

Pediatric Crohn's: Finding the Right Path to Care

An educational program for children with Crohn's disease, their caregivers, and pediatricians.



TRANSCRIPT

Program Overview

Operator

Hello, and thank you for joining us today for the *Pediatric Crohn's: Finding the Right Path to Care* teleconference/webcast. It is our pleasure to introduce today's moderator, Ms. Laura Wingate, Senior Director of Field and National Programs for the Crohn's & Colitis Foundation of America (CCFA).

Laura Wingate

Hello everyone. On behalf of the Crohn's & Colitis Foundation of America, welcome and thank you for attending today's program, *Pediatric Crohn's: Finding the Right Path to Care*, which is supported by an educational grant from Centocor Ortho Biotech.

We chose today's topic based on feedback we received in the program evaluations from previous teleconferences. You asked for it, and we're delighted to be able to deliver a program dedicated to pediatric Crohn's disease (CD). To help guide future program topics, we encourage you to complete the online Program Evaluation Form.

We would also like to thank all of you who submitted questions in advance of the program. We worked hard to address many of those content areas in today's program. After our keynote presentations by Dr. Kim and Ms. Arnold, we will open the program up for your questions. We will take as many questions as time allows both from telephone and webcast participants. If we are not able to take your question, our Information Resource Center can be reached at 1-888-694-8872, Monday through Friday, from 9:00 AM to 5:00 PM Eastern Time.

I now have the distinct pleasure of introducing our speakers for today's program, Dr. Sandra Kim and Janis Arnold.

Dr. Kim is Assistant Professor in the Department of Pediatrics, Division of Gastroenterology at the University of North Carolina (UNC). Dr. Kim's clinical interests focus on effective multiple and disciplinary care of pediatric and adolescent patients with inflammatory bowel diseases (IBD).

After receiving, her undergraduate degrees and her medical degree from the University of Michigan, she completed her residency in General Pediatrics and clinical fellowship in Pediatric Gastroenterology at the Baylor College of Medicine Texas Children's Hospital in Houston, Texas. Dr. Kim is the University of North Carolina site Principal Investigator for the CCFA-funded PRO-KIIDS

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Pediatric IBD Research Network. Dr. Kim also serves as the co-chair for the CCFA Pediatric Affairs Committee, the Education and Support Committee for the Executive Planning and Steering Committee, and chair of the Missions Committee for the Carolina CCFA chapter. She has also served as a volunteer physician for our Camp Oasis program.

Ms. Arnold is a clinical social worker at the Center of Inflammatory Bowel Diseases at Children's Hospital in Boston. After graduating from the University of Michigan, Ms. Arnold completed her Master's degree in Social Work at the University of Chicago. Her medical social work career has always been in pediatrics and chronic illness, with a focus on family systems. She has served on the CCFA's Pediatric Affairs Committee and Professional Education Committee and has been involved in task forces focused on advocacy, transition to adulthood, and educational programming. She is currently a member of the New England CCFA Medical Advisory Committee and also serves as a voluntary health clinician for the CCFA Camp Oasis program.

Thank you both for joining us today. We will start our program with Dr. Kim's presentation.

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Presentation

Sandra C. Kim, MD

Laura, thank you so much for that kind introduction. I want to welcome all the webcast participants tonight. I am absolutely delighted as a pediatrician who cares for kids and teens with Crohn's that there are so many people who are actively interested in participating tonight. My hope is that with this talk that I can at least give you a global perspective of some of the things that are so crucial for our understanding in pediatric and adolescent Crohn's disease.

I would like to talk a little bit about the differences between children and adults who have Crohn's, and talk to you about overarching principles when we discuss and carry out management for the children who are entrusted to our care with Crohn's disease. Then, I will end my part of the discussion with growth and developmental issues that I think are unique to children that our adult counterparts do not have to actually deal with nearly as much. Then, my wonderful collaborator on this webcast, Janis Arnold, will end by talking about quality of life and psychosocial issues associated with Crohn's disease.

The first thing that I want to do is just define Crohn's disease, and if you all will just bear with me. As many of you already know on this call, Crohn's disease, along with one of its sister diseases, ulcerative colitis, are inflammatory bowel diseases. Crohn's disease is a chronic recurrent disorder which involves the entire gastrointestinal tract. When we say that, it can be anywhere from the mouth to the anus. When I bring that up and I say chronic and I say relapsing or recurrent, folks hear the word "chronic" and they think that this is something that is fatal and it's not, but we do say chronic because there's not a specific cure. But as we'll discuss on the duration of this presentation, we'll talk about some of the ways that we can approach this.

For Crohn's disease specifically, it most commonly affects the small intestine, especially a distal part or the end part of the small intestine known as the ileum. Especially in younger children, the presentation often will encompass the colon causing colitis as well. When folks hear colitis, you hear the words ulcerative colitis versus Crohn's and colitis simply means that you have Crohn's disease but you also have inflammation of the colon.

We say that the peak onset is really in the first to second decade of life, so we say 15 to 30 years of age. But what a lot of folks don't realize is that we used to see Crohn's disease as an adult disease, but the reality is 10% to upwards of 25% of all patients who develop IBD will have developed it before they turn 18. There really is a growing component of pediatric disease with Crohn's.

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People always ask me, "So what causes Crohn's disease? Why can't you find the cure?" The reality is we don't know the precise cause, but with all the ongoing research that we've done as a physician-scientist community, we have pretty strong evidence that it's a combination of certain genes that increase your risk or susceptibility of developing IBD, but that in itself is not enough because we know that there are folks who may have these genes but they don't develop IBD, so it has to be something else. So, it's the genes, but it's also certain triggers in the environment or potentially normal bacteria that reside in your intestinal tract which, in individuals who don't have those risk genes, may not lead to IBD. If you happen to have one of those genes, you very well may develop IBD.

To explain this a little bit better, we talk about potential causes of Crohn's disease. There are different things that I'm going to address here briefly. One, again, are the environmental factors. When we say infectious agents, bacteria are one sort of category of "infectious agents." When I say bacteria, it's not like when you get food poisoning and something causes sort of an immediate infection that goes away. A lot of these are bacteria that normally reside in your intestinal tract. But in someone who is susceptible to developing IBD, there may be something about that bacteria or the individual's inability to effectively clear the bacteria that then leads to overstimulating the immune system that then subsequently leads to inflammation. So, that brings us to what we mean by immune cells.

