

About IBD Podcast Episode 106

Every Kid We Take Care of, We Become Part of Their Family

How is IBD different in kids than it is in adults? When should kids be transitioned from pediatric to adult care? What's next for IBD treatments? My guest is Dr Jeffrey Hyams, the head of the Division of Digestive Diseases, Hepatology and Nutrition at Connecticut Children's, and a Professor of Pediatrics at the University of Connecticut School of Medicine. He provides a historical perspective on the treatment of IBD and is able to highlight how therapies have advanced over the last 30 years. He also gives some ideas about what's on the horizon for IBD treatments and what gives him hope for the future.

Concepts discussed on this episode include:

- [How IBD Affects Growth in Kids and Teens](#)
- [Managing Ulcerative Colitis in Children](#)
- [Bradley S. Jerson, PhD, Pediatric Psychologist](#), who appeared on [Episode 77](#), [Episode 78](#), and [Episode 99](#)
- [Comparing 6 Biologic Drugs Used to Treat IBD](#)

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[MUSIC: About IBD Theme]

Amber Tresca 0:05

I'm Amber Tresca and this is About IBD. It's my mission to educate people living with Crohn's disease or ulcerative colitis about their disease and to bring awareness to the patient journey.

Amber Tresca 0:15

Welcome to Episode 106.

Amber Tresca 0:18

Children are not little adults. Kids that are diagnosed with inflammatory bowel disease (IBD) need specialized care. In the last episode, which was 105, we heard from Brooke, a pediatric patient who was diagnosed with ulcerative colitis at the age of 1 and a half. She went through

difficult times with her IBD but now, at the age of 13, she's on the right treatment plan for her, and she is thriving.

Amber Tresca 0:40

My guest this episode is one of Brooke's physicians, Dr Jeffrey Hyams. Dr Hyams is the head of the Division of Digestive Diseases, Hepatology and Nutrition at Connecticut Children's, and a Professor of Pediatrics at the University of Connecticut School of Medicine. He is the recipient of a number awards for his dedication to his patients, including the Humanitarian of the Year from the Crohn's & Colitis Foundation Connecticut/Westchester Chapter in 2021.

Amber Tresca 1:07

He provides a historical perspective on the treatment of IBD and is able to highlight how therapies have advanced over the last 30 years. He also tells me what's on the horizon for IBD treatments and what gives him hope for the future.

Amber Tresca 1:24

Dr. Hyams, I wonder if you would tell me how the care for pediatric patients with IBD has evolved over the course of your career.

Dr Jeffrey Hyams 1:31

I started to take care of pediatric patients with IBD in the late 70s and early 80s. And it was a time in which the medications that we had, that we use to treat these disorders was extraordinarily limited. One anti inflammatory medication called sulfasalazine, prednisone or steroids, and surgery, and it was the age in which we were starting to introduce nutritional therapy. Children often required surgery, we dealt with growth failure a lot because of the effects of chronic inflammation, as well as poor nutrition. And it was difficult and kids were often hospitalized for long, long periods of time.

Dr Jeffrey Hyams 2:23

We never thought of anything other than making people feel better. Because we had no way to actually heal the intestine. Things started to change a bit in the late 90s. It was a time when we started to use more potent medicines called immunomodulators. And clearly people improved, we use less than two way of steroids. But what was also clear was we were not changing the natural history of these disorders, which really meant that people tended to be chronically ill.

Dr Jeffrey Hyams 3:02

That changed dramatically in 1998, with the advent of the era of what are called biologics, and these are medicines that are essentially antibodies, which are directed against key components of the inflammation process itself, so much more targeted therapy. And the first medicine was something called Remicade or infliximab. And that was followed a number of years later by Humira, adalimumab. And then there are a whole bunch of other ones following that, but we finally had therapies that really held a promise not only of being more successful, but we could actually demonstrate that the bow itself was healing.

Dr Jeffrey Hyams 3:54

And if the bowel healed, you didn't develop complications, you for the most part did not need surgery, you are not in the hospital. And if you were a child, you would grow. And that's where we are now. It's better. It's not where we need to be, unfortunately, these medicines don't work for everyone. And even in those for whom they do work. Over time, we start to see a lessening of the effect. So it's an evolution, for sure. But we need more agents in more approaches than we have now.

Amber Tresca 4:33

This is a pretty big question, but I'm wondering how the care for your pediatric patients might differ in the way that adult patients are treated? Like what are some of the key ways or some of the key things that pediatric patients need care for that maybe adult patients don't need?

