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**"ANA recommends treatment from a medical team with substantial acoustic neuroma experience."**

This statement was adopted by the Acoustic Neuroma Association Board of Directors in October 2001 and demonstrates its belief that treatment of acoustic neuroma by a medical team with extensive experience is critical to your best chance for a successful outcome. Criteria to be used in the selection of medical professionals can be found in the Medical Resources link on our website at [www.ANAUSA.org](http://www.ANAUSA.org).

Now available on our website is a listing of medical resources. The physicians and organizations listed have self-reported data to meet criteria established by ANA for having substantial experience in treating acoustic neuromas. The listings should NOT in any way be construed as an endorsement or recommendation by ANA. The ANA does NOT make any independent determinations concerning the qualifications of any listed physician or organization. It is every individual's responsibility to verify the qualifications, education and experience of any healthcare professional.

## MEDICAL REPORT

# What is New in Hearing Restoration after Surgery?

*Editor's note: This is a transcription of a portion of the presentation made at ANA's 19th National Symposium in Chicago.*

BY ROBERT A. BATTISTA, MD

**In general**, there are four options for hearing rehabilitation for patients with an acoustic neuroma: an air-conduction hearing device (i.e., a conventional hearing aid), a bone-conduction hearing device, a cochlear implant and an auditory brainstem implant. There has been tremendous improvement in air-conduction hearing device technology over the last few years, but a discussion of these devices, as well as a discussion of the auditory brainstem implant, is beyond the scope of this article. The improvements in air-conduction hearing devices have translated into improved performance of bone-conduction hearing systems, which, along with cochlear implants, will be discussed in this article.

Currently, there are three bone-conduction hearing devices available in the U.S. **The TransEar®** (Ear Technology Corporation) is a bone-conduction hearing device that is similar in appearance to a conventional hearing aid. The TransEar consists of a speech processor that rests behind the ear and is connected through a thin tube to an ear mold that fits in the ear canal. One of the unique features of the TransEar compared to a conventional hearing aid is that the mold of the TransEar fits very deeply inside the ear canal. In this way, the mold can

directly stimulate the bone underneath the thin skin of the ear canal.

The other two bone-conduction hearing devices are the **Cochlear™ Baha® BP100** (Cochlear Americas) and the **Ponto Pro** (Oticon Medical). Each of these devices became available in the U.S. in late summer/fall of 2009. The BP100 replaced the Baha Divino, which is no longer manufactured. Cochlear Americas plans to support the Baha Divino until June 30, 2012. The Ponto Pro is made by Oticon, which is a well known manufacturer of air-conduction hearing devices.

### How Bone Conduction Works

Each of the three devices listed above transmit sound through bone conduction. Bone conduction hearing is a natural way to hear. For example, whenever someone brushes their teeth and hears the sound of brushing, that sound is conducted through bone to the inner ear. Since the inner ear is encased in the bone of the skull, the inner ear picks up sound when the skull vibrates. Sound travels through bone at nearly the same speed it travels through air. One difference between sounds traveling through air versus bone is that high-frequency sounds are attenuated, or "absorbed", when traveling through bone. Each of the three bone-conduction devices is able to amplify or "boost" specific frequencies that would normally be attenuated through bone conduction. In this way, hearing is made to sound even

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**Robert A. Battista, M.D.** is currently an assistant professor in the Department of Otolaryngology at Northwestern University Medical School. He is in private practice at the Ear Institute of Chicago, LLC whose other members include, Richard J. Wiet, M.D., Arvind Kumar, M.D. and R. Mark Wiet, M.D. He completed an otolaryngology residency at the University of Medicine and Dentistry in New Jersey in 1991, and a fellowship at the Warren Otologic Group in Warren Ohio.

**ANA MISSION:** The mission of 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.

We cannot recommend doctors, medical centers or specific medical procedures and always suggest that one consult with a physician before making any medical decisions.

Your comments, ideas, suggestions and financial support are needed and welcome. ANA is a 501(c)(3) non-profit organization.

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Acoustic Neuroma Association

**FROM THE BOARD**

**Priorities Set for 2010;  
New and Retiring Board Members**

BY AMY PACK  
ANA Board President

**Hard to believe** the Chicago Symposium was nearly a year ago!

Since then, the ANA Board and staff have been hard at work. Last fall was all about by-laws and policy reviews, surveys and their results, planning and priority-setting and board development.

We revisited the by-laws, proposing updated recommendations for Board approval.

With the help of Board Directors Christine Bakalar and Tony Cochran, the Board rated itself and the importance of key ANA initiatives. We looked at the results from those evaluations, the results from the 2007–2008 AN patient survey and Symposium evaluations, to arrive at our top priorities for 2010.

They are:

■ **Research:** a deeper look at the patient survey, and consideration and prioritization of other research-driven projects.

■ **Membership growth and retention:** key to strengthening our position as the nation's go-to place for pre- and post-treatment information about acoustic neuroma.

■ **Continued website enhancements** and development of ANA's most valuable resource.

■ **Local Support Group enhancements** — creating new ways to raise the bar in providing essential “face-time” with patients, caregivers and sometimes, with practitioners.

