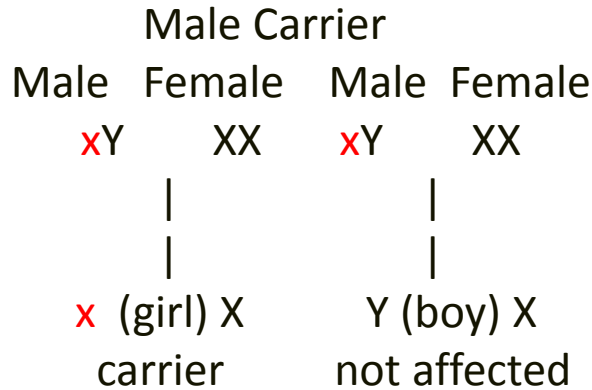
Ex. Everyone is born with the fragile x gene – but how it works in everyone’s body can be different. In Parker, his body isn’t making any of the protein – without this protein, life can be difficult for him.

Important things to point out to children about Fragile X:

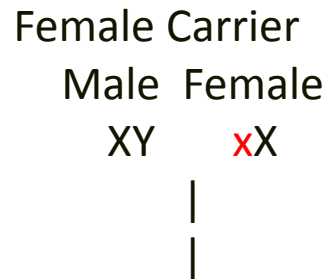
- It's NOT contagious. You can't get fragile x from being Parker's friend.
- People who have fragile x are born with it, they did not get it from doing something wrong or different. It was how they were born.
- I always tell them that Parker got it from me.

4th – 5th cont.

- Talk about how the gene is passed: ex:



(lower case red x represents the “x” with the fragile x mutation)



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

So, what does this mean? Not having protein?

- Talk about all the ways your child could be affected:

Speech delay

Poor muscle tone

Poor eye contact

Sensory Processing difficulty

What to do, what to do....

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.

R*E*S*P*C*T

- 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.”
- 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...

Older kids

- Understanding sensory processing
- Tracy and Mouse's Sensory processing Hands on Experience

Questions

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

Need help or have questions?



Email me anytime!

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