

## American Brain Tumor Association Webinar

### Understanding the Diagnosis and Treatment of Acoustic Neuroma

>> Welcome everyone and thanks for joining us today. Welcome to the American Brain Tumor Association's webinar series. Thank you so much for participating in today's free educational webinar. Today's webinar is on: "Understanding the Diagnosis and Treatment of Acoustic Neuroma." It will be presented by Elizabeth B. Claus, MD, PhD. Please note that all lines during our webinar today are muted. If you have a question you would like to ask, type and submit it using the question box in the control panel on the right-hand side of your screen. Dr. Claus will answer questions at the end of her presentation. Tomorrow you will receive an email asking you to evaluate this webinar. It is a very brief survey. Please take a few minutes to share your comments. Your feedback is important to us as we plan for future webinars. Today's webinar is also being recorded. The recording will post to the ABTA website shortly. Registered participants will receive the webinar link in a follow-up email message once the webinar is available. Let's pause for a moment so we can begin our webinar recording here.

>> The American Brain Tumor Association is pleased to welcome you back to our webinar series. Our webinar today will discuss: "Understanding the Diagnosis and Treatment of Acoustic Neuroma." My name is Andrea Garces, Program Manager here at the American Brain Tumor Association. I am delighted to introduce you to our speaker today: Elizabeth B. Claus, MD, PhD. Dr. Claus is a professor and director of Medical Research at the Yale University School of Public Health, as well as attending neurosurgeon and director of Stereotactic Radiosurgery within the Department of Neurosurgery at Brigham and Women's Hospital in Boston. She is a member of the board of advisors for the Acoustic Neuroma Association (ANA), as well as the Central Brain Tumor Registry of the United States (CBTRUS). Dr. Claus' work is focused in cancer and genetic epidemiology with an emphasis on the development of risk models for breast and brain tumors. In addition to her research activities, Dr. Claus trained as a neurosurgeon at Yale-New Haven Hospital and completed a fellowship in neurosurgical oncology at Brigham and Women's hospital. Her clinical focus is on the treatment of meningioma, glioma, acoustic neuroma and brain metastases. In partnership with national patient brain tumor organizations, including the American Brain Tumor Association (ABTA) and the ANA, Dr. Claus is working to develop cost and time-efficient, web-based recruitment strategies to be used in the study of brain tumors.

>> Thank you very much and good afternoon to everyone. Thank you for joining us and thank you to the American Brain Tumor Association for supporting this webinar. I list here my disclosures and support and then we will get into the main part of the talk. I thought I would begin with giving a definition of Acoustic Neuroma. I have a bit of a schematic here. Essentially, acoustic neuroma is a non-cancerous or non-malignant, generally slow-growing tumor of the nerve that connects the Ear to the brain and you can see a schematic of that here. It's also known as the eighth cranial nerve and it has two components, the auditory and the vestibular component. It turns out that the vestibular portion is the most commonly affected, and that's why many times you'll hear the term vestibular schwannoma used in addition to the term acoustic neuroma. The cells that line the nerve are called schwannoma cells, or schwann cells, and when those overgrow themselves, you come up with an acoustic neuroma or schwannoma. Here is an example of what the nerve looks like unaffected, and here is an example of a good-sized lesion when the tumor has formed. You can see from the location of this – here is the top



the head and here are the ears and the neck - you can have a fairly large legion in a fairly tight space and that's where symptoms come about.

>> I thought I would present some information from the United States in terms of how many people are diagnosed with this tumor and I take data from what is called the Central Brain Tumor Registry of the United States or CBTRUS. Some of the information on acoustic neuromas and other non-malignant tumors have only begun to be collected since 2004. So prior to that there was no organized registration of non-malignant tumors and that began through a federal mandate in 2004. I think some of the numbers are still being collected entirely, but we've got pretty good data at this point in time. If you look over a five-year time period from 2007 to 2011, these are population-based data from the United States. Malignant tumors are listed in the color red and non-malignant tumors, including acoustic neuroma, are listed in blue. When you go to some of these national registries, the acoustic neuromas come under the nerve sheath tumor scenario. About 8% of all brain tumors in the United States are these non-malignant nerve sheath tumors. The majority of them, which is a subset here, are Acoustic Neuromas or vestibular schwannomas. If you do the math it turns out that about 7.5% of brain tumors in the United States are listed or defined as Acoustic Neuroma. We think that includes about 5,000 individuals, at least within the United States every year, being newly diagnosed.

