About My Guest

My guest for this episode is Beth O'Hara. Beth O'Hara is a Functional Naturopath, specializing in complex chronic health conditions related to Mast Cell Activation and Subclinical Porphyria, including Mold Toxicity, Detoxification, Autism Spectrum Disorders, Histamine Intolerance, and Chemical Sensitivities. She is the founder of Mast Cell 360, a Functional Naturopathy Practice designed to look at all factors surrounding health conditions – genetic, biochemical, mental, emotional, social, and environmental. She is a doctoral candidate in Functional Naturopathy through the New Eden School of Natural Health. She also holds a Master's degree in Marriage and Family Therapy and a Bachelor's in Physiological Psychology, She is certified in Functional Genomic Analysis and has training through Functional Medicine University. She is a Research Adviser for the Nutrigenetic Research Institute. She presents at Functional Medicine Conferences and presented at the 2018 Functional Genomics Conference on How Genetic Weaknesses and Functional Dysregulation of the Heme Pathway Can Affect Health. Beth has had to overcome her own difficult health challenges and was once bedridden with severe chronic illness. Her road to health was rocky, with few people able to understand her health issues. She was told frequently by health care providers that there was nothing that could be done for her, but she never accepted this. She eventually discovered how to regain her health through discovering Functional Naturopathic approaches, Functional Genetic Analysis, and Parasympathetic Nervous System balancing. As she healed, she became a passionate advocate for those who fall through the cracks in traditional healthcare, developing the Mast Cell 360 Functional Naturopathic Process. She developed her practice to be the kind of practice those with chronic illness need; one where they are seen and heard and get results in regaining their own health. She focuses on discovering the unique root factors underlying each client's illness, utilizing comprehensive genetic interpretation, symptom and health history, and lab analysis as well as providing emotional support for the journey.

Key Takeaways

- What are heme and heme dysregulation?
- What is secondary porphyria?
- What is the process of creating heme and why is it important?
- How are KPU and porphyria related?
- What are common symptoms of secondary porphyria?
- How does glycine impact heme production?
- What are the key items that stress heme production and lead to secondary porphyria?
- What testing is available for exploring the existence of porphyria?
- How is secondary porphyria treated?

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Transcript

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Episode #101 Heme Dysregulation and Secondary Porphyria with Beth O'Hara

[00:00:01] *Welcome to Better Health Guy Blogcasts, empowering your better health. And now, here's Scott, your Better Health Guy.*

[00:00:14] *The content of this show is for informational purposes only and is not intended to diagnose, treat or cure any illness or medical condition. Nothing in today's discussion is meant to serve as medical advice or is information to facilitate self-treatment. As always, please discuss any potential health-related decisions with your own personal medical authority.*

[00:00:34] Scott: Hello, everyone, and welcome to Episode Number 101 of the Better Health Guy Blogcast series. Today's guest is Beth O'Hara and the topic of the show is Heme Dysregulation and Secondary Porphyria. Beth O'Hara is a Functional Naturopath, specializing in complex chronic health conditions related to Mast Cell Activation and Subclinical Porphyria, including Mold Toxicity, Detoxification, Autism Spectrum Disorders, Histamine Intolerance, and Chemical Sensitivities. She is the founder of Mast Cell 360, a Functional Naturopathy Practice designed to look at all factors surrounding health conditions – genetic, biochemical, mental, emotional, social, and environmental. She is a doctoral candidate in Functional Naturopathy through the New Eden School of Natural Health. She also holds a Master's degree in Marriage and Family Therapy and a Bachelor's in Physiological Psychology. She is certified in Functional Genomic Analysis and has training through Functional Medicine University. She is a Research Adviser for

the Nutrigenetic Research Institute and presents at Functional Medicine Conferences and presented at the 2018 Functional Genomics Conference on How Genetic Weaknesses and Functional Dysregulation of the Heme Pathway Can Affect Health. Beth has had to overcome her own difficult health challenges and was once bedridden with severe chronic illness. Her road to health was rocky, with few people able to understand her health issues. She was told frequently by health care providers that there was nothing that could be done for her, but she never accepted this. She eventually discovered how to regain her health through discovering Functional Naturopathic approaches, Functional Genetic Analysis, and Parasympathetic Nervous System balancing. As she healed, she became a passionate advocate for those who fall through the cracks in traditional healthcare, developing the Mast Cell 360 Functional Naturopathic Process. She developed her practice to be the kind of practice those with chronic illness need; one where they are seen and heard and get results in regaining their own health. She focuses on discovering the unique root factors underlying each client's illness, utilizing comprehensive genetic interpretation, symptom and health history, and lab analysis as well as providing emotional support for the journey. And now, my interview with Beth O'Hara.

[00:02:59] Scott: Today we're going to talk about Heme Dysregulation and Secondary Porphyria and how these are potentially, major missing pieces in mold illness, chronic Lyme disease and metal toxicity. Two of my mentors in this realm include Dr. Dietrich Klinghardt and his work on kryptopyrroluria, which is associated with Heme Dysregulation and is a type of Porphyria. And then Dr. Neil Nathan has been a voice on secondary Porphyria in his patient population, where those long drawn out Herxheimer reactions may not be Herxheimer reactions at all. Today, we have Beth O'Hara on the show to guide us around the deep end of the pool. Thanks for being here today, Beth.

[00:02:38] Beth: Thank you, Scott. I'm so excited to get into this topic with you.

[00:02:41] Scott: Me too. I know I'm going to learn a lot from this conversation so I'm excited as well. How did you become interested in doing the work you do today with Mast Cell Activation Syndrome, Heme Dysregulation, Secondary Porphyria, and many of these really complex chronic illness topics? Did you have some personal journey that led you towards becoming passionate about what you're doing today?

[00:04:05] Beth: It's definitely been a personal journey. So, as you know, I work with Mast Cell Activation Syndrome, Histamine Intolerance, some of those related issues like oxalate, salicylates, mold toxicity. I had to become an expert in these areas as a matter of survival. I had health issues most of my life, and over the course of time, I slowly became debilitated. I ended up bedridden and I had to walk with a cane. My journey took me to over 50 different health care practitioners. I totaled up at one point - I had spent over $100,000, and no one could figure me out. I was one of those mystery patients that just didn't make sense, and eventually, I stumbled upon Yasmina Ykelenstam's work over - she had the website, HealingHistamine.com, and then everything started to make sense and started to fall into place. Then I had a friend that I met through there, Bridgette and she introduced me to genetic analysis several years ago. There were still some big pieces, I was still really miserable, and we started digging into the genetic interpretation back when we mostly just had Amy Yasco's panel to go by.

So, we were looking at about 35 genes, but things finally started to make sense why had these weird reactions; why couldn't take curcumin, why l-glutamine made me really, really anxious. And I started getting better and better and my dramatic-- My recovery was so dramatic that the word started to spread, people started to come to me asking for help. And there are several common root causes in all of these disorders in Mast Cell Activation Syndrome and Histamine Intolerance, but also the Subclinical Porphyria that we're going to talk about today. And I talked about those on my website. I have a free report for people over there at MastCell360.com/freereport, and we'll get into these root causes. But I've got a lot of that detailed in those reports. But I had all of the root causes that I talked about. So, this is definitely been a personal journey.

And then the way I got into the Heme Dysregulation was through a colleague, Sandy Prantl. She brought Subclinical Porphyria to my attention and she's an Occupational Therapist and a Cranial Sacral Worker. She was looking into heme issues and Subclinical Porphyria for herself. And then she just started bringing me stacks and stacks of research. And it was piling up on my table and two, so on fire about it that I wanted to look into what she found. And what we're reading made so much sense for many mystery clients who struggle with supplements, sensitivities, unusual pain presentations, other complex symptoms, people whose protocols kept failing. And it made sense for me as well because one of the strangest symptoms I had when I was so sick was that every year around February or March, I would develop extreme nausea and abdominal pain, and I could only eat raw food. And anything cooked would make me really sick and my anxiety and my pain would get really, really bad. And then a few months later, it would clear up.