Immune cells are white blood cells. We all have them, and white blood cells typically produce chemicals, what we call in the scientific world—cytokines. These chemicals cause inflammation and, to a certain extent, you need to have that ability to have inflammation. But when you have Crohn's disease, there's something that has not quite triggered the dampening down of that immune response. What happens is you get this trigger that may be a certain normal part of your gastrointestinal (GI) tract with bacteria. You stimulate the immune cells; they produce these chemicals or cytokines that cause inflammation; but then it doesn't come back into check. And that's how you develop inflammation and the symptoms that are associated with the Crohn's flare.

It doesn't just often affect the intestinal tract. And as many of you know, with Crohn's disease, you not only have inflammation in the intestines but can also have inflammation in other parts like your joints, skin, your eyes, or even your oral mucosa which means your mouth; you can develop things like mouth sores or mouth ulcers.

People ask us all the time about genes. "Is there that one gene that if I could just be tested for that I could determine whether my child will get Crohn's or if my child's brothers or sisters will?" The

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reality is that there are over 120 genes associated with either Crohn's disease or ulcerative colitis so we know that it's not just that one gene, and these different genes can be put into broad categories. Some control your ability to clear bacteria; some control your ability to control that inflammation that I just talked about. What is really going to be crucial for all of us is to be able to identify the relationship between certain genes and certain bacteria. The hope is that we can increase our understanding and develop new treatments that target specific pathways that involve these genes and the inflammation that may develop if certain things are overstimulated or go awry. Again, we're going to talk a little bit about research and why this is so important and what directions we're going with some of the things that we talked about.

My next slide is always one of my favorite slides as a pediatrician. I always say, "Children with Crohn's do not equal small adults." And I say that if that was the case, I'm fairly petite myself being 4' 11" and I know that I'm certainly not a child although I am in pediatrics. But the reason I emphasize that is because we have to treat kids a little bit differently, although a lot of the treatments and medications we use may be similar to what we use in adults who have Crohn's disease. There are definite similarities between pediatric and adult Crohn's disease, certainly in terms of the overall process of inflammation and the subsequent GI symptoms you develop—things like the abdominal pain, diarrhea, problems with absorption, etc. Certainly, when we say extra-intestinal manifestations, that refers to inflammation in parts of the body outside of the GI tract—your joints, your eyes, and skin. All of that's very similar with what our adult GI colleagues see with their IBD patients.

But the things to really highlight in children that are different than adults, usually, children who develop Crohn's disease will often have more severe presentation. So, what do I mean by that?

One is the development of more aggressive disease phenotypes. So, what that means in real-life terms is that the types of Crohn's disease that children often develop are of more severe sort of manifestations; meaning the kids who develop what we call stricturing disease where things may get narrowed or scarred down, fistulas which simply means connections between the intestine to other parts of the intestinal tract or intestine to the skin, which we know can have often very difficult consequences clinically, and are very difficult to treat. We also know that children who develop Crohn's disease often have a greater progression to surgery because their disease is more aggressive and often medications, no matter which medications that are used, are just not enough to quiet down the more severe flares.

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Things that are even more unique and which will be really the focus of the end of this part of the webcast are the growth and pubertal issues associated with Crohn's in children and teens which adults do not deal with because, obviously, they've already gone through the growth and the pubertal stages, and finally, the psychosocial impact, which Janis Arnold will talk about after this first component of the medical and nutritional aspects of Crohn's, which I will cover in the remainder of my talk.

Regardless of the medication, let's talk about global treatment goals. When my families come in to talk to me, they ask me what my goals are. I always tell them that the overall goals have to be remission of the immediate symptoms and then maintenance to keep things quieted down. We can say that those are the overall goals, but to get to the overall goals we have to think both immediate. So, again, with that immediate flare, we want to suppress that inflammation, that swelling in the lining of the intestinal tract that causes all the symptoms, so that we could, hopefully, heal that lining or mucosa, and by doing that, lead to the decrease or, eradicate and alleviate of the symptoms that our kids who have Crohn's develop when they have inflammation. But that's not enough.

Our continued goals have to be then to prevent relapse of the Crohn's disease, avoid the complication of disease and inflammation that's not under good control, and restore and maintain normal growth and nutritional status which I think is one of the most crucial things that we have to do as pediatric gastroenterologists for our kids.

The ultimate goals, I mean, I can talk about suppressing the inflammation and trying to prevent the disease relapse, but the treatment at the same time has to be reasonable, it has to be cost effective, and it's got to be doable for the kids and teens that we take care of; that's something we take into consideration. It has to improve the quality of life; meaning it doesn't matter if I look at some numbers and they look okay and someone's not having the symptoms of a flare, (i.e., diarrhea per se). If they don't have an appropriate quality of life, we haven't completely done our jobs as pediatric gastroenterologists. Finally, the hope is that we can alter the overall history of the Crohn's disease favorably. This, I think, is one of the toughest things that we are still facing.

So, what are some of the challenges? When we look at pediatric versus adult treatments, we know that there is similar effectiveness of the treatments that we use in kids who are also used in adults. A lot of you are familiar with the medications and I'll go over those in just a moment. The big thing though is unlike the adults, there are fewer children than adults relatively speaking who have Crohn's and, then, only recently have we had more pediatric trials. A lot of the treatments we have

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used, we admit, have been taken from adult studies. And at least past trials often did not look at more pediatric or child-specific outcomes like growth, markers of bone formation, or metabolism. But with time, obviously, as we go forward, clinical trials very much are addressing this.

This has really been helped by the recent mandates by the U.S. Food and Drug Administration that stated that drug safety and efficacy must also be studied in children and adolescents. One thing to remember, whether you're a child, teen, or an adult, is that medications are not "one size fits all" for multiple reasons. Not just in terms of just effectiveness of the medications, but also in terms of how easy it is to take. Depending on the age of the child versus the teen, there are some medications that are more easily taken than others and we have to take that all into consideration.

Finally, I'm just going to bring up what's at the back of most of your minds, the concerns of the medication toxicities themselves. What are the risks of malignancies meaning, quite frankly, cancers—people talk about lymphoma—life-threatening type of infections, and overall the impact on our kids as they approach adulthood, having been on these medications for some time?

Some of you may have heard these terms. If not, I'm going to just take a minute just to explain these. Many of us talk about different ways to approach how we treat IBD. You know, you can say that there is the "top-down" strategy, versus the "bottom-up" strategy. Top-down meaning you start with your more aggressive medications first to really rapidly get our kids' disease under control with the hope that we can help the quality of life. The flip side is the "bottom-up" strategy where you use more standard medications and then, with time, should you need to escalate therapy when disease becomes more severe, you move up the pyramid. In this scenario, you may minimize side effects, but the question is, are you potentially losing valuable time?

