DISCLAIMER

All data collected in the Acoustic Neuroma Association's database 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.

ALL DATA COLLECTED WAS SELF-REPORTED BY RESPONDENTS AND HAVE NOT BEEN VERIFIED BY THE ACOUSTIC NEUROMA ASSOCIATION. THE ACOUSTIC NEUROMA ASSOCIATION MAKES NO REPRESENTATION AS TO THE ACCURACY OF THE DATA COLLECTED OR REPORTED HEREIN.

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

EXECUTIVE SUMMARY

This is the first report drawn from the new registry of patients. This registry contains all responses to online surveys from 2007/2008 to the end of 2014. The registry has been conceived as a way to show the wellbeing of AN patients each year. The registry contains unique records of each AN patient's responses to the same questions each year.

Because of HIPPA restrictions, tying previous survey responses to follow-up surveys is not feasible for ANA. As a result, follow-up data should be thought of as an additional record showing the wellbeing of an ANA patient in another year. This builds a registry that shows how ANA patients fare at certain points in time after their treatment (or decision to W&W), but should not be considered a look at how individual AN patients progress from year to year.

The report contains the responses of 4,172 AN patients who completed a survey and indicated a treatment modality (microsurgery, SSR, FSR, or watch and wait).

The following tables summarize some of the registry information contained in the full report and compare the information to earlier paper surveys conducted in 1983 and 1998.

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

Tumor Size

The tumor size reported by respondents at the time of their diagnosis has changed since 1983. Forty-seven percent of the AN patients in 2014 reported tumors 1.5 cm or less, up from 17% in 1983. This may indicate earlier diagnosis of the tumor now than in 1983.

	Percentage of respondents				
Size	**2014** ***n*** **= 846**	**2012** ***n*** **= 1,349**	**2007–2008** ***n*** **= 1,977**	**1998** ***n*** **= 1,940**	**1983** ***n*** **= 541**
1.5 cm or less	47	47	38	23	17
1.6–2.5 cm	28	26	27	36	42
Larger than 2.5 cm	19	22	27	35	28
Did not know size	5	6	8	6	15

Percentages may not total 100% due to rounding

Symptoms

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. This is an example of a symptom related to treatment and not necessarily just to the existence of a tumor.

Since 1983, more than half of AN patients reported single-sided hearing loss, tinnitus, and vertigo or balance symptoms at diagnosis in each survey before 2014. However, balance was added as a symptom in 2014; thus separating the issue of vertigo and balance. As a result, vertigo or balance disturbance was reported by 41% in 2014, while balance symptoms were reported by 47%.

The following table summarizes information from surveys conducted from 1983 to 2014.

	Percentage of respondents				
Treatment	**2014** ***n*** **= 846**	**2012** ***n*** **= 1,349**	**2007–2008** ***n*** **= 1,977**	**1998** ***n*** **= 1,940**	**1983** ***n*** **= 541**
Single-sided hearing loss or deafness	86	88	88	88	86
Tinnitus	59	71	73	64	57
Balance*	47	NA	NA	NA	NA
Fullness in ear	43	45	38	43	NA
Vertigo or balance disturbance	41	62	61	64	61
Facial weakness or paralysis	25	28	31	14	NA
Headaches	23	28	34	33	37
Fatigue	18	25	35	NA	NA
Depression	15	14	22	NA	NA
Facial numbness	13	22	24	22	NA
Difficulty concentrating	12	16	19	NA	NA
Memory difficulties	10	25	19	NA	NA
Facial twitching	9	16	17	13	NA
Change in smell or taste	8	15	21	10	NA
Eye problems	8	21	33	16	NA
Difficulty swallowing	6	9	12	7	NA

Treatment

The percentage of respondents reporting microsurgery[1] as their treatment has fallen from 100% in 1983 to 51% in 2014. The translabyrinthine surgical approach remains the most frequently reported form of microsurgical resection. However, the percentage of respondents reporting the translabyrinthine approach fell from 72% in 1983 to 23% in 2014.

The percentage of respondents reporting radiosurgery/radiotherapy as their treatment has increased from 5% in 1998 to 29% in 2014. The percentage of watch and wait patients has increased from 4% in 1998 to 20% in 2014.

Details about AN patients' experiences with the different treatment modalities can be found in each treatment modality section.

	Percentage of respondents reporting first treatment				
Treatment	**2014 *n* = 846**	**2012-2013 *n* = 1,394**	**2007–2008 *n* = 1,977**	**1998 *n* = 1,940**	**1983 *n* = 541**
Translabyrinthine approach	23	28	31	51	72
Retrosigmoid/sub-occipital approach	18	16	16	28	11
Middle fossa approach	8	7	8	6	3
Don't know which surgical approach	2	2	2	0	14
Total microsurgical resection	**51**	**54**	**58**	**85**	**100**
Stereotactic radiosurgery, such as Gamma Knife (SSR)	17	18	14	NA	NA
Fractionated stereotactic radiosurgery (FSR)	12	10	8	NA	NA
Total radiosurgery/radiotherapy	**29**	**27**	**22**	**5**	**0**
Watch & wait	**20**	**20**	**20**	**4**	**0**
Total	**100**	**100**	**100**	**94***	**100**

Totals may not add correctly due to rounding
**6% of respondents in 1998 did not know what type of treatment they had*

[1] 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*.

Observation

The percentage of acoustic neuroma patients who reported choosing to observe their tumor–to watch and wait rather than seeking treatment–increased from 5% in 1998 to 20% in 2014. Twenty-nine percent of the AN patients in the registry indicated they have been in the watch and wait mode for 1 year or less. Another 27% have been in the watch and wait mode between 1 and 3 years, 17% between 5 and 10 years, and 8% for more than 10 years.

Post-Treatment Rehabilitation Therapies

Seven percent of AN patients indicated they received treatment or surgery to correct facial weakness. Twenty-seven percent reported receiving treatment for balance, 8% for dizziness and 13% for facial movement. Details on post-treatment rehabilitation therapies can be found in each treatment modality section.

Quality of Life

Online surveys since 2012 contain 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 (87%) indicated they were able to continue regular employment and/or activities after their diagnosis and 73% indicated they were still employed in the same capacity or perform the same activities today. Of those who are not, 74% indicated they had retired (*out of those who responded to the question*).

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 (71%) did not feel the need to use a parking permit.

Thirty-one percent of the respondents reported their symptoms are significantly or moderately better now than at diagnosis. In regards to their quality of life, 24% consider it significantly or moderately better now than at their diagnosis.

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INTRODUCTION

In keeping with the mission of ANA, the ANA database is maintained 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.

THE INFORMATION FROM ALL ANA SURVEYS 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 INFORMATION REGARDING CAUSALITY. READERS SHOULD NOT DISREGARD, UNDER ANY CIRUMCSTANCES, ANY PROFESSIONAL MEDICAL ADVICE OR DELAY IN SEEKING SUCH ADVICE.

Method

This is the first report drawn from the new registry of patients. This registry contains all responses to online surveys from 2007/2008 to the end of 2014. The registry has been conceived as a way to show the wellbeing of AN patients each year. Rather than providing a look at how individual AN patients progress from year to year, the registry provides information on how AN patients fare at different points in time after their last treatment (or their decision to watch and wait). In the coming years, AN patients and researchers will be able to query a large number of records in the registry to answer a number of research questions.

The tables in this report present basic information about 4,172 AN patients who reported a treatment modality. A record was created from a response if the AN patient worked through the survey and exited at the end and **indicated their treatment modality** (microsurgery, SSR, FSR, or watch and wait). 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.

Conversion of Symptom Data to Current Format

In all the online surveys, the AN patients were asked what symptoms they had experienced. In 2007/2008 and in 2012, they were asked a series of questions about frequency and severity of each symptom at *diagnosis* and at *the time of the survey*.

The 2014 survey took a different approach to how AN patients are asked about their symptoms. AN patients were asked to indicate, without indicating frequency or severity, if they experienced the symptom at *diagnosis*, *after surgery/treatment*, and *at time of the survey*. They were also asked to confirm if they *never experienced* the symptoms (rather than leaving the symptom blank).

Questions about Symptoms by Survey Year

Year of survey	Never experienced	At diagnosis	After surgery/ treatment	At time of the survey
2007	not asked	yes	not asked	yes
2012	not asked	yes	yes	not asked
2014	yes	yes	yes	yes

Data received from surveys before 2014 were converted into the 2014 format using a set of conventions. For the 2007 data,

- If an ANA patient indicated that the symptom was experienced *at diagnosis* and/or *at time of the survey* with ***MORE*** frequency than once a month, they were recorded as having experienced the symptom at either or both times.

