Annual Report 2017
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
- 2,835 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

## Other
- 812 Patients kits mailed worldwide
- 936 Patient Registry participants
- 3,946 Members
- 16,003 Newsletters mailed in U.S.
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
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