



2016 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

- Over 14,000 *Notes* Newsletters distributed- issued quarterly
- Over 3,900 Patient Information Booklets distributed, covering eight topics of interest

Complimentary Program

- 798 Complimentary Packets of information sent to acoustic neuroma patients, caregivers, and medical professionals

AN Patient Events/Research Studies

- **2016 Events and Programs**

ABTA – Patient and Family Caregiver Conferences

3/16/16 Minneapolis/St. Paul , MN

05/21/16 Denver, CO

06/18/16 Atlanta, GA

10/15/16 Louisville, KY

USC Keck – AN Patient Education Day, Los Angeles

03/19/16

AAN – Brain Health Fair, Vancouver, BC

4/15/16

DHMC – AN Patient Education Day

4/30/16

ANA Support Groups

59 active ANA support groups listed on our website

- Reactivated groups - 4
 - Phoenix, AZ
 - Springfield, MA
 - Baltimore, MD
 - Milwaukee, WI
- New groups – 3 (areas we have never had groups before)
 - Napa/Sonoma, CA
 - Baton Rouge, LA
 - Salt Lake City, UT
- 15 new leaders/co-leaders
- 7 leaders/co-leaders stepped down
- Total number of meetings – 124 – 4% decrease from 2015
- Total meeting attendance – 1785 attendees vs. 2011 attendees in 2015, 12% decrease
- 2015 Support Group Initiatives
 - ANA volunteer representation at seven patient events
 - 35th Anniversary activities and resources for support group participation – resources on website, new photo gallery
 - Support Group survey sent to all active/inactive members

- Support Group Invitations phase out and successful transition to robocalls
- 6 new videos added to support group video library
- Recruitment for new leaders/new groups is ongoing
- Leader training is ongoing
 - 2 support group leader webinars held
 - 9 issues of *Feedback*, online Support Group newsletter
 - Leader resource notebook sent to leaders / co-leaders
 - New closed Facebook page for leaders
 - Review/update of support group tools/resources to leader notebook and website leader section ongoing

ANetwork

- 49 active participants
 - 13 new participants added
 - 8 participants cycled off
 - Screening/renewal/education is ongoing
 - ANetwork list expanded to include talking points and patient's age at time of treatment

Social Media, Webinars, ANAwareness Week

Facebook

4,898 Likes on Facebook at the end of 2016 - 20% increase from 2015

- 2016 - 1200 Page Likes
- 2015 - 1130 Page Likes
- 2014 - 985 Page Likes
- 2013 - 654 Page Likes

- Average Facebook Post Reach, defined as the number of people our posts were served to was 2,051 - a 61% increase over 2015
- Average Total Reach, defined as the number of people who were served any activity from our page including posts, posts to our page by other people, page like ads, mentions and checkins was 1,250 - this is almost a 100% increase over 2015.
 - Average Likes per post - 40
 - up from 30 in 2015
 - 33% increase
 - Average Comment per post - 10
 - no increase over 2015
 - Average Share per post - 12
 - up from 8 in 2015
 - 50% increase

Twitter

684 followers

- up from 437 - 57% increase in one year

Instagram

202 followers

- New this year - no past data

Pinterest

8 followers

- No past data - page is approximately 2 months old
- 178 pins on 19 boards
- Boards include Awareness, Balance, Brain Teasers, Facial Weakness, Fatigue, Brain Food, Headaches, Hearing, Inspiration, Mindfulness, The Anatomy of AN, Tinnitus, New Normal, Staying Positive, Symptoms, AN Warriors, Memory, AN Humor and Videos

Webinar Program

The webinar program continues to be a successful program with 7 ANA member webinars, 2 public webinars and 2 support group leader webinars, for a total of 11 webinars held in 2016. Nine doctors volunteered their time to present on the following topics: hearing preservation, radiation, tinnitus, cognitive and emotional issues, facial reanimation, facial and eye issues, and balance. We also had three doctors volunteer to sit on a panel and answer patient questions on multiple subjects as well as 3 patients who volunteered to discuss their new normal.

Overall registration for the webinars (excluding the support group leader webinars) totaled 2,596 and overall attendance was 1,250. That is a 48% attendance rate, which exceeds the average 35-40% attendance rate for most webinars.

