



## Episode 238: Cerebral Venous Congestion and Headache

### **Lindsay Weitzel, PhD:**

Hello everyone, and welcome to HeadWise, the weekly videocast and podcast of the National Headache Foundation. I'm Dr. Lindsay Weitzel. I'm the founder of Migraine Nation, and I have a history of chronic and daily migraine that began at the age of four. Our episode today is new and exciting and maybe even a little bit controversial. Today we are talking about something called cerebral venous congestion and headache. Our guest is someone who had a respect and whose work I have been following for quite a while now. This is Dr. Ferdinand Hui. Hello, Dr. Hui, how are you?

### **Ferdinand Hui, MD:**

Hello.

### **Lindsay Weitzel, PhD:**

Dr. Hui is the medical director of neurointerventional surgery at Queens Medical Center at the University of Hawaii. He is one of the most published authors in this field, and he has so much awesome things to say. I love hearing him talk. He also is somewhere way more awesome than I am. He is in Hawaii, so I am a little bit jealous.

Dr. Hui, let's start. Since our topic today is not something we hear about every day and it's your first time as a guest on HeadWise, please go ahead and tell our audience a little bit about yourself and why you choose to work in this field.

### **Ferdinand Hui, MD:**

I think you could make the argument that I didn't choose this part of the field. The field kind of chose me. In 2009, one of my colleagues, Mark Luciano, this was at Cleveland Clinic, he told me about a study where a doctor, Nick Higgins, placed a stent for what we now call idiopathic intracranial hypertension.

A team in Toronto had started showing that patients with IIH (idiopathic intracranial hypertension) had narrowing in the veins of the brain in the transverse sinuses at a very high rate, 90, 93%. And so, he published a series of four patients where they got better after the opened those veins. And fast forward 15, 20 years, thousands of these patients are being done now, opening up the veins of the brain.

And the pulsatile tinnitus, headaches, head pressure, as well as visual disturbances get better in those patients. And so, I started treating those in around 2009 and it worked, but gradually I realized there were patients that didn't quite fit. I would see them in clinic. They didn't meet the criteria for IIH as we've defined them in the last 50 years.

And what this meant was I didn't have a paradigm to treat these patients because they didn't have the same things that defined ITH. They didn't have the same structures we saw from the University of Toronto structure studies. But what they did have were narrowings in the neck, narrowings in other places. And it seemed to me, putting on my engineering hat, if venous narrowings and venous slow flow cause this and we treated it and they got better, why wouldn't venous problems somewhere else in the same chain, in the same sewage network, cause similar problems. And it took a long time another 10 or 15 years.

**Lindsay Weitzel, PhD:**

That is a great story. I actually really love hearing what got you started in this field. I heard you say once to not let anyone gaslight you about your symptoms and that your symptoms are real. What is it about this particular type of patients that you see and the disease models that you work with that made you feel that that was an important thing to say?

**Ferdinand Hui, MD:**

I play a game with my patients when they come and see me. I tell them I'm going to play guess your symptoms. And I guess their symptoms. And I just basically go through the checklist of the most common symptoms that patients with venous disease have. And I find that a lot of the patients start smiling somewhere through, because most patients if they have been taught by the doctors non-verbally, I only want to hear your worst complaint, okay, maybe two complaints. But many patients with these problems have 15 or 20 complaints, and no doctor wants to hear it because we really want to focus on one problem at a time. And so, if it's an ear burning, if it's an eye pressure, if it's a throat discomfort, we don't want to hear all of them. We want to hear oh what are you here to see me today for. What is your worst problem. And so many of the patients actually have 30 problems.

And second, many patients in the media are already seen this way, I'm just going to be frank, if you're a woman and you say I have a headache, most people will just go, oh, you're a woman. You have a headache. That's normal. There's oh, I'm feeling anxious. That's normal. You have some chest discomfort. Oh, I've read about that. That's not a heart attack. That's something that women experience.