We don't always see that kind of seasonal pattern with Subclinical Porphyria, but it was there for me. And this research that we're going to talk about today on Heme Dysregulation and Subclinical Porphyria put even more of the puzzle pieces together for me.

[00:07:33] Scott: ...really are the wounded healer then now taking your personal journey and helping other people with this really fantastic-- You've said that Heme Dysregulation and Secondary Porphyria are underdiagnosed more than Mast Cell Activation and maybe as common. And I know some practitioners that I've spoken with them, the Lyme and mold illness community, they've estimated that maybe 50 to as high as 90% of their patients have some degree Mast Cell Activation Syndrome. So, how common is Heme Dysregulation, how common is Secondary Porphyria, and are these also a spectrum where people may have varying degrees of severity of symptoms presentation?

[00:08:15] Beth: You're exactly right on the spectrum, it's absolutely a spectrum, and I think that's really important to remember as we go through this topic. We don't know yet how common Subclinical Porphyria is, but I completely agree with you that 50 to 90% of people with Lyme and mold toxicity are dealing with Mast Cell Activation Syndrome. The same statistics are true with mast cell issues and autism. So, I see that overlap in my practice every day and I think we're seeing that with Subclinical Porphyria as well. It's just not recognized in traditional medicine, and it isn't even really known by the functional medicine world yet. Except, some of the practitioners you mentioned like Dr. Neil Nathan and Dr. Klinghardt, there's Stephen Rochlitz and - Bob Miller and myself. I hope we can really start to change that because people with Subclinical Porphyria are some of the sickest people I see, and they're usually suffering the most.

[00:09:10] Scott: So, let's step back for a second then and explain to people what is heme, and why is it so important in terms of our ability to support life and health?

[00:09:21] Beth: So, heme occurs in almost all organisms on the planet, but it occurs in different structures. So, in plants heme is a magnesium-based protein, but in humans, heme is an iron-based protein, and heme is a base molecule that's used to create many different types of enzymes and proteins that are used for things like detoxification, nitric oxide production, reducing hydrogen peroxide, even creating NAD and NADPH from tryptophan. Heme is used to deliver oxygen to different cells. So, we can dive into more specifics on these in a bit, but heme was critical to life. There's no way that the human body can function without heme, and without heme, many, many processes in the body will go awry.

[00:10:13] Scott: So, let's talk a little bit at a high level and then we'll dig into it. But at a higher level, what is the process of heme creation, are there multiple steps in that process, what kinds of things might impact the optimal functioning of those steps, and how is Heme Dysregulation associated with Porphyria?

[00:10:32] Beth: So, heme production is an eight-step process, eight enzymes, but it starts in the Krebs cycle. So, if you ever seen the -- I know you know the Krebs cycle, maybe some of the listeners don't. But the Krebs cycle is how we take fats, carbs and proteins and convert them into ATP for cellular energy. In that cycle, at five o'clock in the cycle, there's a step called succinyl CoA, and that's where the heme pathway comes off. So, succinyl CoA combines with glycine and then goes through eight different enzymatic reactions to produce heme. So, with eight steps, there's several places in the heme pathway where things can go wrong. And also, things aren't flowing down through the Krebs cycle, we can have difficulty making heme. And unlike nitric oxide and NADPH, we don't have any backup pathways for heme, we just have this one pathway. So, in those eight steps, eight enzymatic steps to the heme pathway, they're different intermediate compounds created and they're often collectively just called porphyrin, they have their own individual names, but usually, we call them porphyrin as a general name. And these Porphyrins aren't meant to circulate in the body, they're meant to convert rapidly from one phase to the next phase of the heme pathway. But if there's a blockage or slow down, and one or more of these enzymes gets impacted, then the porphyrin will start to pile up. So, I think of it like an interconnected assembly line, where if one of the lines goes down, the products from the previous line piles up. And when the porphyrin piles up like that, they start to fairly circulate in the body. They're very, very toxic. Kind of like what we think about phase one, phase two, detox, the intermediates there, we don't want to get stuck with those intermediates, similar idea here. And if the types of symptoms people have and the types of classic Porphyrias even depend on which are circulating, which are backed up and where they deposit, which tissues they're affecting.

[00:12:57] Scott: So, what are some of the conditions then that might be associated with the heme pathway imbalances? What types of things can it trigger in the body?

[00:13:06] Beth: What most known are the classic Porphyrias, that are described in traditional medicine. These are really rare genetic disorders of the heme pathway. The symptoms tend to be very extreme, really terrible, and people with these diseases, they could have extreme sun sensitivity, so they can't go out in the daytime and it's suspected that that is that form of porphyria's related to the vampire myths. There's some genetic porphyrias that cause extreme hairy growth on the face, hands and they can be related to the werewolf myth. And then there's acute intermittent Porphyria, the most common one, and that typically, goes with nausea, vomiting, diarrhea, constipation, and really debilitating pain. But what we're going to talk about is Subclinical Porphyria. So, it doesn't meet the criteria for those traditional really rare Porphyria diagnosis. But it's similar to how Mast Cell Activation Syndrome was discounted for so long because it was stuff that mast cell disorders were really rare and extreme like mastocytosis. But now we know Mast Cell Activation Syndrome is really common, and I'm confident we're going to come to recognize Subclinical Porphyria as being common as well.

So, what this can trigger are different types of symptoms depending again, where the porphyrins are building up, where they deposit, and so there's a few different types of profiles, kind of like again, Mast Cell Activation Syndrome, but I see clusters of symptoms. So, sometimes I'll see presentation like anxiety, diffuse abdominal pain that doesn't get worse with pressing on the abdomen, nausea, sometimes vomiting, sometimes diarrhea and constipation. Some people get skin symptoms. So, skin sensitivity, you may get unexplained lesions of skin splitting, burning sensations on the skin. People can gett muscle weaknesses, chemical sensitivities are really common. So, anytime I hear chemical sensitivity, I think, do we have a heating issue? I want to look into it. People get insomnia, pain, food cravings, and even addictions.

[00:15:15] Scott: So, let's talk a little bit about the upstream events here. So, what are some of the enzymes in the body that are heme-based or depend on heme, and why is it important for us to really look there, kind of upstream to all of these other things that happen in the body where a lot of times the focus seems to be on trying to support or fix all of the downstream enzymes to optimize their function?

[00:15:39] Beth: This is where this is really, really critical and why heme is so important. So, if we look at the different enzymes - want to break them down. So, we have hemoglobin, myoglobin, neuroglobin, and cytoglobin, these are all heme-based. These are the proteins that deliver oxygen to red blood cells, muscles, nerve cells and brain. So, no heme, no oxygen delivery to those tissues. And then we have the cytochrome p450s, which we know are so critical for the phase one detoxification process. That's a heme molecule. So, if we can't make heme, we can't make cytochrome p450. And then we have this cytochrome b5 and the cytochrome c and the electron transport chain and make ATP. So, no heme no cellular energy. And then we have peroxidases and catalysis, those breakdown hydrogen peroxide, the reactive oxygen species. So, we can get a lot of build up there if we don't have heme. We have tryptophan pyrrolase. So, that converts tryptophan in the - pathway to become NAD and NADPH, really critical for recycling our detoxification enzymes, and involved in energy, it's called the anti-aging molecule. And then we have nitric oxide synthase. So, we need nitric oxide for so many processes. Nitric oxide stabilizes mast cells, and the nitric oxide synthase is one of the major pathways to make nitric oxide from l-arginine and BH4. So, again, that's heme-dependent. Then we have SUOX and sulfite oxidase convert sulfite to sulfates. Sulfates are needed by mast cells to stabilize themselves. So, we can get a lot of Subclinical Porphyria mast cell overlap anytime. And that's my major practice area is Mast Cell Activation Syndrome. Anytime I'm seeing detoxification enzyme issues, a lot of inflammation, immediately want to go look at the heme pathway and see it might be involved. So, we want to look upstream because if you don't have heme, it doesn't matter how much you support the downstream enzymes, you won't make them. So, nitric oxide synthase, no matter how much we support l-arginine and BH4, if we don't have heme, we can't make the enzyme, we can't make nitric oxide.

