

Bertolotti Syndrome Virtual Meeting with Dr. Jenkins and Dr. Haines June 28th

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

Responses are indicated in blue for Jenkins, green for Haines, orange for Kit and gray for other participants

Questions / Comments

Haines: Both Dr. Jenkins and I are thrilled to be here!

Jenkins: ❤️

1. Karley: Kit, I'm also in the Boston area 😊

Kit: Hi Karley! That's awesome, I met two other local Bertolotti friends, we're planning to do a local meet-up soon so I'll make sure to include you too!

2. Donna: Thank you Dr Jenkins and Dr Haines for joining our meeting today. My question is, for older patients who have a fusion, how do they do. Specifically, for 2b how are the patient outcomes?

Kit: I'd pose this question to the doctors when you have a consultation with them (or post it in the Facebook Bertolotti Education Group and see if someone has info on this)

3. Gretchen: I've always said Bert to lot ees, is it Bert to low tees?

Jenkins: I don't think Mario will care...



4. Holly: Can we please have a copy of these slides after the webinar? This is really great info

Kit: You can view the recording to see all slides again.

Recording will also be sent to Temmy "it will be added to FEATURED-PINNED-TO-TOP Post FEAT#001 which contains the top presentations, videos, posted in our group of 5,000+ group members in 25+ countries"

5. Alicia: Hi there! You mentioned fusion is recommended for type 2. I'm type 2b and resection is not recommended for me because of rudimentary discs. Would fusion possibly help me I'm 38

Kit: Every Bertolotti individual is different, other things need to be taken into account too. Best is to get a consultation from one of the Bertolotti Knowledgeable Doctors

6. Bree: How do we determine what type we have?

Kit: After consulting with one of the Bertolotti Knowledgeable Doctors

7. Andrea: Thank you for this information! I have a question about using your classification system. Does the Jenkins classification system denote sacralization vs lumbarization of the LSTV or just the distance between the psuedojoint? As a rehab clinician and kinesiologist and BSy patient, I'm curious about getting this point across to further our rehabilitation programs.

Kit: In Jenkins's paper he states lumbarization/sacralization throughout the article

"Redefining the Classification for Bertolotti Syndrome: Anatomical Findings in Lumbosacral Transitional Vertebrae Guide Treatment Selection", 2023

Table 1. Anatomic Definitions for Proposed Jenkins Classifications		
Classification	Laterality (More Abnormal Side)	Anatomic Description
Primary		
1A	(L)/(R)	Unilateral dysplastic transverse process (<10 mm between TP and ala [e.g., type 1A(L) gap is >2 mm, <10 mm only on left, >10 mm on right])
1B	(L)/(R)	Bilateral dysplastic transverse process (both sides <10 mm gap [e.g., type 1B(R) closer on right than left])
2A	(L)/(R)	Incomplete unilateral lumbarization/sacralization with enlarged transverse process that has a diarthrodial joint between itself and sacrum (<2 mm separation, with planar surface on transverse process parallel to opposite surface of ala but >10-mm gap on opposite side [e.g., type 2A(L): type 2 on left, with >10 mm on right])
2B	(L)/(R)	Incomplete bilateral lumbarization/sacralization with enlarged transverse process that has a pseudojoint between itself and sacrum (<2 mm of separation on both sides, with planar surfaces on transverse process parallel to opposite side of ala [e.g., type 2B is symmetrical but type 2B(R) has a larger interface on right])
2C	(L)/(R)	Dysplastic transverse process on 1 side and incomplete lumbarization/sacralization on other side (<10 mm but >2 mm on 1 side and <2 mm on other side [e.g., type 2C(L): type 1 on right and type 2 on left])
3	(L)/(R)	Bilateral lumbarization/sacralization with complete osseous fusion of transverse process to sacrum (no radiographic fusion plane viable on MRI, CT, or Ferguson radiographic views on either side)
4A	(L)/(R)	Lumbarization/sacralization with complete osseous fusion on 1 side with dysplastic transverse process on other side (type 1 on 1 side and type 3 on other side [e.g., type 4A(L): type 1 is open on right; type 3 on left])
4B	(L)/(R)	Lumbarization/sacralization with complete osseous fusion on 1 side and incomplete lumbarization/sacralization on other side (type 3 on 1 side and type 2 on other side [e.g., type 4B(R): type 2 is open on right; type 3 on left])
4C	(L)/(R)	Lumbarization/sacralization with complete osseous fusion on one side, >10-mm gap on other side (type 3 on 1 side, type 1 on other side [e.g., type 4C(L): open on left; type 3 on right])
Secondary		
+L/R/B	+L/R/B	Denotes which side has contact between TP and iliac crest [e.g., type 2C(L)+L]
L, left side more prominent; R, right side more prominent; +, transverse process touches (within 2 mm) iliac bone; TP, transverse process; C, type 1 lumbosacral transitional vertebra on 1 side and type 2 lumbosacral transitional vertebra on other side; MRI, magnetic resonance imaging; CT, computed tomography.		

8. Justin: My biggest question is, If you need a hip replaced and still need BS fusion. Which one would be better to do first for the best alignment for both?

Kit: Some other issues can be related to Bsy and might be solved after the correct Bsy surgery. Every individual is different and best is to consult with one of the Bertolotti Knowledgeable docs

9. LAPOUGE: Hi everyone, thank you for this meeting. These are my two questions, I am writing from France and doctors are not familiar with this condition so I hope my questions will be answered:

1. Is it common to experience alternating sciatic pain and buttock pain in type 2A Bertolotti Syndrome, without any lower back pain?

