



2014 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.

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

- 19,321 *Notes* newsletter distributed – issued quarterly.
- 7,240 Patient information booklets distributed covering eight topics of interest to AN patients.

Complimentary Program

- 1,153 Complimentary packets of information sent to:
 - 553 Pre-treatment
 - 272 Post-treatment
 - 173 Watch & Wait
 - 120 Family Members and Friends
 - 35 Medical Professionals

Local Support Groups

- 61 active ANA support groups are listed on our website.
- Reactivated groups – 3
 - Louisville, KY
 - Miami, FL
 - Sarasota, FL
- Total number of meetings – 128 – 8% increase from 2013.
- Total meeting attendance – 2,007 – 3% increase from 2013.
- 2014 Support Group Initiatives
 - The Yale University Acoustic Neuroma Study
 - Promoted the study in many Local Support Groups providing the opportunity for the group to work together to complete the questionnaire and sample collection.
 - Virtual Local Support Groups via Google Hangouts
 - Tested in New York City in 2014
- 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 51 participants covering all treatment types, various tumor sizes and representative demographics from across the US and is sent with every ANA 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

- Patient Survey was sent to close to 2,100 members in 2014 and was promoted on the website, Forum and social media with 970 responses.
- The data from the past three surveys in 2007/2008, 2012 and 2014 is being streamlined into a registry of information.
- The 2014 Patient Survey report is work in progress and will be published in 2015.
- 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.

The Yale University Acoustic Neuroma Study

- The Yale University Acoustic Neuroma Study under the direction of 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 2014 more than 800 had enrolled; with close to 500 completed. The goal is to survey 1,000 AN patients.

Website

- Redesign of the ANA website was launched in July 2014. The website has a more current and vibrant design, with the information laid out for ease of use for both pre- and post-treatment AN patients. This new look will make it easier to navigate the site to learn more about acoustic neuroma education and local support opportunities.
- 60,000 Visits monthly to ANA website – 22% increased from 2013.
- 7,562 ANA Discussion Forum Members – 13% increase from 2013.

Social Media

- Interaction on social media continues to increase.
- 2,809 Likes on Facebook – 54% increase from 2013.
- 795 Average Facebook Post Reach – 66% increase from 2013.
- 1,077 Average Facebook Total Reach – 74% increase from 2013.

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 in 2013. This program recognizes 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.
- Thirteen individuals to date have designated ANA in their will.

Endowment Fund

- Endowment Fund was approved in 2012 by the Board of Directors. Policies were then established and the actual fund was established in 2014 with initial investment of \$150,000.

Webinar Program

- In 2013, we launched a new webinar program for acoustic neuroma patients, 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.
- Ten webinars have been coordinated and presented with on average close to 400 registrants with 250 on the live broadcast.

ANAwareness Week

- Second Annual ANAwareness Week was presented in May 2014 with the theme of Learn, Share, Thrive! May is Brain Tumor Awareness Month and the week of May 11-17 was chosen as ANAwareness week.
 - Promotion for the event was on our website, our social media platforms, press releases and to ANA members via email.
 - Sponsors were solicited for the first time for the event with excellent participation.

Peer-to-Peer Fundraising

- Peer-to-Peer fundraising has become increasingly popular over the last few years. ANA worked with several members to raise money by participating in races/walks and sponsoring ANA. Events were coordinated through a member's Facebook page and a crowd funding website, CrowdRise.
 - More than \$8,000 was raised for ANA through this new form of fundraising.

Medicare Proposal

- Medicare Proposal released in July 2014 to eliminate coverage for the auditory osseointegrated implants (such as BAHA). ANA presented this information on our website and in emails to members so that informed decisions could be made to advocate about this if so inclined.
- In October 2014 The Centers for Medicare and Medicaid Services (CMS) announced a final ruling that auditory osseointegrated implants (such as BAHA) are not hearing aids and, therefore, will remain a covered benefit. The July proposal was reversed.

Fundraising Software

- ANA transitioned to new fundraising software from DonorPerfect to enhance additional fundraising activities.

Communications

- Wikipedia entry for acoustic neuroma has been updated with the addition of information about ANA.

