

## TRANSCRIPT (English)

### Bertolotti Syndrome Virtual Meeting with Dr. Jenkins and Dr. Haines - June 28th, 2025



**Number of participants: 90**  
**Duration: 1 hour, 25 minutes**

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#### Summary

Dr. Jenkins and Dr. Haines participated in a virtual meeting to discuss Bertolotti Syndrome. Hosted by Kit, the founder of the Bertolotti Syndrome platform, the meeting highlighted the personal journeys and professional backgrounds of the doctors.

The meeting included discussions about Bertolotti Syndrome, a condition often misunderstood in the medical community. It further covered the diagnostic process, emphasizing the importance of detailed imaging and injections. Treatment options, including resections and fusions, were explored with an emphasis on personalized care. Dr. Jenkins highlighted the need to overcome insurance barriers that classify treatment for Bertolotti Syndrome as experimental.

They advocated for enhanced education for doctors and patients alike and encouraged active advocacy for better access to care. Patient experiences highlighted the range of symptoms and the importance of comprehensive physician training. Both doctors are committed to ongoing research and community involvement to improve understanding and management of Bertolotti Syndrome.

#### 00:00:00 Intro about the Founder of the Bertolotti Syndrome Platform

Hi everyone! Thank you for joining this Bertolotti Syndrome virtual meeting with Dr. Haines and Dr. Jenkins today. My name is Kit, I am the founder of this Bertolotti Syndrome platform which I established about like six months ago.

So far I've been hosting these monthly meetings and this meeting is very special because we have with us today Dr. Haines and Dr. Jenkins. For those who are at the start of their Bertolotti Syndrome or who haven't heard of these doctors yet, Dr. Haines and Dr. Jenkins are one of the few Bertolotti Syndrome Knowledgeable doctors, not only in the States but in the whole world. So it's very special that they are here with us today, so thank you so much again.

#### 00:00:55 Structure of meeting

As for the structure of this meeting, I will be giving a short intro about Dr. Jenkins and Dr. Haines. After this, I did prepare a few questions so that we can go over them. But if you have any presentations that you would like to show, you can. We can also kick off with that. And then afterwards, there will be time for some questions in the Q&A. So if you would like to drop your questions in the chat, you can.

### **00:01:25 Intro about Dr. Jenkins and Dr. Haines**

So, a bit about Dr. Jenkins and Dr. Haines. I've looked in your past a bit. And so Dr. Jenkins, he's based in New York. He studied medicine at the University of Pennsylvania. And he has been a neurosurgery spine fellow also at the Harvard Medical School. And afterwards a neurosurgeon and a spine surgeon at the Mount Sinai Hospital for over 23 years by now. Next to this, he is the founder of Jenkins Neurospine which was established seven years ago.

And on the other side of the virtual table, we have Dr. Haines. Dr. Haines is based in Virginia. He studied medicine at the University of Buffalo. He has done a fellowship at the Cleveland Clinic and afterwards he practiced spine surgery at the Virginia Spine Institute for almost nine years by now, and he's also the Director of Research. You might have also seen him at Fox and ABC News where he's educating others about having a healthy spine and maintaining a healthy spine.

Both have received multiple awards for best doctors year over year. I know this introduction doesn't do justice to everything that you have accomplished, but I think we are all very grateful for you guys to be out there, because it's very difficult to live with Bertolotti Syndrome. And to go to, not knowing what it was, to having now a solution and answer from doctors like you guys who actually listen to us, and have a solution for us. Thank you so much, and without further ado I would like to give the floor to you, would you like to add something to this and anything that you would like to share Dr. Jenkins or Dr. Haines?

### **00:03:26: Dr. Jenkins's presentation**

I know we want to have quite a bit of time for questions from the audience, obviously this is meant to be a partially an interactive talk. I would like to give a little bit of insight, you mentioned having doctors believe you, and I get it. Nobody taught me about Bertolotti's in medical school, in residency, in fellowship, even early in practice. A patient walked in and said, I have Bertolotti's. Turns out he actually didn't, but he had the anatomy, and I started digging deeper into it, and it's still not, to my knowledge... There are even worse problems coming up and that I want to kind of run through a little bit.

I'll try to run through this a little faster than I have in the past if you guys don't mind. But it'll give you an idea of the history of Bertolotti's, why so many people have been gaslit with this condition for so long, and really, what we need to do to go forward. There are headwinds against us, there are storm clouds rising.

### **00:04:56: Dr. Jenkins's presentation - Castellvi Classification should be abandoned**

I would like to share my talk on the subject that I've prepared and I'll try to get through it very quickly. What this all comes down to unfortunately is that a well-regarded excellent surgeon, very young, proposed this Castellvi classification, during his fellowship in 1979 which was pre-MRI era. He was just looking for a way to predict herniations, not Bertolotti Syndrome, disc herniations before they had MRIs.

So he came up with this idea that unfortunately, A, it didn't say the right things, because what he found doesn't reflect anything we find today with modern imaging. But B, it's been so widely misquoted, it's created more problems than it caused. And that's the Castellvi classification, the one that 9 out of 10 radiologists and doctors are aware of.

But the reality is, it's actually hurting you all more than anything else and so we really need to abandon the use of the Castellvi classification. I get no money for doing anything except

seeing patients in spine surgery related to Bertolotti Syndrome, but it's important to understand these are real problems. You have real problems that have real solutions if you take it seriously.

### **00:06:36: Dr. Jenkins's presentation - Jenkins Classification System**

This is my classification system that I developed similar to Castellvi, but really redoing it according to outcomes. These are congenital anomalies, they actually develop in many patients and sometimes this normal pathway gets a little bit blurred.

So instead of having a classic development, you may have a hybrid, where you got parts that are not quite according to the original architectural plans and that can result in underdeveloped discs, underdeveloped muscles, underdeveloped facet joints.

Multiple congenital anomalies, in fact, not just the LSTV level, but at other levels as well, and it causes back pain. And it's one of the few conditions that causes back pain when you lie down. Not everybody has that but many do. Many of you know what I'm talking about.

### **00:07:27: Dr. Jenkins's presentation - WROGMA**

But it's not what you don't know in life that gets you in trouble, but what you know that ain't so and many doctors think these can't cause pain because you were born with them, you'd have had pain from birth, and that's wrogma. That's wrong dogma, it's not true.

### **00:07:43: Dr. Jenkins's presentation - Castellvi's paper misinterpreted**

We first heard about Bertolotti Syndrome from Mario Bertolotti, who unfortunately wrote it in Italian, but it became a little bit better known because over the years, many people wrote about this condition. Unfortunately the elephant in the room was this article, and I've read the article, you actually have to read the article as a scientist to understand all the things that were wrong with this article and then read other people's literature as to how they misinterpreted to realize how much how you take two wrongs don't make a right, but these were well-intentioned people who had some bad ideas. That should have been abandoned, but in this day and age, nobody makes retractions.

But to be fair, Alf Nachemson did issue finally a retraction. He admitted in the late 90s, or actually early 2000s, "I didn't know the origin of back pain and I don't know now". But unfortunately, what he did, he proposed that only discs could cause back pain. Therefore, any other problems in the back and that includes spondylolysis, retrolisthesis, severe lumbar, all these conditions here, he did not think cause back pain. We know they do. There are thousands of articles describing how these cause back pain, but he was obsessed with back pain only coming from discs.

And unfortunately, Antonio Castellvi followed his approach and said we were only looking for disc herniations with his classification system. All it was, was published and it was just meant to look for disc herniations. And we know disc herniations aren't the problem in Bertolotti Syndrome, but it resulted in Bertolotti Syndrome patients. He was famous. Nobody wanted to go against him because he's now dead, and inertia.

