PROBIOTICS AND THEIR ROLE IN GI HEALTH

specifically IBS, CELIAC DISEASE and GLUTEN SENSITIVITY

Tricia: Dan and Shelley, welcome. Thank you for being with me. It's a pleasure always to be chatting with you. Maybe by just a little introduction, I would like to say to everyone on the line that there seems to be a fair amount of interest in this subject probiotics. The registrations have been fast and furious for this workshop and it's really quite wonderful to be on the line tonight with Shelley and Dan talking about both celiac disease and IBS which is where we've got most of our participants and respondents. We've certainly had a lot of support from some wonderful bloggers in the community as well as the NFCA, a joint partner in this workshop. One of the reasons for doing it is that there is a lot of interest in probiotics. In fact, today, I know, Shelley, you and I were both online listening; there was an all-day workshop on the subject, so it seems to be quite timely that this has come up for everyone. So, what I mention is that the format of the workshop has been around the types of questions we received. Also, it's very important to say that the content of what we're presenting is never to give someone a diagnosis.

Obviously, we do refer you to your own health professionals, but it's to give you some new information and updates and different kinds of perspectives on what's been happening in the industry. So, by way of introduction, Dan, it's a pleasure always to have you, certainly you are a preeminent nutrition expert, a gastroenterologist, and in particular you've had a focus on celiac disease. Now, you are the director of clinical research and also a founding member of the Celiac Center at Beth Israel Deaconess Medical Center in Boston, Massachusetts. You see patients, you conduct research and you are on the faculty at the Harvard Medical School. You have published numerous articles, chapters and you do speak internationally on this subject. It's wonderful to have your book as a reference, *Real Life with Celiac Disease*, and I certainly was reviewing it again and I think that cases and the way you formatted the book is terrific.

You do spend quite a bit of time as well talking about IBS in this book. It's not dedicated only to celiac disease and I know you're going to outline some of the relationships there as well you have a terrific chapter on probiotics and the relationship they have to these disease conditions, so we're looking forward to hearing all about that. And then, Shelley, once again, Shelley is a great friend and someone I've had the honor of working with a number of times. She is a registered dietician, a leading international expert on celiac disease and the gluten free diet. She is a

member of the medical advisory boards of the Celiac Disease Foundation and the Gluten Intolerance Group in the United States, and the professional advisory board of Canadian Celiac Association. Many of you might have seen Shelley; she's been on several television and radio programs like the NBC Today Show and CBC News World. She is a very popular speaker and I have certainly had many a workshop that I've attended that she's spoken at.

She is also the author of the *Gluten Free Diet, A Comprehensive Resource Guide*. And again, one of those books I keep on my shelf when I have to look things up and any nutrition information, resources, manufacturers of gluten free products. She's the expert in its fourth edition and it's definitely highly recommended by health professionals and consumers; a very consumer-friendly book. So, Dan, and Shelley, thank you. It's a privilege to have you both here. For those of you listening, again, get out your pencils and paper, if you have any notes you want to take, we will send out transcripts and we will send out an audio version of this. They will also be posted on the Jamisondirect.com/probiotic website, I'm Tricia Ryan, and I want to welcome everyone here.

So, Dan, as a gastroenterologist, can you give us a quick refresher about gut health and the three conditions we're discussing tonight, celiac disease, gluten sensitivity and IBS; how common are they and what are the typical symptoms.

Dan: That's a really important place to start and it gives us a nice framework for going forward. All of these conditions first of all are very common. I'll start with celiac disease. This is between one and two percent of the general population, and that makes it quite common. Just as a frame of reference, that's about twice as prevalent as Type 1 Diabetes or as all of inflammatory bowel disease, so it's a very prevalent condition. It is a systemic autoimmune inflammatory disease that's triggered by the toxic proteins, found for these patients toxic at least, in wheat, rye, barley and a few other related grains. It's characterized by damage to the small intestine and by generation of autoantibodies that can attack virtually any part of your body. It's a lifelong condition that can arise at any age. Moving on to the other side of the spectrum which is irritable bowel syndrome; this is probably the most common gastrointestinal disorder and affects around 20 percent of the general population. While we have a

good understanding of what causes celiac disease, the reason people get irritable bowel syndrome is really unknown. We don't know why people get irritable bowel syndrome, and in general, what triggers it.

Irritable bowel syndrome is not characterized by inflammation in the way that celiac disease is, but the symptoms that it can cause can overlap significantly. And it really is a syndrome where people have gastrointestinal symptoms that exist after exclusion of conditions like celiac disease. Gluten sensitivity sort of is somewhere in the middle. It is a condition where people respond to withdrawal of gluten from the diet, i.e. they feel better when they're on a gluten free or very low gluten diet, but yet they don't have the inflammation, the damage to the small intestine, and in most cases, the antibody production that you see in celiac disease. This out of the three is really the least known of the conditions and the least well studied. It's really unclear at this point how common gluten sensitivity is; although, there are some suggestions that it makes up a significant portion of the irritable bowel syndrome populations. Even if it made up five or ten percent of the irritable bowel syndrome patients, it would be more common in celiac disease itself. So, that really is a space that we're just beginning to explore. It's a very exciting part of the gluten related disorders study.

Tricia: That's a long winded, but covered there. Now, testing or diagnosing, since you can probably make some mistakes, not you personally, but where someone might have one or the other, I know you refer to that in your book. What are the typical testing procedures with the three conditions?

