**Donna Gabriel:** Welcome everyone and thank you for attending our program today where we are going to explore the use of mindfulness meditation to enhance well-being for people living with short bowel syndrome and their caregivers.

Today, I have with me Dr. Marion Winkler, who is professor of surgery at the Alpert Medical School of Brown University and surgical nutrition specialist at Rhode Island Hospital. We also have Dr. Jeff Brantley, who is professor emeritus in the Department of Psychiatry and Behavioral Sciences and founder and former director of the Mindfulness-Based Stress Reduction Program at Duke Integrative Medicine.

We are also excited to be joined by Andrew Jablonski, who is founder and director of the Short Bowel Syndrome Foundation and also a person living with short bowel syndrome. Thank you all of you for joining me today.

My first question is for you, Dr. Winkler. A big area of focus right now in short bowel syndrome is on quality of life concerns for both patients and caregivers. When we use the term “quality of life,” what exactly do we mean by that, and what are the biggest challenges that you've seen with your patients and caregivers in this area?

**Dr. Marion Winkler:** Quality of life is really a very subjective term and all of us may define quality of life very differently. There's many different factors in each of our lives that could influence quality of life, both positively or negatively. In my research, looking at and interviewing patients on home TPN who have short bowel syndrome, they define quality of life as how much they enjoy life and being happy and satisfied with life, and being able to do the activities and participate in events that they are really desiring to do.

Many home TPN consumers described being hooked up or tied down to the equipment, but they balanced that with the energy, and the strength and stamina, and the feeling of health that they get with the nutritional therapy. They feel better and are able to participate in those activities, going to work and traveling, or going to school and being able to do those desirable activities. One thing we know is that diarrhea and pain really influence quality of life. Those are two very, very strong factors that people living with short bowel syndrome usually talk about.

Caregivers and family members also sometimes feel some guilt about eating in front of people who may have difficulty eating. There's also dependency and sometimes these caregivers also avoid their own health and well-being because they're busy taking care of others. Sometimes there are also worries about complications or fear of infection, or even finances, and other things going on in life that could impact quality of life negatively. One thing for sure, I think to overcome all of this is to be able to define your quality of life and share your personal definition with your physician and your healthcare team.

**Donna Gabriel:** Thank you, Dr. Winkler. Andrew, I would like to turn to you. As someone who is living with short bowel syndrome, what factors influence your quality of life the most?

**Andrew Jablonski:** I would say that mental health factors, financial factors, and isolation factors play into my situation per se. Also, I have daily distrust and fatigue, just from being out and doing things that I am doing, like going to Target, going to different appointments during the day, walking around all day. It takes a toll on the body; it makes me fatigued. I pretty much crash early at night and I wake up early in the morning, but in between those hours, I have lots of sleep deprivation. I'll get up between the hours like two and four and have restless sleep and get on my computer and play around for a bit, and I'll fall back asleep until seven. Then I’ve got to get up and do my daily routine.

Then, finally, the financial and economic strain are the real thing. I'm not made of a lot of money. I need economic assistance from the state and from my parents to survive. What I do, doesn’t make a lot of money at all, so I definitely feel that factor as an adult rather than when I was a kid. Isolation, for me, it would be the main thing because even without being on TPN, there’s isolating factors that come with short bowel syndrome.

**Donna Gabriel:** To your point, Dr. Winkler and Andrew, this is a lot to carry for both patients and caregivers. Thank you for that perspective, and Dr. Winkler, what unique challenges do children and adolescents face?

**Dr. Marion Winkler:** Well, interestingly, in a lot of the research, children if they're asked about their quality of life, describe it much better than their parents or their doctors actually perceive their quality of life to be. I think that may be because some children just have only grown up living with the short bowel syndrome condition and/or living on TPN, so they get used to it. One factor that does get in the way of activities is the equipment, having a central line, having to be connected with the pump, and being on a schedule.

Oftentimes, that could interfere with things like sleepovers, or going to school, or going to participate in sportactivities, or even traveling, but always, there are strategies and resources that can be used to balance those activities with taking care of TPN and the medical condition very safely. A lot of effort will be made to try to help children and adolescents take part in the activities they want to do.

