

2022 Annual Report



ACOUSTICNEUROMA
ASSOCIATION

A Message from the CEO

Over 42 years, we have witnessed remarkable advancements in medical care, and I am proud to say that the ANA has been at the forefront of improving the lives of acoustic neuroma patients throughout this journey. We have witnessed firsthand the transformative power of medical progress, and we are committed to ensuring that the ANA continues to evolve alongside it.

Through collaboration with leading medical professionals and researchers, we have developed innovative programs to address the unique needs of acoustic neuroma patients, including comprehensive treatment guidelines, access to cutting-edge therapies, and a strong AN Community. We continually invest in enhancing our online platforms and expanding our outreach efforts. We connect with patients like never before, fostering a sense of community, and facilitating the exchange of knowledge.

To our patients, we are here for you every step of the way. You are our priority, and we remain committed to providing the resources and support you need to navigate your journey. To our supporters, we are immensely grateful for your generosity. Your contributions are put to good use, enabling us to make a lasting impact on the lives of acoustic neuroma patients.

The ANA will continue to innovate, as we strive for excellence in patient care. With unwavering support from the AN Community, the next 42 years will bring even greater advancements and breakthroughs. Thank you for joining us on this inspiring journey.

All the best,

Jim Shea
Chief Executive Officer



Our Mission

“The Acoustic Neuroma Association is the premier resource for the acoustic neuroma community. We inform, educate, and support those affected by acoustic neuroma brain tumors.”

The ANA was created to ensure that each patient diagnosed with an acoustic neuroma has access to information and peer support to help them through their journey.

The organization that Ginny Fickel Ehr – herself an acoustic neuroma patient - created in 1981 continues to do just that, and more. Patients, along with their families and caregivers, continue to be at the forefront of our efforts.

VISION and VALUES

To continually improve the lives of acoustic neuroma patients and their families through communication, support, innovation, funding research, and partnerships with the medical community.

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

Our Impact

Nationwide Patient Support Groups

We manage 50 geographic and virtual topic/affinity support groups throughout the country that hosted 110 in-person and virtual support group meetings with 1,200+ patients in attendance during 2022. Support group meetings also added 20 education-specific videos.

Peer Mentor Program

Our Peer Mentor Program engages patients, family members, and caregivers who are available to provide information, encouragement, and support via telephone, email and Zoom. We have 100 program volunteers nationwide.

ANA Patient Registry

Launched in 2017, 1,400+ patients have shared their journeys through our ANA Patient Registry. This is an industry-leading, patient-driven effort which encourages research, the speeding of therapies, and an overall increase in the general understanding of AN issues.

ANA Membership

More than 3,300 patients and caregivers joined us as members in 2022. Our membership benefits include up-to-the-minute content, in-person support, educational programs, and access to caring, experienced, knowledgeable volunteers.



Our Impact

NOTES Newsletter

Published quarterly, we deliver 14,000+ issues of our high-impact *NOTES* annually through mail and digital version. In addition to inspiring patient stories and highlights from our engaging AN Community, we partner with top healthcare providers and leading researchers to share in-depth knowledge related to diagnosis, treatment options, and post-treatment symptom management.



ANAU.SA.org and Discussion Forum

We hosted 248,000+ website visits and 636,000+ pageviews, while our volunteer-driven discussion forum - open to all members of the AN community - boasts a history of 211,000+ posts by more than 11,500 members covering 19,000+ topics.

Patient Kits

All members of the AN community are offered a complimentary patient kit, along with a three-month ANA membership. In 2022, we delivered 1,200+ patient kits that included information related to our support groups and peer mentor list, the latest issue of our *NOTES* newsletter, and a series of patient booklets.

Patient Booklets

Our informative patient booklets cover a wide range of topics - from balance and hearing to diagnosis and eye care. We entered 2022 with our newest booklet, “*Understanding Emotional, Cognitive and Behavioral Changes*”.

Our Impact

Webinars, Facebook LIVE Events, and Patient Support Group Presentations

In 2022, we hosted 34 virtual patient presentations in partnership with top medical centers and healthcare providers. Our topics included: Balance Issues, Facial/Eye Concerns, Headaches, Hearing/Audiology/Tinnitus, Treatment Options, Microsurgery, Radiation, Regrowth/Post-Treatment Issues, and Quality of Life.

ANAwareness Week

ANAwareness Week is our annual national campaign to increase awareness of symptoms and treatment options, and to highlight the importance of early AN detection. In 2022, we partnered in a virtual ANAwareness Week with our Diamond Sponsor, Ohio State University Wexner Medical Center, hosting 5 distinct webinar presentations.