### **00:09:49: Dr. Jenkins's presentation - Insurance companies use this misinformation to deny coverage for Bertolotti Syndrome!**

And people love to misquote them, this is in the radiology literature. They say "they have no relation to what was initially described as Bertolotti Syndrome". He didn't even say that! But they keep misquoting it, so instead we came up with a new classification system. But what we've discovered recently, this is important for everyone out there to know, insurance companies are using this misinformation to deny coverage for Bertolotti Syndrome.

Aetna one of the three biggest insurance carriers in America, has issued this formal ruling. It's considered experimental to treat Bertolotti Syndrome, they actually made this determination in February, it's that they've revised their class, they deny coverage for Bertolotti Syndrome surgery. If you want to look this up, you can see for yourself it's there, they put it in black and white. They game the system, because you can only complain about a coverage decision after you've been denied care, so no other person who's not an Aetna beneficiary can even complain to Aetna. And there's no basis for requesting for people calling in and saying we think you're wrong reconsider. There's no process for doctors to submit a challenge to these rulings and they hire retired doctors even spine surgeons to parrot the party line of saying, I can't go against their determination.

### **00:11:24: Dr. Jenkins's presentation - Summary**

So in summary, radiologists and clinicians need to be educated to undo 40 years of wrogma and teach people how to take Bertolotti's patients seriously.

All treating physicians need to pull their data, like what Dr. Haines and I are going to start doing in the near future, to try to get to a better understanding so I can learn from what he's doing and anybody else out there can learn if there's anything I have to share.

Insurance companies need to update their criteria. This is not just an American problem. I see here patients from the NHS, Canadian patients, from all over the world come to me because they can't get their care at home. Because their NHS, nationalized health insurances, typically will reduce what they pay for to anything they can put off. They'll treat a hip fracture, they'll treat an acute MI, if you're under a certain age, and they limit care. That's how they maintain their limited pool of funds. And Bertolotti Syndrome is one of the things they just don't want to cover.

But we also have more questions to answer, and that's why people like Dr. Haines and I need to work together, to really put out our good outcomes.

### **00:12:43: Dr. Jenkins's presentation - Fusion vs Resection**

This is how I look at it. I recommend fusions for type 2s. Not everybody does. This is my experience after doing my first 20 resections for this anatomy. I found they just didn't have good long-term results. And so, because they have less muscle in this area, if you look closely, there's very little muscle in many, not all, many of these patients. They have these small discs, and they have these small facets. I just don't see that it's a long-term play, but that's something that I think is open to debate, and I'm looking forward to hearing what Dr. Haines has to say about how he looks at this condition very much.

So in summary, my classification system that I use can be modified to take into account new things as we learn more about this, but I'm looking forward to working more with experienced doctors like Dr. Haines, as well as some of the pain doctors and other doctors in different specialties who are more Bertolotti's aware.

I'm looking forward to educating Bertolotti's curious doctors because, seeing is believing but believing is necessary for seeing. If you don't believe in Bertolotti's you'll never see that patient sitting right in front of you. And finally improvements for the treatments for all of our patients.

### **00:14:06: Dr. Jenkins's presentation - CALL TO ACTION!**

So the call to action, get yourself to a Bertolotti's experienced surgeon.

Verify with your insurance that you'll get coverage.

Go through your HR representative, anybody who you get your insurance through to lobby for coverage and for adequate coverage.

And speak to your state and local representatives and senators because these insurance companies are regulated by the state governments first and national governments through the SEC and other publicly regulated agencies. You can have a voice.

And getting together and pulling people like from this audience, is one way that we can have our voice be heard over the den of delay, defer, deny.

### **00:14:53: Dr. Jenkins's presentation - Acknowledgments**

So I want to thank you guys. I want to thank Dr. Haines for joining us, for Kit-Yi Yam for putting this together and creating this platform to the entire Bertolotti's community, to anybody who cares enough about their loved ones to be part of this conversation, and for anybody who can help us to fight the battle to get your voice heard. I also want to thank my research team and my patients.

And then, so my classification system is the QR code on the left, my outcomes paper. So just, this is what we do. I just throw it out there and you can look at it for yourself and see whether it makes sense to you is in the middle. And my Bertolotti's information page is on the right.

### **00:15:36: Dr. Haines's response to the presentation**

So, yeah, thank you, Dr. Jenkins. That was an amazing talk. And I think that's something that's good for all of us to hear and certainly myself included to learn from, is the history of Bertolotti and certainly your experience, so you know you've been a tremendous assistant to so many patients. So I know we're all incredibly thankful for all your work and the discussion. I think your talk, it had really hit on a couple very important topics is that the lack of curiosity I think in physicians.

### **00:16:03: Dr. Haines first time hearing about Bertolotti Syndrome**

I still remember when I the first time I heard of Bertolotti, I was a fourth year orthopedic resident at a children's hospital and there was a teen who showed up with a lot of back pain and they were presenting this patient and said, "oh, you know, the radiologist said he's got Bertolotti. What's that?" And the attending physicians were like, "oh, that's not a thing." And moved on. And that was really the first time I heard about it.

And, I think that one thing that's important about Dr. Jenkins and myself is, you know, that term would be medically gaslit. I think we see that a lot. And I don't think it's because physicians are trying to. I think it's because the lack of curiosity. If someone hurts, there's almost always, if not always, but at least almost always a direct reason for that pain.

### **00:16:54: Dr. Haines's first Bertolotti Syndrome patient**

I still remember my first patient with this condition. Young, healthy person, skinny, in her late 20s, and she had a lot of terrible back pain. And we did this extensive analysis workup history physical all the things that we're taught as physicians. The common things being common discs, facet joints the SI joints, all these different kind of what we're taught in our training as the major causes of pain they all looked fine. And then I saw, well you know, that's an enlarged transverse process, that's highly suspicious Bertolotti's.

And I had this sort of aha moment where you know what everyone believes, I don't think there's any debate, if you have bone on bone arthritis in the hip, it can hurt right. You have bone on bone arthritis in the knee it can hurt. Even in other parts of the spine, bone on bone

arthritis, there is pretty universally realized that yeah that causes pain, but we have this one artificial carve out for the Bertolotti joint.

So we did an injection and she pops up off the table and says “oh my gosh I have no pain anymore.” So for her, I know we're talking about the classification a lot, so she was a 2A, and with her, she was younger, healthier, and the next disc, the disc above, the Bertolotti segment, looked good. So I said, “well, why don't we create a gap?” And she's about nine years off from her surgery and actually just saw her back. She's had five children since, and her back still doesn't hurt.

So it was this eye-opening moment for me where we diagnosed it in the way we would do in every other condition, we treated it in a manner and she's done really well. So I had this kind of aha moment where I'm like you know, I don't think there are a lot of people doctors myself included and patients especially who are getting the proper information education on it. So I remember I did a quick little tik tok and just said “hey you know, ask your doc, maybe if you're having pain, no one can figure out what it is check out Bertolotti” and it's been this amazing awesome snowball effect.

### **00:19:01: Dr. Haines: Important message to get out and raise awareness on Bertolotti Syndrome**

Both Dr. Jenkins and myself, we're really, really happy to talk to all of you and try to get the word out because, we'll have, both Dr. Jenkins and myself, we'll have patients travel for us for this condition, but, we have patients who will travel for other conditions too. And I'll never forget, I had a patient who came from Calgary, skinny, healthy patient for a simple microdiscectomy, a common procedure that's performed.