>> What are the risk factors for Acoustic Neuroma? There have not been a large number of studies that investigate this question, but we know that genetics plays a role. High-dose ionizing radiation certainly. Immune factors, we're learning more about and that seems to also be associated. There has long been a concern regarding cell phones. In the end it is not completely clear what role, if any, cell phones might play but I thought I would show you the data for that.

>> In terms of genetics, the primary gene that has been associated with Acoustic Neuroma is NF2 or neurofibromatosis 2. It's relatively rare, but it is associated with a high risk of disease and in fact it's associated with a high risk of bilateral Acoustic Neuroma meaning in each ear. There are some other tumors associated with NF2, like meningioma. Although there is a high risk of Acoustic Neuroma in individuals that have NF2, the majority of people diagnosed with Acoustic Neuroma don't actually have a diagnosis of NF2.

>> In terms of ionizing radiation, we have data from a number of different types of studies including following young children that received radiation for treatment when they were at an early age, from atomic bomb data, and also from studies of radiation treatment in countries like Israel. Essentially, we have learned that when children are exposed at high doses that the brain is a high risk site and we see over a lifetime a twofold to threefold increased risk with high-dose ionizing radiation.

>> As I mentioned, there's been an increased interest in things regarding the immune system and we have found now that in addition to glioma and meningioma, we see an inverse relationship between allergy and asthma and risk of acoustic neuroma. That's fairly consistent across most of the brain tumors.

>> As I mentioned, data on cell phones is a bit controversial and becomes difficult to measure because most people that have acoustic neuroma a most people that don't have Acoustic Neuroma use a cell phone. It's very difficult to find individuals that are not "exposed" to a cell phone. There was a fairly well-attended meeting that was at the World Health Organization in May 2011 and essentially this is the conclusion: long-term use of a cell phone might lead to two different types of tumors, glioma and Acoustic Neuroma, but they cannot conclusively confirm or deny this. The thought is they would



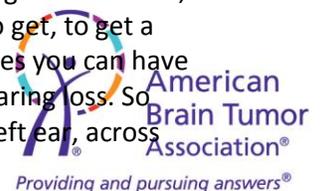
continue to watch this. There are some ongoing studies in children regarding the use of cell phones in Acoustic Neuroma so we might be able to get additional information from those studies.

>> I thought you might be interested, especially for patients, in seeing what are some general characteristics of Acoustic Neuroma patients within the United States. The National Cancer Institute has a data collection program called the Surveillance Epidemiology and End Results, or SEER program and as I mentioned, for noncancerous tumors like Acoustic Neuroma, data collection only began in 2004. But we do have now about 10,000 patients registered, so there are some characteristics that are popping up. There is a slightly greater number of females versus males that are diagnosed with Acoustic Neuroma. The majority of cases report their race as white. About 11% report their ethnicity as of Hispanic origin. If you look at age, the mean age is about 55 years old. You see there is a little bit of a range and there is not a large amount of patients diagnosed in the pediatric population and a good proportion of those are likely individuals diagnosed with NF2. It's pretty much a diagnosis of middle age or beyond. In terms of treatment about half of the individuals listed underwent surgery as their first course of treatment. About one quarter received radiotherapy and about another quarter received observation. If you look at the data, the treatment selected does vary by the size and location of the acoustic neuroma. Across these individuals, the average size at time of presentation was about 1.7 cm. The good news is, although certainly acoustic neuroma is associated with a variety of difficulties, the majority of patients in terms of survival do quite well.