Dan: That's a great point. Anyone, myself included, can mistake patients in the beginning regarding what patients have and don't have. Once again, you can damage the intestinal tract, but it can truly only tell you in so many ways. There's only so many gastrointestinal symptoms out there. You can have abdominal pain. You can have diarrhea. You can have indigestion, but there's a short list. So, all of these GI's diseases, whether you're talking about inflammatory bowel disease or celiac or irritable bowel syndrome, that can have very much overlapping symptoms. So, really the goal is to find anything – rule out the things that need very specific treatments, i.e. celiac disease. So, really we are getting to the point now that we are really suggesting celiac disease testing which is

simple serologic testing, usually for IGA tissue transglutaminase or TTG or anyone who has chronic gastrointestinal symptoms that are not otherwise explained.

If those are positive, then you go on to do endoscopies and you need to confirm celiac disease, if those are negative; however, you can in general and in most cases proceed with the confidence that this is not celiac disease and it's either irritable bowel syndrome with or without a component of gluten sensitivity to it. And once a patient's irritable bowel syndrome, there's a number of things that we'll be talking about throughout the hour that you can do to treat that. One of those is certainly to assess for food sensitivities of which gluten sensitivity is probably one of the most common.

Tricia: Those two often are linked then?

Dan: Yes, quite.

Tricia: So, then, Shelley, from your perspective as the dietician, are there dietary strategies that are used for the treatment of celiac disease gluten sensitivity and IBS and how do you differentiate those?

Shelley: For those people that have a clinical diagnosis of celiac disease or even non-celiac gluten sensitivity, the treatment is still the same. It is a strict gluten free diet. What we don't know if for those people that have gluten sensitivity, whether it's lifelong gluten sensitivity and whether they need to follow it as strictly as someone with celiac disease, but for our purposes today, let's assume that it is both the same. And that gluten, as I mentioned, is the protein found in the grains of wheat, rye and barley, so they need to follow a gluten free diet which means eliminating wheat, including durham, spout, kamut, eincorn, emmer, farrow, couscous, barley, barley malt, barley malt flavoring and extract, malt vinegar, brewer's yeast, beer, ale and lager; and oats unless they are pure, uncontaminated specialty gluten free oats.

So, with that long list, this diet can certainly be very challenging because there's so many foods and ingredients that are derived from gluten, but the good news is there are a wide variety of naturally gluten free options ranging from plain meats, poultry, fish, seafood, eggs, nuts, seeds,

legumes, fruits and vegetables, milk, yogurt, cheese, as well as a lot of gluten free grains, seasoned flours that come from amaranth, arrowroot, buckwheat, corn, flax, millet, legumes and nuts, potato, quinoa, rice, sorghum, soy, tapioca, teff and wild rice. We know now that there's many stores carrying a really good selection of gluten free specialty products ranging from breads and buns and bagels and muffins, cakes and cookies and pizza, baking mixes and hot and cold cereals, crackers, pastas, entrees, soups, sauces, snack bars and snack foods. You can even get gluten free beer, and distilled alcohols like rye, rum, gin and vodka plus wine and liquors can also be enjoyed on a gluten free diet.

So, it is a challenging diet and that's why I really encourage people to work with a registered dietician with expertise in the gluten free diet and celiac disease and gluten sensitivity. And for people with IBS because the cause of IBS is unknown and it's multidoctoral, the dietary strategies really need to be individualized. Foods that may cause some problems vary from person to person, but there are some foods that may make IBS worse. This is why you need to work with a registered dietician who can help you determine what those foods and beverages that may need to be avoided and what things you can eat and make sure you're getting a healthy, adequate nutritious diet. But there's a few good tips in place to start. One is by eating a well-balanced diet and eating regular meals and drinking plenty of fluids as well as eliminating and reducing caffeine, cutting back on sugars and processed foods, avoiding some of the gassy vegetables, decreasing your fat intake and avoiding carbonated beverages can also be helpful.

But it really depends on whether you have diarrhea predominant IBS or constipation predominant or you alternate between constipation and diarrhea that will have an impact on the strategies that you're going to take. The types of fibers consumed will also affect people differently. Insoluble fiber for example dissolves in water and forms a gel in our guts which slow down the digestion and it's often better tolerate. Whereas in soluble fiber that's found in whole wheat and wheat, bran and various fruits and vegetables has a laxative effect. This type of fiber is not always well tolerated, so it can cause more bloating and gas for many people with IBS. For those with constipation predominant IBS, a high fiber diet can help. What I think is really interesting, there's new emerging research coming out of Australia from dieticians Sue Shephard and Dr. Gibson with

the FODMAP diet that may help up to 75 percent of people with IBS. Now, FODMAPS, spelled F-O-D-M-A-P-S, they're a family of sugars and fibers that can produce bloating, pain gas and diarrhea in certain individuals including those with IBS or celiac disease.

And FODMAPS is an acronym for Fermentable Oligo-Saccharides, Di-Saccharides, Monosaccharaides and Polyols. That's quite the words, but in English, that translates to lactose which is a naturally occurring sugar in milk, fructose, the natural fruit sugar, fructoseand galactose which are indigestible fibers found in wheat, rye, legumes. And the polyols which include the sugar alcohol sweeteners, sorbitol, xylitol, mannitol and isomalt that are found in sugar free candies and mints. Polyols are also found in some stone fruits like cherries and peaches. Now, what's interesting Tricia is not normal to absorb FODMAPS very well. Undigested FODMAPS actually pass through the digestive tract and reach the colon where they're rapidly fermented by bacteria, and as a result you get a lot of gas and short chain fatty acids which typically cause the bloating, gas, cramping and diarrhea.

So, in order to figure out whether this FODMAPS are causing your symptoms, you need to avoid all types of these FODMAP foods for six to eight weeks and then you can add back individual FODMAP groups into your diet one category at a time to see if symptoms return. Many people can manage to eat small amounts of these problem foods once they've been stabilized. So, we don't have time to go into the details of the diet, but if people want more information on the IBS dietary strategies including this, there's a dietician by the name of Kate Scarlata and she has a book called, *Eating Well for IBS*, and a blog that goes into great detail about the FODMAPS and that is Kate Scarlata, S-C-A-R-L-A-T-A.com. There's another book written by dietician Patsy Catsos called IBS-Free at Last. And her website is ibsfree.net and both Kate and Pasty have some really good information about FODMAPS.