[00:18:09] Scott: Wow. So, lots of things that really happened when this process of creating heme is dysregulated. My understanding is that this is more common in people of Scandinavian descent. How common is it in that population and do we know why that's the case?

[00:18:26] Beth: What I do know, I don't know the exact statistics here, but we know that in the US, when we're talking about the classic Porphyria is the acute intermittent Porphyria is estimated in the US to be five in 100,000, and that's the most common form. And in Scandinavia, it's estimated to be about four times more common, so about 20 in 100,000. I don't know exactly why it's more common in Scandinavian descent other than sometimes genetic mutations will tend to occur more in isolated populations. So, that's my guess. I didn't come across anything specifically on exactly why.

[00:19:05] Scott: A lot of the listeners will know the article that I wrote on kryptopyrroluria with Dr. Klinghardt. He found that that really plays, that Pyroluria plays a key role in conditions like Lyme disease like autism, many of the complex chronic conditions and leads to a loss of or ultimate deficiency of zinc and B6 and omega 6 and other nutrients. How does pyroluria fit into a discussion on Porphyria? My understanding is that kryptopyrroluria is one of the Porphyrias and if someone has one of those conditions, are they more likely to have another? So, if they have one type of Porphyria, are they then more likely to have others?

[00:19:49] Beth: Right. So, pyrroles are also base-structures for heme, and there's a step towards the end of the pathway. The second to last enzyme is protoporphyrin 9, and this makes-- it's a hemopyrrole versus a kryptopyrrole. And Pyroluria is caused by elevated levels of these kryptopyrroles, which are also called hydroxyhemopyrrolins, and these come from heme intermediate specifically, the ones called, I'm going to try to pronounce it right, porphobilinogen. And in a US, pyroluria and Porphyria are often discussed the separate conditions, but in Europe, they're seen as related. And I agree with that perspective, that they're really intertwined issues, and they go together. So, if somebody has pyroluria, they're going to have a Porphyrin issue and those pyroluria intermediates bind with zinc and B6, that's why we have such a loss of those. And then the other porphyrins also disrupt nutrients in the body as the body tries to deal with them.

[00:21:04] Scott: Is there anything beneficial about a Porphyrin or are they always a problem when they start to backup?

[00:21:14] Beth: Well, they're definitely beneficial in terms of that's the only way we can make heme. So, we have to make the heme and the Porphyrins, when they start to back up, though I don't know of anything beneficial. They're extremely toxic, they're extremely inflammatory, and it's similar to the intermediates that can happen in phase one and phase two detox. Although, with reactive oxygen species, we know we do have a function there in terms of that those reactive oxygen species like superoxide, hydrogen peroxide are used to kill pathogens. I don't know of any use for the Porphyrins that build up, I don't think it's supposed to be happening. Whereas with reactive oxygen species, we have specific mechanisms like any NADPH oxidase to make those to fight off infections.

[00:22:11] Scott: What are some of the factors, then that either upregulate or downregulate these eight different enzymes in the process of creating heme, and how much of that dysregulation is purely genetic versus epigenetically influenced by our environment, levels of stress, food choices, all of those types of things? And can some of these up regulations or down regulations can they then be influenced through various nutrients or supplements?

[00:22:43] Beth: So, the purely genetic Porphyrias are the really rare ones. Now, I do see people that have genetic variants in the heme pathway, and also, in upstream and downstream processes that end up having heme issues.

When we think about factors that upregulating and downregulating the enzymes, the first one I think about is glycine. So, glycine upregulates the pathway, also, some of the cofactors like B12, folate, B6, zinc, magnesium and iron. And I think this is one of the reasons why some people do really poorly on supplements because if these upregulating factors are introduced in an order that is increasing the pace of an earlier part of the heme pathway before we have a block, the Porphyrins are going to build up. So, this is why we want to approach heme in a really logical order. I always start from the end and work backwards. And in terms of down-regulating dextrose or glucose is the major down regulating factor. So, the first enzyme in the pathway has a feedback mechanism so that as glucose builds up, it'll slow down the heme production and that's why glucose or dextrose is given for a Porphyria attack.

[00:24:11] Scott: So, how much of this then would you say is genetic versus more epigenetic?

[00:24:16] Beth: When we're talking about the Subclinical Porphyrias we're definitely talking epigenetic. And so we do need to look at the genetic components. And I look at quite a bit of upstream-downstream genetic factors. So, the - for the glycine production, the Krebs cycle, I look at all the heme pathway genes, but also the genes that are affecting pathways that feed into it. So, anything that's affecting iron regulation, anything that's affecting retinol like the BCMO, factors that are affecting B12. We look at also, what happens at the end of the heme pathway, which is oxygenase, and the gene for that is HMOX. And then the oxidative stress factors, so anything that can contribute to peroxynitrite, SOD issues, catalyst issues, glutathione issues. When people have issues with the heme pathway and they can't produce, you know, they have direct genetic impacts say, catalyst or glutathione, then we've got a double-whammy situation.

[00:25:26] Scott: You talked about some of the symptoms already. You mentioned specifically, some of the GI issues, pain in the abdomen. I have a list here and I just want to kind of rattle some of these off and then see if there's any specific ones that you might want to comment on and kind of tie it back. So, I know anxiety is a big one. Insomnia, a lot of the gut issues, you mentioned vomiting, abdominal pain. I know seizures can play a role, high blood pressure, heart palpitations, constipation, diarrhea, you mentioned nausea, you mentioned muscle weakness, being hungry after eating addictions, multiple chemical sensitivities, sensitivities to essentially anything even EMFs, which interesting, that's such a topic these days; eating disorders, autoimmunity, immunodeficiency, even a connection between Secondary Porphyria and Mast Cell Activation Syndrome. Any of those that kind of stand out that you might want to comment a little more on?

[00:26:27] Beth: ...I think that's a great list that they put together. One of the things that people have is like air hunger, shortness of breath because the oxygen isn't getting delivered to the cells, the muscle weakness because the oxygen isn't getting delivered to the muscles. A big one for me is the food addictions, and issues with being overweight and obesity, and alcoholism. I think, you know, people that have addictions and have difficulty controlling their eating, they often get stigmatized in our culture. But I have really found that people sometimes are just self-medicating the only way they know how. And so things like carbohydrates, even alcohol can help slow down that Porphyrin production. And I had a client who she was really struggling with pain, she was very fatigued, she was always a little out of breath. She was trying so hard to lose weight, she could not lose weight, - not lose weight. She had been body-shamed by some practitioners who thought she was just lack of willpower. And we started increasing her carbs, got her carbs up, got the Porphyrin production down, and then she had some significant Schmidt variants, and she was Scandinavian descent. And we started some glycine, the food cravings were gone like two days, it was amazing. Then we get her energy back, she was able to start losing weight.

[00:28:04] Scott: So, when we kind of sit -- When you sit down with the client and you're digging into their history and kind of considering the potential for them having a secondary Porphyria, what are the kinds of things that you look for in their history?