To say the least, this is a very ambitious list. But these things are what you, our members, told us are most important.

We expressed our gratitude to six retiring board directors and welcomed six new, very talented directors to replace them.

Committees were realigned with the priorities and new directors. Those committees have their work cut out for them as they further analyze and set priorities for each of the initiatives mentioned above.

Member participation on committees is always welcome!

If you would like to serve on an ANA committee, or if you would simply like to offer comments or suggestions in any or all of these areas, please don't hesitate to email Executive Director, Judy Vitucci, at the ANA office.

I would like to recognize and thank retiring board directors who have given most generously of their time, their money and their skills, to advance ANA for the benefit of its members. They will be missed.

Board service includes annually two weekend trips, symposium attendance and many phone hours each year.

It has been my privilege to get to know, and serve with, each of these fine people:

Christine Bakalar, Janice Weaver, Barbara Hyatt, Gordon Seidenberg, Rebecca Pennington, and Dr. Fred Buckner. The latter four will continue serving ANA at the committee level.

We would also like you to meet the directors new to the board as of April. They have already begun contributing.

They are Virginia Barnes Ricketts, Jeff Barr, John Gigliello, Sally Goostrey, Joel Perrell and David Puzzo. Additional information on each of them can be found on page 8 in this edition of *Notes*.

On behalf of the ANA Board, staff and membership, our heartfelt thanks to all of these people, for their continued dedication and service to the Acoustic Neuroma Association, AN patients, caregivers and practitioners.



**Amy Pack,**  
ANA Board  
President



**The new 2010 Board of Directors**  
at their annual April Board Meeting in Dallas.

## LOCAL GROUP SPOTLIGHT: *Washington, DC*

# Supporting Each Other and Our Choices

BY DAVE ATWELL  
Group Leader/Facilitator

**The DC Local Support Group** is dedicated to helping each other cope with lives that are affected by acoustic neuroma. The group support enables us to bond through this common affliction and share trials, disappointments — and celebrate victories that we are unable to fully express outside of the group.



**The Washington, D.C. Support Group** meets three times a year to hear speakers and to share information among themselves.

We find that while some people come and go, there is a core set of members who attend the meetings consistently. Solid friendships have been made and some members socialize outside of the meetings.

Our meetings are generally well attended, ranging from about 12 people to upwards of 36. While we attempt to have an outside speaker at one of the three meetings per year, we always make time for sharing and networking. We are very lucky to have a regular meeting room at the school where our founding group leader is employed.

Our patients and caregivers have always emphasized the importance of caring, sharing and networking. One patient recently said “*I learn so much from others’ experiences at these meet-*

*ings.*” Often there are more personal phone calls exchanged after meetings, with the attendee’s permission.

The meetings are attended primarily by AN patients, with at least one or two caregivers at each meeting. The attendees are about 50% each men and women. Tumor sizes range from very small to as large as 4+ cm. Some of the attendees have had multiple surgeries and multiple tumors, residual facial paralysis, chronic headaches, eye issues and/or balance issues. Some still have tumors, even after surgery.

Among us, we have had a variety of treatments and some are still watching and waiting. There is a diverse representation of doctors, hospitals, surgical approaches and different forms of radiation for treatment.

I had surgery in 2005 and my biggest post-surgery challenge was headaches, which subsided

over time and mostly disappeared late last year.

We respect each others’ choices and understand that each person must decide for himself or herself. We know there is no right or wrong choice, just personal choice. We emphasize the positive direction of looking forward versus the negative direction of looking back.

On average, 15–25% of the attendees are newly diagnosed and/or new to the meeting. With the wide variety of experiences within the support group, we are able to answer questions that the new person may have in evaluating his or her choices for pre- or post-treatment.

The DC Local Support Group was founded in 2002 by Greg Schlosberg and meets three times a year. In 2007 I took over leadership of the group.

### MEMBERS AT LARGE

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**Upcoming  
Meeting**

**ANA /  
New Jersey  
Mini-Conference**

**Sunday,  
Oct. 24, 2010  
www.ananj.org**



# My Clock Is Ticking

BY BOB FISHMAN  
Scottsdale, Arizona

**It was summer . . .** 1986 or 1987. I remember it being warm and the weather was tolerantly pleasant. It was a good time in my life. I was happy with my job, my wife and I were both generally healthy, we were active and had many friends, and although my job required more travel than I would have preferred, I was often able to take her with me.

It seems I had some sort of minor health issue and was being treated by my doctor who had put me on some medication. This caused ringing in my ears. After asking if I should stop the medication, he said “no . . . finish it all.” The ringing continued. I thought eventually it would go away. It hasn’t! Over the years, at times it’s been hardly noticeable. Other times, it was back with a vengeance, but it’s been my constant companion. All this time I assumed the cause of the ringing was the medication, but it was probably my acoustic neuroma.

Being responsible for running network television stations is a job fraught with aggravation. Stress is always present, and although I usually found periods of calm, pride in what I was doing, enjoying myself in a wonderfully exciting business, and often with a feeling of accomplishment . . . a problem could frequently be found in the very next phone call.