Finally, the last thing I wanted to mention, this is a long answer, but the diet is a key component of this, is there have been several studies that have demonstrated positive therapeutic gains with the probiotics and IBS. We've seen a reduction in bloating and gas as a result of certain probiotics. It seems to be a consistent finding in some published studies,

and some strains have also significantly reduced abdominal pain. So, there are lots of strategies that people can use for IBS.

Tricia: That was great, and that sounds really interesting. I'll have to check out that site. And for anyone who didn't get all the notes on that one, we will be giving a transcript, so you can have that as a follow up. So, Daniel, we had a lot of questions from people saying I'm following the gluten free diet, but I'm still having symptoms, what else might be going on? I know that seems broad, but we don't want to get into specific diagnosis here, but what happens when you get case studies like this? What kinds of typical things might be obvious culprits for these kinds of problems?

Dan: No, this is a great question and, in fact it was an early and in some ways more important lines of research that we did at the Celiac Center. It's very, very common. Overall, in patients with celiac disease, there are 30 percent of people will come in with just that complaint. It's very common. What we've found is the most common reason for people that have persistent or recurrent symptoms in celiac disease at least is that some gluten is still sneaking into the diet. This can happen through a variety of ways that are just very difficult for people to pinpoint. If it's a medication, a new medication or an old medication that's switched manufacturers. It's in a grain that should be naturally gluten free such as soy, but it's contaminated somewhere along the process. That's probably the single biggest reason why people with celiac disease have continued or recurrent symptoms.

Beyond that; however, there's a number of other disorders that can coexist with celiac disease including lactose intolerance, fructose intolerance, small intestinal bacterial overgrowth which can be tested for with a simple breath test. Or less common things like microscopic colitis, inflammatory bowel disease. There's a long list, but I think the most important thing to realize that most of them are harmless. A lot of people get very worried when they have recurrent symptoms, when they have refractory celiac disease and thankfully, that's quite uncommon. Really just checking in with your dietician. These are diagnoses that where the core treatment is dietary, and following the gluten free diet as most people are beginning to be aware is really no easy feat. Even for the utmost motivated educated patients. So really checking in with your dietician and going over things

one more time just to make sure there's no new areas where gluten might be sneaking in is really the first step for this issue.

Tricia: Shelley, anything you want to add to that?

Shelley: Of course, I want to always add more. Dan is right. For my practice, I certainly see that it is the gluten getting into the diet. And to learn where all the possible sources are is pretty challenging, especially when you first start out on the diet. As Dan mentioned, it could be in your supplements or medications, but it's often in foods that people are not aware of. They might be using soy sauce not realizing that soy sauce may be a combination of soy and wheat. Some of your salad dressings and seasoning blends and processed meats like ham and hot dogs. I just found a brand of ham the other day and noticed when I was reading the ingredients; it had wheat starch in the glaze. Often it's cornstarch, but in this particular brand, it was wheat starch. A lot of your imitation seafood and some flavored coffees and herbal teas, chocolates, licorice, malt vinegar, these are just some of the things that people that might not be aware of.

They need to really work with the dietician and go through the diet with a fine toothcomb. The other area is they might be aware, but not realizing they're getting contamination, either at home or when they eat out. A few tips that I give people is to make sure you have separate containers for items like your butter and margarine and peanut butter and jam that you label gluten free and put in a separate area of the fridge or cupboard, so that your family members or roommates who are eating gluten containing products don't come in and do the double dip and cross contaminate by them dipping into your butter and buttering their bread and going back again. That's another reason why I recommend people buying squeeze bottles of condiments like catsup and mustard and relish and mayo.

Another thing is that people don't realize you need to have a separate toaster because there's cross contamination. So, if you can't have a separate toaster, you could at least get a toaster oven where you can remove and wash the rack. There's another thing that's kind of neat is you can now get these little reusable toaster bags where you can put your gluten free bread in and use it in a regular toaster. I also recommend that people store all their gluten free flours and dry goods in a separate

cupboard. If that's not possible, at least on the top of the pantry shelf over the gluten containing products because if you do it the other way around when people are going to open those up, crumbs and flour dust can be falling onto the packages of the gluten free items.

The other one that I think Dan you agree on is that eating out is one of the biggest challenges where people are getting the hidden gluten. We can talk all night about that, but I think a few tips if you want to call the restaurant the day before you go or earlier in the day and ask to speak to somebody knowledgeable such as the chef or manager to see what kind of options they have. Can they substitute ingredients or create an alternative menu item? And many restaurants now have gluten free menus but that doesn't mean that you're looked after, you still have to – when you get to the restaurant convey to your server and the chef or manager that you need that strict free gluten free diet. You have to ask a lot of questions about how things are prepared and ingredients used and how they serve it. If listeners are looking for some more ideas on how to help you with eating out, there's a really good resource at the website www.glutenfreepassport.com. Lots of good ideas on how to learn to eat out safely.

Tricia: That was great, thank you. I know that we do want to support the various resources and I know there's a lot of good sites out there. Of course, Dan's book and Shelley's book, which are very different in what they offer, offer great resources. Any others, Dan that you often say to your patients are great places they should go for information?

