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2020 Crohn's & Colitis Congress: Guidance on Caring for Young Patients

Announcer:
You're listening to ReachMD. The following episode was produced in collaboration with the Crohn's & Colitis Foundation & the American Gastroenterological Association.

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. Joining me to talk about the unique care needs of young IBD patients based on a recent session held at the congress is Dr. Jeremy Adler. He's head of the Pediatric IBD Program at the University of Michigan.

Dr. Adler, it's fantastic to have you with us.

Dr. Adler:
Thank you for inviting me. It's great to be here, and it's great to be at the Crohn's & Colitis Congress. It's been a nice session.

Dr. Birnholz:
So, why don't we start with just a big picture question, which is to help define some of the unique care needs for pediatric IBD patients that maybe not all clinicians are going to be up to speed on. Can you walk us through that?

Dr. Adler:
Yeah, I suppose it comes into a few main groups, and I think starting off it's worth saying that Crohn's disease and ulcerative colitis in kids is largely the same disease as in adults with many of the same pathophysiology mechanisms, mainly the same needs in terms of treatment, but there are a lot of specific needs to growing kids, developing kids and, of course, the family dynamics. Children are physically growing, and the medications that we use can have an effect on their growth. They can have an effect on their bone health, which can have long-lasting implications well into adulthood. They are also developmentally maturing and experiencing the world, learning about life, learning about things, and anyone with a chronic illness, that definitely impacts, it can impact their learning, it can impact their perceiving the world, and it certainly affects family dynamics.

Dr. Adler:
So there's a lot that we need to think about when trying to help families, when trying to help kids with Crohn's disease and ulcerative colitis but we also have to treat the disease too.

Dr. Birnholz:
Mm-hmm. And even reaching a diagnosis is a completely different ballpark from adult gastroenterology experiences where getting the history, um, the symptoms and the signs is, some pediatric IBD specialists we've talked to have said it's like trying to tweet out the impossible.

Dr. Adler:
Yeah, I've heard some people, liking it to veterinary medicine.

I don't think that's fair. Uh, kids do have a voice, except the very, very youngest kids, and—and I think kids' experience of their own disease and their ability to at least describe it I think is very important because the parents' perception of how the child is doing is critically important, but they can't always feel what the kid can feel, of course. Um, you know, some people are better historians

regardless of age.

Dr. Birnholz:
That's a very, very good point. Um, but there is, you know, characteristic reluctance I think to articulate fatigue or pain, especially in the —in younger populations, and it can be hard to really tweet that out, I imagine.

Dr. Adler:
Yeah, and—and I think there's… It's hard to tease that out, but it's also, I think, sometimes... You know, kids are very resilient. And they are... They want a normalized life. They want to be kids. They want to do all the stuff that other kids do. They don't want to be sick to the extent that they will minimize their symptoms, either intentionally or subconsciously.

Um, and then there's also the issue of when you have a chronic illness and it's been—you felt this way for a long time, you may not necessarily know what it feels like to be normal and may not even realize how sick you are, and that's a real thing that happens sometimes with kids and the parents may be aware of this or they may not. The parents may perceive the child to be sicker than they are. Uh, they may perceive them to be less sick so there's a lot to try and understand in that, in the family dynamic and in understanding the kids' symptoms because they may not be as forthcoming as we would like all patients to be.

Dr. Birnholz:
Right. But the drivers that compel that are instantly relatable you know, among adults. Adults will often be able to articulate what they're feeling, but they might not have the same reluctance because there isn't necessarily the same driver for normalcy or for being able to just explore everything. Also, there's not the other factor of in most cases of having more than one party that that you're really having to work with, and that, of course, being the parents.

Dr. Adler:
Right. You have to, of course both listen to and talk with and educate both the parent and the child but there... But, you know, that comes with its own challenges, but there's also, you know, great reward there—both to seeing kids grow and get better, but also you know, kids have great senses of humor, and poop jokes are not lost on them.

