



## FA Connect: Question & Answer Transcript

**Session Title:** How to Talk to Children About FA

**Invited Speakers:** Pennie Grubbs and Rebekah Doshi, Cincinnati Children's Hospital Medical Center

**Session Air Date:** November 10<sup>th</sup>, 2021

Access a recording\* of the presentation by visiting [www.fanconi.org](http://www.fanconi.org). The recording has been uploaded with Spanish subtitles.

*\*Please note that this video offers ways in which to talk to children about FA in the context of acute medical care and in ways that are developmentally appropriate by age. It also offers suggestions as how to assist children with establishing age-appropriate coping methods during challenging or traumatic situations, including transplant and grief and loss. The presenters share an example of how to explain FA in terms of bone marrow failure and refer to Fanconi anemia as a blood disorder. We acknowledge that this would not be an appropriate way of describing the many complexities of the FA disease process, but that this example was specific to explaining bone marrow failure to a young child.*

Have additional questions for the speakers? Email Pennie Grubbs directly at [penelope.grubbs@cchmc.org](mailto:penelope.grubbs@cchmc.org) and Rebekah Doshi at [rebekah.doshi@cchmc.org](mailto:rebekah.doshi@cchmc.org)

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**Q:** At what age is it appropriate to have an in-depth conversation about an FA diagnosis?

**A:** We always fall back to giving them what they need and then let your child take the lead. Sometimes when they have a doctor's appointment that can be a good time to talk with them more about what is happening and ask them if they have any questions. You could start with a simple and short explanation then let them ask other questions or guide the conversation.

**Q:** Some families have adolescents or teenagers who might not really want to talk about FA or may not ask about it. Do you have any recommendations for starting these conversations?

**A:** We would think that they will want to know more when it directly affects them like a symptom or even how it will influence their relationships with their peers. You can help them understand that there are behaviors or actions that will more negatively affect their bodies differently than their peers. We do recognize that it is probably very challenging to have these conversations. As a parent you can only try your best even if you tiptoe a little around the issue. You can share with them that you just want to make sure they know why it is important that we are having this conversation and what that means for them now and in the future.

**Q:** Are there ways to help a child (around 8) who is about to go through bone marrow transplant better understand, especially when they don't want to talk about it and will even change the subject when they are asked about it?

**A:** Firstly, this sounds very normal and typical of children of that age. We would suggest giving the information they ask for or the information he needs to know at that time. You can break down what is about to happen to them and hopefully you have a child life specialist or somebody at the hospital that will help the child understand what is going to happen before each step of the journey. You can always ask them if they want to know more or see pictures and some children say no. If they say no, then respect that and maybe try again later.

**Q:** When my son was getting blood draws before a procedure, his child life specialist (he was 6 when this happened) tried to show them all the supplies/tools they use to put in an IV line and draw blood. He seemed to understand, but when it came time to do the actual procedure he really freaked out and got upset. In the past, I had asked the nurses to give him verset to help him relax and not fight the needle. I'm thinking of going back to that next time. What are your thoughts on that?

**A:** This is also very typical. Often fear and anxiety still kick in even after conversations about what to expect. This is very normal and we know all practices are different in different hospitals. Some children might need a little medication to help them relax and remember that you are your child's advocate. You can go in and discuss your concerns while exploring options to help your child whether that's medication or alternative ways to explaining things. Having a needle come at you can be very scary so as a parent you can ask about medication or maybe you ask if they can sit in a chair with their iPad instead of being on their side or if they can be in your lap. It really comes down to you knowing your child best and if they need a little of something to help and the hospital is willing to do it then do it.