Dan: Yes. As you mentioned there are a lot of great resources out there. Finding people, local celiac support groups, if often very helpful, especially in doing things like picking restaurants that are around you that are known to be friendly and knowledgeable about the gluten free diet. The National Foundation for Celiac Awareness is a great site, Celiaccentral.org; the National Institute of Health has a website which has some good information. The other major celiac organizations, Celiac **Sprue** Association, the Celiac Disease Foundation, they all have good sites. We also have one of our own that is just beginning beta testing and will be out called CeliacNow which is devoted much to covering the same stuff that's in our book and teaching the gluten free diet on a basic level in

a way that really isn't out there right now. I think there's a growing number of really great internet sources out there.

Tricia: And of course, the internet is why we're all here today. People are using it and I know that we had a lot of support from our bloggers that are interested in the disease, conditions and the various websites you mentioned. Now, to sort of the heart of the matter. Dan, there's a baffling selection of probiotic foods and supplements crowding the shelves in the health food and grocery stores. We're seeing lots of advertising about probiotics these days. It seems to be one of the hot topics for 2011. Now, we're into 2012. What are probiotics? How do they work with regard to gut health?

Dan: I think the thing – to give some background, the gut is the main way by far that our immune system interacts with the environment. People often think of things like the skin, but really, the skin's job is to prevent your immune system to having to deal with the environment. Really, by and large, the lungs play sort of a distant second, but the GI tract is the way our immune system learns about the environment we're in and responds to it. And because of that being able to modulate what's in your gut, what stimulates or calms your immune system can really have effects throughout your entire body. That's the founding theory behind probiotics. Probiotics are live microorganisms. These are friendly bacteria in yeast and other things that in theory we can add to the intestine to change the makeup of the bacteria and other organisms that live in our intestine. Predominantly in the colon, but to some extent in the small intestine as well.

And by modulating these, we can have effects on gastrointestinal symptoms, gastrointestinal diseases and also potentially diseases far outside of the gastrointestinal tract. Everything from inflammatory arthritis to obesity and the like. This is an area that is just beginning. Before I go on, I would separate probiotics out from something that's often mistaken is prebiotics. Prebiotics are sort of foods you can eat or nutrients that stimulate the growth of very similar types of populations of bacteria. One step removed from probiotics. You're giving the fertilizer for the bacteria that you really want to grow in your intestine. Probiotics come in many different forms. There's tens of thousands of types of microorganisms living in our intestinal tract at any one time. Figuring out

which of these are useful as probiotics which of these we really want to take and can have meaningful effects on how people feel and on disease stages. It's really only just beginning.

There's a handful that have been studied. To some extent, these include lactobacillus, bifidobater, saccharomyces cerevisiae; they're probably some of the most common. There's a variety of other ones out there. But really it is very difficult to give people good recommendations on which probiotic to take for which disorder, how much they need to take, and when they should expect to see improvement or not. We're really just scratching the surface of probiotics in health and disease. I would say in general though the great thing about probiotics is that they are by and large very safe. So, this is one of the reasons that many of us feel comfortable going to probiotics even when it's not entirely clear should we be looking at saccharomyces probiotics. Should we be looking at a lactobacillus probiotic? Should we have a combination, would that be better? Really outside of people who are severely immunosuppressed or have severe acute pancreatitis, those are pretty much the only cases where probiotics are a potential hazard.

And as in everyone else, these are things can be very helpful, but there is some trial and error involved. And often you try one based on your clinical experience or it's been published in literature, but I do tell people not to give up with just one probiotic because there's a number of different combinations. As long as they're from reputable companies, there's nothing wrong with trying a number of them to see which one really works best in your system.

Tricia: So, then it's safe to use them, I've heard you say. If you're a celiac patient or IBS, it's safe to use them. What kinds of positive outcomes have you experienced or seen in your research? I know that in chapter 41 in your book, you start with Cathy, a 19-year-old female and you give a little case there, you spend some time discussing and have a table about probiotics and health benefits. Those are also on the Jamisondirect.com website under probiotics, but IBS, celiac disease, it's a comfortable place for you to work?

Dan: Yes, quite so. For me, the ideal candidate for probiotic therapy is someone in whom if they have celiac disease, they're on a good gluten

free diet, they're celiac blood test is normalized. We don't think there's ongoing intestinal damage, but yet, they're still having some lingering symptoms, things like bloating, alternating diarrhea and constipation, symptoms that in general have some overlap with irritable bowel syndrome. Again, irritable bowel syndrome coexists with all other GI disorders. These aren't diagnoses of exclusion; people can have more than one. In those cases, with lingering, kind of annoying symptoms, a probiotic can really make a big difference in taking people from I'm feeling better, but I'm not where I really want to be to feeling really back to normal again. I think often a lot of other people are now using these very frequently in that exact scenario.

Tricia: In the case of when a patient comes in and that's something you discuss with them, is this a 15 day, 30 day, 90 day; you don't just try it for a week. How do you give them a timeline?

Dan: I say that you should be noticing some difference within two to three weeks. If at a month, you really don't feel any different, then it's time to switch to a different probiotic. On the other hand, it's at a month and you're making some progress but you're not fully back to where you want to be, then you just give it more time. But within a month, you should be seeing some believable consistent improvement. Or else it's just time to try a different avenue.

Tricia: Shelley, there were lots of questions that came in and one that comes up a lot again, and as a dietician, probiotics, we see them in yogurt, cheese, ice cream, all sorts of different foods, when we get a probiotic from food or pills, what's the difference? Is one better than the other?

Shelley: Those are interesting questions and there's no black and white answer because there's so many different factors involved which we don't have time to go into tonight. But listening to this webinar all day from the top experts around the world on probiotics, and I also wanted to see what answers I had for my research and what I know about them, they did concur that there's no one right answer. A few things, there's a real array of probiotics you can find in the yogurts and the fermented drinks and cheese. Now, they're adding to some of the other foods from cereals to juice to baked goods and snack bars. But you can also get the probiotics

as a supplement that come in many different forms. Powders, capsules and tablets.

