Temperature Sensitivity and Rare Neuroimmune Disorders

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Krissy Dilger: [00:00:00] Hello and welcome to the SRNA Ask the Expert podcast series. This podcast is entitled, "Temperature Sensitivity and Rare Neuroimmune Disorders." My name is Krissy Dilger, and I will be moderating this podcast. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. Our 2021 Ask the Expert podcast series is sponsored in part by Alexion, AstraZeneca Rare Disease, Genentech, and Horizon Therapeutics.

[00:00:38] Alexion, AstraZeneca Rare Disease, is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development, and commercialization of life-transforming therapeutic products. Their goal is to deliver medical breakthroughs where none currently exist, and they are committed to ensuring that patient perspective and community engagement is always at the forefront of their work.

[00:01:06] Founded more than 40 years ago, Genentech is a leading biotechnology company that discovers, develops, manufactures, and commercializes medicines to treat patients with serious and life-threatening medical conditions. The company, a member of the Roche group, has headquarters in South San Francisco, California. For additional information about the company, please visit www.gene.com.

[00:01:34] Horizon is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Horizon believes science and compassion must work together to transform lives.

[00:01:59] For today's podcast, we are pleased to be joined by Dr. Gretchen Hawley. A Doctor of Physical Therapy, with years of clinical practice experience, Gretchen is a physical therapist and Multiple Sclerosis certified specialist through the Consortium of Multiple Sclerosis Centres. She has a special interest in the management and wellness of MS patients, helping to improve balance, walking, and energy. She often presents as the Keynote Speaker at numerous MS events, including Living Well With MS events sponsored by the MS Society, in addition to MS Views & News. Other collaborations include national MS organizations, including the National MS Society, MS Association of America, and MS Foundation. Additionally, Dr. Gretchen shares her expertise to MS support groups, podcasts, and on her own YouTube and social media channels.

[00:02:58] Dr. Gretchen developed an online MS Wellness Program specifically geared towards helping people with MS in their own home and uses social media to create more awareness around MS and neuroplasticity exercises that can help improve the quality of life for individuals living with MS worldwide. You can learn more about her at her website at www.MSingLink.com.

[00:03:30] Thank you so much for joining us today. Our first question: is being sensitive to heat or cold the same as experiencing an issue with temperature regulation?

Dr. Gretchen Hawley: [00:03:42] Yes. Thank you so much for having me. So, I believe that differences in temperature regulation is different than having heat sensitivities or cold sensitivities.

[00:03:54] And the reason I say that is because heat intolerance or a cold intolerance is caused from something that is changing your core temperature. And that could be something that you are doing, or it could be an external factor like the sun or the cold. However, thermal or temperature regulation is actually a misfiring.

[00:04:18] So it's basically your body sensing that you're warm. And so, it will make your face red, or maybe you'll start sweating or, on the contrary, your body will sense that you're cold. So, you'll start shivering. When in reality you're not cold. It was a misfiring. Your brain got the wrong message, but it responds as if that message is true.

[00:04:39] So there's a difference between your body interpreting the messages it's receiving versus something actually causing your core temperature to either rise or fall.

Krissy Dilger: [00:04:51] That's a great explanation. Thank you. Our next question: what's the cause of temperature regulation issues and the demyelinating disorders?

Dr. Gretchen Hawley: [00:05:02] So, the cause is the core temperature rising, which might sound obvious. But let me explain that a little further. So what causes, let's start with heat intolerance. So more of the high temperatures. All that is required for heat intolerance to kick in is anything to raise our core temperature by at least half of a degree, which is so small. There, it doesn't take much to raise our core temperature.

[00:05:31] And whether you have an autoimmune disorder or neurological or no disorder at all, our core temperature raises with a lot of different things. So, things that can cause heat intolerance is exercise because exercising heats up our body and that might mean a physical therapy program or just doing some upper body exercises or going for a walk.

