Mount Sinai Virtual Patient Education Event 4/27/24
Q&A

1. **Q - Will gamma knife affect salivary glands and/or teeth?**
A - Gamma knife should not have an effect on salivary glands and teeth like conventional radiation might. It is very targeted.

2. **Q - Is there any time when radiation is not recommended?**
A - We don't recommend radiation upfront if no growth is documented. Also, tumors over 3 cm is not recommended, we usually prefer the tumor to be less than 2.5cm.

3. **Q – For international patients, when do you allow them to return home after surgery?**
A - it is very individualized and depends on where you are traveling from, the size of the tumor, and how someone does after surgery. a safe assumption would be 1-2 weeks after surgery if all goes well.

4. **Q - Why would someone with a small tumor opt for surgery vs gamma knife?**
A - If it is not growing and depending on the hearing status, many would opt to just watch it. if it starts to grow, then we think about surgery vs radiation. If it is radiated, the tumor generally does not shrink—it is frozen—many people do not want lifelong MRIs that come with radiation and many do not want a tumor no matter what and opt for surgery. You can have hearing preservation with surgery (potentially) whereas the risk of hearing loss with radiation in the long term is rather high. With surgery, that risk is more front-loaded.

5. **Q - 1. My wife experienced significant hair loss two months after her acoustic neuroma surgery. Could you explain why this might have happened and suggest ways to prevent further hair loss? 2. Considering the size of my wife's tumor (50mm x 49mm x 39mm) in her right ear and the resulting facial palsy, she is unable to close her right upper eyelid. What can we typically expect in terms of recovery for facial nerve function? When would it be appropriate to start discussing facial reanimation options?**

A - Most patients do not have hair loss after surgery. Sometimes the blood supply to the skin gets disrupted and can cause some hair loss in the short term. I would speak to a dermatologist and your surgeon regarding the hair loss. With respect to the facial nerve function, we typically wait 6-12 months to see what spontaneously recovers. However, early on it is very important to protect the eye and we will often do a gold or platinum weight in the eyelid to help close the eye in the short term. For specifics, it is necessary to know more about what happened during the surgery specifically.

6. **Q - What is malignant transformation that Dr. Wanna mentioned?**
A - When a benign tumor becomes a cancerous tumor

7. **Q - I on the Conservative group, with small tumour and no hearing loss, why I need a contrast MRI? Why not just ordinary MRI?**
A - It increases the chance that you pick up growth and is the most sensitive scan

8. **Q - Any tx more recommended for a tumor that is touching the facial nerve/ facial neuroma?**
A - almost all acoustic neuromas touch the facial nerve but a facial neuroma is treated differently and usually more conservatively bc removing it causes a guaranteed facial paralysis

9. **Q - Is the length of recoop time different if tumor is larger or smaller or is the recoop time same?**
A - it depends on the specific approach and how an individual does—all being equal I would anecdotally say someone with a small tumor has less of a recovery time than someone with a very large tumor

10. **Q - Two weeks after gamma knife I would like to take a 8 hour flight. Is this dangerous… might it make my symptoms worse due to inflammation? Would it be better to take a shorter flight of about 2.5 hours? (I could take a cruise part of the way!)**
A - it should be safe to fly but I would confirm with your treating team.

11. **Q - Is it possible to get rid of the tinnitus with a vestibular schwannoma?**
A - we typically send patients for something called tinnitus retraining therapy with an audiologist to help but tinnitus varies from person to person

12. **Q - I had surgery 2 yrs ago. I still have daily head aches at the scar area and have occipital neuralgia headaches a couple days a month. First question. Am I continuing to heal or is this where I am? Also My tinnitus has increased. Is there anything that can possibly relieve tinnitus?**
A - we typically send patients for something called tinnitus retraining therapy with an audiologist to help but tinnitus varies from person to person. It is hard to say regarding

your headaches, but you should consider speaking to a pain specialist to see if there is anything that can help your specific case

13. **Q - How often hearing test should be done after being dx with hearing loss in AN side.**
A - we typically test hearing once per year unless there is a change noticed by the patient—in that case we test it more frequently

14. **Q - Is there an association between Meniere's Disease and acoustic neuroma (in the same ear)?**
A – None known!