>> How are patients diagnosed? I would say the number one diagnosis is hearing loss that is unilateral, or one-sided hearing loss, and it can present in a variety of different ways. It can be sudden and complete. It can be a slow decrease over time. I have some patients who tend to have episodes of hearing loss or ear fullness - for example, they might have a period of two or three weeks where they have hearing loss and then it gets a bit better and then maybe a year or two later a similar episode occurs. Tinnitus or ringing in the ears is also common. Dizziness or balance problems – we see that a little bit more when the tumor is larger. The same situation for facial numbness or weakness. We also see patients who don't have any symptoms, and I would say that most commonly we run across these individuals after they have had some sort of an accident, like a car accident, and they receive a head CT. We also see patients who are receiving yearly MRIs being screened for other diseases, like multiple sclerosis, and they have an incidental Acoustic Neuroma identified on that.

>> Just to give you a little bit of a picture, the nerve travels through a bony canal called the internal auditory canal. I wanted to point out there are a number of nerve components in that canal. The vestibular component and the cochlear component are part of the acoustic nerve, and nerve number seven is the facial nerve. What you can see here is that when any component of the tumor over grows itself, it comes up quite closely on these other nerves and that's why you have problems not only with hearing but also with balance, with facial nerve difficulties, because all those components are so close to one another physically.

>> What is the workup for acoustic neuroma? Primarily getting a good MR of the brain. It's important to have thin cuts in order to be able to distinguish the anatomy. You need to get IV contrast with good imaging of that ear canal or the internal auditory canal. There are some individuals who for a variety of reasons, like they have a pacemaker or some other diagnosis that makes them unable to get a brain MR, and they can receive a head CT, and then also to get a hearing exam. That is important to get, to get a feel for not only what does the image look like, but how is the patient affected. Sometimes you can have a small lesion on MR and it might not seem impressive, but you can have a significant hearing loss. So it's important to get both pieces of information. Here is an example of a right ear and a left ear, across



the different frequencies, and you can see that one ear is hearing less well and this is actually in a patient who has acoustic neuroma on one side.

>> What is the treatment for acoustic neuroma? There is not one right answer for any given scenario. It's very much an individualized treatment plan. In some instances, we are able to observe the patient and follow them over time, also known as watch and wait. In some instances, particularly when there are larger tumors, surgery is probably the best option. In other instances, radiation therapy is a good option. In some cases, patients will require a combination of therapies, so they might have surgery and because of the location or size of the acoustic neuroma, it may be too dangerous to remove all of it and therefore some residual might be left after surgery, and therefore radiation therapy might be a good additional treatment. In general there is no standard chemotherapy given for acoustic neuroma. There are some special instances in smaller clinical trials for individuals that have refractory acoustic neuroma and they are particularly focused on patients that have NF2. A medication called Avastin which is used for the treatment of glioma and other malignant brain tumors has also been used in certain circumstances. Generally, for standard acoustic neuroma, chemotherapy is not typically a treatment option.

>> How do patients select a treatment? It depends on a variety of different characteristics and obviously tumor size and location is very important. The larger the tumor the more likely the surgical intervention might be needed. The tumor growth rate, we know in general these tumors grow quite slowly over time. Every once in a while we see a patient that has a faster growth rate and that is someone we might be more likely to intervene upon. The hearing status is not only in the affected ear but also the contralateral ear and what you select on the overall hearing status and how that person might be affected by whatever treatment is selected. Also whether the patient has symptoms or not. As I mentioned, some people have no symptoms at all. Other people have quite serious symptoms and that would certainly direct what treatment would be selected. The patient's age and medical condition, so older patients or patients with a number of medical conditions might not be able to undergo surgery or have general anesthesia. We might choose something different for that type of individual. Individuals with NF2 have a special set of circumstances and are looked at quite differently. Frequently we have specialized clinics to follow and treat those patients. It's also a function of what does the patient want and what they are interested in pursuing and what they are comfortable with and what is the experience and preference of the surgeon. What sort of approaches are they comfortable with? What experience do they have with any given approach? We will talk a little bit later on about questions to ask your physician, but that's a very important thing to consider.

>> Talking about observation, people from site to site do things a little bit differently. What I generally do, if it's a new patient and it comes under these categories of small tumor, or asymptomatic or perhaps elderly or with other medical conditions and are considering observation, so we usually get an initial baseline MRI of the brain with a hearing test. In general because we know in most instances the tumor is growing quite slowly that it's reasonable and safe for the patient to get a first recheck at six months where we get another MR and hearing test and if things seem fairly stable typically we follow people on a yearly basis. If we are concerned about any change, either clinically in terms of hearing or picture, we might intervene or continue to follow up at six-month intervals. We tell patients too if they feel any concern or change to let us know to not wait for the prescribed time if they are concerned about anything to re-contact us.