[00:05:57] So any movement, even chores, even making our bed, things like that. Or the sun outside or humidity, even if you're inside in air conditioning. And then, on the contrary, cold intolerance is anything that allows our core temperature to lower by half of a degree. So again, that could be anything. And the trick usually is to do the opposite.

[00:06:21] So if your core temperature is rising by at least half of a degree, there are things you can do to cool it down, or at least neutralize it and vice versa. If it's cold intolerance, you can then do things to raise your temperature. So, it's more of that cause of something that either you're doing, or the surrounding that you're in, or something like stress that brings on that heat and temperature regulation.

Krissy Dilger: [00:06:48] Great. Thank you so much. Our next question: is it the same or possible for all of the rare neuroimmune disorders? For example, will someone with ADEM only experience the same issue as someone with transverse myelitis in the lumbar spine?

Dr. Gretchen Hawley: [00:07:08] So, it is possible for all of the rare neuroimmune disorders to have this as a symptom of irregular temperature regulation, but it's not definitive.

[00:07:25] So, therefore, you and I might have the same neurological disorder or neuroimmune, but we have vastly different symptoms. So, it is possible, but I am an MS specialist and I treat many people with MS, as well as other neuroimmune disorders. And not everyone has the most common symptoms. Heat sensitivity and cold sensitivity being a common one.

[00:07:49] But not everyone has that. With that said, some people don't have those symptoms at first, but they might get them 15 years later or vice versa. They used to have it, but now they don't. So, it's ever changing, and each person is so different. So, it is a possibility, but it's not a guarantee that you will experience this.

Krissy Dilger: [00:08:11] Very interesting. Thank you. Our next question: is temperature regulation an autonomic issue? And what is the autonomic nervous system responsible for?

Dr. Gretchen Hawley: [00:08:23] Yeah, that's a great question. So, the autonomic nervous system is really a component of the peripheral nervous system. And within the autonomic nervous system is the sympathetic and parasympathetic.

[00:08:37] So I know I'm throwing a lot of big words out there. So, the autonomic nervous system is what is responsible for regulating our physiologic responses, meaning our heart rate, our blood pressure, breathing, digestion, sexual arousal. So, it's responsible for a lot of different things. Now, just to break that down a little further, the sympathetic portion nervous system of the autonomic is responsible for our fight or flight responses.

[00:09:10] And then the parasympathetic is what is responsible for the bodily functions, meaning digestion, metabolism, and also actually relaxing. So, the autonomic nervous system can absolutely cause some of these symptoms because it regulates our body, including temperature.

Krissy Dilger: [00:09:31] Thank you so much. Next question is, can too hot or too cold temperatures cause someone to experience autonomic dysreflexia? And can you also just give us a brief explanation of what autonomic dysreflexia is?

Dr. Gretchen Hawley: [00:09:49] Yeah. So autonomic dysreflexia is typically described as either an abnormal or an overreaction of the autonomic nervous system.

[00:09:59] So as we had said, autonomic nervous system is responsible for our bodily functions. And so, basically, this is an overreaction of that. So, if we are, in this case, you know, we're talking about temperature, regulation, sensitivities. So, if we are sweating because it's hot outside or because our internal core temperature is rising, autonomic dysreflexia is an overreaction of that.

[00:10:26] Meaning we could be sweating profusely when someone else might just be sweating a little bit or hardly sweating at all. So, it's that overreaction. And when you have neuroimmune disorders and diseases, that is, it's something that is very common.

[00:10:43] However, autonomic dysreflexia is not necessarily caused by temperatures. It's not caused by it being hot outside or it being cold outside. It's usually caused from a disorder. So spinal cord injury is one of the most common causes of autonomic dysreflexia. Similarly, Guillain-Barre syndrome, some side effects from medications, some severe head traumas. So, it's more of these issues that are the cause versus something external, like the temperature outside.

