



2013 Annual Report

Mission and Purposes

Acoustic Neuroma Association (ANA) is a designated 501(c)(3) non-profit organization.

The mission of ANA is to inform, educate and provide national and local support networks for those affected by acoustic neuromas, and to be an essential resource for health care professionals who treat acoustic neuroma patients.

The purposes are as follows:

- To provide support and information for patients who have been diagnosed with or treated for acoustic neuromas or other tumors affecting the cranial nerves.
- To act as an information source, including current medical advances, for physicians and health care personnel interested in the treatment of benign tumors and the alleviation of post-treatment problems experienced by patients.
- To promote and support research on the cause, development and treatment of acoustic neuromas and other benign cranial tumors.
- To educate the public regarding symptoms suggestive of acoustic neuromas, thus promoting early diagnosis and consequent successful treatment.

Vision

To be the most comprehensive and reliable resource on acoustic neuroma for patients, caregivers and medical professionals, as well as committed advocates in the advancement of research and improvement of patient experience and quality of life worldwide. *(Updated 2011)*

Core Values

- Professionalism: to maintain high ethical standards at all times.
- Objectivity: to remain free of bias in everything we do.
- Research: to constantly learn more about acoustic neuromas.
- Communication: to encourage dialog and disseminate information about acoustic neuromas.
- Innovation: to stay current with technology and emerging, diverse, pre- and post-treatment options.
- Respect: to honor the needs and privacy of acoustic neuroma patients.

Program Highlights

Publications

- 19,205 *Notes* newsletter distributed – issued quarterly.
- 7,105 Patient information booklets distributed covering 8 topics of interest to AN patients.

Complimentary Program

- 1,209 Complimentary packets of information sent to:
 - 570 Pre-treatment
 - 302 Post-treatment
 - 163 Watch & Wait
 - 128 Family Members and Friends
 - 46 Medical Professionals

Local Support Groups

- 59 active ANA support groups are listed on our website – 11% increase from 2012.
- New groups formed – 3
 - Central OR
 - Manchester, NH
 - Southern NJ
- Reactivated groups – 8
 - Baltimore, MD
 - Boston, MA
 - Central GA
 - Ft. Lauderdale, FL
 - Kansas City, MO
 - Orlando, FL
 - Pittsburgh, PA
 - Richmond/Eastern, VA
- New leaders transitioned in existing groups – 4
 - Dayton/Cincinnati, OH
 - Durham, NC
 - Green Bay, WI
 - SW Chicago, IL
- New leaders transitioned in new/reactivated groups – 11
 - Baltimore, MD
 - Boston, MA
 - Central GA
 - Central OR
 - Ft. Lauderdale, FL
 - Kansas City, MO
 - Manchester, NH
 - Orlando, FL
 - Pittsburgh, PA
 - Richmond/Eastern, VA
 - Southern NJ
- Total number of meetings – 119 – 14% increase from 2012.
- Total meeting attendance – 1,949 – 14% increase from 2012.
- Support Group Program Leader Survey completed in April.
- Support Group Leader Mentorship Program initiated.
- Support Group Leader Meeting at Symposium was well attended with 28 leaders/co-leaders present.
- Recruitment for new leaders/new groups is ongoing.
- Leader training is ongoing, sending tools and resources in leadership packet, how-to packets and monthly issues of *Feedback*, our Local Support Group newsletter.
- Collaboration continues to increase with organizations of interest to support groups regarding research studies, other organization support groups, conferences, seminars, etc.

Willing to Talk Program (WTT)

- WTT list includes 49 participants covering all treatment types, various tumor size and representative demographics from across the US and is sent with every complimentary packet of information.
- The WTT list sent includes contact information along with tumor size, treatment dates and types of treatment, to assist the patient in locating someone with similar experiences.

Research

Patient Survey

- Survey was sent to close to 3,000 members in 2012 and was promoted on website, Forum and social media.
- Final patient survey analysis completed in summer of 2013 and published on our website.
- Next steps include sending the survey automatically to all new members and on the anniversary date of their previous reporting of information. Annual reports will be published with these results. Also we are working on plans to make the database interactive to make it possible for a patient to query the database to reveal information that would be more relevant to them personally.