- If the patient indicated that he or she experienced the symptom at either diagnosis or at time of the survey *less than once a month* or did not complete the frequency or severity questions for the symptom, the patient was considered to have never experienced the symptom.

- No symptom data were recorded for *after surgery/treatment* because this timeframe was not included in the survey.

For the 2012 data,

- Patients who checked the symptom either *at diagnosis* or *after surgery/treatment* were recorded as having experienced the symptom at either or both times.

- If the patient ***did not check*** the symptom *at diagnosis* and *after surgery/treatment*, the patient was considered to have never experienced the symptom.

- No symptom data were recorded for *at time of the survey* because this timeframe was not included in the survey.

Information About All Participants and Their AN Tumor

Characteristic	Number of responses	Percentage of responses
Length of time since diagnosis		
< 1 year	493	11.8
1 – 2 years	909	21.8
3 – 4 years	747	17.9
5 – 10 years	1033	24.8
11 – 15 years	438	10.5
16 – 20 years	269	6.4
More than 20 years	254	6.1
No response	29	0.7
Gender		
Female	2591	62.1
Male	1572	37.7
No response	9	0.2
Ethnicity		
Caucasian	3903	93.6
Asian/Pacific Islander	99	2.4
Hispanic/Latino	80	1.9
African/American-American/W. Indian (Black)	41	1.0
Other	29	0.7
Native American	9	0.2
No response	11	0.3
Age when tumor was diagnosed		
12 – 20 years old	23	0.6
21 – 30 years old	171	4.1
31 – 40 years old	586	14.0
41 – 50 years old	1227	19.4
51 – 60 years old	1357	32.5
61 – 70 years old	663	15.9
71 – 80 years old	100	2.4
81 or older	8	0.2
No response	37	0.9

Tumor data	Number of responses	Percentage of responses
Period in which surgery/treatment occurred (*n* = 3,297)		
Prior to 1990	190	5.8
Between 1990 and 1999	547	16.6
Between 2000 and 2009	1825	55.4
Between 2010 and 2014	735	22.3
Tumor side		
Left	2087	50.0
Right	2069	49.6
Bilateral (Both sides)	15	0.4
No response	1	< 0.1
Size of tumor at diagnosis		
0.1 – 0.4 cm	336	8.1
0.5 – 1.0 cm	685	16.4
1.1 – 1.5 cm	749	17.9
1.6 – 2.0 cm	568	13.6
2.1 – 2.5 cm	556	13.3
2.6 – 3.0 cm	318	7.6
3.1 – 3.5 cm	260	6.2
3.6 – 4.0 cm	138	3.3
Larger than 4 cm	276	6.6
Don't know	289	6.9
Diagnostic tests used to diagnose tumor *(multiple responses possible)*		
MRI scan (Magnetic Resonance Image)	3961	94.9
Hearing Test (Audiogram)	2909	69.7
Balance Test (Electronystagmogram – ENG)	802	19.2
CT scan (Computerized Tomography)	764	18.3
Brainstem Auditory Evoked Response (BAER, BSER or ABR)	556	13.3
Don't Know	14	0.3

Treatment choice	Number of responses	Percentage of responses
Microsurgical resection (surgery/craniotomy)	2309	55.3
Watch and wait	827	19.8
Stereotactic radiosurgery (SSR) single session radiation treatment, such as Gamma Knife	638	15.3
Fractionated stereotactic radiosurgery/radiotherapy (FSR) radiation treatment performed in multiple sessions or fractions	398	9.5

Treatment

The database contains information on the first treatment individuals received for their AN tumor. The type of treatment received by AN patients in the database are in the table below and are compared by when data were received.

	Percentage of respondents reporting first treatment				
Treatment	**2014 *n* = 846**	**2012-2013 *n* = 1,394**	**2007–2008 *n* = 1,977**	**1998 *n* = 1,940**	**1983 *n* = 541**
Translabyrinthine approach	23	28	31	51	72
Retrosigmoid/sub-occipital approach	18	16	16	28	11
Middle fossa approach	8	7	8	6	3
Don’t know which surgical approach	2	2	2	0	14
Total microsurgical resection	**51**	**54**	**58**	**85**	**100**
Stereotactic radiosurgery, such as Gamma Knife (SSR)	17	18	14	NA	NA
Fractionated stereotactic radiosurgery (FSR)	12	10	8	NA	NA
Total radiosurgery/radiotherapy	**29**	**27**	**22**	**5**	**0**
Watch & wait	**20**	**20**	**20**	**4**	**0**
Total	**100**	**100**	**100**	**100**	**100**

Totals may not add correctly due to rounding

Symptoms Reported

The data reported in the following table includes responses to two questions on the surveys from 2007/2008 to 2014 from some or all of the 4,172 AN patient records in the registry. The AN patients were asked to indicate what symptoms they experienced at the time of their diagnosis *AND* what symptoms they were experiencing at the time of the survey.

However, the format in which the symptoms were asked or when the symptoms were introduced into the questionnaire varies. Therefore, the number of records used to calculate the percentage varied.

	At diagnosis		At time of surveys					
				Percentage of responses				
Symptom	Number of responses	% of responses	Number of responses	less than 1 year later	1-2 years later	3-5 years later	6-10 years later	more than 10 years later
Single-sided hearing loss or deafness	4217	87.4	846	66.7	69.1	71.3	72.5	76.4
Tinnitus (noise or ringing in the ear)	4040	69.5	2948	59.2	62.1	61.0	64.1	58.8
Vertigo (dizziness/balance disturbance)	4040	57.3	2816	37.3	36.4	31.8	33.0	28.0
Balance	846	46.6	846	51.5	48.2	47.4	55.2	54.0
Fullness in ear	4040	41.4	2948	27.6	28.1	25.3	26.7	23.9
Headaches	4040	29.8	2867	21.3	21.4	24.8	19.1	17.2
Facial weakness or paralysis	4217	28.7	846	9.1	17.3	20.0	21.1	30.8
Fatigue	4040	27.6	2948	26.5	28.1	28.6	28.9	24.3
Eye problems	4040	23.3	2674	22.8	22.6	24.4	25.5	25.4
Facial numbness	4040	20.7	2948	12.6	12.8	14.8	16.0	14.7
Memory difficulties	4040	19.9	2948	20.1	24.6	21.8	23.6	18.9
Depression	4040	17.7	2948	10.9	15.4	13.7	14.1	12.7
Change in smell or taste	4040	16.5	2948	14.6	14.6	16.1	15.7	11.6
Difficulty concentrating	4040	16.5	2948	16.3	19.0	17.7	17.6	12.0
Facial twitching	4040	14.9	2948	7.5	11.0	10.2	12.0	9.1
Difficulty swallowing	4040	9.4	2948	6.8	6.0	7.0	8.1	8.2

Single-Sided Hearing Loss

The following table contains the self-reported Gardner-Robertson class of 3,651 AN patients who reported single-sided hearing loss at the time of their diagnosis.

Self-reported Gardner-Robertson Class*	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100%	731	17.5	162	3.9
Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69%	925	22.2	319	7.6
Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49%	793	11.8	298	7.1
Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4%	357	8.6	295	7.1
Class 5 No Hearing = PTA 0; SD 0%	187	4.5	1856	44.5
Don't know	952	22.8	721	17.3
No response	6	0.1	0	0.0
Total	3651	100.0	3651	100.0

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

The following table contains information on the choices made by 3,750 AN patients receiving treatments or rehabilitation therapies to improve their hearing.

Options to improve hearing ***(multiple responses are possible)***	**Number of responses**	**Percentage of responses**
CROS hearing aid	290	7.9
Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite)	278	7.6
Behind-the-ear (BTE) hearing aid*	237	6.5
In-the-ear (ITE) hearing aid	167	4.6
BiCROS hearing aid	129	3.5
Device to amplify TV	126	3.5
In-the-canal (ITC) hearing aid	68	1.9
Device to amplify telephone	50	1.4
FM system or other amplifier (carried in pocket or placed on a table)	43	1.2
Direct audio input microphone	11	0.3
Completely-in-the-canal (CIC) hearing aid*	9	0.2
Cochlear implants*	6	0.2

* These strategies were not included on 2007/2008 survey. Percentage of responses is based on 1,914 responses after 2008.

Facial Weakness

The following table contains the self-reported House-Brackmann Grade of 371 AN patients who reported ***mild*** to ***complete facial paralysis*** at the time of their diagnosis.

Self-reported House-Brackmann Grade	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Grade I. Normal	NA	NA	58	15.6
Grade II. Mild	206	55.5	112	30.2*
Grade III. Moderate	52	14.0	80	21.6
Grade IV. Moderate severe	28	7.5	48	12.9
Grade V. Severe	19	5.1	15	4.0*
Grade VI. Complete paralysis	20	5.4	27	7.3
Don't Know	46	12.4	31	8.4

**results may be due to pooling responses across multiple survey versions*

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. The percentages in the table are based on the 1,193 AN patients who reported facial weakness at diagnosis.