15. **Q - I underwent acoustic neuroma surgery six weeks ago. I had a tumor measuring 2.5 cm, and my doctor performed the translab procedure. I experienced a CSF leak, which was resolved with a lumbar drain. Although I'm feeling better, I'm still experiencing difficulties with facial movements such as closing my eyes and smiling. My doctor mentioned that it will take time for recovery but didn't specify how long. He confirmed that my facial nerve is functioning properly. Currently, I'm undergoing**
A - it can take several weeks to months for the facial nerve to recover. I believe Dr Rosenberg will be addressing this later

16. **Q - They had on TV news a while back a patient post surgery. and it was mentioned that the patient had to learn to walk again in baby steps…..is this soemthing that is coimmon post any tumor removal surgery or just in**
A - we expect people to be walking shortly after surgery—usually next day. they are often off balance in the beginning. Dr. Kelly will be addressing this in her talk

17. **Q - tumor size 50mmx49mm 1. My wife is now four months post-operation from her acoustic neuroma surgery. Are there specific activities she should avoid to ensure proper recovery? 2. Prior to her surgery, my wife experienced significant stress. Could this have contributed to the development of her acoustic neuroma? 3. Since her surgery, my wife has been undergoing treatment for depression and has gained weight due to changes in her eating habits. What should she avoid in her diet to manage her weight effectively?**
A - 1. we usually advise people to take it easy for the first several weeks. however we recommend normal activities and walking. we usually wait several weeks before recommending a specific exercise regimen. 2. Unlikely 3. This is best answered by a nutritionist or dietician

18. **Q - Doesn’t cross hearing aid, even if very much helpful, put more strain on the healthy ear that may be damaging in the long run?**
A - CROS hearing aids if properly calibrated should not present a risk for further hearing

loss on the contralateral side. It is true that some patients may just not like the experience of hearing sounds coming from the contralateral side since it can make sound localization confusing but while it may feel like it's overwhelming it does not lead to hearing loss. Ultimately some patients will find CROS helpful and some may not.

19. **Q - can hearing ever come back even if deaf?**
A - in very specific cases we place cochlear implants in patients with acoustic neuromas

20. **Q - Do hearing aid options reduce or eliminate tinnitus?**
A - hearing aids are quite sophisticated and some can even have masking noises programmed into them that may help reduce the perception of tinnitus. It doesn't necessarily eliminate but certainly many patients find that it helps them with the perception of their tinnitus

21. **Q - My wife 35 years old underwent surgery for an acoustic neuroma, where approximately 10% of the tumor was intentionally left to preserve facial nerve function. Given this, are there specific foods or dietary factors she should avoid to minimize the risk of tumor regrowth?**
A - there is no recommended diet to prevent further growth

22. **Q - Can you use any of these hearing aides when using a Bluetooth for any other device, like for a phone?**
A - yes! many of them have impressive capabilities

23. **Q - would there be any reason one couldnt wear any type of hearing device?**
A - there is usually an option of some kind for everyone! it would have to be a very specific case to not be able to wear one

24. **Q - I have hypericusis & can't tolerate bone conduction. Can a cochlear implant help yet not hurt. I am 100% deaf left. I am not treating the Irg V.S. Been there 21 yrs. stopped growing yrs ago**
A - cochlear implants can help patients with single sided deafness and their tinnitus however the research is limited in this specific setting

25. **Q - Are EMF radiation exposure from cell phones, laptops, Airport security check increase size of the tumour?**
A – it should not

26. **Q - But could a constant use of two mobile phones for ten years plus on same left year be a cause for AN, as Karolinska in Sweden suggested in a study?**
A - there is no definitive known link between the two

27. **Q - If hearing is preserved after treatment, what is liklihood for furture hearing loss?**

A - that depends on the type of treatment. if after surgery tends to be durable assuming no further growth. after radiation there can still be long term hearing loss

28. **Q - Are bone anchored options good for musicians? As in, do they distort the sound/pitch in any way?**
A - a good way to try this out is to buy bone conduction headphones—they are widely available online and you can try them!

