



2017 Annual Report

Mission and Purposes

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

MISSION

The Acoustic Neuroma Association, the premier resource to the acoustic neuroma community, informs, educates and supports those affected by acoustic neuroma brain tumors.

VISION

To continually improve the lives of Acoustic Neuroma patients and their families through communication, support, innovation and partnerships with the medical community.

VALUES

- Respect: to honor the needs and privacy of acoustic neuroma patients
- Professionalism: to maintain high ethical standards at all times
- Objectivity: to remain free of bias in everything we do
- Patient Centricity: to place the patient and their community at the forefront of all ANA efforts

Publications

Our *Notes* Quarterly Newsletter, mailed to more than 16,000, contains medical articles, patient stories, volunteer highlights and other articles of interest to the acoustic neuroma community.

- ANA offers eight Patient Information Booklets covering: diagnosis, brain anatomy, treatment options, eye issues, vestibular rehabilitation, facial issues, headaches and hearing

Complimentary Program

ANA provides complimentary Patient Kit of information to acoustic neuroma patients, caregivers, and medical professionals, plus a free three-month membership. In addition, ANA provides a free, annual membership to acoustic neuroma patients who cannot afford membership dues.

Membership

ANA membership includes the following benefits:

Receipt of our quarterly ANA newsletter, *Notes*

Access to the member section of our website, which includes:

- Patient information booklets on diagnosis, brain anatomy, treatment options, eye issues, vestibular rehabilitation, facial issues, headaches and hearing

- Webinar library on current treatment trends, emotional and cognitive issues, acoustic neuroma research, balance, facial, and eye issues, coping and much more
- Webinar transcriptions
- Newsletter library of current and back issues of our *Notes* newsletter with valuable medical articles plus patient stories, information about volunteering with ANA, programs and events

ANA Patient Programs

2017 Summary of activities: *Development of new volunteer programs and enhancement of current volunteer programs. Ongoing collaboration and development of partnerships with new and existing peer organizations, medical centers, vendors and others.*

Support Group Program “Support Group” does not fully describe the extent of the support that groups provide. Although support is a big part of what groups do best, they provide so much more! Encouragement, networking opportunities and outstanding presentations from a variety of guest speakers are highlights of these meetings.

Support groups are open to all AN patients, family members, caregivers and interested persons. We welcome AN patients at every stage of their journey, whether just diagnosed and seeking information, or are many years post-treatment and want to support and encourage new attendees. There is no charge to attend.

Group meetings vary based on the educational topic and guest speaker. Some meetings may focus on an educational format only while others may be strictly supportive; frequently meetings feature elements of both. The supportive meetings feature an open format, which allows attendees some degree of anonymity, participating only if they are comfortable. For some, simply attending meetings and listening to the experiences of others can be helpful.

2017 Summary

Support Groups	60
2017 Meetings	140
2017 Attendance	1708
Leaders and Co-Leaders	74

Volunteer resources

- VeDA support group leader quarterly video conference events
- Educational webinars in leader section of website
- *Feedback* – online newsletter - quarterly
- SG Leader Resource Notebook – ongoing updates and additions
- SG Leader Section of website
- Support Group Video Library on website (1,598 page views)
- Support Group Leader closed Facebook page

- Support Group Leader biennial survey
- One-on-one orientation, review of resources
- Ongoing one-on-one education, updates, support
- Connect to a peer mentor
- SG banners/signage
- Customized meeting packets as needed
- Volunteer opportunities at events
- Connection to local research opportunities
- Connection to local peer organizations
- Connections to local, non-ANA meetings/events of interest to AN patients, i.e. hearing expos, health fairs, etc.

ANetwork

- ANetwork handbook
- List of helpful peer organizations
- List of ANA support groups
- Current set of handbooks sent to new participants and at renewal
- ANetwork Participant biennial survey, next one 2019
- One-on-one orientation, review of resources
- Ongoing one-on-one education, updates, support
- Connect to a peer mentor
- Volunteer opportunities at events

The ANetwork, Nationwide Peer Support Program consists of acoustic neuroma patients and family members/caregivers who are willing to talk about their acoustic neuroma experience. These volunteers provide information, encouragement, and support to other acoustic neuroma patients via telephone and email. Personal contact with other patients is a strength of ANA, and we encourage pre- and post-treatment ANA members to take advantage of this important resource.

The ANetwork list includes volunteer participants covering all treatment types, various tumor size and representative demographics from across the U.S. as well as dates and types of treatment and talking points on other acoustic neuroma related treatment issues.

Community Connections are informal meeting opportunities, organized by ANA volunteers, held in local communities across the U.S. Join other acoustic neuroma patients for casual networking time and find encouragement and support through shared experiences. AN patients, family and friends are welcome.