When we're discussing whether you want to do a food or supplement, one advantage of the food source of probiotics is that they do contain a variety of other nutrients in addition to the probiotics. But here's where it gets interesting and listening to several sessions today is that you may not always be getting the therapeutic dose that's beneficial. Sometimes you can, sometimes you may not. It just depends because there's a real problem and a challenge with formulation, so that can affect whether the probiotics remain viable during the food processing and shelf life of the product. It was interesting listening to one of the speakers today talking about the type of food. For example, yogurts and yogurt drinks, you can use a wide variety of different strains that can remain viable whereas in some other heat-treated foods, you have to use certain strains that are encapsulated or they have to be spore like. It gets quite complicated when it comes to the food.

Now, when you go to the supplements it can be more convenient and you can get a higher level of the probiotics that can survive the passage through your acidic contents of the stomach and deliver it to the intestinal tract where they exert their beneficial effects. So I think the bottom line is whether you get probiotics from food or pills, they can both be effective. But the important consideration is that you're getting a high enough number of the specific strain or combinations of strains that have been tested in the research studies for efficacy and works in very specific conditions. The dosage of a probiotic strain when you look at it is measured in something we call CFU's which stands for Colony Forming Units. This is the indication of the number of live microorganisms that are present in your food or supplement. And on average, those doses may range from – to get the beneficial effects, can be anywhere above the 100 million CFU's per day. To be effective, that recommended dosage has got to contain the same number of CFU's that was shown in the research study.

If you look at a lot of the research studies, there has been documented health benefits ranging from 50 million to more than a trillion CFU's per day depending on the strains and the conditions that are being treated. So, I think another key point about the ingestion of probiotics is that it doesn't

need to long-term colonization and survival in the gastrointestinal tract. There are transient microorganisms, so you've got to maintain that colonization, and the only way you can do that is by taking them regularly. Most published studies have used daily consumption and in some cases multiple times per day that are recommended. One of the things that people need to look at is when you're reading the label, it's important that the probiotics that you're buying are guaranteed the potency right through the end of the product's shelf life.

Some manufacturers are just claiming potency at the time of manufacturing as opposed to the time of expiring. So, maybe by the time you consume it, there's nothing left in the product. This webinar that we listened to today from Europe certainly showed us that we have so much more to learn about probiotics and the roles they play in general health and disease management. But it's extremely exciting to see the emerging research, products, and recommendations that are evolving, so I guess the bottom line is you've got to keep reading and stayed tune because we have a lot more to learn.

Tricia: Just a little bit more. One of the consumers that wrote in was asking about the brands on shelf as efficient as the brands kept in the refrigerator. Dan, is there a difference?

Dan: It's really very dependent on the type of microorganism in the combination and the manufacturing process. Some of them, especially things like saccharomyces cerevisiae, that's related to brewer's yeast and we know anyone who bakes knows you can keep that stuff on the shelf in the kitchen for years and when you use it, it still works. Other things are much less tolerant of that. Again, in many ways, there's no hard and fast rule that you can apply across the spectrum of probiotics. That's why I really try to focus on telling people you really have to go with a reputable brand, a reputable manufacturer. Because you're relying on their word that they're producing things in a way that's going to be viable at the time when you take them.

At the moment until there comes a time when there may be some sort of labeling or standardized testing of probiotics, that's sort of the best we can do on that front.

Shelley: I was just going to jump in, Tricia because they discussed you can encapsulate some of these probiotics so they will get passed the gastrointestinal tract and be released into the lower gastrointestinal tract to do their job. Some of them are heat stable, but it's quite an art and a science to develop them. As I mentioned, there's now some category of the – we know about lactobacillus and the bifidobacterium, but these bacillus probiotics are spore forming probiotics, so they can survive against heat and pressure and food processing. And survive the digestion without needing to be encapsulated, so it's quite, from listening to it again today, it's quite an art and science to get the probiotics to get through to the system where you want them to. From what we see over the past years, they've made great strides in doing that.

Tricia: Dan, can you take too high a dose? And can you take them for an unlimited about of time, for example, your lifetime? That was another question we had.

Dan: Yes. As I said, there's very, very little toxicity with this. I have seen people who went a little bit overboard and caused themselves a little more gastrointestinal symptoms. Oftentimes, you may even consider having people ramp up, not take the full-recommended dose on the first day they're trying a probiotic. You never know how people are going to react, but often starting at a low dose and working up to that recommended amount makes some sense. Certainly, if you go beyond the recommended amount, you could develop some gastrointestinal symptoms, but they'll be very transient and once you go back down, they'll fade away. Other than that, there really is no sort of toxicity; there's no overdose risk or no chance of harmful factors building up over time. For the most part, these are things that already live in our intestinal tract to some extent. We're just trying to change the proportions around a little bit by taking probiotics.

Tricia: Dan, to you as well, there was one question from our consumer asking are stool samples reliable in evaluating probiotic populations in the gut?

Dan: That's an interesting question. It's quite a difficult thing to figure out what is actually living in your intestines, especially in proportions. Again, that's what we're talking about. We're not talking about whether or not you have saccharomyces or lack of bacillus in your intestine because you

do, it's just a question of how much you have and how much you have compared to some of the things you don't necessarily want so much of. That type of quantitative analysis of what's actually living in your intestines is very, very difficult. Even by the best research labs, it's no easy thing to do. The technology to do this is still evolving and I do hope that one day in the not too distant future, that this is something that would be clinically available. But at the time being, clinically, there's no useful way to measure what's living in your intestine and really to guide therapy based on that.

Tricia: Shelley, we had another consumer ask about vitamins and minerals and do people with IBS or celiac patients need to take vitamin supplements? And what would be any nutrition concerns or deficiencies they might have?