29. **Q - if some of the tumor was left after surgery because tumor was large does that mean i will have to have surgery again in ten years? i am 40 and 2 years ago when found tumor they guessed it had been there 10 years**
A - not necessarily—many patients do not need further treatment. sometimes if the remnant grows you can radiate it without doing surgery. every case is individual

30. **Q - what % of patients treated w surg have no side effect & or have scores highest QOL**
A - many patients do very well after surgery and most people have a high QOL. the beginning after surgery is different for everyone and everyone has a different and individualized recovery. most of our patients after a few to several weeks are doing well and happy but this is also heavily dependent on characteristics of the tumor and treatment modality

31. **Q - Is it safe for someone to go swimming six months after undergoing acoustic neuroma surgery?**
A - in the case of someone with no active issues, usually yes. for your specific case I would check in with your treatment team

32. **Q - I was first diagnosed with AN and a few years later with Meniere's Disease in the same ear. Have you seen patients with both? Is it a common thing?**
A - Hi Gema, If you have AN than the symptoms are related to it , Menieres is rule out if there is AN in that ear but you can have Meneires symptoms due to the tumor

33. **Q - % of people w/ larg tumors that DON'T Treat (the risks my specific case outweigh benefits And their QOL . My QOL is 100%,**
A - A lot of the discussion regarding treatment relies on risks of further growth and it is very individualized. This can be estimated generally by a patient’s age and tumor growth rate overall. Generally if a tumor is already demonstrating significant levels of compression the concern is that even further minimal growth can lead new problems such as elevated intracranial pressures from hydrocephalus, which may pose signifcant risks to patients.

34. **Q - Is facial nerve damage (Bells Palsy) common 10 months after gamma knife? I am 78 years old and have had heart valves repaired. Is surgery common after radiation and what growth would make this necessary?**

A - you can have bells palsy unrelated to radiation, sometimes the tumor that is radiated can be a facial tumor and hard to tell on MRI that coud be another reason for bells palsy that did not recover. Surgery after radiation is not common but if we suspected over years that we are dealing with AN that did tansform to malignant case than we need to operate to rule it out. usually there is edema after radiation and tumor can be larger in the first 18 months so 10 months could be still edema

35. **Q - can it cause less sense of smell? i used to have a very strong nose and now i hardly smell..**
A – Not the tumor unless it is very large. Did you have surgery because that could happened

36. **Q - What are the key signs and symptoms to monitor after acoustic neuroma surgery to ensure proper recovery and to identify any potential complications early?**
A - Looking out for one of the main complications of surgery: CSF leak is always important. Signs that you have a postoperative CSF leak include having clear fluid running from the nose. More concerning would be the development of fevers or severe headaches that were not present in the initial postoperative period, which could indicate the early onset of meningitis. Fortunately this is quite rare but definitely something we discuss with all our patients. Development of delayed facial paresis/paralysis while concerning to patients generally carries a good prognosis since initial movement indicates the nerve is anatomically intact. Generally hearing loss if it occurs will be quite sudden after surgery and so there may not be much that can be done at the point of noticing it in the postoperative period.

37. **Q - I am leaning toward surgery instead of radation to get the remnants of a tumor that MRIs reveal is likely still growing. I think we are intending to go with the translab approach this time. But, would I also be a candidate for the transcanal approach as I have no hearing and the tumor impacted my nerve (nothing to preserve)?**
A - I have to see the recent MRI because the transcanal required tumor less than 1.5cm

38. **Q - Are bone conduction headphones safe to use if you have a VP shunt in place (after hydrocephalus from Gamma Knife)**
A - Should be ok with headphone and VP shunt as long as there is no magnet

39. **Q - Can I take something to increase my energy? I'm 25 years old and I've had two surgeries and my energy is sometimes too bad.**
A - overall faitgue and lack of energy can be a challenge to treat in patients, particularly those that have undergone multiple treatments. Both radiation and surgery can lead to prolong states of fatigue. Part of the problem may be from the process of vestibular compensation. In some patients enrolling in a robust postoperative rehabilitation

protocol can improve their overall energy levels. Medication side effects can also be the underlying cause of lack of energy as patients may initially require some pain or headache medication. Properly weaning from these can help. It may require the help of a pain specialist in rare cases of persistent pain.