[00:11:20] However, the symptoms of it could be the temperature changes in our body. So, a fever, for example, high blood pressure is another symptom of autonomic dysreflexia.

Krissy Dilger: [00:11:32] Great. Thank you. Our next question is, if someone's sensory nerves are affected by their demyelinating disorder, versus just their motor nerves, is it more likely they will experience issues with temperature regulation? Is it worse for them if they cannot tell differences in temperature?

Dr. Gretchen Hawley: [00:11:52] I'm not sure that it's necessarily more likely that you will experience issues. I will say it's more likely than someone who doesn't have any type of neuroimmune disorder. So, in that sense, yes, it is more likely, but as I mentioned earlier, everyone is different.

[00:12:12] So one person with a neuroimmune disorder might have some type of temperature regulation issue, whereas someone else wouldn't. So, my answer for that one is kind of wishy-washy. But as for if it's worse, if they can't tell the difference, I think, yes, the reason for that is because it's unexpected and it often comes out of nowhere.

[00:12:34] If you can't tell differences in temperature, it's harder for your body to regulate it. And it will often result in an exaggerated response similar to this sweating that we were just talking about. If your body didn't sense that it was warming up, then all of a sudden you start sweating, it might be exaggerated.

[00:12:54] Or, on the contrary, if it's cold and you didn't really notice the temperature outside or something that was causing your core temperature to lower, you might notice some of your symptoms kicking in. And so, when that happens, your body started responding to the temperature change without you even realizing it.

[00:13:16] And therefore resulting in one of your symptoms flaring or temporarily worsening or a symptom like sweating or shivering because you're cold kicking in.

Krissy Dilger: [00:13:28] Okay. Got it. Thank you. Our next question is, do issues with temperature regulation have the same effect on a person, whether they're due to external factors, such as the weather or internal that may occur with exercise?

Dr. Gretchen Hawley: [00:13:46] Right. So, I remember hearing, I can't remember if this was maybe two or three years ago and there has been more research since then. So, I'm not sure if this is still what they are saying, but about two or three years ago, I remember hearing a physical therapist who worked with a lot of people in this population, and he was talking about heat sensitivities and cold sensitivities.

[00:14:09] And he had said that active heat intolerance, meaning internal, so meaning something that you are doing, can be slightly worse than passive. So that would mean that exercising might make your heat and tolerant symptoms kick in more so than if you were just sitting outside on a hot day.

[00:14:30] Now that was according to research at that time. I will say I've had clients where it's hit or miss. For some people, the external temperature outside or humidity or barometric pressure makes them worse compared to the internal things that we do, like exercise.

[00:14:48] So I personally think it depends on the person, but, again, there are things that you can do to change the temperature of your body. So, either way, you are able to either lower your core temperature or raise it, but as for which one affects you more, I think it's pretty individualized.

Krissy Dilger: [00:15:09] Okay, thank you. Our next question is, are there warning signals or clues my body may give me that I'm experiencing temperature regulation issues that I may not be immediately aware of, particularly since I don't have sensation from the chest down?

Dr. Gretchen Hawley: [00:15:28] The most common thing that I will hear from my clients in how they know that something is going on is that one of their symptoms temporarily worsens. With multiple sclerosis, it can be, and as well as any other neuroimmune disorder, it can be something like sensation changes, or vision changes, or fatigue, or weakness. And so, what I tell my clients is if you ever notice a, what I call a flare, in any of your symptoms, it's important to first acknowledge that it's there. And then the first thing I have people do is ask themselves, 'Is there the possibility that I could be overheating right now, that my core temperature could be overheating, even if I feel fine?'

[00:16:18] And that might be a situation like if it's really hot outside, the barometric pressure is high, but you're inside, in air conditioning. You might feel fine because you're in air conditioning, but that barometric pressure can very much still affect you. So yes, there is a possibility that your core temperature could still be rising from that.

