

# 2015 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.

# <u>Vision</u>

• 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

• 18,320 Notes Newsletters distributed- issued quarterly

• Over 4,000 Patient Information Booklets distributed, covering eight topics of interest

#### **Complimentary Program**

• 1,025 Complimentary Packets of information sent to acoustic neuroma patients, caregivers, and medical professionals

### AN Patient Events/Research Studies

• Collaboration with medical facilities and other organizations of interest to acoustic neuroma patients continues to increase and expand opportunities to volunteers and the AN community

- UC Regional Brain Tumor Conference (October)
- Yale AN Study Support Groups continue to promote and recruit participants at meetings
- Support Group Awareness Month (January) social media recognition, reminders about the value of Support Groups
- National Volunteer Week (April 13)- ANA acknowledged our volunteers and gave them recognition on social media
- Research Study at UCSF (Dr. Steven Cheung) Hearing Loss and Tinnitus Brain Imaging Study- local recruitment at Support Groups

### Volunteer Programs

### **ANA Support Groups**

58 active ANA local support groups listed on our website

• Reactivated groups - 3

State of Arkansas Charlotte, NC Nashville, TN

• New groups - 2

Greenville, SC

Bellingham, WA

• Total number of meetings – 129 – 1% increase from 2014

• Total meeting attendance – 2011 attendees vs. 2007 attendees in 2014, not a significant increase

• 2015 Support Group Initiatives

Support Group Leader Biennial Survey sent July Support Group Video Library added to website

- Support Group Leader resource notebook revised
- Recruitment for new leaders/new groups is ongoing
- Leader training is ongoing
  - New webinar program for leaders starting 2016
  - Monthly issues of Feedback, online Support Group newsletter

#### ANetwork

- 46 active participants
  - 13 new participants added

- 9 participants cycled off
- Screening/renewal/education is ongoing
- New Handbook developed and approved at April 2015 BOD meeting

# Social Media and ANA Website

### Facebook

3,939 Likes on Facebook - 40% increase from 2014

- 2013 654 Likes
- 2014 985 Likes
- 2015 1130 Likes
  - 1,271 Average Facebook Post Reach 60% increase from 2014
- Average Likes per post 40
- up from 24 in 2014
- 66% increase
- Average Comment per post 11
- up from 9 in 2014
- 22% increase
- Average Share per post 9
- up from 5 in 2014
- 80% increase

#### Twitter

437 followers, up from 261 - 67% increase in one year

#### Webinar Program

The webinar program continues to be a successful program with 8 webinars held in 2015 on various topics relevant to the AN community. Nine doctors volunteered their time to present on the following topics: The Yale University AN Study, hearing, surgical treatment of AN, a multidisciplinary approach to treatment, decision making and balance and three patients volunteered to sit on a panel to discuss the new normal. The webinars averaged 330 registrations each with an average attendance of 230 each.

#### Website

New features were added to www.anausa.org

- Events Calendar
- Team ANA fundraising platform
- Printable questions for patients to ask their doctors and themselves
- Video library
- Volunteer Opportunities Section
- Staff names and contact information
- Acoustic Neuroma Research Studies section added to home page
- Tribute electronic card section created and updated seasonally or for special events
- Programs and Services page added

Sections of the website were updated

- Support Group Leader resources
- Sliders added to many sections
- Webinar and Symposium sections updated and newly formatted
- Home page graphics, colors and buttons updated
- Latest News section
- ANA store, for purchasing booklets, pins, e-cards

#### **Development**

#### **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. Seventeen individuals total have designated ANA in their will.

#### **ANAwareness Week**

- Third annual ANAwareness Week was presented in May with the theme of Learn, Share, Thrive! May 10-16 was chosen as ANAwareness Week to coincide with Brain Tumor Awareness Month held each May.
  - Promotions for the virtual event were executed on our website, social media platforms, national and local press releases and to the AN community via email.
  - Sponsor solicitations resulted in income of \$45,000 from 11 sponsors as well as increased participation by sponsors in ANAwareness Week activities.

#### **Giving Tuesday**

- ANA's first-ever #GivingTuesday campaign on Dec. 1 made tribute e-cards available for members to donate to ANA while honoring their family and friends. This opportunity engaged members and providing additional revenue of \$1,435 to the year-end fundraiser.
- The office hosted an Open House and Holiday Toy Drive for Atlanta support group members and local and county officials and community leaders.

