

# Engaging Parents in the Care of Patients with IBD

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As one of the larger inflammatory bowel disease (IBD) programs in the nation, the Children's Mercy Kansas City Division of Pediatric Gastroenterology cares for 550 to 600 patients and their families on an ongoing basis. A unique component to the program is the parent engagement.

The IBD program has been recognized as a leader in parent engagement through ImproveCareNow and other national organizations, including the Institute for Healthcare Improvement.

Hear from Julie Bass, DO, on the impacts and benefits of creating a strong partnership with parents in the care for patients with IBD.



Featured Speaker:

**Julie Bass, DO**

Julie Bass, DO, is the Medical Director of the Inflammatory Bowel Disease Program at Children's Mercy Kansas City and Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine. Dr. Bass earned her Doctorate of Osteopathy at Kirksville College of Osteopathic Medicine and completed both her residency and fellowship at Children's Mercy. Dr. Bass is certified in Pediatrics and Pediatric Gastroenterology.

**[Learn more about Julie Bass, DO](http://www.childrensmercy.org/FindADoctor/Details/491)**

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Transcription:

Dr. Michael Smith (Host): Our topic today is "Engaging Parents in the Care of Patients with Inflammatory Bowel Disease". My guest is Julie Bass. She's the Medical Director of the Inflammatory Bowel Disease Program at Children's Mercy and she is the Associate Professor of Pediatrics at the University Missouri-Kansas City, School of Medicine. Dr. Bass, welcome to the show.

Dr. Bass (Guest): Thank you very much.

Dr. Smith: Well, tell us about the Inflammatory Bowel Disease Program at Children's Mercy.

Dr. Bass: Yes. Our program is about 600 patients and families with the diagnosis of inflammatory bowel disease. So, most common types would be Crone's Disease and ulcerative colitis. We have a large multidisciplinary team consisting of several divisions and nurse practitioners. We have a dietician, a social worker, IBD psychologist and several nurses and nurse coordinators. So, a big group and team of staff dedicated to help is patients and their families with a difficult chronic disease.

Dr. Smith: Yes. So, let me ask you this. It's my understanding, Dr. Bass that, many years ago, the suggestion came up that you add kind of a unique component to this program, right? That had to do with parenting engagement. Why don't you tell us about that?

Dr. Bass: Yes, when I became the director of the program in 2012, I was also asked to lead our work in

Improved Care Now, which is a quality improvement network that has now over 90 hospitals, pediatric centers that help take care of children and adolescents with inflammatory bowel disease, and they encouraged that we asked the parent to join our team and then come along to the conferences that we have every 6 months with the Improved Care Now network. So, in 2012, I asked Jamie Hicks, a parent of one of my patients with inflammatory bowel disease to join our group and help us with the issues that we needed to focus on to better provide care for our patients and families. So, Jamie joined us in 2012 and we're still going strong working together and she now leads a group of about 12 parents that they formed a couple of years ago--a patient/family advisory council for our inflammatory bowel disease patients, and it's been really exciting to work with them and have their suggestions help guide our work and what we can do to better care for patients.

Dr. Smith: Well, Dr. Bass, let's back up a little bit and let's talk. Why did this even come up? I mean, obviously, we know and we appreciate that the more the family is involved, that parents are involved, the better the care is in the outcomes. I mean, I think we see that across the board even for adults. So, we get that part of it but was there something specific that happened or some specific outcomes that were looked at that made people think, "Hey, we need to have parents involved at the get-go from this"?

Dr. Bass: I think it is really just the experience that the patients and families can provide that was completely lacking on our healthcare team that's just been recognized in the last several years, and just across everything within healthcare that that's huge in us being able to provide care because our healthcare team thought we understood what challenges our families faced and things that they were going through. We'd often make assumptions about certain aspects of the care that, after inviting a parent to be part of our team, we realized, "Oh, gosh, we've always been thinking this was a major issue when we didn't realize these other challenges existed". So, it's really great to have that perspective on things that were not realized. That the challenges of living with a chronic disease and things with the day to day care of interacting with our clinic and the communication pieces, that having a parent there to ask questions along the way to understand the process and why we do things in a certain way and, ultimately, how we can make it better. In an ideal world, of course, we face challenges along the way as well.

Dr. Smith: Of course.

Dr. Bass: But, working together, we've been able to make some great progress in the things that we can work do for our patients.

Dr. Smith: Why Jamie Hicks? What was it about her that made you reach out to her initially?

