

**ANA/NJ Newsletter**  
**Volume XIII, No. 1, March 2012**

**Chapter Meeting, Berkeley Heights,  
October 23, 2011**

**T**wenty-eight people attended the “Time to Share” meeting held at the Summit Medical Group facility in Berkeley Heights, October 23, 2011. Wilma Ruskin did the introductions and presided. Most ANA/NJ Board members were present. Kristin Ingersoll, who has done many excellent interviews of patients for the newsletter, did photos for the meeting.



The meeting seemed to have a perfect mix of new patients and “old-timers” so that there was a remarkably lively and valuable session. Many good questions were asked and people with the appropriate past experience were there to respond. Much of the discussion involved small tumors and the wait-and-watch option, which reflected the increase in recent years in the number of small tumors being diagnosed and the growing percentage of patients opting for wait-and-watch. The

ANA Survey in 2007-2008 reported this trend. And just recently in *ANA Notes* (Sept 2011) Dr. Michael Link (Mayo Clinic) called our attention to the fact that “more than 90% of ANs in Denmark are allocated to wait and scan if they are less than 2 cm.”

There was also much discussion about Gamma Knife radiosurgery. One patient reported on a failed GK treatment for a 1.5 cm tumor, whereas a second patient described a very successful GK experience for a tumor of the same size. The annoying unpredictability in dealing with ANs showed up again when one patient spoke about a successful middle fossa surgery for a 1.1 cm tumor, whereas a second patient recalled a very unsatisfactory middle fossa outcome for a tumor of the same size.



There was agreement that AN patients need to maintain a positive attitude and recognize that personal problems such as hearing loss will not be perceived readily by everyone; the “new normal” of the AN patient may look entirely “normal” to people who don’t realize there’s a problem.

**Continued**

## Notices

- The ANA/NJ Executive Board is still seeking new members. If you are interested in volunteering to serve on the Board, please contact Wilma Ruskin at 609-799-4442 or at [www.ananjinc@aol.com](mailto:www.ananjinc@aol.com).
- The only woman to lead the National Institutes of Health, Dr. Bernadine Healy (1944-2011) died August 4, 2011, after a 12-year battle with brain cancer. She spearheaded the Women's Health Initiative and the creation of the Institute for Nursing Research. As Donna Shalala, currently president of the University of Miami, has so correctly observed: "She was truly *sui generis* – one of a kind."
- Information about SoundBite, the bone conduction hearing system being designed to transmit sound via the teeth, is available at [www.sonitusmedical.com](http://www.sonitusmedical.com) or call 650-838-0325.
- Hearing loop/ telecoil technology receives high praise for eliminating background noise for hearing aid wearers and people with cochlear implants. In the USA, it's beginning to be installed in stores, banks, museums, restaurants and other public places as well as for home TV and offices. A good place to check it out is the website of the Hearing Loss Association of America, [www.hearingloss.com](http://www.hearingloss.com).
- Thanks to Laura Barbaro for posting on Facebook to call our attention to CapTel, the free captioned telephone service for qualified New Jerseyans with hearing loss. With CapTel, as you listen to incoming calls you can read captions of the call on the small screen of your special phone. You can print out and save the captions for the call. For details, illustrations, brochure, go to [www.NJcaptel.com](http://www.NJcaptel.com).

### In Memory

#### **Norman Wellen (1930-2011)**

A founder-member, "Norm" was instrumental in the creation of ANA/NJ. His thoughtfulness, dedication and infectious sense of humor helped us through many a difficult Board meeting. Our sincere condolences to his wife Jackie, and to all the family.

## Jackey Weightman in the Spotlight

(Note: Jackey Weightman is the Office Manager, Secretary and Newsletter Editor of BANA, the British Acoustic Neuroma Association. Her involvement with the organization grew out of her experience as the spouse of an AN patient. This is their story.)

I met my husband Alan in 1968 when I was 14 and he was 17 at a friend's birthday party. We "courted" for a couple of years then became engaged on Christmas Day 1970. We were married in August 1972 and have two daughters. Tracey is the Financial Controller for Nintendo and lives with Sean about 90 miles from us. Mandy manages Bon Marché, a women's clothing store. She, her husband Mark, and their two daughters, Kirsty and Hayleigh, live on the same island as us, about 9 miles away.

Until undergoing surgery Alan was a builder/handyman by trade. He had his own company fitting windows, doing carpentry jobs, tiling, decorating, fitting kitchens and bathrooms and installing central heating systems. He worked every available hour.

While the children were small I ran a weekly Mother and Toddler group. Later I owned and ran a Playgroup for children aged 2-5. I kept the books for Alan, then gradually expanded and took on other clients which became a successful bookkeeping business.