[00:16:38] Or, on the contrary, if it's cold intolerance, and, therefore, your core temperature has lowered, 'Is there the possibility that my core temperature is lowering right now?' And the answer might be yes, even if it's wintertime, if you're chilly, but you're wrapped in blankets or you're wearing a really warm sweater. You know, that's something that might increase your core temperature.

[00:17:01] Or if it's warm outside, and, therefore, you're taking layers off. Maybe you're just wearing a tank top. That can cause your core temperature to lower. So, it goes both ways. So, asking yourself, 'Is there the possibility that my core temperature could be either rising or lowering causing this symptom that I'm feeling?' And if the answer is yes, then you want to implement one of the things that you can do to either lower or raise your core temperature. So the way that I will tell my clients to just be aware of that is to just be super aware of your symptoms and if anything increases that might be a sign that something's going on.

Krissy Dilger: [00:17:41] Yeah, that makes sense. Thank you. Our next question is, do any of the medications commonly used in neuromyelitis optica spectrum disorder as immunosuppressants affect temperature regulation? And how about common medications used to treat neurogenic bladder or spasticity?

Dr. Gretchen Hawley: [00:18:02] Yeah, that's a great question because a lot of medications, while they are helpful for some diseases and symptoms, they also can have a response on a different symptom. So, I will say that among several of the heat interacting medications, there's several, but the most common ones are antidepressants, antihistamines, antipsychotics, and diuretics. So, if someone is taking any of those four, I will always educate them on how that can play a role in your internal core temperature, because that might be a situation where you just have ice cold water on hand, just in case you do start feeling your core temperature rising. So those four medication groups are the most common ones to play a role in your heat, temperature, thermal temperature within your body.

Krissy Dilger: [00:19:01] Okay. Great. Thank you. Our next question is does someone's ability to sweat impact their tolerance for heat?

Dr. Gretchen Hawley: [00:19:10] It does. So sweating is something that our body automatically does when it senses that it's getting too warm and so it's trying to release some of that heat. So, this can go both ways. If

your body isn't sensing the heat, then you might not be sweating. And then you can, your core temperature really rises because your body's not getting rid of that heat. So that's one situation.

[00:19:36] Another situation is the opposite, where your body excessively feels that heat. So, you start sweating excessively to try to get rid of it. And as we said in the very beginning of this chat, it can either be caused from temperature irregularities, so it is hot outside or your core temperature is rising, or it can be a misfiring of signals, meaning your body feels incorrectly like it's getting hot. So, it helps you to start sweat to get rid of that heat, but in reality, it's not that hot outside. So, it can be caused from heat intolerance and or thermal irregulation.

Krissy Dilger: [00:20:18] Okay, great. Thank you. Our next question is, what is Uhthoff's phenomenon? And please correct me if I said that incorrectly.

Dr. Gretchen Hawley: [00:20:28] Yes. There's a few different ways, 'Uhthoff's, Uhthoff's.' What that means is that your core temperature is rising and that causes a symptom. So pretty much what we're talking about today.

[00:20:40] So what's really important to know about, I pronounce it 'Uhthoff's' phenomenon, is that it's only that half of a degree, which is so important because as I mentioned earlier, it does not take much to raise or lower your core temperature by half of the degree. Now, everyone is different. Some people who are very sensitive will notice if their core temperature changes by half of a degree or one degree or two degrees.

[00:21:07] And they'll notice it because one of their symptoms worsens. However, someone else might have a higher threshold. So, they might not notice any worsening symptoms until it's maybe a five degree change or 10-degree change. So, it's important to know what your body, not know what your body, but know how your body responds to different changes in your core temperature, as well as the temperature around you.

[00:21:37] So Uhthoff's phenomenon, temperature rises causing a symptom. And the tricky thing is that it can be any symptom that you've had before. It can be something that you currently have going on, but it's just exacerbated or flared, or it can be a symptom that you haven't felt in a while. And now it feels like it's coming back. The good news is that to get this symptom to reduce or even go away is to manage your core temperature.