Surgeries and treatments ***(multiple responses are possible)***	**Number of responses**	**Percentage of responses**
Surgery or treatment to correct facial weakness		
Electrical stimulation of the face	97	8.1
12-7 Transfer (transfer of the tongue nerve to the facial nerve)	86	7.1
Face lift - on the tumor side	42	3.5
Facial suspension or sling	33	2.8
Cross face nerve graft	23	1.9
Face lift - Both sides	11	0.9
Masseter muscle transposition	9	0.8
Free muscle transfer, transplanting muscle from other part of body*	3	0.5
Regional muscle transfer*	1	0.2
Surgery to improve eyelid position and/or function		
Gold weight in eyelid	252	21.1
Tarsorrhaphy	91	7.6
Lower eyelid repositioning	66	5.5
Brow elevation	52	4.4
Eyelid spring	42	3.5
Canthoplasty*	5	0.8
Tissue grafts and stents*	3	0.5

* These surgeries and treatments were not included on the 2007/2008 survey. Percentage of responses is based on 643 responses after 2008.

Post-Treatment

The table below contains the percentage of all AN patients 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	1133	27.2
Facial movement	539	12.9
Dizziness (vestibular rehabilitation)*	344	8.2
Psychological issues	271	6.5
Fall risk reduction*	131	3.1

* These treatments, physical therapy, or training were not included on the 2007/2008 survey. Percentage of responses is based on 2,195 responses after 2008.

The size of the AN tumor at diagnosis and at their last MRI is reported in the following table. However, AN patients were not asked to indicate the size of their tumor at their last MRI on the 2007/2008 survey. Information about the size of their tumor at the time of the survey was provided by almost 2,000 AN patients.

	At diagnosis		less than 1 year later*		1-2 years later*		3-5 years later*		6-10 years later*		more than 10 years later*	
Tumor size	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***
0.0 cm**	0	0.0	11	8.7	62	17.5	94	18.4	82	16.9	111	22.6
0.0 – 0.4 cm**	0	0.0	0	0.0	0	0.0	7	1.4	39	8.0	49	10.0
0.1 – 0.4 cm	348	8.3	56	44.4	69	19.4	100	19.5	64	13.2	51	10.4
0.5 – 1.0 cm	696	16.5	8	6.3	47	13.2	65	12.7	60	12.3	55	11.2
1.1 – 1.5 cm	756	17.9	14	11.1	51	14.4	76	14.8	70	14.4	26	5.3
1.6 – 2.0 cm	574	13.6	10	7.9	37	10.4	52	10.2	45	8.6	29	5.9
2.1 – 2.5 cm	558	13.2	4	3.2	16	4.5	26	5.1	27	5.6	29	5.9
2.6 – 3.0 cm	319	7.6	2	1.6	7	2.0	5	1.0	9	1.9	6	1.2
3.1 – 3.5 cm	260	6.2	1	0.8	2	0.6	3	0.6	3	0.6	3	0.6
3.6 – 4.0 cm	138	3.3	0	0.0	1	0.3	0	0.0	1	0.2	2	0.4
> 4.0 cm	277	6.6	1	0.8	4	1.1	4	0.8	3	0.6	3	0.6
Don't know	290	6.9	19	15.1	59	16.6	80	16.6	86	17.7	127	25.9
Total	4,216	100.0	126	6.4	355	18.0	512	26.0	486	24.7	491	24.9

*Size of tumor now (*n* = 1,970)
**these response options were included in the 2013 Follow-up survey and revised in 2014.

Quality of Life

Quality of life questions related to the respondents' employment, use of handicapped parking permits, their perceptions of their symptoms and quality of life since their diagnosis.

These questions were first asked in the 2012. The responses in the following table are based on responses from 2,334 AN patients.

Question	Number of responses	Percentage of responses
Employment		
After diagnosis, able to continue regular employment and/or activities (those who responded after 2008, *n* = 2,191)		
Yes	1915	87.4
No	276	12.6
If yes, still employed in same capacity or perform same activities today? (*n* = 1,915)		
Yes	1404	73.3
No	504	26.3
If no, why not? (*n* = 504)		
Became disabled	33	6.5
Quit to pursue another job or other interests	48	9.5
Retired	226	44.8
No answer	197	39.1
Handicapped parking permit		
Did you use a handicapped parking permit after your treatment? (those who received treatment/surgery and responded after 2008, *n* = 1,695)		
Yes	184	10.9
No	1511	89.1
If no, why did you not use the permit? (*n* = 1,511)		
I did not feel the need to use one.	1070	70.8
I did not know I qualified to use one.	395	26.1
No response	46	3.0

Respondents were asked to consider their symptoms and quality of life at diagnosis and today. The percentages in the next table are based on responses from 2,162 AN patients.

Quality of life	Percentage of respondents						
	Significantly better	Moderately better	Somewhat better	No significant change	Somewhat worse	Moderately worse	Significantly worse
Considering your symptoms at initial onset, how do you consider your symptoms now?	22.4	9.0	9.2	24.0	16.8	9.4	9.2
Considering your quality of life at initial onset, how do you consider your quality of life now?	15.0	8.6	7.4	33.4	21.4	9.1	5.1

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 four parts of the report by treatment modality (microsurgery, SSR, and FSR) or watch and wait contain information reported by AN patients.

MICROSURGERY

The first section of the report on microsurgery is based on the 2,309 AN patients who 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	845	83.4
Personal choice	581	57.4
Because I know someone who had this management option	101	10.0
Because of my insurance situation at the time of the decision	53	5.2
Because of my employment situation at the time of the decision	40	3.9
Because of concerns about my financial situation	22	2.2
Because I know someone who wished he/she had this management option	12	1.2
Because of concerns with my social support system	10	1.0

*These items were not included in the survey until 2012. The percentages are based on the responses of 1,013 AN patients.

Period in which microsurgery occurred	Number of responses	Percentage of responses
Prior to 1990	184	8.0
Between 1990 and 1999	473	20.5
Between 2000 and 2009	1176	50.9
Between 2010 and 2014	444	19.2
No response	32	1.4

Surgical approach	Number of responses	Percentage of responses
Translabyrinthine approach	1186	51.4
Retrosigmoid/sub-occipital approach	695	30.1
Middle fossa approach	319	13.8
Don't know/no response	109	4.7

Length of hospitalization	Number of responses	Percentage of responses
1 day	18	0.8
2 days	26	1.1
3 days	301	13.0
4 days	198	8.6
5 days	883	38.2
6 days	120	5.2
7 days	92	4.0
8 days	321	13.9
9 days	13	0.6
10 days	42	1.8
More than 10 days	283	12.3
No response	12	0.5

Recovery

Time to recover fully from treatment	Number of responses	Percentage of responses*
Approximately 1 week	4	0.4
Approximately 2 weeks	9	0.9
Approximately 1 month	149	14.7
Approximately 3 months	266	26.2
Approximately 6 months	199	19.6
Approximately 12 months	110	10.8
More than 12 months	274	27.1
No response	2	0.2

* This question was not included in the survey until 2012. The percentages are based on the responses of 1,013 AN patients.

Symptoms Reported

The data reported in the following table includes responses to two questions on the surveys from 2007/2008 to 2014 from some or all of the 2,309 AN patient records in the registry that have microsurgery as their treatment modality. The AN patients were asked to indicate what symptoms they experienced at the time of their diagnosis *AND* what symptoms they were experiencing at the time of the survey.

However, the format in which the symptoms were asked or when the symptoms were introduced into the questionnaire varies. Therefore, the number of records used to calculate the percentage varied.

