



2012 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

- 18,568 *Notes* newsletter distributed – issued quarterly.
- 8,030 patient information booklets distributed covering 8 topics of interest to AN patients.

Complimentary Program

- 1,219 Complimentary packets of information sent to:
 - 580 Pre-treatment
 - 130 Family Members and Friends
 - 256 Post-treatment
 - 50 Medical Professionals
 - 203 Watch & Wait

Local Support Groups

- 53 active ANA support groups are listed on our website
 - Formed 1 group:
Roanoke, VA
 - Reactivated 4 groups:
Charlotte, NC
Chicago, IL
Los Angeles, CA
Louisville, KY
 - New leaders transitioned in 2 existing groups:
Columbia, SC
St. Louis, MO
 - Co-leaders added to 7 existing groups:
Dallas, TX
Jacksonville, FL
Knoxville, FL
Roanoke, VA
San Antonio, TX
San Francisco, CA
St. Louis, MO
- Total number of meetings – 104.
- Total meeting attendance - 1,713 – 8% increase from 2011.
- 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)

- The WTT list includes 50 participants covering all treatment types, various tumor size and representative demographics from across the US.
- The actual WTT list includes contact information referenced with tumor size, 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 who had not taken the 2007-2008 patient survey. Survey was promoted on website, Forum and social media.
- Follow-up survey was sent to responders to the 2007-2008 survey – for whom we still have current email addresses.
- Analysis of the data will be done with the creation of a report with all results.
- These are the first two steps that will then lead to setting up an automatic renewal on the anniversary date of their previous reporting of information to the survey - so we can follow their progress. Also we plan to make it possible for a patient to query the database to reveal information that would be more relevant to them personally – making it the “living database.”

AN Patient Survey Article

- Plans under way now for a research study from our 2007-2008 patient survey with Siviero Agazzi, MD, University of South Florida in Tampa. He submitted a paper 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 will also be presented in March 2013 at the annual meeting of the North America Skull Base Society.

AN Causation Research Study

- Dr. Elizabeth Claus, Yale University, is developing the initial plans for a research study to discover why some people develop an acoustic neuroma while others do not.

Website

- Enhancements added to the website throughout the year including enhancing existing information and adding new information to help AN patients make important treatment decisions and about possible post-treatment issues. New sections are in the Symptoms page, Treatment Options Summary, AN Decision Tree, Questions to Ask Yourself, Types of Post-treatment Issues and AN Keywords.
- 384,528 visits to ANA website, averaging 32,044 per month, approximately 11% increase from 2011.
- ANA Discussion Forum Members – 5,867, approximately 14% increase from 2011.

Social Media

- 1,170 Likes on Facebook – 90% increase from 2011.
- 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 Planning

- Hotel selected and contract negotiated.
- Program planned and guest speakers invited.
- Sponsors brochure produced and sponsors invited to participate.
- Budget planned.
- Symposium theme and logo developed.
- Marketing planned including promoting with our members, in our newsletter, on our website, ANA Discussion Forum and social media.
- Closed captioning planned.
- Website updated with all symposium information.
- Registration new software designed and implemented.
- Local Support Group Leader invitation sent for their meeting at the symposium.

Planned Giving Program

- As part of the planned giving initiative, ANA has formed the Acoustic Neuroma Legacy Society. This program will recognize those who have named ANA in their will or another type of planned gift and encourage others to do the same. Participants will be acknowledged in the newsletter, on the website and at our National Symposium.
- Plans in development to market to select loyal and life members of ANA.

Webinar Program

- Plans are in development to launch a new webinar program for acoustic neuroma patients, friends and family who are ANA members. These educational webinars will cover key areas of interest relevant to AN patients with plenty of time for questions and answers, presented by leading acoustic neuroma medical professionals.

Membership

- New Member Growth for 2012– 14%.
- 472 New Members joined ANA in 2012, representing a 9% increase from 2011.
- Renewal Rate in 2011 – 72% , representing a 3% increase from 2011.

Communications

- 632 telephone calls responded to for information.
- 4,587 emails responded to for information, representing a 21% increase from 2011.

Office Expansion

- To increase space for current staff and planned additional staff, office space was increased by 50%, expanding into adjacent office location.