Krissy Dilger: [00:22:08] Great. Thank you so much. Our last question is what can someone do to deal with temperature issues? And this could either be like preventative measures or, if they're experiencing temperature issues, are there any medications or remedies that can help relieve the issue?

Dr. Gretchen Hawley: [00:22:27] Absolutely. So, the best thing to do if possible is to be proactive. So, if you're someone who's listening to this and you feel like you're resonating with a lot of what we're talking about, then what I would suggest you do is make a list. And this can be a pen and paper list, or just a list in your mind, but make a list of all the things that you've noticed caused heat intolerance or cold intolerance.

[00:22:53] And this list will be different for everyone. For some people it's going to be the temperature outside, the humidity, maybe it's exercise, maybe it's a hot shower, maybe it's stress, overwhelm, anxiousness. Write a list of all the things that have caused you to overheat or cause any of your symptoms to worsen. And you can use that as a guide.

[00:23:16] So, for example, if you're leading into the holiday season and you know lots of families going to be around and it's going to be a little bit stressful, that might actually cause your core temperature to rise

because it's a stressful situation. Or if exercise is something that gets your heat intolerance kicking in, then before you exercise, you can take some of these precautions that I'm about to mention.

[00:23:43] So if you can be proactive, if you know it's a hot day, if you are about to exercise, if you are entering a stressful situation, then be proactive by cooling your core temperature down. So, my favorite way to cool your core temperature down is to sip ice cold water. And I don't mean just room temperature water, but truly ice-cold water.

[00:24:07] If it's room temperature water, it won't do as much to cool your core temperature down. So, sipping just tiny sips. I know that bladder and urinary frequency incontinence, those can play a role here. So, I'm not talking about chugging your water as fast as you can, but just tiny little sips before you enter that situation or, additionally, while you are in that situation.

[00:24:36] So if you're someone who thinks, you're like, 'Well, I don't know what causes my temperature changes,' and you just find yourself stuck in that situation where you're doing something or just sitting around and you feel that one of your symptoms is worsening, you can implement the same technique of sipping ice-cold water.

[00:24:53] So just always have some ice-cold water nearby. Or if you're more prone to cold intolerance, then you can have some hot water nearby. So that's my favorite because you are ingesting it. So, you're putting something in your body that will help change your core temperature.

[00:25:11] However, there are other things that you can do as well. So, if it is heat intolerance, you can, there's so many different types of cooling garments. There's cooling t-shirts, there's cooling neck wraps, cooling scarves, cooling hats, cooling packs, cooling vests. And there's so many different kinds of, I've been an MS specialist for six years now. And even in the last six years, there are so many new companies coming out with various products that are so much better than what we had six years ago.

[00:25:45] They're lightweight, they are hidden under your clothes, and so people can't tell that you're wearing a cooling device or a garment. So, I really liked those things. And if it's the opposite, if it's cooled in tolerance, then it would just be bundling things up.

[00:26:03] So instead of wearing something cooling, you can either bundle up more sweaters. I actually have something that is called the YuYu Bottle and you can put cold water or hot water in it. And it's like a really long water bottle. It's literally, probably the length of my arm. And what you do is you can put it around your chest. You can put it around your belly area, you can just hold it in your arms.

[00:26:28] And so that's something that can warm your temperature up as well. So ideally being proactive and implementing those strategies, but even if you're not proactive, it's still those same strategies that you would do to help deal with some of these temperature issues.

Krissy Dilger: [00:26:44] Thank you so much. We really appreciate you joining us today and giving us your time and expertise on this topic. I know that it's an issue that a lot of people deal with and we're excited to offer this as a resource to our community.

Dr. Gretchen Hawley: [00:26:59] Of course. Thank you so much for having me.

Krissy Dilger: [00:27:01] Thanks.