Stress was the one thing that exacerbated the ringing in my ear more than anything else. It caused me the most concern and anxiety. I wondered if this condition would ever improve, or hopefully if it might go away permanently. It hasn’t gone away, but rather it’s gotten worse, and now I’m a little afraid of what the future holds for my ability to continue to function as I’ve known!

During the intervening years I saw a couple of ENT docs but no one ever suggested an acoustic neuroma might be lurking in my head. Usually I was sent to see another doctor or specialist. And that’s how it’s been for the last twenty something years.

Like many others, I’ve learned to live with

these strange mostly whistling noises. I didn’t get unduly concerned as I had seen several doctors, and none of whom ever suggested this could be a serious condition! Most had told me it was tinnitus, period! These noises were mostly bothersome more than anything else . . . sometimes sounding like the whistling of a tea kettle, or a sort of pounding noise, or sometimes a kind of hissing, or even bells ringing . . . but always present.

In 2008 my hearing seemed to deteriorate with more noise than ever. I was also having balance issues.

While walking I would list to one side or the other and often would bump into walls, doors, my car, corners of furniture . . . not so bad at first, in fact I found it almost comical, but it was an ominous change in my condition.

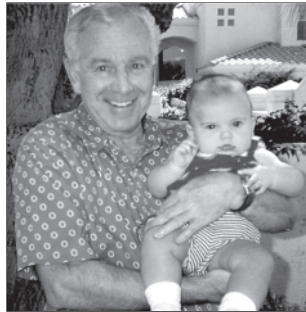
I finally went to another specialist who passed me on to a neurotologist. Next came the first MRI and then I got the bad news . . . they had found an “intracanalicular enhancing mass” . . . an acoustic neuroma in my ear canal. The tumor was small — 6.1 mm. Further, he indicated that radiation was the treatment of choice. At the time, this piece of news seemed like a death sentence. I was shocked and couldn’t believe I had this unthinkable affliction, along with the possibility of needing radiation.

Soon thereafter I was sent to a radiation oncologist who started planning for immediate radiation treatment, but I wasn’t ready for the radiation step yet, no matter what I was being told. I then got another radiation oncologist’s opinion. The decision was to wait and monitor the tumor.

Since early 2009, and after three MRI’s, it’s been explained that the AN is very close to the hearing nerve in the ear canal which itself is very narrow, and that radiation would likely affect it, thus causing me to lose some hearing. In the last 18 months, the tumor had not appeared to show any growth. Was it possible that it might have even stopped growing permanently?

I was told to get a hearing aid which should improve my hearing. At first I was reluctant, but after a few months when things seemed to

*Continued on page 5*



**Bob enjoying time with his granddaughter**

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## MAILBAG

*Email addresses, if available, are included. You can also contact writers of these letters by phone or mail through the ANA office.*

### Easy-to-wear, bone-conducting devices

After 1999 translab surgery in Los Angeles, I was contacted to participate in a trial for FDA approval of a bone-anchored device for single-sided deafness use. I joined other patients across the U.S. for the trial which lasted about six months.

First, I was fitted for a CROS air-conducting hearing aid for four weeks. Then I had the surgical procedure for the Cochlear Baha, where a small titanium abutment was implanted in my skull, behind my deaf ear. I was fitted with the Baha processor about three months later.

Late last year, I began wearing the latest bone-conducting device, Oticon's Ponto Pro. Soon after that, I also began wearing Cochlear's newest Baha, the BP100.

I will never hear as I did before my AN. So for me, wearing a bone-conducting, implanted device is a must-wear, quality-of-life improvement. The sound is not distorted in any way. It is as though someone turned up the volume and increased the treble. The sound quality is enhanced to the point where I no longer concern myself with "which side is my deaf side." My sound localization is 40–50%. Without the device, it is zero.

*Continued on page 6*

## VOYAGES

*Continued from page 4*

continue going downhill even more, I went to get fitted for a hearing aid. There I was told my hearing on the left side was so bad that the aid would be of no help.

Currently my balance and dizziness have also grown a little worse. This part of my problem is strange. It is almost certainly related to the AN but no one seems to have any specific answer for it. The balance and dizziness seem to run in cycles over a period of days or weeks, worse and then it improves, then it gets worse again. Also my hearing has taken on a new dimension . . . it's become more difficult to hear people speaking, the radio, television and most other sounds. Sometimes it's as if I have a head cold with my head stuffed up, causing yet another sensation.

I know many, many people get along with hearing loss on one side . . . but I can't help wondering how my life might change . . . what any new limitations will be . . . will I interact differently with the rest of society? Many of you have already experienced these lifestyle changes, but to someone approaching this precipice, fear of the unknown is large! I am a son, a father, a grandfather and have speculated on how I would deal with my immediate family and friends if all signs indicate it's a go for the radiation treatment.

Over the past year I have distilled my thoughts on what my life might be like "afterwards" . . . after the radiation and probable single-sided deafness, if that's to be . . . and it scared the heck out of me . . . and still does. However, "D-Day" has been coming for so long I keep telling myself, and mentally I've already made some adjustments. How much worse can it be!