I like to tell all my students no disease is without a mechanism. We just don't know what they are. And if you have a sensation, somehow, we've decided that common sensations are normal and don't require further evaluation. That doesn't make sense to me. Again, putting on an engineering hat, our systems, our bodies, are pretty well tuned. So, it's in my opinion unlikely that any adverse sensation you have is fully normal and just a glitch, so I would rather take the approach that discomfort is a warning of some sort. It's a warning light of some sort and we just need to understand what they are. There may be, and there probably are, many warning systems that we will not understand while I'm still alive. And 100 years from now, there will be new ones that we don't understand. But to simply say your discomfort is psychogenic, see ya, I don't find that to be particularly satisfying.

**Lindsay Weitzel, PhD:**

Can you define for us what on earth cerebral venous congestion is?

**Ferdinand Hui, MD:**

So, I will say first that we're still in a hypothesis mode. I think it's a strong hypothesis, but let's say the theory of venous congestion. So, the underlying principle is that every engine in your body, every engine in the real world, needs fuel and it needs exhaust. If your car is running on gas, if you have a gas car, it needs fresh gas, it needs oxygen, and it puts out foul vapors that nobody likes to breathe. At least I hope you don't like breathing. If the exhaust is broken, your engine will fail. It will not work well, and frankly, it'll probably ruin your engine.

Even electric cars, they produce heat, so you can give it energy, fresh power. But if it doesn't have a cooling system, it will stop. I mean, all of us have had the phone on the dashboard or someplace hot. Your phone stops working very well. It's very slow. You're frustrated because your button presses don't respond. Everything, every engine needs fuel and every engine needs exhaust. How to get rid of it, spent, whatever. Throughout the body, although it's still edgy, when you have a DVT, your leg feels terrible. It doesn't work as well.

**Lindsay Weitzel, PhD:**

Can you define that?

**Ferdinand Hui, MD:**

Deep venous thrombosis. So, everybody knows this from riding in airplanes. Be careful, if you develop a clot in your leg it could go to your lungs and kill you. So, we focus on the lungs in medicine because it obviously kills you. But people that have a DVT will tell you that it doesn't feel very good. The leg feels heavy, there's pain, it's pressure. And chronic DVTs feel miserable.

So, if this mechanism exists in venous thrombosis and we accept this in the brain. We certainly have patients that one day thrombosis in the veins of the brain, they die or they are permanently injured. There's a study out of France that 30% of patients after a deep venous thrombosis or a cerebral venous thrombosis have severe cognitive disturbances for the rest of their lives. And when I say severe, sometimes in cognitive tests, they are severely impaired in one or more domains of cognition.

So, there's data. It's piecemeal, but the idea that venous impairment can result in organ dysfunction of whatever is being drained, it's out there. It's well documented. It's just not very well organized in a coherent fashion. We're trying to fix that. Hopefully we'll have a paper coming out later this year reviewing all of that data on cognition and venous disease.

**Lindsay Weitzel, PhD:**

And in your analogy, the venous system would be the exhaust of the car. It's what drains the waste for example from the brain, because we're talking about the brain in this instance.

**Ferdinand Hui, MD:**

Absolutely.

**Lindsay Weitzel, PhD:**

So, idiopathic intracranial hypertension, which we have covered on this podcast, and cerebral venous congestion are not the same thing? Correct?

**Ferdinand Hui, MD:**

In my opinion, they're a Venn diagram with huge amount of overlap. If you have venous congestion and your brain swells to a certain amount and the pressure in the brain gets high enough, you then squish your transverse sinuses and then you get to the state that we now known as IIH. And we don't like that name because at this point. We treat the veins, they get better. Why are we still calling it idiopathic? The "idiopathic" currently bothers me. And so, we're writing on that topic.

**Lindsay Weitzel, PhD:**

I'm just going to define that really quick for everyone. The reason Dr. Hui says that is idiopathic means we don't know what causes it. And his argument is perhaps we're starting to understand what causes it.

**Ferdinand Hui, MD:**

And certainly, there's going to be people with idiopathic intracranial hypertension, as in I can't find a venous source and it's really still idiopathic. I'm sure those patients exist. But for the vast majority of patients that present with elevated pressures, at this point, we look at the veins. And then after we figured out we can't find anything to treat in the veins, then we go into a shunt, etc. or we can't treat the veins. But at this point the majority of the high-volume centers go for the vein first and then look for other causes afterwards.

