



ACOUSTIC**NEUROMA**
ASSOCIATION

2020 Annual Report

A message from the CEO

This year marks the 40th Anniversary of the Acoustic Neuroma Association. Founded by Ginny Fickel Ehr in 1981, the ANA has had a remarkable impact supporting patients, and is established now as the premier resource for the AN community.

If you're reading this, you've probably played a role in that success. Thank you! Patients, volunteers, medical partners, staff, friends, family, and donors have helped make the ANA what it is today. When you reflect on how many patients have benefited from the work of the ANA, consider your own impact. In whichever ways you are engaged with us, please know we appreciate your support.

So, what's next? The future of the ANA can be found in what we're doing today:

Expanding the ways we connect with patients and deliver much-needed support;

Engaging leading medical experts representing an ever-widening range of specialties;

Broadening our substantial menu of topics and content for all of our educational opportunities, both online and in-person;

Increasing our investment in support of cutting-edge research.

We continue to build on an impressive record of success, providing countless opportunities for education, engagement, support, and research. The Acoustic Neuroma Association is at the forefront in the AN community, serving as leader, partner, and advocate. With our unwavering commitment to patients, we hope you will create our future with us.

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

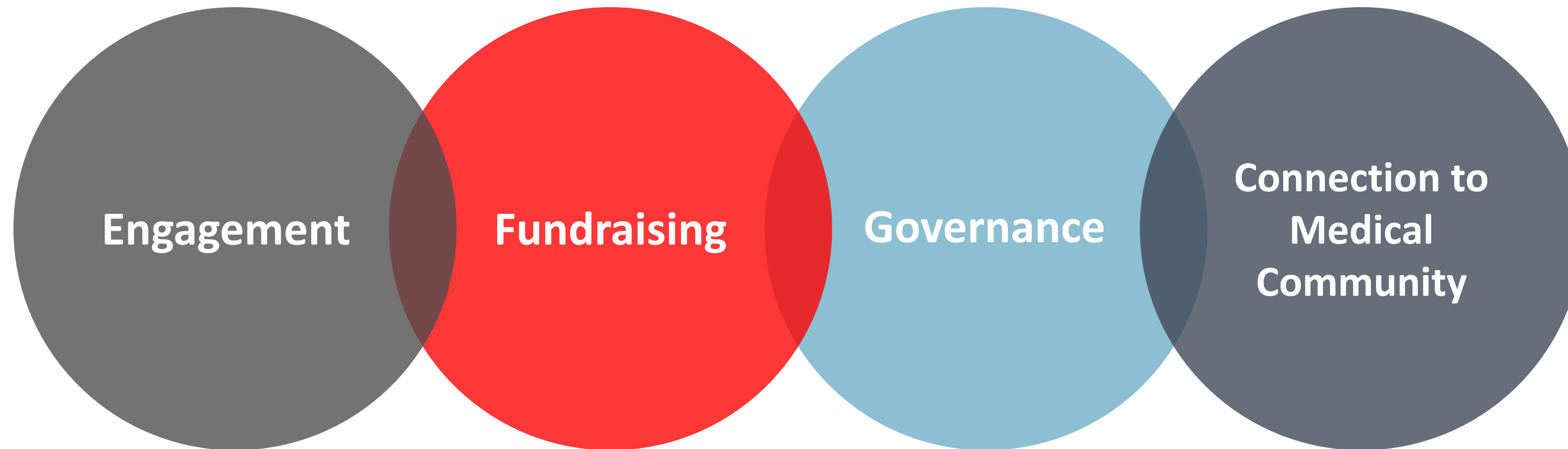
Respect: to honor the needs and privacy of acoustic neuroma patients

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 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 geographic and virtual topic/affinity support groups throughout the country that hosted 91 in-person and virtual support group meetings during 2020.

Peer Mentor Program

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

ANA Patient Registry

Launched in 2017, we have 1,400+ 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 3,400 patients and caregivers joined us as members in 2020. 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 21,000+ issues of our high-impact *Notes* annually through mail and electronic delivery.

ANA Virtual Patient Education Events

We partnered with UC San Diego Health and UT Southwestern Medical Center to host virtual conferences in 2020, providing patients, family members and caregivers opportunities to engage with medical experts on a wide range of topics.

ANUSA.org and Discussion Forum

We had 210,000+ 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 6 research studies in 2020, providing opportunities for patients to participate. Funded research in 2020 includes partnerships with the University of Southern California – Keck School of Medicine and Mayo Clinic.

Our Impact

Webinars and 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 2020, we delivered 950+ patient kits that included information related to our support groups and 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. In 2020, we presented our first-ever *virtual* ANAwareness Week, in partnership with our Diamond Sponsor, UC San Diego Health.

Our 2020 Partnerships

Diamond
Sponsor

UC San Diego Health

Our 2020 Partnerships

Platinum
Sponsors



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

Our 2020 Partnerships

Gold
Sponsors



Our 2020 Partnerships

Silver
Sponsors



Our 2020 Partnerships

Bronze
Sponsors

ACCURAY



Our Team

Melissa Baumbick
Manager, Development & Outreach

Melanie Hutchins
Manager, Volunteer Programs

Stephanie Rommer
Project Manager

Jim Shea
Chief Executive Officer

Kristin von Meyer
Manager, Analytics

Our 2021-22 Board of Directors

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Megan Sherod, PhD

University of Central Florida - Orlando, FL

Kris Siwek

UC San Diego Health - La Jolla, CA

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R. Mark Wiet, MD, FACS

Rush University Medical Center - Chicago, IL

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Virginia Mason Medical Center - Seattle, WA

Our Audited Financial Information

As of December 31, 2020 and 2019

UNRESTRICITED NET ASSETS

| | <u>2020</u> | | <u>2019</u> |
|---|-------------------|----|----------------|
| REVENUE, SUPPORT AND GAINS | | | |
| Contributions | \$ 403,172 | \$ | 396,282 |
| Membership | 92,047 | | 98,641 |
| Website Listings, Grants, Sale of materials, misc. income | 70,776 | | 78,896 |
| PPP Loan forgiveness | 35,000 | | - |
| Investment return | <u>42,122</u> | | <u>55,437</u> |
| | | | |
| Total unrestricted revenue, support and gains | <u>643,117</u> | | <u>629,256</u> |
| | | | |
| Contributions released from restrictions | <u>-</u> | | <u>-</u> |
| | | | |
| EXPENSES AND LOSSES | | | |
| Programs | 260,501 | | 349,985 |
| Support services | 190,490 | | 122,111 |
| Fundraising | <u>80,061</u> | | <u>72,178</u> |
| | | | |
| Total expenses and losses | <u>531,052</u> | | <u>544,274</u> |
| | | | |
| Change in Unrestricted Net Assets | 112,065 | | 84,982 |
| | | | |
| Change in Temporarily Restricted Net Assets | 10,000 | | - |
| Change in Permanently Restricted Net Assets | - | | - |
| | | | |
| Change in Net Assets | 122,065 | | 84,982 |
| | | | |
| Net Assets - beginning of year | 782,509 | | 697,527 |
| | | | |
| Net Assets – end of year | \$ <u>904,574</u> | \$ | <u>782,509</u> |

www.anausa.org

Acoustic Neuroma Association

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