Dr. Birnholz:
Yeah, and hopefully not lost on too many adults. But you're absolutely right. You know, there are a number of rewarding elements, uh, to it, and I wouldn't, uh, want to paint this as simply challenges. Why don't we get into that a little bit? Um, what are some of the aspects that drew you towards pediatric IBD that were—that were rewarding on a different level than, perhaps, working from the adult side?

Dr. Adler:
Yeah, so... Well, having never been an internist, I don't have that perspective, but the things that drew me to IBD are in some ways some of the things that drew me to pediatrics in general is I like having relationships, building relationships with families, you know, having continuity watching, kids, see how they do over time you know, and I find it very rewarding to take care of children with chronic illnesses and especially nowadays that we have more treatment options, and, um, more often than not I can watch them get better which is a very rewarding thing. We weren't able to say that as confidently 15, 20+ years ago, so that's one of many things that drew me into this field. Uh, everybody has their own, you know, personal experience or patient that left a big imprint on them, but to me, it's the continuity of care. It's the being able to help families through a very difficult time and hopefully watching them get better.

Dr. Birnholz:
Have you seen an evolution of the field? Has it been a massive acceleration in terms of people's understanding of the pediatric side of IBD, for instance?

Dr. Adler:
Yes, there's definitely been an evolution of the field. I think when the first biologics, first anti-TNF drugs, when infliximab came out, of course everybody was taken aback; everybody was a little bit scared—"This is too good to be true"—but the truth is that it actually wasn't too good to be true. It was the drug that finally was working on the mechanism that was relevant to the disease, and—and it—and it changed everything. We had, uh… All of a sudden we had a medication that would not only, um, help to reduce the inflammation heal the mucosa, help kids to feel better, but also help them to grow. You know, the anti-TNF medications like infliximab, adalimumab, they're the only medicines for which we have any evidence at all that it improves growth in children, and so we're seeing fewer children who are—have stunted growth, um, when they reach the end of adolescence. We're seeing fewer children, uh, that are chronically malnourished.

And it's particularly interesting talking with families, with parents or adults who themselves had Crohn's or colitis in the pre-biologic era because their expectations, their worries for their children based on their own experience are very different from the current-day

experience, so the surgery rates are going down.

Uh, quality of life is going up. Um, rates of even disease-related complications appear to be going down. I see the field as moving in a very positive direction. And I don't mean that in the abstract academic sense. I mean that in the real world sense of helping children get better, not just feel better but stay better, keep them in remission, not just to the sense that they feel good and are able to go to school now, but they're able to stay well, stay out of the hospital, avoid complications and, uh, continue to be kids.

And I see that has really, truly changed a lot in the last… I don't know, in my career. Last 20 years.

Dr. Birnholz:
Last 20 years, yeah. I mean, clearly the entrance of the biologic era into pediatrics was a long time coming. Uh, just like any new medical therapeutic approach, it's gonna be a long time coming, coming into pediatrics. You're in a unique role because you have certainly a very strong hand in the clinical side, but you're also involved in research, if I understand so you have a firsthand account of how things do ultimately translate on to pediatric care. Is it a common pain point in terms of the length of time even for the best reasonsfor new therapeutic options to reach the pediatric realm or are there positive aspects to it?

Dr. Adler:
I'm not sure about the positive aspects, but I think that the... So I think as pediatricians—and this is probably true for even beyond gastroenterology—pediatricians are used to this. I mean, historically, nobody did drug trials in children because it was thought to be unethical, and they had real legitimate reasons not to do the drug trials on children. There's been a shift in thinking over time, and what I think the medical world, medical ethics community has recognized is that it's also ethic—unethical to treat children blindly without evidence.

Um, and so that's led to a change in the field where there is more research now than there used to be. Uh, it's still a slow process. Drugs get tested in adults before they get tested in children and the FDA, though they have also recognized this and they've improved and sped up their approval of pediatric drugs, is still very slow, um, and so, as a result, the pediatric community uses a lot of drugs approved for adults off label in children, and I think the pain comes from 1) wishing that we had better evidence but 2) advocating for children to get the best treatment, the best drugs that we know they should get based on the current evidence and then fighting for them to get those medicines because they're not approved, which sets up barriers for funders, insurance—et cetera.

