

DISCLAIMER

All data collected in the Acoustic Neuroma Association's 2012 survey is intended for use by the Acoustic Neuroma Association on behalf of its members. Best efforts have been made to ensure participant confidentiality and personal information collected was used for authentication purposes only.

Survey results are intended to provide helpful information. Survey results are not a substitute for professional medical advice, care, diagnosis or treatment and are not designed to promote any medical practice, program or agenda or any medical tests, products, treatments or procedures.

Furthermore, survey results are SELF-REPORTED and MAY NOT BE ACCURATE and do not contain all information that may be relevant to acoustic neuroma patients.

Under no circumstances, should you disregard any professional medical advice or delay in seeking such advice in reliance on any information provided by this survey. Your reliance on any information provided by this survey is solely at your own risk.

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SURVEY RESULTS ARE BEING PROVIDED "AS IS," WITHOUT ANY IMPLIED OR EXPRESSED WARRANTIES OF ANY KIND.

EXECUTIVE SUMMARY

In 2012, two online surveys were designed to collect data from new patients and from individuals who responded to the 2007–2008 survey. Emails requesting participation in a revised Initial Contact survey were sent in November 2012 to 2,731 patients who visited the ANA website since the 2007–2008 survey closed.

Emails were sent to an additional 1,272 people who responded to the 2007–2008 survey and who had valid email addresses. Reminder emails were sent four times until mid-January 2013. Responses to the Initial Contact survey were received from 1,150 individuals; 1,015 were usable.

Responses to the Follow-Up survey were received from 399 individuals; 371 were usable; however, an updated report of these individuals could be made for only 323 because 48 records from 2012 could not be matched to email addresses reported in the 2007–2008 database.

Please note: Percentages throughout the Executive Summary may not total 100% due to rounding.

The following tables summarize some of the information contained in the full report. The tumor size reported by respondents at the time of their diagnosis has changed since 1983. Almost half (43%) of the respondents in 2012 reported tumors 1.5 cm or less, a 13% increase from 2007–2008 and a 153% increase from 1983.

| Size | Percent of respondents | | | |
|--------------------|------------------------|-----------|------|------|
| | 2012 | 2007–2008 | 1998 | 1983 |
| 1.5 cm or less | 43 | 38 | 23 | 17 |
| 1.6–2.5 cm | 25 | 27 | 36 | 42 |
| Larger than 2.5 cm | 20 | 27 | 35 | 28 |
| Did not know size | 12 | 8 | 6 | 15 |

Symptoms

The primary acoustic neuroma symptoms from all four surveys remain similar with more than half of the respondents reporting issues with single-sided hearing loss and tinnitus and balance issues. In the 2012 survey, single-sided hearing loss was reported by 88% of respondents, tinnitus by 74% and balance issues (vertigo/dizziness) by 63%. These symptoms are followed by fullness in the ear, reported by 45% of respondents, facial weakness or paralysis by 33%, headaches by 28%, fatigue by 25%, facial numbness by 23%, eye problems by 21% and memory difficulties by 20%.

Respondents to the 2012 survey were asked to report which symptoms they experienced because of their tumor. They were then asked follow-up questions about their experience with those symptoms at initial tumor diagnosis and at the time they completed the survey¹.

The following table contains the percentages of respondents experiencing symptoms related to their tumor in each of the four surveys conducted by the ANA.

| Symptoms | Percentage of respondents | | | |
|---------------------------------------|---------------------------|-----------|------|------|
| | 2012 | 2007–2008 | 1998 | 1983 |
| Single-sided hearing loss or deafness | 88 | 88 | 88 | 86 |
| Tinnitus | 74 | 73 | 64 | 57 |
| Vertigo or balance disturbance | 63 | 59 | 64 | 61 |
| Facial weakness or paralysis | 33 | 28 | 14 | NA |
| Headaches | 28 | 33 | 33 | 37 |
| Eye problems | 21 | 31 | 16 | NA |
| Change in smell or taste | 15 | 20 | 10 | NA |
| Facial twitching | 15 | 16 | 13 | NA |
| Facial numbness | 23 | 23 | 22 | NA |
| Fullness in ear | 45 | 38 | 43 | NA |
| Difficulty swallowing | 9 | 11 | 7 | NA |
| Difficulty concentrating | 16 | 17 | NA | NA |
| Fatigue | 25 | 33 | NA | NA |
| Depression | 14 | 19 | NA | NA |
| Memory difficulties | 20 | 24 | NA | NA |
| No symptoms | 11 | 1 | NA | NA |

¹ Respondents who had received treatment prior to the time they completed the survey reported information regarding their symptoms at the time of initial diagnosis (or pre-treatment) versus the time at which they completed the survey (or post-treatment). Respondents who were still watching and waiting at the time they completed the survey reported information regarding their symptoms at the time of initial diagnosis and at the time they completed the survey, with no treatment in the interim.

Treatment

The 2012 Initial Contact survey asked participants to indicate the number and type of treatments they had received for their tumor. A number of respondents from the Follow-Up survey reported receiving additional treatments since 2008. Their responses are in the table below and are compared to those from the previous surveys conducted by the ANA. The percentage of respondents reporting microsurgery² as their treatment has fallen from 61% in 2007–2008 to 50% in the 2012 survey. The percentage of respondents reporting radiosurgery/radiotherapy as their treatment has increased from 20% in 2007–2008 to 24% in 2012. The percentage of watch and wait patients has increased from 20% in 2007–2008 to 26% in 2012.

| Treatment ** | Percentage of respondents | | | |
|--|---------------------------|------------|------------|------------|
| | 2012* | 2007–2008 | 1998 | 1983 |
| Translabrynthine approach | 25 | 33 | 51 | 72 |
| Retrosigmoid/sub-occipital approach | 15 | 17 | 28 | 11 |
| Middle fossa approach | 7 | 10 | 6 | 3 |
| Don't know which surgical approach | 2 | 0 | 0 | 14 |
| Total microsurgical resection | 50 | 61 | 85 | 100 |
| Stereotactic radiosurgery, such as Gamma Knife (SSR) | 15 | 12 | NA | NA |
| Fractionated stereotactic radiosurgery (FSR) | 9 | 8 | NA | NA |
| Total radiosurgery/radiotherapy | 24 | 20 | 5 | 0 |
| Watch & wait | 26 | 20 | 4 | 0 |
| Total | 100 | 100 | 100 | 100 |

*Percentages in 2012 are based on 1,174 treatments reported by 1,116 individuals who completed the Initial Contact survey or Follow-Up survey

**Another 278 individuals completed the Follow-Up survey and reported they have had no further treatment since 2008

² The use of the terms *surgery* and *microsurgery* in each survey can be attributed to the fact that in 1983, although the operating microscope was in use for procedures of this type by 1970, there was often no verbal distinction made between surgery and microsurgery. By 1998, the operating microscope was used in virtually all operations for acoustic neuroma, hence the description *microsurgery*.

Surgery

The translabyrinthine surgical approach remains the most frequently reported form of microsurgical resection with 25% of all survey respondents reporting this approach in 2012. The percentage of respondents reporting the translabyrinthine approach as treatment has fallen from 33% in 2007–2008 to 25% in 2012. Notably, 62% of the respondents in 2012 who reported having had surgery indicated they had no complications following surgery. The most common complication following surgery was cerebrospinal fluid (CSF) leak, reported by 14% of respondents who had surgery, similar to the 2007–2008 reported result of 17% (see page 16 of the 2012 survey results for details regarding complications reported by respondents indicating they had undergone microsurgery).

Tumor re-growth following initial microsurgery was reported by 8% in the 2012 survey. Of those respondents, 35% reported that the re-growth occurred more than 4 years after surgery. For detailed information reported by respondents who indicated they had undergone microsurgery, see the *microsurgery* section (pages 14–27).

Radiosurgery/Radiotherapy

The percentage of respondents who reported they had been treated by some form of radiosurgery/radiotherapy increased from 20% in the 2007–2008 survey to 24% in the 2012 survey. In the 2012 survey, 61% of those having radiation treatment reported having single-stereotactic radiosurgery (SSR) and 39% reported having fractionated stereotactic radiosurgery (FSR). For detailed information reported by respondents indicating they had undergone SSR, see the *SSR* section (page 28). For information reported by respondents indicating they had undergone FSR, see the *FSR* section (page 44).

Observation

The percentage of acoustic neuroma patients who reported choosing to observe their tumor—to watch and wait rather than seeking treatment—increased from 20% in the 2007–2008 survey to 26% in the 2012 survey. Twenty-six percent of the respondents indicated they have been in the watch and wait mode for 1 year or less. Another one-quarter of the respondents has been in the watch and wait mode between 1 and 3 years; 21% between 5 and 10 years, and 9% between 10 and 20 years. For results from the watch and wait respondents, see the *Watch and Wait* section (page 58).

Post-Treatment Rehabilitation Therapies

In the 2012 survey, 33% of the respondents indicated they received treatment or surgery to correct facial weakness. Fewer than 25% reported receiving treatment for balance (22%), 12% for dizziness and 11% for facial movement. Details on post-treatment rehabilitation therapies can be found in each section; *microsurgery* (page 25), *SSR* (page 40), and *FSR* (page 54). Information about rehabilitation therapies for respondents who have decided to watch and wait is in the *Watch and Wait* section (page 67).

Quality of Life

The 2012 Initial Contact survey and Follow-Up survey contained new questions related to the respondents' employment, use of handicapped parking permits and their perceptions of their symptoms and quality of life since their diagnosis. Almost all the respondents (88%) indicated they were able to continue regular employment and/or activities after their diagnosis and 72% indicated they were still employed in the same capacity or perform the same activities today. Of those who are not, 71% indicated they had retired.

Almost all (89%) of the respondents reported that they did not use a handicapped parking permit after their surgery or treatment. A large percentage of those individuals (70%) did not feel the need to use a parking permit.

Thirty-six percent of the respondents reported their symptoms are significantly or moderately better now than at diagnosis. Fifty-three percent reported their symptoms are significantly or moderately better now than just after treatment. In regards to their quality of life, 27% consider it significantly or moderately better now than at their diagnosis. Fifty-two percent consider their quality of life significantly or moderately better now than just after treatment.

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INTRODUCTION

The ultimate goal of the ANA is to provide an interactive database for members to query at the ANA website. The two surveys used in the 2012 survey process were developed with this goal in mind. The report that follows provides basic information about AN patients and preliminary data about those patients who agreed to provide follow-up data about their AN experiences. All information collected by the online surveys will be available in the future at the ANA website.

Purpose

In keeping with the mission of ANA, the 2012 survey was conducted to provide information regarding the symptoms, diagnosis, treatment and post-treatment issues experienced by AN patients. Although this information is self-reported and therefore could not be verified for accuracy, it is meant to provide a basic set of data for newly diagnosed, pre-, and post-treatment AN patients who share a condition for which such data is lacking.

THE INFORMATION FROM ALL ANA SUREYES WAS SELF-REPORTED. NO ATTEMPT WAS MADE TO CONFIRM OR VERIFY THE ACCURACY OF REPORTED DATA. THE RESULTS ARE A COMPILATION OF THIS SELF-REPORTED DATA ONLY. THEY ARE NOT INTENDED TO PROVIDE CONCLUSIVE INFORMATIN REGARDING CAUSALITY. READERS SHOULD NOT DISREGARD, UNDER ANY CIRUMCSTANCES, ANY PROFESSIONAL MEDICAL ADVICE OR DELAY IN SEEKING SUCH ADVICE.

Method

Emails were sent in November 2012 to 2,731 patients requesting their participation in the Initial Contact survey. Emails were sent to an additional 1,272 people who responded to the 2007–2008 survey and who had valid email addresses. Reminder emails were sent four times until mid-January 2013. Responses to the Initial Contact survey were received from 1,150 individuals; 1,015 were usable. Responses to the Follow-Up survey were received from 399 individuals; 371 were usable. Responses from these 371 individuals could be used when reporting aggregated data for all respondents in 2012. However, an updated report of these individuals could be made for only 323 because 48 records from 2012 could not be matched to email addresses reported in the 2007–2008 database.

A survey was considered complete if the AN patient worked through the survey and exited at the end of the questionnaire. However, not all questions were answered by all participants.

Therefore, slight differences in frequency reported in different tables can be attributed to respondents answering some parts of the question, but not others. Queries of the database were made using the same criteria throughout each section; however, not all respondents replied to all questions.

The online survey was adaptive, meaning it queried respondents about only those symptoms and treatments they indicated they had experienced. This was an attempt to minimize questions not applicable to a respondent's situation. This was a self-assessment survey rather than a clinical

one. Not all surveys were completed and those not completed are not in the results presented here.

Please note: Percentages throughout the report may not total 100% due to rounding.

Information about All Participants and Their AN Tumor

The following tables present basic information about 1,394 individuals who responded to both the Initial Contact survey and the Follow-Up survey.

| Characteristic | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Gender | | |
| Male | 509 | 37 |
| Female | 821 | 59 |
| No response | 64 | 5 |
| Ethnicity | | |
| Caucasian | 1245 | 89 |
| African/American-American/W. Indian (Black) | 17 | 1 |
| Asian/Pacific Islander | 33 | 2 |
| Hispanic/Latino | 27 | 2 |
| Native American | 1 | < 1 |
| Other | 1 | < 1 |
| No response | 70 | 5 |
| Age when tumor was diagnosed | | |
| Less than 12 years old | 0 | 0 |
| 12 – 20 years old | 6 | 0 |
| 21 – 30 years old | 40 | 3 |
| 31 – 40 years old | 178 | 13 |
| 41 – 50 years old | 373 | 27 |
| 51 – 60 years old | 452 | 32 |
| 61 – 70 years old | 249 | 18 |
| 71 – 80 years old | 39 | 3 |
| 81 or older | 2 | 0 |
| No response | 55 | 4 |

| Tumor data | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Tumor side | | |
| Right | 666 | 48 |
| Left | 682 | 49 |
| Bilateral (Both sides) | 6 | < 1 |
| Meningioma | 3 | < 1 |
| No response | 37 | 3 |
| Size of tumor at diagnosis | | |
| 0.1 – 0.4 cm | 98 | 7 |
| 0.5 – 1.0 cm | 236 | 17 |
| 1.1 – 1.5 cm | 274 | 20 |
| 1.6 – 2.0 cm | 176 | 13 |
| 2.1 – 2.5 cm | 172 | 12 |
| 2.6 – 3.0 cm | 93 | 7 |
| 3.1 – 3.5 cm | 79 | 6 |
| 3.6 – 4.0 cm | 37 | 3 |
| Larger than 4 cm | 75 | 5 |
| Don't know | 82 | 6 |
| No Response | 72 | 5 |
| Diagnostic tests used to diagnose tumor <i>(multiple responses possible)</i> | | |
| CT scan (Computerized Tomography) | 221 | 16 |
| MRI scan (Magnetic Resonance Image) | 1285 | 92 |
| Brainstem Auditory Evoked Response (BAER, BSER or ABR) | 165 | 12 |
| Hearing Test (Audiogram) | 954 | 68 |
| Balance Test (Electronystagmogram – ENG) | 261 | 19 |
| Don't Know | 6 | <1 |

The following table illustrates the number of distinct treatments the 1,394 respondents have undergone related to their AN.

| Number of treatments received | Number of responses | Percentage of responses |
|--|----------------------------|--------------------------------|
| Have not received any treatment (watching & waiting) | 306 | 22 |
| Have received 1 treatment to date | 722 | 52 |
| Have received 2 treatments to date | 69 | 5 |
| Have received 3 or more treatments to date | 8 | 1 |
| Have not received any further treatments since 2008 | 278 | 20 |
| No answer | 11 | 1 |
| Total | 1394 | 100 |

The next table presents the *number of different* treatments received.

| Treatment modality | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Microsurgical resection (surgery/craniotomy) | 587 | 68 |
| Stereotactic radiosurgery (SSR) single session radiation treatment, such as Gamma Knife | 172 | 20 |
| Fractionated stereotactic radiosurgery/radiotherapy (FSR) radiation treatment performed in multiple sessions or fractions | 109 | 13 |
| Total | 868 | 100 |

Symptoms Reported

Discussion of *symptoms* throughout this report refers to symptoms respondents reported related to their tumor. Some literature places a distinction on symptoms that relate to the existence of an AN tumor and distinguishes those from symptoms that result from some type of intervention or treatment. For example, medical literature indicates that post-surgery headaches may sometimes be associated with sub-occipital (also known as retrosigmoid) surgery, as this approach may leave skull fragments due to intra-dural drilling. This is an example of a symptom related to treatment and not necessarily just to the existence of a tumor.