I will tell you that these strategies have really been developed in the adult GI world. I think in pediatrics it's a little bit tougher to make this an absolute. I think you really have to understand and tailor and really balance before you just assume that you will go one route or the other, and I think part of that is just understanding the severity of disease of the child that you are treating at hand and not just taking one approach versus the next.

So, in terms of medications, I could probably spend another hour or so going through every category of medication. Rather than doing that, there are some considerations that I want you all to know that we consider when we're healthcare providers and that you as parents and family members should all think about when you have that open dialogue. Remember that medications cannot cure Crohn's disease, at least not at this stage of the game. We also know that you may

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need more than one medication as well as adjunctive nutritional therapy at times to reduce the disease symptoms, and it may take a while to figure out which ones work the best. Each medication has both its risks and its benefits and really I say that the bottom line, you can go through the different types of medications versus nutritional therapy and some families will even say versus holding off and hoping that the disease goes away.

The reality is what you need to do is sit there and go through the benefits and risks with your healthcare providers and think about what the pros and cons are before you make the choice working with your healthcare team; I always tell folks that as family members, as caregivers. How do you decide? Remember, you have resources. Utilize your healthcare team. The CCFA has several brochures as well as the Information Resource Center. We have information not just for adults, but there are plenty of information materials for pediatrics as well.

In terms of the Internet, I always say, "Use it with caution." Just really being careful and making sure that what you look at you do in guidance with your healthcare providers to ensure that you're looking at the best evidence-based information possible. And, again, keep that open dialogue as you move forward.

I've been asked a lot about surgery, as have you all prior to this webcast. And, in fact, people have asked, "You know, with ulcerative colitis surgery can be curative but with Crohn's it's not. So should we just never do surgery?" The reality is surgery in certain scenarios is something that works hand-in-hand with the treatment of Crohn's disease. Epidemiologic studies, which means looking at a whole population of patients who have IBD, have shown that up to 80% at some point will have some form of surgery. The things that we would recommend surgery for are if you have that more complicated disease type that I talked about, stricturing that leads to an intestinal obstruction or blockage, medications are probably not going to help; if there's excessive bleeding that's not coming under control; if there's any type of tears in the intestine itself; if there are persistent fistulas or an abscess that's an infected area because of the fistulas with Crohn's, those are times that you really need to consider it. In a pediatric-specific way in children who are not growing because they have disease that is not under control and the doctors and surgeons know that there is a very specific area of disease that isn't responding to medications, that would be a scenario that you would consider surgery. And, again, and I'm going to emphasize this a little bit more in the final part of my talk, whatever we do as pediatricians using surgery judiciously, we cannot compromise the growth and nutrition of our kids.

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I mentioned a little bit about how we can't predict precisely how people are going to respond. I will tell you, as a pediatric gastroenterologist who has the privilege of caring for children and doing research, that if you look at this continuum here, basic research is what people do in the laboratory. Translational is taking what you do at the bench, so to speak, and moving it into clinical trials which then allow us to push forward and to, hopefully, improve how we care for children who have Crohn's disease. One of the very tangible ways that we're hoping that we can better predict how children will do is this incredible network with 29 pediatric inflammatory bowel disease centers in North America. We are looking at children at the time of diagnoses and looking at their genes, looking at the types of bacteria that they have in their GI tracts, looking at blood work for certain types of immune responses that children have, and we are following and seeing the type of Crohn's disease they develop and whether they develop any complications or not, with the hope that if we can understand how these all come together, we will be able to develop a model of better predicting which children will respond better to which medications.

So, I've sort of hinted at the last part of my talk throughout this presentation in terms of nutrition and bone health and so I just want to emphasize some key points when we talk about bone health and nutrition. One is that bone health is a really big issue. Children with Crohn's often have decreased bone densities which increases your risk for getting things like fractures, and that's really bad because I know the kids that I take care of are very active and athletic, and we encourage that, and we want to keep them safe and be able to do those activities. The reasons for having poor bone densities can be multiple factors including poor intake of things like calcium, vitamin D deficiencies, or decreased physical activity. Just inflammation itself, independent of all these things, can cause your bones to be a little bit weaker. We know that it's important that we really catch kids by their mid-teen years because this is when you maximize how you strengthen your bones as you accumulate calcium and other minerals in your bones to make them strong.

Growth is something else that I have really emphasized throughout this talk, and I cannot highlight this enough. Here you see what we call a growth curve, and for a lot of you who've been at your pediatrician's office, you know that your pediatrician and your peds GI physicians and nurses really focus on growth and how well you gain weight. This is an example of a child who was dropping off both curves, was finally diagnosed with Crohn's, and you can see when treatments were initiated and you can see how we were able to get his/her growth and his/her nutrition better. I always emphasize this because we know a lot of kids with Crohn's have growth issues both before and after they're diagnosed. We absolutely stress that the real goal has to be that we get disease as under good control as possible. When I talk about this growth window being so crucial, that growth window occurs as you enter puberty and we have to make sure that kids enter puberty

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doing well so that they can reach their adult genetic potential. I always tell folks that independent of other GI symptoms, growth is one of the crucial markers for how active the disease is in a patient with Crohn's disease.

There are different reasons here that I list include disease flare, the time from the actual diagnoses to getting treatment, where the disease is located—namely, in the small intestine there's going to be a higher risk—and, finally, again if you have to, not only intervening medically but making sure if need be intervening with our surgical colleagues to do surgery if necessary to ensure that the kids grow and get better appropriately.

And, again, we talked the same things that affect growth and bone health also affect puberty, as you can see. We really need to make sure that this happens. It's important medically. It's also important psychologically. We need to make sure that the kids do well. I always say that these are my overall principles in terms of growth. We want to make sure that we intervene medically and surgically and nutritionally before puberty starts if at all possible; we need to always re-assess how well a child is doing from a disease standpoint even if they're not complaining of GI symptoms, we work with our other colleagues like endocrinologists if we need to, and we want to make sure that we combine effective nutrition and medical therapy and decrease steroid use as much as possible.

Finally, with nutrition, I know this is a real topic of interest. It's important. I mean, you have to have good nutrition. When folks ask to define "diet" versus "nutrition?," I always like to say, "Diet is the nutrition," food you eat daily. Nutrition is how your body uses it." So making wise food choices can often help perhaps lessen the symptoms and may prevent disease flares. And when I say this, I always tell families, "Food did not cause you to develop this disease, but once you have Crohn's, especially when you're in a flare, we want to be judicious about the foods that your child may be taking in which may worsen symptoms."