And I was thrilled to help her out but I also had this epiphany where, there were a lot of doctors who I think who could have done that procedure appropriately well that she basically flew over to see me for, and I was very happy to help her out but there were other doctors I think could.

When it comes to this condition that the community of doctors who can treat this, is very small it's become a very big mission of mine, and certainly Dr. Jenkins and a lot of other and the other kind of inner crew of physicians who are treating this. This is an important message to get out, because we have this feeling that if it's not us, then we wonder about, will people be able to get back to the lives that they're designed to?

### **00:20:12: Dr. Haines: Resection vs fusion as treatment**

There are many different treatments, as we talked about, for this condition, and I think we will probably delve into a little bit more of the why. I tend to trend more towards a resection. One of the things with fusion, we think about the adjacent level, so we're always, when we do a resection, we think about how long is that disc at the resection level going to last. We think about a fusion, we think about what about the potential for that next disc going going bad. I in general, if it's an isolated Bertolotti's unilateral more commonly, occasionally bilaterally, I'll do resections as well, healthy disc above I typically do a resection if I decide that the disc above is painful.

Actually fusions work extremely well as well. Basically you know the analogy I always think about it's kind of like the reverse goldilocks. If there's just the wrong amount of bone it hurts. So if you've got a gap in general, no rubbing and no pain, if it's fused together solidly then also no rubbing and no pain, just when it's that wrong amount that bone grinds on itself. So I think fusion is a very effective treatment.

One treatment I did this week for a gentleman who had initially the right treatment from Canada and the doctor's in Canada did a fusion, but he didn't fully heal so for that patient he actually developed a painful disc above. So for him we revised the fusion of the Bertolotti's and then did a disc replacement above and you know he's two days out but his old Bertolotti's pain seems to be gone already which is really exciting.

So moral of the story is I think both fusions and resections are very very effective, I think it's for Dr. Jenkins and myself who look very person by person and situation by situation when we define the two. And when we may decide that one's a better option than the other. Ultimately, the big thing is just getting the information out.

I think that the information error has been so profound in the management of not just this condition but other medical conditions that patients are oftentimes not believed by their physicians about. So we're thrilled, you know, Dr. Jenkins is a great guy, we get to partner together. We're working on future research we have pearls in the community.

I think our education for the doctors, I think that getting the word out to patients and then as Dr. Jenkins really articulately put, insurance companies, unfortunately they seem to be coming for this condition and it's not that, they're businesses, they try to save money so even the more we can prove and the more that as physicians, but especially as patients, as we get this outreach going, it's critical and huge for the bigger community.

So with that, Kit we wanted to save some time for questions so is there anything in particular you would like to ask Dr. Jenkins or myself.

### **00:23:03: Introduction to the questions**

I thank you both, Dr. Jenkins for giving that presentation and also the news about the Aetna, and Dr. Haines, thank you for commenting on the resection versus fusion. I have some questions that I prepared, we can go over it and some of those you already answered, but I guess we can have a more elaborate discussion and then we can switch over to the questions.

If I may share my screen. So I have this overview. Let me increase, can you all see my screen. Yes okay, so Dr. Jenkins and Dr. Haines, you already went over it a bit of what was your first case, so Dr. Jenkins you mentioned about the wrogma, how can we change that.

**QUESTION - "What can we do in our lives, for now, to change the next generation? How can we make it easier for the people that are the surgeons and also the patients about Bertolotti Syndrome? What can we do right now?"**

### **Jenkins's response:**

Honestly, I think the best thing you can do is try to find a way to get common ground with the doctors you're speaking to.

Unfortunately there's a lot of ego involved and so you have to find a way to broach their lack of insight without making them feel that you're antagonizing or talking down to them, but I do know that having some published literature on the subject at least say "look, I know you may not believe this but there there are a number of people". I looked at the PubMed graph, the amount of people publishing on Bertolotti is exponential in the last five years, and so there are a lot of people publishing on this. You can even send them to Wikipedia or other things because now they recognize it. If you ask Chat GPT they recognize this condition.

You know there are ways to try to get around and say “look you may not you may not believe in this but I do and I would like to move on to the next step of making a diagnosis and potentially a treatment and I'd like you to be part of that journey”. And invite them in even if they're non-believers to say “I'd like you to be part of this journey and maybe you'll change your mind about it too”.

I mean you want to engage, not alienate your caregivers, and like Dr. Haines said, they don't mean to be gaslighters, they were raised that way you know they were taught by all the wrogma that these can't cause pain. And why? Because it's a mental shortcut that lets them not think about it. They can move on to something else. They can shorten their differential diagnosis.

You learn how to do that as a junior resident and intern, because when you're on rounds and you've got to get through rounds, if you have too many things on your list of what could be causing this problem you want to have the bullet points that are key and ignore the chaff, you want to ignore the stuff that's not relevant. And you know it's just this whole efficiency in modern medicine that drives people to take mental shortcuts.

You just want to encourage people not to do that for this particular condition. Why? Because the prevalence of the anatomy is so common, the likelihood is that many of these people will become symptomatic at some point in their life. This is a frequent problem and it's a frequently overlooked problem and that's what Dr. Haines and you guys, obviously, Temi and the work that she's done with the Bertolotti's Education Facebook group, and Kit, what you've done in such a short time in getting the awareness out through your website and your webinars is great, but it has to be viral and it also has to be exponential. You tell two people, they tell two people, each one of them tells two people. Next thing you know, we've got a pandemic of information and insight instead of a zombie apocalypse.

**00:28:05 - QUESTION: “Going back to what has been taught in medicine like back in school, is that still the current, the status quo that an LSTV cannot cause any pain or Bertolotti Syndrome is not a real condition?”**

**Haines's response:**

Yeah it's not being taught much at all.

During my training I really learned nothing about it, I know Dr. Steinmetz very well he's a fantastic doctor and he treats Bertolotti's at a high level and I didn't do a single Bertolotti surgery with him actually during my training. I did lots of other surgeries but even if Cleveland, when I trained there was 11 years ago, we weren't really seeing these patients that much, and we weren't really talking about it much.

The training isn't there, so I think there are two major hurdles: we have a major hurdle to physicians in terms of the accurate diagnosis. I think that really diagnosis with this condition is by far and away the most important characteristic of treatment. A lot of people, as Dr. Jenkins mentioned, have elements of this but don't have the, so if you take their X-rays they have an enlarged transverse process, they may have a pseudo articulation but not everyone with those imaging findings has pain, and because of that it's led doctors to say “oh well I want to look at an X-ray and if that doesn't show me the answer right away, got to move on”.

I think that sort of the way that both I and Dr. Jenkins we like to practice, is that's not our style of medicine. We can't be in a seat in three minutes and walk out, I think the individualized care is critical so there are a lot of hurdles in the medical community to adequately diagnose treat this and really talk to people like people.

The other side, which I think Kit you deserve a lot of credit for this and the whole team, is the patient education. It's exciting with the information age, how we can get information out. And it's amazing how patients are able to be so knowledgeable about this. I think patients in general are far more knowledgeable than the vast majority of spinal surgeons and spinal specialists.

So getting the information out, sharing your stories is so critical. It always saddens me a bit that patients with Bertolotti have to do so much of their own education, but I'm thrilled that the whole community is, because that's really what's allowing both Dr. Jenkins and myself to connect with you, to meet with you as well as other physicians, but to then also hopefully give you a diagnosis, a fix and getting back to your life.