**Donna Gabriel:** Got you. Andrew, can you speak on some of the challenges you faced when you were growing up as someone living with SBS?

**Andrew Jablonski:** When I was teenager, I was very healthy for my age and for what I had. I was able to do some sports such as baseball, basketball in grade school. I did cross country my freshman year of high school. I have always been able to travel even with TPN. Truth be told, even when I did travel, I would ditch it at home for a week with my doctor's permission. That way, I didn't have to go through the airport trouble. When I drove, I always took it. I always went to sleepovers as a kid. I usually hosted the sleepovers, though, because I had urinary incontinence and no one wants to pee at their friend's house on the floor—it's true.

School attendance and learning: school attendance, I had relatively good school attendance. I didn't like missing school. In fact, there were many arguments with my parents about missing school, where they would have to block the door to keep me from going because I was too sick. But learning—missing school could affect that, and could often turn into learning disabilities. Common factors are speech, motor skills, and social skills. All of those play into the school environment factor, and usually, some support is needed for one of those three things.

**Donna Gabriel:** Andrew, did you ever experience or see maybe the child you're caring for experience any social anxiety or bullying or anything like thatbecause of...

**Andrew Jablonski:** Oh, yes—the bullying for sure. Fifth grade, they almost kicked him out of school because he was bullied and he stood up for himself and it was his word against the other kid. There was some bullying fifth and sixth grade; he's in eighth grade now, doing very well, but overall he hates missing school.

**Donna Gabriel:** Okay, thank you. Dr. Winkler, so for people who are not as resilient as Andrew, who might be experiencing some challenges in managing this process? What do you recommend to help enhance their quality of life?

**Dr. Marion Winkler:** I think there are a number of things individuals can do. First and foremost, I think it's important to describe in your own words what makes quality of life good or bad. That way, we as healthcare team or other peer support can help guide the person or reach out with some strategies to improve quality of life. Some excellent resources are to find other people in similar situations, and great options here are the Short Bowel Foundation, the Oley Foundation, other social media or Facebook sites where people living with short bowelor home TPN can meet and share experiences.

Some other individual things that people could do is journaling, writing things down, or using dance and art and music to express themselves, as well as to de-stress. I think getting ample sleep, because the fatigue is really important, certainly is a helpful thing, and yoga and meditation are also wonderful ways to give people renewed sense of well-being.

**Donna Gabriel:** Great, thank you. Okay, Dr. Brantley, I'm going to pivot over to you as we dive into the topic of mindfulness. What do you think the most important things are that people should understand about mindfulness?

**Dr. Jeff Brantley:** Well, thank you, Donna, and everyone else for making this available. I think something I learned in the years, in my own practice years, probably the most important thing to start with is that mindfulness refers to the part of ourselves that we've all got, or at least asa potential.

It's the part of us that is aware, that notices the way things are in the present moment. Our life is only in the present moment and the part of us that notices. Like, as you're sitting there, or if you're listening to this, if you pause for just a minute, you will notice, there's hearing; you'll notice sensations of your body. You probably notice your mind is talking about something, reacting somehow with thoughts or other feelings. The part that notices is the mindfulness and we all have it.

I say to people in the classes that we teach and the events like this, you don't have to create it. You're born with this sense of noticing—the awareness that notices—it's nonjudging, it's friendly, really welcoming and allowing. What we need to do is to

learn to recognize that part of ourselves that notices, and to trust it and develop certain skillsabout establishing ourselves in awareness, in the midst of challenging situations.

Most of all, really to understand the mindfulness as a way of empowering ourselves, of befriending ourselves, to deal with whatever challenges life offers—we've got all the mindfulness we need. There are many different methods, you might say. I thinkabout them as there's one mindfulness. As we focus the attention, we gain more understanding and connect more deeply with whatever is here with us in the present moment, whether it's our body, our breath, the thoughts, the emotions, or whatever it might be.

**Donna Gabriel:** Thank you. Thank you. What do you see as some of the benefits of mindfulness meditation?

**Dr. Jeff Brantley:** Well, there's a great deal of research about all this now. Of course, it's an ancient practice that in some traditions, notably the Buddhist tradition, it was offered as a pathway to gaining freedom from suffering, and that's a much-discussed word and everything else. In our modern era in medical science and psychological health science, when wetalk about suffering, Jon Kabat-Zinn talked about mindfulness-based stress reduction.

