The Yale University Acoustic Neuroma 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. ANA has awarded a grant to Yale University to assist in the funding for this first phase of data collection.

• The goal of the study is to determine whether or not there are possible genetic risk factors that cause AN. Little is known about risk factors for acoustic neuromas. The purpose of this study is to discover why some people develop acoustic neuroma while others do not.

• Why is this study so important? Acoustic Neuroma is a rare disease and there has never been a large-scale study of this type to determine the cause for it.

• Why should I participate? Yale needs at least 1,000 participants in the study. We need your help to make this happen.

• How is the DNA saliva test done? Your local support group leader will provide each eligible participant with a saliva sample collection kit to help you get started. The kit consists of a container in which you spit a small amount of your liquid saliva to provide a DNA sample.

• Who can enter the study? Any person over the age of 20 years with a diagnosis of acoustic neuroma. Pre-treatment, post-treatment and watch and wait patients are invited to participate.

Requirements to Participate

A. Confirm your eligibility for the study. Yale will need a copy of your surgery pathology report (if you had surgery) or your MRI report (if you did not have surgery).

B. What are study participants asked to do?
   1. Complete an online questionnaire on medical and family history.
   2. Provide a saliva sample for the genetic portion of the study.
   3. Complete consent forms:
      a. DNA consent form for saliva collection
      b. Medical Release form
      c. Participant Contact Information Sheet

C. What do I need to bring to the meeting?
   1. Please bring copies of your surgery pathology or MRI report (disk or hard copy). These will not be returned to you.
   2. Please DO NOT eat, drink, smoke or chew gum 30 minutes prior to the meeting to submit a saliva sample. This will provide the best quality DNA sample. DO NOT drink water as this will dilute the sample.
   3. Please bring your laptop or tablet device so that you can complete the online questionnaire.

What if I am unable to attend the support group meeting? You can still participate! Please visit the ANA website, www.ANAUSA.org. Here you can find more information and access a link to complete the online questionnaire.