



ACOUSTIC **NEUROMA**
ASSOCIATION

2019 Annual Report

A message from the CEO

As an organization, our staff and board of directors work to improve lives. That's a simple statement – much more involved in practice, I promise you – but one that drives everyone here at the Acoustic Neuroma Association.

When I'm asked about the current state of the ANA, "fortunate" comes to mind. We engage with volunteers across the country who are committed to our mission. We have relationships with donors who make generous philanthropic contributions each and every year. Our members share a unique, empathetic and supportive bond, and our collaborations within the medical community are true partnerships – and they're considerably strong.

The ANA is fortunate, for sure. Acoustic neuromas are relentless, though, and diagnoses, treatments, and recoveries continue. So does our critically important mission – we are relentless, too. We have more work to do to advance our role as the premier resource to the acoustic neuroma community and help improve the lives of patients and their families.

We commit to that in so many ways: in our communications, how we facilitate patient support, our approach to innovation, and, of course, our collaborations with medical professionals, including our commitment to partnering in – and funding – research.

As you read through our Annual Report and understand more about all that we do, I'd like you to consider your role in the AN community. You are part of a considerable effort to improve outcomes, to improve lives. We are so appreciative that you are with us.

If you are not already engaged with the ANA, I'd invite you to become involved. We're fortunate that we partner with – and are supported by – so many dedicated colleagues in service to acoustic neuroma patients and their families. Visit us at anausa.org to learn more.

All the best,

Jim Shea

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

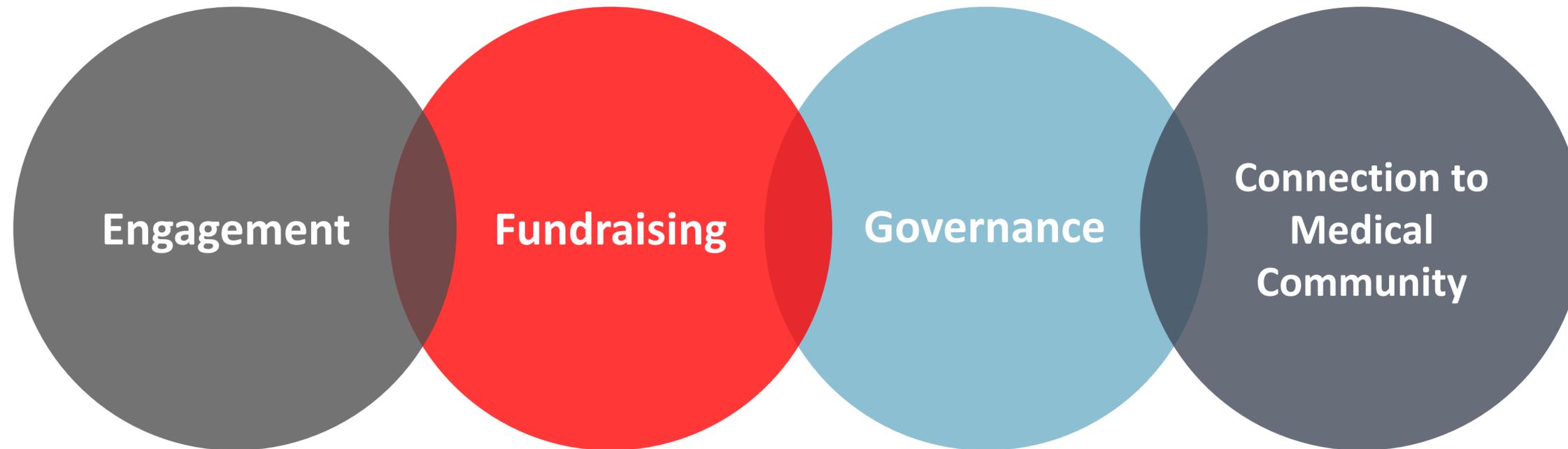
Respect: to honor the needs and privacy of acoustic neuroma patients

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 Areas of Priority



The ANA continues to provide information, education, and support, designed to ultimately increase the likelihood for optimal outcomes for patients. We've increased our emphasis on strategy, fundraising, and financial stability, including our duty for oversight and transparency. We're expanding our efforts in research, including a commitment to increase funding. We're focused on effective volunteer management and cultivating our partnerships within the medical community in the broadest and most inclusive sense.

Our Impact

Nationwide Patient Support Groups

We manage 50 active groups throughout the country that hosted 127 in-person meetings during 2019. Coming in 2020: launch of our virtual support group meetings.

Peer Mentor Program

Patients, family members and caregivers provided information, encouragement, and support to other AN patients via telephone & email. We have 55 volunteers nationwide.

ANA Patient Registry

Launched in 2017, we have 1,168 completed surveys. 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 3,500 patients and caregivers joined us as members in 2019. Our members are provided with up-to-the-minute content, in-person support, educational programs, and access to quality volunteers.

Our Impact

NOTES Newsletter

Published quarterly, we deliver close to 15,000 issues of our high-impact *Notes* annually.