**00:31:01 - QUESTION: “Thank you, Dr. Haines for that explanation and your insights. Moving on to question two and three, it's kind of like on the same line and some of those you already answered. So how did you learn about these surgeries and about the resection versus fusion. Just in general, what is the best way for someone who's experiencing lower back pain, some hints towards Bertolotti Syndrome, what's the best way for them to get to a real diagnosis?”**

***I have heard one of your presentations before, Dr. Jenkins, about that the CT scan is the best imaging method to see the LSTV as compared to an MRI or as compared to an x-ray because of the oblique view that makes it complicated to view it. So would you say you would direct your patients to a CT scan first, or would any scan be sufficient?”***

#### **Jenkins's response:**

Well, I think the issue really comes down to it's in the detail. MRI can be fantastic for making the diagnosis, if they do the coronal, which many MRIs don't. Or if they just go far enough out laterally with the sagittal images to look at the transverse ala interface, which most of them don't.

X-rays are great for looking at this anatomy, if done at the right angle. There's an angle called the Ferguson view. It's widely known, it's been around for like 100 years, but it's not part of the routine angles. There's an AP, a lateral, there's often a spot L5S1, but there's no routine use of this Ferguson view. So when I order x-rays, anybody who's had an x-ray ordered by me knows, we always ask for five views. I don't ask for the L5S1 spot, we ask for the AP, the lateral, the Ferguson view, the look up the disc space, and then the flexion extension. Because most patients with a type two or higher LSTV don't move at the LSTV level.

But the ones above, you know, the type ones, typically do. And so, it's also critical to look at the level above, as Dr. Haines has said, because it's been shown, even using the outdated Castellvi classification system, the incidence of having a problem at the level above, de novo, without any surgery, is 40% if you have an LSTV. And so I suspect it might even be higher if we included the 75% of type ones, that fall out of Castellvi that are symptomatic but not even classified as having an LSTV by Castellvi.

And so it is critical for you to look at something that looks at the imaging. CAT scans are great because I can reconstruct them. Even if they don't send me the reconstructions, I can do it on my own. And I can look at how are the bones, how close are they? Are they touching? What's

the nature of that interface? What's the size? All of these things can be done. And they can't be done with any images.

And we're trying to get the medical community to be more open to, if they do an AP and suspect that there is an LSTV, to realize there's a reason to do that Ferguson view. Now most x-ray facilities are looking at, we're only going to do what's ordered because we're only going to get paid for what was ordered. And so even doing one extra view slows down the tech a little bit and exposes the patient to a minuscule amount of radiation.

So their argument is benevolence but the reality is it's probably cost and time, but we have to show them that these are valuable images and they do help us. So you can get a really quick Ferguson view in an ER and you'll know right away, do I have an LSTV could this be part of my pain.

***“Dr. Haines do you have anything to add onto this?”***

**Haines's response:**

I agree with that, I have a model of the spine and essentially when we take our x-rays normally, a straight AP or the straight in shot goes like this. Like Dr. Jenkins says well it's usually tilted down like this so if we shoot straight this way, we get a very obscured view so that Ferguson view is looking straight on like that, that's really the critical picture to see that joint well. A big thing, you know CT scan is a wonderful tool, the MRI gives us some information on the Bertolotti's level.

It also very importantly helps look at other conditions. I always get an MRI to make sure there's not another disc issue going on. There's no swelling in the facet joints or the joints in the back part of the spine or some other obvious cause of the symptoms.

And then a big thing is the diagnostic injection. I think we're both very dogmatic about making sure that we get a lidocaine injection in that joint. It's that functional piece where if someone has a lot of pain and you inject a spot and the pain goes away, you know that's the bullseye. So that's something that I'm a big believer in, is that diagnostic injection to practically confirm that that's where the pain is coming from.

***00:36:41 - QUESTION: “Yes, along this line, when someone goes for diagnostic injections it can still be very tricky depending on a person who will inject the lidocaine in the right locations. I know, Dr. Jenkins, you always draw on the image, saying exactly where to inject, but in reality it can be maybe just a bit next to it or even not in that location. Do you refer your patients to certain locations where you know injections have been done correctly before, to also again reduce the time for the patient in getting the correct diagnostic outcomes, do you have a kind of like a database for that or do you refer to certain locations?”***

**Jenkins's response:**

I have a few that I work with regularly locally. I have tried keeping a database of practitioners who do injections that have had good outcomes. And unfortunately, I've also then had bad outcomes from those same practitioners when the next patient went to them. And so I've gotten out of the habit of trying to refer to. But I will also say that of the, maybe hundreds of patients that I've seen, I think we're getting close to a thousand in terms of consults given, is

that 70% of the doctors for patients who come to me for surgery were injected locally by somebody at home with the guidance that we give.

But the key is they have to inject, just as we've talked about the Ferguson view is looking from down to up because the image, the source is actually in front of the patient. The injection has to be done at a very down angle starting higher in the back and aiming down into the LSTV, because that's the interface of the contact when you have a type 2 or higher LSTV and so if your contact is at this angle you come in at this angle you're not going to get into that angle down here. And I've had anesthesiologists and radiologists who do CT say "you can't get there from here", I'm like what are you talking about, it's just a straight line you just have to take a longer needle and come down at this angle.

And then I always demand the screenshots because whenever they do them under x-ray guidance the first thing they do is they inject a little dye to show where the tip of the needle is in the body so you can see, is the dye in that interface or is the dye just kind of spreading on the surface. And if it's not in the interface and they have a type 2 anatomy and you didn't get relief, that's probably the reason.

But ultimately the LSTV injections are probably the most sensitive and specific injection we have in the practice of medicine. If you get relief from that, it's almost never anything else. And so it's as Dr. Haines's said, that's a critical part of the diagnosis, getting it done right, but confirm. I'm a trust but verify kind of guy, so confirm with the screenshots that they were where they said they were.

### Haines's response:

I agree with that perfectly. This is an injection that not everyone can do, and it certainly has to be with someone, yeah, trust and verify is a wonderful term. We say that a lot in medicine, and I agree with that 100%. I will say this is kind of occasionally annoying for patients. I know it gives me a pushback, but I do the injections myself. Just to be clear, like Dr. Jenkins said, it's a steep angle. The LSTV is like this. One thing I always tell patients, it's not a straight-in shot, so I always kind of remind them, "by the way, this is gonna feel, where I numb up, it's going to feel a whole lot higher in your back than where it ends", and it's just because of that steep angle.

So yeah, this is a procedure I do myself. So a common scenario, someone comes in after we think that they do have a painful Bertolotti's joint, and on that same day, especially because a lot of people do travel to see both Dr. Jenkins and myself, typically that same day I do an injection and then road test it.

So I had a patient just yesterday on Friday who is a high-level softball and basketball player, and it really bothers her back when she swings a bat. So we had her go down to our therapy office to get one of the bats and do some swings. It's funny, it's softball again, but I had someone who's another high-level softball player, and it bothered her when she was pitching, so the road test for her was in front of my office after her injection. She went and pitched with her dad. I like to do that diagnostic lidocaine injection, and then it's game time to road test it. The injection's not going to last three days and maybe three hours, though. So during that first moment, I like to see what sort of relief people get, and I really want to be pretty dogmatic about making sure they're doing the things that do bother them.