AN Research – Patient Research Studies

The Acoustic Neuroma Association partners with researchers, healthcare providers, and medical centers to engage with the AN community in an effort to provide information and opportunities for AN patients to participate in research studies. The ANA partnered in five research studies during 2022, including partnerships with Washington University in St. Louis, UC San Diego Health, Mayo Clinic, Pacific Neuroscience Institute, and Massachusetts Eye and Ear Infirmary.

Our Impact

ANA Funded Research

In 2022, the ANA received unprecedented support, made possible through the generosity of The Greathouse Family Foundation. The Foundation provided a \$100,000 challenge grant – the largest contribution ever received by the ANA.

With this commitment came a challenge to raise an additional \$50,000. The AN Community exceeded that goal, adding \$62,500. This collaboration provided the funding for four additional acoustic neuroma research projects.

Current Research Efforts

The ANA has recently completed two funded research efforts in partnership with Mayo Clinic and UCLA Health, and we have invested \$170,000+ in current research through seven awards in partnership with leading researchers. Emory University, Keck School of Medicine (USC), Mount Sinai Medical Center, Washington University in St. Louis, University of California - San Diego Health, and University of California - San Francisco.



Our 2022 Partnerships

Diamond
Sponsor



Our 2022 Partnerships

Platinum
Sponsors

UC San Diego Health

MAYO
CLINIC



VANDERBILT  UNIVERSITY
MEDICAL CENTER

BARROW
Neurological Institute



Keck Medicine of **USC**
USC Acoustic Neuroma Center

Our 2022 Partnerships

Gold
Sponsors



Our 2022 Partnerships

Silver Sponsors



Our 2022 Partnerships

Bronze Sponsors



Our Team

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Manager, Membership and Development

Suvarna Damodaran

Operations Coordinator

Melanie Hutchins

Manager, Volunteer Programs and Publications

Holly Green

Manager, Healthcare Community Partnerships

Christina McCurdy

Accounting Coordinator

Stephanie Rommer

Manager, Digital Communications and Events

Jim Shea

Chief Executive Officer

Donna Sweigart

Outreach & Support Coordinator

Our 2022-23 Board of Directors

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Cameron Wick, MD
Washington Univ. Center for
Hearing and Balance Disorders

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Northwestern Medical Center

Daniel M. Zeitler, MD, FACS
Virginia Mason Medical Center

Our Audited Financial Information

As of December 31, 2022

Statement of Financial Position

ASSETS		LIABILITIES AND NET ASSETS	
Current Assets		Current Liabilities	
Cash and cash equivalents	\$ 534,825	Accounts payable	\$ 162,121
Investments, at fair value	<u>735,279</u>	Deferred Revenue	<u>10,000</u>
		Total current liabilities	<u>\$ 172,121</u>
Total Assets	\$ 1,270,104		
		Net Assets without donor restrictions	
		Undesignated	\$ 858,632
		Board designated endowment	<u>153,407</u>
			1,012,039
		Net Assets with donor restrictions	
		Temporarily restricted	<u>85,944</u>
		Total Net Assets	<u>1,097,983</u>
		Total Liabilities and Net Assets	1,270,104

Our Audited Financial Information

As of December 31, 2022

Statement of Activities

	Without Donor Restrictions	With Donors Restrictions	Total
Public Support and Revenue			
Contributions and grants	\$ 286,466	\$ 164,787	\$ 451,253
Membership dues	77,904	---	77,904
Sponsorships	203,500	---	203,500
Website Listings	48,560	---	48,560
Merchandise Revenue	9,827	---	9,827
Investment return	<87,392>	---	<87,392>
Miscellaneous Income	2,292	---	2,292
Total public support and revenue	541,157	164,787	705,944
Net Assets released from restrictions:			
Satisfaction of program restrictions	101,393	(101,393)	---
Total Public Support and Revenues	642,550	63,394	705,944

Our Audited Financial Information

As of December 31, 2022

Statement of Activities

	Without Donor Restrictions	With Donors Restrictions	Total
Expenses			
Program Expenses	\$ 398,638	\$ ---	\$ 398,638
Supporting Services:			
General Administrative	166,659	---	166,659
Fundraising	108,426	---	108,426
Total Expenses	673,723	---	673,723
Change in Net Assets	<31,173>	63,394	32,221
Net Assets at beginning of year	1,043,212	22,550	1,065,
Net Assets at end of year	\$ 1,012,039	\$ 85,944	\$ 1,097,983

www.anausa.org

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