**Acoustic Neuroma Subtotal Resection Study (A.N.S.R.S.)**

**What is the purpose of this study?** The study is designed to investigate treatment outcomes in patients with large acoustic neuromas. Large acoustic neuromas tend to compress the brainstem and the facial nerve and in most cases the tumor is tightly adherent to these structures. In such circumstances it is not possible to remove the entire tumor during surgery as it may cause facial paralysis or brainstem complications. It has become a standard of practice for surgeons to remove all (called total resection), about 99% by volume (called near-total resection), or between 80-99% by volume (called subtotal resection) of these tumors depending on tumor characteristics encountered in the operating room. After surgery patients are monitored using MRI scans to make sure the residual tumor does not grow. If the residual tumor shows signs of growth patients receive stereotactic radiation therapy such as Cyberknife or Gammaknife. The potential advantage of leaving small residual tumor would be less chance of facial paralysis and other complications. However, this may come at the expense of residual tumor growth in future. It is our goal to investigate if one can optimize removal of the tumor and preserve excellent facial nerve function without increasing possibility of tumor growth and need for further treatment in future.

**Who qualifies to participate?** Patients with large acoustic neuromas (measuring 2.5 cm in the widest diameter in cerebellopontine angle) who have never received prior treatment.

**What Centers are participating in the study?**
- Stanford University, Palo Alto California (Robert Jackler, MD; Nikolas Blevins, MD; John Oghalai, MD)
- George Washington University, Washington DC (Ashkan Monfared, MD)
- Weill Cornell University, New York (Samuel Selesnick, MD)
- University of Iowa, Iowa city (Bruce Gantz, MD; Marlan Hansen, MD)
- University of Texas Southwestern, Dallas (Walter Kutz, MD; Brandon Isaacson, MD)
- Louisiana State University, Baton Rouge and New Orleans (Moises Arriaga, MD)
- Indiana University, Indianapolis (Rick Nelson, MD)
- University of Cincinnati in Ohio and Baylor College of Medicine in Houston are no longer accepting new patients

**Questions?** More detail about the study is listed on US National Institute of Health Clinical Trial website, at https://clinicaltrials.gov/ct2/show/NCT01129687?term=acoustic+neuroma&rank=12. You may also email Dr. Ashkan Monfared at amonfared@mfw.gwu.edu.

**How do I participate?** If you are able to receive your treatment at any of the participating Centers, please contact Dr. Monfared to put you in touch with that Center’s coordinator.

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**Mayo Clinic Prospective Quality-of-Life Study**

**What is the purpose of this study?** The study collects and analyzes ongoing data about how the diagnosis and treatment of an acoustic neuroma affect quality of life and what symptoms or problems most impact quality of life. The goal is to develop recommendations to improve quality of life in people with acoustic neuromas or determine what treatment strategies least negatively impact quality of life.

**How is the study being done?** The study is being done via a mailed hard copy questionnaire. The questionnaire includes 64 questions relevant to your symptoms and quality of life. Most of the questions require simple yes or no answers or ask you to rate a symptom on a scale of 1 to 10. Completion of the questionnaire is estimated to take only 10 to 15 minutes. A postage-paid, self-addressed envelope is included to return the completed survey.

Surveys are mailed in the spring and fall. The first year you will be asked to complete the survey twice (six months apart), and then, once a year (annually) for approximately 10 years if you choose to continue in the study.

**What are my obligations if I agree to participate?** Participants need only to complete the questionnaire to the best of their ability, honestly answering each of the questions as they pertain to how they are feeling at the time of completing the survey. There is no cost to you, and you can withdraw or decline to participate at any time. Your decision to participate does not in any way affect your relationship with the Acoustic Neuroma Association (ANA), and no funding from the ANA is being used to complete this study. Your personal information is never shared.

**What if I haven’t yet had treatment for my acoustic neuroma or had treatment many years ago?** It doesn’t matter whether you had treatment a long time ago or which treatment strategy you have had (observation or "wait and scan," radiation, or surgery); we want to know how you are doing, what symptoms you are having and how they are affecting your quality of life. Even if you haven’t yet had any treatment, knowing how the diagnosis has affected you is helpful to the study.

