

# 2023 Annual Report



**ACOUSTICNEUROMA**  
ASSOCIATION

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# A Message from the CEO

Imagine, for just a moment, the transformative power of the ANA mission and its impact on the journeys of those affected by acoustic neuromas. It's been happening for more than 40 years.

The Acoustic Neuroma Association is at the forefront of patient support, providing groundbreaking educational resources, a robust patient and medical community network, and one-of-a-kind research funding. You'll read more about all that in this annual report. The real message is this: As this superb AN Community continues to grow, so does the importance of our mission.

If you are reading this, we're in this together. If you're actively engaged with the ANA, thank you. We hope you're continuing to learn all that you need to know, and that you stay involved – it matters.

For those new to the ANA, we encourage you to take advantage of all that we offer. We'd also ask that you volunteer, make a donation, and be an ambassador for this terrific organization.

Together, we'll continue to make a difference in the lives of those affected by acoustic neuromas. The mission of the ANA matters, very much.

All the best,

Jim Shea  
Chief Executive Officer

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# 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



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# Our Impact

## ***ANA Membership***

*In 2023, 3,100+ patients and caregivers engaged with the ANA as members. Our membership benefits include expert content from AN healthcare providers, in-person support, educational programs, and access to caring, experienced, and knowledgeable volunteers.*

## ***Nationwide Patient Support Groups***

We oversee 50 geographic and virtual topic/affinity support groups across the country, which hosted 114 in-person and virtual meetings with over 1,500 patients in attendance throughout 2023. Thirty-nine of these meetings featured medical expert guest speakers.

## ***ANA In-Person Patient Education Events***

Our one-day, in-person events are held in various locations to allow patients and caregivers access to education, support, and networking with others in the AN community. Healthcare teams share expertise and insight, complete with one-on-one engagement with patients. UC San Diego Health and UH-Cleveland Medical Center hosted events in 2023 while Mount Sinai (virtual) and Pacific Neuroscience Institute will welcome patients for events in 2024.





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# Our Impact

## ***Peer Mentor Program***

Our Peer Mentor Program actively engages patients, family members, and caregivers, providing information, encouragement, and support, with 100+ program volunteers nationwide.

## ***NOTES Newsletter***

Published quarterly, our high-impact *NOTES* reaches 14,000+ recipients annually through both mail and digital formats. Each issue features inspiring patient stories and highlights from our vibrant AN Community. We collaborate with top healthcare providers and leading researchers to deliver in-depth knowledge on diagnosis, treatment options, and post-treatment symptom management.

## ***Patient Kits and Patient Booklets***

All members of the AN community are offered a complimentary patient kit, along with a one-month ANA membership. In 2023, 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.

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



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# Our Impact

## *Webinars and Facebook LIVE Events*

In 2023, 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 AN, symptoms, and treatment options, and to highlight the importance of early AN detection. In 2023, we partnered in a virtual ANAwareness Week with Akouos, hosting 6 distinct webinar presentations in partnership with UC San Diego Health, Mayo Clinic, Vanderbilt Health, Ohio State Wexner Medical Center, Cedars-Sinai, and University of Central Florida.

## *ANUSA.org and Discussion Forum*

We hosted 270,000+ website visits and 601,000+ pageviews, while our patient-moderated discussion forum - open to all members of the AN community - boasts a history of 212,000+ posts by more than 12,800 members covering 19,000+ topics.

**Acoustic neuroma: Observation versus early intervention - the evolution in treatment paradigms, and implications for long-term function**



**Tuesday, April 9th  
1pm ET**

**Dr. Rupa Juthani**





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# Our Impact

## *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 six research studies during 2023, including partnerships with Washington University in St. Louis, UC San Diego Health, Mayo Clinic, Pacific University, University of Miami, and Massachusetts Eye and Ear Infirmary.



## *ANA Funded Research*

In 2023, the Acoustic Neuroma Association received exceptional support, facilitated by the generosity of The Greathouse Family Foundation. The Foundation awarded a \$100,000 grant, matching the largest contribution ever received by the ANA, and bringing the Foundation's total research support to \$250,000.

## *Current Research Efforts*

The ANA has recently completed three funded research efforts in partnership with Mayo Clinic, UCLA Health, and USC Keck, and we have invested \$221,000+ in current research through eight awards in partnership with leading researchers. Emory University, Keck School of Medicine (USC), Mayo Clinic, Mount Sinai Medical Center, Washington University in St. Louis, UCLA Health, University of California - San Diego Health, and University of California - San Francisco.

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# Our 2023 Partnerships

ANAwareness  
Week  
Sponsor

The logo for AKOIOS, featuring the letters A, K, O, I, O, S in a teal, sans-serif font. The letters are stylized with some gaps and a modern, clean aesthetic.