>> If surgery turns out to be the option that is right for a given patient, there are variations on any theme, but there are three general surgical approaches called retrosigmoid, middle fossa, and



translabrynthine. The choice depends on the factors that we were talking about. The location, the size of the Acoustic Neuroma and each individual patient's anatomy. People can vary in terms of where a particular blood vessel or nerve or anatomical components are located and all that needs to be taken into account. You need to think about how much pre-operative hearing loss exists in the affected ear as well as the contralateral ear.

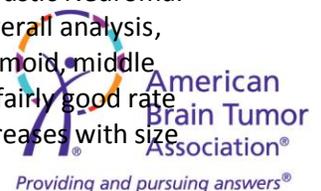
>> Retrosigmoid is probably the procedure that is most commonly used in neurosurgery. That's across the board. It's something that most neurosurgeons are fairly familiar with. It's used not only for Acoustic Neuroma but a number of other neurosurgical conditions. All of these are under general anesthesia. In this instance you enter behind the ear. It is a surgery or operation that can be used when you are attempting to save hearing as well as in instances where you might realize that the probability of sacrificing hearing is relatively high. The one caveat is that small Acoustic Neuromas that are in the far lateral portion of the hearing canal are not well seen, so it is a less good option in that particular instance.

>> Middle fossa is for individuals that have tumors within the internal auditory canal and have hearing so you can see here this would be the outside the ear. What happens here is you approach from above the ear and you lift up a portion of the brain that's called the temporal lobe. Finally, the Tranlabrynthine is the less common surgical approach, but I would say that many surgeons who have extensive experience in Acoustic Neuroma surgery use this quite frequently. In this approach, hearing sacrifice is complete, but it is a good approach when one is trying to preserve the function of the facial nerve. Also, as some of these cochlear nerve implants are more frequently being used, an effort can be made to spare the cochlear division of the nerve, in the event that a patient might later on down the road be a candidate for that sort of implant. That's an important thing to talk to your surgeon about as well as whether an effort can be made to do that.

>> Surgery is done under general anesthesia and as we talked about, a patient has to be healthy enough to undergo general anesthesia. In the operating room, surgeons use a microscope so they are able to remove the tumor while protecting other structures such as the facial nerve. In some instances, and more and more over time, surgeons – that's what the picture shows here, both the use of a microscope and also a special camera called an endoscope can be used at the time of surgery, which is helpful in seeing around corners and places that might be difficult to see with only the microscope. That is another nice advance that is coming into play. Monitoring of the cranial nerves is done during the surgery so that the surgeon knows if they are advancing towards a nerve. Sometimes, the tumor can hide cranial nerves especially if it's a larger tumor.

>> The goals, benefits, and risk vary by type of surgery and it's an important conversation to have with your surgeon. Find out what their experiences with any given approach. The greatest risk is hearing loss and that varies by type of approach. Also facial nerve damage, headache, CSF leak, or the fluid that's within the head can be seen in hydrocephalus and either of those can end up needing to be treated with a second surgery or placement of what is called a shunt to reroute some of the fluid. Obviously as with any craniotomy or general anesthesia there is a risk, although low, of other morbidity and mortality.

>> This is a paper from a 2012 issue of neurosurgical focus which is a review issue on Acoustic Neuroma. It's giving some of the estimated risks by type of surgery. These authors performed an overall analysis, pulling together a lot of papers from literature and looking by the three types so retrosigmoid, middle fossa, and trans-lab , what the sorts of risks were for hearing loss. You can see there is a fairly good rate of hearing loss and it increases with size of the tumor. Facial nerve dysfunction again increases with size



of the tumor, relatively low for smaller tumors but increasing when you get up to a large which is greater than 3 cm. These are rough estimates of CSF leak, of headache and also of having residual tumor left behind that might need additional treatment.