[00:28:29] Beth: I really look for anything that can be a trigger. So, there's so many things that can shut down the heme enzyme. So, one, I look for chronic infections. Has there been Lyme, Epstein-Barr, mold toxicity and mycotoxins build up, Chlamydia pneumoniae is a big one? So, I like to see if people might have Chlamydia pneumoniae in their bodies. And then I look for other toxins; heavy metals, chemical toxins. I think about symptoms like poor tolerance to medications and supplements. And if there's any kind of family history that fits the picture, and then, but it doesn't have to be a family history, people can have completely acquired Subclinical Porphyria. I always asked about ethnicity. And then, you know, we look at those genetic factors. So, do quite a bit of genetic analysis with Bob Miller's - genetic resource kit and his functional genomic analysis software because all of this is really mapped out and makes it so much easier. We've got to think systemically here when we're looking at these issues.

[00:29:32] Scott: Yes, I'm a big Bob Miller fan so I'm glad that you're working with him. Super, super bright guy. When people have Secondary Porphyria, is it generally the case that they experience symptoms to some degree all of the time? Does it wax and wane? Is it fairly consistent?

[00:29:53] Beth: It really again, depends. And so some people have more of the intermittent, it comes and goes depending on exposures. Some people do have constant symptoms, it depends on what the source is. So, if you think about somebody who's got an ongoing chronic infections, constantly releasing biotoxins, they may have a constant stream of symptoms. I did have a young man whose symptoms start at 13 after his family moved near a microprocessing plant, and this plant was releasing a lot of toxins in the air. He had never had symptoms before. He started having vomiting, reflux, anxiety, insomnia, and severe abdominal pain. And once they moved, then -- I think he lived there about four years around this plant. So, finally, they tracked it down, figured out that the plant toxins were triggering him. And when they moved, things started to calm down, but it was like the door was already open.

And so if he got too much exposure to say, car pollution, too much car exhaust, certain supplements, certain medications would throw him into another attack.

[00:31:12] Scott: If someone is a paradoxical reactor, meaning that the practitioner expects them to respond one way to a supplement or medication and they respond the opposite, if they're super sensitive and can't tolerate or take most supplements or medications, is that a clue for you for the possibility of Secondary Porphyria?

[00:31:32] Beth: It is. I definitely think Secondary Porphyria, I started the mycotoxins, Lyme toxins, which can be causing Secondary Porphyria, I started thinking about Mast Cell Activation Syndrome. And I start to wonder about some of the unusual genetic variants like I've had that may be super sensitive. And so when these supplements and meds that people are reacting to, they're upper gating or down-regulating the heme enzymes that can cause that Porphyrin build up. And these people are the ones we have to be really careful with when setting up interventions for them. So, I've had people come to my office after they were given glutathione IV and became absolutely debilitated by it because that glutathione can liberate more toxins than the body can deal with. And if they're already a predisposition here, then we can get that perfect storm that really just takes somebody down.

[00:32:31] Scott: Yeah. So, if somebody has, let's say, Mast Cell Activation Syndrome, is it then more likely that they also have Secondary Porphyria or vice versa? Do you do commonly see them coming together, and if so, is the treatment focus better served on one versus the other or do you need to work on them simultaneously?

[00:32:53] Beth: That's a great question. I do often see them together, particularly in cases where we've got chronic infections, where we've got chronic toxicity. So, things that both stimulate mast cell degranulation and dysregulation, and that can shut down heme enzymes. Now, when it's more of a genetic-based piece, I don't always see them to go together. But when we're looking at these acquired issues, they often do come together. And it's really complicated when we have both because we use a lot of supplements, typically to help calm down Mast Cell Activation. But then many people can't tolerate them if they've got these Heme Dysregulation. So, we've got to proceed really cautiously. And when it's that scenario, I do a lot of work with lifestyle intervention, food changes, see as much as we can do outside of supplementation. And then we start working on things that really support both areas like binders, and so on.

[00:34:01] Scott: And I think those are cases too, where a lot of practitioners find some of the limbic system work can be really helpful for allowing people to better tolerate and create a broader toolbox of potential interventions. I've seen a lot of people have really great responses to things like the dynamic neural retraining system. I know Dr. Nathan uses it as well. Have you seen that come into your work at all?

[00:34:24] Beth: It's huge. I also have a Master's in Marriage and Family Therapy, which I know you know, and a background in psychology. I got into that because I love the interplays between the mind and the body, not from the perspective of the disservice that happens to a lot of people where they're told everything is in their head. That is absolutely not okay.

[00:34:36] Scott: Yes.

[00:34:37] Beth: How does stress levels impact chronic health? Why is there a much larger percentage of people in the chronic health population that have early childhood traumas? What's the relationship there? Now, it comes down to that field of psycho neuro immunology, that everything that happens in terms of stress levels, affects our hormones, affects our immune system, affects our nervous system. So, the more that we can work from that angle as well, I find people heal much faster. And I think DNRS is a great system, the Gupta program is a good system. I usually have people start with coherent breathing because it's very simple. It's free. And I use a lot of coherent breathing, and then tailor things based on what people's predispositions are. Some people are more comfortable with some things like Qigongs, some people are less comfortable and so we might go a different route. But absolutely, I always incorporate that for people that have stress as a factor, and especially if they've had early traumas.

[00:35:57] Scott: Let's come back to glycine for just a minute. So, you mentioned the beginning of the heme pathway is coming off of succinyl CoA from the Krebs cycle, that, that then utilizes glycine. So, glycine, we know is fairly commonly used in functional medicine for detoxifying a number of solvents and chemicals and toxins. Talk to us a little about the pros and cons of supplemental glycine and can it be then therapeutic potentially, in terms of optimization of the heme cycle? Or do we need to be cautious because I know earlier you said you work backwards, and this is really starting from the beginning of the cycle? So, what are your thoughts on glycine?

[00:36:40] Beth: This is a great example of where we really have to individualize things. So, for people that are sensitive, blanket protocols, they just don't work. And I really specialize in kind of, by chance, develop the reputation for the people that keep falling through the cracks and are hard to figure out and this is one of the areas. So, we think of glycine, if you mentioned for detox, we think of it as - calming. But this is a supplement we definitely have to be careful with if people have Subclinical Porphyria issues, also they have glutamate issues. So, glycine will increase transit down the heme pathway. So, if there's a blockage anywhere in the heme pathway, and when I say blockage, it could be partial. So, blockage could be an enzyme is only working at 30% or 50%, but it can lead to an attack if we give somebody glycine. And so sometimes what people think are herx reactions or detox reactions, they may be Porphyrin build up. And then glycine also stimulates the NMDA receptors. And this is relevant to what we're talking about here because Porphyrins block the GABA receptors, and that's what contributes to the anxiety symptoms in Porphyria. So, we can get a glycine glutamate backlash, where the glycine starts stimulating glutamate worsens the anxiety for people with Subclinical Porphyria. But I've even seen this with people just with Mast Cell Activation Syndrome. Now, if glycine is the main issue, like the client I talked about before, who, once we increased her carbs

sum, and then we gave her some glycine, it took away her fatigue, her pain got much better, food cravings got much better. But when I do glycine, I do it really low and slow. So, we start with sprinkles maybe three times a day, just go up little bits at a time so we can monitor how somebody is doing with.

[00:38:40] Scott: Stephanie Seneff has talked about how glyphosate disrupts glycine and potentially even gets substituted in the body in places where glycine should be. So, does that potentially mean that glyphosate exposure from food or other environmental contamination can put more stress on that initial step in the heme creation process?

[00:39:04] Beth: Yes, absolutely. Stephanie Seneff is doing some amazing work here. And when the glyphosate substitutes for glycine, then the glycine isn't available to start the heme pathway. So, glyphosate can affect team production in people that don't even have any other team-related issues. Because if you can't start the pathway, you're never going to make heme, you're not going to make those downstream enzymes we talked about for detox and nitric oxide. Kind of like if you don't have the gas, you're never going to get the car running to go someplace. And this was a big factor in my health issues. I grew up around farms where they sprayed glyphosate from planes flying over the fields and this was part of why I got sick so early.