2. Could the pseudoarticulation between my transverse process and the sacrum be directly causing nerve irritation leading to these symptoms without any disc involvement ?

Kit: Many of us have pain in other areas, such as hip, SI joint, neck etc. Every individual is different and it could be possible that it is all related to the LSTV pain. Consult with one of the Bertolotti Knowledgeable doctors and upload any images you have, they will be able to also look at other things, such as nerves, discs etc

Holly: Bonjour: I cannot speak for #2, but prior to my disc-replacement/ALIF/PLIF surgeries, I definitely had severe sciatic pain (which immediately went away after surgery)

LAPOUGE: What is ALIF / PLIF ? Thank you

Holly: Anterior Lumbar Interbody Fusion (ALIF) and Posterior Lumbar Interbody Fusion (PLIF)

10. Aksel: Hello from Finland! - In a patient with a type 2b anatomy, not causing pain. Is it still beneficial to have a surgeon knowledgeable with Bertolotti's perform a fusion/ADR on a degenerated disc above the LSTV? If so, why?

Kit: If the LSTV is not causing pain (confirmed by diagnostic injection), it might not be considered Bertolotti, but best is to consult with a Bertolotti Knowledgeable doc in case there are other issues around that LSTV

11. Aksel: In patients with a LSTV, can they have more than one hypoplastic disc? For example, can the adjacent level above the lumbosacral transitional vertebra be slightly hypoplastic and at risk for over distraction in a fusion/ADR surgery? (Surgeon believing it has lost height when it necessarily has not)

TBD

12. Coach Beau: I am a manual therapist, currently working with my first Bertolotti's patient after a MVA, who lives in 8/10 pn. They are now able to receive therapeutic touch without hyperesthesia. But I want to get them

further along. My question is about the effectiveness & use of kinesiotaping. Is it more helpful to offload the side with Bertolotti's, or a different strategy? Thank you for any guidance.

Kit: That's great Coach Beau! I will send you a message. I'll have a meeting with another PT in NYC who has been treating Bertolotti patients (not sure how many yet but I'll get that info soon). I'm planning to host a meeting with her to present and focus on PT for Bertolotti Syndrome patients

13. Emma: Is there a correlation between Bertolotti and Ehler Danlos/CCI?

Jenkins: Yes. Not always, but is often associated

Holly: I've long suspected that I have hEDS - also a grossly-misunderstood condition 😊

14. Aksel: In a patient with a type 2b anatomy, not causing pain. Thoughts on ALIF without posterior fixation for a degenerated adjacent level above the LSTV? Do you prefer posterior fusion/fixation, why? In general. What are your thoughts on Fusion (ALIF, TLIF) vs ADR (for example a Prodisc) for a degenerated adjacent level above the lumbosacral transitional vertebra?

Kit: Great questions again. See recorded meeting, Jenkins and Haines went over the posterior vs anterior approach. Although it can be different for each individual based on other factors

15. Vinessa: Hi, through an xray a radiologist mentioned I may have bertolotti's but how do we know what type I have? is it something I should seek info from the radiologist?

Kit: That's great that your radiologist mentioned Bertolotti's, many don't even mention it in reports. After consultation with a Bertolotti Knowledgeable doc you will know what type you are

16. Gretchen: Are you all on the FB group Temmy started as well?

Kit: Go to: <https://www.facebook.com/share/g/1ZcPjTEaBu/> to sign up!

17. Annemarie: Can you tell us something about your knowledge/experience with the BS and hip problems? I (female, 31yo) had a successful resection in January in the Netherlands with a backsurgeon, but very bad hip problems which makes it difficult for me to function. They don't know if it is the muscle or the joint that is causing the pain. I had a CAM/Pincher resection before the resection but benefited from it for a year.

Angelica: I had hip dysplasia surgically corrected and then developed bertolotti syndrome from my LSTV. I think fixing my hip caused my back to move differently and my anatomy became an issue

Kit: Many of the Bertolotti patients also experience hip and other related issues unfortunately.. Sometimes fixing the LSTV through surgery can lessen the pain in other areas. Every individual's anatomy and recovery is different, best is to consult with a knowledgeable doctor

18. Gerallt: Thanks Dr J and Dr H. You're both GOATS. Even if the diagnostic injection doesnt give positive result but the assimilation joint cause biomechanics and posture problems would this still be considered for fusion or resection?

Jenkins: Depends on the details of the patient's presentation and exam

19. Purple: I'm from Calgary and no spine surgeon will even consult with me. Its heartbreaking.

Jenkins: 😞

Holly: I'm so sorry 😞 I had to fly from Seattle to see Dr Haines. I saw 12 other neurosurgeons between MI and WA before I found him. The gaslighting for this condition is horrific

20. Gretchen: Do you find lordosis in most cases and then the fusion is preferred or is the resection preferred?

TBD

21. Jooyoung: I have an MRI and consultation with an orthopedic surgeon scheduled in the next two weeks. Appointment with a pain management doctor about injections in a month. Any advice on how to navigate the conversation in order to get the most benefit out of the meeting with the ortho surgeon? If it is relevant, it is with Dr. James Bruffey at Scripps in San Diego. I do know that he has performed a surgery for a patient who

coordinated with Dr. Jenkins and Dr. Bruffey. I hope to get a consult with Dr. Jenkins and Dr. Haines once I've received the MRI imaging. Should I try to get a CT scan? I've received X-rays of course.