Dr Jeffrey Hyams 4:51

It's a whole different world. And what I can tell you is, it's a rare pediatric patient of ours who graduates to the adult world who does not want to come running back to the pediatric world. So as a general rule, these are children. Now the most common age that we see diagnosis of IBD, and kids is in the preteen and early teen years 12, 13, 14. As you can imagine, that is a very difficult time for children. Forget having IBD. It's middle school years, people understand what that means.

Dr Jeffrey Hyams 5:33

And we also get a lot of very young children 2, 3, 4, 5, we have to worry about the effects of the disease, as well as the therapies on growth, we have to worry about these disorders and their therapies on psychosocial development, we have to work on these therapies and try to mitigate the influence of disease. So children can grow up, become secure, and confident, young adults.

Dr Jeffrey Hyams 6:07

So unfortunately, when you have an illness, or illnesses like these that occurred during childhood or early adolescence, you can quickly see the incredible impact of these disorders. Body image is another one to think of. People who lose a tremendous amount of weight or people who have cosmetic changes, because of some of the therapies. It's a very challenging time.

Dr Jeffrey Hyams 6:34

Every kid that we take care of, we become part of their family. And the message that I give to families literally, from the moment I'm sitting down with them, at the time of diagnosis is I hope you get to like me, because we're going to be spending a lot of time together at least to start. And I'm going to get to know you well, you're going to get to know me, well. I'm going to celebrate graduations and sporting events along with you. Because my job is to minimize the impact of disease on your child's life.

Dr Jeffrey Hyams 7:09

I talk to children starting at a very young age, I talk to them, yes, their parents are in the room. But I'm talking to my patient. I'm looking them in the eye, and I'm trying to explain things. It'll language that they understand. So it's rewarding. It's challenging, it's fun. There's nothing else that I'd rather do.

[Music: About IBD Piano Transition]

Amber Tresca 7:42

You said that pediatric patients often want to come back to pediatric care when they're transitioned to adult care. And I had to laugh a little bit because I've heard that more than once from patients actually who've gone through that transition. But it is a big thing that does need to take place. So about what age do you start transitioning your pediatric patients and what might that look like?

Dr Jeffrey Hyams 8:03

So I do think it's different for different kids and different families who have different needs different wishes. And it's changed a bit because we now take care of our patients into their early to even mid 20s. That's a huge change. It used to be when I first started to practice, really 18 was the demarcation people would move on.

Dr Jeffrey Hyams 8:28

But for many reasons. psychosocial reasons, societal reasons insurance reasons, will now take care of people into their mid 20s. There are some patients and families who are ready for a sort of transition of who's going to be in charge of medicines who is going to be in charge of making appointments. They're ready in their mid teens, and others are not ready into their early 20s.

Dr Jeffrey Hyams 8:58

But I have to say and it gets back to my comments a moment ago, I'm pretty much looking at the kid. I'm pretty much looking at my patient, talking to the families for sure. But my world and the child's world, the patient's world is our interaction. We certainly encourage taking responsibility. The biggest one is take your medicines, medicines do not work if they are not taken. And it's one of the greatest reasons for therapeutic failures that we see. And that's something we need to watch very carefully. I would say getting back in a long winded way by mid to late teens. We are transferring ownership more and more to the kids to our patients but it really varies from family to family.

Amber Tresca 9:51

Yeah, I know that adherence is a really big problem. But other than adherence, what would you like the kids who live with IBD or their parents to know about the disease or about the transition from pediatric care to adult care?

Dr Jeffrey Hyams 10:06

Well, the most important thing I want them to know is that although these are serious disorders, my job and for all pediatric IBD doctors is to work with them, too. I said this a

moment ago, mitigate the effects on their lives, the overwhelming majority of people we take care of, are never hospitalized, they don't have surgery, they're able to participate in age appropriate activities. So we encourage normal lives.

Dr Jeffrey Hyams 10:41

People who want to go to college a little bit further away, I tell them, if it's your dream to go there, we'll work with you to get there within the confines, obviously, about what your family is able to do, what their resources are to be able to meet some of these other things. But again, my approach may be different than others. I really individualize it.

Dr Jeffrey Hyams 11:06

But I but I ask them to take ownership. taking ownership means understanding their bodies, being truthful, about reporting how they feel, kids tend to minimize their symptoms, parents tend to catastrophize the symptoms. Sometimes the truth is somewhere in the middle. And that's part of my job to be able to figure out where is truth?