[00:39:51] Scott: I want to-- similar to what we did with the symptoms I want to throw out some of the factors that can lead to the secondary Porphyrias and then we'll kind of drill into them a bit more. But you've mentioned already Lyme, Chlamydia pneumoniae, other chronic infections, biotoxins, mycotoxins, heavy metals. I know lead specifically is one, mercury, arsenic, a lot of the pesticides and chemicals, we'll come back to this one later, but I know intermittent fasting and Ketogenic diets can be tricky. And so that's something I definitely want to touch on as well. And then rapid weight loss, things that burden the CYP 450; alcohol, ultraviolet light, you mentioned the sunlight issue, reactive oxygen species, ozone, various drugs, even sulfur foods. I mean, it's a pretty, pretty big list of things that can really stress this whole pathway it sounds like.

[00:40:53] Beth: It really isn't. This is why I'm confident that it is way more common than we understand at all. And I want to touch on one that doesn't get talked about much, which is hypoxia. And so when we think about hypoxia, this is anything that's disrupting our air supply, and airway obstruction. So, these can be our typical, what you think of is your classic sleep apnea issues. But also, people can have airway obstruction for other reasons. So, I have an airway obstruction and it's because I have Ehlers-Danlos hypermobility. So, my trachea collapses when I lie down. And it's made a huge difference in my life to do things like I told you at the beginning when we were talking before we started that, I have braces, and I just got this new lingual arch, and it's affecting my ability to make some sounds. But what it's doing is it's expanding my dental arch because it was all too narrow and there wasn't enough room in my tongue so my tongue can fall back in my throat and my airway was 70% blocked. And fortunately, somebody recognized that for me because that's not something we typically check for when we're working in the kind of work that we do. But I always do an airway assessment that one of the practitioners here, Dr. Nelson Diers trained me to do so I know whether or not to refer to an airway evaluation. And that's a big one that I want to put on people's radars to be paying attention to, is the dental plate narrow? When people smile are there gaps between the teeth and the edges of their smile? Are there scallop marks on the edge of the tongue showing that the tongue is really crowded against the teeth? We did one on Mast Cell Activation Syndrome as well.

[00:42:46] Scott: Yeah, this is what's great about these conversations because that will connect the dots for someone that will then lead them to go and explore that and improve their life. So, thanks for bringing that up. Let's talk a little bit about Herxheimer reactions. So, it is fairly common in the Lyme community when treating microbial overgrowth, whether it's Borrelia, Bartonella, Babesia or something else, that people kind of expect and even become excited about the possibility of having a Herxheimer reaction. I'm personally not one of those people. I think it's not necessarily a good thing. And that oftentimes, that's an indication that we need more detox support, maybe we're being a little too aggressive. But one of the things that Dr. Neil Nathan brought into my consciousness was the idea that our Herxheimer reaction, generally, two to three days kind of thing. But if it's a prolonged Herxheimer reaction, it may not actually be a Herxheimer reaction, that it may be falling into this secondary Porphyria. So, how do you differentiate between those two possibilities?

[00:43:45] Beth: I'm completely on board with you here, Scott. It really worries me when people are told to just keep pushing through more than a couple days on something. And it's definitely a big concern for both Subclinical Porphyria and for Mast Cell Activation Syndrome because you can set off a mast cell cascade that can last for months. And I've seen that where people kept pushing through. Once you had a mast cell cascade going, that's like a forest fire out of control. And it can really-- it really can take months to settle back down. So, I'm absolutely adamant that in the sensitive population, you cannot get overly aggressive with people who are dealing with infections or detoxifying toxins. And I've seen people like the woman I mentioned with the glutathione IV, it was a very, you know, good-hearted intention. But she was just the wrong person for that glutathione IV and she became so debilitated she couldn't leave her house. So, it isn't that there's not a place for things like glutathione IVs or more intense protocols and sometimes they are necessary, people are incredibly sick and they're in a dire situation. But I think we need to scream better for Subclinical Porphyria and Mast Cell Activation Syndrome. And also, practitioners and I know you're great at this and I know probably a lot of our practitioners listening here are, but I have people come in every week you tell me about that their practitioner told them that just to keep pushing through, that this was really more in their head. I have people every week come in and tell me they've been ridiculed and told that there's no way these symptoms could happen and that it's crazy. And this just isn't in any way okay, and people end up with trauma from it. And so I think the big lesson is if you're a sensitive patient, you aren't being taken seriously by your practitioner; you

can't keep just pushing through or ignoring it because it can debilitate people. And it's always really important to find somebody who listens to you, who takes you seriously believes what you're telling them.

[00:46:02] Scott: Absolutely agree. Amen to that. Let's talk a little about Chlamydia pneumoniae. So that is a common microbe that's seen in people with Lyme disease, but it's also very common in the general population. I would say the majority of people probably have Chlamydia pneumoniae, and long term it can affect the cardiovascular system. What's unique about that particular microbe that then can trigger a secondary Porphyria when we really try to treat it, and then is it only the pharmaceutical interventions or can herbal antimicrobials have a similar effect when you're dealing with this particular bug?

[00:46:41] Beth: That's a really good question as well. What's interesting about Chlamydia pneumoniae is that when it dies, it releases Porphyrins. And this is why it can throw somebody into an attack. And especially somebody that's already got, maybe they've got Porphyrin build up, that's just under the threshold for symptoms. And then they start killing off Chlamydia pneumoniae, and you cross that threshold and then somebody starts to have issues. So, it will happen. That kind of case can happen with antibiotics or herbal interventions. It's not about the interventions were using in that case, it's really about the Chlamydia pneumoniae itself. And so that's why it's helpful to check and see if somebody might have that infection before you do any kind of microbial intervention to know the total load that you're dealing with. And if somebody is a good candidate, they might be dealing with Subclinical Porphyria, then you want to make sure you're going to be able to mop up those Porphyrins and deal with what could occur. And I've seen people end up in attacks after they were treated for Chlamydia pneumoniae.

[00:47:53] Scott: I think it's also a reason why many Lyme practitioners will do Chlamydia treatment towards the end their overall kind of Lyme protocol so that they've addressed a lot of the body burden before they start dealing with the Chlamydia. Because this potential of really having a significant response to Chlamydia pneumoniae treatment.

[00:48:16] Beth: Right. And there's a really good website out there, I don't remember the exact name, but if you Google Secondary Porphyria and Chlamydia pneumoniae, it has quite a bit of information on this issue.

[00:48:26] Scott: Is this the same one that Thomas MacPherson brown site like CPNhelp.org or--

[00:48:32] Beth: That's it.

[00:48:34] Scott: Okay, beautiful. So, let's talk a little about heavy metals. I know lead can be a trigger for Porphyria. Does heavy metal detoxification lead to reduction or resolution of Porphyria over time and is it possible that treating heavy metals and mobilizing them in the body with more aggressive interventions could actually be a trigger for a Porphyria attack? I know that can be the case with mast cell activation syndrome.

[00:49:02] Beth: Right. So, people who -- even mobilization of metals as the treatment, but I've also seen people get really, really ill from provoked mental testing. So, DMSA or other provocations that are pulling those metals. So, anytime we've got sensitive people, I'm really leery of doing the provoked testing because of that because even that provocation just for the test could trigger porphyric attack. But you're also right that if we can do the heavy metal detoxification in a way that's done deliberately and carefully, we would definitely be reducing the risk for these kind of Subclinical Porphyria attacks over time.

[00:49:52] Scott: I want to touch briefly on bone broth, that's long been considered a really powerful healing tool. Why might it not be a good tool in this discussion?

