

Acoustic Neuroma Association History

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Diagnosis and treatment of acoustic neuroma is a pivotal event in the life of a patient. Much of the rest of his or her life is defined in terms of "before or after my acoustic neuroma."

The physician who frequently deals with cranial tumors may be relieved that the etiology of the patient's symptoms is discovered and that the cause is a benign tumor. The patient, on the other hand, may never have dealt with surgery or serious illness and may be devastated by new and uncertain information, fearing the worst. After treatment, the physician's appraisal of his patient's results may be quite positive, while the patient's assessment of the same results can differ. Altered levels of hearing and balance, or perhaps some loss of facial function, are often a source of ongoing distress to the acoustic neuroma patient.

The Acoustic Neuroma Association (ANA) was established in an effort to improve the patient's treatment experience and subsequent recovery by providing realistic and accurate patient information and by offering opportunities for positive interaction with other acoustic tumor patients.

ANA's 25 years of contact with patients has indicated that:

- (1) **most find encouragement** and support from association with other acoustic neuroma patients
- (2) **realistic patient information** can reduce anxiety and fear prior to treatment, and provide guidance for rehabilitative alternatives and coping strategies later
- (3) **outcomes have improved** in recent years and many patients find themselves able to return to normal lives, grateful for early involvement with ANA, and no longer needing ongoing support
- (4) **the desire to help others** is often a motivating factor for patients wishing to remain involved with the Acoustic Neuroma Association, thus perpetuating its existence.

Founded by a recovered patient

ANA was founded in Carlisle, Pennsylvania, in 1981 by a recovered patient, Virginia Fickel Ehr, who found no patient information or patient support available when she had surgery for the removal of an acoustic tumor in 1977. She resolved that future patients diagnosed with acoustic neuroma would not face the same difficulties. With the help of her surgeon, she assembled eight patients who made up ANA's first volunteer Executive Board, and the first annual meeting of that Board was held in Vestal, New York. The Association was incorporated and received tax-exempt status 501(c)(3).

ANA was initially funded with member donations. Since 1981, additional programs to

serve patients have been established and are being maintained, some providing vital funding. ANA continues to be primarily member-funded, but additional fundraising sources are continuously being explored.

Within a year of ANA's founding, the National Institutes of Health, a number of international experts in this field, and other recovered patients recognized the need for an information and support group for those affected by acoustic neuroma. Support from several recognized surgeons involved in acoustic neuroma treatment was quickly forthcoming, thereby paving the way for immediate growth of this patient-founded, patient-led nonprofit association. ANA has grown; there are currently over 5,000 members.

Purposes

The following purposes of ANA were established in 1981:

1. **To provide support and information** for patients who have experienced acoustic neuromas or other tumors affecting the cranial nerves
2. **To act as an information source**, including current medical advances, for physicians and health care personnel interested in the treatment of benign tumors and the alleviation of post-surgical problems experienced by patients
3. **To promote and support research** on the cause, development, and treatment of acoustic neuroma and other benign cranial tumors
4. **To educate the public** regarding symptoms suggestive of acoustic neuroma, thus promoting early diagnosis and consequent successful treatment.

A mission statement was adopted by the Board in April 2006 and reads as follows:

The mission of Acoustic Neuroma Association (ANA) is to inform, educate and provide national and local support networks for those affected by acoustic neuromas, and to be an essential resource for health care professionals who treat acoustic neuroma patients.

Medical Advisory Board

A small Medical Advisory Board was established when ANA was founded. While unwritten criteria had previously existed for Medical Advisory Board membership, formal criteria were not established until 1995, when this body also began to hold regular annual meetings. ANA currently has 14 Medical Advisory Board members, 2 of whom serve as co-chairmen—a neurosurgeon and a neurotologist. Members serve for terms of 5 years, and

- (1) **function as advisors to ANA** on medical matters, recommending policy when appropriate
- (2) **write and/or review articles** written for newsletter publication
- (3) **create, revise, and/or update patient-education literature**
- (4) **provide sponsorship for ANA national symposia** when possible.