Board of Directors

Officers

President – Alan Goldberg, *New York, NY*

Vice President – Karla Jacobus, *Cary, NC*

Treasurer – John Gigliello, EA, MBA, *Niskayuna, NY*

Secretary – Scott Van Ells, *Manitowoc, WI (Resigned March 2014)*

David Puzzo, *St. Petersburg, FL (Started as Secretary April 2014)*

Members at Large

Luke Bagato, *Western Springs, IL*

Laura Barbaro, *Andover, MA*

David Begnaud, *West Hollywood, CA*

Marla Bronstein, *Bellingham, WA*

Roberta C. Hutchings, *Westminster, CO*

Leah Keith, *Los Angeles, CA*

Chad Nye, *Lakeland, FL*

Joel Perrell Jr., *Baltimore, MD*

Kristine Siwek, *Oconomowoc, WI*

Miranda Sacharin, *New York, NY*

Thomas A. Sattler, MD, *San Francisco, CA*

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

Immediate Past President – Jeffrey D. Barr, *West Palm Beach, FL*

Medical Advisory Board

Co-Chairmen

Rick Friedman, MD, PhD - Neurotology/Radiosurgery - *Los Angeles, CA*

Michael J. Link, MD - Neurosurgery/Radiosurgery - *Rochester, MN*

Members

David W. Andrews, MD - Neurosurgery/Radiosurgery - *Philadelphia, PA*
Patrick J. Antonelli, MD - Neurotology - *Gainesville, FL*
Babak Azizzadeh, MD, FACS – Facial and Nasal Plastic Surgeon - *Beverly Hills, CA*
Fred Barker, MD - Neurosurgery - *Boston, MA*
Derald E. Brackmann, MD - Neurotology - *Los Angeles, CA*
Steven D. Chang, MD - Neurosurgery/Radiosurgery - *Stanford, CA*
Elizabeth B. Claus, MD, PhD - Epidemiology/Neurosurgery - *Boston, MA*
H. Jacqueline Diels, OT - Facial Retraining Specialist - *McFarland, WI*
Aaron Fay, MD – Ophthalmic Plastic Surgeon – *Boston, MA*
Douglas Kondziolka, MD - Neurosurgery/Radiosurgery - *New York, NY*
Robert E. Levine, MD - Ophthalmology/Ophthalmic Plastic Surgery - *Los Angeles, CA*
John K. Niparko, MD - Neurotology - *Los Angeles, CA*
Andrew T. Parsa, MD, PhD - Neurosurgery - *Chicago, IL*
J. Thomas Roland, Jr. MD – Neurotology – *New York, NY*
Marc Schwartz, MD - Neurosurgery - *Los Angeles, CA*
Patrick Shumrick, BS, MHS, DPT - Physical Therapist - *Cincinnati, OH*
Rafael J. Tamargo, MD – Neurosurgery/ Radiosurgery – *Baltimore, MD*
Fred F. Telischi, MD, FACS - Neurotology - *Miami, FL*
John M. Tew, Jr., MD - Neurosurgery - *Cincinnati, OH*
Philip V. Theodosopoulos, MD - Neurosurgery - *San Francisco, CA*

Chairman Emeriti

Albert L. Rhoton, Jr., MD

Staff

Judy Vitucci, *Chief Executive Officer*
Kristen Hamel, *Director of Programs and Development (Resigned September 2014)*
Jennifer Farmer, *Director of Programs and Development (Started December 2014)*
Melanie Hutchins, *Support Group Coordinator*
Marie Cowart, *Office Manager*
Theresa Harris, *Assistant to CEO*
Elaine Maida, *Office Assistant (Resigned December 2014)*
Lynn Macaluso, *Office Assistant (Started December 2014)*

Audit

An audit of 2014 financial records for ANA was completed on February 24, 2015 by Wilcox & Bivings, P.C., Certified Public Accountants.

Financials

P & L – 2014 Compared to 2013

Note: 2013 and 2014 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 Programs and Development. Increased expenditures for this were funded by the reserved funds.