Shelley: That's a good question. Where do I start? Why don't I split it up and do celiac disease and gluten sensitivity and IBS. For people with newly diagnosed celiac disease, they've certainly got a lot of nutritional concerns depending on how long they've had the disease before they got diagnosed, the degree of small intestinal damage and whether they've got any other associated health conditions. The thing we start out with first is always getting them on the gluten free diet because once the villi begin to heal, you can absorb a lot of the vitamins and minerals. So, taking a lot of vitamin and mineral supplements in the beginning, you're just going to probably waste it, it's going to go out the other end. One of the common problems we see in people with newly diagnosed celiac disease is anemia.

In the research study I was involved with, what we called the Canadian Celiac Health Survey of over 2,600 adults, we found that 66 percent had anemia prior to diagnosis, and this can be due to iron, folic acid or even B12 deficiency. Although, it's usually iron deficiency that's the most common, so what I encourage people to do is obviously follow the diet strictly and then consume iron rich foods like lean meats and shrimp, oysters, sardines, eggs, nuts, seeds, legumes, some of the gluten free grains like amaranth and keenwah. Using things like blackstrap molasses, dried fruits and looking for enriched gluten free cereals and breads. That's one thing dealing with the iron. The other problem is osteopenia or osteoporosis that's common in undiagnosed and untreated celiac disease. So, you need to follow that strict gluten free diet so you can absorb that calcium and vitamin D, plus choosing calcium rich foods like milk,

yogurt, cheese, and fortified orange juice or fortified soy or almond or rice beverages. Things like canned salmon and sardines with the bones, figs, kale, bok choy and almonds are a few examples.

It's often tough to get enough vitamin D from foods because it's only added to milk and some fortified soy beverages and juice, so getting fish oil supplements or vitamin D supplements would be important. The other things is that with people with celiac disease if they started out with diarrhea, they do need to follow that strict gluten free diet so they can heal and the diarrhea will be resolved. Then you can start absorbing a lot of your vitamins and minerals. Those are just a couple of the nutritional things and supplements that people need to be aware of for celiac. For gluten sensitivity, usually they present with diarrhea, constipation, or both, so you would do similar dietary strategies as you would for those with celiac disease, that is following the strict gluten free diet, getting plenty of fluids and choosing appropriate fiber sources in adequate amounts.

Now, for people with IBS, nutritional concerns really vary considerably as I mentioned, depending on whether they have diarrhea, constipation or both. They may have nutritional deficiencies depending on how many foods they've been restricting. That's why they really need to work with a dietician. The dietary recommendations for the fiber and supplements have to be individualized, so they may need to take some supplements if they have lactose intolerance, they may need to use lactose reduced dairy products or they could take the lactase enzymes when they consume the dairy products. We talked about the FODMAPS and using the probiotics, so those are some of the little things you would need to pay attention to from a nutritional perspective and supplements. By that way as well, you need to be aware that if you're getting supplements, you want to find the ones that are gluten free.

Tricia: Dan, it seems sometimes like maybe not an earth-shattering question, is there a time of day for taking a probiotic? Is it better with food, after a meal, or before? Is there anything about it like that?

Dan: There's probably not a specific time of day that's better or worse, but we do generally recommend taking them with a meal. The predominant reason for that is so you dilute out some of the stomach acid and other enzymes that could potentially degrade or kill off some of the active

microorganisms. So, we do suggest taking them with a meal. Other than that, the goal is to take them regularly. So, whatever works for people and they can remember to do it on a regular basis, it's going to be the best option.

Tricia: Shelley, we've got questions around constipation and diverticulitis, would probiotics help with these problems? What are some recommendations for people with IBS or celiac disease around constipation? I know that comes up a lot for us in workshops.

Shelley: Yes, constipation is definitely a very common problem with people with celiac disease. For people that started out with diarrhea, once they get on the gluten free diet, they often get constipated because you're suddenly removing the wheat bran and other high fiber gluten containing grains, but surprisingly there's about a third of the celiac population that actually presents with constipation, not diarrhea, so then once they remove those high fiber gluten containing sources, the constipation gets worse. We like to encourage a lot of fluids and then high fiber gluten free sources because most of the gluten free products are made from refined flours and starches like your white rice flour, corn and potato starch. So, looking to incorporate more nuts and seeds, legumes and legume flours like your chickpea garbanzo flour and bean flours, adding ground flax's, getting more getting more fruits and vegetables, some of the higher fiber gluten free grains like amaranth, buckwheat, millet, keenwah, brown and wild rice, using something called mesquite flour, you can get the mesquite pods you can grind up and add to your gluten free recipes; and gluten free oats, dried fruits and popcorn.

I always remind people that if they're going to start adding fiber, especially new ones to the diet that they do it gradually and gradually increase that intake, and make sure to get enough fluids. If you pack in all that fiber and don't add enough fluids, it'll just get worse.

Tricia: Great, thanks for that. And Dan, one of the respondents in our workshop wanted to know what is the latest research on IBS. In fact, there was some other questions around is IBS just sort of a way to provide a diagnosis for things people don't understand in the gut. Is this really a disease, a condition? That grouping of questions around that.

Dan: Not too long ago, I think a lot of people would have agreed that IBS was just an umbrella to a bunch of things we didn't understand. But the more research that's been done on it, the more it does appear to be a real distinct medical entity. There are changes with nerve sensitivity. There are changes with some very subtle, but probably quite real inflammation, dealing with mass cells and some other types of immune cells, that wouldn't be typically active in celiac disease or inflammatory bowel diseases. So, I think irritable bowel syndrome is a real entity. Again, we don't know what causes it what triggers it, but there are real changes that appear to be fairly standard in large groups of patients being researched. I think is really going to lead to new understandings and potential therapy for irritable bowel syndrome in the near future. It's an interesting time for that condition.