40. **Q - For how long post-surgery should we vigilantly monitor for a CSF leak to ensure that any potential complications are addressed in a timely manner?**
A - Generally speaking by far the majority of CSF leaks will declare themselves in the first month of the postoperative period. However, just keeping in mind the types of symptoms associated with CSF leak such as runny nose, particularly only on the same side of the surgery or swelling and leakage through the incision or ear as Dr. Schwam just presented should always raise concern to contact your physician in order to have this evaluated as quickly as possible. The key is to have it looked at as early as possible since the risks of infection increase the longer the leak is present.

41. **Q - Do you have tinnitus retraining resources at your hospital?**
A - we send all of them to Tinnitus Center in Manhattan that is not affiliated to us. if you live in NYC will send you the place name

42. **Q - After acoustic neuroma surgery, what is the typical timeframe for cranial recovery, and when can a patient expect to resume normal activities?**
A - This can vary between patients but generally we consider patients should be able to resume normal activities after the first 1-2 months following surgery.

43. **Q - I feel as though my right side of the head is still under the effect of sedatives, even four months post-surgery. Could you explain why this might be happening? this question is still unanswered please help**
A - I'm assuming you may mean sensation of numbness on the side of the head. This can definitely be a common symptom following surgery as sensory nerves may need time to regrow/re-inervate the skin. While unfortunately there isn't much that can be done to speed up this process, the good news is that the majority of patients will recover sensation around the area of the incision but it can take several months for this to occur.

44. **Q - I had translab surgery 6 years ago…SSD, left small bit to preserve facial nerve. I still have significant facial paralysis (only move mouth). Is this a lost cause hoping for it to recover? Thank you to you and all the wonderful surgeons**
A - After 6 years it is unlikely to recover however there is lot of technique that dr rosenberg will present and can help stay tuned

45. **Q - Hello, Will occipital neuralgia/post-surgery head pain be addressed?**
A - Some people get nerve blocks others can get prescribed high doses of Neurontin and others will be referred to pain management

46. **Q - What's the % of people who have NO side efects after surgery**
A - in the beginning, some side effects are common. in the long term it is relatively low. it’s impossible to give you a concrete %

47. **Q - Are any recorded cases where the tumour shrink without intervention?**
A - yes but rarely

48. **Q - I’ve been experiencing loss of taste now, and a new feeling of fullness in my head. Also new: vertigo, dizziness, and body fatigue, and imbalance. Old 24/7 symptoms: awful tinnitus and right side loss of hearing. My AN is 1.3 cm as of the last MRI on Feb. 6, 2024. Why are all these symptoms developing when my tumor is small? And what can we do to get rid of the symptoms?**
A - sometimes symptoms are related to biochemical secretions of the tumor regardless of the size. Tinnitus is the result of the hearing loss and i dont know if your hearing is serviceable or not. If you dont want any intervention for the small tumor you get hearing aid if the hearing is aidable and tinnitus retraining

49. **Q - I can improve my hearing by popping the pressure in my ear. Is that pressure that can be cleared from my AN ?**
A - As you can imagine patients suffering from vestibular schwannomas still have other common conditions such as eustachian tube dysfunction. It is likely that part of the sensation of fullness if not all of it in your case may be secondary suboptimal pressure equalization in your ear (eustachian tube dysfunction) and so it is very possible that removing the tumor may not necessarily have in

50. **Q - After my second surgery, 5 days later, my arm on the affected side began to shake, on the same side, my lower limbs were left with too much weakness, pain and mobility was difficult. Is it possible that permanent damage had occurred? I understand that it was a very aggressive surgery due to the size.**
A - we always have monitoring electrodes in the arms and legs to ensure motor function is intact. the brainstem is the highway for all functions of the brain. it is possible there were some issues from brainstem compression or compromise from decreased blood supply to the brainstem. in such cases it is also critical to rule out a stroke. I would discuss this with your treatment team

51. **Q - Are those with balance issues more prone to seasickness? Would scopolamine be safe to use on the side of the acoustic neuroma?**
A - Certainly if you are suffering from baseline imbalance being placed in a challenging vestibular environment such as a rocking boat can lead to more significant symptoms of seasickness. Having a tumor does not necessarily impact your ability to take typical seasickness medications.