Originally when I thought about doing this article for ANA, I wanted to really let loose and talk about how frightened and scary this illness was for me. How I was in disbelief when I heard I had a brain tumor. I suppose I wanted lots of comfort from those of you out there who had experienced this awful punishment . . . but had gone through it and had positive things to say. I wanted lots of tea and sympathy for being caught up in this terrible business.

But the more I thought about it and read the outcomes of you all who have courageously accepted all sorts of difficulties . . . major hearing loss, facial paralysis, constant headaches, serious balance disturbances . . . well I've come to the conclusion that one damn tumor won't be

the end for me! I still have more living to do.

However, unfortunately I have another major challenge facing me right now as well. During these past few years, my wife has experienced two strokes and also was diagnosed with Alzheimer's. I've been caring for her at home. Now she has required more care to the point where she is in hospice care, although still at home with me. When I think how healthy and vibrant we were, what's happened has been a tough pill to swallow. She and I were active people involved in many activities and organizations. I served on several boards and still would like to continue this, if not for the caregiver life I've taken on. This aspect of my life, plus the AN have sometimes made me question my very belief in a higher power.

*"I offer respect and salute every one of you who has written about your individual problem..."*

I recently went for one more hearing evaluation and in April had another MRI. The most recent pronouncement from my doctor was that he now felt that I "likely would lose all the hearing on my left side," when and if the radiation is performed. I asked the next logical question and that was, would the noise I hear stop after radiation? "Every case is different," he told me. He said he just didn't know, but not to expect too much. No comfort there.

It appears the tumor has now shown growth — about two millimeters, and he feels that I have a choice to make, either to go for the radiation soon or continue to monitor it for the next several months. No one wants to undergo this sort of procedure unnecessarily, but I've pretty much decided that the AN isn't going to get smaller, if anything it will grow. Also presumably my hearing could continue to worsen, and therefore I am almost certain I will proceed with the procedure!

In closing, I offer respect and salute every one of you who has written about your individual problem(s) here (as well as many more who have not) and most seemingly have come through with flying colors. And that's the way I'm now approaching my turn with Gamma Knife. As for my other challenge, that's going to be more difficult to deal with, and so I'm counting on the guy upstairs to help me through that one.

## From the Caregiver's Perspective

BY GEORGE WEAVER  
Anchorage, AK

**My role as a caregiver** started the moment my wife, Janice, called me and advised me that she had volunteered to take a MRI at work as a test. She went on to say that during that process the radiologist had found a small brain tumor which he felt was an acoustic neuroma.

Now I'm in shock, what is an acoustic neuroma, never heard of it, what does this mean, how is Janice handling it, lots of questions. During the next few days and weeks I became an expert regarding what an acoustic neuroma is, treatment options, surgery outcomes — and none of it sounded good to me at the time. Janice, being the positive person she is, was somewhat in denial about the seriousness of her situation, but I was very worried.

Over the next few months we learned that Janice was going to have surgery to remove the tumor. I was apprehensive, but this was her decision, and I was there to support that decision. To tell you the truth even though my wife had the tumor, I felt I also had been diagnosed with one.

Prior to the surgery Janice seemed to be at peace with her decision and had a positive attitude toward the whole thing. I, on the other hand, was scared — as much as I tried to stay upbeat. During the surgery and after, family and friends were there for support, and I needed every bit of it. I would like to express how important it is for the caregiver to get support.

Janice had a long surgery and when her surgeon came out at the end, he said things had gone well. He felt he had gotten the entire tumor, but Janice's facial nerve had gone to sleep, resulting in facial paralysis along with hearing loss. What did that really mean? I nearly lost it right there. My emotions were running on overtime as this was not what I wanted to hear and was not good. Her doctor had hoped that this would only be a temporary condition and her facial nerve would wake up.

As her husband and primary caregiver, how was I going to face her and let this beautiful woman know that her worst fear regarding this surgery may have happened? And wouldn't you know it, the first thing she asked me was how she looked, not the question I wanted to answer. She amazed me on how well she took the news, but inside I was devastated, as I knew she was just putting up a good front for me.

There were many nights of putting drops in her eye and taping it shut so it would not dry out. In addition — helping her to get her balance back, driving her to work and errands until she felt comfortable to start driving again, dealing with her hearing loss and the painfully slow progress of her facial nerve regeneration.

Janice is a very strong woman, but she had her meltdowns, and those were very hard times. As a caregiver you will feel every bit of their pain, and it is emotionally draining. Caregivers: remember you may not be walking in their shoes but

you will be with them every step of the way.

How to cope with being a caregiver can take on many forms from person to person. The first six months of the recovery period is very trying and tiring.

You may need to find some space and time for yourself. I started building custom knives, and this process would take me from 8 to 10 hours of work on each knife. This took my mind off Janice and let her recovery move forward without me hovering over her day after day. It also gave her space and time to start doing things by her self and not to be so dependent on me — but I was always close by.

There have been a number of days of tough love for both of us. This is not an easy road that we are on, and this journey is far from over. We are now 5½ years post-op and our lives are pretty much back to normal and going well, although she has her ups and downs but still continues to improve.

My message is — don't give up. Through all of this I still have Janice, and I'm very thankful for that.



George and Janice Weaver  
in beautiful Alaska.