Dr. Birnholz:
And I could delve with you probably for hours in terms of how that plays out in your day-to-day having the dual backgrounds that you have and how that reflects upon your—your advice, your counsel, your recommendations to—to patients and their families, but other than just kind a posing that out there and seeing what you think in general why don't we turn to a couple specific areas that I know that were a part of the sessions that you talked about and that you helped organize for your colleagues, one of them dietary therapies for children. We've talked with some other—other of your colleagues about that tightrope that needs to be walked in the pediatric realm in terms of creating the right exclusionary diets to help manage their symptoms and help treat their disease even but still giving them the nutrients that they need to grow and how to walk that tightrope. Can you talk to that a little bit?

Dr. Adler:
Yeah, that's a very important tightrope to walk, and it's a very important tightrope to walk with limited evidence and little—limited tools. I'd say first and foremost it's important to make sure that kids have adequate nutrition.

Um, a substantial number of kids at the time of diagnosis and even for a lasting time after diagnosis are malnourished, have stunted growth, as I referred to earlier, and can have both overall nutrient deficiencies and micronutrient deficiencies, and I think it's most important, first of all, to make sure they're just getting adequate nutrition.

Um, and then the other thing that goes along with it is often times there's a lag between the onset of the disease and when kids actually are diagnosed with Crohn's disease or ulcerative colitis, and people don't know what is causing their symptoms, and it's human nature to try and figure things out. You may draw associations. "Oh, I ate…" you know, whatever it was. "I hate pizza last night. I feel sick today. It must be that." So it's actually quite common for kids to be—have all kinds of dietary restrictions and dietary avoidances based on either their personal experience or advice they got from people or something they read on the, you know, social media, the internet and once your experiences you believe that "this caused my symptoms," it's actually very hard to undo that. There was a wonderful session at the conference about how, you know, a team approach, both the gastroenterologist, dietitian, mental health professional all working together to try and help families navigate this. Um, there are real reasons that certain foods might need to be avoided but often times it's more an issue of treating the disease and then just getting a kid the nutrition that they need.

Dr. Adler:
As far as the specifics of dietary therapy, I think, hit the nail on the head. There's 2 aspects to it—3 aspects: 1) getting adequate

nutrition, which we talked about, 2) helping kids with symptoms if there's a dietary role there, and 3) helping with the disease if there's a dietary role there. Um, there is also a... It is quite common for kids to have concomitant inflammatory bowel disease, so either Crohn's disease or ulcerative colitis as well as irritable bowel syndrome. So the symptoms somebody can have and the inflammation or scarring going on in the gut may both coexist but may actually not be related. You can treat and improve the inflammation, but yet the symptoms persist. You can treat the symptoms, but the inflammation persists, so we really have to treat both. There are many people who feel better when they're off of—when lactose is removed for their diet—from their diet, or gluten, or they're on a low-FODMAP diet or something like that, because it really truly can help their symptoms. It may not help the inflammation. We really need to be paying attention to both.

Dr. Birnholz:
Right. But on the other side of that, let's take, for instance, exclusive enteral nutrition plans. Imagine pretty difficult to implement in pediatric patients just in terms of their day-to-day life, the striving towards normalcy, for instance. Um, it's a very aggressive type of diet.

Dr. Adler:
It is, it is, um, but it's—it's fascinating because there is some pretty good evidence that exclusive enteral nutrition works for inducing remission, at least in a substantial number of kids with inflammatory bowel disease. But like you said, it's hard. It's both normal human nature to want to eat, to eat, but it's also a social thing, and it tastes good, and you want... It's just part of life, and asking somebody to not eat and drink only formula… No matter how good the formula might taste, you're drinking the exact same thing all day every day.

Uh, that's a hard thing to do. Um, the evidence that we have shows that using exclusive—exclusive enteral nutrition for induction of remission can be quite effective. Uh, the evidence for maintaining remission on exclusive enteral nutritional therapy is not there and that may be for a variety of reasons. It may be that it simply doesn't work. It may also be that just people don't stick with it. And it's maybe a little bit of both.