52. **Q - 12 years post stereotactic radiation (26 tx) Complete hearing losss and some balance issues COVID infection in Sept in OCT in hospital with vestibular neurits Doc says due to damage from radiation and covid**
A - certainly possible yes

53. **Q - is it common to lose balance easier when it is dark?**
A - yes because you lose the spatial orientation for the vision

54. **Q - my balance was really off after surgery but got so much better. surgery was march 2023. but in the last month it has gotten worse. is this normal.**
A - if it got significantly better and then got worse I Would touch base with your treatment team

55. **Q - It is possible and recommended to do rehabilitation after 9 months of the procedure**
A - if you are having difficulty, vestibular rehab can be helpful even at that time point

56. **Q - Ten days following the acoustic neuroma surgery, I experienced a visual distortion where my right hand appeared very small, though this has since resolved. Could you explain the cause of this temporary change in perception?**
A - it's possible that you may have experienced some form of temporary increased intracranial pressure that may have led to impaired vision. Sometimes the process of compensating for the acute vestibular loss can also lead to visual disturbances as just stated by Jennifer Kelly. Glad to hear your symptoms resolved.

57. **Q - I had gamma knife 2 years ago. Year 1 had necrosis, year 2 the tumor has started to grow again. I am not a candidate for re radiation I am 2 cm now; was 1.6 pre radiation. I am now on observation every 6 months to avoid surgery. Hemifacial spasms about 6-9X day. Is there anything else I should be considering in terms of care?**
A - Hemifacial spasms regardless of underlying etiology (from irritation caused by the tumor or in a non-tumor patient most commonly a blood vessel impinging on the nerve) can be treated conservatively with medication sometimes even botox injections in patients trying to avoid surgery. Of course it is imperative that the tumor be observed very closely. If it is demonstrating evidence of fast growth following failed radiation a strong consideration for surgery should be made. Although surgery itself obviously will present risk of facial dysfunction

58. **Q - SRS 10/19 for 10mm tumor. Hearing preserved but I have disequilibium, especially in the dark. Question: from time to time, I also get true positional vertigo with nystagmus, especially in the dark. Might last hours or days. Is this tumor-related or just BPPV?**

A - BPPV could be the reason for your true vertigo and nystagmus , it is easy to assess if it is BPPV vs weakness for the tumor.

59. **Q - I never heard of biochemcial secretions of the tumor. I see it in the answer from Dr. Wanna. What is that?**
A - It has been demonstrated that vestibular schwannomas can secrete certian proteins that are toxic to the inner ear and delicate cells inside the cochlea. There is actually pretty good evidence of patients having higher risk for hearing loss when high definition MRIs demonstrate abnormal signal inside the cochlea, which may indicate that the tumor may be causing some level of inflammation inside

60. **Q - Is it generally safe to resume gym activities and more strenuous exercise five months after acoustic neuroma surgery? What precautions should be taken if so?**
A - you should be fine after 5 months.

61. **Q - Is there a way to prepare before surgery for a faster recovery ?**
A - there has been research indicating that in patients with significant pre-treatment vestibular symptoms a pre-treatment dedicated vestibular rehabilitation protocol can help patients compesate faster in the post-treatment period

62. **Q - Does vestibular therapy prior to surgery/radiation help?**
A - Depends if you are off balance before or dizzy, it might not hurt
A(2) - there has been research indicating that in patients with significant pre-treatment vestibular symptoms a pre-treatment dedicated vestibular rehabilitation protocol can help patients compesate faster in the post-treatment period

63. **Q - I am 18 months post retrosig. I was symptomatic pre op and balance, oscillopscia and dizziness are basically unchanged. I have mild-moderate peripheral neuropathy in my right foot. I have had extensive VR with no improvement. Are there specific interventions that I should try considering the neuropathy? I am 68.**
A - i would speak to a neurologist; sometimes there are treatments that can help with that

64. **Q - I'm currently taking 2x 50mg of sertraline and 2.5mg of olanzapine for depression treatment, as well as 100mg of benfotiamine post-operation. Could this combination of medications for depression affect or slow down my recovery from acoustic neuroma surgery?**
A - many medications used for depression have side effects that can mimic certain things people experience after surgery. i fyou have been on these meds for a while without major effects it should be safe to continue. I would touch base with your treating psychiatrist if you are having issues

65. **Q - How many surgeries would it take for you to consider an institution “high volume”?**
A - I would say over 50 surgery a year some centers like ours are way over that number but I would be comfortable with over 50