**What if I am doing fine and don’t have any symptoms or problems related to my acoustic neuroma or its treatment?** Even if you are not currently having symptoms or quality-of-life concerns related to acoustic neuroma, your answers and input may still help determine how more people can live symptom-free and enjoy a high quality of life. In this way, your input may help other people.

**What if I have other questions?** If you have questions about the study, email: RStacousticneuromastudy@mayo.edu or visit http://www.mayo.edu/research

**How do I get started?** Simply email RStacousticneuromastudy@mayo.edu. Include your name and mailing address. Your first survey will be mailed within the next six months.
University of California, Irvine Decision Making in Acoustic Neuroma Study

The goal of the study is to better understand the decision-making process for patients with an acoustic neuroma. Researchers intend to use this data to assess challenges and important factors used to decide on which treatment course to undertake. Identification of these issues can better inform physicians on treatment care. You are eligible to participate in this study if you have had a diagnosis of acoustic neuroma. Participating in this study is optional. If you choose to participate, please complete this survey, which will take approximately 15 minutes. This survey is completely anonymous; no identifying factors will be recorded. No information that you provide will be able to be traced back to you. There are no direct benefits from participation in the study, but you will be providing physicians with valuable insight into the decision-making process for those diagnosed with an acoustic neuroma.

The principal investigators are Dr. Harrison W. Lin and Dr. Hamid R. Djalilian, of the University of California, Irvine. Please email the research team at UCIAcousticNeuroma@gmail.com if you have any questions or concerns.

To participate in the survey, click on the following link: https://ci-redcap.hs.uci.edu/surveys/?s=C8F749XXXD

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The Yale University Acoustic Neuroma Study

ANA has awarded a grant to the Yale University to assist in the funding for this first phase of the data collection. *PHASE I- DATA COLLECTION IS ONGOING. THERE IS CURRENTLY NO FUNDING FOR PHASE II OF THIS STUDY. Overview - Dr. Elizabeth B. Claus from Yale University launched the collection of data from acoustic neuroma patients at the ANA National Symposium in Los Angeles in August 2013, to initiate the first AN causation research study of this type.

What is the goal of the study? Little is known about risk factors for acoustic neuroma. The purpose of this study is to discover why some people develop acoustic neuroma while other people do not.

Who is organizing the study? The study is organized by Dr. Elizabeth B. Claus from Yale University.

Who can enter the study? Any person over the age of 20 years with a diagnosis of acoustic neuroma.

What are study participants asked to do? There are two parts to being a study participant:

1) an online interview with questions on medical and family history, and
2) a saliva sample that will permit us to look at changes in DNA.

If you allow us, we will also review your tissue specimens and MRI scans of your acoustic neuroma.

To complete the online questionnaire: Visit the ANA website at www.ANAUSA.org.

There is a Visitor option available on the online questionnaire if you would like to review the questionnaire in advance.

For questions and more information, email acousticneuroma@yale.edu or call 203-764-8422.

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Disclaimer

The Acoustic Neuroma Association® posts information about Acoustic Neuroma medical studies and trials which may be of interest to ANA members. These listing are provided as a convenience only and are not to be considered an endorsement or recommendation by ANA.

All studies and trials listed have IRB or Ethics Committee approval. An Institutional Review Board (IRB) is a committee established to review and approve research involving human subjects. The purpose of the IRB is to ensure that all human subject research be conducted in accordance with all federal, institutional, and ethical guidelines.

Clinical study involves research using human volunteers (also called participants) that is intended to add to medical knowledge. There are two main types of clinical studies: clinical trials (also called interventional studies) and observational studies.

In a clinical trial, participants receive specific interventions according to the research plan or protocol created by the investigators. These interventions may be medical products, such as drugs or devices; procedures; or changes to participants’ behavior, such as diet. Clinical trials may compare a new medical approach to a standard one that is already available, to a placebo that contains no active ingredients, or to no intervention. Some clinical trials compare interventions that are already available to each other.

When a new product or approach is being studied, it is not usually known whether it will be helpful, harmful, or no different than available alternatives (including no intervention). The investigators try to determine the safety and efficacy of the intervention by measuring certain outcomes in the participants.

The ANA website provides a brief introduction to studies and trials, with links to the study and contact information. All information is provided by the research organization. AN patients should contact the research organization for more information using the contact information provided.

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