[00:50:02] Beth: Well, bone broth definitely can be great for some people for gut healing. But again, we have to individualize everything. If somebody is using bone broth, we want it to be organic because conventional bone broth is often loaded with lead. But also, bone broth is high in glutamate and histamine, which are issues in Histamine Intolerance and Mast Cell Activation Syndrome. And I personally got much worse when I started. I thought I was being really healthy. I thought I was doing all the right things for myself. And it started getting into the Weston A. Price movement and all of the work there. And I was drinking bone broth every day that I was making myself from pasture-raised animals. And I was getting really gung ho and doing the chicken feet broth, and I was making my own kombucha and ferments. And I got really, really worse. I didn't know I had Mast Cell Activation Syndrome and Histamine Intolerance at the time. And so on we just have to remember everything comes down to individualization. So, what's wonderful for one person, maybe poison for another.

[00:51:07] Scott: Right. And for people listening, just to the kombucha comment in Mast Cell Activation Syndrome, that potentially can be something that also is a bad thing for some people. So, I personally am not of the opinion that kombucha is a health food. There may be some people that it is healthy for, but I would say the majority of people that are really significantly chronically ill, especially with Mast Cell Activation, probably not something to really have in your diet. In your thoughts, do agree?

[00:51:38] Beth: Yeah, I do. It's a good probiotic if you're really healthy if you've got any kind of histamine sensitivity or Mast Cell Activation, that can really stir things up more.

[00:51:50] Scott: So, I know this next question is a whole podcast on its own, I've had Morley Robbins on the show, previously. But let's talk a little about the role of iron and the creation heme I know you mentioned earlier that in plants, if I remember correctly, magnesium is at the center, in humans, iron is at the center. So, where do you fall on the iron debate? Is it good for us? Is it potentially a problem? Where does copper fit into the conversation? How do we get bioavailable copper? What kind of, at a 30,000-foot level, what are your thoughts on iron and copper relative to Porphyrins?

[00:52:24] Beth: So, iron in the reduced form is necessary for life, we can't live without it. And it's needed at the final step of the heme pathway. So, this is where the fetch enzyme attaches iron to what's called protoporphyria 9 to create heme. This is also why the iron regulation is so essential because if iron stays in the oxidized state, where it's dysregulated, it's not available to make heme and then it's going to go off to be involved in hydroxyl radical creation, which is really inflammatory. But fetch is also a copper-based enzyme. So, bioavailable copper is necessary to create the fetch enzyme. Also, interesting is diamine oxidase, which breaks down histamine is a copper-based enzymes. Many of our enzymes are iron based and copper based. And when iron and copper stay dysregulated, their oxidizes is very toxic. So, I think we do have to be careful about iron supplementation because many people have issues with dysregulated iron. And I'm sure you've covered most of this so I'll just hit some highlights, we can't just look at - and go oh, we see the low -. Let's give this person iron because we've got to consider what's being stored in the tissues and stuck in the tissues. And when iron starts to oxidize, so if we give iron supplementation, it's more than the body can utilize, it will oxidize, which in the body is a similar process to resting and creates a lot of inflammation. It's one of the most inflammatory processes in the body, and is a big contributor to Mast Cell Activation Syndrome. So, when we do need to do iron support, I like to do pasture raised liver, pasture-raised meat cooked to medium rare, rare, as long as it's been frozen for an extended period of time. We actually get heme from that meat, from red meats and so that's a good source for people that are having trouble producing heme. And then we can get bioavailable copper liver, pasteurize liver, nuts and there's even a topical copper salicylate paste that's available out of Australia. There's a possibility for people who are really struggling to get that copper up.

[00:54:46] Scott: Wow, cool, great stuff. Let's talk a little about high-fat diets and fasting, ketogenic diets. Most of us I think, don't really stop to think that there are potential downsides. So, why is a ketogenic diet or even fasting potentially, something that can be a stress in terms of Secondary Porphyria, and what might we feel as a result of those types of dietary changes?

[00:55:13] Beth: So, I do really like ketogenic diets and fasting for certain people at the right time, and I do it myself, and they work really great for me, but I really listened to my body as well. And sometimes my body starts really craving carbs and I don't crave carbs normally. But if I'm really feeling like I need carbs, I listened to that because my body's needing it for reason. So, we have to really consider who we're recommending this to and when in terms of their health journey. The one other telltale signs of Subclinical Porphyria is someone gets sick doing ketogenic diets or fasting. They just feel really bad, they just have absolutely no energy, they start to have an increase in the symptoms that we've talked about before. This is because carbohydrates flow faster through the Krebs cycle into the heme pathway than fats or proteins do. Fats or proteins convert much more slowly. So, this is part of the link between Heme Dysregulation and obesity and food addictions and alcoholism as well where people are trying to self-medicate.

[00:56:23] Scott: I know speaking of medications, I know there's a number of medications that can also be triggers for Porphyria. In getting ready for this show, I know one of the resources that you make available is the PorphyriaFoundation.com/drug-database site, where people can go and look those things up. So, worth checking to see what medications you're on and whether those might be contributors to Porphyria. Any comments on that?

[00:56:50] Beth: I think is a great resource, especially people who've been really, really sensitive to medications and suspect they have Subclinical Porphyria. I have like any clients, we're looking at that with them, I give them that resource and just tell them to always check it, share it with their prescriber, look up medications before they take them so you can really consider what an impact may be. And it may not mean if somebody may have to take a medication for specific reasons, but we can check there and see if that might have an impact on the heme pathway.

[00:57:25] Scott: Porphyrinogens can build up in the skin. You mentioned this a little earlier, leading to sensitivity to ultraviolet light, blistering of the skin, various skin symptoms, particularly when people are fasting. People may develop sun rashes or maybe don't tolerate the sun. And that's an interesting-- I've heard lots of people over the years even before really coming on to this topic that say they just don't tolerate the sun, really, myself included. I'm not someone who really enjoys being out in the sun. So, I generally, thought of that sun sensitivity as more of a mast cell issue, but kind of connect the dots for us for those people that don't seem to tolerate sunlight.

[00:58:05] Beth: Right. It can be either one. With mast cell issues and the sun sensitivity, we tend to see more rashes, hives, itching, we can get redness, things like that. When it's a Porphyrin and or porphyrinogen issue, which is the type of Porphyrin, then that type of Porphyrin will deposit in the skin and it tends to cause lesions, cracking and spontaneous bleeds. And this is what the stigmata has been attributed to. So, Saints would fast for 40 days and likely that length of fasting would cause the development of Porphyria and the skin to crack and bleed.

[00:58:47] Scott: Wow. Interesting. Let's talk a little about the potential downside of oxidative therapy. So, ozone very commonly employed in Lyme disease, for example, what are some of the reasons that ozone maybe a problem relative to Heme Dysregulation and Porphyria?

[00:59:05] Beth: Well, ozone is definitely a great killing mechanism. And when we're thinking about Porphyria issues, even mast cell issues, if there's too much die off too fast, those toxins can build up. And if there's a weakness and the heme pathway, it can cause too much down-regulation of heme enzymes. And if somebody has trouble with the very top of the pathway, second enzyme, ALAD, this enzyme is oxygen dependent. And since ozone is changing the oxygen balance it can shut that insulin down. So, again, we want to think about who's the right candidate for what intervention, and how do we screen people so that we can tell more, we can predict better ahead of time? Who's going to respond well, and who may respond very poorly.

[00:59:55] Scott: What's the connection between Heme Dysregulation, Porphyria, and then Mast Cell Activation Syndrome, and what role does bilirubin play in that connection?