Things that we need to remember are when you have Crohn's, you are at increased risk for having more malnutrition which then leads to growth issues for numerous reasons. One is just the loss of appetite because of the symptoms. You also have increased needs in general. When you have inflammation, your body needs more calories. And, finally, if you have inflammation, you're just not absorbing nutrients and digesting as well as you could be.

Just overall principles, you just want good nutrition so you can work hand-in-hand with the medications and make them more effective. You can have better healing, hopefully; boost the energy level so that improves quality of life. Often with right choices, you can prevent or help

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minimize some of the GI symptoms associated with the flare. Poor nutrition, obviously, leads to poor growth, poor hormone levels, especially in girls, and weaker bones. In terms of diets that people have asked about, I will just say that everybody is different. The biggest concerns are a lot of these, anecdotally, may work well for individuals and I am not discounting that at all. There are not really good evidence-based studies. I know that folks have certainly talked about the effects of diet and the claims are not covering overall populations. Most importantly, some of the diets, while they have some really good principles, are often so restrictive that they may not give enough calories and appropriate variety of nutrition, especially for children and teens who are growing. So, I think the best way to approach it is to talk to your healthcare provider and make sure that you address diet in a very effective way.

We included this slide for good nutritional choices for your reference. Same thing with this slide; again, this is not an absolute. In general, if you're having a flare, keeping on a more low-residue, less roughage diet will probably help with some of the pain and diarrhea, eating more frequent and smaller meals, and definitely adding nutritional supplements to replenish your body (i.e., vitamins) which you're probably not getting enough of. And, again, here are some examples of some low-residue foods you can refer to.

Here are different ways that we can provide nutritional support, not just as support but in some cases as primary therapy itself.

That concludes my portion of the webcast. Thank you so much. I am now going to turn over the remainder of the presentation to my colleague, Janis Arnold.

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Presentation

Janis Arnold, MA, LICSW

Thank you, Dr. Kim, for such comprehensive information. I, too, would like to thank the CCFA for the invitation and honor of contributing to such a vital program that appreciates the role of the psychosocial aspects of care.

When considering pediatric Crohn's disease specifically, we recognize that the medical demands come at a precise developmental time when relatability to others is often a primary goal. This can add an additional layer of quality of life considerations. Children and teens are still developing a sense of themselves both emotionally and physically, and so that in and of itself can be a difficult hurdle. Then when you add Crohn's disease on top of that, it poses an additional vulnerability to the sense of well-being or security.

Specific issues facing children and teens with Crohn's disease can include simply defining what it means to have a chronic illness, to figuring out how to trust your body, how to work this into forging it as part of your identity; coping with recurrent procedures, often invasive, sometimes violating; clinic visits and recurrent hospitalizations; and adhering to very complicated medical and dietary regimens which often brings with it often a loss of control. The quality of life and social interactions are impacted sometimes self-inhibited and sometimes inhibited by the disease pattern.

Body image and disordered eating patterns do become relevant at this point. There are many cosmetic changes that occur as side effects to the medications are noted. Given the anti-social nature of many of the symptoms of Crohn's disease, it can certainly impact the sense of dignity that a lot of our children and teens feel. The very nature of Crohn's involves the role of nutrition and food and that allows us to change the relationship with food that many of our children and teens experience. Foods can quickly become quite dichotomous, either all good or all bad, and this can lead to confusion and disordered eating patterns. There's a need for support systems both at home and at school given that these two main spheres that our patients navigate.

Children and teens with chronic disease and Crohn's disease are indeed at a greater risk for psychological stressors. I think it is important to note that this is not in lieu of resiliency or their own separate strengths, but we do want to be mindful of this because it would allow us to identify these risk factors and, hopefully, be proactive in our interventions. So, this could include low self-esteem and poor social functioning, and this is often because the Crohn's disease and the demands associated with it often remove the children and teens from their normal peer play and social

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arenas. So, there are not the same benchmarks for success or developmental milestones sometimes.

Mood disorders can also coexist with Crohn's disease. Sometimes these might independently precede the diagnosis of Crohn's disease and, therefore, impact the way the patient is able to frame the disease, and sometimes it can just be a direct causal comorbidity of getting the diagnosis.

We do know that children with chronic physical illnesses of many types have an increased risk of subclinical mental health problems meaning that it may not rise to the full threshold of a formal mental health diagnosis, but almost a quiet hum where some of these symptoms could slowly creep into quality of life issues. We also know that youngsters with IBD do have high rates of depressive symptoms when compared with youth without a chronic illness or even with other chronic conditions such as CF (cystic fibrosis) or diabetes. We do know that depression severity has been associated with IBD, physical severity, and the use of steroids. As such, the quality of life and support resources are key.

Psychosocial screening, and approaching assessment from a biopsychosocial model can sometimes offer a lens that best promote adaptation in the multiple spheres in which our patients are part. So this would include the biological sphere, which is really the disease activity. It's the level of physical functioning, the amount of visibility of the Crohn's disease, what I often consider the typography of their specific course. Has it been filled with many flare-ups? Has it escalated and plateaued?

The psychological sphere would include temperament, motivation, problem-solving ability, any pre-existing mood disorders, and the social sphere which would relate to school and work issues and peer networks; just the daily hassles that any child or teenager faces.

We would want to assess the psychosocial issues in addition to the medical issues really at every independent pediatric GI visit. This would include the general well-being, the energy level, the GI symptoms, the diet, and then move on to the emotional functioning no matter how long it's been since the time of diagnosis. We know that as kids grow up and go through different developmental stages, no matter how long it's been since they've managed the Crohn's, the new developmental stages can bring about new levels of anxieties or different self and body image issues.

The activities of daily living, having a sense of when school is becoming difficult, if there are hobbies that aren't being participated in or that are changing as a result of the Crohn's disease. What the day-to-day challenges are now. So I will often ask patients, "Now that's it's been a month

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since you've had Crohn's, now that it's been 2 years, now that it's been 10 years, what's the hardest part of this for you now and what's the easiest part of this for you now? Whether that's an answer that has stayed the same or there's a new challenge can help us guide quality of life interventions.

The medication regimens—we often hear about medication burnout or challenges to adhering to that plan and whether or not there have been any normal activities that have had to be abandoned.

And last, but not least, relationships. Kids so much relate to the peer networks at this stage and that's often the biggest influence in their sense of relatability and normalization. So, having a sense of where their friendship spans, who knows what about their Crohn's disease and how we can help them feel more comfortable about who knows what, and certainly, what their relationship with family members is.