In 1995 my mum died from cancer. My dad was disabled and after losing mum was very despondent.



Our girls had left home so Alan and I decided to sell up and move in with my dad so we could look after him. We bought dad's house and set about renovating it. Life was very settled until 2001 when my dad was diagnosed with terminal cancer. By the middle of 2002 dad was too ill to do much for himself so we started caring for him. It was about this time that Alan was diagnosed with an Acoustic Neuroma, about two years following his first symptoms of single sided hearing loss and tinnitus.

Alan had initially visited his GP about tinnitus many years before diagnosis to be told there was nothing that could be done. He was later prescribed tablets which made the symptoms much worse and had to be discontinued. In hindsight Alan realized he had also been gradually experiencing increasing imbalance, especially on ladders, but his brain had learned to compensate quite well. Alan was eventually referred to the local ENT hospital but it took several months to get an appointment and then several more before being given an MRI.

The first ENT told us Alan had a benign brain cancer which could cause him to die on the table or end up in a wheelchair. Obviously there is no such thing as a benign brain cancer, but being very inexperienced we believed what we were told and lived with these fears for several weeks before seeing a neurosurgeon who explained things properly. Luckily he was unbiased about treatment options and gave us plenty of information about both Gamma Knife and Surgery. He put us in touch with BANA which was very helpful in giving information and support.

Our neurosurgeon explained that surgery was the usual treatment but that Alan might be a candidate for Gamma Knife radiosurgery. He sent us away and told me to trawl the Internet to learn all I could about Gamma Knife. When we returned a couple of weeks later, Alan had decided that he wanted the Gamma Knife. Unfortunately the neurosurgeon then informed us that on closer inspection it appeared that Alan's AN was 2.5 cm and so was a bit too big for radiosurgery. He told us that surgery was the only option but there was no urgency and that they wouldn't operate until Easter-time 2003 so it would give him time to settle his business matters.

My dad died at the end of November 2003 and a few days later the hospital called to ask if Alan would like to have his final 'pre-op' MRI the following week as they had a cancellation. Alan accepted and five days later he had a letter saying he would be operated on at the beginning of January. No reason for bringing the operation forward was given but Alan felt sure it was because the tumor had grown.

Although we weren't given a choice of procedures and at the time we didn't have the confidence to question anything, the Translabyrinthine approach was used and this was probably for the best as Alan had lost the hearing in that ear already and it is the most straightforward approach.

Alan had no immediate problems after the surgery, but a few days following surgery the nurse removed the drain and, as she pulled the tube out, his face dropped. At the time he was looking out of the window at the "London Eye," and as the tube came out he lost vision completely on the AN side. It was a real shock for me when I visited him that afternoon to see that he had Grade VI palsy.

Alan has found fatigue his most debilitating side effect. He also experienced serious dizziness and imbalance, poor coordination, and an inability to concentrate on things. He has problems swallowing due to the paralysis in half his throat. He often chokes on food and it seems like food goes into his lungs causing him to get infections.

To me, the worst thing was the terrible depression Alan suffered a few months after surgery. When Alan realized he wouldn't be able to return to work he became depressed, moody and argumentative. We sold our house in London and moved to a bungalow in the country which needed some work. This gave Alan a purpose again although the work takes him 10 times longer to do. Alan is definitely more emotional now. He can be quite short-tempered at times and certainly doesn't suffer fools gladly. Moving out of his old work environment lifted him out of his depression almost overnight and he became more like the old Alan again. He is generally a very happy person and is pretty upbeat about everything these days. He isn't bothered by his appearance, copes well with his hearing loss, and although he gets frustrated that things are harder now, he is determined and doesn't let things get him down for too long.

Alan suffers from dry eye and only Lacrilube is helpful without irritating his eye. Since he is unable to apply it, I have to do it for him every hour or so. This means we are now virtually 'joined at the hip'. He has had several procedures on his eye, partial tarsorrhaphy, derma filler in lower lid to tighten it up, and he had a static facelift.

Being together 24/7 also took a lot of getting used to but we have now settled into a 'routine'. Alan had to take early retirement and as he needed care I had to give up working too. We now do everything together. I think the hardest thing for him to cope with is his loss of freedom. He no longer drives as he becomes disorientated in a car and his perception of speed is virtually non-existent these days. If he wants to go anywhere he has to rely on me to take him and this can be very soul-destroying for him.