[01:00:09] Beth: So, many of the things that can trigger Subclinical Porphyria issues and Heme Dysregulation also trigger mast cells. So, there's a big connection there, especially in the acquired mast cell. Porphyrins will stimulate mast cells because they're so toxic, they can stimulate muscles to create more inflammation. And the bilirubin is really interesting. So, bilirubin for anybody that may not be familiar with it, is a breakdown process of heme by an enzyme called heme oxygenase. And there's a study in 2002 that showed that bilirubin is anti-inflammatory and desensitizes and stabilizes mast cells. So, when I'm looking at Mast Cell Activation Syndrome, I also look at heme oxygenase. And I like to look at the bilirubin levels. And if we don't have heme, if we're not creating heme, we don't have bilirubin, and then we can't use the bilirubin to stabilize the mast cells.

[01:01:13] Scott: Cool. This is so fun.

[01:01:15] Beth: It's all connected.

[01:01:16] Scott: Yeah. Let's talk a little just briefly on testing and then we'll start wrapping up with treatment conversation. So, urinary Porphyrin testing, I know is one available test. Is that essentially, one of the best ways to look at these eight different enzymes and how the poor friends are potentially building up and can we measure the intermediates at each of those steps or are we not able to be that specific at this point?

[01:01:42] Beth: Well, there is a urine, blood and, feces testing for all the different types of Porphyrin intermediate. Some are more reliable for checking some types of Porphyrins than others. The blood and the feces testings are usually used for the more rare genetic testing, and the urine is typically used when we're looking at the Subclinical Porphyrin issues, although, if we're not using all three types of samples, we could miss some elevations. Unfortunately, the urine testing frequently, results-- all the testing frequently results in false negatives due to difficulty with storage and laboratory methods, and it's hard to get accurate results. Sometimes the crystallized Porphyrins gets stuck in the gallbladder and they might not make it to the feces, they don't show up then. And also Porphyrins, it really varies when they're going to be excreted. So, kind of like oxalate, they can be stored in the tissues and may not be excreted. So, when we look at, say, a Great Plains organic acid test, that oxalate level, if it's in a normal range may not be true with body stores. Same with Porphyrins. And so sometimes people, there was a case of a woman who had a genetic Porphyria, and she was so sick, she was on a ventilator for 19 days before they got a Porphyrin sample, an elevation in the urine because she was holding on to it. She wasn't excreting it. That we can check. And so I always take it seriously when I see elevated Porphyrins on some of the labs so we can check their LabCorp, Great Plains, Doctors Data, ARUP Laboratories, and if we're lucky enough to get an elevation, it's worthy of attention.

[01:03:35] Scott: Is it generally true that it's best to do the testing in the middle of asymptomatic presentation or attack, rather than when people are feeling better?

[01:03:46] Beth: You have a better chance doing it during an attack. But again, you may not actually excrete this Porphyrin after. So, yeah, it's tricky. If we had unlimited funds, we would test somebody's daily and make sure the lab could handle a sample correctly. But I just don't -- I guess the point I'm making is I don't rule it out. if we get a negative result.

[01:04:09] Scott: Yeah, just like Mast Cell Activation Syndrome, right? It's very difficult to really pin down some of those tests. I was introduced to the urinary porphyrin testing, gosh, 10 to 13 years ago, probably through Dr. Klinghardt's work. At the time, we actually would get it from a lab in France. I don't think it was even available here yet. One of his reasons for looking at Porphyrins was really more of an indication of body burden of heavy metals. And so I'm interested in your thoughts around if someone has elevated Porphyrins on these tests, can it be an indication of heavy metals but not necessarily of a Secondary Porphyria? What's the connection there?

[01:04:54] Beth: Well, I think, you know, if we're getting elevated Porphyrins, even if it's from heavy metals, and that can be a form of Secondary Porphyria. And there's a whole interpretation system of looking at which Porphyrins were excreted to determine which metals might be affecting it. So, certain metals will affect different enzymes in the pathway. So, you can use that interpretation matrix.

[01:05:21] Scott: Like the Uroporphyrin and the Coproporphyrins and some of those, I think, right? Yeah.

[01:05:28] Beth: That's a big one for lead and mercury are big ones.

[01:05:32] Scott: Let's jump in now to some treatment conversation. So, you have kind of a treatment approach that looks at structural factors, biochemistry, stress, emotions, can you walk us through a little bit, high level in terms of the treatment of Porphyria and some of the key things that you would explore? And how similar is treating Porphyria to treating Mast Cell Activation where you have to consider both treating the presentation but also simultaneously dealing with the underlying triggers?

[01:06:02] Beth: Right. So, one, let's talk about the traditional treatment approach. So, traditional treatment approach is going to include some medications that can have severe side effects like Panhematin, along with glucose IVs and fluids. Now, I am not a medical provider, I'm a Functional Naturopath. So, I'm always looking at supporting natural pathways, addressing root causes. And my approach is based on really looking at and identifying what those triggers are, how do we support the pathway? How do we avoid creating more Porphyrin build up, if that's going on? So, it gets really complex and very individualized for the person. But how do you want me to walk you through, where would you like me to start?

[01:06:56] Scott: Well, we can -- So, you mentioned that there's the structural piece, the biochemical piece, we talked a little about the structural piece being the airway piece, we've talked a little about biochemical, we talked about stress and emotion. So, I mean, I can just kind of maybe jump into the more specific questions and see where we go. I know you mentioned dextrose, so that can be a rescue for people that are having a Porphyria attack. Why is dextrose helpful and many times people think of that as kind of the opposite of what they would be doing when they're not treating Porphyria, right, that it may not be good to have a high carb diet, for example, but if you have secondary Porphyria, then that may actually be a good thing. So, what's the role of dextrose in terms of Porphyria?

[01:07:43] Beth: So, dextrose will slow down the top of the heme pathway. So, let's say in this eight-step pathway, at step seven, with that a block and Porphyrins are building up, building up. If we're using dextrose, it'll slow down the flow. And it's not because of the dextrose metabolism in the Krebs cycle is actually a feedback mechanism on that beginning enzyme itself that responds to dextrose and gets downregulated when there's dextrose. We can use other carbs as well. So, honey can work, to cassava can work, so that can slow it down. So, that would be step one, if somebody is having an attack is how do we slow down the heme pathway for them at that moment, not forever, but just at that moment, use some binders to mop up the porphyrins and then in terms of the whole approach, just to outline it from a high level. Then we look at the prevention issues addressing triggers, digging up the triggers, cleaning up the pathway inhibitors that we talked about, the heavy metals, the biotoxins, the reactive oxygen species work on iron dysregulation, and the last thing that we do are direct team supports.

[01:09:05] Scott: So, let's talk then about the detox side of things. So, we know that toxins like metals and other toxins can be triggers for Porphyria in someone that has Porphyria and isn't detoxifying well, are we better serve to focus on addressing their Porphyria, to optimize their detoxification? Do we need to do both simultaneously, and is there a role for things like colon hydrotherapy, infrared saunas, what role do they play?

[01:09:33] Beth: So, we think about that heme is needed to again, make a lot of the detoxification enzymes, then my approach is to reduce the Subclinical Porphyria symptoms first. So, if somebody's in an attack, we don't want to go straight to detox because that can exacerbate that attack. But once the attack is calm down, then we start to again proceed logically and slowly to reduce the toxins. Definitely supporting the colon, the liver makes sense at that point. Again, we want to do them cautiously, we want to make sure with that binders on board, we've got gallbladder and colon supports, kidney supports on board. So, whatever toxins are being mobilized, can be excluded pretty rapidly.

[01:10:21] Scott: And my understanding is, you can correct me if I'm wrong, but that it's easier to try and prevent an attack than it is to clean things up after the attack is underway. So, if that's true, what are the things we do to prevent an attack?

