NATIONAL HEADACHE FOUNDATION
HEADWISE™ PODCAST

Episode 231: Idiopathic Intracranial Hypertension Explained

Lindsay Weitzel, PhD:
Hello everyone, and welcome to HeadWise, the videocast and podcast of the National Headache Foundation. I'm Dr. Lindsay Weitzel, founder of Migraine Nation and lindsay.com. I have a history of chronic and daily migraine that began at the age of four. And our guest today is Dr. Betsy Grunch. Hello, Dr. Grunch, how are you?

Betsy Grunch, MD:
I'm good. How are you?

Lindsay Weitzel, PhD:
I am great. So many of you may know Dr. Grunch from social media as Ladyspinedoc. Dr. Grunch is a neurosurgeon specializing in minimally invasive spine surgery. She works out of the Long Street Clinic for neurosurgery in Georgia. She is really fun. We are excited to have her on today and we are going to learn about pseudotumor cerebri, also known as idiopathic intracranial hypertension [IIH], and the role of a neurosurgeon. So, let's start just talking about what we should call, because the name can be confusing and it has a lot of names. So, I find it to be kind of difficult. Some people call it pseudotumor, high pressure headache, IIH. What do you like to call it Dr. Grunch?

Betsy Grunch, MD:
I think all of those names are commonly used, and I think it's important to know that they're all the same thing. The preferred way I like to refer to it is idiopathic intracranial hypertension. Pseudotumor just sounds kind of more scary in my opinion because it has the word tumor in it. But IIH is what I kind of typically refer to it with my patients.

Lindsay Weitzel, PhD:
And can we break that down? What does that mean in idiopathic intracranial hypertension?

Betsy Grunch, MD:
Very good question. So intracranial hypertension, “intracranial” first off, means inside the head or inside the cranium. And “hypertension” means elevated pressure. So, when we talk about blood pressure, we call that hypertension. But when we're talking about CSF pressure, that's intracranial hypertension. So too much pressure inside of the head also is known as hydrocephalus. But when we're talking specifically about IIH, there's not a known cause.

In other cases of elevated intracranial pressure, there may be something that's causing it, whether it be tumor blockage of the pathways, head trauma with swelling of the brain, bleeding on the brain, stroke, other reasons. But idiopathic means we really don't know why someone has it. So it kind of happens without a known cause. And that's why we call it idiopathic intracranial hypertension. Say that five times fast.

Lindsay Weitzel, PhD:
Yeah, I know. So, we're going to call it IIH. Now that everyone knows what it is. And the other reason, there's a few reasons, it's difficult to discuss on the podcast sometimes, but the other one is that maybe not everyone knows what CSF or cerebral spinal fluid is. Can you give a quick discussion of what that is and why we have it?

Betsy Grunch, MD:
Yeah. So, CSF or spinal fluid, I think most people kind of have an idea of what spinal fluid is. It's a fluid that naturally bathes the brain and spinal cord. Our brain and our spinal cord are part of our central nervous system that makes us who we are. It makes all the nerves conduct in our body to feel, to move, all of those things. And so it's kind of suspended or floats around inside of our body in CSF or fluid, so it's buoyant and our brain produces this fluid. And it circulates inside of the brain, around our spinal cord, through our spinal cord, and then circulates back all the way back to our brain to be resorbed. And that fluid provides nutrients to our brain. And then it also excretes waste, so it allows our brain to kind of clear itself. So, it's the circulatory system of the nervous system, if you will.

Lindsay Weitzel, PhD:
This is one of the things I think it's so important to make clear because often it isn't clear. Let's talk about these symptoms of IIH. What are the symptoms and how can we make them stand out perhaps from other types of headache? How do we know that IIH is different from these other headaches that so many of us get?

Betsy Grunch, MD:
The symptoms of IIH can range. So, it can be headaches to visual disturbances to cranial nerve palsies. So headaches is the most common. I mean if we have too much pressure inside of our skull, patients will complain of headaches. It's usually diffuse. It's dull, it's throbbing. Usually, it's worse in the morning because you've been lying down all night. Or it's worse when you lie down. And then it can be improved a little bit if you stand up because then the fluid will kind of flow out of your brain.

The headache can worsen when you do things with a Valsalva maneuver. So, think of Valsalva meaning bearing down. So, like if you're going to poop or strain or you're coughing or sneezing, that headache can worsen. And then if the pressure builds up high, higher, patients can then have visual symptoms.

