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2020 Crohn's & Colitis Congress: Transitioning Pediatric IBD Patients to an Adult Practice

Announcer:
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Here's your host, Dr. Matt Birnholz.

Dr. Birnholz:
Coming to you from the Third Annual Crohn's & Colitis Congress in Austin, Texas, this is ReachMD. I'm Dr. Matt Birnholz. Here with me today is Dr. Robin Sockolow, Professor of Clinical Pediatrics and Chief of Pediatric Gastroenterology at Weill Cornell Medicine, and together we'll be reviewing highlights from her presentation on transitioning pediatric IBD patients to an adult practice.

Dr. Sockolow, welcome to you.

Dr. Sockolow:
Thank you so much for having me.

Dr. Birnholz:
Yeah, great to have you with us. So, why don't we start with a quick overview of your presentation, which you just provided recently. What were you looking to impart to your audience?

Dr. Sockolow:
Well, one of the first things I wanted to really discuss and to highlight is how important a transition program is, because there are so many times where we don't think about what it's like to be a pediatric patient with inflammatory bowel disease and how they react to their environment, and then all of a sudden they sort of grow up and they're sort of handed off to the adult GI world with really no one being prepared, specifically the patient, but as important the people who take care of them.

Dr. Birnholz:
Mm-hmm. And so, considering this handoff at both ends of the spectrum, from the adult providers, the pediatric providers, what do you think would be one, if not more, of the most important takeaways for clinicians to keep in mind about some of the perils or the challenges or even the pitfalls that can happen in that handoff, a really important transition?

Dr. Sockolow:
So, I think if we were to divide it up into the 2 healthcare providers, so the pediatric and the adult world, I would first start off with the pediatric side. And what I think is the most important thing is that you start the conversation about what is gonna happen as this patient gets older, what are the things that we are going to do as the pediatric gastroenterology office and staff to be able to allow them to mature into the whole process, and so really starting that whole conversation really at the age of 12, 13, and I would even tell you 14 the latest, is really the most important thing. So it's really just to get used to the whole idea that at one point you will be transitioned to the adult GI provider. Just like we talk to our kids all the time, like, "What are you gonna do when you grow up?" or, "Where do you wanna be for college?" so it should just be part of the natural discussion that you have with that patient.

The next thing for the pediatric providers and the families is really to begin to plan that process, so understand what is needed for this particular patient. Some patients are really pretty self-reliant as they grow up, and some patients really need an extra hand. But as importantly, with parents being so much part of that process, that if they're diagnosed while they're quite young, the parent naturally has

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this very protective personality that goes along with their patient's care, and at some point we also have to allow the parent to mature into this process and to let go and to trust that their child will ultimately be able to take care of themselves, so it's planning and preparing and preparing.

And I would say to you probably the last thing that I would talk about is that during that whole transition process, that it's really a discussion that happens between the pediatric providers and the adult providers, and that depending on where you are in the country, whether you're in a children's hospital or whether you are in a pediatric program within a larger hospital, there has to be some communication with the adult and the pediatric population and—and their providers about what this transition process would look like in that area.

Dr. Birnholz:
And it sounds like an ideal circumstance, certainly, of being able to have those discussions in advance. In the realistic settings from your own vantage point, your experience, is that happening enough, or is there a disparity there?

Dr. Sockolow:
It's definitely not happening enough. So, IBD is just one of the many chronic illnesses that begin during childhood, but if you think about how many patients have other conditions, such as congenital heart disease, cystic fibrosis, these are many, many patients who ultimately can get through the pediatric process but absolutely have to have some proper handoff and training so that they can go into the adult world. And frankly, the adult providers really don't have that training, and so… You know, if you think about it, you go through your 3 years of your general, either internal medicine or pediatrics, and then you go on to your subspecialty. I would say to you that most adult gastroenterologists haven't really taken care of adolescent patients or even young adults, per se, sometimes not, and it's a whole different approach.

If you think about how the pediatric gastroenterology patient walks into an office, they have their mom, they have their dad, there's usually a nutritionist, a social worker, a psychologist that's part of the team, and often pediatric patients take much more of a passive role, and so part of that transition process is encouraging them to have their own voice within that office. And then you think about: Well, what happens in the adult environment? Well, it's pretty businesslike, as appropriate, that you go in, you speak directly with your adult provider, it's you as the patient, and sometimes it's quite difficult for that kid, now young adult, who now has to go into the office and not have that same environment, who maybe never found their voice. And that's so important, because if they don't speak up, if they don't learn what the names of their procedures are, if they don't learn about insurance, if they don't know how to call in a refill, then that gives us an enormous opportunity to have gaps in proper care.

And probably one of the most vulnerable points in a young patient with IBD is when they're transitioning from their pediatric provider to their adult provider, where they haven't learned how to be self-reliant, haven't learned even to make an appointment, but what is sometimes and more often the case is that they go to the adult provider but yet they don't have refills on their medications, or they're really due for a colonoscopy, or they can't really get through to the adult office, or maybe they haven't even found an adult provider and they're lost to follow-up and there's a huge gap in their care, which puts them at enormous risk for a flare, so this is critically important to get that process done and done well no matter where you are in the country and no matter where your current system is—again, whether it's a pediatric population within a hospital or whether it's a children's hospital to an adult care provider.