AN Patient Survey Article

- Siviero Agazzi, MD, University of South Florida in Tampa has conducted a research study from our 2007-2008 patient survey, titled "Acoustic Neuroma Observation Leads to an Increase in Symptomatic Tinnitus: Results of the 2007-2008 Acoustic Neuroma Association Survey" to the "Journal of Neurosurgery." This paper was formally accepted and is published.
- Dr. Siviero Agazzi has also received confirmation of acceptance for publication – “The Changing Face of Acoustic neuroma Management in the USA: Analysis of the 1998 and 2008 Patient Surveys from the Acoustic Neuroma Association.” This has been published by the British Journal of Neurosurgery.

The Yale University Acoustic Neuroma Study

- Dr. Elizabeth B. Claus from Yale University began the collection of data from acoustic neuroma patients at our 2013 Symposium in Los Angeles to initiate the first AN causation research study of this type. The goal of the study is to determine whether or not there are possible genetic risk factors that cause an AN.
- The first phase of the study is only the collection of data, which includes a questionnaire and a saliva sample from acoustic neuroma patients. After the data collection is completed, Dr. Claus will seek additional funds to analyze the data.
- ANA approved funding for a portion of the initial collection phase of AN data for the AN causation study for \$49,199.
- By the end of 2013 more than 250 had enrolled; the goal is to survey 1,000 AN patients.

Website

- Enhancements added to the website throughout the year include adding new information to help AN patents make important treatment decisions and about possible post-treatment issues.
- Website redesign plan approved with plans to launch in early 2014.
- 49,191 Visits monthly to ANA website – 28% increased from 2012.
- 6,685 ANA Discussion Forum Members – 14% increase from 2012.

Social Media

- Interaction on social media continues to increase.
- 1,824 Likes on Facebook – 56% increase from 2012.
- 400 People Reached per post on average.
- 62 People on average, liking, commenting or sharing ANA FB posts.
- Videos added to YouTube about positive AN experiences.

2013 Symposium Results

Attendance

• Total attendance	2013	2011	2009	2007	2005	2003	2001	1999
Registrants – Full Mtg.	242	182	271	255	213	254	269	
Registrants – Day Rate	54	11	32	5				
Total	296	193	303					
Speakers and Exhibitors	80	68	51	23	19	47	49	
Staff	6	20	9	8	9	12	22	
Total	382	281	363	291	241	313	340	351

Note: For the total registrants, 70 were guests.

- Overall the symposium was a success and evaluations are very good although, there were a few hotel related negative issues.
- Mark Ruffalo video interview was premiered at the symposium.
- The Yale University Acoustic Neuroma Research Study was launched at the symposium.
- Final expenses and income were close to budget, but unfortunately will not break even.
- Pluses
 - Attendance increased 53% compared to Cincinnati and almost flat with Chicago.
 - Hotel worked well – staff friendly and accommodating – with the exceptions noted above.
 - Meeting management services through American College of Surgeons were good.
 - Individual information sessions – a record 150 AN patients met with a medical professional.

Future Symposiums

ANA Board of Directors reviewed the 2013 symposium at their fall board meeting and made the decision to not hold a symposium in 2015 in order to focus their time and effort with the other initiatives and to review how to best reach and serve our community. The Board has committed to discuss the future of other symposia before the end of 2015, including whether or not the format and content of future symposia might be modified to better meet the needs of participants.

Planned Giving Program

- Acoustic Neuroma Legacy Society was created. This program will recognize those who have named ANA in their will or another type of planned gift. This will encourage others to do the same. Participants will be acknowledged in the newsletter and on the website.
- Brochures and postcards were sent to loyal donors and life members along with promoting this new program on our website and in our newsletter.
- Acoustic Neuroma Legacy Society logo designed.
- By year end response cards were received from five individuals designating ANA in their will.

Webinar Program

- In 2013, we launched a new webinar program for acoustic neuroma patients, medical professionals, friends and family. This is an ANA member benefit. These educational webinars cover key areas of interest relevant to AN patients with plenty of time for questions and answers. They are presented by leading acoustic neuroma medical professionals.
- Three webinars were coordinated and presented:
 - **Radiosurgery Realities for Patients with Acoustic Neuromas**
Dr. Douglas Kondziolka, MD, MSc, FRCSC, FACS
Professor of Neurosurgery and Radiation Oncology, New York University Langone Medical Center, New York, NY
 - **Natural History and Surgery for Long-term Hearing Preservation**
Rick A. Friedman, MD, PhD
House Clinic, Los Angeles, CA - (*Now with The USC Acoustic Neuroma Center of Keck Medicine, Los Angeles, CA*)
 - **Non-surgical Neuromuscular Retraining for Facial Paralysis after Acoustic Neuroma Surgery**
Jacqueline Diels, OT, McFarland, WI

AN Awareness Week

Launched the first AN Awareness Week in May 2013, tied with Brain Tumor Awareness Month. It was our most popular week on Facebook with 11,096 views. Promotion was on social media and our website.