References to *symptoms* throughout this report make no such distinction. All symptoms reported are those experienced by respondents regardless of their treatment status. The reader can delve into each symptom reported on a pre- and post-treatment basis to determine if the symptom appears to be associated with the existence of the tumor or if it appears to be the result of treatment. The following table illustrates the number of individuals responding to the Initial Contact survey and the Follow-Up survey who experienced each symptom. The respondents could choose multiple symptoms and the percentages listed are of the 1,394 respondents who completed either the Initial Contact survey or the Follow-Up survey. More than half the respondents indicated they experienced single-sided hearing loss or deafness, tinnitus and vertigo.

| Symptoms related to tumor | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Single-sided hearing loss or deafness | 1224 | 88 |
| Tinnitus (noise or ringing in the ear) | 1029 | 74 |
| Vertigo (dizziness/balance disturbance) | 885 | 63 |
| Fullness in ear | 626 | 45 |
| Headaches | 390 | 28 |
| Fatigue | 344 | 25 |
| Eye problems | 286 | 21 |
| Facial weakness or paralysis | 458 | 33 |
| Memory difficulties | 275 | 20 |
| Facial numbness | 316 | 23 |
| Change in smell or taste | 212 | 15 |
| Depression | 202 | 14 |
| Difficulty concentrating | 226 | 15 |
| Facial twitching | 216 | 15 |
| Difficulty swallowing | 124 | 9 |
| No symptoms | 151 | 11 |

The data above represents symptoms reported by respondents without regard to their treatment status. Information about what symptoms were experienced pre-treatment versus post-treatment will be discussed in later sections of this report.

The percentage of respondents reporting some of the more common symptoms related to their AN from 1983 to 2012 is similar across the four surveys. Almost 90% of the respondents reported single-sided hearing loss or deafness, while approximately 60% report experiencing vertigo.

| Common symptoms reported | Percentage of responses | | | |
|---|-------------------------|-----------|------|------|
| | 2012 | 2007–2008 | 1998 | 1983 |
| Single-sided hearing loss or deafness | 88 | 88 | 88 | 86 |
| Tinnitus (noise or ringing in the ear) | 74 | 73 | 64 | 57 |
| Vertigo (dizziness/balance disturbance) | 63 | 59 | 64 | 61 |
| Headaches | 28 | 33 | 33 | 37 |

Single-Sided Hearing Loss

Of the 1,394 respondents who responded to the Initial Contact survey and the Follow-Up survey, 1,224 reported experiencing some single-sided hearing loss or deafness related to their tumor. The following table contains the self-reported Gardner-Robertson class for these individuals at their diagnosis and at the time of the survey.

| Self-reported Gardner-Robertson Class* | At diagnosis | | At time of survey | |
|---|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100% | 259 | 21 | 66 | 5 |
| Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69% | 322 | 26 | 124 | 10 |
| Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49% | 172 | 14 | 106 | 9 |
| Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4% | 140 | 11 | 124 | 10 |
| Class 5 No Hearing = PTA 0; SD 0% | 66 | 5 | 605 | 49 |
| Don't Know | 265 | 22 | 199 | 16 |
| Total | 1224 | 100 | 1224 | 100 |

* PTA = Pure Tone Average; dB = Decibels; SD = Speech Discrimination Score

The following table contains the number and percentage of respondents receiving treatments or rehabilitation therapies to improve their hearing. The percentages listed are of the 1,224 respondents who responded to both the Initial Contact survey and the Follow-Up survey and who reported some single-sided hearing loss or deafness related to their tumor.

| Strategies to improve hearing | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Behind-the-ear (BTE) hearing aid | 145 | 12 |
| BiCROS hearing aid | 52 | 4 |
| Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite) | 102 | 8 |
| Cochlear implants | 4 | < 1 |
| Completely-in-the-canal (CIC) hearing aid | 2 | < 1 |
| CROS hearing aid | 96 | 8 |
| Device to amplify telephone | 18 | 1 |
| Device to amplify TV | 45 | 4 |
| Direct audio to input microphone | 3 | < 1 |
| FM system or other amplifier (carried in pocket or placed on a table) | 16 | 1 |
| In-the-canal (ITC) hearing aid | 24 | 2 |
| In-the-ear (ITE) hearing aid | 47 | 4 |

Facial Weakness

Of the 1,394 respondents who responded to the Initial Contact survey and the Follow-Up survey, 458 reported experiencing some facial weakness or paralysis related to their tumor. The following table contains the self-reported House-Brackmann Grade for these individuals at their diagnosis and at the time of the survey.

| Self-reported House-Brackmann Grade | At diagnosis | | At time of survey | |
|-------------------------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Grade I. Normal | 316 | 69 | 115 | 25 |
| Grade II. Mild | 87 | 19 | 162 | 35 |
| Grade III. Moderate | 24 | 5 | 76 | 17 |
| Grade IV. Moderate severe | 8 | 2 | 69 | 15 |
| Grade V. Severe | 8 | 2 | 15 | 3 |
| Grade VI. Complete paralysis | 9 | 2 | 19 | 4 |
| Don't Know | 6 | 1 | 2 | < 1 |
| Total | 458 | 100 | 458 | 100 |

Definition of House-Brackmann Grades

| | |
|-----------|---|
| Grade I | Normal facial function in all areas. |
| Grade II | Mild movement weakness, normal symmetry at rest. Slight weakness noticeable on close inspection; may have very slight synkinesis (inappropriate movement with voluntary movement of another muscle), moderate to good forehead motion, complete eye closure with minimum effort, only slight mouth disturbance. |
| Grade III | Moderate dysfunction with noticeable asymmetry, good eye closure. Obvious but not disfiguring difference between two sides; noticeable but not severe synkinesis. Normal balance and tone at rest, slight to moderate movement of forehead, complete eye closure with effort, mouth movement slightly weak with maximum effort. |
| Grade IV | Moderately severe dysfunction with gross asymmetry and incomplete eye closure. Obvious facial weakness and/or disfiguring asymmetry with gross movement. Normal symmetry and tone at rest. No forehead movement on affected side, incomplete eye closure, mouth asymmetric with maximum effort. |
| Grade V | Severe dysfunction with minimal facial movement. Only barely perceptible motion with attempted movement. Face unbalanced at rest. No forehead motion, incomplete eye closure. Slight mouth movement possible. |
| Grade VI | Complete paralysis. No movement. |

The following table contains the number and percentage of respondents who received treatments or rehabilitation therapies to correct facial weakness. Please keep in mind that respondents had the ability to choose multiple post-surgical treatments and rehabilitation therapies from the list below. The percentages listed are of the 458 respondents who experienced some facial weakness or paralysis related to their tumor.

| Surgeries and treatments | Number of responses | Percentage of responses |
|--|----------------------------|--------------------------------|
| Surgery or treatment to correct facial weakness | | |
| 12-7 Transfer (transfer of the tongue nerve to the facial nerve) | 25 | 5 |
| Cross face nerve graft | 6 | 1 |
| Facial suspension or sling | 8 | 2 |
| Face lift - on the tumor side | 13 | 3 |
| Face lift - Both sides | 6 | 1 |
| Masseter muscle transposition | 1 | < 1 |
| Electrical stimulation of the face | 31 | 7 |
| Regional muscle transfer | 0 | 0 |
| Free muscle transfer, transplanting muscle from other part of body | 1 | < 1 |
| Surgery to improve eyelid position and/or function | | |
| Brow elevation | 19 | 4 |
| Canthoplasty | 3 | 1 |
| Eyelid spring | 12 | 3 |
| Gold weight in eyelid | 79 | 17 |
| Lower eyelid repositioning | 16 | 3 |
| Tarsorrhaphy | 29 | 6 |
| Tissue grafts and stents | 1 | < 1 |

Post-Treatment

The table below contains the percentage of the whole group ($n = 1,394$) who received treatments, physical therapy or training to improve several issues surrounding their AN tumor.

| Treatment, physical therapy or training to improve | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Balance | 312 | 22 |
| Dizziness (vestibular rehabilitation) | 171 | 12 |
| Facial movement | 154 | 11 |
| Fall risk reduction | 60 | 4 |
| Psychological issues | 74 | 5 |

Quality of Life

The 2012 Initial Contact survey and Follow-Up survey contained new questions related to the respondents' employment, use of handicapped parking permits, their perceptions of their symptoms and quality of life since their diagnosis.

| Question | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Employment (1,378 responses) | | |
| After diagnosis, able to continue regular employment and/or activities | | |
| No | 163 | 12 |
| Yes | 1215 | 88 |
| If yes, still employed in same capacity or perform same activities today? | | |
| Yes | 874 | 72 |
| No | 335 | 28 |
| No answer | 6 | < 1 |
| If no, why not? | | |
| Became disabled | 36 | 11 |
| Quit to pursue another job or other interests | 52 | 16 |
| Retired | 238 | 71 |
| No answer | 9 | 3 |
| Handicapped parking permit (795 responses) | | |
| Did you use a handicapped parking permit after your treatment? | | |
| Yes | 88 | 11 |
| No | 707 | 89 |
| If no, why did you not use the permit? (<i>n</i> = 684) | | |
| I did not feel the need to use one. | 476 | 70 |
| I did not know I qualified to use one. | 208 | 30 |

Respondents who received treatment(s) were asked to consider their symptoms and quality of life before treatment, after treatment, and today. The table below contains the percentage of AN patients who provided responses.

| Question | Percentage of respondents | | | | | | |
|---|---------------------------|-------------------|-----------------|-----------------------|----------------|------------------|---------------------|
| | Significantly better | Moderately better | Somewhat better | No significant change | Somewhat worse | Moderately worse | Significantly worse |
| Considering your symptoms at diagnosis, how do you consider your symptoms now? | 27 | 9 | 11 | 19 | 14 | 8 | 11 |
| Considering your symptoms just after treatment, how do you consider your symptoms now? | 37 | 16 | 15 | 18 | 7 | 4 | 3 |
| Considering your quality of life at diagnosis, how do you consider your quality of life now? | 18 | 9 | 9 | 28 | 22 | 9 | 6 |
| Considering your quality of life after treatment, how do you consider your quality of life now? | 36 | 16 | 12 | 21 | 8 | 5 | 2 |

Structure of the Report

The remainder of this report segments the respondents by which treatment modality they underwent, as well as those who are watching and waiting. The first four parts of the report by treatment modality (microsurgery, SSR, and FSR) or watch and wait contain information reported by respondents who participated in either the Initial Contact survey or the Follow-Up survey.

However, questions about symptoms were asked differently in the two surveys. Individuals participating in the Initial Contact survey were asked to describe their symptoms at diagnosis and six months after treatment. However, individuals who responded to the Follow-Up survey were asked to describe their symptoms at diagnosis and at the time of the survey.

As a result, each of the four parts contains basic descriptions of their treatment modality for individuals who responded to both surveys. However, reports of symptoms contain only the responses of individuals who responded to the Initial Contact survey.

Patient who responded to the 2007–2008 survey were invited to participate in a follow-up survey in November 2012. Responses were received from 399 individuals; however, only 371 were completed. The Follow-Up section of the 2012 report updates 2007–2008 responses with those made in the most recent survey. The 2012 responses were matched by email address with the 2007–2008 responses. Fewer than 300 ($n = 298$) provided complete data from both surveys. Therefore, the Follow-up section of the report contains the responses of 298 individuals who provided information about their AN experiences in both 2007–2008 and 2012.

MICROSURGERY

The first section of the report on microsurgery is based on the 587 individuals who responded to the Initial Contact survey and the Follow-Up survey and indicated they had microsurgery to treat their acoustic neuroma. The following tables contain a description of the respondents and their experiences with microsurgery.

Information About Microsurgery Patients and Their AN Tumor

| Reasons to choose microsurgical resection as a treatment/management option | Number of responses | Percentage of responses |
|--|---------------------|-------------------------|
| Followed my physician's advice | 488 | 83 |
| Personal choice | 330 | 56 |
| Because I know someone who had this management option | 59 | 10 |
| Because I know someone who wished he/she had this management option | 9 | 2 |
| Because of my employment situation at the time of the decision | 26 | 4 |
| Because of my insurance situation at the time of the decision | 33 | 6 |
| Because of concerns with my social support system | 7 | 1 |
| Because of concerns about my financial situation | 18 | 3 |

| Period in which microsurgery occurred | Number of responses | Percentage of responses |
|---------------------------------------|---------------------|-------------------------|
| Prior to 1990 | 34 | 6 |
| Between 1990 and 1999 | 93 | 16 |
| Between 2000 and 2009 | 188 | 32 |
| Between 2010 and 2012 | 243 | 41 |
| No response | 29 | 5 |
| Total | 587 | 100 |

Respondents indicated that they were treated by dozens of physicians at several dozen institutions around the country. The following table illustrates those institutions and physicians cited by at least three respondents.

| Institution/hospital | Location | Physicians listed by respondents |
|--|-----------------|---|
| Barrow Neurological Institute, St. Joseph's Hospital | Phoenix, AZ | Spetzler, Syms, Weisskopf |
| Duke-Raleigh Hospital | Raleigh, NC | Cunningham, Friedman, Fukushima, Kaylie, McElveen, Zomorod |
| Johns Hopkins Hospital | Baltimore, MD | Francis, Holliday, Long, Minor, Niparko, Olivi, Stewart, Tamargo, Weingart |
| Massachusetts General Hospital | Boston, MA | Barker, Lee, Martuza, McKenna, Nadol, Odjemann, Poe, Quesnell, Smullen, Worthington |
| New York University Medical Center | New York, NY | Cohen, Golfinos, Gutin, Kelly, Ransohoff, Roland, Selesnick, Sen |
| Stanford Physicians | Palo Alto, CA | Blevins, Chang, Harsh, Jackler |
| St. Vincent Hospital/House Ear Clinic Los Angeles | Los Angeles, CA | Brackmann, Day, De La Cruz, Fayad, Friedman, Hasselbach, Herzog, Hitselberger, House, Luxford, Schwartz, Slattery |

| Length of hospitalization | Number of responses | Percentage of responses |
|----------------------------------|----------------------------|--------------------------------|
| 1 day | 3 | < 1 |
| 2-3 days | 90 | 15 |
| 4-6 days | 317 | 54 |
| 7-10 days | 101 | 17 |
| More than 10 days | 3 | < 1 |
| No response | 73 | 12 |
| Total | 587 | 100 |

| Surgical approach | Number of responses | Percentage of responses |
|-------------------------------------|----------------------------|--------------------------------|
| Translabyrinthine approach | 297 | 51 |
| Retrosigmoid/sub-occipital approach | 181 | 31 |
| Middle fossa approach | 81 | 14 |
| Don't know/no response | 28 | 5 |
| Total | 587 | 100 |

Recovery

The following table contains information about the respondents' complications and recovery period after microsurgery. Respondents were able to select having experienced multiple complications so the percentage of responses indicate percentage of the 587 individuals.

| Complications related to surgery | Number of responses | Percentage of responses* |
|---|----------------------------|---------------------------------|
| Cerebrospinal Fluid Leak (CSF leak) | 85 | 14 |
| Hydrocephalus (Water on the brain) | 10 | 2 |
| Meningitis | 15 | 3 |
| Wound infection | 21 | 4 |
| Coma | 4 | < 1 |
| Intractable vertigo (sustained vertigo lasting longer than 30 days) | 33 | 6 |
| Other | 119 | 20 |
| No complications | 363 | 62 |

Time to recover fully from treatment

| | | |
|-------------------------|-----|----|
| Approximately 1 week | 6 | 1 |
| Approximately 2 weeks | 0 | 0 |
| Approximately 1 month | 84 | 14 |
| Approximately 3 months | 171 | 29 |
| Approximately 6 months | 116 | 20 |
| Approximately 12 months | 60 | 10 |
| More than 12 months | 150 | 26 |
| No response | 0 | 0 |

**based on 587 respondents*

Symptoms Reported

This section of symptoms reports only the responses of those individuals who responded to the Initial Contact survey.