>> Radiation therapy is also an important type of treatment for Acoustic Neuroma. Radiation therapy generally goes under the term stereotactic radiosurgery when we talk about Acoustic Neuroma.

>> The name radiosurgery makes patients think about intraoperative surgery using a knife, but there is no use of knives in this. It's all using radiation and computer targeting. It allows us to direct focused radiation so not whole brain radiation but focused to a specific target and lets us go to that target while protecting other important structures in the brain. It's fairly widely used throughout neurosurgery. We use it for a lot of different types of brain tumors. The example I have is for metastatic lesions, but it's used for pretty much any type of tumor that comes up in neurosurgery.

>> The process varies a little bit by what type of equipment or software a particular facility uses. Some imaging of the head through a head CT or an MRI or frequently both is obtained from the patient. What a team will do and that includes a neurosurgeon, a radiation oncologist, a radiation physicist, is basically we work together and using computer programming and here is an example, outlined the lesion and take care to mark off important areas such as the brainstem and other important optic nerves in the brain so those are not targeted. Then we deliver radiation to the Acoustic Neuroma. There is a fair amount of experience with this now. It's been done for a number of years and is generally quite a safe procedure.

>> I list here a number of different types of software and equipment. There is gamma radiation and probably people have frequently heard about gamma knife surgery. Also photon radiation, linear accelerators, another term is LINAC, Cyberknife, and protons. Although probably the greatest experience is with gamma knife surgery and LINAC, good control of Acoustic Neuroma has been reported for all of the methods listed.

>> There are a number of different permutations. There are frame-based methods where a frame is placed and then imaging is done. The patient would then sit and wait while the team prepares the plan, as we just talked about. There is also frameless technology and this is one example here. There are some other technologies using fiducials as well as a mouthpiece so there are a lot of different advances and changes coming forward using stereotactic radiosurgery. There are also a number of different ways in terms of how the dosing is done. In some instances a single dose is given and in other instances multiple doses, which is termed a fractionated dosing regime, are given. Both work quite well in terms of tumor control. There is some thought that the fractionated regime can offer a slight advantage in terms of hearing preservation. It's important when you're going to a facility to talk about what sort of technique they might be using, what their experience is, whether a frame would be used, one dose or multiple doses.

>> Benefits of stereotactic radiosurgery are obviously you are avoiding open surgery, avoiding anesthesia and avoiding any associated complications that might be associated with surgery such as CSF leak and there is no hospital stay. As for surgery, there is good tumor control and most of the series that are out now suggest there is a 95% or even better control of the tumor at 10 years.



>> There are also risks as with anything in medicine. Hearing loss is certainly a risk and the feeling is that over the long term, the hearing loss can be similar to what it would be for open surgery. It may not happen as quickly, but as the effects of radiation take place over time, people can continue to have risk of hearing loss. There is also risk, any time radiation is completed, that the tumor can temporarily swell. This can cause symptoms like hydrocephalus, or vertigo, or facial palsy. It can also sometimes make it difficult to know if the tumor is increasing in size i.e. growing, or whether it's temporarily swelling from the effects of radiation. You have to be careful as you are watching and following up after radiation to not too readily assume that it's growth in tumor, it might just be swelling. The swelling and difficulty in knowing which direction we are going can take over two or three years.

>> What are the questions to ask? We touched on this, but these are some questions that are probably good to take along if you are considering some sort of intervention or treatment plan for an Acoustic Neuroma. It's very important to go to a center that has a team that focuses on Acoustic Neuroma. You want to know what is the level of experience of the team you're working with, what member is doing what, what treatment they would select for you and why they would select it for you. For example, if they would like to observe a patient, how frequently would you be seen? Also, who would be the person doing the follow-up? Would it be a primary care doctor, the neurologist, surgeon, radiation oncologist? It's important to figure that out ahead of time. If surgery is the approach that seems to be the most reasonable, what approach would be taken? When patients undergo this sort of surgery they generally spend at least one night in a nurse surgical intensive care unit - so you would want to know if such a unit is available to the patient after surgery. Also, is there an intensive care team that would be taking care of the patient? If radiation therapy is selected, what type of equipment and software would be used? As we mentioned, is there a frame or frameless-based approach? Would it be one dose or would you come back for multiple doses? And at any center, what sort of outcomes are to be expected? How would any problems that might arise be managed and who would be managing that and what follow up would be necessary? It's also important, as many people travel outside of their home area to visit some of these Acoustic Neuroma specialties, to know when you go home who will be following the patient, who will order the MR or hearing test or any therapy or treatment needed to get the plan together and make sure you know who is doing what.