Board of Directors

President – Jeffrey D. Barr, *Livingston, NJ*

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

Treasurer – Tony Cochran, *Albertville, AL*

Secretary – Steve Houghton, *Florida and Michigan*

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

Pam Golum, *Valley Village, CA*

Roberta C. Hutchings, *Westminster, CO*

Leah Keith, *Los Angeles, CA*

Joel Perrell, Jr., *Baltimore, MD*

David Puzzo, *St. Petersburg, FL*

Virginia Barnes Ricketts, MS, LCPC, *Annapolis, MD*

Kristine Siwek, *Oconomowoc, WI*

Yvette Spratt, *Chaska, MN*

Scott Van Ells, *Manitowoc, WI*

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

Past President – Amy Pack, *Visalia, CA*

Staff

Judy Vitucci, *Chief Executive Officer*

Melanie Hutchins, *Support Group Coordinator*

Marie Cowart, *Office Manager*

Jennifer Dugan, *Assistant to Executive Director*

Elaine Maida, *Office Assistant*

Audit

An audit of 2012 financial records for ANA was completed on February 28, 2013 by Wilcox & Bivings, P.C., Certified Public Accountants.

Financials

P & L – 2012 Compared to 2011

| | Jan - Dec 12 | Jan - Dec 11 | \$ Change | % Change |
|---|-------------------|-------------------|------------------|----------------|
| Income | | | | |
| 4030-1 · Realized Gain/Loss / Security | 0.00 | 5,250.01 | -5,250.01 | -100.0% |
| 4200 · Website Listing Adm. Fee | 29,425.00 | 29,750.00 | -325.00 | -1.09% |
| 4010 · Membership | 106,462.50 | 98,421.00 | 8,041.50 | 8.17% |
| 4020 · Donations | | | | |
| 4020-2 · Estates | 28,500.00 | 74.60 | 28,425.40 | 38,103.75% |
| 4020-1 · Federal Campaign donations | 8,915.72 | 10,629.42 | -1,713.70 | -16.12% |
| 4020 · Donations - Other | 143,900.40 | 123,587.11 | 20,313.29 | 16.44% |
| Total 4020 · Donations | 181,316.12 | 134,291.13 | 47,024.99 | 35.02% |
| 4030 · Return on Investments | | | | |
| 4030-4 · Dividends | 12,122.40 | 12,963.71 | -841.31 | -6.49% |
| 4030-2 · Unrealized Gain/Loss / Security | 14,205.00 | 4,336.55 | 9,868.45 | 227.57% |
| 4030-3 · Interest income | 57.36 | 67.07 | -9.71 | -14.48% |
| Total 4030 · Return on Investments | 26,384.76 | 17,367.33 | 9,017.43 | 51.92% |
| 4040 · Sale of material | 2,970.60 | 4,525.55 | -1,554.95 | -34.36% |
| 4050 · Grants | 5,000.00 | 5,000.00 | 0.00 | 0.0% |
| 4056 · Symposium - | | | | |
| 4056-1 · Symposium Registrations | 0.00 | 31,265.50 | 31,265.50 | -100.0% |
| 4056-2 · Symposium Donations | 0.00 | 18,750.00 | 18,750.00 | -100.0% |
| 4056-3 · Symposium Expenses | 0.00 | -93,215.67 | 93,215.67 | 100.0% |
| 4056-4 · Symposium Exhibits | 0.00 | 51,250.00 | 51,250.00 | -100.0% |
| Total 4056 · Symposium - | 0.00 | 8,049.83 | -8,049.83 | -100.0% |
| 4100 · Scholarship Donations | 2,100.00 | 3,000.00 | -900.00 | -30.0% |
| Total Income | 353,658.98 | 305,654.85 | 48,004.13 | 15.71% |
| Expense | | | | |
| 66900 · Reconciliation Discrepancies | 0.00 | -50.00 | 50.00 | 100.0% |
| 5001 · PROGRAM EXPENSES | | | | |
| 5150 · Grants Given | 0.00 | 0.00 | 0.00 | 0.0% |
| 5149 · Social Media | 990.00 | 6,880.00 | -5,890.00 | -85.61% |
| 5148 · Posting Journal Articles Fees | 3,868.25 | 3,307.25 | 561.00 | 16.96% |
| 5147 · Website Development | 0.00 | 2,250.00 | -2,250.00 | -100.0% |
| 5040-1 · Board meetings | 23,368.63 | 19,881.41 | 3,487.22 | 17.54% |
| 5010 · Newsletter | 34,522.00 | 36,305.97 | -1,783.97 | -4.91% |
| 5020 · Booklets | 5,031.82 | 4,967.58 | 64.24 | 1.29% |
| 5021 · Member services | 0.00 | 5,952.38 | -5,952.38 | -100.0% |
| 5023 · Survey | 9,453.28 | 1,625.00 | 7,828.28 | 481.74% |