The survey asked respondents to indicate which symptoms they experienced related to their acoustic neuroma. Only those respondents who reported experiencing a specific symptom were queried about their experience with that symptom. Percentages reported below are from respondents of the Initial Contact survey indicating that they had undergone 562 microsurgical resections of their tumor.

Slight differences in frequency reported in this table and in the two tables following it can be attributed to respondents who indicated they had a symptom, but not reporting frequency or severity AND reporting a symptom six months after treatment that they did not report at diagnosis.

Individuals who responded to the Follow-Up survey are not included in this summary of symptoms.

| Symptoms treated via microsurgical resection | Number of responses | Percentage of responses |
|--|---------------------|-------------------------|
| Tinnitus (noise or ringing in the ear) | 390 | 69 |
| Vertigo (dizziness/balance disturbance) | 382 | 68 |
| Fullness in ear | 229 | 41 |
| Headaches | 198 | 35 |
| Facial numbness | 165 | 29 |
| Fatigue | 162 | 29 |
| Eye problems | 156 | 28 |
| Single-sided hearing loss or deafness | 139 | 25 |
| Memory issues | 139 | 25 |
| Change in smell or taste | 117 | 21 |
| Difficulty concentrating | 115 | 20 |
| Facial twitching | 102 | 18 |
| Depression | 96 | 17 |
| Difficulty swallowing | 69 | 12 |
| I had no symptoms | 54 | 10 |

The frequency and severity of the most common symptoms (tinnitus, vertigo/balance disturbance, and headaches) at diagnosis and six months after microsurgical resection of the tumor are reported below.

| Symptom | At diagnosis | | Six months after treatment | |
|--|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Tinnitus–Frequency | | | | |
| Constantly | 244 | 65 | 250 | 63 |
| Daily (At least once a day) | 74 | 20 | 56 | 14 |
| Weekly (At least once a week) | 29 | 8 | 20 | 5 |
| Monthly (At least once a month) | 12 | 3 | 29 | 7 |
| Less frequent than once a month | 19 | 5 | 44 | 11 |
| Total | 378 | 100 | 399 | 100 |
| Tinnitus–Severity | | | | |
| 5 (Most severe/disabling) | 21 | 6 | 57 | 14 |
| 4 | 54 | 14 | 59 | 14 |
| 3 | 149 | 40 | 102 | 25 |
| 2 | 74 | 20 | 75 | 18 |
| 1 (Least severe/mild) | 79 | 21 | 120 | 29 |
| Total | 377 | 100 | 413 | 100 |
| Vertigo/balance disturbance–Frequency | | | | |
| Constantly | 75 | 21 | 68 | 17 |
| Daily (At least once a day) | 134 | 37 | 140 | 34 |
| Weekly (At least once a week) | 70 | 19 | 48 | 12 |
| Monthly (At least once a month) | 28 | 8 | 35 | 9 |
| Less frequent than once a month | 56 | 15 | 119 | 29 |
| Total | 363 | 100 | 410 | 100 |
| Vertigo/balance disturbance–Severity | | | | |
| 5 (Most severe/disabling) | 38 | 10 | 18 | 4 |
| 4 | 48 | 13 | 53 | 13 |
| 3 | 125 | 34 | 70 | 17 |
| 2 | 80 | 22 | 82 | 20 |
| 1 (Least severe/mild) | 74 | 20 | 186 | 45 |
| Total | 365 | 100 | 409 | 100 |
| Headaches –Frequency | | | | |
| Constantly | 23 | 12 | 23 | 11 |
| Daily (At least once a day) | 64 | 34 | 45 | 21 |
| Weekly (At least once a week) | 58 | 31 | 53 | 25 |
| Monthly (At least once a month) | 24 | 13 | 24 | 11 |
| Less frequent than once a month | 18 | 10 | 70 | 33 |
| Total | 187 | 100 | 215 | 100 |
| Headaches–Severity | | | | |
| 5 (Most severe/disabling) | 57 | 30 | 35 | 17 |
| 4 | 37 | 20 | 14 | 7 |
| 3 | 43 | 23 | 35 | 17 |
| 2 | 29 | 16 | 41 | 20 |
| 1 (Least severe/mild) | 21 | 11 | 85 | 40 |
| Total | 187 | 100 | 210 | 100 |

The frequency of other symptoms related to the tumor at diagnosis and six months after microsurgical resection of the tumor are reported below.

| Symptom | At diagnosis | | Six months after treatment | |
|---|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Eye problems | | | | |
| Constantly | 76 | 51 | 64 | 40 |
| Daily (At least once a day) | 53 | 35 | 52 | 33 |
| Weekly (At least once a week) | 10 | 7 | 13 | 8 |
| Monthly (At least once a month) | 5 | 3 | 8 | 5 |
| Less frequent than once a month | 6 | 4 | 22 | 14 |
| Total Respondents | 150 | 100 | 159 | 100 |
| Changes in sense of taste or smell | | | | |
| Constantly | 62 | 57 | 45 | 40 |
| Daily (At least once a day) | 21 | 19 | 19 | 17 |
| Weekly (At least once a week) | 13 | 12 | 7 | 6 |
| Monthly (At least once a month) | 2 | 2 | 5 | 4 |
| Less frequent than once a month | 10 | 9 | 36 | 32 |
| Total Respondents | 108 | 100 | 112 | 100 |
| Facial twitching | | | | |
| Constantly | 9 | 9 | 5 | 5 |
| Daily (At least once a day) | 38 | 38 | 29 | 28 |
| Weekly (At least once a week) | 28 | 28 | 18 | 17 |
| Monthly (At least once a month) | 13 | 13 | 17 | 16 |
| Less frequent than once a month | 11 | 11 | 36 | 34 |
| Total Respondents | 99 | 100 | 105 | 100 |
| Facial numbness | | | | |
| Constantly | 97 | 62 | 88 | 50 |
| Daily (At least once a day) | 33 | 21 | 26 | 14 |
| Weekly (At least once a week) | 11 | 7 | 7 | 4 |
| Monthly (At least once a month) | 5 | 3 | 5 | 3 |
| Less frequent than once a month | 10 | 6 | 50 | 28 |
| Total Respondents | 156 | 100 | 176 | 100 |
| Fullness in tumor-side ear | | | | |
| Constantly | 122 | 57 | 81 | 40 |
| Daily (At least once a day) | 44 | 21 | 28 | 14 |
| Weekly (At least once a week) | 25 | 12 | 22 | 11 |
| Monthly (At least once a month) | 10 | 5 | 11 | 5 |
| Less frequent than once a month | 12 | 6 | 60 | 30 |
| Total Respondents | 213 | 100 | 202 | 100 |
| Difficulty swallowing | | | | |
| Constantly | 17 | 26 | 11 | 11 |
| Daily (At least once a day) | 24 | 36 | 27 | 28 |
| Weekly (At least once a week) | 15 | 23 | 21 | 22 |
| Monthly (At least once a month) | 1 | 2 | 7 | 7 |
| Less frequent than once a month | 9 | 14 | 30 | 31 |
| Total Respondents | 66 | 100 | 96 | 100 |

| Symptom | At diagnosis | | Six months after treatment | |
|---------------------------------|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Difficulty concentrating | | | | |
| Constantly | 20 | 18 | 29 | 20 |
| Daily (At least once a day) | 59 | 54 | 53 | 37 |
| Weekly (At least once a week) | 23 | 21 | 35 | 25 |
| Monthly (At least once a month) | 3 | 3 | 10 | 7 |
| Less frequent than once a month | 4 | 4 | 15 | 11 |
| Total Respondents | 109 | 100 | 142 | 100 |
| Fatigue | | | | |
| Constantly | 44 | 29 | 37 | 20 |
| Daily (At least once a day) | 73 | 47 | 68 | 37 |
| Weekly (At least once a week) | 26 | 17 | 38 | 21 |
| Monthly (At least once a month) | 10 | 6 | 16 | 9 |
| Less frequent than once a month | 1 | 1 | 24 | 13 |
| Total Respondents | 154 | 100 | 183 | 100 |
| Depression | | | | |
| Constantly | 21 | 23 | 21 | 19 |
| Daily (At least once a day) | 23 | 25 | 29 | 26 |
| Weekly (At least once a week) | 29 | 32 | 20 | 18 |
| Monthly (At least once a month) | 14 | 15 | 19 | 17 |
| Less frequent than once a month | 4 | 4 | 24 | 21 |
| Total Respondents | 91 | 100 | 113 | 100 |
| Memory difficulties | | | | |
| Constantly | 27 | 21 | 28 | 16 |
| Daily (At least once a day) | 55 | 43 | 52 | 30 |
| Weekly (At least once a week) | 33 | 26 | 46 | 27 |
| Monthly (At least once a month) | 4 | 3 | 23 | 13 |
| Less frequent than once a month | 8 | 6 | 22 | 13 |
| Total Respondents | 127 | 100 | 171 | 100 |

Single-Sided Hearing Loss

The following table contains the self-reported Gardner-Robertson class for respondents who underwent microsurgery via the retrosigmoid/sub-occipital or middle fossa approaches at the date of their diagnosis and at the time of the survey. Respondents reporting they had been operated on via the translabyrinthine approach were excluded from this data as this approach results in guaranteed tumor side deafness.

| Self-reported Gardner-Robertson Class* | At diagnosis | | At time of survey | |
|---|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100% | 75 | 35 | 17 | 8 |
| Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69% | 60 | 28 | 20 | 9 |
| Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49% | 24 | 11 | 14 | 7 |
| Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4% | 9 | 4 | 16 | 7 |
| Class 5 No Hearing = PTA 0; SD 0% | 5 | 2 | 116 | 54 |
| Don't Know | 41 | 19 | 31 | 14 |
| Total | 214 | 100 | 214 | 100 |

* PTA = Pure Tone Average; dB = Decibels; SD = Speech Discrimination Score

The following table contains the number and percentage of respondents receiving treatments or rehabilitation therapies to improve their hearing. Please keep in mind that respondents had the ability to choose multiple treatments and rehabilitation therapies from the list below. The percentages listed are based on the 587 respondents who indicated that they had undergone microsurgical resection of their tumor.

| Strategies to improve hearing | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Behind-the-ear (BTE) hearing aid | 39 | 7 |
| BiCROS hearing aid | 24 | 4 |
| Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite) | 64 | 11 |
| Cochlear implants | 1 | < 1 |
| Completely-in-the-canal (CIC) hearing aid | 1 | < 1 |
| CROS hearing aid | 54 | 9 |
| Device to amplify telephone | 5 | 1 |
| Device to amplify TV | 17 | 3 |
| Direct audio to input microphone | 1 | < 1 |
| FM system or other amplifier (carried in pocket or placed on a table) | 8 | 1 |
| In-the-canal (ITC) hearing aid | 7 | 1 |
| In-the-ear (ITE) hearing aid | 9 | 2 |

Facial Weakness

Of the 587 respondents who reported microsurgery as a treatment, 248 reported experiencing some facial weakness or paralysis related to their tumor. The following table contains the self-reported House-Brackmann Grade for these individuals at their diagnosis and at the time of the survey.

| Self-reported House-Brackmann Grade | At diagnosis | | At time of survey | |
|-------------------------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Grade I. Normal | 182 | 73 | 68 | 27 |
| Grade II. Mild | 41 | 17 | 71 | 29 |
| Grade III. Moderate | 10 | 4 | 41 | 17 |
| Grade IV. Moderate severe | 5 | 2 | 48 | 19 |
| Grade V. Severe | 6 | 2 | 11 | 4 |
| Grade VI. Complete paralysis | 4 | 2 | 9 | 4 |
| Total | 248 | 100 | 248 | 100 |

Definition of House-Brackmann Grades

| | |
|-----------|---|
| Grade I | Normal facial function in all areas. |
| Grade II | Mild movement weakness, normal symmetry at rest. Slight weakness noticeable on close inspection; may have very slight synkinesis (inappropriate movement with voluntary movement of another muscle), moderate to good forehead motion, complete eye closure with minimum effort, only slight mouth disturbance. |
| Grade III | Moderate dysfunction with noticeable asymmetry, good eye closure. Obvious but not disfiguring difference between two sides; noticeable but not severe synkinesis. Normal balance and tone at rest, slight to moderate movement of forehead, complete eye closure with effort, mouth movement slightly weak with maximum effort. |
| Grade IV | Moderately severe dysfunction with gross asymmetry and incomplete eye closure. Obvious facial weakness and/or disfiguring asymmetry with gross movement. Normal symmetry and tone at rest. No forehead movement on affected side, incomplete eye closure, mouth asymmetric with maximum effort. |
| Grade V | Severe dysfunction with minimal facial movement. Only barely perceptible motion with attempted movement. Face unbalanced at rest. No forehead motion, incomplete eye closure. Slight mouth movement possible. |
| Grade VI | Complete paralysis. No movement. |

The following table illustrates the number and percentage of respondents receiving treatments or rehabilitation therapies to correct facial weakness. Please keep in mind that respondents had the ability to choose multiple post-surgical treatments and rehabilitation therapies from the list below. The percentages listed are of the 248 respondents who reported experiencing some facial weakness or paralysis related to their tumor and reported that they had undergone microsurgical resection of their tumor.

| Surgeries and treatments | Number of responses | Percentage of responses |
|--|----------------------------|--------------------------------|
| Surgery or treatment to correct facial weakness | | |
| 12-7 Transfer (transfer of the tongue nerve to the facial nerve) | 15 | 6 |
| Cross face nerve graft | 2 | 1 |
| Facial suspension or sling | 6 | 2 |
| Face lift - on the tumor side | 8 | 3 |
| Face lift - Both sides | 5 | 2 |
| Masseter muscle transposition | 1 | < 1 |
| Electrical stimulation of the face | 21 | 8 |
| Regional muscle transfer | 0 | 0 |
| Free muscle transfer, transplanting muscle from other part of body | 1 | < 1 |
| Surgery to improve eyelid position and/or function | | |
| Brow elevation | 10 | 4 |
| Canthoplasty | 1 | < 1 |
| Eyelid spring | 7 | 3 |
| Gold weight in eyelid | 53 | 21 |
| Lower eyelid repositioning | 11 | 4 |
| Tarsorrhaphy | 19 | 8 |
| Tissue grafts and stents | 1 | < 1 |

Post-Treatment

Forty-nine respondents (8%) indicated regrowth or reoccurrence of growth after surgery (debulking). The following table contains number of years during which this re-growth was observed after the respondent had undergone surgery.

| Tumor re-growth first observed | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Less than 1 year after surgery | 10 | 20 |
| 1-2 years after surgery | 14 | 29 |
| 2-3 years after surgery | 6 | 12 |
| 3-4 years after surgery | 2 | 4 |
| More than 4 years after surgery | 17 | 35 |
| Total respondents reporting re-growth after surgery | 49 | 100 |

It should be noted that there are several potential alternative explanations for the observation of “re-growth” of the tumor following surgery where none may have actually occurred. Such explanations could possibly include

- (i) only partial microsurgical resection (also known as de-bulking) may have been performed whereby some residual tumor is left in place. In this case, subsequent diagnostic imaging may show that portion of the tumor that was intentionally left in place and may be mistakenly referred to as re-growth.
- (ii) diagnostic imaging is not perfectly accurate and may indicate slight change in tumor size when compared to prior images. Tumor re-growth may have been reported as a result of this inherent inaccuracy (possibly due to use of different equipment) rather than actual changes in tumor size.