## MAILBAG

*Continued from page 5*

Some considerations:

- The procedure for the implant for these two bone-conducting devices is minor, virtually no side effects, and quick recovery. I returned to work the day following the implant procedure.

- Unlike most air-conducting devices, these two, because they snap onto a tiny, implanted abutment, are very comfortable. In fact, it is easy to forget that I am wearing mine, and I wear it all day, every day.

- While the manufacturers do not claim that these devices help tinnitus, they do amplify sound which enables me to hear better, thus the tinnitus is subdued.

- Patients considering these devices can be tested to give them a sense of how the devices will affect their hearing. Once implanted, the sound is even better.

- These devices are programmed by the audiologist, conforming to the patient's audiology.

- They are sturdy and moisture resistant, the primary cause for damage or repair.

- The devices come in hair colors, serving as camouflage when worn by someone with short hair.

- Both devices take standard hearing aid batteries. I get about three weeks to one battery.

- Most insurance companies cover all or part of these devices. Practitioners should have this info.

- Both units come with various warranties, options and accessories. My favorite accessory is the audio

*Continued on page 7*



## MAILBAG

*Continued from page 6*  
adapter, a cord that enables the patient to connect an external device such as an MP3 player directly to the bone-conducting device, eliminating the need for headphones or ear buds.

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amypack@hotmail.com

### **Botox® for Headaches**

Last January I began receiving Botox® injections for my post-op headaches, which I have had for 7 years. The first treatment was around 10 injections in the forehead and back of the upper neck. I had fairly good results for 3 months, especially with the forehead shots. I had very few of those “eyeball” headaches.

In April I had another series of injections, this time more focused on the sub-occipital and neck region as well as the forehead. I expect even better results as the treatments are cumulative. My previous insurance would not cover this treatment — around \$900, but my new provider (Medicare) covers most of the cost. More and more providers are covering this treatment which may give us “headachers” some much needed relief.

Deb Purves, Sugar Grove, NC  
pjpurves@charter.net

*In no case does ANA endorse any commercial product, physician, surgeon, medical procedure, medical institution or its staff.*

*Although occasionally a brand name may appear in Notes, it is strictly for educational purposes.*

## ANA NEWS

# Cell Phones and Acoustic Neuroma

*The widespread use of cell phones and many studies on cell phones and possible associated health risks prompted the ANA Board of Directors to initiate a statement regarding cell phone usage and acoustic neuroma.*

*This statement is endorsed by our ANA Medical Advisory Board.*

*This is intended as a cautionary alert. This information is not intended to take the place of advice and guidance from your personal physician. You should always consult with your physician with questions and concerns. It is important to remember that early diagnosis of small tumors provides more treatment options and greater success, with the greater possibility of fewer long-term complications.*

**There has been** much interest and controversy in the past decade regarding the possible role of mobile phones as a cause of brain tumors.

The use of cell phones has become ubiquitous around the world and if they played a causative role in a disease process, even such as causing a benign tumor like an acoustic neuroma (AN), it would have tremendous public health implications.

According to the International Telecommunication Union, by 2006, 91 persons out of 100 were cell phone subscribers in developed countries. As many as 32 persons per 100 were subscribers in the developing world.

There have been 25 epidemiologic studies published between 1999 and 2008 trying to examine the role of mobile phones in the etiology of brain tumors, including ANs. Most notably, a large study from Sweden by Hardell and colleagues, and a multi-institutional study involving 16 centers in 13 countries called INTERPHONE, have admirably tried to answer this important question.

Overall, the best interpretation of the results of these studies does not demonstrate support for an increased risk of developing an AN in frequent cell phone users.

However, the science is very suggestive that the most malignant brain cancer (glioblastoma) and a benign brain tumor of the auditory nerve (acoustic neuroma) increased in cell phone users after 10 years of use, and the effect is more pronounced in children’s brains. But the science is not absolutely positive, and research in this area is continuing.

The World Health Organization (WHO) announced that long-term use of cell phones may be linked to elevated risk of some types of brain issues. The conclusion, which is reportedly still inconclusive, is derived from a landmark international study overseen by the WHO that has lasted for decades.

The results, though not entirely conclusive, clearly have concerned the WHO. Dr. Elizabeth Cardis, from WHO, is quoted as saying “In the absence of definitive results and in the light of a number of studies which, though limited, suggest a possible effect of radio-frequency radiation, precautions are important.”

There is particular concern regarding use by children, as their thinner skulls are less likely to shield the brain from harmful frequencies.

The Food and Drug Administration says the research “does not allow us to conclude that mobile phones are absolutely safe, or that they are unsafe.”

**Those who cannot avoid using cell phones may consider the advice offered by the Environmental Working Group to minimize their exposure to radiation.**

- **Use a low-level radiation cell phone.**

Check out [www.ewg.org](http://www.ewg.org) for the best 10 cell phones that emit low-level radiation.

- **Use a headset or speaker.**

■ **Listen more and talk less.** Cell phones emit radiation when you talk or text, but not when you are receiving signals or messages.

- **Hold your cell phone away from your body.**

- **Text more** and talk less.

