



## FA Connect: Question & Answer Transcript

**Session Title:** The COVID Vaccines and Fanconi Anemia (FA)

**Invited Speakers:** Dr. Stella Davies and Dr. Lara Danziger-Isakov; Cincinnati Children's Hospital Medical Center

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Access a recording this Q&A session by visiting [www.fanconi.org](http://www.fanconi.org). The recording has been uploaded with Spanish subtitles.

Have additional questions for the speakers? Email Dr. Davies at [Stella.Davies@cchmc.org](mailto:Stella.Davies@cchmc.org) or Dr. Danziger-Isakov at [Lara.Danziger-Isakov@cchmc.org](mailto:Lara.Danziger-Isakov@cchmc.org).

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**Q:** Can you talk a little bit about those who the vaccine wouldn't work as well for, including immunocompromised groups, and what they can do if the vaccines wouldn't necessarily work for them?

**Stella:** There are very few people for whom the vaccine absolutely wouldn't work, so our current recommendation is that if you've had a transplant within the last 90-days, you probably don't need to have the vaccine (you need to wait for your immune system to get a little more mature) but after that period, you should get immunized. This is a really outstanding vaccine. It's very, very effective and there are very few people whom it would be inappropriate and ineffective. Lara, what would you say?

**Lara:** I would completely echo that. I think we're just now learning some of the people in whom it doesn't produce antibodies potentially as much as in other people. Those groups are pretty narrow, mostly patients who are on chronic immunosuppressive therapy who are getting specific types of immunosuppressants, so that doesn't necessarily include people after a bone marrow transplant (BMT) because after they've recovered after 90-days and their immune systems are starting to re-emerge, they should have the capacity to respond. What else can you do? You can ensure that you have a whole circle of protection around patients who might respond less well. We certainly advocate for everyone to be vaccinated who's eligible, and there are very few people that would be ineligible mainly based on the fact that they would have gotten COVID recently and gotten one of those monoclonal antibodies where you have to wait 90-days after you get those before you can be vaccinated. But otherwise, everyone who's eligible should get it, and the best way to protect the people who might not respond quite as well, is to have everyone around them get vaccinated. It's also important to have them continue to practice masking and handwashing and avoidance of situations that would put them at risk a bit more carefully than someone else who is more likely to have a robust response.

**Q:** For FA patients, what would you recommend between mRNA and DNA type vaccines, based on any known side effects (i.e., the Johnson and Johnson from Pfizer and Moderna).

**Lara:** From my perspective, we're learning data all the time. I don't personally have a preference as to which vaccine people should get. The question would be (and this is a question for Stella) is there an anticipation that you'd expect an increased risk of having any type of clotting issues in patients with FA, and if there isn't, then I don't see a reason why you would prefer one to the other. They both work very well. And they both are available and sometimes it's more of an availability issue than it is anything else, so if something's available quickly, that's where I would gravitate and it's going to be really regionalized and very specific to your local community as to what you can get access to. Sooner is actually better.

**Stella:** Unless you have a personal history of clots, in which case you might prefer Moderna or Pfizer, I agree with Lara. You get what you want and what you can. Now, there is a lot more vaccine available in the community now than there was a month ago, three months ago. So, if you feel strongly, you probably can shop around and get something that you feel more comfortable with, but it is important with the mRNA vaccines to do both doses, so you get the best benefit and the best response possible.

**Q:** I have a 15-year-old daughter with FA who is non-transplanted. My husband, myself and our son are all fully vaccinated. A month after us all getting the second dose, my daughter wants to spend time with friends, but we're very cautious since the other friends she's wanting to be around also can't get vaccinated yet. Is it appropriate to let her go to an outdoor mall, go for an ice cream or go into a store with a friend? She knows not to congregate around people, so what is your general thought?

**Stella:** Absolutely. No question that outdoor events are much, much safer than anything indoors, but you know everybody's community is significantly improving. As Laura mentioned, I think Pfizer will be available very soon for her age, or at 16, she'll be eligible for Pfizer, so I would get immunized at the earliest opportunity. But I think you could lighten up a bit, particularly with outdoor events.