So why do I say it's an overlap? My view and our view is, so the standard IIH paradigm that we've worked with for the last 60 years would be a young, overweight, female, high BMI. And the putative mechanism is that the mass, the pressure on the thorax and abdomen cause central venous congestion. Now, your brain has a hard time draining into your abdomen and pelvis. And so backed up, the brain is slightly swollen. The CSF can't drain. That pressure then creates a pressure cooker in the skull that squishes your transverse sinuses, and that amps up like a feedback loop, that amps up all the intracranial symptoms. And then you have all of this.

So, one of the conversations that I had as a young attending at Cleveland Clinic with Mark Luciano was, Mark, you shunted several hundred of these patients by now. How many of them become normal? He thought about it for a little bit, he said, less than 20%. They still have complaints, and we don't fully understand them. But the shunting does a great job of relieving the visual symptoms. The papilledema goes away at a very high rate. Some people even have some improvement in headaches, but very few of them go, wow, I'm completely normal. And so, we thought about that a long time. In my view, and again, I don't have the science to back this yet, is that you treat the CSF pressurization. I mean that's what the VP shunt does. It gives more space for the brain to relax.

**Lindsay Weitzel, PhD:**

Can you tell them really quick what it is, what the shunt is?

**Ferdinand Hui, MD:**

A VP shunt is a ventriculoperitoneal shunt. It's basically an escape valve for pressurized CSF. And they typically drain to the peritoneum, which is to say in the abdomen. And so, the fluid then drains around your gut and gets absorbed by your body. And this is one of the early ways that we developed to try to relieve highly pressurized CSF (cerebrospinal fluid), fluid that bathes the brain and spine.

**Lindsay Weitzel, PhD:**

So about 20% got better.

**Ferdinand Hui, MD:**

Feel normal I should say or feels fully normal. So that means the majority don't feel fully normal. And again, I don't want to disparage VP shunts. They're absolutely essential. I have my colleagues that do them. It's very very important work. But as we start understanding the disease process better, our view is that you want to treat the root cause. If it's high BMI, you want to help weight loss. If it's a venous stenosis somewhere else, our view is treat the vein if you can. And so we'll see. This is again, we're only ten years into this research. We have a long, long way to go.

**Lindsay Weitzel, PhD:**

Since this is a headache podcast, can you explain why cerebral venous congestion causes head pain and what types of head pain it usually causes? What does it feel like? And also, which veins are usually the problem.

**Ferdinand Hui, MD:**

So, the first experiment I tell patients to do is take your hand, lift it up, grip your wrist moderately gently and within 10-20 seconds your hand starts feeling funny. I guarantee you you're not gripping your wrist hard enough to block the arterial blood flow. What you're doing is you're blocking venous blood flow. When you have a blood pressure cuff, you're not stopping the arterial blood. It's still getting to your arm. But what you are doing is blocking venous return out of your arm. That's why people put a tourniquet on your arm before they draw your blood. So, you can induce venous congestion relatively easily anywhere on your body, so feel how that feels. You won't like it.

My view is there's a reason why people stopped using Q-Collar. I don't know why that reason is, but you used to see when it first was approved, athletes using it. I have not seen any in the last half year. It's because it feels terrible. Nobody likes having a tight collar. And the reason why is you can't get the blood out of your head.

And so why does it feel bad? Because that always feels bad. When you have too tight socks, when you have two tight..., you all have done this. We've all lived long enough. And if you need to experiment, go do it to yourself. Go do it to your hand. It sucks. And so why does it feel bad? I think there are several reasons. We don't know but there's evolving data.

So first, there's a paper out of China by Wei et al. out of Xuanwu Hospital. And what they did was they took rats and they tied off their jugular veins, and then they sampled the chemicals that were different in quantity in those brains. And so, we now have some early data that shows that if you screw up the venous drainage, the chemicals, you start having waste products accumulate, and changes in the chemical composition of the brain, as well as in the blood supply to and fro. So that data is showing up.