The table below contains the number and percentage of treatments, physical therapy or training received to improve several issues surrounding their AN tumor as reported by those who had undergone microsurgery.

| Treatment, physical therapy or training to improve | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Balance | 279 | 48 |
| Dizziness (vestibular rehabilitation) | 155 | 26 |
| Facial movement | 159 | 27 |
| Fall risk reduction | 89 | 15 |
| Psychological issues | 61 | 10 |

Quality of Life

| Questions | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Employment | | |
| After diagnosis, able to continue regular employment and/or activities | | |
| No | 93 | 16 |
| Yes | 493 | 84 |
| No answer | 1 | < 1 |
| If yes, still employed in same capacity or perform same activities today? (<i>n</i> = 493) | | |
| Yes | 353 | 72 |
| No | 139 | 28 |
| No answer | 1 | < 1 |
| If no, why not? (<i>n</i> = 139) | | |
| Became disabled | 48 | 35 |
| Quit to pursue another job or other interests | 7 | 5 |
| Retired | 24 | 17 |
| No answer | 60 | 43 |
| Handicapped parking permit | | |
| Did you use a handicapped parking permit after your treatment? | | |
| Yes | 76 | 13 |
| No | 509 | 87 |
| No answer | 2 | < 1 |
| If no, why did you not use the permit? (<i>n</i> = 509) | | |
| I did not feel the need to use one. | 335 | 66 |
| I did not know I qualified to use one. | 162 | 32 |
| No answer | 12 | 2 |

| Question | Percentage of respondents | | | | | | |
|---|---------------------------|-------------------|-----------------|-----------------------|----------------|------------------|---------------------|
| | Significantly better | Moderately better | Somewhat better | No significant change | Somewhat worse | Moderately worse | Significantly worse |
| Considering your symptoms at diagnosis, how do you consider your symptoms now? | 32 | 10 | 10 | 14 | 11 | 9 | 14 |
| Considering your symptoms just after treatment, how do you consider your symptoms now? | 47 | 18 | 12 | 10 | 6 | 4 | 3 |
| Considering your quality of life at diagnosis, how do you consider your quality of life now? | 22 | 9 | 8 | 21 | 22 | 10 | 7 |
| Considering your quality of life after treatment, how do you consider your quality of life now? | 46 | 19 | 10 | 11 | 7 | 5 | 2 |

SINGLE DOSE STEREOTACTIC RADIOSURGERY (SSR)

The first section of the report on single dose stereotactic radiosurgery is based on the 172 individuals who reported on the Initial Contact survey and the Follow-Up survey that their tumor was treated using SSR. The following tables contain a description of the respondents and their experiences with SSR.

Information About SSR Patients and Their AN Tumor

| Reasons to choose SSR as a treatment/management option | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Followed my physician's advice | 104 | 60 |
| Personal choice | 127 | 74 |
| Because I know someone who had this management option | 17 | 10 |
| Because I know someone who wished he/she had this management option | 4 | 2 |
| Because of my employment situation at the time of the decision | 15 | 9 |
| Because of my insurance situation at the time of the decision | 5 | 3 |
| Because of concerns with my social support system | 4 | 2 |
| Because of concerns about my financial situation | 5 | 3 |
| Total | 172 | 100 |

| Period in which SSR occurred | Number of responses | Percentage of responses |
|------------------------------|---------------------|-------------------------|
| Prior to 1990 | 0 | 0 |
| Between 1990 and 1999 | 14 | 8 |
| Between 2000 and 2009 | 71 | 41 |
| Between 2010 and 2012 | 83 | 48 |
| No response/Don't know | 4 | 2 |
| Total | 172 | 100 |

Respondents indicated that they were treated by dozens of physicians at several dozen institutions around the country. The following table illustrates only those institutions cited by at least two respondents.

| Institution/hospital | Location | Physicians listed by respondents |
|---|-------------------------------|--|
| Baptist Hospital | Nashville, TN | Glascok |
| Hinsdale Adventist Hospital | Hinsdale, IL | Kazan, Kozar, Wiet |
| Kaiser Permanente | San Diego and Los Angeles, CA | Cueva, Hitselberger, Mastrodimos, Di Tirro |
| Loyola Medical Center | Chicago, IL | Anderson, Leonetti |
| MD Anderson | Houston, TX | DeMonte, Levine, Gidley |
| Mount Sinai Medical Center | New York, NY | Bederson, Catalano, Choe, Post, Smouha |
| OHSU | Portland, OR | Delashaw, McMenomy |
| Seton | Austin, TX | Kemper, Slater |
| Shands at the University of Florida | Gainesville, FL | Antonelli, Friedman, Lewis |
| Tampa General | Tampa, FL | Aggazi, Bartels, Danner, van Loveren |
| Trinity Lutheran | Kansas City, KS | Luetje, Thedinger, Whittaker |
| UCSF | San Francisco, CA | Cheung, Jackler, Parsa, Pitts |
| University of Iowa Hospitals and Clinics/Department of Otolaryngology | Iowa City, IA | Gantz |
| University of Utah Hospital | Salt Lake City, UT | MacDonald, Shelton |
| UT Southwestern Hospital/Zale Lipshy | Dallas, TX | Kutz, Mickey, Roland |

Description of Radiation Treatment(s)

The table below contains the type of equipment used and the marginal radiation dose the 172 respondents reported they received. This is the amount of radiation delivered to the tumor margin or the 50% isodose line. Radiation delivered to the tumor site is measured in Gray (Gy) or Rads (Note: 1 Gy=100 Rads).

| Description | Number of responses | Percentage of responses |
|--|---------------------|-------------------------|
| Type of equipment | | |
| Gamma Knife (Leksell Gamma Knife – Elekta Corporation) | 145 | 84 |
| Linear accelerator (LINAC – various manufacturers) | 6 | 3 |
| Proton accelerator (Proton Beam radiation treatment) | 2 | 1 |
| Don't know what type of delivery system was used | 15 | 9 |
| Other–CyberKnife | 4 | 2 |
| Marginal dose of radiation received | | |
| Less than 10 Gy | 1 | 1 |
| 10.0 – 10.9 Gy | 1 | 1 |
| 11.0 – 11.9 Gy | 7 | 4 |
| 12.0 – 12.9 Gy | 24 | 14 |
| 13.0 – 13.9 Gy | 5 | 3 |
| 14.0 – 14.9 Gy | 1 | 1 |
| 15.0 – 15.9 Gy | 1 | 1 |
| 16.0 – 16.9 Gy | 3 | 2 |
| Greater than 16.9 Gy | 5 | 3 |
| Don't Know | 124 | 71 |

Recovery

The following table contains information about the respondents' complications and recovery period after their SSR treatment. The percentages are based on 172 respondents who indicated they received SSR for their tumor.

| Complications related to SSR treatment | Number of responses | Percentage of responses* |
|---|----------------------------|---------------------------------|
| Cerebrospinal Fluid Leak (CSF leak) | 6 | 4 |
| Hydrocephalus (Water on the brain) | 1 | < 1 |
| Wound infection | 2 | 1 |
| Coma | 0 | 0 |
| Intractable vertigo (sustained vertigo lasting longer than 30 days) | 6 | 4 |
| Other | 31 | 18 |
| No complications | 102 | 61 |
| Time to recover fully from treatment | | |
| Approximately 1 week | 76 | 44 |
| Approximately 2 weeks | 15 | 9 |
| Approximately 1 month | 14 | 8 |
| Approximately 3 months | 14 | 8 |
| Approximately 6 months | 20 | 12 |
| Approximately 12 months | 3 | 2 |
| More than 12 months | 27 | 16 |
| No response | 3 | 2 |

**based on 172 respondents*

Symptoms Reported

This section of symptoms reports only the responses of those individuals who responded to the Initial Contact survey.

The survey asked respondents to indicate which symptoms they experienced related to their acoustic neuroma. Only those respondents who reported experiencing a specific symptom were queried about their experience with that symptom. Percentages reported in the following tables are from the 166 respondents to the Initial Contact survey indicating that they had undergone SSR of their tumor.

Slight differences in frequency reported in this table and in the two tables following it can be attributed to respondents who indicated they had a symptom, but not reporting frequency or severity AND reporting a symptom six months after treatment that they did not report at diagnosis.

Individuals who responded to the Follow-Up survey are not included in this summary of symptoms.

| Reported symptoms | Number of responses | Percentage of responses |
|--|---------------------|-------------------------|
| Single-sided loss of hearing or deafness | 135 | 81 |
| Tinnitus (noise or ringing in the ear) | 132 | 80 |
| Vertigo (dizziness/balance disturbance) | 112 | 67 |
| Fullness in ear | 86 | 52 |
| Fatigue | 52 | 31 |
| Headaches | 39 | 23 |
| Facial numbness | 39 | 23 |
| Facial twitching | 38 | 23 |
| Eye problems | 37 | 22 |
| Memory issues | 35 | 21 |
| Difficulty concentrating | 31 | 19 |
| Depression | 27 | 16 |
| Change in smell or taste | 24 | 14 |
| Difficulty swallowing | 20 | 12 |
| I had no symptoms | 9 | 5 |

The frequency and severity of the most common symptoms (tinnitus, vertigo/balance disturbance, and headaches) at diagnosis and six months after single dose stereotactic radiosurgery are reported below.

| Symptom | At diagnosis | | Six months after treatment | |
|--|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Tinnitus–Frequency | | | | |
| Constantly | 22 | 21 | 104 | 72 |
| Daily (At least once a day) | 35 | 34 | 23 | 16 |
| Weekly (At least once a week) | 27 | 26 | 2 | 1 |
| Monthly (At least once a month) | 5 | 5 | 1 | 1 |
| Less frequent than once a month | 15 | 14 | 14 | 10 |
| Total | 104 | 100 | 144 | 100 |
| Tinnitus–Severity | | | | |
| 5 (Most severe/disabling) | 10 | 8 | 21 | 14 |
| 4 | 18 | 14 | 25 | 16 |
| 3 | 38 | 30 | 43 | 28 |
| 2 | 36 | 29 | 32 | 21 |
| 1 (Least severe/mild) | 24 | 19 | 33 | 21 |
| Total | 126 | 100 | 154 | 100 |
| Vertigo/balance disturbance–Frequency | | | | |
| Constantly | 22 | 21 | 22 | 17 |
| Daily (At least once a day) | 35 | 34 | 43 | 32 |
| Weekly (At least once a week) | 27 | 26 | 24 | 18 |
| Monthly (At least once a month) | 5 | 5 | 8 | 6 |
| Less frequent than once a month | 15 | 14 | 36 | 27 |
| Total | 104 | 100 | 133 | 100 |
| Vertigo/balance disturbance–Severity | | | | |
| 5 (Most severe/disabling) | 13 | 12 | 7 | 5 |
| 4 | 12 | 11 | 13 | 9 |
| 3 | 29 | 27 | 21 | 15 |
| 2 | 31 | 29 | 41 | 30 |
| 1 (Least severe/mild) | 23 | 21 | 55 | 40 |
| Total | 108 | 100 | 137 | 100 |
| Headaches –Frequency | | | | |
| Constantly | 6 | 17 | 5 | 9 |
| Daily (At least once a day) | 10 | 29 | 13 | 24 |
| Weekly (At least once a week) | 9 | 26 | 11 | 20 |
| Monthly (At least once a month) | 5 | 14 | 6 | 11 |
| Less frequent than once a month | 5 | 14 | 20 | 36 |
| Total | 35 | 100 | 55 | 100 |
| Headaches–Severity | | | | |
| 5 (Most severe/disabling) | 10 | 28 | 13 | 22 |
| 4 | 9 | 25 | 2 | 3 |
| 3 | 8 | 22 | 12 | 20 |
| 2 | 8 | 22 | 13 | 22 |
| 1 (Least severe/mild) | 1 | 3 | 19 | 32 |
| Total | 36 | 100 | 59 | 100 |

The frequency of other symptoms related to the tumor at diagnosis and six months after SSR treatment are reported below.

| Symptom | At diagnosis | | Six months after treatment | |
|---|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Eye problems | | | | |
| Constantly | 12 | 38 | 11 | 22 |
| Daily (At least once a day) | 16 | 50 | 18 | 37 |
| Weekly (At least once a week) | 1 | 3 | 7 | 14 |
| Monthly (At least once a month) | 0 | 0 | 2 | 4 |
| Less frequent than once a month | 3 | 9 | 11 | 22 |
| Total Respondents | 32 | 100 | 49 | 100 |
| Changes in sense of taste or smell | | | | |
| Constantly | 15 | 75 | 12 | 55 |
| Daily (At least once a day) | 2 | 10 | 3 | 14 |
| Weekly (At least once a week) | 3 | 15 | 1 | 5 |
| Monthly (At least once a month) | 0 | 0 | 1 | 5 |
| Less frequent than once a month | 0 | 0 | 5 | 23 |
| Total Respondents | 20 | 100 | 22 | 100 |
| Facial twitching | | | | |
| Constantly | 0 | 0 | 1 | 2 |
| Daily (At least once a day) | 17 | 53 | 18 | 35 |
| Weekly (At least once a week) | 6 | 19 | 6 | 12 |
| Monthly (At least once a month) | 5 | 16 | 10 | 19 |
| Less frequent than once a month | 4 | 13 | 17 | 33 |
| Total Respondents | 32 | 100 | 52 | 100 |
| Facial numbness | | | | |
| Constantly | 17 | 55 | 15 | 31 |
| Daily (At least once a day) | 5 | 16 | 10 | 21 |
| Weekly (At least once a week) | 5 | 16 | 1 | 2 |
| Monthly (At least once a month) | 2 | 6 | 3 | 6 |
| Less frequent than once a month | 2 | 6 | 19 | 40 |
| Total Respondents | 31 | 100 | 48 | 100 |
| Fullness in tumor-side ear | | | | |
| Constantly | 50 | 65 | 45 | 48 |
| Daily (At least once a day) | 10 | 13 | 7 | 8 |
| Weekly (At least once a week) | 11 | 14 | 9 | 10 |
| Monthly (At least once a month) | 3 | 4 | 7 | 8 |
| Less frequent than once a month | 3 | 4 | 25 | 27 |
| Total Respondents | 77 | 100 | 93 | 100 |
| Difficulty swallowing | | | | |
| Constantly | 4 | 27 | 5 | 17 |
| Daily (At least once a day) | 5 | 33 | 10 | 34 |
| Weekly (At least once a week) | 4 | 27 | 2 | 7 |
| Monthly (At least once a month) | 0 | 0 | 0 | 0 |
| Less frequent than once a month | 2 | 13 | 12 | 41 |
| Total Respondents | 15 | 100 | 29 | 100 |

| Symptom | At diagnosis | | Six months after treatment | |
|---------------------------------|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Difficulty concentrating | | | | |
| Constantly | 6 | 22 | 6 | 22 |
| Daily (At least once a day) | 15 | 56 | 15 | 56 |
| Weekly (At least once a week) | 6 | 22 | 6 | 22 |
| Monthly (At least once a month) | 0 | 0 | 0 | 0 |
| Less frequent than once a month | 0 | 0 | 0 | 0 |
| Total Respondents | 27 | 100 | 27 | 100 |
| Fatigue | | | | |
| Constantly | 9 | 20 | 9 | 20 |
| Daily (At least once a day) | 25 | 54 | 25 | 54 |
| Weekly (At least once a week) | 12 | 26 | 12 | 26 |
| Monthly (At least once a month) | 0 | 0 | 0 | 0 |
| Less frequent than once a month | 0 | 0 | 0 | 0 |
| Total Respondents | 46 | 100 | 46 | 100 |
| Depression | | | | |
| Constantly | 7 | 29 | 7 | 29 |
| Daily (At least once a day) | 5 | 21 | 5 | 21 |
| Weekly (At least once a week) | 6 | 25 | 6 | 25 |
| Monthly (At least once a month) | 4 | 17 | 4 | 17 |
| Less frequent than once a month | 2 | 8 | 2 | 8 |
| Total Respondents | 24 | 100 | 24 | 100 |
| Memory difficulties | | | | |
| Constantly | 8 | 26 | 8 | 26 |
| Daily (At least once a day) | 14 | 45 | 14 | 45 |
| Weekly (At least once a week) | 8 | 26 | 8 | 26 |
| Monthly (At least once a month) | 0 | 0 | 0 | 0 |
| Less frequent than once a month | 1 | 3 | 1 | 3 |
| Total Respondents | 31 | 100 | 31 | 100 |