A pivotal event in ANA's evolution involved a statement recommended by the Medical Advisory Board in early 2001, adopted by the Executive Board in October of that year, reading as follows: "ANA recommends treatment from a medical team with substantial

acoustic neuroma experience.” The adoption of that statement was intended to enhance outcomes by demonstrating ANA’s belief that treatment of acoustic neuroma by a medical team with extensive experience is critical to a patient’s best chance for a successful outcome. This policy statement appears on the front page of every issue of ANA NOTES, the quarterly newsletter of the Acoustic Neuroma Association.

Quarterly Newsletter

The development of ANA's member programs began in 1981 with the publication of a quarterly newsletter, NOTES. The newsletters began then and continue today to contain medical articles, letters from patients, information about ANA activities around the country and the world, a list of contributors, and other items of interest to acoustic neuroma patients and their families. In December 1986, an addition was made to NOTES called VOYAGES, an annual newsletter insert containing longer patient narratives, and has since become part of every newsletter. NOTES are sent to all members of ANA and are one of the primary sources for disseminating information to patients about acoustic neuroma and ANA.

Critical to the dissemination of information by ANA, the previously discussed policy statement is now prominently displayed in every issue of ANA NOTES, and patients are directed to the Medical Resources link on the ANA website to find medical criteria to be used in the selection of medical professionals.

National Symposia

The first national ANA symposium for members was a 1-day meeting held in 1982 in Hershey, Pennsylvania, with the purposes of--
(1) determining how to help one another and
(2) determining how to find other acoustic tumor patients.

Early symposia were held annually, and gradually began to include more and more medical information, until 1989 when the Executive Board voted to hold future national symposia biennially beginning in 1991 with the Atlanta symposium. The location of these meetings was determined by a sponsoring physician willing to undertake a project of this magnitude, and the existence of a local group of ANA volunteers.

National symposia have grown to three-day meetings. Programs have expanded, but original goals have been maintained. There is a keynote speaker (usually the sponsoring physician), workshops on various medical and non-medical aspects of acoustic neuroma, sharing opportunities and social gatherings. In the early years, these meetings were entirely organized and financed by one of ANA's local groups with local donations, and always with the advice and consent of national ANA. Today, national symposia are a joint financial and organizational effort between the sponsoring physician and the national ANA office, with valuable help and input from a local group of ANA volunteers.

In 1985, the Executive Board began allocating funds dedicated to providing financial aid to members who were unable to attend national ANA symposia. The amount allocated

each year increased until the first scholarship fund was established for this purpose in 1989, dedicated as a memorial to a former Executive Board member. Today, four such scholarship funds exist, financed through separate donations, to provide symposium attendance for ANA members in need of financial assistance, with funds distributed based on the number of applications received.

The composition of attendees at these national meetings has changed over the years, and symposia now include a relatively equal number of pre-treatment and post-treatment patients.

Patient Information Publications

Publication of ANA's first comprehensive booklet written for the lay person about acoustic neuroma (*Acoustic Neuroma*) was published in 1983, along with an information pamphlet about acoustic neuroma and the existence of the Acoustic Neuroma Association. The original *Acoustic Neuroma* booklet was eventually updated to be a basic overview of acoustic neuroma, and additional patient information booklets have been added to ANA's list of publications:

- *Acoustic Neuroma Basic Overview*
- *A Glimpse of the Brain*
- *Diagnosis: Acoustic Neuroma: What Next?*
- *Improving Balance Following Treatment for Acoustic Neuroma*
- *Eye Care After Acoustic Neuroma Surgery*
- *Facial Nerve and Acoustic Neuroma: Possible Damage and Rehabilitation*
- *Headache Associated with Acoustic Neuroma Treatment*
- *Acoustic Neuroma Experience – 1998 Member Survey*
- *Hearing Loss – Rehabilitation for Acoustic Neuroma Patients*

All booklets are periodically updated and new publications are added when appropriate. A single copy of each booklet is provided to patients upon request, and all booklets are available in the ANA office for purchase in bulk by medical professionals and interested others.

Patient Surveys

In 1983, a nine-page questionnaire was mailed to 832 ANA members in 44 states, Canada, and Australia, with 541 returns (65%). This self-assessment survey was conducted with the assistance of ANA's medical research advisor. Results were published in several issues of *NOTES* from December, 1984, until December, 1986, in a patient

information booklet in 1988 (*The Acoustic Neuroma Experience*), and in *Laryngoscope* in 1989. Other smaller patient surveys have been conducted on headache, tinnitus, and facial paralysis, and results have been published in *NOTES*.