66. **Q - Will there be a discussion regarding post-treament headache occurence/ managment? What’s the liklihood of headaches with different treatment modalities?**
A - It’s important to understand the type of headache that occurs in VS patients and post-treatment patients. Generally surgical patients understandibly incur a higher incidence of post treatment, post-craniotomy-type headaches. These are more tension type headaches that generally improve over the course of the first several months and are most oftenly treated with non-steroidal anti-inflammatory type medications like tylenol and ibuprofen type medications. This differs from neuropathic type pain leading to headaches, which may benefit from nerve blocks. Also research has demonstrated that risk factors for headaches post-treatment are similar in vestibular schwannoma patients as general population: age, gender, anxiety. Hence it’s important to understand that VS patients may still have underlying headache disorders such as migraines that may be independent of the disease and require its own management with the help of a neurologist headache specialist with migraine medications.

67. **Q - I had retro surgery at UCLA Med in Dec '21. I had total hearing loss on my right side. I developed occipital neuralgia after the surgery which has not subsided. I've used medication to manage the pain, but it doesn't fully eliminate the pain. Unfortunately, the tumor grew back quite rapidly. Their may have been too much tumor left behind as my neurosurgeon said it was bundled in the nerves. It has regrown to the same size as it was (small) before surgery. Now, my ENT wanted to do a translab. and put in a cochlear implant. A second doctor suggested that it would be far less risky to use focused radiation to stop the growth. So--now I'm leaning toward radiation - knowing that it would complicate any later surgery - and I'm seriously considering having my occipital nerve cut to stop the chronic pain. I've been participating in thw UCLA Migrain Pain Clinic for about 9 months and and still haven't eliminated the pain.**
A - I am sorry that you are going through this, Translab is not bad options similar to radiation depends on of course the size of the tumor, did u get injection for the pain

68. **Q - does radiation stop the growth? Can it shrink the tumor? What causes rapid growth in a slow growing tumor?**
A - radiation often stops the growth but does not usually shrink the tumor. various genetic factors of the tumor itself affect the growth rate

69. **Q - Do the patients get to be at the rehearsal?**
A - not typically

70. **Q - What is the prognosis (with regard to improving balance) for a patient who has had Gamma Knife and then undergoes Vestibular therapy— being that the tumor has not been removed and remains on the balance nerve**
A - In general they do well, especially if you are in good vestibular rehab center.

71. **Q - For someone who will personally fund for the surgery, can I ask what is the average cost of surgery and average post -op recovery.**
A - I don't think anyone can answer this question on the panel we will need to have you work with the financial department to give you the estimate. They do that all the time for our international patients.

72. **Q - Can 7T be done without contrast?**
A - yes but ideally we do it with

73. **Q - I had a retrosigmoid approach 15 months ago. A day after the sx I developed Hydrocephalus and had a cerebellum stroke. I needed a craniotomy to relieve the pressure. Shortly after I developed a pseudomangiocele that resolved wih a course of steroids. I noticed I alays have a "drunk like" feeling and always tired. Will this feeling go away ith time or will I always continue to feel this way. I have done vestibular therapy but this hasn't helped much with that drunk feeling i always have.**
A - everyone is different and it sounds like you had a complicated course after surgery. many people take a long time to recover after such issues but for more specifics I would talk to your neurosurgeon

74. **Q - Is the radiation technique used at Mt. Sinai Gamma Knife?**
A - Mount Sinai offers the full spectrum of radiation treatment for skull base tumors. We work together with our radiation oncologists as part of our dedicated skull base team.

75. **Q - for wait and see patients, is there data on long term impact from contrast agents resulting from the multiple MRIs required ?**
A - We dont have data on over 20 years but more and more we are not giving contrast after 5 years and rely on CISS sequences
A(2) - There really is no data on the negative effect of contrast. typically it clears out of your circulation, assuming no kidney disorders

76. **Q - I am 3 years post translab and have had synkenisis, facial paralysis, vestibular issues and hearing loss. Recently, I have had neck pain (with certain movements). Might this be related to my facial palsy?**
A - Unlikely after 3 years check your neck first.