Single-Sided Hearing Loss

The following tables contain the self-reported Gardner-Robertson Class of 159 respondents who underwent SSR and reported single-sided hearing loss or deafness. The Gardner-Roberts Class is reported at the time of their diagnosis and at the time of the survey. The strategies these individuals used to improve their hearing are also reported.

| Self-reported Gardner-Robertson Class* | At diagnosis | | At time of survey | |
|---|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100% | 24 | 15 | 5 | 3 |
| Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69% | 48 | 30 | 21 | 14 |
| Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49% | 24 | 15 | 20 | 14 |
| Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4% | 26 | 16 | 34 | 23 |
| Class 5 No Hearing = PTA 0; SD 0% | 7 | 4 | 51 | 34 |
| Don't Know | 30 | 19 | 17 | 11 |
| Total | 159 | 100 | 148 | 100 |

* PTA = Pure Tone Average; dB = Decibels; SD = Speech Discrimination Score

| Strategies to improve hearing | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Behind-the-ear (BTE) hearing aid | 23 | 13 |
| BiCROS hearing aid | 3 | 2 |
| Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite) | 7 | 4 |
| Cochlear implants | 1 | 1 |
| Completely-in-the-canal (CIC) hearing aid | 0 | 0 |
| CROS hearing aid | 7 | 4 |
| Device to amplify telephone | 2 | 1 |
| Device to amplify TV | 7 | 4 |
| Direct audio to input microphone | 0 | 0 |
| FM system or other amplifier (carried in pocket or placed on a table) | 2 | 1 |
| In-the-canal (ITC) hearing aid | 4 | 2 |
| In-the-ear (ITE) hearing aid | 9 | 5 |
| None | 106 | 61 |

Facial Weakness

Of the 172 respondents who reported their tumor was treated using SSR, 46 reported experiencing some facial weakness or paralysis related to the tumor. The following table contains the self-reported House-Brackmann Grade for these individuals at their diagnosis and at the time of the survey.

| Respondents self-reported House-Brackmann Grade | At diagnosis | | At time of survey | |
|---|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Grade I. Normal | 29 | 62 | 15 | 33 |
| Grade II. Mild | 10 | 22 | 16 | 36 |
| Grade III. Moderate | 5 | 11 | 3 | 7 |
| Grade IV. Moderate severe | 0 | 0 | 5 | 11 |
| Grade V. Severe | 2 | 4 | 5 | 9 |
| Grade VI. Complete paralysis | 0 | 0 | 2 | 4 |
| Total Respondents | 46 | 100 | 46 | 100 |

| Definition of House-Brackmann Grades | |
|--------------------------------------|---|
| Grade I | Normal facial function in all areas. |
| Grade II | Mild movement weakness, normal symmetry at rest. Slight weakness noticeable on close inspection; may have very slight synkinesis (inappropriate movement with voluntary movement of another muscle), moderate to good forehead motion, complete eye closure with minimum effort, only slight mouth disturbance. |
| Grade III | Moderate dysfunction with noticeable asymmetry, good eye closure. Obvious but not disfiguring difference between two sides; noticeable but not severe synkinesis. Normal balance and tone at rest, slight to moderate movement of forehead, complete eye closure with effort, mouth movement slightly weak with maximum effort. |
| Grade IV | Moderately severe dysfunction with gross asymmetry and incomplete eye closure. Obvious facial weakness and/or disfiguring asymmetry with gross movement. Normal symmetry and tone at rest. No forehead movement on affected side, incomplete eye closure, mouth asymmetric with maximum effort. |
| Grade V | Severe dysfunction with minimal facial movement. Only barely perceptible motion with attempted movement. Face unbalanced at rest. No forehead motion, incomplete eye closure. Slight mouth movement possible. |
| Grade VI | Complete paralysis. No movement. |

The following table contains the number and frequency of respondents receiving post-surgery treatments or rehabilitation therapies to correct facial weakness. Please keep in mind that respondents had the ability to choose multiple post-surgical treatments and rehabilitation therapies from the list below. The percentages listed are of the 46 respondents who indicated they had undergone SSR to treat their tumor and they experienced facial weakness.

| Surgeries and treatments | Number of responses | Percentage of responses |
|--|----------------------------|--------------------------------|
| Surgery or treatment to correct facial weakness | | |
| 12-7 Transfer (transfer of the tongue nerve to the facial nerve) | 0 | 0 |
| Cross face nerve graft | 0 | 0 |
| Facial suspension or sling | 1 | 2 |
| Face lift - on the tumor side | 1 | 2 |
| Face lift - Both sides | 0 | 0 |
| Masseter muscle transposition | 1 | 2 |
| Electrical stimulation of the face | 5 | 11 |
| Regional muscle transfer | 0 | 0 |
| Free muscle transfer, transplanting muscle from other part of body | 0 | 0 |
| Surgery to improve eyelid position and/or function | | |
| Brow elevation | 1 | 2 |
| Canthoplasty | 0 | 0 |
| Eyelid spring | 2 | 4 |
| Gold weight in eyelid | 4 | 9 |
| Lower eyelid repositioning | 1 | 2 |
| Tarsorrhaphy | 0 | 0 |
| Tissue grafts and stents | 0 | 0 |

Post-Treatment

The following tables contain information about post-treatment issues respondents' reported after SSR treatment of their tumor.

| Tumor size | At diagnosis | | Post-treatment | |
|--------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| 0.1 – 0.4 cm | 12 | 7 | 7 | 4 |
| 0.5 – 1.0 cm | 31 | 19 | 13 | 8 |
| 1.1 – 1.5 cm | 37 | 22 | 24 | 14 |
| 1.6 – 2.0 cm | 27 | 16 | 10 | 6 |
| 2.1 – 2.5 cm | 22 | 13 | 10 | 6 |
| 2.6 – 3.0 cm | 13 | 8 | 4 | 2 |
| 3.1 – 3.5 cm | 11 | 7 | 0 | 0 |
| 3.6 – 4.0 cm | 1 | 1 | 0 | 0 |
| Larger than 4.0 cm | 5 | 3 | 0 | 0 |
| Don't know | 6 | 4 | 20 | 12 |
| No response | 0 | 0 | 78 | 47 |
| Total | 165 | 100 | 166 | 100 |

| Change in tumor size and enhancement characteristics since treatment | Number of responses | Percentage of responses |
|--|----------------------------|--------------------------------|
| Experience any change in tumor size since treatment | | |
| No | 61 | 35 |
| Yes, it has either grown or shrunk | 109 | 63 |
| No answer | 2 | 1 |
| Evidence of central death of the tumor (<i>n</i> = 166) | | |
| No | 28 | 17 |
| Yes | 62 | 37 |
| Don't know | 76 | 46 |
| Has the brightness with which the tumor <i>lights up</i> on MRI film changed since your treatment? (<i>n</i> = 166) | | |
| No | 29 | 17 |
| Don't know/Not sure | 109 | 66 |
| Yes | 28 | 17 |
| If yes, What change in enhancement characteristics (brightness) have you experienced? (<i>n</i> = 28) | | |
| The tumor appears brighter now than it did upon diagnosis | 1 | 4 |
| The tumor appears darker now than it did upon diagnosis | 15 | 54 |
| Don't know/Not sure | 12 | 43 |

| Treatment, physical therapy or training to improve | Number of responses | Percentage of responses* |
|---|----------------------------|---------------------------------|
| Balance | 45 | 26 |
| Dizziness (vestibular rehabilitation) | 20 | 12 |
| Facial movement | 16 | 9 |
| Fall risk reduction | 10 | 6 |
| Psychological issues | 10 | 6 |

*based on 172 respondents

Quality of Life

| Question | Number of responses | Percentage of responses* |
|---|---------------------|--------------------------|
| Employment | | |
| After diagnosis, able to continue regular employment and/or activities | | |
| No | 17 | 10 |
| Yes | 153 | 90 |
| If yes, still employed in same capacity or perform same activities today? | | |
| Yes | 120 | 78 |
| No | 33 | 22 |
| If no, why not? | | |
| Became disabled | 12 | 36 |
| Quit to pursue another job or other interests | 3 | 9 |
| Retired | 18 | 55 |
| Handicapped parking permit | | |
| Did you use a handicapped parking permit after your treatment? | | |
| Yes | 21 | 12 |
| No | 149 | 88 |
| If no, why did you not use the permit? (<i>n</i> = 149) | | |
| I did not feel the need to use one. | 105 | 70 |
| I did not know I qualified to use one. | 36 | 24 |
| No answer | 8 | 54 |

**based on 170 responses*

| Question | Percentage of respondents | | | | | | |
|---|---------------------------|-------------------|-----------------|-----------------------|----------------|------------------|---------------------|
| | Significantly better | Moderately better | Somewhat better | No significant change | Somewhat worse | Moderately worse | Significantly worse |
| Considering your symptoms at diagnosis, how do you consider your symptoms now? | 17 | 8 | 15 | 31 | 17 | 7 | 6 |
| Considering your symptoms just after treatment, how do you consider your symptoms now? | 20 | 12 | 12 | 36 | 11 | 7 | 2 |
| Considering your quality of life at diagnosis, how do you consider your quality of life now? | 11 | 8 | 9 | 44 | 18 | 6 | 4 |
| Considering your quality of life after treatment, how do you consider your quality of life now? | 21 | 11 | 11 | 41 | 11 | 4 | 2 |

FRACTIONATED STEREOTACTIC RADIOSURGERY (FSR)

The first section of the report on fractionated stereotactic radiosurgery (FSR) is based on the 109 individuals who responded to the Initial Contact survey and the Follow-Up survey. The following tables contain a description of the respondents and their experiences with FSR.

Information About FSR Patients and Their AN Tumor

| Reasons to choose FSR | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Followed my physician's advice | 66 | 61 |
| Personal choice | 81 | 74 |
| Because I know someone who had this management option | 13 | 12 |
| Because I know someone who wished he/she had this management option | 3 | 3 |
| Because of my employment situation at the time of the decision | 10 | 9 |
| Because of my insurance situation at the time of the decision | 2 | 2 |
| Because of concerns with my social support system | 6 | 6 |
| Because of concerns about my financial situation | 4 | 4 |

| Period in which FSR occurred | Number of responses | Percentage of responses |
|------------------------------|---------------------|-------------------------|
| Prior to 1990 | 1 | 1 |
| Between 1991 and 1999 | 4 | 4 |
| Between 2000 and 2009 | 40 | 37 |
| Between 2010 and 2012 | 61 | 56 |
| No response/don't know | 3 | 3 |
| Total | 109 | 100 |

The following table contains only those institutions cited by at least two respondents.

| Institution/hospital | Location | Physicians listed by respondents |
|------------------------------|-------------------|----------------------------------|
| Johns Hopkins | Baltimore, MD | Williams |
| Kaiser Cancer Center | San Francisco, CA | Tse, Wara |
| Stanford University Hospital | Palo Alto, CA | Chang, Gibbs, Solstys |
| Thomas Jefferson University | Philadelphia, PA | Andrews |

Description of FSR Treatment(s)

| Description | Number of responses | Percentage of responses |
|--|---------------------|-------------------------|
| Duration of treatment | | |
| Less than one week | 60 | 55 |
| Between 1 and 2 weeks | 14 | 13 |
| Between 2 and 3 weeks | 1 | 1 |
| Between 3 and 4 weeks | 4 | 4 |
| Between 4 and 5 weeks | 11 | 10 |
| More than 5 weeks | 17 | 16 |
| No response | 2 | 2 |
| Number of fractions (treatments) received | | |
| Fewer than 5 fractions | 59 | 54 |
| Between 5 and 10 fractions | 20 | 18 |
| Between 11 and 15 fractions | 0 | 0 |
| Between 16 and 20 fractions | 0 | 0 |
| Between 21 and 25 fractions | 6 | 6 |
| Between 26 and 30 fractions | 18 | 17 |
| More than 30 fractions | 4 | 4 |
| No response | 2 | 2 |
| Equipment used to deliver treatment(s) | | |
| Linear accelerator (LINAC - various manufacturers) | 23 | 21 |
| CyberKnife (Accuray Incorporated) | 62 | 57 |
| Proton accelerator (Proton Beam radiation treatment) | 6 | 6 |
| Don't know what type of delivery system was used | 11 | 10 |
| Other – Gamma Knife, Novalis, Trilogy, Varian TrueBeam | 4 | 4 |

Recovery

The following table contains information about the respondents' complications and recovery period after fractionated stereotactic radiosurgery. The percentages are based on 109 respondents who indicated they received FSR for their tumor.

| Recovery | Number of responses | Percentage of responses* |
|---|---------------------|--------------------------|
| Complications related to treatment | | |
| Cerebrospinal Fluid Leak (CSF leak) | 0 | 0 |
| Hydrocephalus (Water on the brain) | 0 | 0 |
| Intractable vertigo (sustained vertigo lasting longer than 30 days) | 1 | 1 |
| Other | 0 | 0 |
| No complications | 9 | 8 |
| Time to recover fully from treatment | | |
| Approximately 1 week | 46 | 42 |
| Approximately 2 weeks | 9 | 8 |
| Approximately 1 month | 13 | 12 |
| Approximately 3 months | 5 | 5 |
| Approximately 6 months | 4 | 4 |
| Approximately 12 months | 8 | 7 |
| More than 12 months | 22 | 20 |
| No response | 2 | 2 |

**based on 109 respondents*

Symptoms Reported

This section of symptoms reports only the responses of those individuals who responded to the Initial Contact survey.

The survey asked respondents to indicate which symptoms they experienced related to their acoustic neuroma. Only those respondents who reported experiencing a specific symptom were queried about their experience with that symptom. Percentages reported below are from the 109 respondents of the Initial Contact survey indicating that they had undergone FSR to treat their tumor.

Slight differences in frequency reported in this table and in the two tables following it can be attributed to respondents who indicated they had a symptom, but not reporting frequency or severity AND reporting a symptom six months after treatment that they did not report at diagnosis.