	At diagnosis		At time of surveys					
				Percentage of responses				
Symptom	**Number of responses**	**% of responses**	**Number of responses**	**less than 1 year later**	**1-2 years later**	**3-5 years later**	**6-10 years later**	**more than 10 years later**
Single-sided hearing loss or deafness	2309	89.6	431	71.4	73.2	76.6	77.5	78.0
Tinnitus (noise or ringing in the ear)	2207	66.2	1645	61.3	65.1	60.2	64.3	56.9
Vertigo (dizziness/balance disturbance)	2207	58.1	1574	41.7	35.7	32.9	38.4	28.5
Balance	431	42.9	431	71.4	51.8	50.5	61.8	57.7
Facial weakness or paralysis	2309	40.4	431	42.9	33.9	32.4	37.1	38.1
Fullness in ear	2207	38.7	1645	29.2	23.5	23.6	25.7	21.0
Headaches	2207	32.7	1603	26.9	21.9	27.9	21.3	18.4
Fatigue	2207	27.9	1645	30.2	27.7	28.8	34.9	25.2
Eye problems	2207	26.1	1502	27.4	20.6	27.4	31.0	27.7
Facial numbness	2207	23.1	1645	15.1	14.7	15.3	19.4	15.4
Memory difficulties	2207	20.4	1645	20.8	26.1	22.6	27.4	19.7
Change in smell or taste	2207	18.6	1645	16.0	16.4	17.0	18.0	12.9
Depression	2207	18.4	1645	13.2	13.9	14.5	19.2	12.9
Difficulty concentrating	2207	16.7	1645	19.8	20.2	17.5	22.0	12.1
Facial twitching	2207	15.7	1645	7.5	10.9	9.5	13.4	8.3
Difficulty swallowing	2207	9.4	1645	5.7	4.6	7.8	10.3	8.5

Single-Sided Hearing Loss

The following table contains the self-reported Gardner-Robertson class of 939 AN patients who underwent microsurgery via the retrosigmoid/sub-occipital or middle fossa approaches and who reported single-sided hearing loss at the time of their diagnosis. 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.

	At diagnosis		At time of surveys	
Self-reported Gardner-Robertson Class*	**Number of responses**	**Percentage of responses**	**Number of responses**	**Percentage of responses**
Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100%	266	28.3	49	5.2
Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69%	272	29.0	77	8.2
Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49%	94	10.0	54	5.8
Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4%	51	5.4	66	7.0
Class 5 No Hearing = PTA 0; SD 0%	36	3.8	564	60.1
Don't Know	320	23.4	129	13.7

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

Options to improve hearing ***(multiple responses are possible)***	**Number of responses**	**Percentage of responses†**
CROS hearing aid	217	10.0
Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite)	216	10.0
Behind-the-ear (BTE) hearing aid*	79	7.8
BiCROS hearing aid	82	3.8
In-the-ear (ITE) hearing aid	80	3.7
Device to amplify TV	64	3.0
In-the-canal (ITC) hearing aid	39	1.8
Device to amplify telephone	32	1.5
FM system or other amplifier (carried in pocket or placed on a table)	29	1.3
Direct audio input microphone	5	0.2
Completely-in-the-canal (CIC) hearing aid*	4	0.4
Cochlear implants*	1	0.1

† The percentages of most strategies are based on 2,172 responses
* These strategies were not included on the 2007/2008 survey. Percentage of responses is based on 1,016 responses.

Facial Weakness

The following table contains the self-reported House-Brackmann Grade of 277 AN patients who reported ***mild*** to ***complete facial paralysis*** at the time of their diagnosis.

Self-reported House-Brackmann Grade	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Grade I. Normal	0	0.0	38	13.7
Grade II. Mild	143	51.6	74	26.7*
Grade III. Moderate	40	14.4	63	22.7
Grade IV. Moderate severe	23	8.3	38	13.7
Grade V. Severe	16	5.8	15	5.4
Grade VI. Complete paralysis	20	7.2	27	9.7
Don't know	35	12.6	22	7.9

**results may be due to pooling responses across multiple survey versions*

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. The percentages listed are of the 932 AN patients 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 ***(multiple responses are possible)***	**Number of responses**	**Percentage of responses†**
Surgery or treatment to correct facial weakness		
Electrical stimulation of the face	87	9.3
12-7 Transfer (transfer of the tongue nerve to the facial nerve)	83	8.9
Face lift - on the tumor side	35	3.8
Facial suspension or sling	27	2.9
Cross face nerve graft	21	2.3
Face lift - Both sides	11	1.2
Masseter muscle transposition	7	0.8
Free muscle transfer, transplanting muscle from other part of body*	3	0.6
Regional muscle transfer*	0	0.0
Surgery to improve eyelid position and/or function		
Gold weight in eyelid	234	25.1
Tarsorrhaphy	88	9.4
Lower eyelid repositioning	59	6.3
Brow elevation	44	4.7
Eyelid spring	37	4.0
Canthoplasty*	5	1.0
Tissue grafts and stents*	3	0.6

† The percentages of most strategies are based on 932 responses

* These surgeries and treatments were not included on the 2007/2008 survey. Percentage of responses is based on 479 responses after 2008.

Post-Treatment

This table contains the number of years in which the AN patient experienced any tumor re-growth or recurrence since surgery.

Tumor re-growth first observed	Number of responses	Percentage of responses
Less than 1 year after surgery	18	20.7
1-2 years after surgery	13	14.9
2-3 years after surgery	8	9.2
3-4 years after surgery	4	4.6
More than 4 years after surgery	35	40.2
No response	9	10.3
Total respondents reporting re-growth after surgery	87	100.0

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 size of the AN tumor at diagnosis and at their last MRI is reported in the following table. However, AN patients were not asked to indicate the size of their tumor at their last MRI on the 2007/2008 survey. Information about the size of their tumor at the time of the survey was provided by 655 AN patients who reported microsurgery as their treatment modality.

	At diagnosis		**less than 1 year later***		**1-2 years later***		**3-5 years later***		**6-10 years later***		**more than 10 years later***	
Tumor size	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***
0.0 cm**			4	44.4	25	37.9	60	42.3	55	34.8	98	35.0
0.0 – 0.4 cm**			0	0.0	0	0.0	6	4.2	28	17.7	40	14.3
0.1 – 0.4 cm	93	4.0	1	11.1	7	10.6	21	14.8	13	8.2	15	5.4
0.5 – 1.0 cm	267	11.6	0	0.0	4	6.1	11	7.7	10	6.3	17	6.1
1.1 – 1.5 cm	346	15.0	1	11.1	4	6.1	6	4.2	4	2.5	10	3.6
1.6 – 2.0 cm	287	12.4	0	0.0	4	6.1	7	4.9	2	1.3	4	1.4
2.1 – 2.5 cm	364	15.8	0	0.0	1	1.5	2	1.4	5	3.2	14	5.0
2.6 – 3.0 cm	230	10.0	0	0.0	0	0.0	1	0.7	0	0.0	5	1.8
3.1 – 3.5 cm	209	9.1	0	0.0	0	0.0	0	0.0	2	1.3	2	.07
3.6 – 4.0 cm	109	4.7	0	0.0	1	1.5	0	0.0	1	0.6	2	0.7
> 4.0 cm	223	9.7	1	11.1	0	0.0	1	0.7	0	0.0	3	1.1
Don't know	181	7.8	2	22.2	20	30.3	27	19.0	38	24.1	70	25.0
Total	2309	100.0	9	1.4	66	10.1	142	21.7	158	24.1	280	42.7

*Size of tumor now (n = 655)

**these response options were included in the 2013 Follow-up survey and revised in 2014.

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	894	38.7
Dizziness (vestibular rehabilitation)*	252	21.7
Facial movement	488	21.1
Psychological issues	205	8.9
Fall risk reduction*	99	8.5

† The percentages of most strategies are based on 2,309 responses

* These treatments, physical therapy, or training were not included on the 2007/2008 survey. Percentage of responses is based on 1,016 responses after 2008.

Quality of Life

Quality of life questions related to the respondents' employment, use of handicapped parking permits, their perceptions of their symptoms and quality of life since their diagnosis.

These questions were first asked in the 2012. The responses in the following table are based on responses from 1,160 AN patients.

Questions	Number of responses	Percentage of responses
Employment		
After diagnosis, able to continue regular employment and/or activities		
Yes	974	84.0
No	183	15.8
No answer	3	0.3
If yes, still employed in same capacity or perform same activities today? (*n* = 974)		
Yes	686	70.4
No	285	29.3
No answer	3	0.3
If no, why not? (*n* = 285)		
Became disabled	22	7.7
Quit to pursue another job or other interests	36	12.6
Retired	125	43.9
No answer	102	35.8
Handicapped parking permit		
Did you use a handicapped parking permit after your treatment?		
Yes	122	12.0
No	891	88.0
No answer	0	0.0
If no, why did you not use the permit? (*n* = 891)		
I did not feel the need to use one.	608	68.2
I did not know I qualified to use one.	269	30.2
No answer	14	1.6

These questions were first asked in the 2012. The responses in the following table are based on responses from 1,160 AN patients.