Stephanie Lenck in Salpêtrière is doing similar research aimed at assessing the behavior of glymphatics and lymphatics of the brain, so waste clearance. Early data, she hasn't published yet, but also tying off the veins for a mouse model, and it shows that basically you have impairment in the waste disposal system inside the brain. So, I don't think any of that feels good. So my view is some of it is pressure, some of it is waste products, toxic if you will. But we've got a long way to go.

**Lindsay Weitzel, PhD:**

I have another question. Basically the sensation I think, as you're trying to explain, that someone might feel who has this problem is it's like almost a strangulation type feeling in their head. Can it also lead to traditional migraine symptoms?

**Ferdinand Hui, MD:**

This is where I'm going to plead the fifth. I'm a plumber and I work with fluids, and I'm not going to tell the headache specialist what is and what isn't a headache and what is and what isn't a migraine. My view, though, is that headache is extremely polymorphic and mechanistically complex. And so, my view is there's probably a bunch of patients that have venous disorders that are lumped into the migraine world.

How many? I don't know. I bet you there's a bunch. The ones that I think need to see specialists that do venous disease, in my opinion, would be the ones with daily persistent headache. So, if you're a headache specialist and you have a patient that you can't fix and that they have a headache 15, 17, 30 days out of the year, send them to your local neighborhood plumber. Well, actually, you can't, not enough of us do this yet, but there's about a half a dozen of us that are good entry portals into looking at these diseases. Feel free to send them. We're already really backed up, but we're trying to train more of us to look for these diseases and try to understand how to diagnose and then of course how to treat.

**Lindsay Weitzel, PhD:**

So I have another question to add on to that. When you say daily head pain, does it matter if it's bilateral or unilateral? Do you see patients with both?

**Ferdinand Hui, MD:**

We've seen patients with both. I would say that the problem if you will in the veins is they don't follow the textbook as well. Arteries are pretty predictable. Most people have an arterial system that looks a lot like what's in the textbook. The venous system is incredibly variable.

**Lindsay Weitzel, PhD:**

This is probably key to my question when I said do some of these patients get migraine symptoms as well as other types of headache. What are some of the other symptoms of cerebral venous congestion?

**Ferdinand Hui, MD:**

Dandy's paper is the best place to go, because at least we all agree that he was he describing something. So cranial nerve palsies, we gloss that over in the modern definitions and just say abducens nerve palsy is the most common. But in fact, if you read...

**Lindsay Weitzel, PhD:**

What does that mean to the common person?

**Ferdinand Hui, MD:**

It's a muscle that controls one of the eye muscles. You may have some double vision because your eyes aren't controlled properly anymore. But we've seen patients with all sorts of cranial nerve. So, they're 12 sets of cranial nerves, and all of them can be irritated by cerebral venous congestion. And that makes sense, right?

The cranial nerves have to come out of your skull base. They come out of your brainstem, and if you have pissed off venous drainage, you have pissed off brain physiology. That's our view. And so, it's all stuck in a box. Your skull is a little pressure cooker. And if you have venous congestion, and this is one of the reasons why I think it's hard to map. We're taught in neuroscience to look at the brain through two lenses. One is the electrical network, where the wires go, where is white matter where the nuclei. And the other map is arterial. Where does the arterial system go? And if you block off an artery, what is likely to die?

And the veins don't follow either of those maps. And so that's one of the reasons why I think it's a little harder to get your head around. The veins can, depending on how it was routed, one blocked vein can be a totally variable presentation in one person than another.

**Lindsay Weitzel, PhD:**

And you did use a term. I'm just going to make sure everyone understands. You used a term earlier, venous decompression etc. And now you're talking about blocked veins. And I believe, correct me if I'm wrong, just so everyone understands, these are usually anatomical structures in people that have cerebral venous congestion that are sort of blocking people's veins, whether it be a muscle or a bone, etc. Is that correct?

**Ferdinand Hui, MD:**

Yeah. And let me just take a quick sidetrack to talk about veins and arteries and how they're different. We understand arteries pretty well by now. There's still a lot to do, but we've studied arteries pretty intensively for the last 100 years. Veins don't get enough love, in my opinion. But as an engineer, if you think about it, there are more veins by length and width than arteries.