**00:41:55 - QUESTION:** *“Okay, wow, that's great information, actually. So continuing on that line, so after the diagnostic injections, let's say it's confirmed that one has a Bertolotti Syndrome, and then comes the option of having a resection or fusion. So it's great to have you two out there, but to be honest, for us, when we have to make the decision, it's very difficult. Because we get these great advice from you two, but then it's kind of like a hard decision to choose one over the other.*

*Dr. Haines, you have done a lot of resections. Over time, how do you deal with the different techniques for your resections? For example, do you put bone wax? Do you see bone regrowth? How do you deal with, patients who have an extra vertebrae, so the L6 patients. Do you recommend doing fusions instead? And do you work together with Dr. Jenkins to maybe provide the best outcome for the patient? How has it been for you?”*

**Haines's response:**

My general thought process is, for me, I prefer to have a resection. And this is an area that Dr. Jenkins and I both, clearly he's an expert. We're working collaboratively together to learn from each other. I tend to do recessions more if it's unilateral. If it's a deep-seated, in general, if the level is very deep-seated, we tend to think it's a little more protected by the pelvis, so I feel even more comfortable in those scenarios. The discs typically are somewhat rudimentary when someone has a Bertolotti's condition.

So because of that, on one hand, we think, well, is that disc going to last 50, 60 years, the length of time we're hoping for? On the other hand, because of the congenital nature of this condition in most patients, that disc has never really had to work hard. So it's kind of a double-edged sword. It's never had to work before, but it's also never had to work, so it never fully developed.

I've been doing this for, and certainly time will tell as time goes on, just my first Bertolotti's resection was approximately 10 years ago, and the one who came back and hasn't had pain. So I haven't seen that disc wear down yet on any of my resections.

I did have a patient who had a, we did a resection at the Bertolotti's level and she had a somewhat degenerative disc above, but it was not painful before surgery. Then we did the resection and actually I would think that that should preserve the disc above but she actually then developed some disc degeneration at the level above and we did a disc replacement and she's in the early healing phase but is doing very well.

So typically unilateral if an adjacent disc is healthy I'm pretty much doing a resection, I've done some bilateral resections and maybe higher level athletes where we're trying to hold off on a fusion. A common scenario that I do recommend a fusion, I'm chatting with one person in particular and there are a couple of patients who've had that condition on this chat right now, but is when I do a disc replacement adjacent to it.

So if someone has a painful disc at the level above the pseudoarticulation level, there are a couple of different options. One of the things that I actually do a lot for discogenic pain or disc-related pain, irrespective of a concomitant Bertolotti's, is a stem cell injection. That's a potential wonderful non-surgical option.

Usually, if we're doing a treatment on the Bertolotti's level, we're looking at the disc above anyways, and typically do an anterior approach for the fusion at the Bertolotti's, and then typically a disc replacement at the level above, if that's been defined as a pain generator. When it comes to disc replacement, there are a lot of qualifiers, so it's probably a whole other talk, where there are a lot of potential reasons why someone is a good candidate for disc replacement and why someone may not be. So it's not a universal law but I would say if someone has a painful disc above I actually do like doing a fusion of the disc above because then it's one incision as opposed to a resection incision plus a disc replacement incision.

### **Jenkins's response:**

Yeah so that those are all great points and I agree a thousand percent, I would rather have a resection than a fusion if I thought it was going to last. And so and this is also why it's great for us to to compare notes and to discuss and to learn from each other. As I said, when I looked at my early experience with resections for type 2 anatomy, I just didn't see the great outcomes.

And so most of the patients I have this discussion, I say we could do a resection with the knowledge that there's, in my hands, there's a greater than 50 chance you're coming back for a fusion later and if we're coming back for a fusion later we've already resected the bridge of bone that I want to actually create in the fusion, so and because I've created this fusion procedure that's an outpatient procedure, most patients that I have this discussion with agree, let's just do the fusion.

The LSTV level isn't moving now, and I'm okay with that motion. Therefore, I'm not really losing any motion by doing a fusion. I'm fusing across the level that looks like it was trying to fuse in the first place, and I'm just finishing what nature started. But there are a few patients that will say, let's give it a shot and see what happens.

As I said, not all of my patients came back for surgery. I have one patient who we actually called him up five years later for our routine follow-up. And he's like "why are you bothering me", I'm like "well, how's your back feeling", "it's great why are you asking?" I'm like "good talk ok".

So you know there are there are many patients who do well, and I would love to do more resections as long as I have the confidence that the long-term outcomes will, and this is where Dr. Haines and I can discuss and I can learn from him.

But in terms of figuring it out, for me it's type 1's get a resection, type 2's get a fusion unless there's a reason not to, type 4's we do a unilateral fusion on the open side which almost always solves the problem on both sides. And it seems something counterintuitive because many of them are painful on that one side, the side that's already fused and they're like but why is it hurting me if it's fused, and the answer is, because it still has open disc open facets and you're flexing the other side, you're stressing, you're basically developing a stress fracture at the side that is fused.

And sometimes the CT fools us and it looks like it's fused but I get in there and it's actually not fused. So there's a number of reasons why these things do play out but it's a patient by patient basis, it is a decision, it's a conversation that we have as to whether this is the right for them and especially for many of the patients who are coming long distances they're afraid they're not going to be able to come back a second time. They just want to be one and done.

And to me, as I said, here's the funny thing. We talk about in spine surgery, if you fuse a normal disc for good reasons, let's assume that the indications are solid, they needed to have that

level fused, and it was normal anatomy to begin with. We talk about a 20% incidence of the adjacent level breaking down. 20% requiring surgery down the road at a later time.

We already mentioned that there are multiple studies that show up to 40% incidence of having an adjacent level problem. And as Dr. Haines said, about half of my patients that I wind up operating on, I wind up operating doing something at the next level. Maybe they have a disc herniation. Maybe they have a second level of LSTV where they have type 2 at L6-S1 and type 1 at L5-L6, and they're symptomatic there.

Or they're so badly broken down they already have a massive mobile slip at L4-5 with a 5/1 LSTV, and we would fuse both of those levels. So there is a spectrum of what I call Bertolotti's Plus, but what we have found in our series is that even if they have a non-painful anatomic problem at the level above, we've done an epidural, we've done medial branch blocks, we've done other treatments to see, is the, let's call it 4 or 5, is the 4 or 5 level generating your pain? And if the answer is no, even if they have a slip, we just treat the 5-1 level. And even with the fusion at 5-1, there's only about a 5 to 10% incidence of that next level getting worse, because it's not actually adding more stress to fuse a level that was never moving to begin with.

So it is what it is. It's complicated. It's patient by patient. It's a ground war. I get into the trenches with every single patient to figure out what each one needs. And so while I have these guidelines and these rules, there are times that we'll go off the menu and do something that's very patient-specific.

#### **Haines's response:**

I want to jump on one thing that Dr. Jenkins said I think is 100% spot on, that I've been fooled on that I've learned lessons on is, you know we think that if it's completely fused that one of the sides is completely fused, that it shouldn't cause pain and a CT scan looks like it's not fused, and we do an injection and all the pain goes away and I'm scratching my head, at least early on and we realize even though everything seems like it's fused you get this forced transfer you get pain on the other side.

And often times there's just like you said a potential for stress fracture, or maybe some of the plastic nature, some deformation of the bone that's causing pain. Situations that I've been wrong on that initially I look at a CT and say oh it's fused will be that shouldn't cause the pain and then the injection just tells us differently and so does the treatment.

**00:52:21 - QUESTION: “Do you have any comments on surgeries done from the front so like anterior versus from the back, or do you only do those that are coming from the back?”**

#### **Haines's response:**

Sorry Kit was that for me to start

#### **Jenkins's response:**

Why don't you go ahead because I have strong opinions on this, so why don't you go ahead

#### **Haines's response:**

This will actually be a good one because I typically do an anterior approach, there are some risks with it but I typically do an anterior approach for this. In general I do more, and this is in my hands, I tend to find that there's more of a risk of muscular disruption going through the posterior or through the back. One of the things that I see in my hands is actually the potential

for those screws to cause some physical pain there or SI pain nearby, so oftentimes I'm removing the screws.