Question	Percentage of respondents						
	Significantly better	Moderately better	Somewhat better	No significant change	Somewhat worse	Moderately worse	Significantly worse
Considering your symptoms at initial onset, how do you consider your symptoms now?	31.6	10.4	9.2	14.2	12.85	9.8	12.0
Considering your quality of life at initial onset, how do you consider your quality of life now?	19.8	10.5	7.7	22.1	22.7	10.9	6.2

SINGLE DOSE STEREOTACTIC RADIOSURGERY (SSR)

The first section of the report on single dose stereotactic radiosurgery is based on 638 AN patients who reported 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
Personal choice	224	72.3
Followed my physician's advice	195	63.5
Because of my employment situation at the time of the decision	30	9.7
Because I know someone who had this management option	29	9.4
Because of concerns with my social support system	17	5.5
Because I know someone who wished he/she had this management option	10	3.2
Because of my insurance situation at the time of the decision	9	2.9
Because of concerns about my financial situation	6	1.9

*These items were not included in the survey until 2012. The percentages are based on the responses of 331 AN patients.

Period in which SSR occurred	Number of responses	Percentage of responses
Prior to 1990	3	0.5
Between 1990 and 1999	53	8.3
Between 2000 and 2009	400	62.7
Between 2010 and 2014	171	26.8
No response/Don't know	11	1.7

Description of Radiation Treatment(s)

The next table contains the type of equipment used duration of treatment and the marginal radiation dose the 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)	253	86.6
Don't know what type of delivery system was used	21	7.2
Linear accelerator (LINAC – various manufacturers)	15	5.1
Proton accelerator (Proton Beam radiation treatment)	3	1.0
Marginal dose of radiation received		
Less than 10 Gy	7	1.1
10.0 – 10.9 Gy	4	0.6
11.0 – 11.9 Gy	19	3.0
12.0 – 12.9 Gy	87	13.6
13.0 – 13.9 Gy	35	5.5
14.0 – 14.9 Gy	8	1.3
15.0 – 15.9 Gy	6	0.9
16.0 – 16.9 Gy	7	1.31
Greater than 16.9 Gy	11	1.7
Don't Know	450	70.5
No response	4	0.6

* This question was not asked in 2007/2008. The percentages are based on 292 responses.

Recovery

Time to recover fully from SSR treatment	Number of responses	Percentage of responses
Approximately 1 week	173	55.8
Approximately 2 weeks	31	10.0
Approximately 1 month	26	7.4
Approximately 3 months	9	2.9
Approximately 6 months	21	6.8
Approximately 12 months	8	2.6
More than 12 months	45	14.5

* These items were not included in the survey until 2012. The percentages are based on the responses of 310 AN patients.

Symptoms Reported

The data reported in the following table includes responses to two questions on the surveys from 2007/2008 to 2014 from some or all of the 638 AN patient records in the registry that have SSR as their treatment modality. The AN patients were asked to indicate what symptoms they experienced at the time of their diagnosis *AND* what symptoms they were experiencing at the time of the survey.

However, the format in which the symptoms were asked or when the symptoms were introduced into the questionnaire varies. Therefore, the number of records used to calculate the percentage varied.

	At diagnosis		At time of surveys					
				Percentage of responses				
Symptom	Number of responses	% of responses	Number of responses	less than 1 year later	1-2 years later	3-5 years later	6-10 years later	more than 10 years later
Single-sided hearing loss or deafness	638	90.6	148	100.0	72.4	67.5	78.4	73.2
Tinnitus (noise or ringing in the ear)	609	71.8	449	59.0	64.1	57.6	59.6	59.4
Vertigo (dizziness/balance disturbance)	609	57.3	429	34.2	42.0	28.8	28.3	31.2
Balance	148	52.7	148	100.0	62.1	40.0	56.8	51.2
Fullness in ear	609	44.3	449	28.2	37.0	28.8	27.9	32.3
Fatigue	609	29.9	449	25.6	30.4	32.2	24.0	24.0
Headaches	609	26.7	436	29.7	23.9	20.2	11.7	16.0
Eye problems	609	22.7	394	25.6	23.9	24.6	17.7	24.3
Memory difficulties	609	21.3	449	23.1	28.3	26.3	19.2	20.8
Facial weakness or paralysis	638	20.7	148	0.0	10.3	15.0	13.5	22.0
Facial numbness	609	20.5	449	15.4	10.9	16.1	13.5	17.7
Difficulty concentrating	609	17.9	449	12.8	22.8	20.3	9.6	14.6
Depression	609	16.6	449	7.7	18.5	13.6	6.7	10.4
Facial twitching	609	16.6	449	12.8	8.7	10.2	10.6	14.6
Change in smell or taste	609	14.4	449	17.9	12.0	14.4	11.5	10.4
Difficulty swallowing	609	10.0	449	7.7	8.7	5.9	3.8	7.3

Single-Sided Hearing Loss

The following tables contain the self-reported Gardner-Robertson Class of 578 AN patients who underwent SSR and reported single-sided hearing loss or deafness at the time of their diagnosis. The strategies these individuals used to improve their hearing are also reported.

Self-reported Gardner-Robertson Class*	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100%	102	17.6	14	2.4
Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69%	154	26.6	64	11.1
Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49%	79	13.7	83	14.4
Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4%	68	11.8	100	17.3
Class 5 No Hearing = PTA 0; SD 0%	25	4.3	170	29.4
Don't Know	149	25.8	146	25.3
No response	1	0.2	1	0.2

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

Options to improve hearing	Number of responses	Percentage of responses
Behind-the-ear (BTE) hearing aid*	54	9.3
In-the-ear (ITE) hearing aid	39	6.7
Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite)	32	5.5
CROS hearing aid	32	5.5
Device to amplify TV	25	4.3
BiCROS hearing aid	21	3.6
Device to amplify telephone	11	1.9
In-the-canal (ITC) hearing aid	11	1.9
FM system or other amplifier (carried in pocket or placed on a table)	8	1.4
Completely-in-the-canal (CIC) hearing aid*	2	0.6
Cochlear implants*	2	0.6
Direct audio input microphone	2	0.3

* These strategies were not included on the 2007/2008 survey. Percentage of responses is based on 339 responses.

Facial Weakness

The following table contains the self-reported House-Brackmann Grade of 42 AN patients who reported ***mild*** to ***complete facial paralysis*** at the time of their diagnosis.

Respondents self-reported House-Brackmann Grade	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Grade I. Normal	0	0.0	10	23.8*
Grade II. Mild	30	71.4	16	38.1*
Grade III. Moderate	7	16.7	8	19.0
Grade IV. Moderate severe	1	2.4	7	16.7*
Grade V. Severe	2	1.5	0	0.0
Grade VI. Complete paralysis	0	0.0	0	0.0
No response	2	4.8	1	2.4

**results may be due to pooling responses across multiple survey versions*

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 ***(multiple responses are possible)***	**Number of responses**	**Percentage of responses†**
Surgery or treatment to correct facial weakness		
Electrical stimulation of the face	9	6.8
Facial suspension or sling	4	3.0
Face lift - on the tumor side	3	2.3
12-7 Transfer (transfer of the tongue nerve to the facial nerve)	2	1.5
Cross face nerve graft	2	1.5
Masseter muscle transposition	2	1.5
Regional muscle transfer*	1	1.1
Face lift - Both sides	0	0.0
Free muscle transfer, transplanting muscle from other part of body*	0	0.0
Surgery to improve eyelid position and/or function		
Gold weight in eyelid	9	6.8
Brow elevation	5	3.8
Eyelid spring	4	3.0
Lower eyelid repositioning	4	3.0
Canthoplasty*	0	0.0
Tarsorrhaphy	0	0.0
Tissue grafts and stents*	0	0.0

† The percentages of most strategies are based on 132 responses from AN patients who reported facial weakness

* These surgeries and treatments were not included on the 2007/2008 survey. Percentage of responses is based on 90 responses after 2008.

Post-Treatment

The size of the AN tumor at diagnosis and at their last MRI is reported in the following table. However, AN patients were not asked to indicate the size of their tumor at their last MRI on the 2007/2008 survey. Information about the size of their tumor at the time of the survey was provided by 568 AN patients who reported SSR as their treatment modality.