Kit: It's great that you found a surgeon who is open to learn and involved in previous surgery for a Bertolotti patient already. You can see if s/he is knowledgeable in defining where to place the injections and what has been done for the previous patient. Alternatively, you can consult with a Bertolotti Knowledgeable doc so that the diagnostic injections can also be indicated correctly. This way you don't risk the chance to have to redo it all. As Jenkins and Haines mentioned in the call, MRI might be sufficient depending on the way they perform imaging, best is to consult with them. CT might be best but also exposes you to ionizing radiation that is higher than usual x-ray radiation (MRI = no radiation as it's based on a magnetic field), something to also keep in mind

22. Haines: Glad we have been able to connect, Holly! I'll see you next week and will be good to discuss your thoughts on the webinar!

23. Alicia: Where is the fusion done on the spine, is it on the LSTV or the discs

Haines: Alicia, either fusion can work. I prefer to do an anterior approach, in my patients it's been an easier recovery. called and ALIF

Kit: I have an L6, mine was L6-S1 fusion, so not on the actual LSTV as that will be fused eventually. It might differ for others depending on what other issues they might have

24. Anastasiagak: Question to both doctors. I was diagnosed with 2C type by a Spine doctor in Boston. What is the typical approach to injections with this type? Also my Doctor is extremely interested in learning about this condition! What is the best way to collaborate with you on my case?

Kit: Hi! I will still reach out to you soon as I found two others who are located in Boston too so we can do a local meet-up! I went to MGH for diagnostic injection, I found this one through another member Gina who already went there and had positive experiences

25. Donna's: I've had two positive Bertolotti injections, why do I feel better when laying down? You mentioned it hurts most people with Bertolotti. I'm type 2b+b.

Jenkins: Everyone is different. But 60% of patients who need surgery are worse in bed or lying down

Holly: I'm also Type 2b and I'm most comfortable when I'm lying back at a 150-degree angle with a pillow under my knees

Angelica: Yes for me it's pressure on my LSTV lying down that causes pain

26. Jenna: if there is too much bone bilaterally for a resection, but the disc above the LSTV is herniated, would an ADR be a viable option? Also, if a rudimentary disc is present (with an L6) is it ever possible that can be a pain generator?

Haines: Jenna, I think that in general you may be a candidate for a lumbar hybrid surgery. Fusion at the bertolottis, disc replacement above

Jenkins: I've seen bad outcomes from ADR at the LSTV level, as well as ADR's done above the LSTV level thinking that was the problem level

27. Gretchen: Many of us can't afford to get surgery, what other things do you all do to function?

Kit: Many of us have been trying to manage the pain through PT, chiropractic, PRP, nerve ablation to name a few, some of it helps for some individuals and sometimes for a long time until nothing really works anymore unfortunately

28. Lee-Ann: Dr. Haines you were the first doctor that had me in tears because he acknowledged my BSy was real and not because I was dismissed.

Jenkins: 👍

Haines: thank you, Lee-Ann! that means so much

Haines: Also so kind of you, Holly!

Purple kumai: ❤️

Holly: Same 🙄 I was so choked up at my first call w/ him bc I'd been gaslit for most of my life from my limited mobility in my lower back and then the amount of pain I was in later on

Lee-Ann: ❤️

29. Canif: Is there a long recovery process after a resection surgery that utilizes physical therapy?

Kit: Recovery is different for each individual. PT is done after a certain period of recovery

30. iPhone: When they do fusion or resection surgery for BS, do they correct the spine/pelvic alignment first before fusion esp? Because BS patients have pelvic tilts, joint mal alignments, muscle spasms etc and need to be fused in a corrected position otherwise it can be detrimental. I say this because I do experience all this and when corrected by my chiropractor it's such a relief. Can Dr. J or H comment on this important step before fusion?

Kit: Most of the cases I've heard, no alignment were done prior to surgery. It is possible that pain due to the tilt etc will be relieved too after BSy surgery

Holly: I would be really careful with chiropractic care with this condition, fwiw. Anecdotally, I started having a lot more pain after chiros started trying to "treat" my BSy

31. Bree: If insurance denies most Bertolotti's procedures, how can we move forward

Donna: 🙄

Gretchen: I think people take out loans for their surgeries- I have heard 40K

Kit: See if you can appeal it. Matyas is compiling a document to gain more insights in the different insurances and has more knowledge about this. Fusion with Jenkins was out of network for me, but hospital costs were in network and all covered

32. Tracy: I had resection and told I need fusion l4l5 I have spondy- are you familiar with tops by premia spine

Kit: Best is to consult with a Bertolotti Knowledgeable doctor and see if other treatment is needed next to the resection

33. Bryt: Good day, everyone! I've been wondering whether the onset of pain tending to occur in patients' twenties and thirties is thought to have to do with the way our sacrum form — namely, that the sacral vertebrae remaining unfused until (typically) sometime between ages eighteen and thirty allows for enough space, but as they fuse, soft tissue becomes impinged/restricted and/or the LSTV begins rubbing against bony structures in the area.

Kit: Great thought process! I think the onset of many of us was due to a high impact injury/incident to our body. That explains why we were fine until that incident. Your hypothesis might be valid too, but unconfirmed so far

34. Sarah: Is surgery for an female 18 year old with 2a (Cast classification) to have a fusion surgery now or wait until older?

Kit: Best is to consult with a Bertolotti Knowledgeable doctor, and eventually the choice is up to the individual themselves. Some people "wait" it out, hoping that the pain is manageable over the years. Keep in mind that collateral damage might happen over time too

35. Cheryl: Hello. I'm having major technical issues. I see this is being recorded. Will it be shared with this group?

Kit: Yes :) See link: <https://youtu.be/OfTd8huq1hk?si=7nKGfKFUjO7MUOqR>

36. Lorena: @Colin Haines started my aquatic therapy today. I loved it. Thank you so much for your support.



Haines: Love the aquatic, Lorena! Glad to hear!