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# Our 2023 Partnerships

Platinum  
Sponsors



UC San Diego Health



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# Our 2023 Partnerships

Gold  
Sponsors





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# Our 2023 Partnerships

Silver  
Sponsors



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# Our 2023 Partnerships

Bronze  
Sponsors





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## Our Team

**Matthew Balte**

*Manager, Development and Healthcare Partnerships*

**Suvarna Damodaran**

*Operations Coordinator*

**Melanie Hutchins**

*Manager, Volunteer Programs and Publications*

**Christina McCurdy**

*Accounting Coordinator*

**Stephanie Rommer**

*Manager, Communications and Engagement*

**Jim Shea**

*Chief Executive Officer*

**Donna Sweigart**

*Outreach & Support Coordinator*

## Our 2024-25 Board of Directors

**Ronson Mahla**

President

**Tracy Denmark Schwimmer**

Treasurer

**Meredith Mueller Daly, CPC**

Past President

**Kimberly Ary**

**Robin Batra**

**Randall Berger**

**Robert Chernoff**

**Cody Cooper**

**Amanda Nugent Divine**

**Samira Rajabi, Ph.D.**

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**David Kellogg**

Secretary

**Kathy Hill**

**Hela Kelsch, D.O.**

**Greg Kingsley**

**Jay Magrisso**

**Mary Ann Mugel**

**Tom Rand**

**Nancy Rhein**

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# Our 2024 Medical Advisory Board

**Co-Chair**

**Matthew L. Carlson, MD**  
Mayo Clinic

**Co-Chair**

**Ravi N. Samy, MD, FACS**  
Lehigh Valley Health Network

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Bascom Palmer Eye Institute

**Franco DeMonte, MD, FRCS (C), FACS**  
University of Texas MD Anderson  
Cancer Center

**Sheri Donaldson, PT, DPT, NCS**  
Balance Concepts/Face First Physical Therapy  
& Facial Retraining

**Christopher J. Farrell, MD**  
Thomas Jefferson University Hospital

**Melvin Field, MD**  
Advent Health

**Rick A. Friedman, MD, PhD**  
UC San Diego Health

**Rinki Goswami, MD, MSc**  
New York University

**Michael S. Harris, MD**  
Froedtert Medical College of Wisconsin

**P. Daniel Knott, MD, FACS**  
UC San Francisco

**J. Walter Kutz, Jr., MD**  
UT Southwestern Medical Center

**Jeffrey D. Markey, MD**  
Ascentist Healthcare

**Jennifer Moliterno, MD, FAANS**  
Yale University

**Randall Porter, MD, FAANS**  
Barrow Neurological Institute

**Gregory Russo, MD**  
Dartmouth – Hitchcock Medical Center

**Megan Sherod, PhD**  
University of Central Florida

**William H. Slattery, III, MD**  
House Clinic

**Konstantina Stankovic, MD, PhD, FACS**  
Stanford University School of Medicine

**Courtney Voelker, MD, PhD**  
Pacific Neuroscience Institute

**George Wanna, MD, MHCM, FACS**  
New York Eye and Ear Infirmary of Mount Sinai

**Cameron Wick, MD**  
Washington University School of Medicine

**R. Mark Wiet, MD, FACS**  
Northwestern Medicine

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



# Our Audited Financial Information

*As of December 31, 2023*

## Statement of Financial Position

ASSETS		LIABILITIES AND NET ASSETS	
<b>Current Assets</b>		<b>Current Liabilities</b>	
Cash and cash equivalents	\$ 476,525	Accounts payable	\$ 50,000
Investments, at fair value	810,599	Accrued expenses	11,510
Right-of-use assets	<u>4,867</u>	Lease liability	<u>1,775</u>
		Total current liabilities	\$ 63,285
<b>Total Assets</b>	<b>\$ 1,291,991</b>	Long-term liabilities – Lease	3,270
		<b>Net Assets without donor restrictions</b>	
		Undesignated	\$ 881,534
		Board designated endowment	<u>153,407</u>
			1,034,941
		Net Assets with donor restrictions	190,495
		Total Net Assets	<u>1,225,436</u>
		<b>Total Liabilities and Net Assets</b>	<b>1,291,991</b>

# Our Audited Financial Information

*As of December 31, 2023*

## Statement of Activities

	Without Donor Restrictions	With Donor Restrictions	Total
<b>Public Support and Revenue</b>			
Contributions and grants	\$ 281,646	\$ 105,565	\$ 387,211
Membership dues	74,540	---	74,540
Sponsorships	210,000	---	210,000
Website Listings	47,915	---	47,915
Merchandise Revenue	10,302	---	10,302
Investment income, net	80,481	---	80,481
	<hr/>	<hr/>	<hr/>
Total public support and revenue	704,884	105,565	810,449
	<hr/>	<hr/>	<hr/>
Net Assets released from restrictions: Satisfaction of program restrictions	1,014	(1,014)	---
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<b>Total Public Support and Revenues</b>	<b>705,898</b>	<b>104,551</b>	<b>810,449</b>



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# Our Audited Financial Information

*As of December 31, 2023*

## Statement of Activities

	Without Donor Restrictions	With Donors Restrictions	Total
<b>Expenses</b>			
Program Expenses	\$ 380,916	\$ ---	\$ 370,916
Supporting Services:			
General Administrative	186,700	---	166,659
Fundraising	125,380	---	125,380
<b>Total Expenses</b>	<b>682,996</b>	<b>---</b>	<b>682,996</b>
Change in Net Assets	22,902	104,551	127,453
Net Assets at beginning of year	1,012,039	85,944	1,097,983
<b>Net Assets at end of year</b>	<b>\$ 1,034,941</b>	<b>\$ 190,495</b>	<b>\$ 1,225,436</b>

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[www.anausa.org](http://www.anausa.org)

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