Dr. Birnholz:
And where do you think the highest onus of responsibility lies in handling this transition successfully? Certainly, there is a level of responsibility on the pediatric provider to help set up the patient and family—because, of course, in pediatrics it's never about just the patient. It's also the parents that you're treating and setting that person and family up to be able to, manage their own care such that they can come into the adult care situation and not be 10 steps behind. But on the adult provider side, they have to be able to take that baton and run with it. And where does the responsibility sit in making sure that this transition or handoff is done the best way it can be done?

Dr. Sockolow:
Well, I would say to you, just by the natural course of it, it's really we in pediatric or pediatric gastroenterology that has the greatest opportunity to make that right, because by the time they walk into that adult GI office, you would have hoped they would have been prepared. So I guess in a way we do take responsibility in the pediatric side to really do the proper raising, if you will, of that patient so that they ultimately can be transitioned in a seamless way to the adult world. However, I will say that probably the part that's most critical is the very end, and depending on where you are, it could be 18 is the cutoff. We at Weill Cornell, usually do 21, sometimes 22, 23, could be that late, but what is really so important is really that last year, making sure that the patient is properly prepared and now self-advocating, but it's also making sure that all of the information about what previously happened for that patient's care is translated and communicated over to your adult provider. And it's not just what's in that note, because the note will tell you what somebody's last CBC is, maybe what surgeries they have had, etc., but it's that phone call that the pediatric gastroenterologist makes to that adult

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gastroenterologist that is absolutely critical because you cannot give the flavor or the background of the psychosocial part of the patient in a note.

Dr. Birnholz:
Right.

Dr. Sockolow:
So you really have to be able to talk to the adult provider, really let them know who is that young adult as a person that is now moving from my pediatric office to their adult GI office. I think that phone call is probably the last and one of the most important things that we need to do. It also gives an opportunity for that adult provider to maybe have some of the questions answered that they routinely like to know. They might want to know, “Well, what other meds has that patient been on and had to be taken care—taken off of?” “What specifically are the biggest barriers for that patient?” It could be financial. It could be location. It could be maturity. You know, not all of the patients who leave my office are developmentally appropriate. There may be some children that have had developmental delays, and so that’s another very important aspect of talking to that adult provider to consider when that patient and maybe that parent walks into that office.

Dr. Birnholz:
Well, I think you’re answering by default one of the pressing questions for me, which is: What kind of best practice protocol would be in place, maybe ushered in in clinics or being followed as part of some sort of either listed on unlisted recommendations or guidelines to make sure that that transition is as smooth as possible? And certainly making that call, as intuitive as it sounds, is critical in that.

Dr. Sockolow:
Yes.

Dr. Birnholz:
And having a plan for that final year, that’s fundamentally different model of care than the prior years because of handling that transition. Any other recommendations that help to smoothen that transition?

Dr. Sockolow:
So I think for any handoff, so whether I was sending somebody to another specialist, let’s say an ophthalmologist, or whether I was sending to the adult GI provider, it’s medical information. That’s critical. So, hopefully that what’s been going on in the past few years is somebody’s kept a record of everything that’s ever happened to the patient. So again, whether it was their last MRI, whether it was their last CBC, whether there was last endoscopy histology, just to make sure that you have a track record of it. The other thing is making sure that you’ve listed all of the medications that the patient has been on so that there’s not a search again for what therapies have worked and not worked, so again, keeping a great record.

And the other thing that may be important, since so many of our centers are on the electronic medical record, we know for sure that there are certain electronic medical records that will allow care everywhere, and so one of the things that maybe the pediatric gastroenterology office or the adult office may ask is: Do you have care everywhere? So, in the Epic system, it’s just a matter of getting permission that the adult provider, if it’s in a different institution, maybe you can be able to get access to, but obviously, if you stay within the same institution, they just open up that same record and they’re able to look.

Dr. Birnholz:
Right. Well, those are excellent comments, I think a perfect way to kind of close out our interview, just talking about how do we implement this practice and make it the best way possible. I really want to thank you. This is clearly a crucial subject. I might be a tiny bit biased having a pediatric background myself, but to maintain that clear and consistent continuum of care for IBD patients is such an important, if not the most important, phase in being able to prepare them for good care as adults. So I really want to thank you for taking the time to share some of these insights from the sessions that you’ve led and from the practice paradigms that you’ve helped usher in to make that transition smoother. Thanks so much.

Dr. Sockolow:
Thank you very much for having me.

Dr. Birnholz:
For ReachMD, I’m Dr. Matt Birnholz. I’ve been speaking with Dr. Sockolow from Weill Cornell Medicine. Thanks again.

Dr. Sockolow:
You’re welcome, thanks.

Announcer:

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