37. Gerallt: My hip groin and groin and pain behind the leg is usually worse than my back pain. My back is only bad when i overdo it but the groin hip and leg pain is near constant. Does this still indicate that the lstv is the main cause?

Kit: A diagnostic injection will confirm if LSTV is the main pain generator. Many of us unfortunately also have collateral damage and pain in other areas (but perhaps not as severe as the pain directly related to LSTV)

38. Nicole: 15 year old with transitional L5 with pseudoarticulation on left, disc above has herniation. We are confused as one dr has recommended resection, another treating the disc. How can we find specialist with both knowledge and skill? Australia.

Kit: Consult with only a Bertolotti Knowledgeable doc as it otherwise can do more harm than good. You can still do virtual consultations and upload the scans. Some local doctors are open to work and learn from Jenkins/Haines

39. Jennifer: The radiologist that read my x-ray noted "this could cause chronic pain." Yet the doctors I brought my x-ray up to totally brushed it off. This was 8 years ago. Now I'm having pretty significant issues impacting my life and trying to seek help. I have nerve pain in my legs (mostly left) and supposed pelvic floor dysfunction. I plan to ask for current imaging. What should I ask for?

Holly: 😞

Lee-Ann: I was given the Chronic Pain diagnosis years ago. But that is a symptom what is causing the pain??

Haines: Lee-ann, there's almost always an answer. "chronic pain syndrome" means the medical team probably doesn't know the answer, not that there's an answer

Kit: If they notice an LSTV on the x-ray, best is to consult with a Bertolotti Knowledgeable doc. Your pain is real and many don't know of this condition but it doesn't mean it's not real. Reach out to a Bertolotti Knowledgeable doc and you'll be in good hands with them for the next steps

40. Susan: Hi! Dr. Haines..This is Elisianna's mom. She 9 days post op. She is doing good. She's had good and bad days but more good than bad. She just needs to learn to still take it easy on the days she feels good. She does still get knee pain but I am hoping with PT and time that knee pain will go away.

Haines: Great to hear, susan! She's absolutely going to get there!

41. Liv: Hello from Sweden! B/S confirmed 2016 and 2 times surgery to remove a big transversal bone L5. Also got many injections with no effect. Last surgery 2021. Now I have big problems and lumbar discs have completely collapsed so now they want to fuse L6-L3. Know to the question: is it possible to get my MRI evaluated by Dr. Jenkins ? Best regards Liv Strandvik

Kit: I'm so sorry to hear this all Liv.. but yes you can make an appointment with Jenkins's office and they will send a link to upload your images prior to consultation

Anders: He is doing telemed, go to jenkinsneurospine.com

Jenkins: 👍

42. Andrea: Is the deAlmedia algorithm still the best up to date treatment protocol for Bsy patient treatment trajectory prior to surgery (fusion or laminectomy depending on subtype) ? See Figure 3 here: <https://www.scielo.br/j/anp/a/XGHm3MxFJCHjd6BWH9P3FYt/>

TBD

43. Bree: How do we determine what type I have?

Kit: After getting a consultation with a Bertolotti Knowledgeable Doctor, have your scans uploaded prior to meeting if possible

44. Amanda: My dad attended a conference and the speaker there was a Kansas lady who talked about having bertolottis and surgery with Dr. Haines. He said she was really inspiring and talked about curiosity being important. Afterward she visited with him and gave him a lot of information to pass on to me and that's how I ended up finding out more about this condition. I hope that means the word about bertolottis is getting out if its being talked about in conferences all the way here in Oklahoma! 🙌

Haines: ❤️

Jenkins: 👍 Treating the doctors can help treat their patients as well...

Gretchen: I had 25 years of pain and chiro treatment, and 5 years ago my chiro told me about Bertolottis, he has it too. And another young lady in the office as well!

45. Tina: Dr Haines how far out are your new virtual consults (if you do virtual) being scheduled? Wondering how long it would take.

Haines: Usually virtual consults very quickly!

46. Nicole: Does the injection need to be done on both left and right side?

Jenkins: Depends on the symptoms

47. Emma: Does having EDS make things more complicated?

Kit: Might depend on the symptoms, best is to consult with a Bertolotti Knowledgeable doctor and address your EDS symptoms

48. Elise's: Hi! Elise in UK! Can facet joint degeneration cause pain in si joints? My si joints are fine according to mri, but this is now my main pain... 🙏

Jenkins: SI Joints are right next to the LSTV level. Often mistaken for the pain generator

Kit: Best is to consult with a Bertolotti Knowledgeable doctor and bring up your SI pain. Many of us experience pain in this area, could be collateral damage while living with Bertolotti.

Holly: I have experienced a fair amount of SI joint degeneration because it took so long to properly diagnose and fix my BSy 😞

49. Aksel: Dr. Haines, can I contact you for a virtual consult from Finland?

Haines: yes! my office number ins 7037091114

50. Emma: How can we make an appointment? What should we do to prepare for it?

Matyas: <https://spinemd.com/contact-us/schedule-appointment/> - For Dr. Haines

<https://jenkinsneurospine.com/contact-us/> Dr. Jenkins

51. Temmy: When xrays and/or CT Scans are done, for the Extra-L6 and/or S1/L6 cases, how can a group member make sure the prescription for the imaging goes low enough?