>> There are some great information resources available both through the American Brain Tumor Association, as well as the Acoustic Neuroma Association and I have the websites for both those organizations listed here.

>> I wanted to highlight that we have obviously been very interested in studying risk factors for Acoustic Neuroma and so one of the things that we are trying to do is involve patients a bit more in looking at such research. We have a study where we are looking to identify genetic risk factors, both inherited, meaning that would be in the blood or saliva, as well as genetic risk factors in the tumor and to see if we can learn more about these things. If you have any interest in learning more about that, we have our study at the Acoustic Neuroma website and you can go there and find us.

>> Other than that I thank you very much for your time and for listening. I hope I might be able to answer any questions that you might have.

>> Thank you so much for that wonderful presentation. Everyone, Dr. Claus will now take questions so if you have a question you would like to ask please type and submit it using the question box in the webinar control panel on the right-hand side of your screen. We have a few questions that came in during your presentation. One of them, Dr. Claus, is how do Acoustic Neuromas get reported to



CBTRUS? Given there is no mandatory reporting of Acoustic Neuroma, could there be underreporting in the CBTRUS registry?

>> Actually, now as of 2004 there is mandatory reporting, but that began at that point in time. CBTRUS gets data both from SEER as well as other population-based registries. It's a central clearinghouse for tumors of the brain. But I think since we're only about 11 years into this, I am sure they are still underreporting. It's getting better and I've looked at the data over each year for the past 11 years and you can see the numbers rising. I think we have work to do but we are getting better than where we were.

>> Thank you for that. You also talked a little bit about how it is diagnosed - can an Acoustic Neuroma be missed on an MRI?

>> Absolutely. I have a number of patients where it was missed. If they are small and in particular if no contrast enhancement is available, so if it was an MR that might've been for another reason perhaps a stroke or some other diagnoses where contrast might not have been given, it could be very easy to miss it.

>> A follow-up to that, what are some common misdiagnoses and how long do patients experience symptoms before they are accurately diagnosed?

>> That varies and I don't think there is any set time. I think probably the biggest delay in diagnosis is patients tend to, as they mature, accept some hearing loss and to attribute it to age or perhaps to attending too many rock concerts during their younger days. I think people accept a bit of hearing loss until it becomes more severe or something they bring to physician attention. I don't think there is a set amount of time between symptoms beginning and diagnosis occurring. We are probably getting better at it over time, I would say.

>> Thank you. Another question was what can be done if the Acoustic Neuroma is swelling?

>> If it is swelling, and I am assuming that would be after radiation therapy, the primary thing we can do is to offer some steroid treatment. It depends on if the patient is symptomatic. Sometimes we can see a bit of swelling but the patient remains asymptomatic so we can watch them carefully. If it's a situation where the patient becomes symptomatic, then the most frequent course of action is to try to use steroids. If it became a serious problem, it could be a situation where they may have to undergo surgical intervention.

>> Another question we had was about using Bluetooth ear pieces, instead of cell phones into the ear. Does that reduce the risk of Acoustic Neuroma?

>> That's a great question and the short answer is we don't know. There has not been any formal study. Probably so few people have that technology that it would be tough for us to get a sample size that would be large enough for us to answer the question. Unfortunately we don't know the answer to that one.

>> Thank you. Another question is after stereotactic radiosurgery, is there a chance that hearing loss or partial hearing loss that was there before the surgery, can be restored after the surgery?



>> It certainly is always possible, but I think in general that hearing loss that exists at either time of surgery or time of start of radiation therapy typically does not improve. It tends to either stay the same, or worsen in the majority of cases. I think we have all had a patient or two for whom it became better, but I don't think that is the typical scenario.

>> Thank you. Another question was if you knew of any of the early findings that you had so far from the Yale Acoustic Neuroma study?