So that's because of pressure on the optic nerve. So patients can have blurry vision, double vision. And they can have visual field deficits where they actually can't see peripheral field. And papilledema is kind of sometimes how they find it. They may go to their eye doctor because of these blurry vision. The eye doctor will look in the back of your eyes. You know, you've been to the eye doctor. They'll put those

dilating drops and look. And what they're doing is really opening up that pupil so they can get a good light. And that exam is so cool because it allows us to really see directly into the brain, really into our nervous system. So, if they see signs of swelling of the optic nerve, that means the brain is swollen too. And so that can lead to the diagnosis of pseudotumor. And then if it's untreated, this vision loss can even be permanent. And that's one of like the scary things about IIH is it can result in that.

Other symptoms can be pulsatile tinnitus. That means like hearing a whooshing sound or pulsing sound in your ears. Often that's pretty common and overlooked. It can even cause back pain, neck pain, nausea, vomiting, dizziness, balance, other things like that too.

Lindsay Weitzel, PhD:
Does IIH often cause brain fog?

Betsy Grunch, MD:
It can. Absolutely. I mean, anything where our brain isn't functioning at our best, from disturbances related to pressure, absolutely causes brain fog.

Lindsay Weitzel, PhD:
Are there any people that are more likely to develop this, or do we know are there any risk factors?

Betsy Grunch, MD:
Yes. So, we know that patients that are overweight are more subjected to develop IIH, particularly if it's central obesity, so where weight is more distributed on our belly. And the thought is that that increase in your abdominal pressure can cause increased venous pressure and then impair the way we're resorbing CSF.

Sometimes these adipose-derived hormones like leptin, inflammatory cytokines, those can also affect the way our CSF dynamics work. And those are some of the issues. We also know it happens in women, usually of childbearing age. So the typical demographic we think of as a physician, now it can vary, the more generalized is a young, women of childbearing age, so in their 20s, 30s, that's overweight. And that's because women of childbearing age, there may be a hormonal link to that type of thing. So, yeah.

Lindsay Weitzel, PhD:
What type of physician usually diagnoses this? And how is it diagnosed?

Betsy Grunch, MD:
It can be diagnosed by any physician that really detects these symptoms. And that's why awareness of this as a pathology is so important. Because usually young women is the typical age demographic. And to be honest, young women is the population that is typically gaslit for these unusual symptoms– headaches, migraines, brain fog. Like, how many of us complain of that. And so they get blown off.

But it's important to recognize that in patients with migraines and blurry vision, that's not normal. And so investigating that further, asking these questions, is it worse when you lay down? Is it worse when you cough? And to know that it can be outside of that demographic. So primary care can diagnose it. It's often, as I mentioned a minute ago, can be diagnosed by eye doctors who are doing that examination looking at the retina, seeing papilledema. I would say a lot of my patients come to me with pseudotumor because they were diagnosed by their eye doctor because of those vision complaints. And then neurology, they often get sent to neurology for intractable headaches that can't be necessarily managed by the PCP, so they get sent on to neurology. So, those are the typically three most common specialties that will identify this.

Lindsay Weitzel, PhD:
And how is it diagnosed other than with the eye exam? Do you generally need to have a CSF pressure reading for a diagnosis.

Betsy Grunch, MD:
Yes. So, if we suspect it, then how it's diagnosed is by a lumbar puncture because, I mean, the intrinsic name of the diagnosis is intracranial hypertension, so you kind of need to know what the pressure is to make the diagnosis. So that can be done on a spinal tap. And you measure that opening pressure. So you measure the pressure within the spinal canal. And there's a range of numbers. Usually, we use 20mm of mercury as our threshold, for being above that would be abnormal. So, if they're opening pressure is greater than 20, then we would be suspect that it's abnormal, and then they may have some type of hypertension going on and looking at that further.

Lindsay Weitzel, PhD:
So is the first line of therapy, is it something conservative? Are there medications? Do you go straight to some sort of procedure or surgery? What types of therapies are done for IIH?

Betsy Grunch, MD:
Typically, the first line treatment is going to be medication. And it depends on how severe the symptoms are. Like if it's impending vision loss, those kinds of things. But most times we're going to start with, if they are obese, talking about weight loss because that's going to be the most effective long-term treatment. And we're not talking about massive weight loss, even a 5 to 10% reduction of body weight can significantly improve your symptoms. Bariatric surgery can be considered too.