Kit: Depends on the instructions on the script. Dr. Jenkins indicated the angles/views etc so that the radiologist follows them as such

52. Emma: @Arthur Jenkins MD would you trust Dr. Siefferman to do the diagnostic block?

Jenkins: Yes. He's very experienced and very knowledgeable

53. Emma: What should we have prepared before we come for a consultation?

Kit: If you have images, upload them prior to the consultation. Make a list of all your questions that you'd like to be answered. Make an overview of the symptoms over the years you have experienced, even those that are not directly linked to your lower back pain, it's good for the docs to have an overall overview and assessment of your symptoms

Holly: 1) How long have you had symptoms (if applicable)? Pain doesn't necessarily have to be a symptom (e.g. limited mobility) - just any impact to your life. 2) What is the nature of any applicable pain - e.g. aching, burning, stabbing, ripping, tearing. 3) What other docs have you met with and what feedback/imaging did you get (if any)?

54. Kindra: Do you ever get a false positive with injections?

Jenkins: VERY RARELY.

Haines: Agree, almost never

55. Donna's: Does Bertolotti cause pain in the SI joint area. I've been told it's SI by 4 surgeons and 1 pain management it's SI. Had 2 SI injections that were negative. Had 2 Bertolotti that were positive. Very confusing.

Jenkins: SI Joints are right next to the LSTV level. Often mistaken for the pain generator

56. Brandon: Dr. Jenkins, I heard you say in one of your previous videos that its common for 2B's to also experience issues with their SI Joints, but that most people adapt and improve with physical therapy after having surgical intervention for Bertolotti's. I am wondering how someone can differentiate post operatively

between SI pain/dysfunctional that is adaptable vs. dysfunctional. For example, how would you know if/when additional intervention was needed? Is there a window of time you should expect to see the SI joint improve?

Jenkins: IMHO: I find most SI joints can be rehabilitated

Haines: Agree with the SI rehab protocol, I don't believe it needs surgical treatment often since the nonoperative treatments work well

Donna: I've had 4 surgeons and 1 pain management tell me it's SI. Had 2 negative SI and 2 positive Bertolotti

Nicole: Thank you very much- we have direction now

57. Lee-Ann: Are you able to get ADRs covered through any insurances?

TBD

58. Olivia: What is the big difference between a fusion that the typical orthopedic surgeon is recommending vs the fusion you perform?

See meeting for the fusion discussion

59. Bryt: How often do you see a true L6?

TBD, but stay tuned as I'm in the process of something exciting that sheds more light on the data of the doctors (Dr. Jenkins and Dr. Steinmetz are already onboard :) and I'll try to get Dr. Haines and Dr. Fogelson too, so sit tight!)

60. Kindra: If you get a resection, can you get a fusion later on, or is it only one or the other?

Lee-Ann: Dr. H recommended 2 stage procedure for me with both resection and fusion. and also ADR level above

61. Gretchen: Is there any way to have it covered by calling it other things than bertolotti? It's important to have diagnosed you said, but it will lead to gaslighting so it's a catch 22.

Tina: I had diagnostic injections, the Dr had to say he was doing a SI injections in order to get it covered by insurance

62. Aksel: Dr. Haines. Have you seen stem cells work for a degenerated disc with an annular tear causing sinuvertebral nerve irritation? Chemical irritation.

Haines: aksel, yes I have. We did a study that saw about 70% of patients get good relief from stem cells in the disc. Very patient by patient

Aksel: Great to hear! Is the study publicly available?

Haines: yes, on pubmed

63. LAPOUGE: @Arthur Jenkins MD @Colin Haines Is it common to experience alternating sciatic pain and buttock pain in type 2A Bertolotti Syndrome, without any lower back pain? And can I have a consultation with one of you before getting the injection with a local doctor? Thank you.

Kit: This is their information:

<https://spinemd.com/contact-us/schedule-appointment/>

<https://jenkinsneurospine.com/contact-us/>

64. Angelica: Do you ever see the L5 nerve displaced? Where does this nerve run in Bertolotti's?

Jenkins: Right over the LSTV

65. Emma: How many times would you recommend a dx block done? Would it make sense to look at CCI first then low back?

Kit: Best is to consult with a Bertolotti Knowledgeable Doc

66. Gretchen: If someone has had this a long time (almost 50) and as a result a lot of neck pain, do you see that much? DO you treat that aspect?

Kit: There have been many cases of people above 50 going for Bertolotti surgeries. Since I'm a patient of Dr. Jenkins, I can share based on my experiences that he looks at the whole spine and if you have other pains, he will also help with those instances. For example, he saw that I have cervical stenosis at C3-C4 while others didn't see this before

67. Elise's: How would you both treat 2cr+r with pain presenting in si joints area? And how long would you leave it before doing surgery? Thank you 🙏

Kit: Best is to consult with a Bertolotti Knowledgeable Doc, every individual is different. With some of us, the SI joint pain disappears after doing the LSTV surgery

68. Tracy: are either of you using the tops device by premia spine for l4-l5 fusions

Haines: Hi tracy, yes familiar with TOPS. A very good potential option for some conditions

Tracy: TY, I have been told good candidate by Steinmetz- insurance wont cover, they consider it experimental, trying to get this

69. Justin: with type 2B+r has any of your EDS patients had both a fusion with a resection from the iliac crest to relieve the bone on bone pain to the hip.

TBD

70. iPhone: @Kit Yam are you going to be discussing the questions asked in the chat? That would be very helpful.

Kit: Due to the high demand of questions, we only got to answer a few. Dr. Jenkins and Dr. Haines commented on some of the questions, but I hope this overview helps to recap everything!