So that being said, so my bias in general, I'm a much more anteriorly based surgeon. To avoid those things, I will say that there are some risks with it, and this is, especially when there's a level that's been, when someone has this painful transitional anatomy, I think that the spine has been more fixed in that position and there are many times you're going to fusion. Well actually, I have a model, this is the type of fusion I do anteriorly based through the front, so that's a cage that puts a separation and gets bone to fuse through the middle.

There are many circumstances where if someone has a spondylolisthesis or slippages of the bones causing nerve pressure, where we really want to distract and open up that space, and this is one of the conditions where we definitely don't, if you're doing it anteriorly it can irritate the nerves you can get definite post-operative nerve tension and one of the downsides of doing anteriorly is that the space is usually smaller so if you have to stretch it out there's a little bit more risk to that. I use very small very narrow implants but that's a lesson I've learned because you know you don't want anyone just shoving a cage in there because that can cause a lot of nerve symptoms.

### Jenkins's response:

Yeah no those are those are all great points and they're certainly points that live by what I do.

So for me, when I'm doing my fusions, I've actually seen patients come to me for second opinions after having a full, beautiful fuse on CT scan, anterior fusion, and they still have their Bertolotti's pain. I think there's some kind of plastic deformation still going on, and I went back and I just did a posterior onlay fusion, didn't even have to put screws in, I just dropped bone graft in the trans and the pain went away.

So, to me, the point you make about, it's a hypoplastic disc to begin with, if they have, because not every patient does. I've seen plenty of patients with Bertolotti's who have a tall, normal-sized 5'1 disc. What's interesting, and I'm sure Dr. Haines, you've seen this, is that there's so much of the literature on the normal anatomy of the disc height, they include that most of the time the average L5S1 disc height is smaller than the 4-5 and the 3-4. Why? Because they're including LSTV patients in their normal patients, because it's so common they were afraid to eliminate them.

And so what I have found is that the average LSTV patient has a disc height at 5-1 that is 70 percent of the height of a normal. Some are 50% so that means you've got a tiny little disc there that I just find it's difficult to get either from the front or from the back an inner body cage into that space and if it's already so small eventually that disc will fuse.

I will also say that if you have 6 lumbar vertebrae, the odds are that L6 S1 may be angled so far down, that it's below the symphysis pubis, so it's actually very hard to get to from a normal ALIF approach. And I'm sure Dr. Haines is aware of those, doesn't recommend those for fusion unless he's got a very good approach surgeon who can get them around that corner. But that's just some of the things that I see.

So for my routine, and as I said, I have this MIS posterior outpatient procedure, for fusions that works 90% of my Bertolotti's fusions are done where the patient does not spend one night in the hospital, they just leave the same day. And we will not comment on what people say on the internet about their post-operative day one, day zero recovery cause it's a spectrum and some people are in miserable pain and some people are in no pain, and everyone's different and you can't expect anything other than that we'll do the best to manage it.

**00:57:18 - QUESTION:** *“Thank you, so moving along to the next questions, I think we covered it all, also thinking about the past what has been taught and also what can be changed. Going to the last part of this, Dr. Jenkins I've been following you on LinkedIn and Dr. Haines I've been following you a lot on social media and Instagram, it seems that you're very passionate to get the word out there, so I, and I think I can speak for the whole Bertolotti community, we are very grateful for you. Isn't it frustrating when you're in a clinic when you're seeing all the doctors when you're at meetings and you're trying to advocate, but then hearing someone not being open to it, how do you deal with that?”*

### **Jenkins's response:**

I honestly, I just I very often especially at some of the big meetings where I've had a chance to present I'll say “let's see a show of hands how many people here know transitional anatomy can cause pain”, and I'll see people who will raise their hands. I will say “the patients are seeing you are you seeing them”, and so I'm just kind of pushing back and I'm challenging them to recognize and to be open their minds to the possibility that the wrogma that they've been relying on is, it's a castle built on sand, it's really not a stable ground to base your clinical decisions on and that you need to use evidence-based medicine. And here's the evidence.

I teach my residents, I give talks wherever I can, and I think the most important thing that we as clinicians can do is to question everything. Question the evidence. Make sure that what you're basing your decisions on is evidence-based and not just what your mentor told you once and that you've taken that to heart forever.

You don't have to be loyal when it comes to your patients. Your loyalty should be your patients first and your mentors second. But our mentors are how we all got to where we are. So it's not to discount it, but it gets back to that whole trust but verify mentality of trust your mentors, but verify that what they're saying is evidence-based and not just what his mentor taught him without presenting the evidence for it.

And as I said, if you want to see the value of that, read the actual Castellvi article and realize there's a lot of not great literature out there. And in this day and age, there's even more not great literature because many of these journals are for-profit entities where they're encouraged to publish anything because then they get fees for publishing.

### **Haines's response:**

Yeah I certainly agree with everything you said, I think that I've spoken on this or some other conditions that some physicians think of as controversial and it's always funny because Dr. Jenkins and I will be speaking on the podium and in public doctors will give a little resistance and then they grab you after and when you step off your talk and say “boy I got this patient and I think that's it I just don't know what to do with it, it's so good to hear you talking about that, can you give me some advice”, and that's a common thing we hear that doctors are interested, but you have to have a specific type of I think an interest to help patients with this.

I think that we're all, Dr. Jenkins and I trained at, in my opinion very very good institutions, I love my training with my mentors but I don't think I could really probably practice medicine the way that I think we need to in that sort of setting. A lot of times it's just a way of conveyor belt health care where you're told by administrator you got to see 10 patients an hour and in and out and that's just not how this condition works.

One of the things talking about fusion specifically, you heard Dr. Jenkins and I talk about the subtleties and the intricacies of fusion and talking about how deep seated is in the pelvis. This is so exciting to be able to talk about this with him and have you guys hear this because most places say “oh fuse bottom level just fuse it right”, we're not thinking about all the intricacies that come into play, so we try to teach, we try to educate and then importantly, we talk about these nuances even with doctors, because a standard doctor is not thinking about all this when it comes to treatment of this condition.

**01:02:13 - QUESTION: “Thank you. So, as for the last question that I have, do you have any last words or advice towards the Bertolotti Syndrome community?”**

**Jenkins’s response:**

Never, ever give up. You are your own best advocate, and don't be afraid to go through intermediaries to help you get where you need to go. You know, find back channels, but also be an advocate, have a voice, like Kit has done and create a platform for discussions. But reach out to your your state representatives, reach out to your state senators, reach out to your your elected, federal, your congressmen and your senators, let them know that this is an area that requires more awareness. They don't know and I've tried teaching them as well and they have a certain amount of bandwidth, for example when it's budget season, when it's campaign season and it's this season and it's that season.

They're focusing on what they can, but find ways to have your voice and make your voice heard, without sounding like you're a crazy person and that's a challenge. I know that by being a doctor who treats a lot of poorly understood conditions, there are a few doctors out there who think that I'm not mainstream and that I'm one of those wackadoos who listens to his patients. Yeah I'm always going to choose that over conformity, because my patients have taught me more than most of my faculty and senior residents ever did. So, you know, listening takes time, and as Dr. Haines said, this efficiency-g geared medical factory system, but efficiency is not the most important outcome.

**Haines’s response:**

Great sentiment, great words, and I certainly agree with you.

This is unfortunately it has become because I think of lack of overall medical knowledge and insurance challenges, this has become a condition that patients self-educate a lot on. I mean it's really without technology like this and different forms of web pages and webinars it's very hard for patients to find the stories that really propel us to get people feeling better and the stories that give people hope.