**Lara:** You know, this is something that is a huge mental health issue for our kids. Smaller is better and having those relationships and being able to do things in smaller groups is beneficial for all our kids mental health. I think doing that in a safe way and having the conversation with the parents of the other kids that she wants to be with about where they are with everything (so that everyone is on the same page) is really helpful.

**Q:** I have two children who are under 12 (8 y.o. and 10 y.o.). My 8-year-old has FA and is pre-transplant. We've kept both of them home from school, but he's really struggling with the virtual learning. What are the risks of sending him back to school? Our school is not taking very many precautions to keep kids safe in the fall and I'm not sure if they will even mandate masks. His age group won't be eligible for the vaccine yet, so do we continue to keep him home?

**Lara:** This is a really personal decision, and I think it's a really difficult balance with everything we go through. It's balancing risk and understanding what the balance of risk is. I would encourage you to have the conversation, starting now. And over the summer, with the school, about what they think their policies are going to be and how they're going to work. The number of 8-year-olds that are getting infected in school is very small, mostly because they're able to mask and they're doing things like creating cohorts and putting kids in the classroom all day—it's much easier to keep a class of third or fourth graders in the same classroom all day, than it is for 15- or 16-year-olds in high school, and that's certainly decreased their risk of spreading.

**Follow-up Q:** Our school isn't doing any of those things, so there's 25-30 kids in a single classroom and they're mixing into other classrooms frequently throughout the day. I guess I'm interested to know, with his levels pre-transplant, what are the risks for kids with FA? Have we seen kids with FA get COVID? What are the results?

**Lara:** The only thing that's going to impact your decision making around this is also the community prevalence of COVID, and if that's dropped substantially, the rest of your child's risk is exceptionally low. There's very little information that we've seen about specifically COVID infections in a population of patients who have FA—there's just not a lot of data yet. I don't know if that's because people aren't seeing it or kids aren't getting that sick from it. Certainly, we do see low lymphocyte counts, not low neutrophil counts, and platelets can be moderately affected, but that is a rare circumstance.

**Stella:** There has not been a lot of COVID happily in the FA community, and at Cincinnati, we haven't had anybody severely affected—no one ill enough to be in the hospital—and a very small number with actual infections. I am aware of someone at a different hospital who was severely ill, but that's only one person at the height of the pandemic. I am so sorry that there are not precautions being taken at his school because I absolutely agree with you that it's really hard for an 8-year-old to learn on Zoom. Speaking as a mom, not a doctor, I would be very keen to get my kid back in school, too. But I can see your concern when there are no precautions being taken. With any viral infection, platelets can drop—usually they recover, but again as I'm sure you know, sometimes this is not back to where they were, so that is an anxiety. Now having said this, I'm presuming you're not going back to school until August. Now with the changes that are happening in the community over the last few weeks (which are all good), there is significant improvement in the prevalence across the whole U.S. If this were my kid, I think I'd be trying to make plans expecting them to go into school, but I would be camped out in the school office saying "what can you do for me—this is my position, how can you help...?". Maybe there could be smaller groups or learning environments where they would be willing to accommodate you. But I'd absolutely have that conversation with the school to ensure that

the staff be supportive if my kid wore a mask and others didn't, or that they wouldn't be called out or embarrassed because of doing so.

**Q:** Do you have an idea on the timing of when immunizations for these younger age groups will be available?

**Lara:** My understanding of the timeline is that it may be late fall or early winter. But that's always subject to bumps in the road or things that can happen. You don't know the results of the study until you do the study, unfortunately, and they want to make sure things are safe first.

**Q:** I have two twin boys with FA and they're 11-years-old. They are not transplanted yet and are both in moderate bone marrow failure, so I have kind of a three-part question: (1) have you had any non-transplanted FA patients to receive the COVID vaccine that you know of? (2) there has been some concern of acute thrombocytopenia and people with the AstraZenica vaccine, so I just wanted to know if you had any concerns about that for Moderna or Pfizer vaccines in a non-transplanted FA patient (or anyone with aplastic anemia or anything like that who have had the vaccine) and (3) my pediatrician is willing to give my 11-year-olds the vaccine off label if we could get the okay from our hematologist, but we will be in Cincinnati this summer and will probably wait until then to gather some more data—what are your thoughts on all that?