ANA In-Person Patient Education Events

We partnered with Stanford University Health and University of Cincinnati Health to host conferences in 2019, providing more than 480 patients, family members and caregivers opportunities to connect, in person, with medical experts on a wide range of topics.

ANUSA.org and Discussion Forum

We had 279,000 website visits, while our volunteer-driven discussion forum - open to all members of the AN community - boasts 10,000+ members.

ANA Research

We partnered with four online and four in-person research studies in 2019. One research grant was awarded, to University of Southern California – Keck School of Medicine, with results expected in 2020.

Our Impact

Webinars and Facebook LIVE Events

870 viewers joined our 2019 webinars while 23,000+ participants joined us for our Facebook LIVE events. Our topics included: Balance Issues, Facial/Eye Concerns, Headaches, Hearing/Audiology/Tinnitus, Treatment Options, Microsurgery, Radiation, Regrowth/Post-Treatment Issues and Quality of Life.

Patient Kits

All members of the AN community are offered a free patient kit, along with a complimentary three-month ANA membership. In 2019, we delivered 950+ patient kits that included information related to our support groups, our peer mentor list, the latest issue of our newsletter (*NOTES*) and a series of patient booklets.

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. Through social media, our reach through various channels such as Facebook, Instagram and Twitter extended past 92,000 imprints.

Our 2019 Partnerships

Platinum
Sponsors



UC San Diego Health



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



Our 2019 Partnerships

Gold
Sponsors



Our 2019 Partnerships

Silver
Sponsors



Our 2019 Partnerships

Bronze
Sponsors



Our Team

Melissa Baumbick
Manager, Development & Outreach

Melanie Hutchins
Manager, Volunteer Programs

Angela Johnson
Member Services Coordinator

Stephanie Rommer
Project Manager

Jim Shea
Chief Executive Officer

Kristin von Meyer
Manager, Analytics

Our 2020-21 Board of Directors

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Tracy Denmark Schwimmer

Our 2020-21 Medical Advisory Board

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Co-Chair

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Nashville, TN

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Bascom Palmer Eye Institute - Miami, FL

Matthew L. Carlson, MD

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Thomas Jefferson University Hospital
Philadelphia, PA

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Orlando Neurosurgery - Winter Park, FL

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UT Southwestern Medical Center - Dallas, TX

Jeffrey D. Markey, MD

ENT Associates of Greater Kansas City
Kansas City, MO

Joseph J. Montano, Ed.D.

Weill Cornell Medicine - New York, NY

Ravi N. Samy, MD, FACS

UC Gardner Neuroscience Institute - Cincinnati, OH

Marc S. Schwartz, MD

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

William H. Slattery, III, MD

House Clinic - Los Angeles, CA

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, 2019 and 2018

	ASSETS			
		<u>2019</u>		<u>2018</u>
CURRENT ASSETS				
Cash and cash equivalents	\$	248,855	\$	339,588
Investments, at fair value		248,113		159,582
Accounts Receivable		15,650		9,226
Prepaid expenses		-		764
Deposits		744		744
Endowment Investments		<u>271,242</u>		<u>188,223</u>
	\$	<u>784,604</u>	\$	<u>698,127</u>
LIABILITIES AND NET ASSETS				
CURRENT LIABILITIES				
Accounts payable	\$	<u>2,095</u>	\$	<u>600</u>
Total current liabilities		2,095		600
NET ASSETS				
Unrestricted – undesignated		619,102		534,120
Unrestricted – designated		153,407		153,407
Temporarily restricted		-		-
Permanently restricted		<u>10,000</u>		<u>10,000</u>
		<u>782,509</u>		<u>697,527</u>
	\$	<u>784,604</u>	\$	<u>698,127</u>

Our Audited Financial Information

As of December 31, 2019 and 2018

UNRESTRICITED NET ASSETS

	<u>2019</u>		<u>2018</u>
REVENUE, SUPPORT AND GAINS			
Contributions	\$ 396,282	\$	339,388
Membership	98,641		96,665
Web, Grants, Sale of materials, miscellaneous income	78,896		70,273
Investment return	<u>55,437</u>		<u>(8,750)</u>
 Total unrestricted revenue, support and gains	 <u>629,256</u>		 <u>497,576</u>
Contributions released from restrictions	<u>-</u>		<u>13,188</u>
 EXPENSES AND LOSSES			
Programs	349,985		267,544
Support services	122,111		123,259
Fundraising	<u>72,178</u>		<u>71,851</u>
 Total expenses and losses	 <u>544,274</u>		 <u>462,654</u>
 Change in Unrestricted Net Assets	 84,982		 48,110
Change in Temporarily Restricted Net Assets	-		(11,188)
Change in Permanently Restricted Net Assets	-		-
 Change in Net Assets	 84,982		 36,922
 Net Assets - beginning of year	 697,527		 660,605
 Net Assets – end of year	 \$ <u>782,509</u>	 \$	 <u>697,527</u>

www.anausa.org

Acoustic Neuroma Association
600 Peachtree Parkway, Suite 108
Cumming, GA 30041
770.205.8211