Again, we come back to this notion that we all have all the mindfulness we need, and we can begin to understand our own personal experience of stress, whatever the stress or the stressors are, and we can be empowered to deal more effectively. We like to say in the mindfulness-based stress reduction language when people learn to respond rather than react to the stressors.

The mental health improvement that research shows, depression, anxiety, and so on, resiliency, a more objective, less reactive, improvement in sleep disturbances, and other sorts of hyperarousal conditions. All of those come back to the fact that we take a different relationship when we practice mindfulness to whatever is happening in the present moment. So the benefits of meditation are growing all the time. They're well documented and strong research, as well as some that's not so in the early days, but they all come back to this empowerment to take a different relationship to the conditions we are experiencing in this moment, inside and around us.

**Donna Gabriel:** That's such a great point, Dr. Brantley, and to what you just said, there is a growing body of research, examining the use of mindfulness meditation in a lot of areas of health and well-being, and time and time again, it is showing these beneficial outcomes. Also, a lot of people probably think that mindfulness meditation is this tuning out or turning off, maybe, thinking. But to your point, it's actually being aware of what you're thinking and, what you said, befriending what you're thinking so that you can move through it more effectively.

**Dr. Jeff Brantley:** Yes, that's right. What we are trying to do is gain some wisdom but also learn how to access the parts of ourselves, the awareness and the good-heartedness—I like to call it—the parts of ourselves where we can take refuge.

**Donna Gabriel:** In that same vein, because people may think that it is an escape or you're going into some deep, meditative state, that it might not resonate well with children or adolescents, but that's not true, is it?

**Dr. Jeff Brantley:** It's not. Again, this notion that mindfulness is something we're born with, we don't have to learn it or create it. It's important to learn about it and maybe develop some skills of practicing, and some experience with what happens when we practice, but we're born with it. It turns out that—particularly in the field of education—that I've heard about some educators have taken to teaching children about mindfulness in different ways, and also mental health professionals and others, because children are naturally available to be mindful.

I remember watching a video of a young, probably four- or five-year-old, girl that was on one of the mindfulness conferences I attended, a video of her, and so described to the audience, described to us, what is mindfulness. She talked in her little five-year-old voice, and she says, "Imagine a snow globe and you turn it upside down, then you turn it back and the snow is pouring down and you just keep watching that snow and watching it, and after a bit, it's clear. That's the way your mind is when you keep watching that snow globe." This was out ofliterally the mouth of a young child. I think that this is something that all children and teens, if they're encouraged, can take advantage of.

**Donna Gabriel:** That's great. Yes, the research does show there's a lot of focus on mindfulness practices in early childhood education or higher education and in other environments with young people, especially in children with rare diseases, inflammatory bowel disease is another example, Crohn's, where the research continues to show that the use of mindfulness meditation supports those healthy responses to stress, helps them to learn better, have more focused attention, and then sleep better, and then improve their self-esteem. This has been studied from children as young as five, for example, all the way up to adolescent, college, and then beyond. It's very impactful.

Andrew, have any of your healthcare providers ever mentioned mindfulness meditation as a potential tool for you?

**Andrew Jablonski:** Not in those exact words, but they've given me exercises like deep breathing exercises and stuff like that—my therapist, psychotherapist—never my GI doctor. It does help reduce the symptoms of depression and anxiety about that one particular situation. It does help me sleep better. I will say all those points are spot on, butI was thinking about this as Dr. Brantley was speaking, but mindfulness is not always at the forefront of your brain, especially when there's a disconnect between the intestine and the brain because of the short gut syndrome. A lot of behaviors come into play. A lot of anger comes into play, and it's not always controllable.

**Dr. Jeff Brantley:** Let me address a couple of those points. First of all, Andrew, I think you are very much like people I've met that didn't have short bowel syndrome but had anger. When they came to our classes, they had a reason to be angry about something. Many people come with the idea and their thoughts or whatever. What I've come to understand about mindfulness is it's always here. We don't have to create it. It's always with us in the moment, but what happens is we can be forgetful about it. We can be hijacked, really, by the intensity of our reactions in a given situation, whether it's anger or grief, or whatever it is, or physical distress or whatever it might be.