#### **Peer-to-Peer Fundraising**

- Peer-to-peer fundraising is a way for ANA supporters to help ANA by fundraising within their local communities and with friends and family.
- ANA supporters participated in 23 events/activities raising more than \$14,000.
- Events included various marathons, races, runs and walks, a corporate workplace giving event, a car magnet sale and a fitness challenge.

#### **Board of Directors**

ANA Board of Directors - 2015

<u>President</u>

Alan Goldberg, MSW - New York, NY Vice President Karla Jacobus, RN, MS - Cary, NC **Treasurer** John Gigliello, MBA - Niskayuna, NY Secretary David Puzzo - St. Petersburg, FL 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 Miranda Sacharin - New York, NY Tom Sattler, MD - San Francisco, CA Kristine Siwek - Oconomowoc, WI Deborah R. Walls, MSW, LCSW - New Whitehead, IN **Immediate Past President** Jeffrey D. Barr - West Palm Beach, FL

Founder/President Emeritus

Virginia Fickel Ehr - Brevard, NC

# ANA Medical Advisory Board

#### **Co-Chairmen**

Rick A. Friedman, MD, PhD - Neurotology/Radiosurgery - Los Angeles, CA Michael J. Link, MD - Neurosurgery/Radiosurgery - Rochester, MN **MAB Members** David W. Andrews, MD - Neurosurgery/Radiosurgery - Philadelphia, PA Patrick J. Antonelli, MD - Neurotology - Gainesville, FL Babak Azizzadeh, MD, FACS - Facial/Nasal Plastic Surgery - Beverly Hills, CA Fred Barker, MD - Neurosurgery - Boston, MA Derald E. Brackmann, MD - Neurotology/Radiosurgery - Los Angeles, CA Steven D. Chang, MD - Neuosurgery/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 Surgery - 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 J. Thomas Roland, Jr., MD - Neurotology - New York, NY

Marc Schwartz, MD - Neurosurgery/Radiosurgery - Los Angeles, CA Patrick Shumrick, BS, MHS, DPT - Physical Therapist - Cincinnati, OH Rafael J. Tamargo, MD - Neurosurgery - 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 (Retired July 2015) Allison Feldman, Chief Executive Officer (Started July 2015) Jennifer Farmer, Director of Programs and Development Melanie Hutchins, Manager of Volunteer Programs (Formerly Local Support Group Coordinator) Karen Davare, Assistant to CEO Lynn Macaluso, Office Assistant (Resigned June 2015) Christie Cullinan, Office Assistant (Started July 2015) Courtney Johnson, Office Manager (Ended February 2015) Melissa Baumbick, Communications Specialist

#### Audit

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

#### **Financials**

#### P & L- 2015 Compared to 2014

	Jan - Dec 15	Jan - Dec 14	\$ Change	% Change
Ordinary Income/Expense Income				
4010 · Membership	143,329.94	133,851.50	9,478.44	7.08%
4020-3 · Donations - Endowment	10,000.00	0.00	10,000.00	100.0%
4020 · Donations				
4020-1 · Federal Campaign donations	7,063.14	8,635.72	-1,572.58	-18.21%
4020-2 · Estates	37,532.67	0.00	37,532.67	100.0%
4020 · Donations - Other	222,696.57	184,362.14	38,334.43	20.79%
Total 4020 · Donations	267,292.38	192,997.86	74,294.52	38.5%
4030 · Return on Investments				
4030-1 · Realized Gain/Loss / Security 4030-2 · Unrealized Gain/Loss /	-888.12	28,568.00	29,456.12	103.11%
Security	-14,503.55	-17,367.18	2,863.63	16.49%
4030-3 · Interest income	28.33	27.03	1.30	4.81%
4030-4 · Dividends	14,607.89	11,460.58	3,147.31	27.46%
Total 4030 · Return on Investments	-755.45	22,688.43	- 23,443.88	- 103.33%