Membership

- New Member Growth for 2013– 16% .
- 584 New Members joined ANA in 2013, representing a 3% increase from 2012.
- Renewal Rate in 2013 – 71%, representing a 4% increase from 2012.

Communications

- 727 Telephone calls responded to for information – 15% increase from 2012.
- 5,293 Emails responded to for information – 15% increased from 2012.

Board of Directors

President – Jeffrey D. Barr, *Livingston, NJ and West Palm Beach, FL*

Vice President – Alan Goldberg, *New York, NY*

Secretary – Tony Cochran *Albertville, AL (Resigned August 2013)*

John Gigliello, EA, MBA, *Niskayuna, NY (Started as Treasurer October 2013)*

Treasurer – Steve Houghton *Florida (and Michigan) (Term expired April 2013)*

Scott Van Ells, *Manitowoc, WI (Started as Secretary April 2013)*

Pam Golum, *Valley Village, CA*

Roberta C. Hutchings, *Westminster, CO*

Karla Jacobus, *Cary, NC*

Joel Perrell Jr., *Baltimore, MD*

Leah Keith, *Los Angeles, CA*

David Puzzo, *St. Petersburg, FL*

Kristine Siwek, *Oconomowoc, WI*

Yvette Spratt, *Chaska, MN*

Deborah R. Walls, MSW, LCSW, CDVD, *New Whitehead, IL*

Immediate Past President – Amy Pack, *Visalia, CA*

Staff

Judy Vitucci, *Chief Executive Officer*

Leigh Faulk, *Director of Development (Resigned June 2013)*

Melanie Hutchins, *Support Group Coordinator*

Marie Cowart, *Office Manager*

Jennifer Dugan, *Assistant to CEO (Resigned July 2013)*

Theresa Harris, *Assistant to CEO (Started October 2013)*

Elaine Maida, *Office Assistant*

Audit

An audit of 2013 financial records for ANA was completed on February 7, 2014 by Wilcox & Bivings, P.C., Certified Public Accountants.

Financials

P & L – 2013 Compared to 2012

Note: 2013 negative Net Income was due to the Board of Directors decision to grow ANA. To accomplish this, the office space was increased 50% and another full time employee was added to the staff for the position of Director of Development. Increased expenditures for this were funded by the reserved funds.

	<u>Jan - Dec 2014</u>	<u>Jan - Dec 2013</u>	<u>\$ Change</u>	<u>% Change</u>
Income				
4030-1 · Realized Gain/Loss / Security	12,964.03	0.00	12,964.03	100.0%
4200 · Website Listing Adm. Fee	30,900.00	29,425.00	1,475.00	5.01%
4010 · Membership	124,835.00	106,462.50	18,372.50	17.26%
4020 · Donations				
4020-2 · Estates	10,091.45	28,500.00	-18,408.55	-64.59%
4020-1 · Federal Campaign donations	8,885.97	8,915.72	-29.75	-0.33%
4020 · Donations - Other	153,994.70	143,900.40	10,094.30	7.02%
Total 4020 · Donations	<u>172,972.12</u>	<u>181,316.12</u>	<u>-8,344.00</u>	<u>-4.6%</u>
4030 · Return on Investments				
4030-4 · Dividends	8,600.36	12,122.40	-3,522.04	-29.05%
4030-2 · Unrealized Gain/Loss / Security	3,654.42	14,205.00	-10,550.58	-74.27%
4030-3 · Interest income	65.44	57.36	8.08	14.09%
Total 4030 · Return on Investments	<u>12,320.22</u>	<u>26,384.76</u>	<u>-14,064.54</u>	<u>-53.31%</u>
4040 · Sale of material	3,338.69	2,970.60	368.09	12.39%
4050 · Grants	5,000.00	5,000.00	0.00	0.0%
4056 · Symposium -				
4056-1 · Symposium Registrations	60,851.31	0.00	60,851.31	100.0%
4056-2 · Symposium Donations	34,780.00	0.00	34,780.00	100.0%
4056-3 · Symposium Expenses	-183,641.07	0.00	-183,641.07	-100.0%
4056-4 · Symposium Exhibits	74,788.50	0.00	74,788.50	100.0%
Total 4056 · Symposium -	<u>-13,221.26</u>	<u>0.00</u>	<u>-13,221.26</u>	<u>-100.0%</u>
4100 · Scholarship Donations	3,968.90	2,100.00	1,868.90	89.0%
Total Income	<u>353,077.70</u>	<u>353,658.98</u>	<u>-581.28</u>	<u>-0.16%</u>
Gross Profit	353,077.70	353,658.98	-581.28	-0.16%

