Invisible Disabilities
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Kellie: Hello everyone. Welcome back. I'm introducing Mark.

Mark: Hello. How are you?

Kellie: I'm great. How did you get into this field?

Mark: I was always interested in gastroenterology, not because my favorite color is brown. The part that was confusing to me was the movements of the gut. There are many disorders, such as Irritable Bowel Syndrome, that needed more research. I was interested in studying those.

Kellie: What does lost diseases mean?

Mark: These are the kids of my neighbors. They were given the assignment IBS. The symptoms didn't seem psychological. It was an opportunity to try to help these folks.

Kellie: Tell us about the journey of these people.

Mark: I started research in 1990. These patients were tossed around. Being a woman meant that was why you got IBS. You were blaming the disease on gender. Women have more psychological diseases than men? It was an odd time.

IBS was thought to be a wastebasket disease. You get tests done. If you find nothing, it could be IBS. The final thing that sticks for me is the name. Imagine if someone said you are irritable. The whole name is dismissive.

Two years ago, a doctor was teaching doctors to get ready for gastroenterology. He said it was the disease of hysterical women. It was shocking to me. We've come a long way, but we aren't done.

Kellie: How are you going about this?

Mark: It started in 1996 when I began training in gastroenterology. What is causing IBS? We began publishing papers on IBS coming from a change in the gut, as more bacteria was building up.

Our first papers showed that there is more bacteria overgrowth in IBS, so those with IBS are getting it from the overgrowth?

It is now well accepted that IBS is a microbiome disease. We've come a long way.

Kellie: Are those the same terms?

Mark: I get that a lot from people. The answer is yes.

I don't know who remembers the discovery of H. pylori. They were thought to be psychological. It causes ulcers, but not always. H. pylori was present in 70% of people. The same goes for IBS. 60-70% of people with IBS did.

Kellie: That's huge.

Mark: There are people with overgrowth that don't have IBS. We think IBS is part of SIBO.

Kellie: You helped discover a blood test for this.

Mark: We discovered the bacterial overgrowth. That wasn't the end of the story. You want to know why like a two-year-old does. Why is there this buildup? We think food poisoning started it. We don't think, we know.

Kellie: In every case?

Mark: 60-70%, yes. Food poisoning think of salmonella. We found that a toxin is caused by IBS. We could give animals IBS using this toxin. Humans get an antibody, but that results in autoimmunity. IBS is an autoimmune disease.

There's a protein that's super important. If you have the antibody at a high level, you end up with slowing and then bacteria building up.

The blood test saves money. If you can do this, you won't do things like colonoscopies. It also validates the patient. They know they have a disease. It's not in their head. It's not because they're female.

Kellie: How does that diagnose change the previous diagnostic material?

Mark: IBS used to be diagnosed as having pain. You might not have strain with bowel movements. If you met these symptoms, you probably had IBS. That's how it used to be done.

Kellie: What are other IBS myths?

Mark: I don't think IBS is a woman's disease. That is a myth I continue to pound on. Women get more autoimmune diseases. We don't know why.

IBS is triggered by a psychological event? That's not true.

A study was done on a large number of soldiers sent overseas. They came back with IBS. They looked at whether they shot guns or were injured. These were traumatic life experiences, but they didn't cause IBS. The only link with IBS to those deployments was food poisoning.

Food poisoning started it, even alongside those traumatic experiences.

Kellie: Interesting. What have patients taught you?

Mark: Everything. You don't learn unless you see patients. I believe that. I like to say that I have thousands of researchers. All of these patients teach me things. They pull and push me. We try something and it doesn't work. We try something and it does. That tells me what is going on with patients.

For example, there was one patient that decided to swim in a neighbor's swimming pool. The pool wasn't filtered. He got sick. He shouldn't have been swimming there! They weren't home.

He got IBS. He developed the antibodies, but only the toxin one. After two years, the IBS went away.

Patients are teaching me constantly. You have that relationship with patients, and it benefits everybody.

Kellie: It's refreshing to hear that from a doctor.

Mark: These diseases are difficult to understand, so that's the only way. You have to dig deep and not dismiss things. There's that thing where a patent comes to a doctor about back pain and they just say they do too. That's dismissive.

Kellie: What advice would you give to somebody who is newly diagnosed or about to start that process?

Mark: You need a doctor that understands these new ideas. If you get a doctor who thinks it's a hysterical condition, walk out. Pick the correct doctor.

Have a degree of opportunism. I have more than I did. We think IBS will disappear. We have examples of that.

The future is looking bright for this disease. I like "Invisible Incourage." Doctors don't like IBS because they look for lumps and find nothing. Every test has nothing. There aren't markers. Now, in 2020, we have a test for the first time. We have a drug for this approved by the FDA. We have new drugs coming for the various aspects of this disease.

The future is looking bright for this condition.

Kellie: I can't imagine how much of people's lives they could get back.

Mark: People compare IBS to Crone's. They have inflammation. It's not a mystery disease. I don't want to dismiss Crone's. In a flare, you have diarrhea all the time. You can predict it. With IBS, you can't. It could happen at any time, in traffic, in dates, at work. When you have a condition that is unpredictable, it is more devastating. It ruins any possible opportunity to do something.