Being involved with BANA has given us a shared interest. I am more involved with the administrative side but he gets involved talking to other members at meetings or on the phone and is happy to spend time searching the Internet if something is needed for the office or the charity as a whole. I began as Secretary of BANA and helped get the website up and running. I then tackled our information booklets, updating them ready for trustee approval. Alan was made the official Branch Liaison officer but I do the job. I keep in touch with branch leaders and help them if necessary. Getting people to take on administrative roles is a problem so I run the majority of the groups, sending out invitations to meetings, keeping a list of attendees etc, so the hosts only have to worry about holding the actual meeting. It works very well on the whole. When BANA needed to find a new editor of the magazine, no one else was interested so I took that role on and I thoroughly enjoy it! I finally took on the role of Office Manager as I work closely with the girls in the office and was called upon to make several "executive decisions," so this was the next step.

I can't imagine what life was like pre-BANA. I love every aspect of my voluntary work and have met so many wonderful people. Until Alan had his operation he always did the driving. The furthest *I ever drove was the few miles back and forth to work. I now drive around 15,000 miles per year, mainly for BANA.* We travel all over the country meeting up with members and their families at meetings, lunches

etc. I have learned so much about Acoustic Neuromas, NF2 and other related conditions and am in my element working on two computers every day helping BANA to run smoothly. I couldn't have a better life than I have right now.

Although in an ideal world Alan would never have had to go through his AN journey, in one way I feel it may have saved his life. Before AN he was a total workaholic – out before 7 a.m. and often not home until 10 p.m. He was on call night and day. If his customers had a water leak, or a problem with their electricity or any other problem, he couldn't say no to anyone, and if he had continued at that rate I am sure he would have been dead from a heart attack by now!

Although the AN has changed his personality, in many ways it has actually brought us closer together. It has forced Alan to try new things. Instead of mixing up concrete Alan now mixes up cakes. His sponge cakes are amazing and he makes over 20 Christmas cakes each year for family and friends. He has taken over in the kitchen and now does the majority of the cooking as well as most of the housework. He also grows fruit and vegetables in our garden, although he still maintains he hates gardening!

Being involved with a charity like BANA has given a purpose to my life. I know that sounds dramatic, but I can honestly say this is probably the happiest I have ever been. I know Alan would give his eye teeth to be back at work but I am just thankful that I still have him around to drive me mad (and keep me supplied with tea and cake!)

*Interview by Kristin Ingersoll*

### **“Incidental” Acoustic Neuroma**

Some acoustic neuromas are never discovered. How many is not known exactly -- perhaps as high as 1%? In the past they were detected only at autopsy. Asymptomatic, or at least never diagnosed, they are referred to in the literature as “occult” (hidden or unsuspected) ANs.<sup>1</sup> It's interesting, as Dr. Samuel Selesnick and others have reported, that the new imaging technology is now discovering these asymptomatic ANs. They are being found incidentally in individuals undergoing MRI brain scans for completely unrelated reasons and are therefore called “incidental” acoustic neuroma.<sup>2</sup>

How many of these unsuspected ANs might be found? One 2005 retrospective search of 46,414 MRI brain scans at UCSF in California found eight patients with incidental AN. Tumor size ranged from 3 to 28mm. The prevalence of incidental AN was concluded to be roughly 2 in 10,000 people (0.02% of population).<sup>3</sup> An earlier (2000) search of 24,246 MRI brain scans at the University of Pennsylvania Medical Center found seventeen patients with unsuspected ANs. “Eight tumors were smaller than 1cm, 6 were between 1 and 2cm, and 3 were 2cm or larger.” The prevalence of incidental AN was concluded to be 7 in 10,000 people (0.07% of population).<sup>4</sup> Reviews such as these of large numbers of MRI scans obtained for purposes other than AN diagnosis will help to define the real prevalence of asymptomatic ANs. It remains to be seen whether or not the final count will be sufficient to make the overall frequency of AN significantly greater than reported by epidemiological studies (i.e., 10-11 per million of population per year).<sup>5</sup>

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<sup>1</sup> S.Karjalainen et al, “The Incidence of Acoustic Neuroma in Autopsy Material” (1984). Note: Full references provided on request.

<sup>2</sup> S.Selesnick et al, “The Changing Clinical Presentation of Acoustic Tumors in the MRI Era” (1993); “Incidental Discovery of Acoustic Neuromas” (1999).

<sup>3</sup> D.Lin et al, “The Prevalence of ‘Incidental’ Acoustic Neuroma” (2005).

<sup>4</sup> T.D.Anderson et al, “Prevalence of Unsuspected Acoustic Neuroma Found by Magnetic Resonance Imaging” (2000).

<sup>5</sup> For Denmark, the overall incidence has been reported as high as 13 per million/year. See M.Tos et al, “What is the Real Incidence of Vestibular Schwannoma?” (2004).