	<u>Jan - Dec 14</u>	<u>Jan - Dec 13</u>	<u>\$ Change</u>	<u>% Change</u>
Income				
4010 · Membership	133,851.50	124,835.00	9,016.50	7.22%
4020 · Donations				
4020-1 · Federal Campaign donations	8,635.72	8,885.97	-250.25	-2.82%
4020-2 · Estates	0.00	10,091.45	-10,091.45	-100.0%
4020 · Donations - Other	<u>184,362.14</u>	<u>153,994.70</u>	<u>30,367.44</u>	<u>19.72%</u>
Total 4020 · Donations	192,997.86	172,972.12	20,025.74	11.58%
4030 · Return on Investments				
4030-1 · Realized Gain/Loss / Security	28,568.00	12,964.03	15,603.97	120.36%
4030-2 · Unrealized Gain/Loss / Security	-17,367.18	3,654.42	-21,021.60	-575.24%
4030-3 · Interest income	27.03	65.44	-38.41	-58.7%
4030-4 · Dividends	<u>11,460.58</u>	<u>8,600.36</u>	<u>2,860.22</u>	<u>33.26%</u>
Total 4030 · Return on Investments	22,688.43	25,284.25	-2,595.82	-10.27%
4040 · Sale of material	2,384.22	3,338.69	-954.47	-28.59%
4050 · Grants	6,000.00	5,000.00	1,000.00	20.0%
4056 · Symposium -				
4056-1 · Symposium Registrations	0.00	60,851.31	-60,851.31	-100.0%
4056-2 · Symposium Donations	0.00	34,780.00	-34,780.00	-100.0%
4056-3 · Symposium Expenses	0.00	183,641.07	183,641.07	100.0%
4056-4 · Symposium Exhibits	<u>0.00</u>	<u>74,788.50</u>	<u>-74,788.50</u>	<u>-100.0%</u>
Total 4056 · Symposium -	0.00	-13,221.26	13,221.26	100.0%
4100 · Scholarship Donations	2,000.00	3,968.90	-1,968.90	-49.61%
4200 · Website Listing Adm. Fee	<u>32,892.00</u>	<u>30,900.00</u>	<u>1,992.00</u>	<u>6.45%</u>
Total Income	<u>392,814.01</u>	<u>353,077.70</u>	<u>39,736.31</u>	<u>11.25%</u>
Gross Profit	392,814.01	353,077.70	39,736.31	11.25%
Expense				
5001 · PROGRAM EXPENSES				
5010 · Newsletter	37,613.65	37,754.79	-141.14	-0.37%
5020 · Booklets	4,418.61	5,864.98	-1,446.37	-24.66%
5021 · Member services	9,199.35	8,366.11	833.24	9.96%
5023 · Survey	7,562.00	7,494.75	67.25	0.9%
5040-1 · Board meetings	14,326.99	12,710.14	1,616.85	12.72%
5145 · General Scholarship	0.00	5,158.66	-5,158.66	-100.0%
5147 · Website Development	10,750.00	1,385.00	9,365.00	676.17%
5148 · Posting Journal Articles Fees	0.00	3,956.50	-3,956.50	-100.0%
5149 · Social Media	0.00	150.00	-150.00	-100.0%
5150 · Grants Given	27,846.34	16,319.75	11,526.59	70.63%
5151 · Webinar	<u>3,215.90</u>	<u>2,003.59</u>	<u>1,212.31</u>	<u>60.51%</u>
Total 5001 · PROGRAM EXPENSES	114,932.84	101,164.27	13,768.57	13.61%
5069 · SUPPORTING SERVICES				
5070 · Postage	17,530.57	22,109.61	-4,579.04	-20.71%
5075 · Insurance	3,656.94	2,077.39	1,579.55	76.04%
5076 · Insurance - Health	6,505.73	8,132.34	-1,626.61	-20.0%

5077 · Miscellaneous	6,604.05	11,713.30	-5,109.25	-43.62%
5080 · Office supplies	5,775.91	18,370.44	-12,594.53	-68.56%
5081 · Equipment, supplies & maint.	3,054.22	3,314.18	-259.96	-7.84%
5091 · Computer systems	8,040.41	9,358.16	-1,317.75	-14.08%
5095 · Salaries	199,535.84	159,369.50	40,166.34	25.2%
5096 · Temporary help & recruitment	2,141.25	1,605.32	535.93	33.39%
5097 · Outside Services	21,228.25	21,350.32	-122.07	-0.57%
5100 · Rent	17,400.00	17,345.00	55.00	0.32%
5105 · Utilities & Maid	4,905.17	4,823.70	81.47	1.69%
5110 · Telephone expense	5,617.10	6,025.01	-407.91	-6.77%
5120 · Accounting	7,327.06	7,095.40	231.66	3.27%
5125 · Payroll tax expense	15,287.21	12,214.43	3,072.78	25.16%
5130 · Depreciation expense	728.25	1,042.87	-314.62	-30.17%
5140 · Fundraising Software	5,554.60	0.00	5,554.60	100.0%
5160 · Fundraising - Mailhouse	9,898.00	0.00	9,898.00	100.0%
5161 · Fundraising - Postage	5,298.00	0.00	5,298.00	100.0%
5162 · Fundraising - Stationery	4,338.00	0.00	4,338.00	100.0%
Total 5069 · SUPPORTING SERVICES	350,426.56	305,946.97	44,479.59	14.54%
Total Expense	465,359.40	407,111.24	58,248.16	14.31%
Net Income	-72,545.39	-54,033.54	-18,511.85	-34.26%

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	466	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	32,879
Unrestricted – designated for research grant	5,033	
Temporarily restricted	4,755	2,755
Total net assets	412,963	485,507
Total liabilities and net assets	\$412,963	\$489,212