When we screen patients to determine what their quality of life and support systems are, we want to know what the support network is of family members and friends, community members, the different peers of folks that our patients will use when they have various needs. We want to determine if there is a need for formal counseling or mental health treatment. Sometimes there's a lot of coping work to be done and sometimes it reaches a level where formal treatment is going to be what best allows goal setting and some cognitive restructuring of ways that they manage coping and reconciling this with their day-to-day needs.

Are school accommodations needed or in place and are the ones that are in place adequate? Does a child or adolescent need help with stress reduction? We do know that while stress does not cause Crohn's disease, that it can certainly precipitate a flare-up or perhaps even exacerbate symptoms that are already present during a flare-up.

Self-management—disease education and knowledge is key. If we're expecting our patients to make healthy decisions about taking medicines and do their own pro and con lists of why these decisions matter, we need to provide them the right education and information to fill in those lists. We want to encourage the use of resources that are age appropriate and available and review these educational materials with them together to really start to invite them into the knowledge base.

We help them learn the necessary skills, and those will change over time, too. At one point, it just might be knowing how to swallow pills, and then it might progress to knowing how to fill the pill box, and eventually how to refill a prescription. This all allows them to prepare for eventual independence.

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Education equity is a center piece of advocacy, and we can't talk about a pediatric condition without talking about school being the center point given that is where so many of our patients spend so much of their time. School advocacy can in and of itself be an intervention. It can often help reduce the anticipatory anxiety that our patients might feel worried about whether or not they will have the accommodations that they need in a school building.

Thankfully, there are laws to help protect this. The Section 504 law is probably the most helpful one to know about and this is an excerpt from the relevant portion of the law. It says, "All qualified persons with disabilities within the jurisdiction of the school district are entitled to a free and appropriate public education." This defines a person with a disability as someone who has a physical or mental impairment which substantially limits a major life activity.

So, for the purpose of Crohn's disease, that major life activity involves bowel function and digestion and regulation of the immune system. If a student is at a public school, then having the diagnosis of Crohn's automatically qualifies them for a 504 Plan. This is different than other educational plans that might address learning vulnerabilities. A 504 Plan is really specifically to address the medical vulnerabilities. The idea is that we want to look at how the Crohn's is affecting access to the curriculum, performance, things like academic competency measures, and ultimately the emotional comfort in a school setting which we know does affect readiness to learn.

So, at the time of an initial diagnosis, if a family is comfortable alerting the school, which we would certainly encourage, then there are some key collaterals that are good to inform because they all serve a different role in the school system. The school nurses, obviously, because they are going to be best positioned to monitor some of the symptoms. The guidance counselor is often the best broker on the school side to adjust schedules and assignments. The school social worker or adjustment counselor is very helpful in terms of monitoring some of the peer and social implications. The teachers are the ones who we need to directly honor these accommodations in the buildings, and the administrators are the ones who really have the authority to authorize the accommodations.

The accommodations can't be granted without a piece of medical documentation and so a letter from the physician's office that establishes eligibility and outlines the diagnosis is critical to setting the wheels in motion. It may not be exhaustive, but it needs to have a platform of why a student would qualify for this. This would include the definition of Crohn's, the associated symptoms. It would emphasize that this is a remitting and relapsing condition and is not linear, it is not progressive, and that's something important for a school to know.

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For the home tutoring option, many schools require a number of consecutive days of absences to be eligible for tutoring and it's not the way that Crohn's presents often. We know Crohn's can be quite cyclical and absences can be cumulative but still interfere with access to a curriculum.

Gym considerations—someone has the stamina to get to school but perhaps not the stamina to participate in gym, and emphasizing the mind and gut connection. The role that stress and anxiety can play so that the school is aware of academic anxieties that might contribute to symptoms.

Requesting a 504 Plan should typically be in writing in addition to a phone call. I think documentation and paper trails are always important because many additional collaterals start to get included. It would include the initial letter from the physician's office and it would lead to a meeting. Ideally at the meeting would be any of the caregivers, the patient themselves, if age appropriate—middle school or high school—the school nurse, an administrator, a vice principal perhaps, and the guidance counselor. They sit, and you, essentially, come up with a list of accommodations that get typed out and become the 504 Plan. If you're in a private school setting, it's often called an individualized health plan. The same laws don't automatically apply, but some of the same accommodations certainly should because they're all the same means to an end.

Sample 504 Plan accommodations can range from things that are environmental in nature—moving about the school building—to things that are academic in nature—protecting performance. So, these are a list of potential examples: anytime bathroom passes; nurse's office passes; nurse's training for medication administration like injections; being able to eat or drink in class if increased appetite or dry mouth is a side effect of a medication; stop-the-clock testing so that if there is a timed test or a state-wide test and a student has to use the restroom, that the time that is allotted for that test stops until they returned from the restroom they're not in the position of being penalized for listening to their body; postponement of cumulative grades if they've missed work related to Crohn's; seating charts that allow them to have easier access to the door; an extra set of books if bone issues are an issue; increased time between classes; copies of syllabi and lesson plans if they've missed coursework; permission to Xerox class notes; the tutoring piece that might kick in prior to what the district's prolonged threshold of absence is; and then access to field trips and transportation through their own means. Many schools have rules that you have to take school-sponsored transportation and we have many students who feel that they need an exit strategy, understandably, and then might be told that then they can't participate on the field trip. We want to make sure that they have access to that which they would be entitled to if they didn't have Crohn's. These are equal rights and not special rights.

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So, the take home tips are really to prioritize what the accommodations are that feel relevant; to advocate for what a student is entitled to; to communicate with the staff and all of the relevant collaterals; to maintain a very collaborative tone and remember that these are people and educators who are going to be involved with our patients and children; to ask others for help when indicated; to maintain the relationships with the key staff; to keep that paper trail so that we're all clear on what was agreed upon; to educate yourself as caregivers and families about what the student's rights are; and to be very willing to educate others. My experience is that schools want to help. They often just don't know how to help. The goal is that the patients and the students with Crohn's, their health, and their academic success should really never be mutually exclusive.

The Family Medical Leave Act is another federal law, and this is almost an insurance policy for parents. This is a synopsis of the law. The most relevant bullet point here is that it applies to time off of work to care for an immediate family member with a serious medical health condition. This is something that parents can potentially qualify for based on some eligibility, which includes having been at a place of employment for over a year, and the company must have a certain number of employees within a certain radius. It's paperwork that is obtained from a human resources department and it affords parents time off with job protection to be able to care for their child with Crohn's disease.

