

# Annual Report 2018



ACOUSTIC**NEUROMA**  
ASSOCIATION

# Mission, Vision, Values

When Virginia Fickel Ehr founded 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-seven 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 are designed to enhance patient knowledge and understanding of acoustic neuroma so they can make an informed decision about their diagnosis and treatment.

## 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 2018

60 Support groups

138 meetings

1,638 attendees

## VOLUNTEERS

48 Peer Mentors

165 ANA-trained volunteers

10,416 Discussion Forum members

## 2018 Programs

435 Patient Education Event registrants

934 Webinar registrants

976 Patient Kits mailed worldwide

1,418 Patient Registry participants

3,677 Active members

16,755 Newsletters mailed

36,356 Average monthly website users

42,351 Facebook Live Event views



# ANA Programs and Services

ANA's programs are made possible because of volunteers, charitable donors, board leadership, medical advisory board and staff who are united in our mission to inform, educate, and support members of the acoustic neuroma community. 2018 programs included:

## **PATIENT AND CAREGIVER SUPPORT- led by trained volunteers**

- Support Groups: formal, in-person support meetings
- Peer Mentors: telephone, email and/or in-person support network
- Community Connections: informal, in-person support
- Discussion Forum: moderated online forum for AN patients and care partners

## **EDUCATION AND AWARENESS**

- Webinars, Facebook Live events, Video Presentations
- *Notes* Newsletter: quarterly news source available in print and digital formats
- 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

**ANA Patient Registry-** an online survey of the acoustic neuroma experience of diagnosis, treatment and quality of life

[WWW.ANAUSA.ORG](http://WWW.ANAUSA.ORG)- Our translatable website garners more than 30,000 views per month, and provides the most up-to-date information on acoustic neuroma.

# ANA 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. In 2018, the Board of Directors continued to guide the organization through this plan.

## PRIORITY AREAS

### **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

### **FUNDRAISING *Goals***

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

### **GOVERNANCE *Goals***

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

### **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 2018

## Revenues

Contributions	\$339,388
Membership	\$96,665
Website Listings	\$66,700
Sale of Materials	\$3,573
Investment Returns	(\$8,750)

<b>Total Revenues</b>	<b>\$497,576</b>
-----------------------	------------------

## Expenses

Programs	\$267,544
Administration	\$123,259
Fundraising	\$71,851

<b>Total Expenses</b>	<b>\$462,654</b>
-----------------------	------------------