So if you're an engineer and I tell you this car is about 70% plastic trim, you're going to go, at some point that plastic trim is going to break because everything breaks. So, what happens when your veins break? Varicoceles, varices are the ones we understand best, but frankly it's such an extensive system, it has to go wrong.

So what happens when it goes wrong? Okay. How does it go wrong, one, clotting. So, we divide venous impairment in general two ways, and I actually think there's a third. But okay let's be thorough three ways. So venous impairment, one, right heart failure. If your heart venous pump breaks, the whole system sucks. So, if your right heart isn't working, your entire venous network is backed up. So in right heart failure the right atrial pressure, absolute pressure, goes up because your right heart isn't able to push that blood into your lungs. Pulmonary hypertension does the same thing. If your lungs don't work, if they're very fibrous, you can't get blood into them. The pressure in your right heart goes up, and that means your entire body venous system will be backed up.

And so those patients with congestive heart failure, they get pressure ulcers, they get breakdown, they're swollen. Their entire body is swollen. They basically become a swamp. That's one. That's the most fundamental I suppose.

Two is intrinsic. So what do I mean by intrinsic. Inside the veins, so what can happen. The most common one is you clot. So if you clot that's backed up. Another example of intrinsic is let's say a tumor grows and accumulates in there, so that would be two. There are not many intrinsic. There's a couple other ones in the brain that occur. But I'm going to just glosses over.

So, three and this is the most common when it comes to venous disorders, it's a compression by another anatomic structure. Now let's talk briefly about how veins and arteries are different. Arteries are muscular there. They have balance. There's high pressure inside, and so they don't compress as readily. Veins are floppy. They have no muscles. The pressure is extremely low. It doesn't take a lot of pressure to collapse a vein. And veins carry much more capacity.

They are 30 times more compliant than arteries. And at any given time, 70% of your blood volume is in your veins and not your arteries. So what does this mean? It means when you're dehydrated, your veins collapse. That's why when you go to get your blood draw, they say, have you been drinking water? It's because you don't have enough water in your system. Your veins have collapsed. Nobody can draw your blood.

So that's part one. Part two is it can collapse because of lack of blood volume. But it can also collapse because you have muscles compressing it or tendons or bones or ligaments. So all of those things occur in this edge gray area of medicine of venous compression disorders.

**Lindsay Weitzel, PhD:**

I'm glad we set that straight so everyone understands what we're talking about here. So if they do do a surgery to help with this, they often do something to either widen the veins so the blood flows easier or which would be often a stent, or they remove a structure that's sort of compressing the vein. Correct?

**Ferdinand Hui, MD:**

Correct. And I will that comment that we need drugs in this space. So one of the things that we think goes on with neuro long Covid is injury to the endothelium. We know very well there's good published data that endothelium, the lubrication of arteries goes away when you get Covid. And that's why people had clots and they had lung damage and muscle damage and liver damage and brain damage during Covid version one. We think that Covid also damages the venous system. So one of the things that we eventually hope to see out of pharma is drugs that help lubricate your blood vessels.

**Lindsay Weitzel, PhD:**

Interesting. So how common is it, because now we start talking about the structure of the veins in the arteries. How common is it for people who have cerebral venous congestion to have a connective tissue disorder?

**Ferdinand Hui, MD:**

Great question. I don't know, but our observation is a very large number of patients that see us have EDS spectrum diseases. Why might that be? We think it's because people with EDS don't partition pressure very well in their body. If you don't have strong tissue that means one part of your body can push into another part where a person with normal tissue, there's a barrier.

With EDS, the barrier may not be very strong. It sounds like a supernatural movie. Here the barrier between the spirit world is not anything, obviously. But the reality is, if you can't barricade the high pressure of one place to the low pressure of another, you may squish parts of your body that aren't meant to be squished. We think that's one part.

Another part may be if your ligaments are soft, your bones slide against each other more than another person. And so you can imagine how bones moving out of place may impair flow, that may impair those vulnerable veins more. And then the lastly, the stretchiness of your meninges, your dura, that probably has a lot of effect on how you feel because....