Um, so people have developed a bunch of different strategies of trying to deal with the difficulty. Um, some kids are willing to drink it, and they'll do it if they know there's a light at the end of the tunnel. You know, "I'm going to move on to some other medicine." Um, some kids that's just a hard thing to do and we put down NG tubes, nasogastric tubes to deliver the formula. Um, kids can learn to put it in themselves, families can learn to do it, uh, and we can do the formula at night so that they can go to school without a tube hanging out of their nose during the day.

Uh, uh, so it can be done, um, uh, but it—it is challenging.

Dr. Birnholz:
Time has flown by in the best of ways, um, but I just wanna put back out to you regarding the sessions at the congress a lot of great focus on multidisciplinary teamwork within pediatric IBD. But from the sessions that you helped organize and that your colleagues were —were presenting and running in turn, any standout areas, or standout novel insights that you'd love to impart to our audience?

Dr. Adler:
Yeah, I'd say some of the really key takeaway points from the Crohn's & Colitis Congress on the pediatric side were—and this is in a way pediatric—is we now have a growing number of medications to use. Uh, we struggle sometimes with positioning those medications but what we know—and this has been seen consistently drug after drug after drug—is essentially your first drug is your best drug. You have the best response to the first biologic agent, so we need to do everything that we can to optimize that drug, um, including therapeutic drug monitoring, dose optimization, following the disease, looking for mucosal healing through whatever way, uh, uh, the clinician feels is appropriate. Um, and it's really the question of combination therapy, monotherapy.

Dr. Joel Rosh said it's really about the drug level. Getting the drug level up to a therapeutic level is really what it takes, both to, uh, adequately treat the disease but also to maintain longevity of the drug, because we also have this problem with burning through therapies. Um, get the drug level up into a therapeutic range and keep it there to try and not only help the kids stay well in the short term but well in the long term. I'd say that's one really key takeaway point.

The other… One of the other key points was there's going to be a presentation later today about iron deficiency anemia, about how—how common it is that we under-identify and under-treat it, and iron deficiency can lead to poor quality of life even in the absence of overt symptoms.

Um, and we already talked about the nutritional therapy. The evidence for using primary nutritional therapy for treating the disease just isn't there yet. There's some really exciting data out there from the recent paper from the Israeli group, Dr. Levine's group that showed that perhaps you could use the diet and enteral therapy together for induction of remission and it would be more tolerant. Uh, kids tolerate that clearly better than full enteral therapy. Now, what happens after week 6 is not clear yet.

But that's maybe a more humane way of inducing remission than just sticking them on formula entirely. Um, there's a lot of exciting new medications in the pipeline, uh, with new mechanisms of action, lower immunogenicity rates, lower side effect rates, less immune suppression possibly, so I think the future is looking bright. But as you alluded to earlier, we need data. We need pediatric data. We need to understand best how to use these drugs and how to position—position these drugs.

And I'd say the last piece that I think is an important takeaway from this conference is the multidisciplinary care is critical, both critical for delivering the best care for the family but also critical for us all building on the strengths of our colleagues, having the gastroenterologist, the radiologist, the surgeon, all of us, really communicating closely with each other and with the family so that we really do what's right for the kid.

Dr. Birnholz:
Well, Dr. Adler, I have about 16 other lines of inquiry that I wish we had time to cover, but unfortunately, I think our IBD sportscasting hour is up. I very much want to thank my guest, Dr. Jeremy Adler, from the University of Michigan to help us better understand some of the unique care needs for pediatric patients with IBD. For ReachMD, I'm Dr. Matt Birnholz. Dr. Adler, thanks again for your time.

Dr. Adler:
Well, thank you very much. Thanks for covering this important topic.

Announcer:
This program was brought to you in collaboration with the Crohn's & Colitis Foundation & the American Gastroenterological Association. If you missed any part of this discussion, or to find others in this series, visit ReachMD.com/foundation, where you can be part of the knowledge.