



ACOUSTICNEUROMA
ASSOCIATION

2021 Annual Report

A Message from the CEO

Every five years, the ANA connects with patients, caregivers, volunteers, healthcare providers, researchers, donors – our AN community – to develop impactful strategies that will drive our future efforts. We delve into programming, engagement, research, events, revenue distribution, and governance to chart a path forward. This past year, we began work on what will become our next Strategic Plan.

The staff and volunteer leadership of the ANA enthusiastically embrace the significance of this effort – the future of the Acoustic Neuroma Association depends on it.

In 2021, our 40th Anniversary, we engaged with tens of thousands of patients, managed more than 110+ support group meetings, worked with 100+ volunteers, produced meaningful educational webinars hosted by top medical experts, and, through generous philanthropy, funded our operation beyond our goals. This was a stellar year, and we continue to look forward.

We asked, as virtual interaction has become mainstream, what are the best ways we can support patients and caregivers, and how can we strike the ideal balance? We've made a significant commitment to research – how can we best develop that effort over the next five years? How do we make the most of the opportunities to strengthen our relationships within the medical community? How can we best fund all of the programs that have – and can have – the most impact for patients? Patients will always be at the forefront of our mission.

A robust future for the ANA is such an important goal - we can see now the many patients and caregivers experiencing the benefits of a strong ANA. We need to be here for these members of the AN community, and for those who have yet to receive an AN diagnosis. I hope that you will join us in creating the future of the Acoustic Neuroma Association.

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 had access to information and peer support to help them through their acoustic neuroma 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

To continually improve the lives of acoustic neuroma patients and their families through communication, support, innovation, funding research, 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

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 1,377 patients in attendance during 2021. 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 to other AN patients and caregivers via telephone & email. We have 46 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 3,400 patients and caregivers joined us as members in 2021. 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 12,500+ 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.

ANAUSA.org and Discussion Forum

We hosted 269,000+ website visits, while our volunteer-driven discussion forum - open to all members of the AN community - boasts a history of 210,000+ posts by more than 11,000 members covering 19,000+ topics.

Patient Kits

All members of the AN community are offered a free patient kit, along with a complimentary three-month ANA membership. In 2021, we delivered 940+ 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. 2021 saw us introduce a new booklet, “*Understanding Emotional, Cognitive and Behavioral Changes.*”

Our Impact

Webinars and Facebook LIVE Events

In 2021, we hosted 28 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 2021, we partnered in a virtual ANAwareness Week with our Diamond Sponsor, Mayo Clinic, hosting 13 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 2021, including partnerships with Washington University in St. Louis, UC San Diego Health, Mayo Clinic, and Massachusetts Eye and Ear Infirmary.

Our Impact

ANA Funded Research

In 2021, with leadership from our board – specifically, a Research Committee that included directors with backgrounds as researchers and healthcare providers – the ANA established new, comprehensive standards for our program. These definitive proposal and eligibility guidelines confirmed to the research community our mission to “further all aspects of scientific knowledge related to acoustic neuromas, including its cause(s), development, and treatment, thus improving the lives of individuals living with AN, and finding its ultimate cure.”

We received an unprecedented number of proposals from leading medical centers throughout the country. Through the generosity of the Greathouse Family Foundation – a \$50,000 grant representing the largest contribution ever received by the ANA – the ANA ultimately approved three proposals for funding during 2021.

The ANA currently funds five research studies, deploying \$109,000+ through partnerships with the University of Southern California – Keck School of Medicine (2), UCLA, Mayo Clinic, and Emory University.

Our 2021 Partnerships

Diamond
Sponsor



Our 2021 Partnerships

Platinum
Sponsors

UC San Diego Health



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



Our 2021 Partnerships

Gold
Sponsors



Our 2021 Partnerships

Silver
Sponsors



Our 2021 Partnerships

Bronze
Sponsors

ACCURAY



Our Team

Melissa Baumbick
Manager, Development & Outreach

Holly Green
Finance and Data Manager

Melanie Hutchins
Manager, Volunteer Programs

Stephanie Rommer
Project Manager

Jim Shea
Chief Executive Officer

Donna Sweigart
Outreach and Support Coordinator

Our 2022-23 Board of Directors

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Our 2021 Medical Advisory Board

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OH

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UC San Diego Health - La Jolla, CA

Megan Sherod, PhD

University of Central Florida - Orlando, FL

Kris Siwek

UC San Diego Health - La Jolla, CA

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Konstantina Stankovic, MD, PhD, FACS

Harvard Medical School - Boston, MA

R. Mark Wiet, MD, FACS

Rush University Medical Center - Chicago, IL

Daniel M. Zeitler, MD, FACS

Virginia Mason Medical Center - Seattle, WA

Our Audited Financial Information

As of December 31, 2021

Statement of Financial Position

ASSETS		LIABILITIES AND NET ASSETS	
Current Assets		Current Liabilities	
Cash and cash equivalents	\$ 393,067	Accounts payable	\$ 70,502
Investments, at fair value	762,453	Deferred Revenue	20,000
Deposits	<u>744</u>		
		Total current liabilities	\$ <u>90,502</u>
Total Assets	\$ 1,156,264	Net Assets without donor restrictions	
		Undesignated	\$ 889,805
		Board designated endowment	<u>153,407</u>
			1,043,212
		Net Assets with donor restrictions	
		Temporarily restricted	<u>22,550</u>
		Total Net Assets	<u>1,065,762</u>
		Total Liabilities and Net Assets	1,156,264

Our Audited Financial Information

As of December 31, 2021

Statement of Activities

	Without Donor Restrictions	With Donors Restrictions	Total
Public Support and Revenue			
Contributions and grants	\$ 311,901	\$ 55,550	\$ 366,451
Membership dues	86,092	---	86,092
Sponsorships	220,500	---	220,500
Website Listings	51,325	---	51,325
Merchandise Revenue	10,284	---	10,284
PPP Loan forgiveness	55,000	---	55,000
Investment return	44,435	---	44,435
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Total public support and revenue	779,537	55,550	835,087
	<hr/>	<hr/>	<hr/>
Net Assets released from restrictions: Satisfaction of program restrictions	53,000	(53,000)	---
	<hr/>	<hr/>	<hr/>
Total Public Support and Revenues	832,537	2,550	835,087

Our Audited Financial Information

As of December 31, 2021

Statement of Activities

	Without Donor Restrictions	With Donors Restrictions	Total
Public Support and Revenue			
Program Expenses	\$ 399,839	\$ ---	\$ 399,839
Supporting Services:			
General Administrative	185,580	---	185,580
Fundraising	88,480	---	88,480
Total Expenses	673,899	---	673,899
Change in Net Assets	158,638	2,550	161,188
Net Assets at beginning of year	884,574	20,000	904,574
Net Assets at end of year	\$ 1,043,212	\$ 22,550	\$ 1,065,762

www.anausa.org

Acoustic Neuroma Association

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