4040 · Sale of material	3,189.95	2,384.22	805.73	33.79%
4050 · Grants	7,000.00	6,000.00	1,000.00	16.67%
4100 · Scholarship Donations	1,000.00	2,000.00	-1,000.00	-50.0%
4200 · Website Listing Adm. Fee	27,205.00	32,892.00	-5,687.00	-17.29%
Total Income	458,261.82	392,814.01	65,447.81	16.66%
Gross Profit	458,261.82	392,814.01	65,447.81	16.66%
Expense				
5001 · PROGRAM EXPENSES				
5010 · Newsletter	33,882.52	37,613.65	-3,731.13	-9.92%
5020 · Booklets	3,896.90	4,418.61	-521.71	-11.81%
5021 · Member services	2,105.14	9,199.35	-7,094.21	-77.12%
5023 · Survey	6,085.94	7,562.00	-1,476.06	-19.52%
5040-1 · Board meetings	12,637.96	14,326.99	-1,689.03	-11.79%
5040 · Meetings	51.00	0.00	51.00	100.0%
5146 · Website Admin Expense	121.50	0.00	121.50	100.0%
5147 · Website Development	0.00	10,750.00	10,750.00	-100.0%
5150 · Grants Given	4,734.24	27,846.34	- 23,112.10	-83.0%
5151 · Webinar	3,404.90	3,215.90	189.00	5.88%
Total 5001 · PROGRAM EXPENSES	66,920.10	114,932.84	- 48,012.74	-41.78%
5069 · SUPPORTING SERVICES				
5070 · Postage	19,159.15	17,530.57	1,628.58	9.29%
5075 · Insurance	5,817.62	3,656.94	2,160.68	59.08%
5076 · Insurance - Health	4,173.79	6,505.73	-2,331.94	-35.84%
5077 · Miscellaneous	4,794.17	6,604.05	-1,809.88	-27.41%
5078 · Bank Fees	4,154.56	0.00	4,154.56	100.0%
5080 · Office supplies	5,500.32	5,775.91	-275.59	-4.77%
5081 · Equipment, supplies & maint.	3,830.74	3,054.22	776.52	25.42%
5091 · Computer systems	10,005.45	8,040.41	1,965.04	24.44%
5095 · Salaries	235,125.95	199,535.84	35,590.11	17.84%
5096 · Temporary help & recruitment	255.00	2,141.25	-1,886.25	-88.09%
5097 · Outside Services	23,417.50	21,228.25	2,189.25	10.31%
5100 · Rent	17,400.00	17,400.00	0.00	0.0%
5105 · Utilities & Maid	4,887.98	4,905.17	-17.19	-0.35%
5110 · Telephone expense	6,077.57	5,617.10	460.47	8.2%
5120 · Accounting	7,610.35	7,327.06	283.29	3.87%
5125 · Payroll tax expense	18,181.50	15,287.21	2,894.29	18.93%
5130 · Depreciation expense	466.23	728.25	-262.02	-35.98%
5140 · Fundraising Software	4,367.79	5,554.60	-1,186.81	-21.37%
5160 · Fundraising - Mailhouse	8,576.81	9,898.00	-1,321.19	-13.35%
5161 · Fundraising - Postage	4,807.22	5,298.00	-490.78	-9.26%
5162 · Fundraising - Stationery	4,089.75	4,338.00	-248.25	-5.72%
5069 · SUPPORTING SERVICES - Other	0.00	0.00	0.00	0.0%
Total 5069 · SUPPORTING SERVICES	392,699.45	350,426.56	42,272.89	12.06%
Total Expense	459,619.55	465,359.40	-5,739.85	-1.23%
Ordinary Income	-1,357.73	-72,545.39	71,187.66	98.13%

Other Income/Expense

Other Income				
3906 · Permanently Restricted	10,000.00	0.00	10,000.00	100.0%
Total Other Income	10,000.00	0.00	10,000.00	100.0%
Net Other Income	10,000.00	0.00	10,000.00	100.0%
Net Income	8,642.27	-72,545.39	81,187.6 6	111.91 %

# ACOUSTIC NEUROMA ASSOCIATION STATEMENTS OF FINANCIAL POSITION DECEMBER 31, 2015 AND 2014

	2015	2014
ASSETS		
Cash and cash equivalents	\$ 64,350	\$ 73,748
Investments	175,256	175,939
Prepaid expenses	2,596	2,894
Deposits	744	744
Restricted cash and cash equivalents	5,755	4,755
Property and equipment	-	466
Endowment investments	163,407	154,417
Total assets	\$ 412,108	\$ 412,963
LIABILITIES Accounts payable	\$ 503	\$ -
Total liabilities	503	-
NET ASSETS		
Unrestricted - undesignated	242,443	248,758
Unrestricted - designated for endowment	153,407	154,417
Unrestricted - designated for research grant	-	5,033
Temporarily restricted	5,755	4,755
Permanently restricted	10,000	-
Total net assets	411,605	412,963

Total liabilities and net assets