ANAwareness Week

- The Fourth Annual ANAwareness Week was presented in May 2016 with a brand new theme of I cAN! We simplified the program focusing on patient interaction, information dissemination and fundraising.
- We asked people to send inspiring photos and videos of themselves doing things they thought might be impossible after their diagnoses
- We held two webinars - one "Ask the Docs" and one on Tinnitus - that were viewed by over 300 people
- We had record viewings/interactions on Facebook
- We updated the ANAwareness Week portion of the ANA website to a simpler, more visually appealing and easy-to-navigate format
- We created and sold t-shirts, which can be seen in many of the submitted photos
- Promotion for the event was on The ANA website, our social media platforms, and blast emails to ANA members
- The sponsorship program grew from 11 sponsors in 2015 to 18 sponsors in 2016!

Development

Planned Giving Program

Acoustic Neuroma Legacy Society was created in 2013. This program recognizes those who have included ANA in their estate plans. Participants are acknowledged in the newsletter and on the website. Since the inception of the Legacy Society, twenty-two individuals have designated ANA in their will or other planned giving.

ANAwareness Week

- Fourth annual ANAwareness Week, a national campaign to make the public aware of the symptoms and treatment options and highlight the importance of early detection of acoustic neuromas, was presented May 8-14 and coincided with Brain Tumor Awareness Month in 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.
- Eighteen corporations and medical centers served as sponsors for the event and participated in ANAwareness Week activities.

Giving Tuesday

- ANA's #GivingTuesday campaign on Nov. 29 was a grassroots fundraising campaign in which ANA supporters emailed friends, family, colleagues and others to request support for our important cause.

Peer-to-Peer Fundraising

- TEAM ANA, peer-to-peer fundraising program, is a way for supporters to help ANA by fundraising within their local communities and with friends and family.
- The TEAM ANA online fundraising platform was launched in March enabling supporters to create personal fundraising webpages, promote fundraisers and collect donations all without leaving the ANA website. This platform will allow ANA to keep nearly 100% of all funds raised.
- ANA supporters participated in 8 events/activities. Events included various runs and walks, a dinner party and two fitness challenges.

Board of Directors

[ANA Board of Directors - 2016](#)

President

Karla Jacobus, - Cary, NC

Vice President

Laura Barbaro – Andover, MA

Treasurer

John Gigliello - Niskayuna, NY

Secretary

David Puzzo - St. Petersburg, FL

Members at Large

Luke Bagato – Western Springs, IL

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 - San Francisco, CA
Kim Simington - Ringoes, NJ
Joseph A. Vargo, III – Cresson, PA
Deborah R. Walls - New Whitehead, IN

Immediate Past President

Alan Goldberg - New York, NY

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

Babak Azzizadeh, MD, FACS - Facial/Nasal Plastic Surgery - Beverly Hills, CA
Fred Barker, MD - Neurosurgery - Boston, MA
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 Surgery - Boston, MA
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
Philip V. Theodosopoulos, MD - Neurosurgery - San Francisco, CA

Chairman Emeriti

Albert L. Rhoton, Jr., MD

Staff

Allison Feldman, Chief Executive Officer
Jennifer Farmer, Director of Programs and Development
Melanie Hutchins, Manager of Volunteer Programs
Karen Davare, Assistant to CEO
Christie Cullinan, Office Assistant
Melissa Baumbick, Communications Specialist

Audit

An audit of 2016 financial records for ANA was completed in February 2015 by Shawn Orth, WBO CPA Group

STATEMENTS OF FINANCIAL POSITION
As of December 31, 2016 and 2015

ASSETS		
	2016	2015
CURRENT ASSETS		
Cash and cash equivalents	\$ 194,485	\$ 64,350
Investments, at fair value Accounts Receivable	136,190	175,256
Prepaid expenses	4,250	
	5,579	2,596
Deposits	744	744
Restricted cash and cash equivalents Endowment Investments	\$ 528,051	\$ 412,108
	<u>179,048</u>	<u>163,407</u>
	<u>528,051</u>	
Accounts payable	\$ -	503
Total current liabilities		503
NET ASSETS		
Unrestricted - undesignated	341,248	
Unrestricted - designated for endowment	169,048	153,407
Temporarily restricted	7,755	5,755
Permanently restricted	10,000	10,000
		\$ <u>503</u>
LIABILITIES AND NET ASSETS CURRENT LIABILITIES:		
	528,051	411,605
	<u>528,051</u>	<u>412,108</u>
	\$ <u>528,051</u>	\$ <u>412,108</u>