**Stella:** Yes, so we've heard here that a couple of other people with FA (non-transplanted) who have had the vaccine haven't experienced any remarkable side effects afterwards. The issue of thrombocytopenia is present in people who have no bone marrow issues at all and can actually occur with other vaccines too. It's an immune stimulus and sometimes your immune system just gets it a bit wrong and makes an antibody that matches up the platelets, and this is response to treatment. Usually in that circumstance, the platelets bounce right back to wherever they were before. It's really quite rare that it hasn't occurred with a high frequency—though oddly enough, it happened to one of my friends and she had a course of steroids and counts returned to normal. So that's a bit different from the concern with FA where a viral infection or a stimulus (immunization) could potentially kick off some high cytokines that would just suppress the platelets. I'd think the bigger risk of that happening (an FA-specific decline) is if one got a life infection rather than getting the immunization, but the ITP thing happens in regular people with regular immune systems, but at a very low frequency.

**Lara:** I would say the risk for that, with the Moderna and Pfizer, the mRNA vaccines is much lower than it is with the other formulation that you mentioned (the AstraZenica vaccine) which is not currently approved in the United States. And then the one thing I will just say is that these vaccines are only available through an emergency use authorization and they really should not be given outside because they're not technically approved by the FDA. And therefore, they can't be given off label. They really only should be given to people who fall under the emergency use, because if they are given outside of that and that is discovered, that puts the person who's giving those vaccines license at risk. It's a really big deal. So just be cautious about that, not that I wouldn't want your children to get vaccinated, but I just think that it's a bigger issue that people, who may have the vaccine available for other populations, may realize. I know that no one here would want to create a situation that was uncomfortable for anyone.

**Q:** As a follow-up question, I live in Canada and we have the Moderna and Pfizer vaccines approved, but we also have AstraZenica which I actually just got last week. For my son (non-transplanted with FA), would you recommend one of the mRNA vaccines for him versus the AstraZenica if there was a choice?

**Lara:** You know, I don't think that I've personally seen enough of the data about the AstraZenica to comment on that just because it hasn't come through our system to look at. All of the reports around that haven't been published, so I would feel uncomfortable making that distinction at this point. Certainly, I feel very comfortable with the mRNA vaccines, but you know I haven't seen specific reports that are overwhelmingly stating there's any specific worse safety profile for the AstraZenica. But I'm going to plead lack of complete knowledge and I don't want to give you incorrect advice.

**Follow-up Q:** I suspect, just to follow-up on that last point, that when they do open it up to under 16 here in Canada, it will be one of the mRNA vaccines. I don't know that for sure, but I just thought it was worth asking the question.

**Lara:** Right. So, mRNA vaccines have been the ones that are being tested in kids who are under 18 primarily and we haven't seen trials of the AstraZenica. The Johnson and Johnson vaccine is also being tested in children, although that was held up a little bit with the issues that happened in the past month, but I'm not aware of the testing and younger kids for AstraZenica yet. And there'll be another one that may come to light (the Novavax vaccine) which is a subunit vaccine, which also should be very safe. But that data hasn't come out yet.

**Q:** I am a mother of a 21-year-old man with FA. We already got our full vaccinations from Pfizer. He had no discomfort: the first dose was fine; the second one had a bit of a sore arm. I had a terrible time for both doses. My question is: they are already going back to school now, but he goes to a special education school. My concern is that the vaccination is not mandatory for anyone and the other young people that attend won't necessarily wear the face masks. Face masks for some of these students are even being recommended by their doctors to not wear at school. I don't feel comfortable sending him to this environment, but I understand that staying home will also be harmful for him. What would you recommend in this situation?

**Lara:** That's a really hard situation to be in and I think you do the best you can with the things you can control. For me, it's if you can control that your child can wear a mask and your child can be fully vaccinated—which you can. That's really the most important thing—that and working with the school to ensure that they have the best policies in place and helping them to understand your concerns. That's really as much as you can do at this point.

