

Acoustic Neuroma Association History

By Agnes Garino
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When former Acoustic Neuroma Association president Sallye Anderson wrote the history of ANA's first 25 years in 2006-2007, I'm sure none of us involved with ANA realized how far a great organization could progress in such a short five-year span.

Since 2007, when we celebrated our first 25 years, ANA has been committed to not only keep up with the needs of patients but to reach them in the traditional as well as the new ways of communications.

ANA members are familiar with the variety of services we provide to them and their families. During the past five years we have not only improved and expanded many of these services but added even more.

Alphabetically, since they are all important.

Booklets - We now have eight patient information booklets covering the issues of interest, such as what questions to ask a physician, diagnosis and related issues to AN patients. All are kept up-to-date with the latest information in the field.

Communications - Every year ANA responds to thousands of phone calls, emails and written requests for information, many from newly diagnosed patients. Each year close to 1,000 complimentary packets of information are sent to patients, family members and medical professionals. The number of emails has increased substantially in the past five years.

Surveys are periodically included with membership invoices seeking input about ANA services.

Plans are underway for ANA to become a major participant in social media. ANA is now on Facebook, Twitter and YouTube.

Local Support Groups - Even in this age of internet support, many members continue to realize the value of meeting other patients face-to-face and in many instances learn from medical professionals. We have more support groups - right now 52, - more annual meetings - almost 110 (as of 2010) - and more annual attendees - over 1,600 (as of 2010) - than in 2007. Members receive mailed notification of meetings as well as reminders of meetings via email. At each national symposium, ANA brings together support group leaders to share ideas and learn about different ways to support their local members.

Medical Advisory Board (MAB) - We are pleased to have the continued advice and assistance of the MAB, current co-chairmen Dr. John Tew, Jr., Cincinnati, and Dr. Richard Wiet, Chicago. The size of the MAB has grown as ANA has broadened the group to include a variety of specialists who serve AN patients.

Membership - ANA membership makes ANA services possible. Because of the support of our membership we are able not only to continue our services but to expand these services and add new ones i.e., expanded website to meet the needs of today's patients. Our Member Section at www.ANAUSA.org is a key membership benefit.

Notes - our quarterly newsletter, the most popular membership benefit. It is now accessible online to members, often as much as three weeks earlier than the mailed copy. Our newsletter continues to provide in-depth articles on issues important to AN patients whether pre- or post-treatment, or watch and wait.

Research

- **Surveys** - ANA conducted the third survey of AN patients in 2007-2008, the results were compiled and are on our website. Almost 2,000 acoustic neuroma patients participated. The survey provided valuable insights into patients and treatments, including the major changes in selection of treatment methods since the 1998 survey. This survey is the beginning of ANA efforts to provide an ongoing resource of information of patient issues/results/treatments.
- **Research project** - Plans have been initiated for a research grant for a graduate medical student to analyze the results of the survey.

Symposia - Every two years, ANA in cooperation with a major medical facility provides three days of invaluable presentations, information and opportunities for networking for AN patients. In 2007 in Philadelphia and 2009 in Chicago close to 300 patients and family members participated in a symposium along with more than 50 medical professionals.

Website - Probably no initiative of ANA has had a greater impact on the way services are provided than our new improved and regularly updated website: www.ANAUSA.org. During the past five years we have focused on not only making our traditional services easier to access but to add new services to the website. To list just a few of these new resources:

- **Medical Resources** - In 2007 with the guidance of our MAB, we solicited qualified medical professionals to help us meet the needs of AN patients and compiled a growing list of doctors and medical centers across the country who meet our criteria to be listed on our website. Currently there are 109 physicians and 20 medical centers from 19 states, listed on the website.
- **Member Section** - One of the newest ANA member benefits is access to the special section of the website available exclusively to those who join ANA. Members also have access to *Notes*, including issues from the past five years; patient information booklets; more than 100 published medical journal articles on acoustic neuroma and 2009 symposium speaker presentations.
- **ANA Discussion Forum** - Since we introduced our new ANA Discussion Forum on our website in 2005, over 162,000 posts in more than 12,000 topics by more than 5,000 members have been made – which indicates the incredible popularity of this ANA resource online.
- **Local Support Group Information** - While support group information is mailed to ANA members, it is also available by accessing our website, including the contact information for local groups, a listing of upcoming meetings, as well as the benefits of joining a support group. Information on support group meetings is also included on the ANA Discussion Forum.

Willing to Talk Program (WTT) - Gives patients the opportunity to communicate with other AN patients sharing their expertise and answering questions on a variety of topics including treatments and post-treatment issues.

Acoustic Neuroma Association is a 501(c)(3) non-profit, founded by Ginny Fickel Ehr in 1981, and is currently governed by a Board of Directors consisting of AN patients. The national office in Cumming, GA (metropolitan Atlanta, GA), is headed by Executive Director Judy Vitucci who joined our organization in 2005. She is ably assisted by a part-time staff of four.

PLANNING FOR ANA'S Future

The ANA board has completed a process of developing a strategic plan, reflecting the organization's mission: 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.

The board also adopted the following:

Vision

To be the most relied upon resource for acoustic neuroma patients, their families, and practitioners.

Core Values

- Professionalism: to maintain high ethical standards at all times.
- Objectivity: to remain free of bias in everything we do.
- Research: to constantly learn more about acoustic neuromas.
- Communication: to encourage dialog and disseminate information about acoustic neuromas.
- Innovation: to stay current with technology and emerging, diverse, pre- and post-treatment options.
- Respect: to honor the needs and privacy of acoustic neuroma patients.

This year, the Acoustic Neuroma Association celebrates its 30th Anniversary. It's been an incredibly productive 30 years and we look forward to being here for current patients and many more in the future.

Note: Agnes Garino was treated for an acoustic neuroma in 1996 and has been a member of ANA since then. In 1997 she attended her first symposium in Dallas, and has attended each symposium since. She was elected to the Board of Directors in 2001, serving as Vice President in 2003 and 2004 and elected President serving from 2005—2008. She is currently serving as the Immediate Board President.