Individuals who responded to the Follow-Up survey are not included in this summary of symptoms.

| Symptoms | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Tinnitus (noise or ringing in the ear) | 92 | 84 |
| Vertigo (dizziness/balance disturbance) | 83 | 76 |
| Single-sided hearing loss or deafness | 82 | 75 |
| Fullness in ear | 62 | 57 |
| Fatigue | 43 | 39 |
| Headaches | 36 | 33 |
| Facial numbness | 30 | 28 |
| Facial twitching | 28 | 26 |
| Memory issues | 27 | 25 |
| Difficulty concentrating | 25 | 22 |
| Depression | 25 | 23 |
| Eye problems | 18 | 17 |
| Change in smell or taste | 17 | 16 |
| Difficulty swallowing | 11 | 10 |
| I had no symptoms | 6 | 6 |

The frequency and severity of the most common symptoms (tinnitus, vertigo/balance disturbance, and headaches) at diagnosis and six months after FSR are reported below.

| Symptom | At diagnosis | | Six months after treatment | |
|--|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Tinnitus–Frequency | | | | |
| Constantly | 62 | 71 | 63 | 68 |
| Daily (At least once a day) | 17 | 20 | 15 | 16 |
| Weekly (At least once a week) | 6 | 7 | 4 | 4 |
| Monthly (At least once a month) | 1 | 1 | 6 | 7 |
| Less frequent than once a month | 1 | 1 | 4 | 4 |
| Total | 87 | 100 | 92 | 100 |
| Tinnitus–Severity | | | | |
| 5 (Most severe/disabling) | 10 | 11 | 11 | 12 |
| 4 | 15 | 17 | 18 | 19 |
| 3 | 28 | 32 | 23 | 25 |
| 2 | 13 | 15 | 17 | 18 |
| 1 (Least severe/mild) | 21 | 24 | 24 | 26 |
| Total | 87 | 100 | 93 | 100 |
| Vertigo/balance disturbance–Frequency | | | | |
| Constantly | 14 | 18 | 19 | 23 |
| Daily (At least once a day) | 33 | 42 | 30 | 36 |
| Weekly (At least once a week) | 10 | 13 | 13 | 15 |
| Monthly (At least once a month) | 5 | 6 | 4 | 5 |
| Less frequent than once a month | 6 | 16 | 18 | 21 |
| Total | 78 | 100 | 84 | 100 |
| Vertigo/balance disturbance–Severity | | | | |
| 5 (Most severe/disabling) | 6 | 8 | 6 | 7 |
| 4 | 11 | 14 | 12 | 14 |
| 3 | 22 | 28 | 23 | 27 |
| 2 | 19 | 24 | 14 | 16 |
| 1 (Least severe/mild) | 21 | 27 | 31 | 36 |
| Total | 79 | 100 | 86 | 100 |
| Headaches –Frequency | | | | |
| Constantly | 1 | 3 | 3 | 9 |
| Daily (At least once a day) | 18 | 55 | 11 | 31 |
| Weekly (At least once a week) | 6 | 18 | 12 | 34 |
| Monthly (At least once a month) | 5 | 15 | 3 | 9 |
| Less frequent than once a month | 3 | 9 | 6 | 17 |
| Total | 33 | 100 | 35 | 100 |
| Headaches–Severity | | | | |
| 5 (Most severe/disabling) | 2 | 6 | 5 | 14 |
| 4 | 5 | 15 | 2 | 6 |
| 3 | 12 | 35 | 8 | 22 |
| 2 | 8 | 24 | 8 | 22 |
| 1 (Least severe/mild) | 7 | 21 | 13 | 36 |
| Total | 34 | 100 | 36 | 100 |

The frequency of other symptoms related to the tumor at diagnosis and six months after FSR treatment are reported below.

| Symptom | At diagnosis | | Six months after treatment | |
|---|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Eye problems | | | | |
| Constantly | 4 | 22 | 5 | 25 |
| Daily (At least once a day) | 10 | 56 | 5 | 25 |
| Weekly (At least once a week) | 1 | 6 | 2 | 10 |
| Monthly (At least once a month) | 1 | 6 | 1 | 5 |
| Less frequent than once a month | 2 | 11 | 7 | 35 |
| Total Respondents | 18 | 100 | 20 | 100 |
| Changes in sense of taste or smell | | | | |
| Constantly | 7 | 44 | 4 | 21 |
| Daily (At least once a day) | 4 | 25 | 1 | 5 |
| Weekly (At least once a week) | 2 | 13 | 3 | 16 |
| Monthly (At least once a month) | 0 | 0 | 2 | 11 |
| Less frequent than once a month | 3 | 19 | 9 | 47 |
| Total Respondents | 16 | 100 | 19 | 100 |
| Facial twitching | | | | |
| Constantly | 1 | 4 | 2 | 7 |
| Daily (At least once a day) | 13 | 48 | 9 | 33 |
| Weekly (At least once a week) | 4 | 15 | 5 | 19 |
| Monthly (At least once a month) | 4 | 15 | 1 | 4 |
| Less frequent than once a month | 5 | 19 | 10 | 37 |
| Total Respondents | 27 | 100 | 27 | 100 |
| Facial numbness | | | | |
| Constantly | 9 | 30 | 12 | 35 |
| Daily (At least once a day) | 9 | 30 | 5 | 15 |
| Weekly (At least once a week) | 3 | 10 | 2 | 6 |
| Monthly (At least once a month) | 4 | 13 | 5 | 15 |
| Less frequent than once a month | 5 | 17 | 10 | 29 |
| Total Respondents | 30 | 100 | 34 | 100 |
| Fullness in tumor-side ear | | | | |
| Constantly | 23 | 40 | 21 | 38 |
| Daily (At least once a day) | 23 | 40 | 11 | 20 |
| Weekly (At least once a week) | 5 | 9 | 6 | 11 |
| Monthly (At least once a month) | 5 | 9 | 5 | 9 |
| Less frequent than once a month | 2 | 3 | 12 | 22 |
| Total Respondents | 58 | 100 | 55 | 100 |
| Difficulty swallowing | | | | |
| Constantly | 2 | 18 | 4 | 22 |
| Daily (At least once a day) | 4 | 36 | 4 | 22 |
| Weekly (At least once a week) | 2 | 18 | 3 | 17 |
| Monthly (At least once a month) | 1 | 9 | 4 | 22 |
| Less frequent than once a month | 2 | 18 | 3 | 17 |
| Total Respondents | 11 | 100 | 18 | 100 |

| Symptom | At diagnosis | | Six months after treatment | |
|---------------------------------|---------------------|-------------------------|----------------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Difficulty concentrating | | | | |
| Constantly | 5 | 21 | 5 | 15 |
| Daily (At least once a day) | 9 | 38 | 10 | 30 |
| Weekly (At least once a week) | 7 | 29 | 12 | 36 |
| Monthly (At least once a month) | 2 | 8 | 4 | 12 |
| Less frequent than once a month | 1 | 4 | 2 | 6 |
| Total Respondents | 24 | 100 | 33 | 100 |
| Fatigue | | | | |
| Constantly | 10 | 25 | 11 | 24 |
| Daily (At least once a day) | 21 | 53 | 18 | 39 |
| Weekly (At least once a week) | 8 | 20 | 12 | 26 |
| Monthly (At least once a month) | 0 | 0 | 3 | 7 |
| Less frequent than once a month | 1 | 3 | 2 | 4 |
| Total Respondents | 40 | 100 | 46 | 100 |
| Depression | | | | |
| Constantly | 4 | 16 | 6 | 20 |
| Daily (At least once a day) | 6 | 24 | 4 | 13 |
| Weekly (At least once a week) | 7 | 28 | 10 | 33 |
| Monthly (At least once a month) | 7 | 28 | 8 | 27 |
| Less frequent than once a month | 1 | 4 | 2 | 7 |
| Total Respondents | 25 | 100 | 30 | 100 |
| Memory difficulties | | | | |
| Constantly | 5 | 19 | 8 | 24 |
| Daily (At least once a day) | 13 | 48 | 10 | 29 |
| Weekly (At least once a week) | 8 | 30 | 8 | 24 |
| Monthly (At least once a month) | 1 | 4 | 6 | 18 |
| Less frequent than once a month | 0 | 0 | 2 | 6 |
| Total Respondents | 27 | 100 | 34 | 100 |

Single-Sided Hearing Loss

The following table contains the self-reported Gardner-Robertson Class at diagnosis and at the time of the survey of the 100 respondents who reported single-sided hearing loss or deafness and underwent FSR.

| Self-reported Gardner-Robertson Class* | At diagnosis | | At time of survey | |
|---|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100% | 18 | 18 | 7 | 7 |
| Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69% | 31 | 31 | 11 | 11 |
| Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49% | 19 | 19 | 18 | 18 |
| Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4% | 9 | 9 | 19 | 19 |
| Class 5 No Hearing = PTA 0; SD 0% | 4 | 4 | 20 | 20 |
| Don't Know | 19 | 19 | 24 | 24 |
| Total | 100 | 100 | 99 | 100 |

* PTA = Pure Tone Average; dB = Decibels; SD = Speech Discrimination Score

| Strategies to improve hearing | Number of responses | Percentage of responses* |
|---|---------------------|--------------------------|
| Behind-the-ear (BTE) hearing aid | 22 | 22 |
| BiCROS hearing aid | 4 | 4 |
| Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite) | 3 | 3 |
| Cochlear implants | 1 | 1 |
| CROS hearing aid | 4 | 4 |
| Device to amplify telephone | 1 | 1 |
| Device to amplify TV | 8 | 8 |
| Direct audio input microphone | 1 | 1 |
| FM system or other amplifier (carried in pocket or placed on a table) | 2 | 2 |
| In-the-canal (ITC) hearing aid | 3 | 3 |
| In-the-ear (ITE) hearing aid | 5 | 5 |
| None | 60 | 60 |

*based on 100 respondents

Facial Weakness

Of the 109 respondents who indicated in the Initial Contact survey and the Follow-Up survey that they had undergone FSR, 27 reported experiencing some facial weakness or paralysis related to their tumor. The following table contains the self-reported House-Brackmann Grade for these individuals at their diagnosis and at the time of the survey.

| Self-reported House-Brackmann Grade | At diagnosis | | At time of survey | |
|-------------------------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Grade I. Normal | 18 | 67 | 8 | 30 |
| Grade II. Mild | 7 | 26 | 13 | 48 |
| Grade III. Moderate | 1 | 4 | 4 | 15 |
| Grade IV. Moderate severe | 1 | 4 | 1 | 4 |
| Grade V. Severe | 0 | 0 | 0 | 0 |
| Grade VI. Complete paralysis | 0 | 0 | 1 | 4 |
| Total | 27 | 100 | 27 | 100 |

| Definition of House-Brackmann Grades | |
|--------------------------------------|---|
| Grade I | Normal facial function in all areas. |
| Grade II | Mild movement weakness, normal symmetry at rest. Slight weakness noticeable on close inspection; may have very slight synkinesis (inappropriate movement with voluntary movement of another muscle), moderate to good forehead motion, complete eye closure with minimum effort, only slight mouth disturbance. |
| Grade III | Moderate dysfunction with noticeable asymmetry, good eye closure. Obvious but not disfiguring difference between two sides; noticeable but not severe synkinesis. Normal balance and tone at rest, slight to moderate movement of forehead, complete eye closure with effort, mouth movement slightly weak with maximum effort. |
| Grade IV | Moderately severe dysfunction with gross asymmetry and incomplete eye closure. Obvious facial weakness and/or disfiguring asymmetry with gross movement. Normal symmetry and tone at rest. No forehead movement on affected side, incomplete eye closure, mouth asymmetric with maximum effort. |
| Grade V | Severe dysfunction with minimal facial movement. Only barely perceptible motion with attempted movement. Face unbalanced at rest. No forehead motion, incomplete eye closure. Slight mouth movement possible. |
| Grade VI | Complete paralysis. No movement. |

| Surgeries and treatments | Number of responses | Percentage of responses* |
|---|----------------------------|---------------------------------|
| Surgery or treatment to correct facial weakness | | |
| 12-7 Anastomosis (transfer of the tongue nerve to the facial nerve, also called Hypoglossal-Facial Anastomosis) | 0 | 0 |
| Cross face nerve graft | 0 | 0 |
| Facial suspension or sling | 0 | 0 |
| Face lift (tumor side) | 0 | 0 |
| Face lift (both sides) | 0 | 0 |
| Masseter muscle transposition | 0 | 0 |
| Electrical stimulation of the face | 0 | 0 |
| Surgery to improve eyelid position and/or function | | |
| Brow elevation | 1 | 4 |
| Canthoplasty | 1 | 4 |
| Eyelid spring | 0 | 0 |
| Gold weight in eyelid | 5 | 19 |
| Lower eyelid reposition | 0 | 0 |
| Tarsorrhaphy | 2 | 7 |
| Tissue grafts and stents | 0 | 0 |

**based on 27 respondents*

Post-Treatment

The following tables contain information about post-treatment issues related to the FSR treatment of respondents' tumor.

| Tumor size | At diagnosis | | Post-treatment | |
|--------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| 0.1 – 0.4 cm | 5 | 5 | 3 | 3 |
| 0.5 – 1.0 cm | 16 | 15 | 12 | 12 |
| 1.1 – 1.5 cm | 27 | 26 | 14 | 13 |
| 1.6 – 2.0 cm | 25 | 24 | 9 | 9 |
| 2.1 – 2.5 cm | 10 | 10 | 7 | 7 |
| 2.6 – 3.0 cm | 6 | 6 | 1 | 1 |
| 3.1 – 3.5 cm | 4 | 4 | 0 | 0 |
| 3.6 – 4.0 cm | 2 | 2 | 1 | 1 |
| Larger than 4.0 cm | 2 | 2 | 0 | 0 |
| Don't Know | 7 | 7 | 10 | 10 |
| No response | 0 | 0 | 47 | 45 |
| Total | 104 | 100 | 104 | 100 |

| Treatment, physical therapy or training to improve | Number of responses | Percentage of responses* |
|--|---------------------|--------------------------|
| Balance | 32 | 31 |
| Dizziness (vestibular rehabilitation) | 20 | 19 |
| Facial movement | 8 | 8 |
| Fall risk reduction | 5 | 5 |
| Psychological issues | 16 | 15 |

**based on 104 responses*

| Change in tumor size and enhancement characteristics since treatment | Number of responses | Percentage of responses* |
|--|----------------------------|---------------------------------|
| Experience any change in tumor size since treatment | | |
| No | 39 | 38 |
| Yes, it has either grown or shrunk | 65 | 62 |
| Evidence of central death of the tumor | | |
| No | 16 | 15 |
| Yes | 48 | 46 |
| Don't know | 40 | 38 |
| Has the brightness with which the tumor "lights up" on MRI film changed since your treatment? | | |
| No | 8 | 8 |
| Don't know/Not sure | 73 | 70 |
| Yes | 23 | 22 |
| If yes, What change in enhancement characteristics (brightness) have you experienced? (n = 23) | | |
| The tumor appears brighter now than it did upon diagnosis | 3 | 13 |
| The tumor appears darker now than it did upon diagnosis | 13 | 57 |
| Don't know/Not sure | 7 | 30 |

* based on 104 responses

Quality of Life

| Question | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Employment | | |
| After diagnosis, able to continue regular employment and/or activities | | |
| No | 16 | 15 |
| Yes | 91 | 85 |
| If yes, still employed in same capacity or perform same activities today? | | |
| Yes | 68 | 75 |
| No | 23 | 25 |
| If no, why not? | | |
| Became disabled | 11 | 48 |
| Quit to pursue another job or other interests | 0 | 0 |
| Retired | 3 | 13 |
| No response | 9 | 39 |
| Handicapped parking permit | | |
| Did you use a handicapped parking permit after your treatment? | | |
| Yes | 4 | 4 |
| No | 103 | 96 |
| If no, why did you not use the permit? ($n = 103$) | | |
| I did not feel the need to use one. | 70 | 68 |
| I did not know I qualified to use one. | 28 | 27 |
| No response | 5 | 5 |

| Question | Percentage of respondents | | | | | | |
|---|---------------------------|-------------------|-----------------|-----------------------|----------------|------------------|---------------------|
| | Significantly better | Moderately better | Somewhat better | No significant change | Somewhat worse | Moderately worse | Significantly worse |
| Considering your symptoms at diagnosis, how do you consider your symptoms now? | 14 | 10 | 12 | 25 | 22 | 9 | 8 |
| Considering your symptoms just after treatment, how do you consider your symptoms now? | 21 | 14 | 22 | 24 | 12 | 5 | 2 |
| Considering your quality of life at diagnosis, how do you consider your quality of life now? | 13 | 7 | 12 | 34 | 20 | 9 | 5 |
| Considering your quality of life after treatment, how do you consider your quality of life now? | 16 | 13 | 16 | 32 | 10 | 6 | 5 |

WATCH AND WAIT/OBSERVATION

The first section of the report on Watch and Wait is based on the 306 individuals who responded to the Initial Contact survey and the Follow-Up survey. The following tables contain a description of the respondents and their watch and wait experiences.