Plans began in 1996 for an updated patient satisfaction survey, again assisted by ANA's medical research advisor, with a professional statistician. This questionnaire was mailed to 2,372 ANA members, and 1,940 questionnaires were returned (82%). Some of the responders to this new survey may have participated in the first survey. Results were again published in several issues of *NOTES* beginning in 1999, in a new patient information booklet shortly thereafter, and discussed in *Laryngoscope* in 2004.

The Board of Directors is developing plans to conduct a new patient survey in the near future.

Local Groups

By 1983, ANA's mailing list had grown to over 1,000 people, with members in every state. In some areas, members wanting more frequent contact with other members were able to meet occasionally. In 1985, the Executive Board issued ANA's first Local Group Guidelines, signaling the beginning of ANA's organized effort to establish local groups around the United States.

Today there are over 5,000 people on ANA's mailing list, with 50 local groups in 27 states. They range from small social group meetings for coffee, to large, well-organized groups, meeting from one to four times a year. Some larger groups have occasionally held a regional meeting in a year when there was no national ANA symposium.

While composed primarily of ANA members, local groups operate autonomously and function as local extensions of the national effort, operating with the same goals as ANA. They are asked to encourage national ANA membership, and to refrain from planning activities in conflict with national ANA events. Guidelines were most recently updated in 2005, and ANA continues to fulfill its purpose of support and information.

Leaders of local groups are provided with:

- (1) guidance and assistance in planning and conducting local meetings
- (2) ANA's patient information literature
- (3) a list of all ANA members in their areas
- (4) a newsletter for local leaders.

In 1987, a local leaders meeting was established which meets at each symposium, with representatives attending from each local group. ANA provides financial support for local leader attendance.

New groups continue to be established as recovered patients choose to contribute to the support process for others.

Exhibits

Virginia Ehr's early efforts at informing professionals about ANA services and disseminating ANA patient literature began in 1983 when she was allowed to exhibit at a national physician association meeting. For many years after that, ANA was provided with complimentary exhibit space at annual meetings for several professional associations, among them American Academy of Otolaryngology-Head and Neck Surgeons, Society of Otorhinolaryngology and Head-Neck Nurses, American Association of Neurological Surgeons, Congress of Neurological Surgeons, American Association of Neuroscience Nurses, North American Skull Base Society, and American Association of Audiology. This practice was gradually discontinued in the mid-90's due to ANA's increased national and international profile in the medical community, increased ANA exposure on the internet, and rising costs of travel.

International Affiliations

In 1984, ANA's Executive Board established reciprocal affiliations with national acoustic neuroma associations in other countries when patients in Canada and Australia organized their own organizations. Associations have subsequently been founded in Denmark, Germany, Great Britain, New Zealand, and a second association in Australia, all officially affiliated with ANA-USA.

Acoustic Neuroma Registry

In 1988, funds were allocated by the ANA Executive Board for an acoustic neuroma registry. In 1989, information packets were sent to surgeons, and data began to be collected. The Acoustic Neuroma Registry contained a representative database of information in statistical form on acoustic neuroma, submitted voluntarily from dozens of multi-institutional sources. The registry included data on most aspects of acoustic neuroma including symptoms, tumor size, surgical approach or radiosurgery, effects of monitoring, hearing preservation, facial and other morbidity and follow-up examination reports. The goal was a long-term acquisition of a large volume of information concerning this disorder. Registry results were discussed in many issues of NOTES beginning in February, 1991, issue #37, and in a *Laryngoscope* article published in January 1996. By June 1996, information on over 3,000 cases had been entered.

ANA was the only patient organization to own a registry of medical data provided by surgeons (over 30 of them). There was no other broad, multi-source base in existence for determination of statistics about acoustic neuroma, and the broader the participant base, the more diversified the information, so additional participation was sought. Physician-participants received semi-annual reports on Registry data, and could request additional Registry information in statistical form. All data sources were anonymous. ANA funded the management of the Registry as a program, fulfilling its goal to support research on the treatment of acoustic neuroma and rehabilitation of acoustic tumor patients.

The goals of the Registry were laudable, and for the time it was collected, it was valuable and unique information with implications for future use. Results, however, became increasingly difficult to obtain due to new privacy laws and a declining ability to follow up. The Board of Directors decided to discontinue this project in the late 1990's.