■ **Stop trying to communicate when the signal is poor.** Poor signals mean your cell phone needs to send stronger signals (higher level radiation) to the tower.

■ **Don’t allow your children to use or play with your cell phones.** Children’s brains absorb twice as much radiation as adults.

■ **Don’t use the “radiation shield.”** Radiation shields such as antenna caps or keypad covers reduce the connection quality and force the machine to emit higher radiation to deliver a stronger signal.

# Special Appreciation and Thanks to Retiring ANA Board of Directors

**Christine Bakalar** completed her third term on the Board serving from 2004–2010. She served as chair of the fundraising committee, instrumental in leading many successful fundraising campaigns. She also served on the Chicago Symposium and website development committees.

**Fred Buckner, MD**, completed his second term on the Board serving from 2006–2010. He worked on the website development committee, initiating posting medical journal articles to the website.

**Barbara Hyatt, MSW, LCSW**, completed her third term on the Board serving from 2004–2010. She participated in the website medical listing committee, guiding the development of this program. She was instrumental in local support group development and presented workshops at three symposiums on Coping with Emotional Impact of AN Treatment. She also served on the caregivers and membership committees.

**Rebecca Pennington** completed her second term on the Board serving from 2006–2010. She served as our legal counsel and participated in the by-laws, policies and website development committees.

**Gordon Seidenberg** completed his third term on the Board serving from 2004–2010. He participated in the website medical listing committee, guiding the development of this program. He was our liaison with the Medical Advisory Board and served on the patient survey, governance and nomination committees.

**Janice Weaver** completed her first term on the Board serving from 2008–2010. She served on the caregivers committee.

## Welcome to New ANA Board of Directors elected at the 2010 annual spring board meeting

**Jeffrey D. Barr**, Livingston, NJ, Chief Investment Officer for Azimuth Investment Management LLC in New York City. He is a watch and wait AN patient for the last year.

**John Gigliello**, Niskayuna, NY, is a Financial Planner in Albany, NY and had translab microsurgery nine years ago. He is the Albany, NY local support group leader since 2007.

**Sally Goostrey**, Kalamazoo, MI, former IT Management Consultant for the W Group in Malvern, PA. She had retrosigmoid/sub-occipital microsurgery two years ago.

**Joel Perrell, Jr.**, Baltimore, MD, Attorney for Miles & Stockbridge, PC. He had retrosigmoid/sub-occipital microsurgery three years ago. He is the Baltimore, MD local support group co-leader since 2008.

**David Puzzo**, St. Petersburg, FL, is a Technical Writer and instructor doing contract work with the U.S. Postal Service. He is a watch and wait AN patient for the past seven years. He is the Sarasota, FL local support group leader since 2007.

**Virginia Barnes Ricketts, MS, LGPC**, Annapolis, MD, Psychotherapist and counselor, working for Psychotherapists of Maryland and ADEPT. She is a watch and wait AN patient for the past seven years. She is the Baltimore, MD local support group leader since 2008.

## Save the Date



*Sponsored by:*  
Brain Tumor Center at the University of Cincinnati Neuroscience Institute, University Hospital, Mayfield Clinic and University of Cincinnati Department of Otolaryngology — Head and Neck Surgery, Cincinnati, OH

## ANA Website Member Section

**ANA members can now access** a special ANA Member Section on our website, [www.ANAUSA.org](http://www.ANAUSA.org).

In this section you will find the following:

- **ANA Newsletter, Notes**, quarterly issues, 2006 to 2009.
- **ANA patient information** booklets.
- **AN Articles**: published medical journal articles related to acoustic neuroma.
- **2009 Symposium PowerPoint presentations** from some workshops and general sessions.

To access this section, we will need your current email address.

You will also need your personal username and password.

Information regarding this was sent to you in a prior email.

If you want to notify us of your email address or have a question about your username and password, you can do this online on our website at:

[www.ANAUSA.org](http://www.ANAUSA.org)  
or via email to [info@ANAUSA.org](mailto:info@ANAUSA.org).



## Medical

Continued from page 1

more natural.

Bone-conduction hearing devices are an option for those patients who have no hearing in one ear, single-sided deafness, and normal hearing in the opposite ear. The bone-conduction device is worn on the deaf side. In this way, sound is picked up by the bone-conduction device and then transmitted to the inner ear of the other, normal hearing ear. Since the hearing device is on the deaf side, the perception is that hearing is coming from the side with no hearing. Hearing in the deaf ear is not restored; the hearing loss is rehabilitated. All three devices (TransEar, BP100 and Ponto Pro) could be used in the hearing situation just described.

For those with no hearing in one ear *and* with a moderate hearing loss in the other, hearing ear, a special type of bone-conduction hearing device is an option. This option is known as the Cochlear Baha Intenso, a slightly larger and more powerful device than the BP100. In the hearing situation just described, our practice is to fit the deaf side with an Intenso and the opposite side with a hearing aid. The more powerful Intenso is necessary to adequately amplify sound to the opposite side.