77. **Q - Why does facial paralysis occur from radiation?**
A - While this is quite rare it is possible that radiation can cause direct injury to the facial nerve, which is always directly adjacent to the tumor. Also, radiation treatment can cause damage to some of the small blood vessels supplying blood to the tumor. Unfortunately, some of these same vessels can also be feeders of blood to the facial nerve and hence the nerve can have an ischemic injury or in other words blood supply diminishes to the nerve.

78. **Q - I've had cat scan guided nerve blocks, botox, and a lot of drugs to control the pain, I still can get pain spikes which are debilitating. Also, with the regrowth of tumor, many of my initial symptoms--dizziness, etc.--have worsened. And of course this makes me think that maybe I should have it removed but I know that surgery is far more risky. The occipital nerve may have been pricked by the clamp system to secure my head and or nerve tendrils that have regrown without the mylin sheath. It's been very difficult. The drugs help--but then the side effects can cause a lot of the same symptoms--dizziness, fatigue, etc--so hard to determine what is being caused by the tumor or the drugs. Help!**
A - Occipital pain can also be treated through “nerve stimulation” in whichj external stimulators are placed and can help modulate pain. They are done by Pain specialized neurosurgeons. In our center Dr. TedPanov is the expert in treating this time of pain.

79. **Q - In experienced hands, what is the chance of a surgical result of facial paralysis in a tumor that has been previously radiated?**
A - it depends on the size, it is higher than non radiated but we need to know the size because it is a single digit percent if the tumor is small
A(2) - single digit percent if the tumor is less than 1.5 cm it goes higher if the tumor is larger

80. **Q - For 1cm, 58 year old... why not start with Gamma Knife as less aggressive, first line of defense? Especially since I believe you can either do another Gamma Knife session OR surgery later on if needed.**
A - I would argue if your tumor is not growing perhaps even a period of observation first may be the best option, particularly if your hearing is excellent and you are ok with this option. Should the tumor demonstrate growth over time you can still very easily opt for the radiation treatment considering the tumor would still be fairly small particularly if there is no evidence of fast growth. Radiating a tumor that is not growing always poses the question of what sort of outcome you are looking to achieve considering that tumor growth control is the primary goal of radiation treatment.

81. **Q - Is it safe to scuba dive? I had radiation for my AN. My concern is my “good ear” could possibly be damaged.**
A - that is a risk any time you scuba dive!

82. **Q - why would a person start with surgery? ... why not start with radiation, then if needed do surgery?**
A - many reason why not radiation first. longer follow up if you are young and potential growth over time and risk of harder surgery to remove it or lower risk of malignancy. Patients dont want to get MRI every year or patients doesnt want to live with tumor in their head. Radiation is not a bad choice but it should be a share decision with patient and customized to their need
A(2) - I think everyone'symptoms are different and that matters too in deciding the best treatment. Also age, tumor consistency matter too. I do radiosurgery often and its important to stress that the treatment should be tailored specifically to the patient

83. **Q - is facial paralysis usually seen with radiation?**
A - only very rarely

84. **Q - Do you have a list of neuro-muscular facial retraining therapists you work with?**
A - dr. rosenberg has several he works with if you contact his office. 212-241-9410

85. **Q - as newly dignosed, our concern has been preserving my husband's hearing, but it sounds like preserving the facial nerve is the greater risk?**
A - Hearing loss by far carries a much higher risk than facial paralysis with upfront surgical treatment and even for long term outcomes in both observation and radiation management. Facial dysfunction tends to be a concern for more large tumors where the nerve has been significantly splayed by the large tumor as well as patients with fairly large tumors that have already been radiated who need to undergo surgery due to new growth.

86. **Q - I get occasional shooting pains in about 3 different areas of my head (not the AN area). Does that mean I have other brain tumors?**
A - Pain itself does not directly correlate to brain tumors, its really the constellation of syptoms, frequency and progression that matter. As always please see your doctor for guidnace and work up

87. **Q - I am an acoustic neuroma patient since 2017, last MRI in 2022 noted a 9 mm tumor, slow growth. I have had some symptoms that started in March of a feeling like my brain is being shaken,, associated with some nausea. I have right side deafness, and daily symptoms of vertigo, and dizziness. Is this a common symptom**
A - deafness and vertigo are very common yes

