

**ANA/NJ Newsletter**  
**Vol X, No. 2 April 2006**

**Meeting at East Brunswick Public Library,  
February 19, 2006**



This was a meeting for sharing experiences, conducted by Kathie Belonger, who also provided the delicious refreshments. There were 15 people in attendance. In the course of an informal and wide-ranging discussion, we learned about (1) coping with an AN back in the 1970s, and dealing today with the outcome (2) handling the annoyance of one-sided loss of hearing (3) a highly respected surgeon at St. Barnabas in Livingston, NJ (4) carrying on with life after surgery and radiation treatment for a large AN (5) carrying on with life while monitoring a small AN (6) the importance of making any new surgeon aware of your earlier AN surgery (7) difficulties in making a decision about the type of treatment to have for an AN (8) the value of support group meetings for learning about post-surgery treatment remediation sites and medical specialists (9) improvements in radiation techniques and outcomes during the last decade.

**Notices**

- *We were deeply saddened to learn of the death of **Dr. Frederick Evans**, a long-time friend and original member of ANA/NJ's Medical Advisory Board. Dr. Evans was a popular speaker at our meetings and regional conferences. We will miss him greatly and offer our sincere condolences to his wife and family.*
- We are pleased to announce that Nancie Boughton (Basking Ridge) is a new member of the ANA/NJ Board of Directors. Nancie wrote about her personal experience with acoustic neuroma for the December 2002 newsletter. The Board continues to encourage ANA/NJ members interested in serving to contact Wilma Ruskin by phone or email.
- The BAHA hearing system – a mastoid implant and detach-able sound processor that transfers sound to the cochlea of the good ear directly via bone conduction – is now covered by Medicare, as noted in the January 2006 newsletter. For more information about the BAHA system, call 800-523-5798 or go to Cochlear Americas at [www.cochlear.com](http://www.cochlear.com).

## CyberKnife at Stanford

A preliminary report on AN patients treated by CyberKnife at Stanford University shows good results. Since 1999, 270 patients were treated. The report deals with 61 patients who had follow-up of 36 months or more. The mean transverse tumor diameter for the study group was 1.85 cm, and the total marginal dose for treatment was 18 or 21 Gy delivered in three fractions of 6 or 7 Gy. Serviceable hearing was maintained for 74% of the patients, and no patient lost all hearing on the treated side. Only one tumor grew after treatment; 29 (48%) decreased in size; and 31 (50%) remained stable. No patient developed trigeminal dysfunction or experienced any permanent injury to the facial nerve. Two cases of facial twitching were transient only. (See S.D. Chang et al., "Staged Stereotactic Irradiation for Acoustic Neuroma," *Neurosurgery*, 6 (2005))

## Money Matters

- As noted in the Survey Report (p.3), ANA/NJ needs to improve its financial base. At the January 22 meeting of the Board, Jane Huck reported only \$692.33 in our treasury, which is not too much more than the cost of printing and mailing a single newsletter. Money matters will be a main agenda item at the next meeting of the Board. As suggested by many respondents to the Survey, the possibility of raising dues will be considered. In the meantime ~
  - To help reduce printing and mailing costs, let us know if you no longer need to receive our mailings, keeping in mind that notices and the newsletter in particular can be found online at [www.ananj.org](http://www.ananj.org).
  - ANA/NJ special occasion Donation Cards are available at meetings or by calling Phyllis Schreiber at 201-944-9874 (email [fyls717@aol.com](mailto:fyls717@aol.com)). If you wish, Phyllis can provide packets of three or five cards.
  - When making special contributions to ANA/NJ, check to see if your employer has a matching donations policy.
  - We thank all who have recently become members of ANA/NJ and all those who have renewed their membership and /or have made special contributions.

## Survey Report - with Observations

ANA/NJ Board members were pleased with the response to the recent mail survey. Certainly it was nice to have so many write to say "Keep up with the good work!" Volunteers need to hear this – often. The survey prompted several requests for assistance, which we were very happy to respond to by phone or email. It was gratifying how many people wrote to say, in effect, "I'm OK, I'm no longer in need of support." It's always good to learn that someone we know has coped successfully and is ready to move on.