	At diagnosis		**less than 1 year later***		**1-2 years later***		**3-5 years later***		**6-10 years later***		**more than 10 years later***	
Tumor size	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***
0.0 cm**			0	0.0	1	0.8	0	0.0	2	1.6	1	0.9
0.0 – 0.4 cm**			0	0.0	0	0.0	0	0.0	0	0.0	2	1.8
0.1 – 0.4 cm	38	6.0	30	65.2	27	22.3	44	27.5	22	17.2	19	16.8
0.5 – 1.0 cm	111	17.4	2	4.3	17	14.0	18	11.3	13	10.2	20	17.7
1.1 – 1.5 cm	149	23.4	4	8.7	17	14.0	33	20.6	27	21.1	6	5.3
1.6 – 2.0 cm	107	16.8	2	4.3	13	10.7	20	12.5	19	14.8	12	10.6
2.1 – 2.5 cm	87	13.6	1	2.2	10	8.3	11	6.9	9	7.0	11	9.7
2.6 – 3.0 cm	44	6.9	0	0.0	6	5.0	4	2.5	6	4.7	1	0.9
3.1 – 3.5 cm	23	3.6	0	0.0	1	0.8	1	0.6	0	0.0	1	0.9
3.6 – 4.0 cm	19	3.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
> 4.0 cm	28	4.4	0	0.0	0	0.0	3	1.9	0	0.0	0	0.0
Don't know	32	5.0	7	15.2	29	24.0	26	16.3	30	23.4	40	35.4
Total	638	100.0	46	8.1	121	21.3	160	28.2	128	22.5	113	19.9

*Size of tumor now (n = 568)

**These response options were included in the 2013 Follow-up survey and revised in 2014.

Change in tumor size and enhancement characteristics since treatment	Number of responses	Percentage of responses
Experience any change in tumor size since treatment (*n* = 381)		
Yes, it has either grown or shrunk	6	1.6
No	375	98.4
Evidence of central death of the tumor (*n* = 310)		
Yes	120	38.7
No	55	17.7
Don't know	135	43.5
Has the brightness with which the tumor *lights up* on MRI film changed since your treatment? (*n* = 638)		
Yes	174	27.3
No	281	44.0
Don't know/Not sure	183	28.7
If yes, What change in enhancement characteristics (brightness) have you experienced?		
The tumor appears brighter now than it did upon diagnosis	32	18.4
The tumor appears darker now than it did upon diagnosis	119	68.4
Don't know/Not sure	23	13.2

Treatment, physical therapy or training to improve	Number of responses	Percentage of responses
Balance	133	20.8
Dizziness (vestibular rehabilitation)*	42	11.5
Facial movement	38	6.0
Psychological issues	31	4.9
Fall risk reduction*	16	4.4

* These treatments, physical therapy, or training were not included on the 2007/2008 survey. Percentage of responses is based on 365 responses after 2008.

Quality of Life

Quality of life questions related to the respondents' employment, use of handicapped parking permits, their perceptions of their symptoms and quality of life since their diagnosis.

These questions were first asked in the 2012. The responses in the following table are based on responses from 365 AN patients.

Question	Number of responses	Percentage of responses
Employment		
After diagnosis, able to continue regular employment and/or activities		
Yes	331	90.7
No	34	9.3
If yes, still employed in same capacity or perform same activities today? (*n* = 331)		
Yes	243	73.4
No	88	26.6
If no, why not? (*n* = 88)		
Became disabled	5	5.7
Quit to pursue another job or other interests	6	6.8
Retired	37	42.0
No response	40	45.5
Handicapped parking permit		
Did you use a handicapped parking permit after your treatment? (*n* = 310)		
Yes	39	12.6
No	271	87.4
If no, why did you not use the permit? (*n* = 271)		
I did not feel the need to use one.	202	74.5
I did not know I qualified to use one.	62	22.9
No answer	7	2.6

These questions were first asked in the 2012. The responses in the following table are based on responses from 365 AN patients.

Question	Percentage of respondents						
	Significantly better	Moderately better	Somewhat better	No significant change	Somewhat worse	Moderately worse	Significantly worse
Considering your symptoms at initial onset, how do you consider your symptoms now?	14.8	8.8	12.1	28.8	15.4	11.5	8.5
Considering your quality of life at initial onset, how do you consider your quality of life now?	10.8	9.4	8.3	38.8	18.6	8.9	5.3

FRACTIONATED STEREOTACTIC RADIOSURGERY (FSR)

The first section of the report on fractionated stereotactic radiosurgery (FSR) is based on 398 AN patients who reported that their tumor was treated using SSR. The following tables contain a description of the respondents and their experiences with SSR.

Information About FSR Patients and Their AN Tumor

Reasons to choose FSR	Number of responses	Percentage of responses*
Personal choice	159	78.3
Followed my physician's advice	114	56.2
Because I know someone who had this management option	25	12.3
Because of my employment situation at the time of the decision	23	11.3
Because of concerns with my social support system	17	8.4
Because I know someone who wished he/she had this management option	7	3.4
Because of concerns about my financial situation	7	3.4
Because of my insurance situation at the time of the decision	6	3.0

* These items were not included in the survey until 2012. The percentages are based on the responses of 203 AN patients.

Period in which FSR occurred	Number of responses	Percentage of responses
Prior to 1990	3	0.8
Between 1991 and 1999	21	5.3
Between 2000 and 2009	249	62.6
Between 2010 and 2014	120	30.2
No response/don't know	5	1.3

Treatment issues	Number of responses	Percentage of responses
Duration of treatment		
Less than one week	203	51.0
Between 1 and 2 weeks	58	14.6
Between 2 and 3 weeks	5	1.3
Between 3 and 4 weeks	14	3.5
Between 4 and 5 weeks	41	10.3
More than 5 weeks	76	19.1
No response	1	0.3
Number of fractions (treatments) received		
Fewer than 5 fractions	183	46.0
Between 5 and 10 fractions	91	22.9
Between 11 and 15 fractions	2	0.5
Between 16 and 20 fractions	2	0.5
Between 21 and 25 fractions	20	5.1
Between 26 and 30 fractions	84	21.1
More than 30 fractions	10	2.5
Don't know	3	0.8
No response	3	.08
Equipment used to deliver treatment(s)*		
CyberKnife (Accuray Incorporated)	110	54.2
Linear accelerator (LINAC - various manufacturers)	45	22.2
Don't know what type of delivery system was used	25	12.3
Proton accelerator (Proton Beam radiation treatment)	10	4.9
Other – Gamma Knife, Novalis, Trilogy, Varian TrueBeam	0	0.0
No response	13	6.4

* These items were not included in the survey until 2012. The percentages are based on the responses of 203 AN patients.

Recovery

Time to recover fully from treatment*	Number of responses	Percentage of responses
Approximately 1 week	77	37.9
Approximately 2 weeks	24	11.8
Approximately 1 month	22	10.8
Approximately 3 months	11	5.4
Approximately 6 months	13	6.4
Approximately 12 months	16	7.9
More than 12 months	40	19.7

* These items were not included in the survey until 2012. The percentages are based on the responses of 203 AN patients.

Symptoms Reported

The data reported in the following table includes responses to two questions on the surveys from 2007/2008 to 2014 from some or all of the 398 AN patient records in the registry that have microsurgery as their treatment modality. The AN patients were asked to indicate what symptoms they experienced at the time of their diagnosis *AND* what symptoms they were experiencing at the time of the survey.

However, the format in which the symptoms were asked or when the symptoms were introduced into the questionnaire varies. Therefore, the number of records used to calculate the percentage varied.

	At diagnosis		At time of surveys					
				Percentage of responses				
Symptom	**Number of responses**	**% of responses**	**Number of responses**	**less than 1 year later**	**1-2 years later**	**3-5 years later**	**6-10 years later**	**more than 10 years later**
Single-sided hearing loss or deafness	398	93.0	99	50.0	77.8	79.3	77.8	78.3
Tinnitus (noise or ringing in the ear)	387	79.1	285	55.6	54.4	69.2	78.3	67.5
Vertigo (dizziness/balance disturbance)	387	59.9	273	27.8	34.0	37.3	31.1	22.5
Balance	99	54.5	99	50.0	38.9	58.6	51.9	39.1
Fullness in ear	387	48.1	285	22.2	24.6	23.1	30.4	27.5
Fatigue	387	31.8	285	22.2	29.8	28.2	18.5	15.0
Headaches	387	31.0	277	22.2	20.4	21.3	18.9	7.5
Memory difficulties	387	22.0	285	16.7	24.6	22.8	15.0	15.0
Facial numbness	387	20.9	285	5.6	14.0	14.1	9.8	7.5
Eye problems	387	19.6	253	27.8	22.8	27.3	23.6	20.7
Depression	387	19.4	285	5.6	15.8	15.4	6.5	7.5
Facial twitching	387	18.6	285	0.0	8.8	15.4	15.2	10.0
Change in smell or taste	387	17.8	285	0.0	15.8	24.4	20.7	5.0
Difficulty concentrating	387	17.6	285	11.1	17.5	19.2	18.5	5.0
Facial weakness or paralysis	398	15.6	285	0.0	5.6	6.9	7.4	17.4
Difficulty swallowing	387	10.6	285	5.6	7.0	9.0	6.5	7.5

Single-Sided Hearing Loss

The following table contains the self-reported Gardner-Robertson Class of 370 AN patients who reported single-sided hearing loss or deafness at the time of their diagnosis and underwent FSR.