| | | | | |
|---|-------------------|-------------------|------------------|----------------|
| 5040 · Meetings | 0.00 | 3,000.00 | -3,000.00 | -100.0% |
| 5145 · General Scholarship | 0.00 | 5,214.78 | -5,214.78 | -100.0% |
| Total 5001 · PROGRAM EXPENSES | 77,233.98 | 89,384.37 | 12,150.39 | -13.59% |
| 5069 · SUPPORTING SERVICES | | | | |
| 5097 · Outside Services | 18,393.75 | 0.00 | 18,393.75 | 100.0% |
| 5070 · Postage | 19,179.11 | 17,311.87 | 1,867.24 | 10.79% |
| 5075 · Insurance | 1,996.14 | 1,466.87 | 529.27 | 36.08% |
| 5076 · Insurance - Health | 8,161.05 | 7,641.39 | 519.66 | 6.8% |
| 5077 · Miscellaneous | 4,840.77 | 4,993.92 | -153.15 | -3.07% |
| 5080 · Office supplies | 18,716.10 | 15,171.74 | 3,544.36 | 23.36% |
| 5081 · Equipment, supplies & maint. | 2,767.12 | 2,446.43 | 320.69 | 13.11% |
| 5091 · Computer systems | 6,611.79 | 5,507.06 | 1,104.73 | 20.06% |
| 5095 · Salaries | 129,518.37 | 121,653.17 | 7,865.20 | 6.47% |
| 5096 · Temporary help & recruitment | 516.66 | 173.16 | 343.50 | 198.37% |
| 5100 · Rent | 12,590.00 | 11,420.00 | 1,170.00 | 10.25% |
| 5105 · Utilities & Maid | 3,396.11 | 3,478.37 | -82.26 | -2.37% |
| 5110 · Telephone expense | 4,107.93 | 3,902.24 | 205.69 | 5.27% |
| 5120 · Accounting | 6,817.25 | 6,330.42 | 486.83 | 7.69% |
| 5125 · Payroll tax expense | 9,924.65 | 9,318.60 | 606.05 | 6.5% |
| 5130 · Depreciation expense | 1,036.05 | 774.03 | 262.02 | 33.85% |
| Total 5069 · SUPPORTING SERVICES | 248,572.85 | 211,589.27 | 36,983.58 | 17.48% |
| Total Expense | 325,806.83 | 300,923.64 | 24,883.19 | 8.27% |
| Net Income | 27,852.15 | 4,731.21 | 23,120.94 | 488.69% |

ANA Statement of Financial Position December 31, 2012 and 2011

| | 2012 | 2011 |
|--------------------------------------|-----------|-----------|
| ASSETS | | |
| Cash and cash equivalents | \$85,843 | \$108,026 |
| Investments | 422,489 | 396,181 |
| Prepaid expenses | 30,299 | 2,164 |
| Deposits | 744 | 744 |
| Restricted cash and cash equivalents | 3,945 | 3,976 |
| Property and equipment | 2,237 | 1,748 |
| Total assets | \$545,557 | \$512,839 |
| LIABILITIES | | |
| Accounts Payable | \$ 1,526 | \$ 1,150 |
| Deferred revenue | 4,490 | -- |
| Total liabilities | \$ 6,016 | \$ 1,150 |
| NET ASSETS | | |
| Unrestricted - undesignated | \$535,596 | \$507,713 |
| Temporarily restricted | 3,945 | 3,976 |
| Total net assets | 539,541 | 511,689 |
| Total liabilities and net assets | \$545,557 | \$512,839 |