There was one comment earlier that said I have chronic pain syndrome, and Dr. Jenkins and I treat a lot of patients who have chronic pain syndrome that get fixed with a procedure, and it's because they didn't have a chronic pain syndrome, they just had a condition that they got mislabeled on. And there are true syndromes, but I'd say the majority of them end up being, the doctor didn't know the answer because it didn't fit the textbook on chapter one, so they got labeled chronic pain syndrome, and then that's kind of a scarlet letter that that patient carries with them unfairly.

Keep digging, keep searching, keep communicating. And I certainly mean this from the heart. Dr. Jenkins is incredibly knowledgeable and skilled on this, I like to think that I know this condition pretty well too so search and reach out to us and reach out to each other. Keep up with the good fight.

### 01:05:56: Closing remarks + Q&A

Thank you Dr. Haines and also thank you Dr. Jenkins for all your insights information for being here in our call today this has been very helpful I think. I just went through the chat, we have many many questions so I am not sure well, I probably don't think we can go through all of them. I see that Dr. Jenkins you did respond to a couple of them. I guess since it's so many, would you like to go through some of them and pick out the ones that you would like to respond to?

### Jenkins's response:

You know, here's one that's actually very near and dear to my heart because I have done this a few times and it is a thrash. "Can CCI and Bertolotti's be fixed in one surgery instead of two different days?"

Yes but it's a miserable experience and I've only done it when I've had patients who were so severely disabled that they couldn't recover from one procedure adequately without doing both. For those who don't know, CCI is cranio cervical instability, many patients with Bertolotti's are also hyper mobile, when they go like this they can push their thumb much closer to their forearm than I can and that's just one of the many markers that's on the the Beighton scale as well that's a way of measuring your degree of hypermobility and Ehlers-danlos syndrome hypermobile type is one type of hypermobility. Those patients can have excess movement at their head and where actually we wind up stretching the cranial nerves, the vagus nerve which runs with the jugular vein.

The point is, this causes dysautonomia. It can cause brain fog from venous backup and temporary increased brain pressure. It can cause all sorts of other physical symptoms that may seem completely unrelated. Abdominal pain, perineal pain. The symptoms that I've seen improve with treatment of these conditions are shocking how broad they are.

It's a big operation for one and it's a big operation for the other and they hurt and that means you're doubling up the amount of pain, you're doubling up a brace in the neck and most likely a brace in the low back, it's a lot to recover from so it is not recommended, but once again you got to get in the trenches and you got to see what it is because as I said 50% of my patients who come in with one diagnosis have more than one diagnosis.

To that point, I know I've seen it in the Bertolotti's education group the discussion about how many patients come to me and they walk in with I got Bertolotti's and I look at them and I say yeah but you walk like a drunken sailor you probably have cervical myelopathy as well we find out and we may treat the cervical stenosis first and then they get better with their low back symptoms, and that's great. But frequently, and I'm sure Dr. Haines would agree, spinal cord level problems typically trump non-spinal cord level problems. And so we will usually do that first, unless the symptoms from one are so benign we think that there is time to wait and reevaluate until later.

So it's this whole, you know, what is associated with Bertolotti Syndrome? Congenital cervical stenosis, Chiari malformation, tethered cords, other transitional anatomy like cervical ribs if you are likely to have a misalignment of your spine in the lumbar spine, you probably also have ribs that are not quite normal either, because that's a transitional region as well. So I look at the whole big picture so every patient walks into my office gets a full evaluation head to toe, but some are more specific than others because once you find one symptom that kind of piques your interest you dig a little deeper.

### **Haines's response:**

Thank you, I know there are a ton of questions on here one of the things and we didn't talk about a ton was non-operative treatment for this condition. I think Dr. Jenkins and myself both see a lot of people and probably largely of you who have been really saddled with this condition for a long period of time. You know, the nice thing about most of the patients we see, nine times out of ten, we get them better non-surgically overall.

One of the areas that that ratio isn't the case is Bertolotti's for me, and it's a lot of times it's because people have already done all the injections and already done the therapy and the diagnostics. A couple of potential options, and it's very transparent, we have not seen a ton of long-term or even mid-term success with it. So if someone has an injection usually it's done with cortisone for symptomatic relief, people can get some relief but tends to wear off not all the time but if it's really symptomatic Bertolotti's it typically does.

A couple of backup options sometimes people talk about regenerative medicine PRP or stem cells as an option, usually it's a little more PRP that I hear about, largely because PRP is not quite an expensive procedure, insurances don't cover those, no ones do unfortunately. Whether it's stem cells or PRP, which the body's growth factors, the stem cells are the cells that grow into stuff. Largely, I think, intellectually, it tends not to work because you already have that bone-on-bone arthritis, right? It's grinding, it's already painful, so the non-operative treatments or those regenerative haven't worked terribly well.

One that is a reasonable option, but I also similarly just have not seen good mid- to long-term results of it is a radiofrequency ablation. Essentially it's a heat probe, it's a common thing done for facet pain which is pain in your spinal these joints in the back, it's a reasonable option to try for a Bertolotti's, I just haven't seen that be successful so usually it gets the point of "hey I'm miserable it's not working" tends to be more of a surgical correction. If it's more earlier on in the process that's when PT, cortisone injections, maybe radio frequency ablation can buy some time until it progresses.

### **Jenkins's response:**

Yeah my experience with ablations is they work at all half the time and they work for a durable period almost never, they they usually wear off. Like ablations are an actually pretty good way of dealing with facet mediated pain for up to three to six months of relief but for Bertolotti's it's almost very quickly gone, because it's a bone-on-bone problem that doesn't go away. So the nerves either regrow or become painful again very quickly and it's also not a typical, most of the pain docs aren't used to where those pain fibers are coming from. So Bertolotti's can be managed conservatively until it can't and that's the problem once it gets to the point where it can't be managed with anything else you're doing then yes, surgery is the next step.

So not every patient who comes into my office with Bertolotti's gets an operation for Bertolotti's because sometimes they're just not ready and they just want to know what are my options. And when I explain to them the options, they're like, well, I'm not ready for that. I'm like, okay, great. Great. That's fantastic. Because when you are ready, you will know. And so it's a patient by patient evaluation.

### **01:13:50: Q&A continued**

Thank you, Dr. Jenkins. I guess maybe because of the time, let's maybe move to two people who have their hands raised for any questions. Maybe, Mathias, if you would like to pose your question.

### **Mathias's question**

Hi. Thanks, Dr. Haines and Dr. Jenkins for coming today for this conversation. It has been very useful. I just had two questions, one on the diagnostic side and one on the surgical side. On the diagnostic side, what are the common congenital findings that you have seemed to find with Bertolotti's? Typical thing at least from my review is EDS as Dr. Jenkins mentioned as well as an extra L6. Are there other things that you have found and is there a genetic underpinning that you think could be at play here?

### **Jenkins's response:**

So I can say that we've looked into genetic underpinnings, we are in the process, we've actually applied for funding and have not gotten funding to actually run a clinical trial of doing genetic analysis of all Bertolotti's patients. So that is something we keep coming back for looking to get funded we do believe that there are genes like the MTHFR gene and others that may have relationships with congenital anomalies. But as far as the congenital anomaly most common is actually the congenital cervical stenosis so it's just that's a common association. It's not clear that it's causative, but it's clearly associated.