Expense

5001 · PROGRAM EXPENSES

5151 · Webinar	2,003.59	0.00	2,003.59	100.0%
5150 · Grants Given	16,319.75	0.00	16,319.75	100.0%
5149 · Social Media	150.00	990.00	-840.00	-84.85%
5148 · Posting Journal Articles Fees	3,956.50	3,868.25	88.25	2.28%
5147 · Website Development	1,385.00	0.00	1,385.00	100.0%
5040-1 · Board meetings	12,710.14	23,368.63	-10,658.49	-45.61%
5010 · Newsletter	37,754.79	34,522.00	3,232.79	9.36%
5020 · Booklets	5,864.98	5,031.82	833.16	16.56%
5021 · Member services	8,366.11	0.00	8,366.11	100.0%
5023 · Survey	7,494.75	9,453.28	-1,958.53	-20.72%
5145 · General Scholarship	5,158.66	0.00	5,158.66	100.0%

Total 5001 · PROGRAM EXPENSES	101,164.27	77,233.98	23,930.29	30.98%
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5069 · SUPPORTING SERVICES

5097 · Outside Services	21,350.32	18,393.75	2,956.57	16.07%
5070 · Postage	22,109.61	19,179.11	2,930.50	15.28%
5075 · Insurance	2,077.39	1,996.14	81.25	4.07%
5076 · Insurance - Health	8,132.34	8,161.05	-28.71	-0.35%
5077 · Miscellaneous	11,713.30	4,840.77	6,872.53	141.97%
5080 · Office supplies	18,370.44	18,716.10	-345.66	-1.85%
5081 · Equipment, supplies & maint.	3,314.18	2,767.12	547.06	19.77%
5091 · Computer systems	9,358.16	6,611.79	2,746.37	41.54%
5095 · Salaries	159,369.50	129,518.37	29,851.13	23.05%
5096 · Temporary help & recruitment	1,605.32	516.66	1,088.66	210.71%
5100 · Rent	17,345.00	12,590.00	4,755.00	37.77%
5105 · Utilities & Maid	4,823.70	3,396.11	1,427.59	42.04%
5110 · Telephone expense	6,025.01	4,107.93	1,917.08	46.67%
5120 · Accounting	7,095.40	6,817.25	278.15	4.08%
5125 · Payroll tax expense	12,214.43	9,924.65	2,289.78	23.07%
5130 · Depreciation expense	1,042.87	1,036.05	6.82	0.66%

Total 5069 · SUPPORTING SERVICES	305,946.97	248,572.85	57,374.12	23.08%
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Total Expense	407,111.24	325,806.83	81,304.41	24.96%
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Net Income	<u>-54,033.54</u>	<u>27,852.15</u>	<u>-81,885.69</u>	<u>294.0%</u>
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**ANA Statement of Financial Position
December 31, 2014 and 2013**

	2014	2013
ASSETS		
Cash and cash equivalents	\$73,748	\$106,021
Investments	175,939	377,697
Prepaid expenses	2,894	801
Deposits	744	744
Restricted cash and cash equivalents	4,755	2,755
Property and equipment	46,694	1,194
Endowment investments	154,417	
Total assets	\$412,963	\$489,212
LIABILITIES		
Accounts Payable	--	\$3,705
Deferred revenue	--	--
Total liabilities	--	\$3,705
NET ASSETS		
Unrestricted - undesignated	\$248,758	\$449,873
Unrestricted – designated for endowment	154,417	
Unrestricted – designated for research grant	5,033	32,879
Temporarily restricted	4,755	2,755
Total net assets	412,963	485,507
Total liabilities and net assets	\$412,963	\$489,212