

# **News and Announcements – July 2023**

### ANA Live - View on Facebook or Zoom

Wednesday, July 12 at 2 pm ET

**Decision Making and Treatment Options for Acoustic Neuroma Patients,** Presented by Richard M. Wiet, MD, Stephan Munich, MD and Ken Tatebe, MD, PhD, Rush University

#### ANAwareness Week – August 6-12

We look forward to sharing presentations from a variety of presenters on AN topics and helping to raise awareness of acoustic neuroma. Thank you to our presenting sponsor, Akouos, for partnering with us in *Sharing Knowledge, Supporting Patients*.

### **Patient Education Event – Registration opens soon!**

Saturday, September 23, 2023 - UH Cleveland Medical Center, Cleveland, OH

### Notes Quarterly Newsletter - June 2023 highlights

- Medical Report, Facial Nerve Preservation in Radiosurgery and Surgical Resection: A review of data and future innovations, By Anubhav Chandla, Mahlet Mekonnen, B.S., Yelena Malkhasyan, B.S., Isaac Yang, M.D., FAANS, F.A.C.S., UCLA Health
- Patient Stories Facial Paralysis Journeys and Helpful Tips
- ANA Research Grant Updates
- Ally's Act H.R. 2439 and S. 1135 2023 Update

#### **ANA Membership**

Thousands of acoustic neuroma patients and caregivers understand the value of ANA membership. In return, we value our members by providing up-to-the-minute content, in-person support and educational programs and access to our quality volunteers. Membership benefits include:

- Subscription to our quarterly ANA newsletter, Notes
- List of patient/care partner volunteers for one-on-one peer support
- Access to the member section of our website:
  - Newsletter library
  - Patient booklets
  - Webinar library
  - Peer Mentor volunteers for one-on-one support
  - Q & A with Providers Video Library

### The ANA's Newest and Updated Publications

- Hearing Loss Rehabilitation for Acoustic Neuroma Patients (Revised/Updated May 2022)
  - Hearing loss is the most common disability in acoustic neuroma patients and impacts one's quality of life. This booklet can help you understand options for pre-treatment hearing preservation as well as the many rehabilitation options available for both bilateral and unilateral hearing loss.
- Newly Diagnosed Handbook (Published Feb. 2022)
  - This handbook is intended to help people who are newly diagnosed with acoustic neuromas navigate what is often an overwhelming amount of information related to the diagnosis and treatment of this benign brain tumor.
- Acoustic Neuroma: Understanding Emotional, Cognitive and Behavioral Changes (Published June 2021)

  This educational booklet helps you understand the emotional, cognitive and behavioral changes associated with AN and provide you with information about what you may be experiencing and offer strategies to help you manage your symptoms and concerns.

Booklets are free to ANA members. You can view the electronic version in the <u>Member Section</u> of the ANA website or <u>contact us</u> to request the print version. If you are not an ANA member, <u>join today</u> or <u>order</u> the booklets only for a small fee.

### **Employment Considerations Reference Guide**

We've created an employment reference guide as a starting point for you. The information comes from patients, volunteers, and caregivers. Each AN journey is unique, and employment situations can certainly be distinctive. We encourage you to use this resource to consider a variety of situations, questions, and options. This is not meant to be comprehensive, nor should it be considered legal advice. Please reach out to us with comments/suggestions at info@anausa.org.

## **Resources for Young Adults with Acoustic Neuroma**

- Young Adult Facebook Group
  - This is a closed group moderated by ANA Staff and Volunteers. https://www.facebook.com/groups/ANAYoungAdults
- Young Adult Online Support Group
  - The group meets quarterly via Zoom and is moderated by ANA volunteers.
  - For more information, contact: Emily Truell, Peer Mentor, emily@lacampground.com
- Peer Mentor Program

Peer Mentors are volunteers who are acoustic neuroma patients and caregivers that are willing to talk about their acoustic neuroma experience. They provide information, encouragement, and support to other acoustic neuroma patients via phone and email. Information about peer mentors is provided in our free patient kit or contact us to request a peer match today.

## **Support Groups**

The ANA offers a variety of support groups so that you can find what is best for you and your situation, including:

- Geographic support groups across the U.S.
- Specialty support groups
- Co-sponsored support group with a medical partner

All Support Group meetings are free and open to anyone affected by acoustic neuroma, we look forward to welcoming you at a meeting soon. When you are ready, we are here. Visit the <u>ANA website</u> for more information and to find a group.

### **ANA Website Resources**

- ANA Store Shop for ANA branded merchandise and help support ANA programs.
- AN Research Learn more and participate in AN studies
- Community Features include patient stories, fundraising ideas and volunteer opportunities.
- <u>Events</u> View upcoming events calendar and register today.
- Get Involved Explore volunteer opportunities and increase awareness and raise funds for ANA.
- Healthcare Provider Listing A starting place to locate healthcare providers.
- Member Portal Find information booklets, newsletters, educational webinars and list of peer mentors
- News and Announcements stay up-to-date on news, events, and other items of interest.
- Social Media stay connected on <u>Facebook</u>, <u>YouTube</u>, <u>Instagram</u> and <u>Pinterest</u>
- Video Library Browse webinars, Facebook Live events, support group meetings

### **Team ANA - Fundraise for the ANA!**

- Increase awareness of acoustic neuroma while raising funds for the ANA.
- Create your own fundraisers through Facebook, Walk4Hearing, or any individual fundraiser held locally.
- Contact Matthew Balte at <a href="matthewbalte@anausa.org">matthewbalte@anausa.org</a> if you are interested in raising funds for the ANA!

# **ANA Legacy Society**

Philanthropic support is critically important to fulfilling the mission of the ANA. Our Legacy Society represents unique, exceptionally generous contributors who have included the ANA in their estate plans. This forward-looking philanthropy will have a remarkable impact on the future of the ANA. We are so very grateful for the commitments made by our Legacy Society members.

- To begin the conversation, please contact us at 770-205-8211 or email <u>development@ANAUSA.org</u>.
- You will also want to seek the advice of an attorney who specializes in estate planning.