

It is a great idea to personally visit your FOP child's class to help them understand what is FOP and how they can be a great classmate. The information below can be personalized for any FOP family.

Classroom talk to Students About FOP

FOP and MY SON: (sit on floor in earlier grades so that you are at eye level with the children)

1. Hi, my name is Mrs. Cali. I am Ian's Mom.
2. I feel special today to be able to come and talk with you about something that is important to me, and Ian, and our family.
3. You see 5 years ago, we found out Ian had a rare genetic condition called F...O...P That's a very long and complicated sounding name isn't it ??
4. We are ALL born with genes inside us that help to make up who we are and what we look like. For example; I have green eyes – I have a green eye gene inside me. Tall...Short...Dark hair...Light hair, maybe even a gene that determines how fast you run! Sometimes genes determine diseases or a condition for someone. Does anyone know someone who has Down Syndrome? Or is diabetic?
5. We don't choose what genes we get – they are given to us.
6. FOP is a condition that causes EXTRA BONE to form in Ian's body. FOP bones are just like regular bones except they grow in the wrong places and they stay there forever. Ian's FOP bones have grown in his muscles in his back and his shoulders. You might have noticed that Ian always sits up so straight – like a soldier would at attention. That is because his back is fortified with extra bone.
7. FOP bones make it hard for Ian to move sometimes. Like this way...(demonstrate the limitations Ian currently has).
8. Ian has a hard time sitting or getting his books out of this desk. Ian uses a pick-me-stick to raise his hand so that the teacher can call on him and he has a cushioned chair for comfort. You may ask Ian to borrow his tools sometimes.
9. Sometimes FOP causes lumps to grow on Ian's head and back – these lumps are painful when touched but luckily they go away after a while.
10. The reason I am sharing all this information about Ian is we need your HELP. YOU CAN HELP IAN FEEL BETTER BY:

Never pulling on his arms
No rough play around Ian
No pushing Ian
If Ian falls – go get help

All of these ways of helping Ian are the same courtesies we would give others – right?

11. Mrs. _____ is Ian's aide – she is here to help Ian whenever he needs her assistance. You will also see Mrs. _____ doing things for your teachers or even helping other students in the class. You will get to know her well. Mrs. _____ will help Ian write sometimes, when he is not feeling well –

but she will not be giving him any answers – you will see her help Ian with his backpack, books and take care of him if he should have a fall.

CHALLENGES Exercise:

1. We all have challenges?? Reading is easier for some than others

Some can run faster than others

Some children cannot see

(explain more in detail)

2. Each person in this world has Obvious and Not so obvious challenges

3. I have a very obvious challenge and a not so obvious challenge – can anyone guess my challenges?

Obvious - Eye glasses – obvious challenge – I see better using my glasses

Not obvious - I am dyslexic – that means I have trouble reading and spelling sometimes.

Would you know that I have these challenges?

Why do you think you may not see other people's challenges? (Discuss how people compensate for their challenges to reduce their limitation – give examples – I have a tool (glasses to help me see better) – perhaps to see as well as you might without glasses or I always have my mom check my spelling before I send something out or I use the spell check on my computer a lot)

4. I wonder if anyone else in the class knows of someone with a challenge or would like to share his or her own challenges– obvious or not obvious? (allow time for children to share and they will share!) Listen and ask them how they help the person with challenges in their life.

IT'S IMPORTANT TO REMEMBER:

1. Challenges are only part of who we are. I may need glasses to see and I may need some extra help to write a report but these challenges help make up the person I am. I am also funny, kind, patient and hard working.

2. There are only a few people in this world that have FOP. They live around the globe.

3. Do you have any questions you would like to ask Ian or myself?

4. I want you to know that I will always be available to answer your questions you may have about Ian, FOP or why Ian does something a certain way. You may call me at home or stop me in the halls. It is important to me that you get the correct answer to your questions. If I don't know the answer – we'll go search the answer down together.

Thank you for sharing so many of your stories with me today.

I am glad to see that you are so smart and sensitive to the many challenges that people have.