There's really exciting data that I reviewed in the past about even GLP-1s and the thought that these medications, yeah, of course, they help with weight loss, but they can actually change the way CSF production happens. And so if we make less spinal fluid, then it would help the symptoms of IIH outside of weight loss. So like you start your Ozempic or whatever, your headaches can be immediately beneficial even before your weight loss. So that's very interesting. And I think more data remains to be seen on that.

But outside of weight loss, acetazolamide is a medicine that we'll start. It's a carbonic anhydrase inhibitor, so it actually reduces production of CSF. That's the first-line treatment. And then Topamax is another one that can also help reduce CSF production and help with headaches. And it's often used

again in weight loss, and it can help with that as well. So those are the most common medication treatments.

And then we kind of step it up a little bit. Sometimes we'll do a therapeutic lumbar puncture. So, what I mean by them is we can drain off spinal fluid, and that might temporize someone. It's not a long-term solution, but that could definitely help symptoms. Our CSF reproduces very quickly, so again, it's not long term.

If it's more visual field, optic nerve sheath fenestration can be helpful. So we have swelling of the optic nerve which is the nerve that comes from our brain to our eyes. And if those nerves swell because of high pressure, there's swelling inside of that casing of the nerve. So sometimes we'll fenestrate or cut little slits into that casing to allow it to swell a little bit more so it will help the vision. So that's kind of interesting. It can help prevent vision loss. And of course, for someone like me may become involved in a case of IIH, is a surgical procedure called a shunt which will actually take fluid off of the brain and then drain it. Drain it into usually the abdomen to help reduce that pressure.

Lindsay Weitzel, PhD:
So it sounds like there's a lot of options, both medication wise, lifestyle intervention wise and procedure wise for this specific diagnosis. I think the question is more getting the diagnosis for someone who has this problem instead of just assuming you have migraine, etc., etc. Do you think that that can be a problem in this instance? Do you think a lot of people assume they have some other type of headache?

Betsy Grunch, MD:
I think initially, I mean, when it gets into the vision problems, that's often late in the game and sadly, that's when most of these diagnoses are made. And it doesn't happen. It doesn't go from 0 to 60. It's usually this process that happens over time. So they don't get diagnosed earlier enough. They're maybe thought to have migraines or another type of headache disorder, and then it's not until these more obvious signs that help us make that diagnosis. And by that time, sometimes these conservative treatments may not be as helpful. And they may kind of intervene and upscale into their next step of treatment and may have to have surgery sooner than anticipated.

Lindsay Weitzel, PhD:
Do you have any statements to make as far as how effective known treatments are for IIH?

Betsy Grunch, MD:
I think the most important thing is making the right diagnosis. I think the treatments really vary on where you're at in the game. If you diagnose it and their pressure is incredibly high, there's no way that, probably less effective [using] first line treatments. So, there's a stepwise flow of how we typically treat these patients. And ultimately the last step or shunting is almost curative basically. But those shunts can fail, so it's an ongoing problem. It is a curable condition in some instances, like if there is weight loss. If the weight is really the issue, then lose weight. It could cure this without any other treatments. So, it really just kind of varies on where in the pathway that patient is, and how successful the treatments may be.

Lindsay Weitzel, PhD:
Is there anything that you think we missed or didn't touch on, anything you'd like to add before we go today?

Betsy Grunch, MD:
I just think this is a condition in which this demographic of women that, I say women because they're the most common to have it, get gaslit, and it's often a source of frustration. And they get into the medical circle almost jaded because they've been told that it's okay, that there's nothing wrong or whatever the case may be. The imaging may be normal. And so I think it's important to realize that if you feel like you're having symptoms that aren't being recognized by your provider, to get another opinion. Because it's so important to be proactive about your own health. We all know our own bodies better than anyone else. We live in them. So, if you really think something is wrong, go get another opinion and see. And kind of look into this diagnosis if you're having some of these symptoms that we talked about.

Lindsay Weitzel, PhD:
Well, I'm very glad that you chose to close with that. Gaslighting is something that we have dedicated entire podcast episodes to on this particular podcast. So, thank you so much for sharing that. And thank you so much for being here with us today. And thank you everyone for joining us. And please join us for the next episode of HeadWise.

Betsy Grunch, MD:
Thank you.