Your response to the questionnaire also provided guidance for the association's planning:

- **Meetings** – For regular meetings, favorable location and good speakers were seen as most important for attendance, and some recommended topics for future meetings were AN diagnosis, regrowth, new research, tinnitus and hearing aids. Several people volunteered to host satellite meetings. (The Board has discussed having two regular meetings – currently three – each year with speakers in Sept/Oct and April – and encouraging and assisting with satellite meetings in the more northern and southern locations for May/June.)

- **Finances** – There were many excellent suggestions for improving our financial base, including increasing annual membership dues from \$20 to \$25 or \$30. (The Board has been examining the various ways to encourage special donations, and is seriously considering raising dues.)

- **Directory** – The Directory was applauded and seen as especially useful for newly diagnosed patients. (As a money-saving measure, the Board is considering printing a new Directory every two years instead of annually.)

- **Newsletter** – 100% of respondents said they read and wish to continue receiving the newsletter. There was no ground swell for expanding its length or for including reports on board meetings. Many respondents favored more articles by medical specialists. (The Board has encouraged occasional articles by members of our own Medical Advisory Board, but relies on ANA’s newsletter, *NOTES*, to provide all acoustic neuroma patients with a regular flow of key articles by specialists in the field.

- **Website** – Those who said they had visited the redesigned website (43% of respondents) found it very helpful, and the hope was expressed that doctors would recommend it to their patients.

- **Diagnosis** – For most respondents, the diagnosis of acoustic neuroma was made by their ENT (67%) or neurologist (23%). (For the Board, this is important to know for mailings of informational materials.)

- **Regional Conference** -- About 52% of respondents expressed interest in attending a regional conference; 23% were not interested; 25% undecided. (The last conference was Oct 2002 in Princeton; the Board is currently undecided about undertaking another conference for 2006 or 2008.)

### **The Headache Problem Revisited**

A look at recent ANA Discussion Forum postings ([www.anausa.org](http://www.anausa.org)) shows that persistent and medically intractable post-treatment headaches are still a serious problem for some acoustic neuroma patients. Post-surgery patients in particular are writing to the Forum with their questions and/or complaints, as for example:

*“I am nearly 9 months post-op and am having terrible pain. I thought I only had to ‘survive’ the surgery and I was not prepared for this ongoing pain. (I was told I was in the 1-3 percentile of people where severe headaches and pain may be a problem) . . .”*

*“Why does my doctor tell me I shouldn’t be having headaches when, in fact, I do. . . .”*

*“I am six years post-op and still struggle with headaches. My surgeon told me [he] doesn’t understand why I have them. . . .”*

*“I have had post-AN surgery headaches for 3 years. [I have tried so many medications] I sometimes feel like an in-house chemist.”*

*“I have been having the worst headaches and it’s been over a year since my surgery. I will try just about anything that I can afford. . . .”*

*“The frustrating thing is that no one is willing or able to say what is causing the headaches! I didn’t have them pre-op. . . yet it is repeatedly questioned as to whether the [operation] has anything to do with it. Well, I’m no doctor, but – duh!”*

Patients also use the Forum to share information about medications and other types of headache control. One patient provided a link to her own truly remarkable “medications and treatments log” compiled during her battle with debilitating cluster headaches. Her headaches began four weeks post-op. In greatly abbreviated form, her entries for the most harrowing period, January 2000 to July 2001, record the following sequence ~

Jan 2000 Pulsing pain in left temple wrapping around the head, tense neck. . .