**Lindsay Weitzel, PhD:**

Can you define meninges and dura for everyone, tell them where it is?

**Ferdinand Hui, MD:**

The sac that your body uses to keep the CSF, cerebral spinal fluid around your brain and spine. That is the dura and meninges. So the dura is that holds it in place and bathes your brain. If that area gets a hole, you get a CSF leak. And that can cause what's known as symptomatic intracranial hypotension.

But there are various versions of this that I think don't require a leak that patients with connective tissue diseases have. What happens is their dura, their sac, is so floppy it stretches. And so functionally you get low pressure in the head when you stand up even though you don't have a leak. So that's an unusual version over the population, but much more common in connective tissue patients. So although we have a lot to learn, we definitely see that patients with connective tissue disorders or in the spectrum complain of these types of symptoms much more frequently than non-EDS patients.

**Lindsay Weitzel, PhD:**

And you did mention idiopathic intracranial hypertension. And usually that is diagnosed with a lumbar puncture. Correct? So I'm curious I just want everyone to know because we did do a podcast on that recently. In cerebral venous congestion, is the CSF pressure high in a lumbar puncture?

**Ferdinand Hui, MD:**

The first question is what is high? I'm going to get hate mail from my colleagues. But the reality is we don't do LPs on normal people. Maybe we used to do this in the 1800s, but at this point we don't do this. And what is normal? I mean this sounds like a sociology question, but if we only take people with complaints, how do we know what's normal?

Our view is that we eventually, I would love to have an experiment where we take totally normal people, zero problems, and measure these pressures, and then we'll have a better sense of normal. So our view is we see patients with IIH symptoms. It's defined as greater than 25 in a person with low BMI, it's defined as greater than 35 in a person with high BMI, which, by the way, it should make you wonder what is normal, right?

And then the next. So the patients that we see with jugular venous compression, they typically run around 15, so if they don't meet our IIH criteria. We have seen certainly patients like that.

Now, let me give you a couple examples of why I know that these numbers are funny. So when I was running the CSF leak program at Hopkins and then the Cleveland Clinic from the interventional side. My neurology colleagues are great. They were running it from the medical side, but when they would send me patients, sometimes I would call them, hey, so-and-so is on my table. Opening pressure is 39. Do you really think they have a CSF leak? They'd say to me, they act like a CSF leak patch them. I'm like okay. And then they got better.

So what do you make of it when you have a person with an opening pressure of 39 that acts orthostatic headaches, is it a leak or is it not a leak? I mean, by definition, this is IIH, but I'm now doing a blood patch.

**Lindsay Weitzel, PhD:**

Because the current cutoff, most commonly for IIH, would be above 25. But it's very controversial. Correct?

**Ferdinand Hui, MD:**

The point is what is normal? We use the cut off because it's the best we've got. But my view is we actually just need to learn more. And I personally feel that like blood pressure, some people live in 90 over 40, 50, 90 or 50, probably not 90 over 40. I know those people. You know those people.

And there are other people that live at 120. And if you drop their pressure too much bad things happen to them. And the reality is there's probably a range of normal.

And how do you know what's good for person A versus B versus C? I don't think we know enough. So I think that we should be careful about hard cutoffs. And as we have come to learn that fixing veins can

correct a panoply of other things, eventually I think we're going to have to rethink about where CSF pressures fit in the diagnostic pathway.

**Lindsay Weitzel, PhD:**

Have you ever found that there's a typical body type or typical anything for people with cerebral venous congestion?

**Ferdinand Hui, MD:**

No. First of all, I consider IIH is cerebral venous congestion, so of course that throws it out the window. But I'll give you an example of a patient. One of the last patients I treated while I was at Hopkins. We had a young lady, athlete, skinny as a rail, basketball player, and she was losing her vision. And so everybody looked at her and they were like, how can she have IIH?

We did the exam. She had venous sinus narrowing, had a papilledema. We stented her and she got better by the next day, vision had returned to normal, so on and so forth. But my active theory and we have a chapter coming out on this is normal BMI IIH or low BMI IIH.