88. **Q - I have facial paralysis 10 months after gamma knife. I am doing facial PT and seeing improvement. When should I look at facial reanimating**
A - I think you should seek out consult at least

89. **Q - is it possible to have partial paralysis before even diagnosis**
A - that put the diagnosis of facial tumor in risk

90. **Q - Can you please put the number in the chat for the Dr. Kelly and vestibular PT at Mt. Sinai? Thank you.**
A - 212-614-8379 vestibular rehab at Sinai

91A. **Q - can a 2mm AN cause dizziness, vertigo, and hearing loss? I am on watch and wait for 4 years**
A - yes it can but if you have it stable for 4 years and the hearing is very good to start with the chance that it will stay stable in regards of hearing

91B. **Q - would radiation be recommended due to symptoms or wait for growth?**
A - Growth is the reason to get radiated because the goal is to prevent growth. Some symptoms can get worse after radiation

92. **Q - I hear that some surgeons routinely sever the vestibular nerve to allow the opposite side to completely take over and compensate. Other surgeons do not. Is there any research that shows a difference in outcomes in regards to balance/gaze stability dependent upon whether the never was severed or not?**
A - Most patients compensate or recover better when the nerve is completely severed, but we see many patients who recover well when they have some function on that side

93. Q – Are there vestibular exercises online?
A - you can find them online, but i would recommend following up with a vestibular rehab professional

Answered pre-event:

Q - Are there any treatment options that will restore the hearing loss incurred due to the benign tumor that is slowly growing on the nerve in my left ear?
A – There are a few options for hearing loss that results from having a acoustic neuroma/vestibular schwannoma (benign tumor growth on the vestibular-cochlear nerve—ie hearing and balance nerve). The options depend on the level of your hearing loss, the degree to which it has impacting the clarity of your hearing, the hearing in your other (good) ear and what treatment options you are considering or planning for the tumor. To understand what hearing options are right for you, it is necessary to have a hearing aid consultation. In general, it would be ideal to have this done with an audiologist who has some experience or knowledge of acoustic neuromas. In general, it is not necessary to wait until after treatment for you to pursue a hearing aid consultation. For example, if you are currently observing the tumor with repeat MRI planned, you could schedule a hearing aid consultation. There are a few options for

hearing loss, which include a traditional hearing aid, a CROS aid (contralateral routing of sound) and - in some cases- a cochlear implant may be an option. At present, there are no options for restoration of natural hearing to the ear that has been affected by the benign tumor. All treatment options listed above focus on aiding (or improving) the hearing you still have- many which do so very effectively. Lastly, in some unique cases, treatment with a medication called Avastin has been shown to stabilize the hearing. This treatment is felt to be experimental in many cases and does have some side effects to consider.

Q - I am in a pre-treatment stage with a lot of hearing loss in my right ear. I am 76 years old and my tumor is less than a cm. Sounds are distorted and seem very loud and uncomfortable in that ear. Would you recommend getting hearing aids before treatment or after treatment? Or not at all? Is there a special type of hearing aid I should be looking for?

A - There are many kinds of hearing loss and the hearing loss experienced from an acoustic neuroma/vestibular schwannoma is very unique. The symptoms you are describing with your hearing loss are very common- specifically that loud sounds are uncomfortable, or even painful, and that an increase in volume does not always lead to an improvement in clarity of speech. Overall, treatment of both the tumor and the hearing loss are very individualized. The options also depend in part on the hearing in your other (good) ear. In general, it is not necessary to wait until after treatment for you to pursue a hearing aid consultation. For example, if you are currently observing the tumor with repeat MRI planned, you could schedule a hearing aid consultation. This consultation occurs with an audiologist and would be very informative for you in terms of which technology may be available to you. At these visits, they will look at both ears to see if a contralateral routing of sound option might be a good fit for your needs. This kind of hearing aid sends sounds from the tumor side to the good ear so you have access to sounds on your “bad side” but you hear them in your good ear. OR, you may want to try a traditional hearing aid in your ear. Ideally, the audiologist you meet with should be familiar with acoustic neuromas and can show you all the options. All hearing aids (regardless of type) have a trial period during which you can experience them in your daily life. If you do proceed with a hearing aid consultation, it’s a good idea to make sure you are clear on the details of the trial period.

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