71. LAPOUGE: My husband is a doctor and he've never heard of this syndrome... He's sitting next to me right now

Bryt: ❤️ Really awesome that he's here, watching. One more Doctor who knows, now. 😊

Jenkins: ❤️ Hello, happy to discuss...

LAPOUGE: Yes! Especially in France, NO ONE knows about this, really tired of not being heard

Donna: My son is an orthopedic surgeon and has never heard of this either!

72. Aksel: Dr. Haines. Do you prefer ALIF also for a degenerated painful adjacent disc above the LSTV? (If fusion instead of ADR)

Haines: aksel, sometimes for sure, depends on the scenario if a fusion or replacement is better

73. Aksel: Question to both doctors: In general. What are your thoughts on Fusion (ALIF, TLIF) vs ADR (for example a Prodisc) for a degenerated adjacent level above the lumbosacral transitional vertebra?

Jenkins: Depends on the patient

Holly: I had this! ADR at L3/L4 then ALIF/PLIF from L4 thru S1

74. Lee-Ann: IS it that some doctors are not prepared to fight the (insurance) system

Jenkins: 😞

Angelica: Yes if they can't get reimbursed for treating this condition that seems to be at least part of the reason they won't acknowledge it

Lee-Ann: Exactly! Its why we can't all be treated by these 2 amazing doctors

75. Kindra: Is surgery the only treatment option?

Haines: See response in meeting at 1:10:18

76. Purple: Self advocacy is exhausting, but this group and these doctors give me hope.

Jenkins: 😊

Lee-Ann, Holly Goodwin, Jennifer Stone, Bryt, Angelica Olney, Donna's iPad, Bree Sawyer: ❤️

Gretchen Korf: 👍

77. Aksel: Do you know of any surgeons in Europe you could recommend as knowledgeable in this syndrome?

Haines: not really unfortunately

Jenkins: Sorry, not

Matyas: There are a couple of doctors that patients have had good experience with. One in Germany and one in Netherlands: <https://www.aboutbertolotti.org/specialists-near-you>

LAPOUGE: @Matyas What about France ?

Matyas: @LAPOUGE I have not found any doctors there yet. I am relying on the community to provide information

78. Liv: Dr.Haines and Dr.Jenkins. Are you open for a discussion with a Swedish neurosurgeon?

Jenkins: Always!

Haines: agree! We love communicating with docs

Bryt: ❤️

Aksel: Who would this neurosurgeon be? I am from Finland so very interested in anyone willing to discuss with these surgeons.

Liv: Dr. Peter Nygren in Sahlgrenska university hospital 😊 I'm waiting for my appointment. He already seen my MRI

79. anastasiagak: Do you know anyone in Boston you can recommend for adults and for children at Children's hospital?

TBD

80. Jakki: Sorry, I just got kicked off and had to hop back on and now I can't see any of the previous messages in the chat. But this response is for Leanne's question regarding any insurances that might cover surgery for this. I was able to get my insurance to cover by going through my HR rep and establishing a single case agreement, as Dr. Jenkins eluded to earlier. I have ProviDr's Care Insurance. I know this is not a lot of people's experience, so I created a document that outlines the steps I took with insurance to get coverage that I share with others. If you want to DM me on the facebook group, I'd be happy to share.

Kit: Super Jakki! This will be very helpful for others to learn from your case. Matyas is also compiling data and created a survey. I hope this overview helps you to go through the previous questions!

81. Annemarie: Question: Can you tell us something about your knowledge/experience with the BS and hip problems? Context: I (female, 31yo) had a successful resection in January in the Netherlands with a backsurgeon, but I have very bad hip problems which makes it difficult for me to function. They don't know if it is the muscle or the joint that is causing the pain, MRI/X-ray can't tell what's the problem. In 2022 i had a CAM/Pincher resection and labrumrepair, 3 years before the backresection but only benefited from it for a year. Would love to know where to look for the right information.

Kit: Hi Annemarie! Thanks for connecting with me after the meeting, I will connect you with one of our members who went through hip surgery recently and has more info on how she dealt with that while still battling with Bertolotti

82. Emma: Can CCI and bertolotti be fixed in one surgery instead of two different day?

Jenkins: See response in meeting at 1:06:52

83. Jennifer: Thank you for listen to patients! I appreciate you both. Trying to navigate the medical system can be completely frustrating. It is wonderful to know that doctors like you all exist. Dr. Haines, I'm in Virginia so I'm glad you are fairly close by! I need to get scheduled with you!

84. Justin: CCI Surgery is unbearable I can't even imagine trying to do both surgeries at one time.

85. Angelica: Should surgery be avoided if possible? What else can help us?

Haines: See response in meeting at 1:10:18

Jenkins: Not the only one, but once you get so bad, very little ever helps. Injections wear off 98% of the time. Ablations work about 50% of the time, and for nowhere as long as for other conditions they do ablations for. Stem Cells and PRP don't work in my experience (Your mileage may vary)

86. Bryt: With CCI, is it possible to have symptoms show up as bilateral ear pain with local swelling at the root of helix, or would this be likely unrelated?

Jenkins: 👍

Justin: I had ear pain due to vascular issues from CCI. I had a right styloidectomy which helped with the right but Fusion helped with both

Bryt: @Justin Blair Thank you so much for responding — it's been extremely frustrating getting to figure out what is causing this. Did anyone notice the vascular issue on your imaging, or was it only noticed when going in to treat your CCI?

Justin: I had an ENT do vascular imaging with contrast while i was awake and he had me turn my head left and right and saw the veins being cut off. My symptoms were worse with AAI. Also Dr. Jenkins did a rotational CT which showed a lot vein compression

Bryt: Thank you so much — this is really helpful to know!