Tricia: I know one that comes up a lot, Dan and Shelley, is around you've gone and eliminated gluten from your diet, and then you want to be tested to see if you do have celiac disease or just gluten sensitivity, do they have to introduce it back? What should they do? How does that process work?

Dan: The great thing in many ways about celiac disease is that everything that we can test should normalize after some time on a gluten free diet. That includes intestinal biopsy, blood tests, patient symptoms, so there's no medical test we have that can differentiate a person without celiac disease from a person with celiac disease who is doing a good job on the celiac diet. In general, that's a great thing. The problem is that if people are already on a gluten free diet before they get tested, it makes it very difficult to figure out if they do or do not have celiac disease. There's a number of ways you can handle this, but the classic way, and still the most common and single best way to figure out is to have them introduce gluten back into the diet in a controlled way, so that we can see if the classic signs and symptoms of celiac disease with blood tests and the intestinal biopsy, the damage to the small intestine, those are triggered by gluten exposure.

How much gluten and for how long is actually not well defined. The classic gluten challenge that's been done for 50 or 60 years basically had people go back on a regular diet which is at least two servings of gluten containing products, a minimum of four slices of bread per day for eight weeks before repeat testing was done. That's obviously a lot to ask of

someone who is on a gluten free diet because they've found that gluten makes them feel unwell. We are learning now in some of our research, there's probably an unnecessarily long and more gluten than people need to ingest for the vast majority of people. In some research that we've been recently doing, we've found that up to 85 or 90 percent of people can be diagnoses with just a two week gluten challenge taking just 2 ½ or 3 grams of gluten equal to two slices of bread per day. It's still something that should be done under the supervision of a physician. But it does lower the barrier significantly for evaluation of celiac disease.

This is really the reason why we really try to recommend anyone who is thinking about going on a gluten free diet, at least get the blood testing for celiac disease first. If the blood testing is negative, then the chances they have celiac disease are very low. They can go on a gluten free diet with some confidence. If it's positive, obviously you follow up and make the diagnosis one way or the other. But it's much easier to do with before changing your diet than it is afterwards.

Tricia: Shelley, anything you want to add to that?

Shelley: Yes, I want to just say amen to that one. I probably get one to two calls a week or emails from dieticians or patients saying I've gone on the gluten free diet now for the last two to three months and I feel so much better, but I want to get tested. I'm constantly whenever I do media interviews or talk to anybody is preaching is don't jump on the gluten free diet bandwagon until you get tested. As Dan mentioned, it's challenging. And for some people, it may take only a couple of slices of bread for a couple of weeks. I know we've seen, and I've heard other gastroenterologists in other scenarios wherein some people may have to be three or four months before the tests will trip positive with a significant amount of gluten. Most people can't hack it because if it is celiac disease, just having a few crumbs of bread for some people will make them sick and they won't be able to go through the challenge. Dan, I was going to ask you if you want to chime in too about we do know there are cases of people that I get this quite frequently that they go to get their blood tests done and the TTG is negative. But we know there is a percentage of people where they have either an IGA deficiency or maybe it's early celiac disease and the test is not 100 percent. Can you just concur on that or follow up on that?

Dan: Yes, that's quite true. The TTG and a modern celiac blood test are really fantastic. They're about as good as you can get for any similar type of disease, but they're not perfect, they're just blood tests. They are diseases defined by intestinal damage and probably five percent of patients with celiac disease will never have a positive TTG. There's a variety of reasons for that. One of the big ones is IGA deficiency, it's the most common primary immunodeficiency in the general population, it doesn't have any clinical symptoms. So, people won't know they have IGA deficiency. And one of the reasons that very often we will check for total IGA level as the same time as the TTG just to rule that out. It's about one in 500 in the general population has IGA deficiencies, but it's actually enriched in people with celiac disease, it's probably one in 50 to one in 100. So, again, one to two percent of people with celiac disease will have IGA deficiencies because they don't make IGA, they'll never have an IGA TTG blood test that's positive.

There are other blood tests we can now use, the emanated gland and peptide or DGP can be done and that has an IGG test that's quite good or a combined IGA/IGG test which can also be done in those situations. But really part of it is assessing how much risk that the patient is at for celiac's disease. The things that really put you at high risk is having a family history of celiac disease. That's the big one. It's about ten percent of first-degree relatives and four to five percent in second-degree relatives. Or if it's somebody who has a strong history of other autoimmune diseases. Do they have thyroid disease, type 1 diabetes, these are people that are at higher risk that if they have gastrointestinal symptoms, even in light of a negative TTG, you may want to go on and do an endoscopy to look at their small intestine before they go on a gluten free diet.

Again, it's sort of a case-by-case decision, but it's certainly, again, I think Shelley and I deal with this enough that I really is worth thinking about head of time rather than not doing that work up front and then trying to backtrack later.

Shelley: Dan, do you want to comment about using the HLADQ2 and DQ8 as another something we can use for ruling out celiac?

Dan: Sure. That's a great point. So, genetic testing for celiac disease is something that's done increasingly. Celiac genetic testing is a little

different than genetic testing for almost any other disorder in that it's not a rule in; it's really a rule out. So, in almost all cases, you need to carry the gene HLADQ2 or HLADQ8 to have celiac disease. If you don't have these genes, you can't get celiac disease. So, that means if you test for these genes and you're negative, you know you're off the hook whether you're on the gluten free diet. These are genes you're born with, they never change. The rub is about 30 to 40 percent of the population carry these genes, so if you have a positive test for these genes, it really doesn't help you. It only helps if they're negative. Again, if somebody is on a gluten free diet and they're unwilling to do a gluten challenge or if somebody is at high risk due to family history and they want to see whether they really need to keep an eye on celiac disease for the rest of their lives, HLA testing can be a very useful strategy.

