

Annual Report 2017



ACOUSTICNEUROMA
ASSOCIATION

When Virginia Fickel Ehr found the Acoustic Neuroma Association (ANA) in 1981, her goal was to ensure patients diagnosed with the rare disease had access to information that was easy to read and peer support to comfort and guide individuals through their AN journeys. Thirty-six years later, the organization has grown into the premier resource for the acoustic neuroma community, educating those impacted by acoustic neuroma through print, digital, and in-person experiences, and helping them cope with their diagnosis and manage treatment options.

Since its inception, ANA has been patient-focused, meaning our first priority is individuals diagnosed with acoustic neuroma. Patients have the opportunity to not only become a member, but to lead volunteer efforts for the AN community, or serve on our board of directors and help ensure the sustainability of the organization.

Our programs and services are designed to enhance an individual's knowledge and understanding of acoustic neuroma so they can make an informed decision about their diagnosis and treatment, and have a better quality of life.

We thank our donors for their volunteer time and charitable contributions to inform, educate, and support the AN community.



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

Our vision is 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

ANA

by the Numbers

SUPPORT GROUPS

60	Support groups
140	Support group meetings
1,708	Meeting attendees

VOLUNTEERS

121	ANA trained volunteers
2835	Volunteer hours
\$68,246.90	Total value of volunteer time

**Based on 2017 Independent Sector hourly rate of \$24.14*

DISCUSSION FORUM

10,200	Members
18,500	Topics
207,000	Posts

DIGITAL EDUCATION

7 webinars with 961 attendees
1 Facebook Live event with 4,100 views and 12,872 reach

812

Patients kits mailed worldwide

936

Patient Registry participants

3,946

Members

16,003

Newsletters mailed in U.S.

PROGRAMS

ANA Services

ANA's programs are made possible because of volunteers, charitable donors, board leadership, and staff who are united in our mission to inform, educate, and support members of the acoustic neuroma community. 2017 programs included:

PATIENT AND CAREGIVER SUPPORT

- Support Groups: formal, in-person support meetings led by trained AN peers
- ANetwork: telephone support network led by trained AN peers
- Community Connections: informal, in-person support led by trained AN peers
- Discussion Forum: online forum for AN patients and moderated by trained AN peers

EDUCATION AND AWARENESS

- Webinars / Facebook Live events
- *Notes* Newsletter: quarterly news source available in print and digital formats
- Videos: available in English, French, German, Spanish, and American Sign Language
- ANAwareness Week
- AN Volunteer Training and Volunteer Resource Library
- Patient Kits: Free kits that include booklets on diagnosis, brain anatomy, treatment, eye issues, vestibular rehabilitation, facial issues, headaches, and hearing

RESEARCH

- Patient Registry

PRIORITY AREAS

Strategic Plan 2017-2021

In 2017, the Acoustic Neuroma Association unveiled a strategic plan identifying four priority areas and goals to guide the organization through 2021.

PRIORITY AREA 1: ENGAGEMENT

Goals

- Increase knowledge in AN patients and caregivers by providing access to information through multiple entry points
- Increase support and reduce isolation of AN patients and caregivers
- Increase organizational visibility, relevance, and accessibility

PRIORITY AREA 2: FUNDRAISING

Goals

- Create a long-term financial management plan
- Raise \$3 million by 2022
- Reduce dependency on membership

PRIORITY AREA 3: GOVERNANCE

Goals

- Create an ongoing pipeline for volunteers, board members, and organizational leadership
- Restructure the Medical Advisory Board
- Diversify the Board of Directors

PRIORITY AREA 4: MEDICAL COMMUNITY CONNECTION

Goals

- Advocate for optimal outcomes and care coordination for AN patients at all stages
- Assist the medical community in advocating for ANA and promoting ANA services to the AN community.
- Establish ANA as a critical collaborator in research efforts

FINANCIALS

Fiscal Year 2017

REVENUES

Contributions	\$376,731
Membership Dues	\$116,208
Website Listings	\$52,935
Grants	\$1,500
Sale of Materials	\$4,514
Investment Return	\$31,286

TOTAL REVENUES **\$583,174**

EXPENSES

Program	\$266,577
Administration	\$121,366
Fundraising	\$66,110
Investment Loss	\$0

TOTAL EXPENSES **\$454,053**

2017 SPONSORS

Accuray • Barrow Neurological Institute • BostonSight
Duke Health • House Clinic • Integra
Jackie Diels Facial Retraining • Johns Hopkins Medicine
Keck Medicine of USC • Mayfield Brain & Spine • Mayo Clinic
NSPC Brain & Spine Surgery • NYU Langone Health • Oticon
Rush University Medical Center
The Facial Paralysis Institute • The Ohio State University
Wexner Medical Center • UC Health UC San Diego Health
Weill Cornell