*Aleve, Cold compresses*

*Post-surgery trauma?*

*Excruciating headache pain*

*Neurologist appointment*

Feb 2000 *Cluster headaches diagnosis*

*Verapamil (calcium blocker)*

*Imitrex (sumatriptan)*

*Tylenol*

*Extra Strength Bayer*

*Ice packs*

*Heat packs*

March 2000 *911 call, ER Oxygen*

*Butal/Esgic-Plus (muscle relaxant)*

*Neurontin (anti-seizure)*

*Excedrin Migraine*

*Advil*

*Pain clinic considered*

*911 call, ER Oxygen*

*Prednisone (steroid)*

*Zolof (stress disorder), ice packs*

*Extra Strength Tylenol*

*Problem of rebound headaches?*

*MRI neck scan*

*Oxygen, portable tank*

*Indocin (pain reliever)*

April 2000 *Physical Therapist.*

*Accupuncture*

July 2000 *New neurologist*

*Neurontin, Zomig, Imitrex*

*Massage therapy*

*Chiropractor*

Dec 2000 *Dietary prevention considered*

*Back to work part-time*

July 2001 *Pain Clinic*

*Diagnosis of entrapped nerve*

*Cortisone shots*

*Reducing abortive medications*

July 2001 *Back to work full time*

<http://hometown.aol.com/clfsong/page/MyAcousticNeuromaStory.htm>

Of course, one needs to read between the lines here, or even better, go to the full story – the bare listing of happenings cannot convey this young woman’s nightmarish bouts with headache pain or her growing frustration over becoming practically house-bound on “the short leash of her disability.” The National Headache Foundation ([www.headaches.org](http://www.headaches.org)) warns that cluster headaches are the most severe, piercing and intense of any headache type. They’re often called “alarm clock headaches” since they occur mostly in the early AM or during the night. They are vascular in nature and come most often in clusters with pain-free intervals. For initial treatment, as can be spotted in the listing, “preventive” medication is prescribed (e.g., *Verapamil*) in an attempt to reduce the number and length of attacks; and “abortive” medication (e.g., *Imitrex*) and therapy (pure Oxygen inhalation) are used to try to stop attacks once they have begun. But achieving control is difficult, ongoing and (as this patient strongly advised) should definitely be under the supervision of a neurologist experienced in headache management.

For achieving headache control, Dr. David Buchholz’s recent book, *Heal Your Headache: The 1-2-3 Program for Taking Charge of Your Pain* (Workman, 2002), provides an approach worth considering. Dr. Buchholz, a neurologist at Johns Hopkins, writes that when he first left training he didn’t like seeing headache patients and “considered them to be a nuisance,” but over time he came to welcome and help thousands of the most challenging “failed” cases. Twenty years of experience led him to the hypothesis that nearly all headaches “arise from a single mechanism – the mechanism of migraine – that is built into us by nature and generates painful blood vessel swelling when activated by triggers. This headache mechanism . . . can be controlled. Control starts with reducing your exposure to some of its triggers, especially certain foods and medications. If trigger avoidance alone isn’t effective, preventive medication, which blocks the mechanism, can be added. Painkillers, on the other hand, lead you to lose control. . . As you become more and more dependent on painkillers, and as these drugs become less and less effective, the quick-fix approach creates rebound: a state of never-ending headaches (and inability to respond to preventive treatment that would otherwise control them.”

In brief, Dr. Buchholz’s 1-2-3 Program is as follows:

**Step 1** – Avoid painkillers (“abortives”) or at least use them very infrequently. Some examples cited: *Imitrex*, *Esgic-Plus*, *Zomig*, *Exedrin*.

**Step 2** – Eliminate as far as possible all potential triggers that you can readily control. Some examples cited: caffeine, red wine, nuts, stress, skipping meals, tiredness, birth control pills, *Prozac*, roller coasters.

**Step 3** – If necessary, add a daily preventive medication to make the mechanism for migraine harder to trigger. Some examples cited: *Verapamil*, *Prednisone*, *Ibuprofen*, *Topamax*, possibly *Neurontin*.

These three steps are discussed at length in separate chapters of the book. There are numerous helpful tables listing types of medications, dosages and possible benefits and side effects. It’s noteworthy that preventive medication is Step 3 in Dr. Buchholz’s approach. Why not introduce prevention at the outset? One answer is that he doesn’t want the preventive medication to be on the scene and possibly blamed by the patient as a trigger for headaches. Better to get the quick fixes (Step 1) and dietary triggers (Step 2) off stage before introducing the good guy on the set. Also of interest is that Dr. Buchholz apparently identifies treatments like massage, acupuncture, chiropractic and physical therapy as only “temporarily soothing” quick fixes; they may be useful to reduce stress, but fail to control headaches long-term. He is also not a big fan of botox shots, vitamin B2, or herbal medicines such as Feverfew (*tanacetum parthenium*).