Amber Tresca 11:35

Thank you so much for that answer that bears out with my experience as the mother of an 11 year old and a 14 year old. I definitely try not to do the catastrophizing. What gives you hope about the future for patients who live with IBD, you've seen such a sea change during the course of your career, what do you think is next?

Dr Jeffrey Hyams 11:56

So I have great hope. And the reason I have great hope, is that there are a lot of really, really smart people who are invested in making things change even more. I have been extraordinarily fortunate for the last 15 or 20 years to work with a group of amazing physicians and researchers in collaborative multi site investigations largely supported by either the Crohn's and Colitis Foundation, or for the last 10 years, the NIH. So research is slow, but it gets you there, eventually. And if it weren't for research, we wouldn't have biologics.

Dr Jeffrey Hyams 12:43

The next sort of age is going to be the age of what are called small molecules. As we are discovering more and more about the pathways, which lead to inflammation, and trying to achieve the whole concept of personalized or precision medicine, you really want targeted therapy. And the more targeted it is a the more effective it's going to be and be the less in the way of side effects. So we're getting there.

Dr Jeffrey Hyams 13:20

I you know, I have to say, there are many days where I wish I were 20 or 30 years younger, not just so my knees didn't hurt so much. But because, wow, what an exciting time we're in. And and as you get older and more experienced, there's no question listen, you bring a lot of experience. And I hope you bring wisdom as well. And you know how to not only ask questions, but you know how to answer them as well. But this is not a one person game. This is about a lot

of really smart people working together. And I will tell you in pediatrics, as a general rule, we work really well together.

[Music: About IBD Transition]

Amber Tresca 14:11

Connecticut Children's has an amazing infusion center where patients can come and receive their infusions, if they have IBD, or another condition that needs to be treated in that way. What does it mean to have this infusion center available for your pediatric patients?

Dr Jeffrey Hyams 14:27

This is so beautiful, I will tell you, we had a little, two little dinky rooms in the hospital. we outgrew them like immediately and and Jim Schmeling who's the CEO gets a lot of credit, because he let me bend his ear from the moment he came here five or six years ago, and we were able to get that place built.

Dr Jeffrey Hyams 14:51

And it's a godsend and I don't know what we would have done with the pandemic because it really in the infusion center, we're spread out before it used to be literally need a knee, and the patient chairs were right next to each other, I mean truly next to each other. And that infusion center, we have not missed a beat since March of 2020. We literally have not missed a beat.

Dr Jeffrey Hyams 15:23

So it is an amazing testament to the institution for building it. And the nurses there are so smart, so talented, so committed, I consider myself the luckiest guy in the world for quite frankly, the people that I work with just an amazing group. I know that you talk to Brooke, she's delightful. I mean, I've cared for her since she was I don't know, five or six or whatever. And we went through some low times we are in much better times these days.

Dr Jeffrey Hyams 15:56

And she is an absolute beneficiary of biologic therapy, you know, 30 years ago, she would not have done as well as she's doing right now. For sure. And again, one of the things that we think about, you know, the next generation, not just avoid the GI doctors, obviously, this generation of IBD patients, what are we going to have that's going to be different to offer them that I'm confident we will have more things to offer them.

Amber Tresca 16:27

Thank you so much for taking the time to talk to me. I'm really glad to meet you.

Dr Jeffrey Hyams 16:31

Yeah, eventually we'll get to see each other not just here. Well, yeah, hopefully, I appreciate what you're doing. Good luck. Be safe. Take care.

Amber Tresca 16:44

Hey super listener! Thanks to Dr Hyams for his commitment to his patients and to his research which will benefit all kids who live with an IBD. Extra special thanks again to friend of the pod Dr Brad Jerson, for connecting me with Dr Hyams and for being my unofficial content manager. Links to more information about the topics we discussed is in the show notes and on my Episode 106 page on AboutIBD.com.

Amber Tresca 17:09

If you are a family that's touched by IBD, I'm inviting you to connect with IBDMoms, a non-profit I co-founded with Brooke Abbott of The Crazy Creole Mommy Chronicles. IBDMoms is a space for moms and moms-to-be who live with an IBD and moms of kids with IBD to find help and support. You can find us as IBDMoms across all social media.

Amber Tresca 17:33

You can also follow me, Amber Tresca, across all social media as About IBD

Amber Tresca 17:38

Thanks for listening, and remember, until next time, I want you to know more about IBD.

Amber Tresca 17:44

About IBD is a production of Mal and Tal Enterprises.

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