**Stella:** Yes, that is tough and as we said earlier, I do think it's really important to get the children back into school at the earliest safe opportunity. It's just so important for the growth and development, and after the immunization and being around younger people, I think the risk of exposure and bad infection is quite low. And I don't know if your classroom can keep the children distanced—that's easier said than done, because they do mill around a bit. So, control what you can control and share with the school, and then you just have to look in your heart and say do I feel like this is safe and better for my child? And keeping them out of school for a long time, which absolutely has significant problems, is not trivial.

**Q:** Would you like to share any myth busting thoughts around the vaccine—things you've heard of or learned?

**Stella:** Oh yes, there's been some very strange things out there. Immunizations are one of the biggest improvements in public health over the last 100 years and it's been one of the best things we've done in science and for the society. Vaccines have changed the world, so there's been a lot of things out there on the internet. One popular one was that the vaccine causes infertility. There is no evidence to support that. A lot of people think the vaccines can give you COVID. That's physically impossible. And that thought is a bit more rational. You know, early vaccines were a virus that had been treated to make it less powerful—current vaccines are really not made that way. The mRNA vaccines are completely synthetic. You couldn't make COVID from it if you tried. So, the new vaccines are really good, and we should all take advantage of them as much as we can.

**Q:** I've got a question about breastfeeding and getting the vaccine. Can you pass on some of the immunity through breastfeeding?

**Lara:** So just like any vaccine, when you create antibodies, breast milk is rich in antibodies and those are passed on. So, vaccination can be beneficial (even more so) during pregnancy. Anything that you can do to try to boost that immunity and your antibodies while you're pregnant or you're breastfeeding have the benefit to your child.

**Q:** Are there any risks to infertility?

**Lara:** No, there are not—I was hoping someone would ask! Don't rely on it for birth control. It doesn't affect fertility for women or for men.

**Q:** If family is vaccinated, is it safe for my unvaccinated kids to be indoors without masks with fully vaccinated adults (like grandparents)?

**Lara:** The CDC guidelines currently would say that that's actually quite acceptable. As long as you're in small groups (like immediate family or you know one another) then something like that is okay. They have a whole list of risks and contingencies and I would say if you have interest in the nuances of those things or if you're really into infographics and you're a visual learner, there is a blog that's done by someone called 'Your Local Epidemiologist' and they answer questions from the public that are around these types of questions. They include infographics that are really accessible, and I actually use them a lot to help explain to people, rather than walk through some of the technicalities.

**Q:** Have there been or are there currently any studies being done on COVID vaccines or existing vaccines with any of the bone marrow disorders or demographics in the rare disease community?

**Stella:** So, the people within this community are eligible for the vaccine that's being given, and there is a lot being learned as the vaccine is starting to be used in. Nobody is a year out from having had the vaccine yet, so there's a lot of people paying attention, following along and paying attention and learning. I think we will learn more about specific populations, but a huge number of people have been vaccinated worldwide (hundreds of millions) and there has been no signal that this is particular difficulty in those populations as yet.

**Q:** Is there any update on how long the current studies say antibodies are lasting in the body?

**Lara:** So, the current studies have looked at the six-month data—there were about 70,000 people in that initial first wave and they were vaccinated between June and October or November, so you know we're just now getting six-month data. So far, it's looking good at six months, and they will have assessments at nine months and a year and follow along with that. They are discussing if there needs to be a booster shot—there are studies looking at booster doses and all sorts of other kinds of contingencies, so that data can evolve as we all get closer to those times.

**Q:** Regarding transplants and vaccines, is it safe or should you get the COVID vaccine prior to your other vaccines—or do you get revaccinated with your other vaccines after transplant and then get the COVID vaccine? Is there any particular order?

**Stella:** What we're doing is that we would vaccinate people who are a suitable age—we would do COVID first. 90-days where we would offer the shot to those who would want it, so that's all the first thing. You don't have to work through everything else. That' takes a couple of years, but COVID is the immediate risk.

**Follow-up Q:** And if you are someone who happened to get vaccinated prior to a transplant and then required a transplant afterwards, would you need to get revaccinated with the COVID vaccine after?

**Lara:** Yes, just like all other vaccines.

**Stella:** Correct, we do have them done all over again, just like a brand-new baby.