Second one is actually a spina bifida occulta, where the spinus processes in development didn't form properly and there may be a gap there. And I've even seen some Bertolotti's patients who have a floating spinus process in between their two laminae that's disconnected, when you bend backwards, that pushes the bone back into the nerves. And I've seen patients with back and pelvic pain from that. I will say that the treatment for that condition is not to do a transdural stem cell injection into that disc.

### **Haines's response:**

Yeah don't do that, don't do that.

### **Jenkins's response:**

And I've seen it done, that's why I can say, that's not that's not the treatment but anyway so I had a patient who actually had that and then needed a CSF leak repair, okay but the point being that there are many congenital anomalies and I see especially if you have hypermobility then you've got this whole spectrum of hypermobility related conditions like CCI, thoracic outlet syndrome, popping ribs, you just have to look at that pain diagram and take your time and go through, alright what's this pain coming from, what's this pain coming from, what's this pain coming from, and it just takes time and you got to look at the whole spectrum of congenital anomalies and just keep an open mind.

### **Mathias's question**

So the thoracic outlet syndrome and CCI are typically just let's call them subsets of an EDS, a patient with EDS not necessarily independent of EDS, so you won't see thoracic outlet syndrome in someone that does not have EDS.

### **Jenkins's response:**

Oh you absolutely can get thoracic outlet syndrome from injury to the shoulder and from other conditions as well.

### **Mathias's question**

Yeah I mean congenitally I mean from that generally speaking. No that's very helpful, thank you very much. My second question is the surgical approach. There have been a few papers that have been published by international doctors as well as the US, when they're approaching resections they have tried to do the resection of the transverse process but at the pedicle so

basically they're disconnecting the transverse process from the L5 or like the last segment and just basically just clipping the wings. My assumption is that both you and Dr. Haines do not think this is the best approach but it would be great if you could articulate why that would not be a good approach for a resection.

### **Haines's response:**

Yeah I agree, I mean not the best approach, there are some muscular attachments to transverse processes there so that's not only is in my opinion, that's probably more surgically disrupted than needs to be, you don't have to expose all those areas. It's also potentially impacting, there's a tougher recovery in big picture, part a little bit harder, I mean the transverse processes there are more important parts of the body but you don't want to disrupt the anatomy if you don't have to. That's why I try to anatomically restore the transverse process and do an anatomic resection as opposed to disruption of more anatomy.

The other thought process is as you get closer to the pedicle, the facet joint can live in there. So you can get a little bit too close. Potentially if you're doing a complete transverse process resection at that junction, you could maybe start impacting the facet joint a little bit so I wouldn't recommend that.

### **Jenkins's response:**

Let me just say also, A, what you're describing is an iatrogenic fracture, an iatrogenic being caused by the doctor, an iatrogenic fracture in the transverse process, that can cause pain. And I've seen patients who have had that and have come in with pain that we then had to fix or resect the entire transverse process because they have this floating bone that's now banging around and now they've also lost the muscular attachments as Dr. Haines and me want to preserve as much as possible.

I just don't think that's a long-term solution, I think there you see, especially in the international literature, there's a lot of people who describe a technique but don't have a five year data on its output. So it's a great idea, but as I tell my residents everything works in theory, practice is something else, and you have to be cognizant that not every great idea you have is going to actually be in the patient's best long-term interest.

### **Mathias's question**

That makes sense. Would the corrective surgery for this be an ALIF then, since you don't have the space to put in the pedicle screws for a posterior fusion approach?

### **Jenkins's response:**

You can still put a pedicle screw in.

### **Haines's response:**

Yeah it's not a pedicle resection, so you can still put a pedicle screw for sure.

### **Mathias's question**

Thank you very much for your answers. I will cede the floor.

### **1:20:30: Q&A continued**

Thank you, Dr. Jenkins and Dr. Haines. Would you have time for one more question, maybe, for the person who has her hand raised for quite a while? Marni, if I'm pronouncing it correctly.

### **Marni's question**

Thank you. Hi. Good morning, Thank you Dr. Haines, Dr. Jenkins. I think Dr. Haines knows my daughter is two months post her resection. And one of the things I'm finding frustrating where we are from California is how important the post-op and the PT is. And we are just not finding the support out here that we received at your clinic at VSI. That just that all the techniques are different. The physical therapists have no understanding of Bertolotti's and don't seem to even want to know or speak to the therapist in your facility. I'm just wondering if you have any guidance or advice, because I certainly want my daughter to make the most of her post-op therapy.

### **Haines's response:**

Well, I'll be calling them myself again after this discussion. I think you know that, you know, it is a less common treating condition. One of the things that I see that I make sure we get ahead of, and I'd be interested in hearing Dr. Jenkins' opinion on this, that I definitely notice that when I do a resection, so I saw somewhere in the comments, basically you got this pseudoarticulation, you got this big block of bone and right in front of it is the L5 nerve.

So what I see in my resections and actually it good for everyone to know, I never seen this be permanent but I do have patients who have a post, we call it radiculitis or nerve irritation. It typically kicks in after resection, five, seven, nine days at that point, where people feel good right off the bat. And then they say, you know, I've got back achiness. That gets better, but I still have a little bit of nerve discomfort going down the leg. That's why I love talking to therapists. So my therapists know this, but when patients are traveling, we try to communicate with the therapists wherever they're from as well to prevent this L5 nerve tension.

One of the common things we do to either prevent it or minimize it, it's called nerve glides, basically stretching the nerve, getting some mobility in there. Those are some unique things that I see with the resection. I think the big thing is the communication one of the things that we try to do is get our patients to get like you mentioned PT in the facility, in our facility who are quite knowledgeable therapists before they go back home to a place that may not have the same quality but there are a couple unique things I think are paramount and I glad you brought this up because I call them again and reiterate that to them, because it can be different therapists and they might not communicate.

### **Jenkins's response:**

Yeah, I think sometimes you just have to, if you really not getting the treatment you need in place number one you got to go find some place that will be more open to it and let them know you're coming to them specifically because the first place didn't take you seriously and if they don't take you seriously you're not going to go with them either and so, you know, that sometimes makes people stop.

But to the point of just the general lack of knowledge if you can get to somebody that makes your daughter better then they come back and they are essentially the ambassador of successful treatment of Bertolotti's Syndrome, that makes some of the less Bertolotti's curious doctors say some more curious because wait a minute I didn't think this would work, but hey, this person went from being disabled to being able. Wait a minute, maybe I got to stop and think. So sometimes you have to go a little further afield to get the right treatment. But when you come back, you can re-inform all the people who gaslit you in the first place in an inviting, not shaming sort of way.

### **Kit's comment**

Yeah, and to add to this I know it is very important to find also Bertolotti knowledgeable physical therapists. So I'm actually in contact with one of the physical therapists who has been

treating people with EDS, CCI, and she mentioned that she's also treating Bertolotti Syndrome. She's located in New York City so I will have a meeting with her soon to see what she can do for our Bertolotti community and so stay tuned because there might be another meeting coming up where I will be focusing on physical therapists, and to help the community also in this way.

So yeah I think well okay I don't want the person who has her hand still raising maybe one last question for the person that's called iPhone. If you want to pose your question. Oh, maybe that hand was up by accident. Okay, so I think we spent quite some time together. Thank you again, Dr. Jenkins and Dr. Haines. I've put in the chat the link to Dr. Jenkins' clinic and also Dr. Haines' website where you can do a consultation with them to get all your questions answered. If you are not yet in the Facebook group, the Bertolotti education Facebook group, you can join it and post your question and someone might have the answer already for you. So yeah I would say Dr. Jenkins and Dr. Haines, thank you for joining, for those who still want to stay and chat you can stay around I will be on this call still.