Information About Watch and Wait Patients and Their AN Tumor

| Description | Number of responses | Percentage of responses |
|--|---------------------|-------------------------|
| Length of time in watch and wait mode | | |
| 6 months or less | 41 | 13 |
| 6 months to 1 year | 40 | 13 |
| 1 year to 2 years | 42 | 14 |
| 2 years to 3 years | 34 | 11 |
| 3 years to 4 years | 27 | 9 |
| 4 years to 5 years | 26 | 8 |
| 5 years to 10 years | 63 | 21 |
| 10 years to 20 years | 28 | 9 |
| More than 20 years | 5 | 2 |
| Reasons to watch and wait | | |
| Recommended by a physician | 236 | 77 |
| Personal choice, not recommended by a physician | 54 | 18 |
| I know someone who had this management option | 7 | 2 |
| General health reasons counter-indicate treatment at this time | 18 | 6 |
| Advanced age is considered an issue | 18 | 6 |
| Size of tumor is less than 1.5 cm | 185 | 60 |
| Dissatisfaction with treatment options | 40 | 13 |
| Seeking or using alternative treatments | 11 | 4 |
| Concerned about quality of life after treatment | 144 | 47 |
| Minimal current symptoms | 137 | 45 |
| Unsure about where to get treatment | 18 | 6 |
| Job or employment concerns | 17 | 6 |
| Concerns about my financial situation | 14 | 5 |
| Absence of social support system | 7 | 2 |
| Insurance situation at time of the decision to watch and wait | 9 | 3 |

| Description | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Tumor side | | |
| Right | 153 | 50 |
| Left | 142 | 46 |
| Bilateral (Both sides) | 2 | 1 |
| No response | 9 | 3 |
| Date of last MRI | | |
| 2004 – 2007 | 2 | 1 |
| 2008 – 2009 | 7 | 2 |
| 2010 | 12 | 4 |
| 2011 | 61 | 20 |
| 2012 | 220 | 72 |
| No response | 4 | 1 |
| Diagnostic tests used to diagnose tumor <i>(multiple responses possible)</i> | | |
| CT scan (Computerized Tomography) | 35 | 11 |
| MRI scan (Magnetic Resonance Image) | 291 | 95 |
| Brainstem Auditory Evoked Response (BAER, BSER or ABR) | 25 | 8 |
| Hearing Test (Audiogram) | 213 | 70 |
| Balance Test (Electronystagmogram – ENG) | 63 | 21 |

| Size of tumor | At diagnosis | | At last MRI | |
|------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| 0.0 – 0.4 cm | 13 | 4 | 20 | 7 |
| 0.5 – 1.0 cm | 58 | 19 | 28 | 9 |
| 1.1 – 1.5 cm | 91 | 30 | 26 | 8 |
| 1.6 – 2.0 cm | 74 | 24 | 22 | 7 |
| 2.1 – 2.5 cm | 29 | 9 | 9 | 3 |
| 2.6 – 3.0 cm | 12 | 4 | 3 | 1 |
| 3.1 – 3.5 cm | 3 | 1 | 0 | 0 |
| 3.6 – 4.0 cm | 1 | < 1 | 0 | 0 |
| Larger than 4 cm | 0 | 0 | 1 | < 1 |
| Don't know | 22 | 7 | 19 | 6 |
| No response | 3 | 1 | 165 | 54 |
| Total | 306 | 100 | 306 | 100 |

Symptoms Reported

This section of symptoms reports only the responses of those individuals who responded to the Initial Contact survey.

The survey asked respondents to indicate symptoms they experienced related to their acoustic neuroma. Only those respondents who reported experiencing a specific symptom were queried about their experience with that symptom. Percentages reported below are from the 253 respondents of the Initial Contact survey who indicated they are watching and waiting. *These individuals were only asked about the frequency and severity of their symptoms at initial diagnosis.*

Slight differences in frequency reported in this table and in the two tables following it can be attributed to respondents who indicated they had a symptom, but not reporting frequency or severity.

Individuals who responded to the Follow-Up survey are not included in this summary of symptoms.

| Symptoms | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Tinnitus (noise or ringing in the ear) | 201 | 79 |
| Vertigo (dizziness/balance disturbance) | 154 | 61 |
| Fullness in ear | 124 | 49 |
| Single-sided hearing loss | 120 | 47 |
| Fatigue | 45 | 18 |
| Headaches | 44 | 17 |
| Facial numbness | 24 | 9 |
| Facial twitching | 13 | 5 |
| Memory issues | 34 | 13 |
| Difficulty concentrating | 30 | 12 |
| Depression | 29 | 11 |
| Eye problems | 15 | 6 |
| Change in smell or taste | 12 | 5 |
| Difficulty swallowing | 10 | 4 |
| I had no symptoms | 33 | 13 |

The frequency and severity of the most common symptoms (tinnitus, vertigo/balance disturbance, and headaches) experienced by watch and wait patients at diagnosis are reported below.

| Symptom | Number of responses | Percentage of responses |
|---------------------------------------|---------------------|-------------------------|
| Tinnitus–Frequency | | |
| Constantly | 134 | 72 |
| Daily (At least once a day) | 29 | 16 |
| Weekly (At least once a week) | 12 | 6 |
| Monthly (At least once a month) | 4 | 2 |
| Less frequent than once a month | 8 | 4 |
| Total | 187 | 100 |
| Tinnitus–Severity | | |
| 5 (Most severe/disabling) | 11 | 6 |
| 4 | 23 | 12 |
| 3 | 63 | 33 |
| 2 | 52 | 27 |
| 1 (Least severe/mild) | 41 | 22 |
| Total | 190 | 100 |
| Vertigo/balance disturbance–Frequency | | |
| Constantly | 20 | 14 |
| Daily (At least once a day) | 37 | 27 |
| Weekly (At least once a week) | 25 | 18 |
| Monthly (At least once a month) | 15 | 11 |
| Less frequent than once a month | 41 | 30 |
| Total | 138 | 100 |
| Vertigo/balance disturbance–Severity | | |
| 5 (Most severe/disabling) | 14 | 10 |
| 4 | 22 | 15 |
| 3 | 29 | 20 |
| 2 | 37 | 26 |
| 1 (Least severe/mild) | 40 | 28 |
| Total | 142 | 100 |
| Headaches –Frequency | | |
| Constantly | 1 | 3 |
| Daily (At least once a day) | 12 | 31 |
| Weekly (At least once a week) | 15 | 38 |
| Monthly (At least once a month) | 9 | 23 |
| Less frequent than once a month | 2 | 5 |
| Total | 39 | 100 |
| Headaches–Severity | | |
| 5 (Most severe/disabling) | 4 | 10 |
| 4 | 7 | 18 |
| 3 | 12 | 30 |
| 2 | 13 | 33 |
| 1 (Least severe/mild) | 4 | 10 |
| Total | 40 | 100 |

The frequency of other symptoms related to the tumor at diagnosis for watch and wait respondents are reported below.

| Symptom | Number of responses | Percentage of responses |
|---|---------------------|-------------------------|
| Eye problems | | |
| Constantly | 3 | 21 |
| Daily (At least once a day) | 3 | 21 |
| Weekly (At least once a week) | 3 | 21 |
| Monthly (At least once a month) | 0 | 0 |
| Less frequent than once a month | 5 | 36 |
| Total Respondents | 14 | 100 |
| Changes in sense of taste or smell | | |
| Constantly | 5 | 42 |
| Daily (At least once a day) | 2 | 17 |
| Weekly (At least once a week) | 4 | 33 |
| Monthly (At least once a month) | 1 | 8 |
| Less frequent than once a month | 0 | 0 |
| Total Respondents | 12 | 100 |
| Facial twitching | | |
| Constantly | 0 | 0 |
| Daily (At least once a day) | 1 | 9 |
| Weekly (At least once a week) | 4 | 36 |
| Monthly (At least once a month) | 3 | 27 |
| Less frequent than once a month | 3 | 27 |
| Total Respondents | 11 | 100 |
| Facial numbness | | |
| Constantly | 5 | 23 |
| Daily (At least once a day) | 5 | 23 |
| Weekly (At least once a week) | 8 | 36 |
| Monthly (At least once a month) | 1 | 5 |
| Less frequent than once a month | 3 | 14 |
| Total Respondents | 22 | 100 |
| Fullness in tumor-side ear | | |
| Constantly | 53 | 47 |
| Daily (At least once a day) | 18 | 16 |
| Weekly (At least once a week) | 22 | 20 |
| Monthly (At least once a month) | 10 | 9 |
| Less frequent than once a month | 9 | 8 |
| Total Respondents | 112 | 100 |
| Difficulty swallowing | | |
| Constantly | 2 | 20 |
| Daily (At least once a day) | 4 | 40 |
| Weekly (At least once a week) | 1 | 10 |
| Monthly (At least once a month) | 3 | 30 |
| Less frequent than once a month | 0 | 0 |
| Total Respondents | 10 | 100 |

| Symptom | Number of responses | Percentage of responses |
|---------------------------------|---------------------|-------------------------|
| Difficulty concentrating | | |
| Constantly | 5 | 17 |
| Daily (At least once a day) | 15 | 50 |
| Weekly (At least once a week) | 6 | 20 |
| Monthly (At least once a month) | 2 | 7 |
| Less frequent than once a month | 2 | 7 |
| Total Respondents | 30 | 100 |
| Fatigue | | |
| Constantly | 7 | 17 |
| Daily (At least once a day) | 21 | 51 |
| Weekly (At least once a week) | 10 | 24 |
| Monthly (At least once a month) | 3 | 7 |
| Less frequent than once a month | 0 | 0 |
| Total Respondents | 41 | 100 |
| Depression | | |
| Constantly | 5 | 19 |
| Daily (At least once a day) | 9 | 35 |
| Weekly (At least once a week) | 5 | 19 |
| Monthly (At least once a month) | 3 | 12 |
| Less frequent than once a month | 4 | 15 |
| Total Respondents | 26 | 100 |
| Memory difficulties | | |
| Constantly | 5 | 15 |
| Daily (At least once a day) | 11 | 33 |
| Weekly (At least once a week) | 11 | 33 |
| Monthly (At least once a month) | 3 | 9 |
| Less frequent than once a month | 3 | 9 |
| Total Respondents | 33 | 100 |

Single-Sided Hearing Loss

The following table contains the self-reported Gardner-Robertson Class of 242 respondents who are watching and waiting and who experienced single-sided hearing loss or deafness related to their tumor.

| Self-reported Gardner-Robertson Class* | At diagnosis | | At time of survey | |
|---|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100% | 58 | 24 | 31 | 13 |
| Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69% | 67 | 28 | 52 | 21 |
| Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49% | 21 | 9 | 29 | 12 |
| Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4% | 20 | 8 | 25 | 10 |
| Class 5 No Hearing = PTA 0; SD 0% | 12 | 5 | 35 | 14 |
| Don't Know | 64 | 26 | 70 | 29 |
| Total | 242 | 100 | 242 | 100 |

* PTA = Pure Tone Average; dB = Decibels; SD = Speech Discrimination Score

| Strategies to improve hearing | Number of responses | Percentage of responses* |
|---|---------------------|--------------------------|
| CROS hearing aid | 8 | 3 |
| BiCROS hearing aid | 7 | 3 |
| In-the-ear (ITE) hearing aid | 10 | 4 |
| In-the-canal (ITC) hearing aid | 6 | 3 |
| Bone Conduction Hearing Aid (like Baha and TransEar) | 3 | 1 |
| FM system or other amplifier (carried in pocket or placed on a table) | 2 | 1 |
| Device to amplify TV | 5 | 2 |
| Device to amplify telephone | 4 | 2 |
| Direct audio to input microphone | 1 | < 1 |

*based on 242 responses

Facial Weakness

Of the 306 respondents who indicated they are watch and wait AN patients, 31 reported experiencing some facial weakness or paralysis related to their tumor. The following table reports the self-reported House-Brackmann Grade for these individuals at their diagnosis and at the time of the survey.

| Self-reported House-Brackmann Grade | At diagnosis | | At time of survey | |
|-------------------------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Grade I. Normal | 22 | 71 | 9 | 30 |
| Grade II. Mild | 6 | 19 | 14 | 47 |
| Grade III. Moderate | 1 | 3 | 1 | 3 |
| Grade IV. Moderate severe | 1 | 3 | 4 | 13 |
| Grade V. Severe | 0 | 0 | 1 | 3 |
| Grade VI. Complete paralysis | 1 | 3 | 1 | 3 |
| Total | 31 | 100 | 30 | 100 |

| Definition of House-Brackmann Grades | |
|--------------------------------------|---|
| Grade I | Normal facial function in all areas. |
| Grade II | Mild movement weakness, normal symmetry at rest. Slight weakness noticeable on close inspection; may have very slight synkinesis (inappropriate movement with voluntary movement of another muscle), moderate to good forehead motion, complete eye closure with minimum effort, only slight mouth disturbance. |
| Grade III | Moderate dysfunction with noticeable asymmetry, good eye closure. Obvious but not disfiguring difference between two sides; noticeable but not severe synkinesis. Normal balance and tone at rest, slight to moderate movement of forehead, complete eye closure with effort, mouth movement slightly weak with maximum effort. |
| Grade IV | Moderately severe dysfunction with gross asymmetry and incomplete eye closure. Obvious facial weakness and/or disfiguring asymmetry with gross movement. Normal symmetry and tone at rest. No forehead movement on affected side, incomplete eye closure, mouth asymmetric with maximum effort. |
| Grade V | Severe dysfunction with minimal facial movement. Only barely perceptible motion with attempted movement. Face unbalanced at rest. No forehead motion, incomplete eye closure. Slight mouth movement possible. |
| Grade VI | Complete paralysis. No movement. |

| Surgeries and treatments | Number of responses | Percentage of responses* |
|---|---------------------|--------------------------|
| Surgery or treatment to correct facial weakness | | |
| 12-7 Anastomosis (transfer of the tongue nerve to the facial nerve, also called Hypoglossal-Facial Anastomosis) | 2 | 6 |
| Cross face nerve graft | 0 | 0 |
| Facial suspension or sling | 0 | 0 |
| Face lift (tumor side) | 0 | 0 |
| Face lift (both sides) | 0 | 0 |
| Masseter muscle transposition | 0 | 0 |
| Electrical stimulation of the face | 0 | 0 |
| Other facial surgery | 0 | 0 |
| Surgery to improve eyelid position and/or function | | |
| Tarsorrhaphy (procedure in which lids are sewn together) | 1 | 3 |
| Gold weight in eyelid | 1 | 3 |
| Eyelid spring | 0 | 0 |
| Lower eyelid repositioning | 1 | 3 |
| Brow elevation | 0 | 0 |
| Other eyelid surgery | 0 | 0 |

*based on 31 responses

Quality of Life

| Question | Percentage of respondents* | | | | | | |
|--|----------------------------|-------------------|-----------------|-----------------------|----------------|------------------|---------------------|
| | Significantly better | Moderately better | Somewhat better | No significant change | Somewhat worse | Moderately worse | Significantly worse |
| Considering your symptoms at diagnosis, how do you consider your symptoms now? | 9 | 5 | 5 | 53 | 21 | 5 | 2 |
| Considering your quality of life at diagnosis, how do you consider your quality of life now? | 11 | 6 | 6 | 41 | 26 | 8 | 3 |

*based on 300 responses

FOLLOW-UP SURVEY

A goal of the ANA is to develop a database that contains information about patients as they live with AN. Many patients have provided information about their initial experiences with AN since 1983. However, none of these individuals had been contacted to update their information in a systematic manner. The Follow-Up survey was designed to do this. Almost 1,300 ($n = 1,272$) patients who responded to the 2007–2008 survey were invited to participate in a follow-up survey in November 2012. Responses were received from 399 individuals; however, only 371 were completed.

This section of the 2012 report updates 2007–2008 responses with those made in the most recent survey. In order to provide this data, the 2012 responses had to be matched with the 2007–2008 responses. The unique identifier used was the individuals' email address. Of the 371 completed responses, only 323 could be matched specifically to 2007–2008 responses.

In addition, fewer than 300 ($n = 298$) provided complete data from both surveys. Therefore, this section of the report contains the responses of 298 individuals who provided information about their AN experiences in both 2007–2008 and 2012.