[01:10:35] Beth: Yeah, we definitely want to prevent an attack rather than have to clean it up after the attack goes underway. Because those attacks can last days to even months to calm down. And then they can cause a whole cascade of problems. So, prevention is really about those root factors. So, checking on what sources of toxins does a person have, are they eating diet that's loaded with glyphosate and other pesticides? Do they have continual toxin intake in terms of heavy metals? Are they using aluminum deodorant? Are they using aluminum cookware? What's the water source? How are they filtering the water? Are they using cast iron cookware? And that may not be ideal if there's an iron issue, so there's so much that we can do to prevent the attacks. We can also help make sure that the immune system is functioning optimally so that we don't have onslaught of infections even things like checking, is the person using proton pump inhibitors? Do we have enough stomach acid to prevent those downstream infection issues, prevent malabsorption issues, so we don't have nutrient depletion then it can affect this pathway?

[01:11:53] Scott: So, let's talk just briefly about cofactors and pathway inhibitor. So, what are some of the cofactors that help optimize the heme production?

[01:12:03] Beth: So, there's quite a number of them, and a lot of the B vitamins, B1, 2, and 3, B5 and 6, folate and B12 and biotin, these are cofactors for different enzymes in the heme pathway. And then, lipoic acid, we've already talked about iron and copper, and also zinc are all used as cofactors in heme pathway. And if anybody's interested in more of this, more information on those cofactors, there's a great thesis that was written that came out of New Zealand called “Investigating the Porphyrias Through Analysis of Biochemical Pathways”. And that thesis really digs into what these nutrient cofactors are.

[01:12:46] Scott: Beautiful. So, bringing in some of the cofactors, we've talked quite a bit about the various pathway inhibitors. So, things that we need to clean up or reduce like, oxidative stress, infections, biotoxins, metal, using binders. Let's talk a little bit about the binders because that's one of my really kind of favorite topics in this whole realm. So, what role do binders play in helping with Porphyria? Are they actually binding Porphyrins and are there specific binders that you find helpful?

[01:13:17] Beth: So, charcoal is a great line for binding the Porphyrins. And beyond that, I like to think about what else the person is dealing with and then what would make sense for them. So, for example, if a person also has Mast Cell Activation Syndrome, I really like to use charcoal and zeolite because zeolite also will bind those histamines. Charcoal is really my go-to here for Porphyrins and then we can bring other ones in as they make sense based on what somebody is-- what those root issues are, what else we need to find out.

[01:13:48] Scott: What are some other potential tools that you commonly use in helping someone dealing with Porphyria?

[01:13:55] Beth: There's quite a bit that we can do. Again, customizing it for the person, one of the things I like is making sure that we've got enough Vitamin D, making sure that we've got enough Retinol, that gives some skin protection. Melatonin, maybe necessary if people have low melatonin, and they have insomnia. It's also a great antioxidant, they can neutralize peroxynitrite. And then we can, like we've talked about before work on the iron regulation, make sure we have iron in the proper form available. We can do things to gently detoxify like castor oil packs to help. I like to do things that help support the lymphatic system. So, I always send my clients videos on how they can do lymphatic drainage on themselves or things like gentle rebounding. So, these are some of the areas that we can go into. And then the other thing I want to share with you is that Bob Miller and I are working on some heme pathway support formulas. So, we're going to introduce those at the 2019 Environmental Toxins and Genetics Conference. Neil Nathan's going to be there, Jill Carnahan, and really excited about that coming up in September in Denver, and we'll have those formulas and a lot of other new ones available for people.

[01:15:17] Scott: Beautiful. So, you mentioned castor oil packs for helping to support detoxification. I had mentioned earlier the idea of colon hydrotherapy or sauna, and I think we kind of jumped ahead. So, are those potentially helpful tools or not? I know sometimes people are hesitant with saunas that you can kind of stir things up inside the body that not everything is leading through the sweat and that they can be a little bit aggressive for some people. So, what's your experience been with colon hydrotherapy and sauna therapy?

[01:14:46] Beth: With the saunas -- So, my population is majority of the population work with has had Mast Cell Activation Syndrome. So, most people with Mast Cell Activation Syndrome can't tolerate sauna. Although, I've had a couple people be able to use sunlight and sauna and I think it might be related to the wavelength they're using. I'm not sure yet I haven't been able to get enough info. But most people I know are really feeling bad with saunas, having a lot of Mast Cell Activation, and also, might be mobilizing too much. Colon hydrotherapy is something that I think people are doing really gently. They can try if it's brief, they can try a bit more intense. You know, we got to look at who it is make sure that again, those binders on board, make sure people can handle the toxin load that's being liberated. Some people can do really short sauna sessions. So, it is always important to build people up super slow, make sure they're tolerating things. I'd rather build people up slow then go too fast and they crash.

[01:16:48] Scott: Are there any other pieces of this whole conversation, Heme Dysregulation, Secondary Porphyria that we didn't pull together or that you kind of wanted to make some comments to kind of tie it up in a nice little bow?

[01:17:04] Beth: Sure. Well, I think when we're thinking about Heme dysregulation and Subclinical Porphyria, there's a few different approaches people can take. One, people can do nothing, and they're going to really suffer quite a bit. It doesn't hurt to find out if this might be an issue that you're dealing with, especially if you're sensitive, you're dealing with the symptoms, people can't figure you out. There's the approach of medicating the attacks, just with using dextrose. You can use -- Post people with Subclinical Porphyria are never going to get the medications prescribed for the Panhematin, or in Europe, there's one called Heme arginate because they're just never going to meet the criteria needed for the classic Porphyrias. But people can medicate with fluids and dextrose, and that will handle the symptoms, but the situation will continue to become worse and spiral down over time because the root causes aren't being addressed. Or you can follow what I do, which is the functional approach of looking at those root factors, supporting the proper functioning, getting things working again, and helping to avoid this continual triggering. And once the heme is functioning again and we have heme, then detoxification can get back online, nitric oxide can get back online, we can make more NADPH, and the whole body can work a lot better. It does take a lot of work but for people who are willing to put the work in, it really pays off to get their lives back. And again, if people want to look more at what those root factors are, I do have that free report at MastCell360.com/freereport. It's written for Mast Cell Activation Syndrome, but the root causes are very, very similar in Subclinical Porphyria.

[01:19:02] Scott: Beautiful. So, the last question I ask is the same for every guest and that is, what are some of the key things that you do on a daily basis in support of your own health?

[01:19:12] Beth: My health does take a bit of maintenance. I've been more sick than most people and I have quite a number of unusual genetic variants. But I do let myself sleep the amount I need to. I try not to schedule anything early in the morning. I practice some form of breathing and meditation every day. So, for me, it's usually Coherent breathing and Qigong. I don't have skin involvement. And so, fortunately, and I can get plenty of sunshine. I walk every day. Strengthening is a huge part of myself here because I do have EDS hypermobility. And so weights and strengthening really helped keep my body functioning well. I do a lot of hydrogen water. I love hydrogen water, feel really great on it. And then I'm working on mold toxicity for myself and I really work hard to keep my toxin load down with water filtration, air filtration, eating organic, pasture raised meats. But I also have to eat low histamine, low oxalate, reluctant glutamate, which is a lot of lows, but that's what works great--

[01:20:15] Scott: That's why you like the hydrogen water so much. That's like pretty much all that's left, right?

[01:20:21] Beth: I do have a good big food list. A lot of my clients have food sensitivities so I make lots of cross-reference lists for people. I do to laugh and have fun because that's so healing to the body. And when you've been sick, you know, you gotta have some enjoyment in life.

[01:20:37] Scott: And you're doing important work, and this now is your purpose and passion and helping other people. And so I think that in and of itself is healing and very rewarding as well. This has been a very detailed, complicated conversation, I think. I hope we did a good job at least in trying to introduce listeners to the topic. For more information reach out to MastHealth360.com. I just want to thank you for the time that you spent sharing your

knowledge and your wisdom with listeners today and for everything that you do to help people minimize their struggle and improve the quality of their life.

[01:21:13] Beth: Thank you so much, Scott. It's really an honor and a privilege to be with you today.

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