The benefits of this are indeed the job protection piece, the fact that you could continue to accrue benefits while you take the time off, and that it need not be used consecutively. So, you get three months off and it renews itself every year and those three months don't have to be used consecutively. You could use a day here for an appointment or a day here for an infusion, or if there was an unexpected hospitalization, you could use many days at a time. The downside of Family Medical Leave Act is that it is unpaid leave.

Children and teenagers with Crohn's disease grow up to become adults with Crohn's disease. We certainly want all of our patients to grow up to become successful and productive adults, and self-management of their medical care is no exception. It's important to recognize that transition is really a process. It spans, ideally, many years. It sends a message of empowerment and initiative to our teens; it sends a message of optimism to young adults about their capabilities; and it imparts confidence that the patient is going to be able to manage access of care in the adult healthcare system, whereas the transfer of care is really the culminating single act of this transition process.

There do seem to be some common and distinct differences between the pediatric and adult healthcare systems and providers, and I think it's sometimes helpful to note these cultural

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differences. Neither is better or worse. There are just some differences, and it can sometimes be striking if you spend years in a pediatric culture of medicine and you transition to an adult center.

The pediatric teams are often multidisciplinary; whereas, the adult teams are often focused with just one single MD (medical doctor). In a pediatric center, you often get many allied health professionals, including nurse practitioners and social workers and dietitians. In the pediatric setting, it's often family focused. I think we probably all agree that childhood Crohn's disease is, indeed, family Crohn's disease, whereas in the adult setting it is patient focused.

The pediatric culture can often feel protective whereas the adult culture is collaborative. The pediatric setting really focuses on parental responsibility, understandably, and the adult setting has an expectation of autonomy from the patient. The pediatric setting does often adapt and adopt the biopsychosocial model and it's very generalist and social focused, whereas in the adult setting sometimes you have it just focused on the Crohn's disease.

The goal of transition is really to make sure that there is uninterrupted care, coordinated care and this is a position statement that was put out. There are a couple key words in this which really are continuum, normalization, development, and acquisition, indicating that there is really a graduated increase in patient responsibility for managing his or her disease. We also want to make sure that there's not a sense of abandonment for a patient who's perhaps been under the care of the same medical team for quite some time.

The developmental framework for transition plans typically mirror the stages of development. These stages are commonly accepted to be chronological age, but we recognize that it's not always so linear. Some of the skill development includes communication, resource gathering, decision making, self-care and self-advocacy, assertiveness, and self-determination. But when you're looking at a transition plan, we do take other things into account (for example, emotional maturity, medical status.) It wouldn't be ideal to plan an ultimate transfer for a time of medical instability, and also the emotional readiness of a parent or a caregiver [should be considered].

There are some fundamental principles of transitioning. We want it to be a flexible process, take into account some of those variables of maturity and medical status and readiness. We want it to be responsible and deliberate so that there is a designated proactive healthcare provider who does encourage this dialogue. Written so that it doesn't feel arbitrary, where you really have a sense from the family and from the medical team when this is going to occur and what needs to happen for it to occur successfully. Timely in that the initial discussion and introduction happens during

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adolescence so that there's time to achieve these goals and master these competencies for self-management. And planned, so developing a plan for what'll happen at 18. For many people, age 18 is really just the initial signal and legal benchmark of a shift of responsibility and then it allows us to carry on and determine what role the parents, the patient, or the healthcare provider will have after that point, determining whether we'll complete transfer during or after college or after employment is stabilized, if they're going into the workforce.

This is a busy chart and it's really just a take home matrix that shows an overlay of the number of behavioral measures, skills, initiatives, and tasks that might allow for healthy decision making with the targeted age ranges for gradual shifting of responsibility. So, on the left what you have are some of those behavioral measures, as you move across the chart, you'll just notice an expansion upon some of the layers of the tasks or the knowledge base.

Ideally, the milestones in transition readiness would allow us to start to approach a successful transfer and would occur in concert with one another. So, this would include knowledge of the specific type of illness; the disease location that our patient has; their own understanding of medications; and side effects, what they are, why they're indicated, how long they've been on them.

Adherence to a treatment plan or the ability to problem solve when they are not able to be consistently adherent to a treatment plan; awareness of appropriate nutrition and its vital contribution to overall health; being prepared with self-management skills; being informed about relevant reproductive health issues, transition to a college or workplace setting, insurance details that certainly impact access to care; networks of ongoing adult support; and concrete plans for locating an adult healthcare provider and the pediatric team is usually quite involved in that step.

There are a number of support resources that are available for the various branches of these psychosocial issues. This is a list of educational resources and, again, these are take home resources for you to be able to use and facilitate any of these goals. This will help identify what some of the national benchmarks are for folks with chronic conditions to be able to enter post-secondary education settings and get the services they need in primary schools.

The last bullet point is an example of a 504 template for students with IBD, and I do just want to mention the organization itself—Advocacy for Patients with Chronic Illness—is an extraordinary nonprofit organization that helps with a range of advocacy issues, employment advocacy, educational advocacy, insurance appeals that can help promote access to care.

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Peer and family resources—a site for teens by teens that talks teen speak, and then can certainly increase validation and normalization, a number of support groups that exist, one-on-one support groups and parent groups, the camp that's been mentioned that is a CCFA-sponsored camp for kids with IBD, and this last website is a website that will help kids who are college bound or employment bound dealing with many of the launching topics, logistics of graduating out of parental care.

There are a number of financial, legal, and medical resources that speak to transition from school to the workforce, from high school to college that explain the socio-legal precedence that exist that protect people with Crohn's disease. In addition, there are a number of financial resources that exist that offer copay assistance, that offer patient-assistance programs for certain medications. Most pharmaceutical companies offer those and most states through their Department of Health and Human Services do offer some sort of relief refund reimbursement program. These are all really just an additional level of concrete resources that would facilitate access to care and, ultimately, the ideal health related quality of life for the child and the family who's managing Crohn's disease.

Thank you for your time and we look forward to answering your questions during our Question-and-Answer Session.

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Question-and-Answer Session

Laura Wingate

Thank you, Dr. Kim and Ms. Arnold, for sharing your insights. We will now begin the Question-and-Answer Session. Our first question is from the Web.

Dr. Kim, what criteria do you use to measure the risks-benefits of biologics versus surgery? Do you feel enteral nutrition is currently underutilized in the treatment of children and adolescents with Crohn's?