Self-reported Gardner-Robertson Class*	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100%	85	23.0	24	6.5
Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69%	109	29.5	60	16.2
Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49%	51	13.8	75	20.3
Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4%	21	5.7	65	17.6
Class 5 No Hearing = PTA 0; SD 0%	11	3.0	59	15.9
Don't Know	93	25.1	87	23.5

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

Options to improve hearing	Number of responses	Percentage of responses†
Behind-the-ear (BTE) hearing aid*	49	22.3
In-the-ear (ITE) hearing aid	29	7.8
Device to amplify TV	28	7.6
CROS hearing aid	16	4.3
BiCROS hearing aid	12	3.2
In-the-canal (ITC) hearing aid	9	2.4
Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite)	8	2.2
Completely-in-the-canal (CIC) hearing aid*	3	1.4
Cochlear implants*	2	0.9
FM system or other amplifier (carried in pocket or placed on a table)	2	0.5
Device to amplify telephone	2	0.5
Direct audio input microphone	2	0.5

† The percentages of most strategies are based on 370 responses

* These strategies were not included on the 2007/2008 survey. Percentage of responses is based on 220 responses after 2008.

Facial Weakness

The following table contains the self-reported House-Brackmann Grade of 27 AN patients who reported ***mild*** to ***complete facial paralysis*** at the time of their diagnosis.

Self-reported House-Brackmann Grade	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Grade I. Normal	0	0.0	6	22.2*
Grade II. Mild	19	70.4	12	44.4*
Grade III. Moderate	3	11.1	4	14.8*
Grade IV. Moderate severe	1	3.7	2	7.4*
Grade V. Severe	1	3.7	0	0.0
Grade VI. Complete paralysis	0	0.0	0	0.0
Don't know	3	11.1	3	11.1

**results may be due to pooling responses across multiple survey versions*

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		
Face lift (tumor side)	4	6.5
Facial suspension or sling	2	3.2
Electrical stimulation of the face	1	1.6
12-7 Anastomosis (transfer of the tongue nerve to the facial nerve, also called Hypoglossal-Facial Anastomosis)	0	0.0
Cross face nerve graft	0	0.0
Face lift (both sides)	0	0.0
Masseter muscle transposition	0	0.0
Regional muscle transfer*	0	0.0
Free muscle transfer, transplanting muscle from other part of body*	0	0.0
Surgery to improve eyelid position and/or function		
Gold weight in eyelid	9	14.5
Brow elevation	3	4.8
Lower eyelid repositioning	3	4.8
Tarsorrhaphy	2	3.2
Eyelid spring	1	1.6
Canthoplasty*	0	0.0
Tissue grafts and stents*	0	0.0

† The percentages of most strategies are based on 62 responses from AN patients who reported facial weakness

* These surgeries and treatments were not included on the 2007/2008 survey. Percentage of responses is based on 50 responses after 2008.

Post-Treatment

The size of the AN tumor at diagnosis and at their last MRI is reported in the following table. However, AN patients were not asked to indicate the size of their tumor at their last MRI on the 2007/2008 survey. Information about the size of their tumor at the time of the survey was provided by 352 AN patients who reported SSR as their treatment modality.

	At diagnosis		less than 1 year later*		1-2 years later*		3-5 years later*		6-10 years later*		more than 10 years later*	
Tumor size	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***
0.0 cm**			0	0.0	11	14.5	18	18.0	11	10.4	8	15.7
0.0 – 0.4 cm**			0	0.0	0	0.0	0	0.0	3	2.8	1	2.0
0.1 – 0.4 cm	29	7.3	14	73.7	26	34.2	24	24.0	20	18.9	8	15.7
0.5 – 1.0 cm	64	16.1	1	5.3	6	7.9	8	8.0	13	12.3	7	13.7
1.1 – 1.5 cm	80	20.1	0	0.0	11	14.5	15	15.0	20	18.9	5	9.8
1.6 – 2.0 cm	93	23.4	1	5.3	12	15.8	15	15.0	12	11.3	10	19.6
2.1 – 2.5 cm	63	15.8	0	0.0	4	5.3	6	6.0	10	9.4	2	3.9
2.6 – 3.0 cm	25	6.3	0	0.0	1	1.3	0	0.0	2	1.9	0	0.0
3.1 – 3.5 cm	17	4.3	1	5.3	1	1.3	1	1.0	1	0.9	0	0.0
3.6 – 4.0 cm	4	14.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
> 4.0 cm	8	2.0	0	0.0	0	0.0	0	0.0	2	1.9	0	0.0
Don't know	15	3.8	2	10.5	4	5.3	13	13.0	12	11.3	10	19.6
Total	398	100.0	19	5.4	76	21.6	100	28.4	106	30.1	51	14.5

*Size of tumor now (*n* = 352)
**These response options were included in the 2013 Follow-up survey and revised in 2014.

Treatment, physical therapy or training to improve	Number of responses	Percentage of responses
Balance	80	20.1
Dizziness (vestibular rehabilitation)*	36	15.3
Psychological issues	29	7.3
Fall risk reduction*	11	4.7
Facial movement	13	3.3

* These treatments, physical therapy, or training were not included on the 2007/2008 survey. Percentage of responses is based on 236 responses after 2008.

Change in tumor size and enhancement characteristics since treatment	**Number of responses**	**Percentage of responses**
Experience any change in tumor size since treatment (*n* = 231)		
Yes, it has either grown or shrunk	5	2.2
No	226	97.8
Evidence of central death of the tumor (*n* = 203)		
Yes	102	50.2
No	36	17.7
Don't know	65	32.0
Has the brightness with which the tumor "lights up" on MRI film changed since your treatment? (*n* = 398)		
Yes	123	30.9
No	148	37.2
Don't know/Not sure	127	32.0
If yes, What change in enhancement characteristics (brightness) have you experienced?		
The tumor appears brighter now than it did upon diagnosis	16	13.0
The tumor appears darker now than it did upon diagnosis	95	77.2
Don't know/Not sure	12	9.8

Quality of Life

Quality of life questions related to the respondents' employment, use of handicapped parking permits, their perceptions of their symptoms and quality of life since their diagnosis.

These questions were first asked in the 2012. The responses in the following table are based on responses from 235 AN patients.

Question	Number of responses	Percentage of responses
Employment		
After diagnosis, able to continue regular employment and/or activities		
Yes	203	86.4
No	32	13.6
If yes, still employed in same capacity or perform same activities today? (*n* = 203)		
Yes	151	74.4
No	50	24.6
No response	2	1.0
If no, why not? (*n* = 50)		
Became disabled	3	6.0
Quit to pursue another job or other interests	3	6.0
Retired	26	52.0
No response	18	36.0
Handicapped parking permit		
Did you use a handicapped parking permit after your treatment?		
Yes	15	7.4
No	189	92.6
If no, why did you not use the permit? (*n* = 189)		
I did not feel the need to use one.	142	75.1
I did not know I qualified to use one.	43	22.8
No response	4	2.1

These questions were first asked in the 2012. The responses in the following table are based on responses from 236 AN patients.

Question	Percentage of respondents						
	Significantly better	**Moderately better**	**Somewhat better**	**No significant change**	**Somewhat worse**	**Moderately worse**	**Significantly worse**
Considering your symptoms at initial onset, how do you consider your symptoms now?	16.1	10.9	13.9	25.2	18.7	8.7	6.5
Considering your quality of life at initial onset, how do you consider your quality of life now?	13.4	7.8	11.3	40.3	16.5	6.1	4.8

WATCH AND WAIT/OBSERVATION

The following tables contain a description of the watch and wait experiences of 872 AN patients.

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	124	20.8
6 months to 1 year	84	14.1
1 year to 2 years	86	14.4
2 years to 3 years	59	9.9
3 years to 4 years	47	7.9
4 years to 5 years	48	8.1
5 years to 10 years	95	15.9
10 years to 20 years	41	6.9
More than 20 years	6	1.0
Reasons to watch and wait*		
Recommended by a physician	365	77.2
Size of tumor is less than 1.5 cm	298	63.0
Concerned about quality of life after treatment	236	49.9
Minimal current symptoms	224	47.4
Personal choice, not recommended by a physician	104	22.0
Dissatisfaction with treatment options	83	17.5
Advanced age is considered an issue	34	7.2
Unsure about where to get treatment	33	7.0
General health reasons counter-indicate treatment at this time	30	6.3
Job or employment concerns	29	6.1
Concerns about my financial situation	24	5.1
Seeking or using alternative treatments	18	3.8
I know someone who had this management option	15	3.2
Insurance situation at time of the decision to watch and wait	14	3.0
Absence of social support system	10	2.1

* These items were not included in the survey until 2012. The percentages are based on the responses of 473 AN patients.