Because Dr Buchholz’s focus is on primary headache disorder – that is, headaches that are not “secondary” to some underlying medical condition – it’s not certain how he would advise an acoustic neuroma patient presenting with persistent post-surgery headaches. Consider, for example, cases of headache traceable to, say, a damaged nerve or cut muscle, or scar tissue, or a

missing bone flap – problems discussed mainly with reference to retrosigmoid surgery at the ANA’s 2005 National Symposium (ANA *NOTES*, Sept., 2005). It’s a guess, but it seems most likely that Dr. Buchholz would see the need here for a Step 2 action primarily. In this case, possibly by corrective surgery, Step 2 would involve the simple elimination of an identifiable, physical trigger. Absent the trigger, the headaches should end.

Actually, Dr. Buchholz states that the goal of his 1-2-3 program is not to eliminate your headaches altogether, but rather to eliminate your headache “problem” – that is, “to reduce headache frequency, severity and duration to a level where you’re reasonably satisfied: a situation that you can live with.” There is no longer a “problem,” he says, once you have learned to manage and tolerate relatively mild headaches that occur only from time to time.

A Postscript ~

*“When you’re lying awake with a dismal  
headache, and repose is tabooed by anxiety,  
I conceive you may use any language  
you chose to indulge in without impropriety.”*

(W.S. Gilbert, *Iolanthe*, 1882)

### **Drug “Avastin” Approved**

“Avastin” is the first angiogenesis inhibitor to receive FDA approval (February 2004) for cancer treatment, specifically, as a first-line treatment, in combination with chemotherapy, for metastatic colon cancer. Dr. Judah Folkman, who pioneered the anti-angiogenesis theory, has called the approval “a milestone in a new form of cancer therapy.” Avastin works to stop tumors from growing by preventing them from forming new blood vessels. According to its manufacturer, Genentech, the wholesale cost of Avastin for patient use will be \$4,400 per month; in human trials, most patients underwent ten months of Avastin therapy. Studies are underway to see if Avastin can be used to treat other cancers. The FDA has cautioned that the drug occasionally causes serious side effects, “including holes in the colon, impaired wound healing and internal bleeding.” A recent report on “Best Managed Companies,” in *Forbes* (Jan. 9, 2006), observes that Genentech “eschews mass-market medicines in favor of compounds for severe diseases – even if that means limiting the market to those most likely to benefit.” The report notes that sales of Avastin almost reached \$1.2 billion in 2005 ... “and could hit \$4.7 billion by 2009.” (See also “Stopping Tumor Growth,” ANA/NJ Newsletter, March 2004)

### **Proton Beam**

The University of Texas M.D. Anderson Cancer Center in Houston began construction in May 2003 of a \$12 million proton beam therapy center. Completion is expected early in 2006. The new facility will become the third and largest hospital-based proton radiation center in the USA. The two others are Loma Linda in CA and Massachusetts General Hospital in Boston.

Meeting

**“Making Lemons from Lemonade”  
-Rediscovering Joy and Humor-**

**Nancy Conn-Levin, M.A.**

“When faced with a brain tumor diagnosis, or when coping with the effects of treatments, sometimes it can be difficult to keep joy and humor in your life.” Nancy Conn-Levin, a health educator and specialist in stress management and coping techniques (as well as a 10-year brain tumor survivor), will discuss these important parts of health and wellness.

**April 30, 2006**

**1:30 PM**

**JFK Medical Center  
Neuroscience Conference Room  
65 James Street  
Edison, NJ**

Refreshments

Social Time

Directions to JFK Medical Center, Edison, NJ

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**From New York or Newark.** Take the NJ Turnpike south to Exit 11. Pick up the Garden State Parkway North to Exit 131, making a right turn off the exit to Route 27. At the fourth light (James St), make a right turn . JFK Medical Center and parking Lot A will be a short distance on the left.

**From Garden State Parkway South.** Take the Parkway to Exit 131 and continue as above, except note that you will enter Route 27 past the first traffic light.

**From Philadelphia & South.** Take the NJ Turnpike north to Exit 10 and pick up Route 1 North. At the Menlo Park Mall, exit on the right, going around the jughandle onto **Parsonage Road**. Continue straight past the mall and go through the underpass to the traffic light at Route 27. Go through the light onto James Street. JFK Medical Center will be a short distance on the left.

(Convenient, ample parking in Lot A is by the main entrance. Our meeting room will be posted in the Lobby).