Justin: Feel free to PM if you're in the BS Fb group. Jay Blair

Emma: Did you find that at Miami J collar helps your CCI?

Justin: Miami didn't fit me but the aspen did. just be careful using too much you can get more unstable due to muscle loss. I used the aspen collar in the car the most, especially riding with other people. Huge help or when your really flared up.

87. Emma: Is Prolo beneficial as well or only PRP

TBD

88. Holly: Radiofrequency Ablation did NOTHINGGGGGG for me

Haines: agree

Donna's iPad: 😞

Canif: it did nothing for me either

Emma: I agree!

89. Alicia: So stem cell or pcp do work usually?

Haines: not really unfortunately

90. Katerina: Dr. Haines and Dr. Jenkins, Are there any doctors and/or surgeons you would recommend for treatment of Bertolotti's on the West Coast? Particularly for a teenage patient?

Kit: I created this map, you can visit my website and scroll down:

<https://www.bertolotti-syndrome.com/>

Or click on the map here:

[https://www.google.com/maps/d/u/0/edit?](https://www.google.com/maps/d/u/0/edit?mid=1lwTWc4z8sBjrJQHHxe_n0n3fpnkUbFc&ll=36.1942627148286,-112.2753880593265&z=5)

[mid=1lwTWc4z8sBjrJQHHxe_n0n3fpnkUbFc&ll=36.1942627148286,-112.2753880593265&z=5](https://www.google.com/maps/d/u/0/edit?mid=1lwTWc4z8sBjrJQHHxe_n0n3fpnkUbFc&ll=36.1942627148286,-112.2753880593265&z=5)

On the West Coast, Dr. Metz has been added as he has done surgeries on Bertolotti patients before

91. Jakki: If Insurance companies were to become more willing to covering surgery for Bertolotti's Syndrome, is there then the struggle of getting them to compensate you specialists at a reasonable rate for the increased amount of time needed for your thorough evals? Not knowing all the proper insurance lingo here, if advocating to our state reps to begin covering these surgeries, are there specific terms we should use, such as "cover surgery at a ___ rate or under the category of ___", to ensure that they are not only covered, but covered at a reimbursement rate that is fair and helpful to Docs and Patients.

92. Alicia: Does everyone eventually will need a fusion surgery do you think?

Haines: See response in meeting at 1:10:18

93. Kathy: I have an important question. How many patients do you see that have recurring pain post fusion?

Kit: Many of us have no/less pain post fusion, other issues might act up but the main pain generator from the LSTV is gone/minimal. Some experience this instantly after surgery, others experience it some weeks/months after. Note that many factors play a role, e.g. age, other injuries, other issues etc. The exact data is in the hands of the doctors, so hopefully Dr. Jenkins and Dr. Haines will compile the data one day so that we see the statistics and outcomes!

94. Linh: When Bertolotti causes the pelvis to be stuck in an anterior position, is it common for the sacrum to protrude? I was just told that I had a “bigger than usual sacrum”, but it keeps sticking out with time and it causes unbearable pain

Kit: Best is to consult with a Bertolotti Knowledgeable doc and indicate your pelvis pain.

95. Kit: Thank you all for joining! Due to the high demand of questions we can't get to them all, but Dr. Jenkins and Dr. Haines are open for consultations where you can get all your questions answered:

<https://jenkinsneurospine.com/conditions/bertolottis-syndrome/>

https://spinemd.com/medical_team/dr-colin-haines/

You can also join and post your question in this group: <https://www.facebook.com/share/g/1AatUEbgnA/> | Bertolotti's Syndrome Education Group (USA)

Sometimes Dr. Jenkins responds to questions there!

96. Tracy: I have cervical stenosis, told need fusion c3-c5

Haines: disc replacement may be a better option

Jenkins: That or laminoplasty, depending on the anatomy, symptoms, exam. Your mileage may vary

97. Donna: How do we find patient outcomes ?

Kit: The Bertolotti Education Facebook group has a lot of information and patient's reviews on outcomes. The exact data lies in the hands of the docs and hopefully will be presented and published one day!

98. Alicia: What are our chances of getting disability from this?

Kit: I think I saw a post in the Bertolotti Education Facebook group once about this. Not sure what the process is and what the outcome is...

99. Emma: Thank you so much Kit, Dr. Jenkins and Dr. Haines for all this wonderful information.

100. Kindra: If you are able to do a clinical trial , is there a way those of us here trying to advocate for ourselves can be notified about looking into joining the trial?

TBD

101. Annemarie: Question 1: Can you tell us something about your knowledge/experience with the BS and hip problems? Question 2: Is Chiropractic care allowed to improve mobility after healing from resection? Or do you advise against it?

Kit: Many of us have hip issues and pain, I look forward to having you in our next meeting where we can get more insights from others! I'm still figuring out my hip pain, so I don't want to provide misinformation as I haven't walked that "solving hip issues" road yet. Some have done chiro after surgery, but it really depends on what they adjust and how. Best is to consult with your doctor

102. Jakki: The longer you go with painful Bertolotti's, the more likely you are to have further spinal instability or degeneration at the level above (at a minimum), correct? You say that you should wait until other pain management techniques are no longer working to get surgery, but is there an argument for having surgery sooner so as not to endure that further spinal degeneration/instability?

Kit: I like your thought process, I was thinking the same. For some people it is manageable, degeneration might still take place indeed as we get older, but if the pain is doable one might not opt for surgery as that might have complications as well as financial concerns I can imagine.