As a Crone's person, if you have two bowel movements, you're good. With IBS, you don't know. Their experience is very difficult. You can't find anything and they're suffering? That's tough on them.

Kellie: There's a stigma around talking about this. It's not good manners to talk about bowel movements.

Mark: If you don't find something, it's not real. The doctors tell IBS patients it's in their heads. It's a challenge. I feel bad for them.

Kellie: Are there recommended diets for this?

Mark: It is based on individuals. We do have a recommended option. If they ferment it, there's more pain. There's the FODMAP diet. It's more extreme when it comes to calories.

The diet is not a treatment. It's used after treatment. You get them to a good place and maintain that. We give an antibiotic to treat the SIBO. We use diet to prevent the need for using that antibiotic again.

Kellie: What other treatments are available? Is that an antibiotic?

Mark: It is. By definition, it is an antibiotic, but it only kills what's in the wrong place. There are a lot of different treatments, some FDA approved. A lot have laxative effects. On the diarrhea side, there are two drugs. One is sort of like an opiate. There is also one that blocks serotonin.

They're really just treating a symptom there.

Kellie: You maintained a microbiome. What is that?

Mark: It is all of you, but not you. It is what isn't you in your body. It's things living on you for their benefit and for yours, possibly, but sometimes to your detriment. The largest collection of bacteria is in your gut.

Kellie: What are some prevention tactics besides not getting food poisoning?

Mark: Good tactic. We see, quite often in the US, eating a salad out of a bag. We go to another part of the world and we don't take paper precautions. Travel can be a big risk. Other risks include military deployment or missionary work.

Try to avoid food poisoning. If you have IBS, food poisoning is three times more likely. Things are already damaged. The antibodies go higher. It's important to follow good practices. The food needs to be hot. Beer, wine, are fine. Sodas are fine.

Ice is usually from tap water. Don't eat the salad or raw fruits. Those are the general precautions to avoid food poisoning.

Kellie: The food poisoning risk is three times higher. Anything else?

Mark: This is not well worked on, but there is a possible benefit to IBS. They get less polyps. There is no increased risk of cancer with IBS, but there is chronic fatigue.

One of the things that a lot of IBS patients struggle with is brain fog and feeling like they have a mild flu. The bacteria triggers an immune response.

Kellie: Any accommodations that work well for people with IBS, in the workplace, school, day to day living?

Mark: It's challenging. The bathroom at workplaces is public. If they're in there for a half hour, the boss wonders where they are. You're asking me for accommodations. I'm thinking of the experiences patents have had that are negative. There's flying and you can't take the seat belt off. You need to use the restroom but can't get up. That's tough. There are no accommodations for that.

A lot of people like to work from home because it's easier during a flare. I have heard good experiences. I had a woman who was paranoid about the grocery store. We treated her. It took six months of being normal in her bowel movements before she could relax.

They're burned by so many bad experiences. It's embarrassing. Nobody wants that. It's hard when you have to rush to the bathroom. I feel bad for them.

Kellie: Other ways how much this disease strips people of their livelihood?

Mark: What accommodations are made in the workplace? I have patients who work in the field. That's more challenging. You're in the middle of nowhere and bathrooms aren't accessible. You have to write notes for them.

People pick their occupation based on the IBS. A lot of patients struggle to date or have social activities. You're on such diet restrictions. You are with friends and you're spending 10 minutes figuring out what to eat. You become the difficult person at the table. You don't want to be that person. It's hard. They don't even want to socialize in the end.

Kellie: Women are more likely to have this. Any other high risk categories?

Mark: Look at the extreme form of constipation, it's eight to one for constipation. It depends on the end of the spectrum you're on. It has a lot to do with the autoimmune phenomenon.

Kellie: Besides the autoimmune, why those numbers?

Mark: Women have a greater tendency for constipation. There are estrogen receptors in the colon. I hate to blame estrogen for constipation. We don't know enough. There are people working in that area. I've never seen a woman who was constipated before menopause.

Women who are pregnant and have IBS, their IBS sometimes disappears and doesn't come back for a year. I tell women who are worried about becoming pregnant, things can sometimes get better.

Kellie: I do a lot of work with people with migraines and it's the same. In your experience, in your darkest days and hours, what gets you through?

Mark: The patients. I recall a story from decades ago. She was one of the first we treated for IBS in her 60s. She came back and her bowels were perfect. She brought a paper bag and dumped all the pills on the table. She didn't need them anymore. That's the story that gets me through. You liberate people from all this chunk.

This has simplified things for patients.

Kellie: Anything else you want to speak to?

Mark: The story I'm trying to tell is one of hope, not for just IBS, for a lot of diseases that are invisible. I like to think there are doctor champions trying to find the answers. You can't ignore real symptoms. I hope there is respect to what the patient describes.

Kellie: It's so nice to hear that these symptoms are not made up and you have a home here.

It's such an honor to have you here. We will see everyone Tuesday.

[End of class.]