Storytelling Volunteers provide a unique type of support. Finding common personal experiences are so important to others that may be searching for a story that resembles their own. Anyone affected by acoustic neuroma has a story to tell. It's essential to speak up – one person's story could be invaluable to someone. It is also an important way for

patients and care partners to make a difference, raise awareness and help ANA share the many voices that represent the AN community.

Patient Milestones/Anniversaries There are milestones or anniversaries that people remember as a significant event noting a special achievement during the AN journey from a very personal, individual perspective. For some, a milestone can be making a tough treatment decision after months of information gathering. For others, it may be a treatment anniversary, or perhaps reaching a specific goal after treatment. Whether large or small, milestones and anniversaries are meaningful markers and are as unique as the individual. We hope that seeing these realistic and personal events, submitted by patients, caregivers or family members, will provide a sense that people affected by acoustic neuroma will find comfort from others who have faced similar circumstances.

Bilingual Volunteer Videos - brief video messages promoting ANA resources and how to connect with a bilingual volunteer have been added to our website.

Webinar Program

Eight webinars and one Facebook Live Event were held in 2017, reaching over 5,000 participants:

Resiliency Skills to Improve Symptom Management and Quality of Life

- Hosted by Ana-Maria Vranceanu, PhD, Clinical Health Psychologist and Associate Professor of Psychology - Harvard Medical School

The Treatment of Hearing Loss and Tinnitus in Patients with Acoustic Neuroma

- Hosted by Ravi N. Samy, MD, FACS, Neurotology/Skull Base Surgery - University of Cincinnati Department of Otolaryngology and Lisa Houston, AuD - University of Cincinnati Department of Otolaryngology - Division of Audiology

AN Regrowth: A Discussion of Treatment Options

- Hosted by Dr. Jennifer Moliterno, MD, Neurosurgeon - Yale University School of Medicine and Dr. James Yu, MD, Radiation Oncologist - Yale University School of Medicine

Headaches and Acoustic Neuroma

- Hosted by Dr. Mark B. Eisenberg, MD, FAANS, Chief, Department of Neurosurgery - Long Island Jewish Medical Center

Doctor-Patient Communication in Acoustic Neuroma Decision Making and Management

- Hosted by Dr. Randall Porter, MD, Neurosurgeon - Barrow Neurological Institute

Hearing Solutions for Acoustic Neuroma Patients

- Hosted by Dr. Calhoun Cunningham, MD, Otolaryngologist and Andrea Bailey, Audiologist - Duke Otolaryngology of Raleigh, Duke University Medical Center

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Facebook Live Event - ANA LIVE

“One Couple’s AN Journey”

- Hosted by Kevin and Sherrie Robbins

Ask the Docs

Hosted by Dr. Steven Giannotta, Chair of Neurological Surgery at Keck Medicine of USC, Dr. Paul Lambert, Professor and Chair of the Department of Otolaryngology -- Head and Neck Surgery at the Medical University of South Carolina and Dr. Moises Arriaga, Director of Otology – Neurotology and Professor of Otolaryngology and Neurosurgery at Louisiana State University.

ANAwareness Week

2017 ANAwareness Week was held May 7-13. The fifth annual ANAwareness Week was a great success as the AN community showed its strength, courage, positivity and heart. Patients and loved ones proudly wore AN Warrior t-shirts, submitted photos and videos, shared your stories, spread the word about acoustic neuroma and raised funds for ANA’s patient-focused education and support programs.

During this year’s ANAwareness Week, we aimed to bring patients management strategies to help them be their best. Many AN patients credit their happiness and well-being to their focus on improving quality of life by making smart treatment decisions, finding support, continued AN education, choosing a healthy lifestyle, building stronger relationships, being mindful, staying positive and being their own best advocate for care.

Development

2017 Fundraising Summary Total fundraising in 2017 was \$392,303 - an increase of 7% over 2016.

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-six individuals have designated ANA in their will or other planned giving.

Peer-to-Peer Fundraising Individuals who increase awareness of acoustic neuroma while raising funds for the Acoustic Neuroma Association are considered members of Team ANA. Funds raised by Team ANA are used to advance the knowledge and understanding of acoustic neuroma. Team ANA exists to give supporters a way to make a meaningful difference in their community.