Each of the bone-conduction devices discussed above is helpful for two of the three hearing difficulties that patients experience with single-sided deafness. These three difficulties are: 1) inability to hear on the deaf side, 2) difficulty hearing in background noise, and 3) an inability to localize the direction of sound. Most patients that use any one of the bone-conduction hearing solutions will report that listening on the deaf side is improved considerably, while hearing in background noise is improved, but the difficulty is not eliminated.

There are some anecdotal reports of patients able to localize certain sounds with any one of the bone-conduction devices, although this is not common. Sound localization is dependent on two, functioning ears. If the sound source is to one side of a person, the sound is delayed as it enters the ear compared to the other side. The brain uses this sound delay as a means to localize sound. Since current treatments for single-sided deafness use

only one functioning ear, sound localization is not routinely reported. For those who can localize certain sounds with their bone-conduction device, sound localization may occur as a result of the slight time delay for sound to be transmitted through the skull.

The BP100 and the Ponto Pro are bone *anchored* hearing systems. This means that the conducting mechanism is surgically implanted into the bone of the skull. Both the BP100 and Ponto Pro are three-part systems. The first part is a titanium fixture that is surgically attached to the skull behind the deaf ear. An abutment or “snap” is screwed into the titanium fixture. The abutment sits above the level of skin, so that the third component of the system, the sound processor, can be snapped onto the abutment when the patient wishes to use the device. This system was designed so that, if the abutment is changed in the future, the abutment can be unscrewed and replaced in the physician’s office without the need for further surgery.

The fixture and abutment are installed through an outpatient surgical procedure, averaging 30–45 minutes in length, typically under local anesthesia. Several weeks are allowed to pass after surgery to allow for bone growth (known as osseointegration) to occur into the fixture. Osseointegration allows the fixture to be firmly attached to the skull and results in the direct transfer of sound to the skull. Both the fixture and abutment are MRI safe.

### New Features and Benefits

The current TransEar device, the 380-HF, became available in October 2008. The 380-HF consists of a high frequency bone vibrator, which has its peak energy at 2,100–2,300 Hz. As a result of this peak energy, the 380-HF is able to deliver better high frequency gain compared to its predecessor, the 270, whose peak energy was

between 650–700 Hz. High frequency gain is important, since bone will attenuate or “slow down” sound in the region of 2,000 Hz.

Another new feature of the 380-HF compared to the 270, is that the 380-HF has a four channel digital sound processor with two memories or programs. These two programs are typically set for everyday listening situations and the other program for situations involving background noise. The 380-HF also has digital feedback reduction, which helps prevent feedback when in background noise.

There are several new features of the BP100 relative to the Baha Divino. The BP100 has a Europin, which is a universal connection for FM and phone adaptors. The Divino required proprietary adaptors for these applications. The BP100 has status indicators with beeps and LEDs. There are multiple programs that can be set for various listening situations. The programs are controlled with a single button on top of the sound processor. Volume is controlled with up and down buttons alongside the program button.

The Ponto Pro is shaped differently than the BP100 in that the Ponto Pro has a slight curve to its design, similar to a blue tooth device. The program button is on the side. Features of the Ponto Pro include multiple programming capabilities, a self-learning volume control, a Europin connector and the device is waterproof. In addition, the Ponto Pro fits on the Baha abutment if the abutment was placed before November 2009. In this way, someone may upgrade from the Divino to the Ponto Pro without difficulty. Oticon plans to release an additional, more powerful device similar to the Intenso in the first quarter of 2011. The new device will be digital and programmable.

Both the BP100 and the Ponto Pro

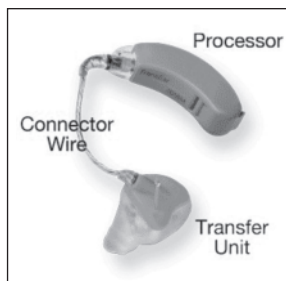
See Medical, page 10



Baha BP100



Ponto Pro



TransEar

## Medical

Continued from page 9

have multiple channels that the audiologist can tune depending on the thickness of the person's skull and hearing capabilities of the opposite ear. The Divino did not allow such fine-tuning.

Finally, in select situations, a cochlear implant may be an option for patients who have had acoustic tumor surgery. The cochlear implant bypasses the damaged parts of the inner ear and stimulates the nerve endings for hearing in the inner ear. For this reason, a cochlear implant re-

quires an intact and functioning hearing nerve to be successful.

The cochlear implant is a two-part system. There is an outer or external part with a headpiece and, most commonly, a behind-the-ear sound processor. The second part is the internal device that is surgically implanted completely under the skin.

Cochlear implant surgery is approximately one to one and one half hours in length, under general anesthesia, and is a same day surgical procedure.

The cochlear implant works by having the external sound processor capture sound, and then the processor converts

the sound into digital information that is transmitted through the skin to the internal device. The internal device converts the digital information into an electrical signal, which is sent along the hearing nerve to the brain.

**In summary**, there have been many new advances in hearing restoration options for patients with an acoustic neuroma. Bone-conduction devices continue to evolve, with plans for a fully implanted bone-conduction device in the future. Hearing aid technology continues to improve and there are some novel uses for a cochlear implant in selected situations.