Tricia: We have quite a few people also ask about children and probiotics. Dan, any position on that?

Dan: No. I think probiotics are safe enough that there really are no restrictions and one of the main places they're used are for premature infants to prevent necrotizing enterocolitis, so there are no age restrictions regarding probiotics. Doses of the amount may change because you're dealing with a much smaller person, but with that being said, by and large the same indications for probiotics apply to adults and children alike.

Tricia: We had quite a few questions around lactose, celiac disease, lactose as well as probiotics. Someone asked can I get a probiotic without the dairy component? Maybe Shelley, you can talk about the lactose and celiac disease. And maybe Dan, you can answer the question about the probiotics and the dairy component.

Shelley: It's hard to say, some of the estimates from clinical practice, we may see 30 or 40 percent of people with celiac disease, especially if they have a lot of diarrhea, they may have a secondary lactose intolerance. The reason being is in the tips of your villi, are the lactase enzyme that's used to digest the lactose which is the normal sugar, the natural sugar in milk. It may be that people have a temporary lactose intolerance while those villi are healing; they have to reduce their lactose in their diet. There's several ways of dealing with that. You can buy the lactaid reduced or lactose reduced dairy products, the milk and other products where they've already

added the lactase enzyme to that dairy product so you can have it and be able to digest it naturally. You can also buy the tablets and capsules you can chew or take to digest the milk products when you have milk or cheese. The nice thing about yogurt is the bacterial culture in the yogurt is already working on that lactose and converting it to lactic acid. So, most people do quite well on the yogurts with the live and active cultures. Where you have to watch out is you might have to watch for things like ice cream and fluid milk if it hasn't been pretreated.

Once the person – what I start my patients out with is starting a strict gluten free diet first and if they're still having a lot of adnominal pain and bloating and gas and diarrhea, then we might look at temporary lactose reduced diet. And usually people can go back on to lactose containing foods once the villi begin to heal. However, as you know, Dan, that really varies. Some people can begin quite quickly, but for some people, if they've had the disease for a long time, especially if they're older and have a lot of damage, it can take up to one or two years for the gut to heal, and in some cases, some people never completely heal. So, I don't know, Dan, do you want to add anything there?

Dan: Unfortunately, I think even that is probably optimistic. In recent studies from the Mayo group showed that two years, about two-thirds of people had some damage in their intestine and in five years, a third of people still had intestinal damage. I would say the good thing about lactose intolerance is it's fairly easy for people to figure out. There are lactose breath tests, but I think they're almost never really necessary. I think if there's any doubt, even a couple of days off lactose, people can usually sort out whether or not that's a component. I agree, especially early on, it can be common. I don't think there's a need to routinely restrict lactose, but it's a great nutritious food source for people who are already beginning to restrict their diet. I like to keep the diet as diverse as possible.

Shelley: The other issue too is because of the higher incidences of early bone disease and even osteoporosis, when you remove those dairy products, you're removing an excellent source of calcium and vitamin D. That's why I think people I've seen over the years, they've been still following a lactose free diet and they've had – they're well controlled with their celiac disease, three, four or five years later, and then they're having bone issues,

so I think it's important for people to realize that you don't need to necessarily remove the dairy.

Dan: I agree. And as for the question about getting a lactose or dairy free probiotic, there are probiotics out there that have lactose and those that don't. In general, that's going to be a small enough amount. Unless you're talking about something different like a milk protein allergy, something like that, you really don't need to worry about the amount of lactose that would be contained in a supplement or a medication.

Tricia: It's that bewitching hour. It's 8:59. I want to thank both of you. This has been really informative. As you know, we had well over 1,000 questions, we couldn't get through all of them, but I will offer to everyone that we will be reviewing all the questions and posting them on the Jamiesondirect.com/probiotics site. We also will be doing biweekly newsletters and we will endeavor to answer some of these questions and get them out to people. We will be sending out a copy of the transcript and the audio link for this workshop tonight. If you have any further questions, feel free to write me directly at the Jamieson Teleseminar, Jamisondirect.com, and I will review everything, collate again. Dan, and Shelley, thank you so much. Jamieson direct for being our terrific sponsor, and as well, the NFCA for their support in getting all these wonderful resources and people together, and the bloggers that helped get the message out.

One last thing, I would like to do before I close is we do promise people, ten winners, copies of Dan and Shelley's book and a two month supply of Jamieson probiotics. So, we will be writing everyone, but we do have Sherry Smith, Dawn Pettit, Cathy Agos, Diane Williams, Cheryl Wastler, Susie Steel, Stella Limo, Joan Terry, Judith Kym, and Mary Marshall, have all been selected randomly from our database and they will all be receiving these wonderful gifts as a token and appreciation for their support and participation sending in questions. Dan and Shelley, anything else you want to say by closing?

Shelley: I just want to say that if people want to get more information about the gluten free diet, what I've tried to do on my website which is glutenfreediet.ca is put out the latest studies and articles and links and resources. I have some good free resources and handouts for patients as

well as dieticians and physicians, so they go to glutenfreediet.ca they can get those. I have a monthly newsletter where I'm sharing the latest information and I'm going to be sharing a lot more about the probiotics from these webinars today and some links to that. So, if people are interested they can go to glutenfreediet.ca.

Dan: I would close with to continue to be aggressive with testing and looking for celiac disease because it's out there. And for people who have been diagnosed, that there's so much exciting important research going on. To be in touch with your local academic centers and look online and see if there's any studies that you might be interested in being a part of. This is a time when even a small amount of effort can make a really big difference.

Tricia: That's great. Thank you, you too. I wish everyone a wonderful evening and we will be following up with the materials as promised. This was great and very informative. Thanks again, everyone.

Duration: 63 minutes