National Office

In early 1992, ANA's president and founder stepped down and the ANA office moved from Carlisle, Pennsylvania, to Atlanta, Georgia. Virginia Fickel Ehr became President Emeritus and a new president was elected. The transition was made from a volunteer staff to a salaried executive director, and was accomplished with no interruption in service to patients.

Today, ANA presidents serve two-year terms, and can be re-elected for one additional term. The office continues to function with its Executive Director and staff in Cumming, GA, north of Atlanta, governed by an executive board of 13. All information is distributed and programs are administered from the ANA office.

Worldwide Web

In the early years of its existence, the ANA office housed a library with reference books and medical article reprints available for members to borrow. Information on acoustic neuroma was limited.

In 1995, two volunteers designed and put into place an ANA homepage on the Internet, thereby providing a new mechanism for distribution of information to patients. All physicians or medical centers wanting to link their homepage with ANA's homepage were invited to do so, thus providing patients with greater access to ANA and acoustic neuroma information.

The method of getting information today, however, is vastly improved, and volumes of information can be found on the Web. In 2005, the Board of Directors decided to update the ANA website. Physicians and medical centers now can discuss with ANA the opportunity of linking to ANA's homepage at www.ANAUSA.org. New on our website is a listing of medical resources.

ANA as a Resource

Most patients today contact the ANA office in Atlanta either by e-mail or via the website, although a few still use the telephone. They may have learned about ANA from a physician, a nurse or other professional, the Internet, a friend or acquaintance, or any of a number of other resources. In response, an information packet is sent immediately, and each new patient contact receives an initial complimentary membership and subsequent ANA mailings including the quarterly newsletter. ANA mails over 1,000 packets of information per year. About 10% of these packets go to either family members or medical professionals requesting them, and the remainder is almost equally divided between pre-treatment and post-treatment patients.

Medical professionals requesting information are sent complimentary samples of ANA patient information booklets with a form for ordering in bulk, an ANA newsletter, and a membership form providing an opportunity to receive *NOTES*. A number of medical professionals order ANA literature to distribute to their new acoustic neuroma patients, and can stay in touch with ongoing patient issues by becoming members and receiving

the ANA newsletter. Some physicians involved in frequent treatment of acoustic neuroma also choose to enroll each newly treated patient in ANA for one year.

New patient contacts receive comprehensive information about acoustic neuroma and treatment options (*Acoustic Neuroma Basic Overview*), pre-treatment information, if appropriate (*Diagnosis Acoustic Neuroma: What Next?*), an ANA brochure, a membership donation form, an order form for additional ANA material, the latest issue of the ANA newsletter, *NOTES*, access to a network of local support groups, and a list of persons willing to talk about their acoustic neuroma experience.

Type of treatment and post-treatment difficulties are tracked in ANA's database, if that information has been provided. New members who request, therefore, can be referred to those patients who have chosen the same type of treatment option or who have experienced similar post-treatment difficulties—headache or cognitive problems, for example—if permission has been given. New ANA members are, therefore, able to find immediate support from other recovering patients as well as a source for additional information to aid in their own successful recovery.

Conclusion

Advances in technology and increased awareness of unilateral hearing loss as a possible indication of acoustic neuroma often allow for earlier diagnosis and, therefore, smaller tumors. This leads to multiple treatment options where ANA can play a greater role. The ANA office, however, still receives mail and phone calls from patients who have had large tumors, and rehabilitation and/or long-term coping strategies may be required. According to members, many patients have found that contact with ANA and one of its local support groups is beneficial.

The growth of ANA since 1981 reflects that ANA plays a key role in the recovery of patients who have been treated for acoustic neuroma. ANA provides a unique opportunity for interaction and information exchange for those sharing a common experience, which can be a positive step before treatment as well as in the rehabilitation process after treatment. ANA, by its existence and growth, continues today to encourage members of the medical community to identify and implement ways to improve the recovery of acoustic neuroma patients.

Note: Sallye Anderson was treated for an acoustic neuroma in 1974 and became a member of ANA in 1984. She served on the Executive Board in 1986 as Secretary for six years. In 1992 she was elected President of ANA, succeeding Ginny Fickel Ehr, founder and first ANA President, relocating the association to Atlanta, GA. She served in this position until 1998 and then served on the Board of Directors as Past President until 2003.