And so in her case, I told her our working theory is you're going to have a narrowing of your veins somewhere between your head and your heart. And in fact, she had completely shut down IJVs, internal jugular veins, on both sides by bony compression. So the good news for her was she felt normal after we put in the stents. She went off to college and to my knowledge, she's still doing well. In her case, if she can stay that way for the rest of her life, that's perfect. But if she develops these types of symptoms, I told her go and find one of us in 10 or 15 years and we'll talk about what to do with your neck.

And that's my view. There is no, I've got patients that were somewhat SWAT team guys, big firefighters, and they have muscular compression. We have women that are skinnier than you are and you're really skinny. So they're really, really skinny. We've got all sorts of shapes. It's really just depends on how they're hooked up.

**Lindsay Weitzel, PhD:**

I wanted to bring that up because you were saying that you consider them the same. But I have also heard you say that there is no body type in cerebral venous congestion. And so that is very interesting. Can you briefly go over the types of surgeries that are being done for people who do feel that their symptoms are bad enough that they want to have surgery. And then, what you say to patients when they're trying to decide whether they should have surgery for these types of problems.

**Ferdinand Hui, MD:**

So first, I think that it's really important to go to a team that has a good experience of diagnosing, because what you don't want is somebody going into your body without having the right targets. So, in our opinion, for the high-volume places, the diagnostic step is really, really important.

You need to know what is compressing. You might have a dural fistula causing these symptoms. So that's life-threatening. So we really think that you need to get somebody who knows how to diagnose,

how to find the anatomic structures that are hurting you and the things that mimic it that might be causing your problems.

So two, who does them? So there's a paper that we're hoping to get out in the next year or two about what anatomic structures exist that we've seen do these things. There's a paper out of Mayo that shows the thyroid cartilage compressing the jugular vein. And that patient got better after they took out a chunk of the thyroid.

And so there's a lot of these types of structures. And if you don't know which is pissing off your system, you may get a bad result. So diagnostic step.

And then what are the ones that exist. So most of the team in Northwell, they have a spine neurosurgeon and an ENT team that does great work for skull base. They we take out, styloid is probably the most common structure that gets taken out. That's a spiky, ossified ligament that exists at the skull base. It can look like a knife. I've seen them as long as 6 or 7cm. And they can act like a little pincer against the C1 transverse process to crush the jugular vein.

That's actually what was first described in this surgery out of the Barrow Neurological Institute about 10 years ago now, that's 13 years ago now. Also other structures, Dr. Kamal and Dr. Yoon-Hee Cha at the University of Minnesota are doing muscular decompressions for mal de debarquement syndrome, so vertigo. And so she found that a bunch of these patients with vertigo, actually have a jugular compression. And their approach is to debulk muscle.

There is a team that does most of the styloid and then lymphatic scarring removal. Ed Hepworth really centers on that approach. Peter Nakaji, who was the team that did this at Barrow. They do styloid and C1 over in Arizona.

Obviously, my team here, puts together the types of approaches we did at Hopkins and Ed's approaches. And so we are really evolving. Oh, and in Australia, Michael Elliott's doing a lot of good work. He's done about 70 patients now in Australia. And we're working together to put out about a 400 patient multicenter paper hopefully next year.

**Lindsay Weitzel, PhD:**

Thank you. I just wanted people to understand and to also know that you are very conservative in recommending surgery for people. I've heard you talk about it to make sure that if you can live with it, not to get surgery because it is a new area of medicine and it's a new surgical area. Was there anything else you wanted to add to this topic related to cerebral venous congestion and head pain before we go?

**Ferdinand Hui, MD:**

For any of you that are headache neurologists listening to this podcast, we want to talk because and thankfully, some of you have come to our meetings, but we have an open invitation. Cerebral Venous and CSF Summit will be in Colorado Springs next year. So, we hope to see you guys at the Broadmoor. And reach out any time. We really need to create trials, we really want to do good scientific work, to look, poke holes in the theories. But if it's real, develop better treatment strategies and collaborations and help patients with continuous headaches.

**Lindsay Weitzel, PhD:**

All right. Well, thank you so much for being here, Dr. Hui. This was very interesting. And thank you everyone for listening in. And please join us for our next episode of HeadWise. Bye bye.

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