Sandra Kim, MD

That's an excellent question. In terms of risks and benefits of medications in surgery, I don't have a specific algorithm. Rather, what I do is discuss, first, you have to assess the situation. When we say surgery, in Crohn's disease especially, are we talking about specific localized disease, are we talking more diffuse inflammation? Secondly, before we just jump to surgery, reminding everyone that, again, surgery is not curative for Crohn's. You want to know that you have tried the medications and/or potentially nutritional therapy, depending on the specific clinical situation, before you just automatically move to surgery. This is something that I have, personally, a discussion with each of my families weighing the risks and benefits, depending on the individual child.

In terms of enteral nutrition, I will say that, traditionally, it has been underutilized to a certain extent in the sense that in this country there aren't as many centers that have the whole multidisciplinary team, nutrition, psychology, and the peds GI physicians as well. I will tell you that, certainly, there is definitely an increase in different colleagues of mine throughout the country in terms of utilizing enteral therapy as a potential viable option. I, myself, do use it and find that I am using it more. There are preliminary studies from different countries outside of the U.S. that show that there may be a role for this and, certainly, we know from the experiences from a single center at the Children's Hospital of Philadelphia that there's definitely a role for enteral therapy as an option, especially in children with Crohn's disease who have small intestinal disease who also have growth and/or nutritional issues that it should at least be part of the discussion.

Laura Wingate

Thank you, Dr. Kim. Ms. Arnold and Dr. Kim, this question I'm going to pose to both of you. Should a child who is almost 18 years of age use a pediatric or adult gastroenterologist?

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Janis Arnold, MA, LICSW

I think that there are a couple more things that I would want to know. I'd want to know how long it's been since the time of diagnosis, if the diagnosis is coming at age 18 or if they've had it for a number of years; and I'd also want to know what the additional social environment is at the time. We would want to take into account whether or not this is an 18-year-old who's still graduating high school, is about to go to college but not necessarily in a city where they will settle permanently. And I'd also make sure that we have a good sense of where their growth status is because a pediatric gastroenterologist will still probably have a heavier focus on that piece of the medical care.

In my experience, age 18 is something that we still very much care for in the pediatric system with a very directed and goal-oriented plan for transition work and a targeted date and age of ultimate transfer.

Sandra Kim, MD

I have to totally agree with that, and I will add as well. What we have found is that, as a healthcare society in pediatrics, we are focused on transition. We could do even better. For example, what we are now actively doing is starting the transitioning process in those for whom we have followed for some time at the age of 13. Transitioning 17- or 18-year-olds who are about to embark on a different phase of their life—whether it be the workforce or college—and they're expected to gain many other skills abruptly and we have not asked them to do things independently—whether it's making appointments, filling prescriptions, knowing who to call when there's a flare, how to approach getting laboratory work. I mean, we can say that 18 technically means you're an adult, but we have to look at both the emotional and cognitive readiness as well as the absolute chronologic age.

Like Ms. Arnold's group in Boston, we take an approach that even though we do follow our young adults through at least part of college, we do have a very focused plan in terms of when we will start transitioning their care to an adult gastroenterologist. We also like to identify ahead of time where they may be so that we can start contacting the adult gastroenterologist so that we can better facilitate care rather than just abruptly moving them to a new system and physician.

Laura Wingate

Thank you. Operator, we'll take our next question from the telephone.

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Operator

Our next question is from Nancy in Wisconsin. Please proceed with your question. Your line is live.

Nancy

Well, thank you. I actually have a double question. I was wondering about what you knew about 6-MP as a treatment and the side effects. And the other thing was about human growth hormone for children between 11 and 13 years old.

Sandra Kim, MD

In terms of 6-MP or 6-mercaptopurine, and sort of the related medication which we know as azathioprine, which is the generic, if you look at evidence-based medicine, certainly in the adult population and even in pediatrics, that when you use 6-MP or the associated counterpart medication, azathioprine, it can help actually decrease the relative need for prednisone or other related steroids, which is really important because we know that often we are forced to use steroids to take care of the acute flares when they can't come under very good control. But there are so many detrimental effects of steroids, namely, on growth as well as other effects on mood and wound healing and the like. Certainly, there have been pediatric studies. One of the first studies, actually, that looked at the ability of 6-MP to minimize steroid exposure was not done in adults but it was actually done in pediatrics back in 2000 by Dr. Jim Markowitz's group in Long Island.

When you look at the newest guidelines that came from the American College of Gastroenterology, they actually looked not only at small trials, but they did an overall overarching comprehensive review looking at recommendations for therapy, looking at it from an evidence-based medicine standpoint. We certainly know that you don't use azathioprine or 6-MP for immediate induction of remission—meaning if you have a bad flare—but in terms of maintaining to, hopefully, prevent further relapses. The best evidence would be either for azathioprine or 6-MP, as well as other medications including anti-TNF agents which would be infliximab and related medications, as well as methotrexate in individuals who have had problem with azathioprine or 6-MP.

In terms of growth hormone, there certainly have been smaller scale trials that have looked at the effects not only on the ability to induce remission but also to help growth, so, sort of a two-pronged effect. Obviously, larger scale studies are going to need to be done. The two most recent studies, one came from the Cincinnati Children's Hospital Medical Center Group, that was led by the senior physician, Dr. Ted Denson. Also, Dr. Mel Heyman from the University of California at San Francisco has looked at growth hormone as well. Studies like the risk stratification research project

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that I had mentioned before are going to be important to pinpoint which children could potentially respond to which medications. Growth hormone could be one of those, whether it's a main medication or used adjunctively.

Laura Wingate

Thank you, Dr. Kim. The next question will be from the Web. What problems generally occur after a Crohn's patient has undergone a J-pouch procedure?

Sandra Kim, MD

I would say that the J-pouch would be more for ulcerative colitis rather than Crohn's disease. I will answer the question just in broad terms, not specifically with Crohn's disease, but with someone who has had a colectomy with a J-pouch.

The biggest thing is something called pouchitis. That basically means chronic, low grade inflammation in the pouch. The pouch is basically created by the surgeons as a reservoir forming a pseudo-rectum in essence. And a lot of times you can have this chronic, low grade inflammation that can manifest by symptoms such as diarrhea. You work very closely with your pediatric gastroenterologist. They may or may not opt to take a look to make sure everything looks okay. They may prescribe antibiotics. Depending on which studies you read, I will tell you the combination of studies that have looked at pouchitis as well as my own clinical experience, usually about a quarter to a third of patients will develop at least some incidence of pouchitis, maybe slightly higher.

But, again, I think in terms of this, this is something that we deal with really predominantly more with ulcerative colitis. But, again, I was answering the question as related to pouchitis in general.

Laura Wingate

Thank you. Operator, we'll take our next question from the phone.

Operator

Our next question is from Sharon in Ohio. Please proceed with your question. Your line is live.