## Hearing Loss Scenarios

**Scenario 1.** The patient has normal hearing in the non-tumor ear and undergoes surgical removal of an acoustic neuroma, whereby the auditory nerve is removed. This person has normal hearing in one ear and no hearing in the other ear. Each of the bone-conduction devices (TransEar, BP100 and Ponto Pro) is an option for hearing rehabilitation. The bone-conduction device would be placed in or behind the deaf ear, so that sound would be transferred to the opposite ear through bone conduction.

In the future, a cochlear implant may be an option for unilateral deafness. This is not an option currently. I mention this option based on the results of a study from Belgium in 2008. In this study, 21 patients with unilateral, intractable tinnitus and same-sided deafness were implanted with a cochlear implant. The implant was

placed to treat the tinnitus. The tinnitus improved in a large majority of patients. In addition, the patients derived hearing benefit from the cochlear implant. I wish to stress that a cochlear implant for unilateral deafness is still in the research stage.

**Scenario 2.** The situation in this scenario is the same as that for scenario 1, except that the patient has a moderate hearing loss in the non-tumor ear and is deaf in the other ear. Neither the TransEar, BP100 nor the Ponto Pro can be used in this situation. The TransEar is indicated only if the hearing ear has normal hearing or has a high frequency hearing loss. The BP100 and the Ponto Pro do not produce enough sound "power" or gain in this situation. Currently, the best option is an air-conduction hearing aid for the side with the moderate hearing loss and the Baha Intenso for the deaf side. The Intenso produces more gain than the other bone-conduction

devices, which would allow proper amplification to the opposite side.

**Scenario 3.** In this scenario an adult has been deaf since birth in the non-tumor ear. (This is a very unique situation.) The acoustic tumor has been removed, the auditory nerve is preserved, but there is no functional hearing. So, this person is deaf in both ears. One option is to place a cochlear implant in the non-tumor ear, but experience has shown that due to the length of hearing loss, the hearing results are usually poor. A second option is to place a cochlear implant on the side of tumor removal. Since scar tissue can form in the inner ear after tumor removal, the implant should be placed during the same surgery as tumor removal, or within a few weeks of surgical removal. The bone-conduction hearing devices are not an option since the patient does not have a functioning inner ear.

## IN MEMORIAM Robert G. Ojemann, M.D.

**Dr. Robert Ojemann**, a world-renowned neurosurgeon who served in the Massachusetts General Hospital's Department of Neurosurgery for 50 years died in March at the age of 78.

Dr. Ojemann earned his medical degree from the University of Iowa College of Medicine in 1955. Brain tumors and cerebrovascular



disease were his clinical and research focus and he published more than 200 articles and chapters on these topics.

He served as president of the American Academy of Neurological Surgeons, the American Association of Neurological Surgeons, the Congress of Neurological Surgeons and the Society of Neurologi-

cal Surgeons. Dr. Ojemann was recognized with the highest awards in his specialty.

He was also Chairman Emeritus of the Acoustic Neuroma Association's Medical Advisory Board.

Known as the "neurosurgeon's neurosurgeon," Dr. Ojemann was a mentor to scores of others practicing locally and abroad.

Dr. Ojemann is survived by four sons and his wife of 54 years, Jean.

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## ANA Membership Benefits

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- Information booklets
- Biennial symposium
- Local support group network
- Website Member Section
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## Tribute to Robert G. Ojemann, MD

Without the support of Dr. Robert Ojemann, the Acoustic Neuroma Association would not have been!

Two years of concentrated effort preceded ANA's formal recognition as a tax exempt corporation in 1981. The "start up" challenges were daunting — creating association goals and purposes, obtaining tax-exempt status, by-laws, patient literature and organization brochures, gathering minimum finances. An urgent priority was to locate those affected by an acoustic tumor and let them know ANA existed. This required establishing credibility with the physicians and nurses who cared for acoustic tumor patients.

Dr. Robert Ojemann perceived that patient "peers" could assist each other in non-technical medical areas and consent-

ed to serve as the "medical figurehead" of ANA. Actually his support embraced the whole spectrum of needs of a fledgling patient group. As an example, his very generous financial help during the "beginning days" was crucial.

Confirming his support for a patient organization, Dr. Ojemann wrote in an article for the first newsletter "... it is evident that a need exists for establishment of communication lines with others having the same experiences ... non-medical needs might be met in many patients by having the opportunity to be in touch with an experienced brain tumor patient. This association will promote understanding and allow communication between patients with a common problem."

Dr. Ojemann authored the patient

information booklet, "A Glimpse of the Brain," a cranial primer for the AN patient that is still available today. He hosted two symposiums in Boston and was a faculty presenter at numerous other meetings, both local and national. He gave a comprehensive overview on acoustic neuroma in a patient video offered by ANA during the 1980s. He served as the chair of the Medical Advisory Board for eleven years. Perhaps most important, he lent the weight of his reputation and prestige to give credibility to ANA as a group that would actively support and responsibly inform patients.

I wrote in that first issue of *Notes* back in 1981: "The Acoustic Neuroma Association is a dream that has become a reality." Dr. Robert G. Ojemann was, to a large extent, the force behind that reality.

Ginny Fickel Ehr, ANA Founder





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6/10

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