>> So far it's a pilot study and we are trying to gather enough observations to then go forward and get funding for it. We are very excited to report over 1,000 participants. We're hoping we get about 2,000. But we have been extremely pleased with the efforts that both the ANA and ABTA and patients and caregivers in general have offered to us - it's been an amazing experience. We have about 1,100 so far and trying to get about 2,000 because that would give us a sufficient number of observations to try and start to look at things.

>> That is great news. You spoke a little bit about some of the symptoms. One question was if many years after, is it common to experience facial stabbing pain? Is that a symptom you have encountered?

>> We have sometimes and we see it a little bit more with larger size tumors. Sometimes people can even have it after treatment. It has been reported both quickly, after either radiosurgery or surgery, and long-term people can have either facial pain or trigeminal neuralgia and facial twitching. I would say the occurrence is low, but certainly has been reported.

>> Thank you. And for those who have smaller tumors but they are experiencing symptoms as if it they are a bigger tumor, would you recommend the patient go by the size or more so by the symptoms if the symptoms are more severe?

>> It's not an either/or kind of scenario. It depends on what the symptoms were, the age of the patient. I think if it's a young and healthy patient and their symptomatic, certainly an option of surgery or radiosurgery would be available to them. It would really depend on that specific person's anatomy, why we thought the symptoms were occurring because sometimes it's not, as you say, just the size but the location, what it is close to, whether it is tightly wedged in the canal and whether it is affecting things like the facial nerve or other anatomical components.

>> Okay. Thank you. Is there a site where some of the participants and those interested in the community can find data regarding the number of radiosurgeries done for Acoustic Neuroma by different facilities? Is that kind of data available?

>> I'm not aware yet, I know that associations like the Neurosurgical Association are working to place that sort of information online. I'm not aware of one, uniform location where that would be listed across sites. I know that most sites that do Acoustic Neuroma surgery, the surgeons that focus on it keep their own statistics and would be able to share that with patients.

>> Thank you. For those who have meningioma on the brainstem and have lost hearing, is that something you experience is very similar to Acoustic Neuroma?



>> It can be. Every once in a while, we mistake an Acoustic Neuroma for a meningioma and vice versa if it is located near where the hearing nerve is. There is always a small proportion that overlap and when you look at them on imaging it's difficult to tell. Certainly a meningioma that arises near that location can certainly act clinically very similar to an Acoustic Neuroma. The treatments are fairly similar as well.

>> Thank you. Can you speak a little bit about some of the neurocognitive complaints?

>> Sure. We see some neurocognitive complaints. I have had patients talk about difficulty with multitasking. Also with being able to concentrate. Sometimes with the ringing in the ears, they find it difficult to concentrate. We have had people who, after any sort of treatment, be it radiosurgery or surgery, have some difficulty. I would say I haven't seen it occur in the majority of patients, but there certainly is a subset of patients who do suffer from the symptoms and whether it's treatment related or secondary to the disease itself isn't always clear. It is certainly something that is real.

>> Thank you for that. After a gamma knife, if it was done 4 or more years ago, can the Acoustic Neuroma still experience swelling?

>> It certainly could. The typical time period that the literature suggests swelling occurs is about 2 to 3 years. The thinking is that by two or three years out, that most of the swelling if it is going to occur has happened. I think it starts to become more concerning if it's four or five years out, whether or not it's growth versus swelling.

>> Thank you. Is there an average amount of surgeries a year that most doctors that perform this type of surgery do? One question is about a daughter with a 3 cm tumor and the doctor does about 50 surgeries a year. Is that something that most do?

>> It varies site to site. I don't think there is any one average, 50 sounds like a reasonable number. It's also years of experience too. It's always nice to go to someone that has an extended number of years of experience. True of anything in life.

>> Very true. Can you clarify what refractory AN is? This was discussed during the chemotherapy Avastin discussion.

>> There is a very small number of patients that, despite either surgery or radiation therapy or even both, that the Acoustic Neuroma tends to recur or continues to grow. We have seen that probably most frequently in patients that have NF2. They have already used surgery, radiation, and are not eligible for any additional treatments of that sort. One thing that has been tried is, as I mentioned, Avastin for those individuals. I will also say I don't think it has occurred much today for Acoustic Neuroma, but we're becoming better and better for all these sorts of tumors at doing genetic profiling and trying to see are there targets within tumors that now with some of these new treatments we might be able to target.