Dr. Bass: She stood out to me and just because her sense of passion, the questions that she would ask. She's a nurse by background so, of course, she has some healthcare knowledge to start with, and then her ability to look beyond just her own individual experience with her son was very apparent as well--kind of for the greater good to move things along. She just really did stand out in that way and really challenged me. I met her when I was in fellowship and training, so he was one of my first patients, actually, her son Colsen, and they were the type of people that just make you want to be in a better position and be able to provide healthcare and answer their questions and get to the bottom of things. So, that part was pretty easy to me to pick her out as somebody who would be a great part of our

team.

Dr. Smith: Yes.

Dr. Bass: Of course, I had no idea at the time how amazing she would be in addition to that.

Dr. Smith: You made a good decision.

Dr. Bass: I got pretty lucky in choosing her because she has done some really amazing things and now is just leading a great group of parents. It's pretty impressive, actually.

Dr. Smith: So, I know that at Children's Mercy, this program has become recognized by different institutions and organizations but what's been the influence in other hospitals? I mean, are you seeing parent engagement programs in other hospitals and even outside of the gastrointestinal world? I mean, is this program expanding? And, if not, what are the plans to help it expand?

Dr. Bass: Sure. I do think it is still slow to catch, even in our network. We are off to speak often about our experience and share with other centers and we do have several individual people come up to us and ask for advice on how do you do it; what do we suggest that they do. So, definitely lots of conversations at these meetings going on and then, we have been asked by some other chronic disease networks to share our experience, like with cystic fibrosis. Jamie actually went to a pediatric liver meeting just recently. Last year, we went to San Francisco to share our experience with the PCORI Research Network. So, I do think that it is slowly expanding across different networks but I do think it's still a little bit of foreign concept to actually incorporate the families into the work in the way that we think we have been able to do here.

Dr. Smith: Yes. Tell us a little bit about that. So, when we talk about the parent engagement, you mentioned incorporating them into the work that you do. What does that really mean? Walk us through how someone like Jamie Hicks would actually participate.

Dr. Bass: So, Jamie serves as our lead parent for the patients of our advisory council, and so she attends our meetings usually via phone because she lives three and a half hours from our center. So, every other week, at least twice month anyway, we have what we call the "improvement IBD meeting", and at least once a month, actually, Jamie will call in and give updates then and just be a part of our discussions about what we're doing at our center just to provide care. There's the one meeting that's focused completely on QI business that she will share. And, she represents the parent group who, they individually, the 12 of them, will meet quarterly and then, once a year now, this summer and the past summer, we got together the whole parent group, and our whole IBD healthcare team together for annual lunch meeting for a few hours, just to go over the different projects and ideas for things to do. So, as a parent group, they give us feedback on things that they would like us to look at within our system at Children's. And then, we also ask them for advice on certain things. We do a newsletter and we ask for a parent's perspective to be a piece of that and ask them to edit what we've put out. They've done a variety of things like giving feedback on our educational materials. When they started their first project, they really wanted a video for newly diagnosed families. This is a really stressful time when you're first diagnosed, and so they actually got an outside production company through our media department to put together this wonderful video now that our newly diagnosed families can watch about

Children's Mercy Inflammatory Bowel Disease Program and providing some reassurance "you're on a good place; you're going get better; you're going to get back to a normal life".

Dr. Smith: And, Dr. Bass, and so, that's a great example where, as physicians, we may not have ever even thought about a nice introductory video to all this, but, yet, here the parents bring that into the conversation; you get it done and I'm sure it's paying back dividends.

Dr. Bass: Yes, yes. And, another example, the parents said that they would like to leave our clinic and have a discharge form—an organized form that says, "Here's what we talked about today; here are your meds; here are your next steps, these are the things that"...You know, some of the providers on our team didn't love this idea, so we kind of went back and forth on what this would include and what we would do, and it includes health maintenance pieces. I thought, prior to this form, that I was providing consistent care across the patient population. But now that we have incorporated this discharge form into our practice, every patient discharged from our clinic, we go through that; what they need. I do truly think that's changed the way I practice and making sure every patient is up to date on all of the things that they need. Did you get your flu shot? You know, did you "xyz". That was really a nice piece that was completely brought on to us as a suggestion from the parent group.

Dr. Smith: Well, when I listen to this, Dr. Bass, it's almost like it's like, "Duh, like, why don't we see more and more of this across the board"? And not even just in pediatrics, but in adult care as well. I love this program. I think that the work that you're doing is so critical and I know it's having a profound impact on the families, but also on the patient outcomes. So, that's hurrah to you. Great job with your program. Dr. Bass, thank you for coming on this show today. You're listening to Transformational Pediatrics from Children's Mercy Kansas City. For more information, you can go to [www.childrensmercy.org](http://www.childrensmercy.org). That's [www.childrensmercy.org](http://www.childrensmercy.org). I'm Dr. Mike Smith. Thanks for listening.

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