Sharon

Yes, thank you. One question I have is probiotics, do they play any part at all in helping with Crohn's?

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Sandra Kim, MD

I think that's an excellent question. I will tell you it is a subject actually near and dear to my heart. Besides being a peds GI physician, I also look at the role of bacteria, both aggressive and more protective bacteria, in the GI tract.

The reality is the theory behind both probiotics and prebiotics, which are sort of food products that help maintain more of the anti-inflammatory types of bacteria, certainly from a theoretical standpoint and from some trials, suggest that there may be a role. One of the theories, and I briefly touched on this, is that part of the reason children and teens develop IBD is that there may be mis-skewing of the balance of more of the aggressive bacteria in the GI tract and more the protective or probiotic strain. The thought is if you can give probiotics and prebiotics, you can help skew that balance somewhat. So it's, obviously, not going to be curative, but that may be something that you can use as a complementary or adjunctive treatment. It's not something that I would say would be the primary treatment, but certainly adjunctively. In certain children and teens, it's not unreasonable.

The individuals where probiotics have been shown to have some actual evidence-based clinical effect are those who've already undergone what we call a colectomy and develop pouchitis, which was what I was just talking about. Still more studies need to be done. There clearly isn't evidence-based medicine that supports one specific bacterial strain, but that's one of the things that we are looking for, not only the overall concept of probiotics but identifying potential bacteria that could be effective probiotic strains.

Laura Wingate

Thank you, Dr. Kim. Ms. Arnold, this is question is for you. What is the medical community doing to teach children to take medications on their own?

Janis Arnold, MA, LICSW

That's a great question and a necessary one. I think it's two-fold. One is making sure that the children are understanding the pros and cons of making the decision about taking medicine, making sure that they understand the risks of not taking it and the benefits of taking it, in terms of their own self-interest. Not necessarily the cost-benefit analysis we, as adults, have for when they're 20 and 30 but putting it back in terms of how it impacts their day-to-day life.

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The other thing is behavioral tasks that get very concrete. Making sure that the kids know how to swallow pills and doing a lot of work on pill swallowing, knowing how to fill a pill box. These [are] behavioral measures that indicate their readiness to take more responsibility. Things like setting a cell phone alarm or a watch alarm that prompts them, or coming up with an idea of a visual trigger, determining whether or not you put the pill bottle next to your toothbrush or put a Post-it Note in your shoe before you leave, but something that gives them the prompt and allows them to then take the responsibility for the act of taking the medicine, which then imparts and increases confidence that they are capable.

Laura Wingate

Thank you. I have one other Web question that I think you would be best suited for. If your friends keep asking you, "What is wrong with you?" What do you say? What would you recommend?

Janis Arnold, MA, LICSW

That is a great question and there are many ways to answer it, and your personal and private health information should be just that. My experience is that most children and teens care about two things: they want to know if their friend is going to be okay and they want to know if it's contagious. Often, giving broad and general information that answers and addresses those two questions is probably enough, and that remembering that people don't know what they don't know. So, sometimes something very casual. "It's a stomach thing. The doctors are on top of it. I'm going to be fine. It's not contagious." Right there the tone is casual. The word "thing" is much more casual than the word "chronic illness" or "disease." The stomach is a much better known organ than the intestine or the bowels, and it really ends on a note of making sure that the friend or peer knows that they're going to be just fine at the end of the day and that it's not something that they can catch.

Laura Wingate

Our last question for this evening is from the Web. I'll give this to both of you to address. My 3-year-old has mild CD. What are the next steps to help him understand and address his nutritional needs and help him outside of his flares.

Janis Arnold, MA, LICSW

Okay, so that's difficult and I think we want to make sure that we put the developmental stage at the priority of the information relayed. We want to make sure that we're just giving the 3-year-old information that he or she can use. Most of the information that we know about the reasons of

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indications for the nutritional status are not going to be information that the 3-year-old can use. So, we want to probably keep it short in terms of time span of why something has to be done and use some negotiation and have the 3-year-old have some participation in the selection and choice process so there's some sense of control, which is pretty central to that developmental stage of individuation.

Sandra Kim, MD

I have to agree. I do actually have children who are under 3 whom I care for. I always work with our psychologists and our recreational therapists to explain things in very plain terms. I will communicate with the families what the overarching plan is; but in front of the child, we will let them know what things are happening, why we get blood. So we'll say, "We are taking blood," for instance, "because we want to make sure that everything is okay because you're not feeling well," rather than going into a long and much more detailed explanation.

I think with nutrition what I have found is that food—more so than medications, more so than labs that is one area of control—is not just a matter of nourishment but also pleasure for these children. So, while we try to discuss why we are limiting foods, we always work very actively with our nutritionist to ensure that we are not allowing the child to feel that they are being completely deprived. Really, it's making sure that they see a friendly face, making sure that when their anxiety is there that we work very closely with our psychologists and with our child life or recreational therapist and making sure that while we involve the parents and they know every step, that we are very careful about not overwhelming the child. I mean, the child is only 3 and we have got to respect that.

Janis Arnold, MA, LICSW

If I could just add one thing to piggyback onto what Dr. Kim was saying that would apply to other ages right around this developmental stage. Sometimes the use of metaphor can be really helpful when we're talking about explaining this on a level that they could understand and identifying perhaps a superhero or a cartoon that they watch and relating what they're doing or what they're fighting or why they're having to make some of these decisions to get blood drawn or to have nutrients delivered to areas of the body. For example, if it's a 3-year-old who watches *Thomas the Train*, using a metaphor of what the train delivers to what the nutrition delivers can be really helpful to have them get behind and get on board, no pun intended, with the plan.

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Summary and Conclusion

Laura Wingate

Thank you, Dr. Kim and Ms. Arnold, for your insightful presentations and the answers to our questions. On behalf of the Crohn's & Colitis Foundation of America and everyone on the phone and on the Web, we would like to thank you for all the work that you do every day to support patients and their families who are touched by Crohn's disease.

To all the patients, caregivers, and family members on the line, if your questions were not answered, you can call the Crohn's & Colitis Foundation of America's Information Resource Center. That number is 1-888-694-8872. The center is available to assist you Monday through Fridays from 9:00 AM to 5:00 PM Eastern Time.

We also want to give a special thank you to Centocor Ortho Biotech for their support of today's program.

I encourage all of you to complete your evaluations for this program. Your feedback helps us shape future programs by selecting topics and making them meaningful for you.

On behalf of the Crohn's & Colitis Foundation of America, Dr. Kim and Ms. Arnold, thank you for joining us.