It can be useful to remember and have some experience practicing that in the moment that we notice that we're angry, even in the middle of the storm, just noticing, "Well, anger is here right now." The part that notices is the mindfulness. What we can do, and this is where the skill building and the practice can be very helpful, we can begin to develop ways to reestablish ourselves in this moment, in the situation, and really paying attention more closely—as paradoxical as that sounds or like people know about breathing with the situation—and letting yourself breathe mindfully, feeling the breath, knowing the anger's here, knowing the pain is here. These kinds of practices are not easy.

People say things like "We can't stop the waves, but you can learn to surf." When we can make that shift, that pivot, mindfully, we protect ourselves against the future reactivity or hypercharge around that. Psychologists call it the difference between suppression and repression. At least, sometimes I've heard it put that way. If we can actually mindfully step away from whatever is bothering us so much in this moment, we also do not fall into actions and reactions that later on we have to go back and clean up with others and within ourselves.

**Donna Gabriel:** Thank you, Dr. Brantley. Dr. Winkler, how do you think your patients and caregivers might benefit from a mindfulness meditation practice or giving these types of things a try?

**Dr. Marion Winkler:** I think that it would be highly desirable. Becoming aware of how you're feeling is such an important skill. It's interesting—in many of our interactions with our patients from the medical healthcare team side of things—we tend to focus more on the lab tests, and the diet, and on the GI symptoms. Our patients are really more desiring of a holistic experience. To be able to dialogue and engage in some of the other things, I think, would make better communication. The totality of the care we give would be so much better if we can explore some of these activities and concepts together. We do, we ask our patients what do you do all day? What would you like to do all day? Do you have enough energy to do it? We talk about some of the psychosocial things and try to be aware or mindful on our own side about not just being stuck in the medical part of the disease or the therapy.

**Donna Gabriel:** For those watching as part of this program, Dr. Brantley has recorded a collection of mindfulness meditation exercises that are available on the activity page for you to listen to, download, and practice on your own. Each exercise is different depending on your preference. Dr. Brantley, can you just take a couple of minutes to give a brief overview of the available exercises so people have more information?

**Dr. Jeff Brantley:** Sure, Donna. We'll do a short guided meditation of each of these different methods. As I said before, there’s one mindfulness, but there are different methods—is the way I think about it—depending on how we focus the attention.

The first one is an introduction to simply discovering, recognizing in yourself, the power to be mindful, to be aware. The first short one, about five minutes, is available for anyone—and I'll probably focus on picking a particular focus for attention—is a very important skill as I mentioned earlier talking with Andrew about the waves. We practice finding a focus for the attention to help establish awareness and mindfulness and a wonderful focus is always the breath sensations. Then, very briefly, the other practice is body awareness—is extraordinarily important.

We'll work with some body awareness practices and maybe a little bit of movement because that's always helpful at any age—also the stillness, the awareness of the still body, and just the sensations.

Mindful seeing is very powerful. Any of our senses can be the object of mindful attention—eating, hearing, seeing, and so on. I will do a little short exercise to practice seeing differently. If we mindfully see what's in front of us like space, color, shapes, movement, stillness, all that, we can practice focusing our attention that way. It can really shift, and even gladden, our experience.

Then, the longer meditation, the fourth one, we’ll work some more with steadying the attention on what we've already practiced—a breath in the body. I thought it would offer, in the last one if anybody would like—and you don't have to—but in the last maybe half of that or so, I'll offer suggestions to help us reconnect, remember that good-heartedness, the kindness that we all carry, the great friendliness.

**Donna Gabriel:** Thank you so much, Dr. Brantley, and there's also a quick survey that will be on the activity page for participants. We'd be grateful if everyone can fill it out and let us know if the information discussed today was helpful and what you thought of the meditation exercises.

I want to extend my gratitude to Dr. Winkler, and Andrew, and Dr. Brantley for joining me today and sharing your expertise. This is a very important topic, and it is our hope that everyone listening, patients and caregivers, will find value in exploring mindfulness meditation to enhance your well-being. Thank you for joining us.