The 298 individuals reported their status in 2012. Fourteen percent of the respondents have received no treatment for their tumor and are in the watch and wait mode. Three-fourths of the respondents reported treatments in the 2007–2008 survey but have had no further treatments. Eleven percent of the group received treatments since 2007–2008.

| Treatment modality | Number of responses | Percentage of responses |
|---------------------------------------|----------------------------|--------------------------------|
| No further treatment since 2007 | 223 | 75 |
| No treatment (watch & wait) | 43 | 14 |
| Received treatment(s) since 2007–2008 | 32 | 11 |

Almost all of the 32 individuals who received treatment since 2007–2008 provided information about their treatments. The majority of the patients underwent microsurgical resection of their tumor. Information about these treatments is in the database, but is not presented here.

| Treatment modality | Number of responses | Percentage of responses |
|--|----------------------------|--------------------------------|
| Fractionated stereotactic radiotherapy(FSR) treatment performed in multiple sessions | 4 | 15 |
| Microsurgical resection (surgery/craniotomy) | 21 | 78 |
| Single dose stereotactic radiosurgery (single session radiation treatment) | 2 | 7 |

The following tables provide information about the patients who make up this follow-up group.

| Descriptor | Number of responses | Percentage of responses |
|---|----------------------------|--------------------------------|
| Gender | | |
| Male | 112 | 38 |
| Female | 186 | 62 |
| Ethnicity | | |
| Caucasian | 287 | 96 |
| African/American-American/W. Indian (Black) | 1 | < 1 |
| Asian/Pacific Islander | 4 | 1 |
| Hispanic/Latino | 5 | 1 |
| Native American | 0 | 0 |
| Other | 1 | < 1 |
| Age when tumor was diagnosed | | |
| Less than 12 years old | 0 | 0 |
| 12 – 20 years old | 2 | 1 |
| 21 – 30 years old | 10 | 3 |
| 31 – 40 years old | 43 | 14 |
| 41 – 50 years old | 91 | 31 |
| 51 – 60 years old | 103 | 35 |
| 61 – 70 years old | 44 | 15 |
| 71 – 80 years old | 4 | 1 |
| 81 or older | 1 | < 1 |

| Tumor side | Number of responses | Percentage of responses |
|------------------------|----------------------------|--------------------------------|
| Right | 133 | 45 |
| Left | 161 | 54 |
| Bilateral (both sides) | 3 | 1 |
| No response | 1 | < 1 |
| Total | 298 | 100 |

Changes Since 2007–2008

The tables in this section provide information about AN patients' tumor, level of hearing and facial weakness, and the therapies and treatments they received as reported in 2007–2008 and in 2012.

| Tumor size | 2007–2008 | | At most recent MRI | |
|--------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| 0.0 - 0.4 cm* | 0 | 0 | 90 | 30 |
| 0.5 - 1.0 cm | 43 | 14 | 32 | 11 |
| 1.1 - 1.5 cm | 54 | 18 | 29 | 10 |
| 1.6 - 2.0 cm | 41 | 14 | 24 | 8 |
| 2.1 - 2.5 cm | 40 | 13 | 20 | 7 |
| 2.6 - 3.0 cm | 25 | 8 | 4 | 1 |
| 3.1 - 3.5 cm | 19 | 6 | 3 | 1 |
| 3.6 - 4.0 cm | 9 | 3 | 1 | 0 |
| Larger than 4.0 cm | 18 | 6 | 2 | 1 |
| Don't know | 20 | 7 | 92 | 31 |
| No response | 29 | 10 | 1 | 0 |
| Total | 298 | 100 | 298 | 100 |

* This tumor size was not an option before 2012

| Self-reported Gardner-Robertson Class* | 2007–2008 | | 2012 | |
|---|----------------------------|--------------------------------|----------------------------|--------------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100% | 6 | 2 | 5 | 2 |
| Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69% | 27 | 9 | 18 | 6 |
| Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49% | 24 | 8 | 33 | 11 |
| Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4% | 20 | 7 | 31 | 10 |
| Class 5 No Hearing = PTA 0; SD 0% | 126 | 42 | 155 | 52 |
| Don't Know | 55 | 18 | 33 | 11 |
| No response | 40 | 13 | 23 | 8 |

* PTA = Pure Tone Average; dB = Decibels; SD = Speech Discrimination Score

| Strategies to improve hearing | 2007–2008 | | 2012 | |
|---|----------------------------|--------------------------------|----------------------------|--------------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| CROS hearing aid | 15 | 5 | 23 | 8 |
| BiCROS hearing aid | 2 | 1 | 13 | 4 |
| Behind-the-ear (BTE) hearing aid | 0 | 0 | 30 | 10 |
| In-the-ear (ITE) hearing aid | 11 | 4 | 12 | 4 |
| In-the-canal (ITC) hearing aid | 5 | 2 | 4 | 1 |
| Completely-in-the-canal (CIC) hearing aid | 0 | 0 | 1 | 0 |
| Bone conduction hearing devices (such as Cochlear) | 14 | 5 | 30 | 10 |
| Cochlear implants | 0 | 0 | 1 | 0 |
| FM system or other amplifier (carried in pocket or placed on a table) | 3 | 1 | 1 | 0 |
| Device to amplify TV | 9 | 3 | 8 | 3 |
| Device to amplify telephone | 6 | 2 | 5 | 2 |
| Direct audio input microphone | 0 | 0 | 0 | 0 |

| Self-reported House-Brackmann Grade | 2007–2008 | | 2012 | |
|-------------------------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Grade I. Normal | 3 | 5 | 23 | 14 |
| Grade II. Mild | 25 | 40 | 49 | 38 |
| Grade III. Moderate | 18 | 29 | 27 | 21 |
| Grade IV. Moderate severe | 10 | 16 | 17 | 13 |
| Grade V. Severe | 4 | 6 | 4 | 3 |
| Grade VI. Complete paralysis | 3 | 5 | 8 | 6 |
| Total | 63 | 100 | 128 | 100 |

| Surgeries and treatments | 2007–2008 | | 2012 | |
|--|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Rehabilitation surgery or therapy for facial weakness | | | | |
| 12-7 Transfer (transfer of the tongue nerve to the facial nerve) | 7 | 2 | 8 | 3 |
| Cross face nerve graft | 0 | 0 | 3 | 1 |
| Electrical stimulation of the face | 4 | 1 | 8 | 3 |
| Face lift - Both sides | 1 | 0 | 2 | 1 |
| Face lift - on the tumor side | 3 | 1 | 5 | 2 |
| Facial suspension or sling | 3 | 1 | 3 | 1 |
| Surgery to improve eyelid position | | | | |
| Tarsorrhaphy | 2 | 1 | 11 | 4 |
| Gold weight in eyelid | 17 | 6 | 21 | 7 |
| Eyelid spring | 5 | 2 | 4 | 1 |
| Lower eyelid repositioning | 2 | 1 | 6 | 2 |
| Brow elevation | 2 | 1 | 8 | 3 |
| Canthoplasty | 0 | 0 | 3 | 1 |
| Tissue grafts and stents | 0 | 0 | 0 | 0 |

Symptoms since 2007–2008

This section presents the percentage of AN patients experiencing symptoms in 2007–2008 and any change in 2012.

Slight differences in frequency reported in this table and in the two tables following it can be attributed to respondents who indicated they had a symptom, but not reporting frequency or severity AND reporting a symptom six months after treatment that they did not report at diagnosis.

| | 2007–2008* | | 2012* | |
|---|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Symptoms reported by all follow-up respondents | | | | |
| Change in smell or taste | 56 | 19 | 42 | 14 |
| Depression | 39 | 13 | 29 | 10 |
| Difficulty concentrating | 48 | 16 | 38 | 13 |
| Difficulty swallowing | 24 | 8 | 24 | 8 |
| Eye problems | 79 | 27 | 64 | 21 |
| Facial numbness | 72 | 24 | 68 | 23 |
| Facial twitching | 41 | 14 | 47 | 16 |
| Facial weakness or paralysis | 68 | 23 | 0 | 0 |
| Fatigue | 84 | 28 | 52 | 17 |
| Fullness in ear | 118 | 40 | 131 | 44 |
| Headaches | 85 | 29 | 75 | 25 |
| Memory issues | 49 | 16 | 52 | 17 |
| Single-sided hearing loss | 237 | 66 | 237 | 80 |
| Tinnitus (noise or ringing in the ear) | 258 | 87 | 210 | 70 |
| Vertigo (dizziness/balance disturbance) | 212 | 71 | 167 | 56 |
| I had no symptoms | 169 | 57 | 45 | 15 |

*based on 298 responses

The frequency and severity of the most common symptoms (tinnitus, vertigo/balance disturbance, and headaches) experienced by all follow-up AN patients ($n = 298$) in 2007–2008 and 2012 are reported below.

| Symptom | 2007–2008 | | 2012 | |
|--|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Tinnitus–Frequency | | | | |
| Constantly | 170 | 81 | 85 | 62 |
| Daily (At least once a day) | 13 | 6 | 26 | 19 |
| Weekly (At least once a week) | 10 | 5 | 10 | 7 |
| Monthly (At least once a month) | 9 | 4 | 3 | 2 |
| Less frequent than once a month | 7 | 3 | 13 | 9 |
| Total | 209 | 100 | 137 | 100 |
| Tinnitus–Severity | | | | |
| 5 (Most severe/disabling) | 5 | 2 | | |
| 4 | 25 | 12 | | |
| 3 | 52 | 25 | | |
| 2 | 51 | 24 | | |
| 1 (Least severe/mild) | 79 | 37 | | |
| Total | 212 | 100 | | |
| Vertigo/balance disturbance–Frequency | | | | |
| Constantly | 50 | 30 | 11 | 10 |
| Daily (At least once a day) | 30 | 18 | 26 | 23 |
| Weekly (At least once a week) | 11 | 7 | 17 | 15 |
| Monthly (At least once a month) | 35 | 21 | 6 | 5 |
| Less frequent than once a month | 42 | 25 | 54 | 47 |
| Total | 168 | 100 | 114 | 100 |
| Vertigo/balance disturbance–Severity | | | | |
| 5 (Most severe/disabling) | 4 | 4 | | |
| 4 | 8 | 9 | | |
| 3 | 41 | 44 | | |
| 2 | 40 | 43 | | |
| 1 (Least severe/mild) | 0 | 0 | | |
| Total | 93 | 100 | | |
| Headaches –Frequency | | | | |
| Constantly | 12 | 14 | 3 | 6 |
| Daily (At least once a day) | 12 | 14 | 6 | 11 |
| Weekly (At least once a week) | 13 | 15 | 12 | 23 |
| Monthly (At least once a month) | 22 | 26 | 9 | 17 |
| Less frequent than once a month | 26 | 31 | 23 | 43 |
| Total | 85 | 100 | 53 | 100 |
| Headaches–Severity | | | | |
| 5 (Most severe/disabling) | 5 | 6 | | |
| 4 | 3 | 4 | | |
| 3 | 25 | 29 | | |
| 2 | 29 | 34 | | |
| 1 (Least severe/mild) | 23 | 27 | | |
| Total | 85 | 100 | | |

The frequency of other symptoms related to the tumor experienced by all follow-up AN patients ($n = 298$) in 2007–2008 and 2012 are reported below.

| Symptom | 2007–2008 | | 2012 | |
|---|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Eye problems | | | | |
| Constantly | 9 | 12 | 15 | 36 |
| Daily (At least once a day) | 7 | 9 | 12 | 29 |
| Weekly (At least once a week) | 2 | 3 | 1 | 2 |
| Monthly (At least once a month) | 9 | 12 | 5 | 12 |
| Less frequent than once a month | 50 | 65 | 9 | 21 |
| Total Respondents | 77 | 100 | 42 | 100 |
| Changes in sense of taste or smell | | | | |
| Constantly | 31 | 57 | 10 | 34 |
| Daily (At least once a day) | 4 | 7 | 7 | 8 |
| Weekly (At least once a week) | 0 | 0 | 4 | 5 |
| Monthly (At least once a month) | 3 | 6 | 3 | 4 |
| Less frequent than once a month | 16 | 30 | 38 | 45 |
| Total Respondents | 54 | 100 | 85 | 100 |
| Facial twitching | | | | |
| Constantly | 10 | 24 | 0 | 0 |
| Daily (At least once a day) | 10 | 24 | 5 | 16 |
| Weekly (At least once a week) | 7 | 17 | 7 | 22 |
| Monthly (At least once a month) | 8 | 20 | 5 | 16 |
| Less frequent than once a month | 6 | 15 | 16 | 47 |
| Total Respondents | 41 | 100 | 32 | 100 |
| Facial numbness | | | | |
| Constantly | 35 | 50 | 0 | 0 |
| Daily (At least once a day) | 6 | 9 | 5 | 16 |
| Weekly (At least once a week) | 6 | 9 | 7 | 22 |
| Monthly (At least once a month) | 8 | 11 | 5 | 16 |
| Less frequent than once a month | 15 | 21 | 15 | 47 |
| Total Respondents | 70 | 100 | 32 | 100 |
| Fullness in tumor-side ear | | | | |
| Constantly | 50 | 44 | 33 | 39 |
| Daily (At least once a day) | 18 | 16 | 7 | 8 |
| Weekly (At least once a week) | 12 | 11 | 4 | 5 |
| Monthly (At least once a month) | 11 | 10 | 3 | 4 |
| Less frequent than once a month | 23 | 20 | 38 | 45 |
| Total Respondents | 114 | 100 | 85 | 100 |
| Difficulty swallowing | | | | |
| Constantly | 11 | 48 | 2 | 13 |
| Daily (At least once a day) | 2 | 9 | 4 | 27 |
| Weekly (At least once a week) | 2 | 9 | 4 | 27 |
| Monthly (At least once a month) | 3 | 13 | 2 | 13 |
| Less frequent than once a month | 5 | 22 | 3 | 20 |
| Total Respondents | 23 | 100 | 15 | 100 |

| Symptom | 2007–2008 | | 2012 | |
|---------------------------------|---------------------|-------------------------|---------------------|-------------------------|
| | Number of responses | Percentage of responses | Number of responses | Percentage of responses |
| Difficulty concentrating | | | | |
| Constantly | 25 | 54 | 7 | 26 |
| Daily (At least once a day) | 13 | 28 | 7 | 26 |
| Weekly (At least once a week) | 2 | 4 | 7 | 26 |
| Monthly (At least once a month) | 2 | 4 | 0 | 0 |
| Less frequent than once a month | 4 | 9 | 6 | 22 |
| Total Respondents | 46 | 100 | 27 | 100 |
| Fatigue | | | | |
| Constantly | 43 | 52 | 5 | 14 |
| Daily (At least once a day) | 25 | 30 | 8 | 22 |
| Weekly (At least once a week) | 7 | 8 | 14 | 38 |
| Monthly (At least once a month) | 4 | 5 | 4 | 11 |
| Less frequent than once a month | 4 | 5 | 6 | 15 |
| Total Respondents | 83 | 100 | 37 | 100 |
| Depression | | | | |
| Constantly | 12 | 32 | 3 | 19 |
| Daily (At least once a day) | 9 | 24 | 0 | 0 |
| Weekly (At least once a week) | 2 | 5 | 3 | 19 |
| Monthly (At least once a month) | 7 | 19 | 2 | 13 |
| Less frequent than once a month | 7 | 19 | 8 | 50 |
| Total Respondents | 37 | 100 | 16 | 100 |
| Memory difficulties | | | | |
| Constantly | 28 | 60 | 10 | 26 |
| Daily (At least once a day) | 12 | 26 | 14 | 37 |
| Weekly (At least once a week) | 2 | 4 | 9 | 24 |
| Monthly (At least once a month) | 4 | 9 | 3 | 8 |
| Less frequent than once a month | 1 | 2 | 2 | 5 |
| Total Respondents | 47 | 100 | 38 | 100 |