Description	Number of responses	Percentage of responses
Tumor side		
Left	415	47.6
Right	448	51.4
Bilateral (Both sides)	7	0.8
No response	2	0.2
Diagnostic tests used to diagnose tumor ***(multiple responses possible)***		
MRI scan (Magnetic Resonance Image)	844	97.0
Hearing Test (Audiogram)	633	72.8
Balance Test (Electronystagmogram – ENG)	180	20.7
CT scan (Computerized Tomography)	109	12.5
Brainstem Auditory Evoked Response (BAER, BSER or ABR)	85	9.8

The size of the AN tumor at diagnosis and at their last MRI is reported in the following table. However, AN patients were not asked to indicate the size of their tumor at their last MRI on the 2007/2008 survey. Information about the size of their tumor at the time of the survey was provided by 395 AN patients who reported their decision to watch and wait.

	At diagnosis*		**less than 1 year later***		**1-2 years later***		**3-5 years later***		**6-10 years later***		**more than 10 years later***	
Tumor size	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***
0.0 cm**			7	13.5	25	27.2	16	14.5	14	14.9	4	8.5
0.0 – 0.4 cm**			0	0.0	0	0.0	1	0.9	8	8.5	6	12.8
0.1 – 0.4 cm	188	21.6	11	21.2	9	9.8	11	10.0	9	9.6	9	19.1
0.5 – 1.0 cm	254	29.2	5	9.6	20	21.7	28	25.5	24	25.5	11	23.4
1.1 – 1.5 cm	181	20.8	9	17.3	19	20.7	22	20.0	19	20.2	5	10.6
1.6 – 2.0 cm	87	10.0	7	13.5	8	8.7	10	9.1	9	9.6	3	6.4
2.1 – 2.5 cm	44	5.1	3	5.8	1	1.1	7	6.4	3	3.2	2	4.3
2.6 – 3.0 cm	20	2.3	2	3.8	0	0.0	0	0.0	1	1.1	0	0.0
3.1 – 3.5 cm	11	1.3	0	0.0	0	0.0	1	0.9	0	0.0	0	0.0
3.6 – 4.0 cm	6	0.7	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
> 4.0 cm	18	2.1	0	0.0	4	4.3	0	0.0	1	1.1	0	0.0
Don't know	62	7.1	8	15.4	6	6.5	14	12.7	6	6.4	7	14.9
Total	871	100.0	52	13.2	92	23.3	110	27.8	94	23.8	47	11.9

*Size of tumor now (*n* = 395)

**These response options were included in the 2013 Follow-up survey and revised in 2014.

Symptoms Reported

The data reported in the following table includes responses to two questions on the surveys from 2007/2008 to 2014 from some or all of the 872 AN patient records in the registry that have microsurgery as their treatment modality. The AN patients were asked to indicate what symptoms they experienced at the time of their diagnosis *AND* what symptoms they were experiencing at the time of the survey.

However, the format in which the symptoms were asked or when the symptoms were introduced into the questionnaire varies. Therefore, the number of records used to calculate the percentage varied.

	At diagnosis		At time of surveys					
				Percentage of responses				
Symptom	Number of responses	% of responses	Number of responses	less than 1 year later	1-2 years later	3-5 years later	6-10 years later	more than 10 years later
Single-sided hearing loss or deafness	872	76.6	97	65.2	55.6	58.0	51.2	66.7
Tinnitus (noise or ringing in the ear)	837	71.9	569	58.0	58.0	61.7	56.3	66.7
Vertigo (dizziness/balance disturbance)	837	53.9	540	35.8	34.3	27.9	22.2	24.0
Balance	168	45.8	168	43.5	36.1	40.0	41.5	44.4
Fullness in ear	837	43.0	569	26.7	32.1	28.6	25.9	32.1
Headaches	837	23.4	551	13.8	18.8	21.2	19.3	16.0
Fatigue	837	23.2	569	24.4	25.9	24.8	23.2	23.5
Eye problems	837	18.0	525	17.6	25.9	12.8	15.4	12.1
Memory difficulties	837	16.5	569	19.1	18.8	14.3	16.1	12.3
Depression	837	16.0	569	10.7	16.1	10.5	10.7	17.3
Difficulty concentrating	837	14.6	569	15.3	14.3	15.0	10.7	11.1
Facial numbness	837	14.5	569	10.7	9.8	12.8	12.5	9.9
Change in smell or taste	837	11.9	569	14.5	12.5	9.8	8.0	7.4
Facial twitching	837	9.7	569	6.9	14.3	9.0	6.3	7.4
Facial weakness or paralysis	872	8.7	168	0.0	2.8	4.0	2.4	0.0
Difficulty swallowing	837	8.2	569	7.6	6.3	4.5	6.3	7.4

Single-Sided Hearing Loss

The following table contains the self-reported Gardner-Robertson Class of 668 AN patients who are watching and waiting and who reported single-sided hearing loss or deafness at the time of their diagnosis.

Self-reported Gardner-Robertson Class*	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Class 1 Good, Excellent Hearing = PTA 0-30 dB; SD 70-100%	137	20.6	70	10.5
Class 2 Serviceable Hearing = PTA 31-50 dB; SD 50-69%	154	23.1	113	17.0
Class 3 Non-Serviceable Hearing = PTA 51-90 dB; SD 5-49%	73	11.0	89	13.4
Class 4 Poor Hearing = PTA 91-100 dB; SD 1-4%	40	6.0	52	7.8
Class 5 No Hearing = PTA 0; SD 0%	32	4.8	101	15.2
Don't Know	230	34.5	241	36.2

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

Options to improve hearing	Number of responses	Percentage of responses†
Behind-the-ear (BTE) hearing aid*	52	10.9
In-the-ear (ITE) hearing aid	18	2.1
CROS hearing aid	12	1.4
Device to amplify TV	11	1.3
BiCROS hearing aid	9	1.0
Device to amplify telephone	7	0.8
Direct audio input microphone	7	0.8
In-the-canal (ITC) hearing aid	6	0.7
Bone conduction hearing devices (such as Cochlear Baha, Oticon Ponto Pro, TransEar, Sophono or SoundBite)	5	0.6
FM system or other amplifier (carried in pocket or placed on a table)	3	0.3
Cochlear implants*	2	0.4
Completely-in-the-canal (CIC) hearing aid*	0	0.0

† The percentages of most strategies are based on 827 responses
* These strategies were not included on the 2007/2008 survey. Percentage of responses is based on 479 responses.

Facial Weakness

The following table contains the self-reported House-Brackmann Grade of 25 AN patients who reported ***mild*** to ***complete facial paralysis*** at the time of their diagnosis.

Self-reported House-Brackmann Grade	At diagnosis		At time of surveys	
	Number of responses	Percentage of responses	Number of responses	Percentage of responses
Grade I. Normal	0	0.0	1	16.0*
Grade II. Mild	14	56.0	10	40.0*
Grade III. Moderate	2	8.0	5	20.0*
Grade IV. Moderate severe	3	12.0	1	4.0*
Grade V. Severe	0	0.0	0	0.0
Grade VI. Complete paralysis	0	0.0	0	0.0
Don't know	6	24.0	5	20.0

**results may be due to pooling responses across multiple survey versions*

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.

Quality of Life

Quality of life questions related to the respondents' employment, use of handicapped parking permits, their perceptions of their symptoms and quality of life since their diagnosis.

These questions were first asked in the 2012. The responses in the following table are based on responses from 434 AN patients.

Question	Number of responses	Percentage of responses
Employment		
After diagnosis, able to continue regular employment and/or activities		
Yes	449	93.7
No	30	6.3
If yes, still employed in same capacity or perform same activities today? (*n* = 449)		
Yes	350	78.3
No	97	21.7
If no, why not? (*n* = 97)		
Became disabled	5	5.2
Quit to pursue another job or other interests	4	4.1
Retired	51	52.6
No response	37	38.1
Handicapped parking permit*		
Did you use a handicapped parking permit after your treatment?		
Yes	8	4.8
No	160	95.2
If no, why did you not use the permit? (*n* = 160)		
I did not feel the need to use one.	116	72.5
I did not know I qualified to use one.	21	13.1
No response	23	14.4

* Watch and wait AN patients were not asked this question until 2014.

These questions were first asked in the 2012. The responses in the following table are based on responses from 479 AN patients.

Question	Percentage of respondents						
	Significantly better	**Moderately better**	**Somewhat better**	**No significant change**	**Somewhat worse**	**Moderately worse**	**Significantly worse**
Considering your symptoms at initial onset, how do you consider your symptoms now?	8.4	4.5	4.1	44.5	27.3	7.0	4.1
Considering your quality of life at initial onset, how do you consider your quality of life now?	6.4	3.9	3.4	54.7	22.9	6.2	2.5