>> Thank you. Can you also speak to recovery after surgery?

>> Generally, the first evening is spent in the intensive care unit and for some individuals especially if they are older or have other medical difficulties might need more time than that. I think in most sites, the goal is to try to get people up and home fairly quickly, get them out of the hospital. A number of people obviously will need rehabilitation services. They may need some sort of support if the facial



nerve has been affected and may need additional procedures by a plastic surgeon or other surgeons, such as a weight that might lower their [indiscernible] if the facial nerve was affected. If they have things like vertigo, they might need training for that, or physical therapy. Sometimes if they have complications, they might end up needing a shunt. I would say the majority of patients are able to go home three or four days after surgery to start their rehab.

>> Thank you. Do you also know if there is a connection between facial pain before surgery and the risk of facial paralysis afterwards?

>> It has been suggested and I think the numbers are fairly small. It would depend a little bit on the reason for the facial pain. Whether it is occurring because the tumor is compressing the nerve or it might even be large and compressing, for example, another group called the trigeminal nerve. It depends what the facial nerve is coming from in terms of whether it would affect the actual facial nerve. You can have facial or pain in the head or face associated with a number of different nerves – it doesn't have to be just the facial nerve.

>> Thank you Dr. Claus. There is a question on how would you determine if symptoms are from the gamma knife or from Acoustic Neuroma?

>> That's probably pretty hard to do. It would depend upon the specific circumstances, but in general that'd be probably pretty difficult to do.

>> Sure. For those who have had surgery to remove the Acoustic Neuroma, one challenge is hearing aids can help them hear one side louder, but then not the other side. Is there any suggestions for how hearing aids can help after the removal of the Acoustic Neuroma?

>> There are and actually there was recently a month or so ago a very nice webinar available to the public on the Acoustic Neuroma website. A hearing specialist at the Mayo Clinic presented all of the different types of hearing aids and what the purpose was in each instance depending on the kind of hearing loss the patient had. I would recommend if people have time to look at that. It's a very nice, straightforward, easy to understand presentation on hearing aids that would be helpful to people.

>> Thank you so much. I think that is all the time we have for questions, but Dr. Claus did you want to add anything or have any last comments?

>> No, I just want to thank everyone for joining us and if we can be of help to anybody please get in touch with us.

>> Thank you so much and thank you so much for this great presentation and for joining us and for your time. For more information on brain tumors and to help patients and caregivers process the diagnosis, understand a new and difficult vocabulary and access resources to help make informed decisions, you can always feel free to call the ABTA Care Line at 800-886-2282. Let's pause for a moment to conclude our webinar recording.

>> We invite you to continue to check back at our website [www.abta.org](http://www.abta.org) for ABTA's library of free on-demand webinars that feature experts addressing a range of brain tumor topics from treatment options and tumor types to diets and coping with the diagnosis. Our next webinar will be Viral Therapies for



Brain Tumors on Thursday, January 21 from 1:00 to 2:00 PM CT. Viruses have the ability to replicate and eradicate cancer cells, according to promising studies. Oncolytic viral therapy is a treatment that can infect and kill cancer cells, leaving normal cells unharmed. In addition, vaccines made from a gene-modified virus, for example the measles vaccine, may help the body build an effective immune response to kill tumor cells. Join Ian F. Parney, MD, PhD, Department of Neurosurgery, Mayo Clinic who will discuss how viral therapies work and future directions in viral treatments for brain tumors. Dr. Parney will also highlight a Phase I clinical trial underway at the Mayo Clinic that is investigating the side effects and dosage of the measles viral therapy in treating brain tumor patients with glioblastoma multiforme (GBM). This webinar includes an interactive Q&A with Dr. Parney. This concludes our webinar for today. Thank you so much for joining us and please be sure to complete the evaluation survey you will receive by email tomorrow. You may now disconnect. Have a wonderful rest of your day.

[Event concluded ]