103. Gina: I concur with you on PT knowledgeable clinics. I too wish there was greater care and knowledge in the PT realm

Marnicunha: Yes seems like as well as surgeons the word needs to be spread/taught for PT as well.

104. Bryt: Has anyone experienced their Bertolotti's pain as being 'ice cold', predominantly?

Jakki: Bryt, I had nerve impingement with mine and my legs started to feel ice cold, wet, and numb

105. Lorena: Not all PT are the same. Just met with my newest PT. He actually researched my condition and went over it with me. Empathetic and kind. Stay positive!

Haines: ❤️

Jenkins: 🙌

Marnicunha: ❤️

Lee-Ann: I had the same experience. I brought some literature and he researched the condition and was very careful and understanding of areas I was apprehensive about

106. Jenna: Thank you Dr. Haines and Dr. Jenkins for your time and for answering so many questions. Thank you Kit for setting this up! I appreciate you all very much!

107. Kit: Thank you Dr. Jenkins and Dr. Haines, this means a lot to the Bertolotti Syndrome community to have you in our meeting. Thanks everyone for joining! Stay around if you'd like to chat more 😊

108. Jakki: I'm almost an inch taller! :)

Jenkins: ❤️

Haines: Love it!

Bryt: ❤️

Matyas: Nice!

Holly: I'm 1.5" taller now post op! Lol...I noticed this when I arrived at the hotel after I was discharged from the hospital and noticed everything looked higher up to me while I was standing up 😊

109. Aksel: From this discussion I get a feeling that whether or not the LSTV is causing pain, it would be highly beneficial to have a surgery with a Bertolotti knowledgeable surgeon for example on other conditions like a fusion/ADR on a disc.

110. Marnicunha: Kit if your PT in NY has any contacts in Northern Cal that has experience in this condition I would love to hear the referral - marni@marnicunha.com - Thank you

Kit: I'll keep you posted!

111. Bree: @Kit Yam Is your shirt available for purchase of did you have it made?

Lorena: She allows customization! I have "cut it out" on mine. and Kits is "forever screwed"

Bree: I love it! Is there a link?

Lorena: I would connect with Kit. Forgot the process, sorry!

Kit: Yes! I'll share the info later in an email, you can donate to the Bertolotti funding and get the T-shirt embroidery customized 😊

Kit: You can go to my website: <https://www.bertolotti-syndrome.com/>

And scroll down to the section:

"Support our cause

Donate [HERE](#) and make a difference today! When donating a minimum of \$49 to the Bertolotti Syndrome cause, you will receive a FREE, unique, and handmade embroidered Bertolotti Syndrome Warrior T-shirt! 🎁*

112. Gina: I agree consult before injections!!!!

113. Crystal:How far out are they normally booked for new patients?

Jooyoung: They will definitely get you in — let them know your timeline, and they WILL get you in for at least a virtual consultation

Matyas: Dr. Haines typically has faster turnaround for consultations. Dr. Jenkins is relatively fast, you just have to call.

Bryt: No problem — speak to Abigail, if you're calling Dr. Jenkins's office

114. Nicole: Is there a resource that helps us find bertolotti knowledgeable practitioners in other countries?

Matyas mentioned this: <https://www.aboutbertolottis.org/specialists-near-you>

Kit: On my website you'll find a link to two maps, one for USA and the other for Europe:

USA

[https://www.google.com/maps/d/u/0/edit?](https://www.google.com/maps/d/u/0/edit?mid=1lwTWc4z8sBjrJQHHe_n0n3fpnkUjFc&ll=36.263458559657124,-98.20516385&z=5)

[mid=1lwTWc4z8sBjrJQHHe_n0n3fpnkUjFc&ll=36.263458559657124,-98.20516385&z=5](https://www.google.com/maps/d/u/0/edit?mid=1lwTWc4z8sBjrJQHHe_n0n3fpnkUjFc&ll=36.263458559657124,-98.20516385&z=5)

Europe

[https://www.google.com/maps/d/u/0/edit?](https://www.google.com/maps/d/u/0/edit?mid=1HtdoJbHDZo2GGr2vSj5s_Ie7Zlckr_o&ll=51.49179718405483,7.229956100000008&z=18)

[mid=1HtdoJbHDZo2GGr2vSj5s_Ie7Zlckr_o&ll=51.49179718405483,7.229956100000008&z=18](https://www.google.com/maps/d/u/0/edit?mid=1HtdoJbHDZo2GGr2vSj5s_Ie7Zlckr_o&ll=51.49179718405483,7.229956100000008&z=18)

115. Marnicunha: We went to Dr Haines and he did our evaluation and injection the same day. It seemed very valuable to have him do the injection.

L: Also, Dr. Haines prefers to re-do the diagnostic injection himself even if you have had it done before. He prefers to verify the results for himself. Dr. Haines also prefers to do imaging in his office when you visit. X-rays that is.. since they can do this quickly in office. Definitely bring any other imaging. MRIs/CT done before the appointment can be helpful so that they can review the imaging.

Crystal: Did they do imaging there or did you bring that info with you?

Marnicunha: Dr Haines did imaging. We brought her MRI's and CT tho. He was not happy that here MRI was only the lower back so before we went home we worked so hard to get our insurance to approve 2 mai's and get us in a clinic, so we did that before we went home. He wanted a full picture of her back. But it is helpful to do the CT and MRI before you go.

116. Canif: You can pay 300\$ to set up your own ct scan at radiologyassist.com

117. Gina: just be certain you have the correct CT views that Dr Jenkins spoke about. Perhaps that info is available on his site