We thought about incidental ANs while reading the recent study by Dr. H.Gilbert Welch entitled *Overdiagnosis :Making People Sick in the Pursuit of Health* (Beacon Press, 2011).<sup>6</sup> Dr. Welch and his colleagues at the Dartmouth Institute for Health Policy and Clinical Practice write about what they see as a serious problem arising from the new imaging technology, namely, that its amazing ability to find things has resulted in overdiagnosis, which they define as “the detection of abnormalities that are not destined ever to bother us.” They call these unsuspected abnormalities “incidentalomas.” Welch and his coauthors argue that such incidentalomas (spots, nodules, polyps, growths) can too often trigger a “cascade” of expensive, anxiety-producing but actually unnecessary additional medical procedures or treatments that may leave patients worse off than if they had never been screened in the first place.

There isn't anything about acoustic neuroma in Welch's study which focuses on instances of overdiagnosis for cancers of the prostate, lung, breast, colon, thyroid. But we wondered: could an incidental AN also be viewed as a case of overdiagnosis? Is the new MRI imaging finding ANs that don't really need to be discovered?

There's room for discussion, but we believe these questions must be answered with be a big NO. Overdiagnosis is not really a problem for AN patients because, in the final analysis, all ANs need to be discovered. Among other things, this is because ANs are so very annoyingly unpredictable. Large ANs, for example, have been a long-standing problem because they are sometimes asymptomatic or produce only very subtle symptoms that may easily be ignored. Even if done incidentally, it's important to establish the presence of these dangerously large ANs. They need to be detected, evaluated and most likely treated as soon as possible.

Or consider the cases of misdiagnosis that we learn about so frequently, as when a gradual loss of hearing (or perhaps some imbalance) is attributed to aging, or when periodic headaches may be said to be a result of some anxiety or stress. Spotting the presence of an AN incidentally can delay a lot of second-guessing about the reasons for discomfort.

And there's the related issue of delayed diagnosis, the often too long gap between first symptoms and identification of AN. We recall the case of one patient in the ANA/NJ Registry who experienced a wide range of AN symptoms over a period of 28 years before being diagnosed at age 70 with a 7mm tumor.<sup>7</sup> How much better it would have been if an MRI scan had discovered the tumor early on.

We think that misdiagnosis and delayed diagnosis are more serious problems than overdiagnosis for AN patients.

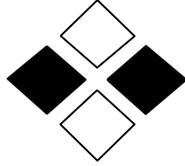
As for any concerns that incidental ANs may be rushed to treatment unnecessarily, actually the excellence of MRI imaging today, as well as our much better understanding of the natural history of ANs, has made a conservative, wait-and-watch approach much more likely.<sup>8</sup> It's noteworthy that Dr. Welch has endorsed this approach for the cancer-related incidentalomas he describes in his book. He writes: “More and more doctors recognize that following incidentalomas over time is generally a more prudent course than immediate surgery. . . I believe that if we could lower the intensity with which we react to incidentalomas, we'd do better by patients.”

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<sup>6</sup> Featured in *Time*, “The Screening Dilemma: Are Some Cancers Better Left Undiscovered?” (June 13, 2011).

<sup>7</sup> See “Acoustic Neuroma Sizes & Symptoms,” in ANA/NJ Newsletter (January 2006).

<sup>8</sup> See for example the articles by Dr. Samuel Selesnick, “The Wait and Scan Approach,” in ANA/NJ Newsletter (April 2011), and Dr. Michael Link, “Comparison of Surgery, Radiation and Natural History,” in ANA *Notes* (September 2011).



## Spring 2012 Chapter Meeting

### ***“A Time to Share”***

#### ***An Open Meeting for Patients, Family & Friends***

**Sunday, March 25, 2012**

1-4 pm

Mercer County Library System  
Lawrence Branch  
2751 Brunswick Pike (Route 1 South)  
Lawrenceville, NJ 08648

Make new friends and ask questions that only AN patients can answer. You do not need to be a member of ANA/NJ to attend. Refreshments will be served. For additional information, directions or to RSVP, please contact Wilma Ruskin at [ananjinc@aol.com](mailto:ananjinc@aol.com) or 609-799-4442.

#### Directions to the Library

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**From North Jersey:** Take Route 1 South. After the I-295 overpass there will be a traffic light at Franklin Corner Rd. Stay to the right onto Business Route 1 and . Make a right turn at the next traffic light, onto Darrah Lane. The Library is to the right.

**From Trenton:** Take Route 1 North to Whitehead Road Exit. Make a left onto Whitehead Road and follow until the traffic light. Make a right onto Business Route 1 and continue North for about one mile. Immediately after the third traffic light, move into the jug-handle to cross over Route 1 onto Darrah Lane. The Library is on the right.

**From Eastern New Jersey:** Take I-195 West to I-295 North. Exit at Route 1 South. Follow the “From North Jersey” directions, above.

**From South Jersey:** Follow I-295 North. Exit at Route 1 South. Follow the “From North Jersey” Directions, above.