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 - 2017](#)

President

Karla Jacobus, Cary, NC

Vice President

Chad Nye, Lakeland, FL

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

Meredith Daly – Atlanta, GA

Neil Donnenfeld – Swampscott, MA

Roberta C. Hutchings - Westminster, CO

Leah Keith - Los Angeles, CA

Joel Perrell, Jr. - Baltimore, MD

Miranda Sacharin – New York, NY

Tom Sattler - San Francisco, CA

Joseph A. Vargo, III – Cresson, PA

Scott Van Ells – Flagstaff, AZ

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

ANA MEDICAL

ADVISORY BOARD

CO-CHAIRMEN

Calhoun D. Cunningham, III, MD

Duke Health, Raleigh, NC

David S. Haynes, MD, FACS

Vanderbilt Medical Center, Nashville, TN

MEMBERS

Siviero Agazzi, MD, FACS

University of South Florida Health, Tampa, FL

Chrisfouad R. Alabiad, MD

Bascom Palmer Eye Institute, Miami, FL

Babak Azizzadeh, MD

Center for Advanced Facial Plastic Surgery, Beverly Hills, CA

Steven D. Chang, MD

Stanford Health Care, Palo Alto, CA

Christopher J. Farrell, MD

Thomas Jefferson University Hospital, Philadelphia, PA

Steven L. Giannotta, MD

Keck School of Medicine of USC, Los Angeles, CA

Shannon E. Kahn, MD

Emory Healthcare, Atlanta, GA

Joseph J. Montano, Ed.D.

Weill Cornell Medical College- NY Presbyterian Hospital, New York, NY

Ravi N. Samy, MD, FACS

University of Cincinnati

Gardner Neuroscience Institute, Cincinnati, OH

Marc S. Schwartz, MD

University of California San Diego, San Diego, CA

Patrick Shumrick, DPT

The Center for Balance and Dizziness, Cincinnati, OH

Kris Siwek

University of California San Diego, San Diego, CA

Rafael J. Tamargo, MD

Johns Hopkins Medicine, Baltimore, MD

Ana-Maria Vranceanu, PhD

Harvard Medical School/ Massachusetts General Hosp., Boston, MA

Staff

Allison Feldman, Chief Executive Officer

Jennifer Farmer, Director of Programs and Development

Melanie Hutchins, Manager of Volunteer Programs

Stephanie Rommer, Project Manager

Kristin von Meyer, Specialist

Holly Stone, Office Assistant

Melissa Baumbick, Communications Specialist

Audit

An audit of 2017 financial records for ANA was completed in February 2018 by Shawn Orth,
WBO CPA Group

ACOUSTIC NEUROMA ASSOCIATION
(A Not-for-Profit Organization)
STATEMENTS OF FINANCIAL POSITION
As of December 31, 2017 and 2016

	ASSETS	
	2017	2016
CURRENT ASSETS		
Cash and cash equivalents	\$ 280,705	\$ 194,485
Investments, at fair value	161,396	136,190
Accounts Receivable	21,600	4,250
Prepaid expenses	764	5,579
Deposits	744	744
Restricted cash and cash equivalents	11,188	7,755
Endowment Investments	186,648	179,048
	\$ 663,045	\$ 528,051
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES:		
Accounts payable	\$ 2,440	\$ -
Total current liabilities	2,440	-
NET ASSETS		
Unrestricted - undesignated	470,369	341,248
Unrestricted - designated for endowment	169,048	169,048
Temporarily restricted	11,188	7,755
Permanently restricted	10,000	10,000
	660,605	528,051
	\$ 663,045	\$ 528,051

See accompanying notes and independent auditors' report

ACOUSTIC NEUROMA ASSOCIATION
(A Not-for-Profit Organization)
STATEMENT OF ACTIVITIES
For the year ended December 31, 2017 and 2016

	<u>2017</u>	<u>2016</u>
<i>UNRESTRICTED NET ASSETS</i>		
REVENUES, SUPPORT AND GAINS	\$ 376,731	\$ 360,016
Contributions	116,208	123,071
Membership	52,935	36,510
Website listings	1,500	6,500
Grants	4,514	2,271
Sale of materials	31,286	22,349
Investment return	<u>583,174</u>	<u>550,717</u>
Total unrestricted revenues, support and gains	<u>583,174</u>	<u>550,717</u>
EXPENSES AND LOSSES	266,577	266,430
Programs	121,366	111,339
Support services	66,110	58,502
Fundraising	<u>454,053</u>	<u>436,271</u>
Total expenses	<u>454,053</u>	<u>436,271</u>
losses on investments	-	-
Total expenses and losses	<u>454,053</u>	<u>436,271</u>
Change is unrestricted net assets	<u>129,121</u>	<u>114,446</u>
<i>TEMPORARILY RESTRICTED NET ASSETS</i>		
Contributions	<u>3,433</u>	<u>2,000</u>
Change in temporarily restricted net assets	<u>3,433</u>	<u>2,000</u>
<i>PERMANENTLY RESTRICTED NET ASSETS</i>		
Contributions	<u>-</u>	<u>-</u>
Change in permanently restricted net assets	<u>-</u>	<u>-</u>
Change in net assets	132,554	116,446
Net assets - beginning of year	<u>528,051</u>	<u>411,605</u>
Net assets - end of year	<u>\$ 660,605</u>	<u>\$ 528,051</u>

See accompanying notes and independent auditors' report