



Acoustic Neuroma Association of New Jersey

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Kathy Dylewski in The Spotlight



Kathy can't wait to turn on her cochlear implant when she wakes up in the morning. Attaching the speech processor portion to the implant opens up the world to her. Until that time she is in a silent world devoid of the sounds others take for granted like the birds chirping, rain on the roof, or even the sound of her alarm clock. In a few short years her world has changed in mysterious and sometimes frightening ways. It has been a challenging journey requiring her to redefine her priorities.

Kathy lived a good and fairly typical life until 1998. She was born in Hackensack, NJ, the daughter of a military man. The family moved frequently with the Air Force until she was in the 8th grade. After graduating from High School in Woodridge, she went on to graduate from Rutgers University with a major in Zoology and a minor in chemistry. Employment opportunities at the time seemed limited to animal experimentation which did not appeal to her so she took a job as an executive secretary in NYC. She married, moved to Sparta, had two children, and found work in a local law firm. There she was trained to do paralegal work in real estate, which became her career and one which has been very good to her. Kathy loves Sussex County with its views and wildlife and has now lived there for over 30 years. After 10 years with the local law firm she sought and obtained employment with Riker, Danzig, Scherer, Hyland and Perretti LLP at Headquarters Plaza in Morristown. Even after 17 years she feels privileged to work there and feels like a member of a corporate family. She is deeply grateful for the support she has experienced there throughout her ordeal.

It all began in 1998. Kathy sought medical attention because of a hearing loss in her right ear. Despite an MRI with contrast and other tests, no explanation was provided for the loss. She accepted this and was grateful for her normal hearing in her left ear. In 2001 she unexplainably lost hearing on the left side. This time when they did an MRI with contrast they found a 14mm acoustic neuroma on the left side. After 6 months of "watching and waiting," and an additional hearing loss in the left ear, a middle fossa craniotomy was done in February of 2002 to decompress the tumor rather than to remove it because of her hearing loss in the other ear. She began searching the Internet and going into related

chatrooms where she heard about FSR (Fractionated Stereotactic Radiotherapy). Her research persuaded her that this was a safer and an effective alternative to Gamma Knife that she understood could cause damage to healthy tissue as well as to the tumor. Having had an unpleasant surgical stay at a NYC hospital, she was determined to seek treatment somewhere other than in NYC. She chose Johns Hopkins Hospital in Baltimore, MD, and can't say enough good things about the care she has received there. They have been compassionate, attentive and responsive to her needs and she gladly travels the extra distance to receive care there. FSR was done there in October of 2002 and she had virtually no aftereffects. 18 months after FSR her tumor has shrunk and darkened in its center, and there has been no damage to surrounding normal tissue. Kathy continued to lose hearing in the left ear. Because of a moderate to severe hearing loss on the AN side and profound deafness on the other side, cochlear implant surgery was performed at Johns Hopkins in December 2003. The implant was activated a month later. She must return periodically for "mapping" of the implant initially at 1 month, 3 months, then at 6 months. Since activation she has been re-learning how to hear. Sound is not the same as it had been and she must re-identify what sounds are, but it has been incredible for her. For the first time in a long time she had hearing on both sides and could even tell what direction sound was coming from! She felt that it opened her world up to her again! She had been told it would be difficult and could be frustrating until she adjusted to it and learned to hear with it, but she was well prepared for the frustrations and found it to be terrific right from the beginning. In fact, when initially approached for an interview she had declined, but after her implant was activated and she realized what a powerful and positive change it made in her life, she wanted to share her story in hopes that it might help someone else.

Then on Mother's Day of 2004, the unbelievable happened. All of a sudden something was wrong. Her first thought was that the implant had stopped working. She soon realized it wasn't the implant but that she had lost even more hearing on the AN side. Without her cochlear implant her world would have been silent. It was a depressing setback for someone who had had one after another and she admits to having her ups and downs to struggle through. Ultimately she gathered her strength and her supports and refocused on her positives of which she is increasingly aware. She acknowledges that her priorities have shifted and material things have diminished in importance. She is determined to live life to the fullest and to take nothing for granted. Things that once upset her don't matter to her any more. Although she says that she refuses to let her hearing problems change her life, in fact it is obvious that they have but in many ways for the better. Now a single woman with grown children, she is doing things that she always intended but put off including joining a gun club for target shooting, taking karate (which has helped her immensely with her balance) and taking art classes. She describes herself as an aviation enthusiast and former pilot and is looking for new ways to contribute as a volunteer at the annual Sussex Airport air show. The one thing which has had to be put off, but which she vows to return to, is ballroom dancing. She thinks she is approaching a time when her ability to interpret the sounds of music will allow her to return to the dance floor, but she hasn't yet since a difficult early effort.

Kathy has actively looked for support along with information in many places throughout this journey and has found ALDA (Association for Late Deafened Adults) to be particularly helpful. She encourages other patients to seek information and support both online and through support groups. She also emphasizes the importance of going where the experience is. In the beginning she accepted what she was told. Now she knows it is essential to educate yourself and be treated by the few doctors in the few hospitals with the most experience doing the procedures you select. The journey has been difficult but with great determination Kathy has proved that life is what you make it with the assets you have.

Interview by Kristin Ingersoll

A letter from Wilma ~

Dear ANA/NJ Members and Friends:

Some months ago we sent a letter telling you about the difficulties between several local chapters and ANA. Although we have attempted to 'set things right' and return to the mutually supportive relationship we once had, we find that the ANA Board and office management are unwilling to have a face-to-face meeting with us to discuss our differences. On June 18, we received a letter from ANA stating that, unless we submit certain required documents by June 30, 2004, they would consider that we are no longer interested in being part of their work. As a matter of fact, nothing could be further from the truth!

Since June of last year, members of the NJ, NY, IL, GA, and WI groups have spent countless hours writing letters and making some simple requests which would enable us to better serve acoustic neuroma patients and their families. One of the stumbling blocks, and what we consider a critical issue, is that although ANA is requiring local chapters to submit patients' names, addresses, etc., they are unwilling to reciprocate. For many years the National office sent names of new contacts to local groups and chapters every month. That practice was abruptly stopped, with no explanation. Receiving those names made it possible for us to reach out to patients who are most in need of information and support and let them know that there are local meetings and other patients they can meet and speak with. As a result of the inflexibility of the national board on this and several other important issues, the ANA/NJ Executive Board at our July 10 meeting, with sincere regret, voted unanimously that we could no longer function under the auspices of ANA. Local groups in several other states also have no formal affiliation with ANA. We will continue to function as a 501(c)(3) non-profit organization and we will continue to need your financial and personal support. We have never been financially supported by ANA and have always depended on our members' dues and the donations of friends and family members to cover our expenses, e.g., our newsletter which is mailed four times a year to 470+ people but is essentially financed by our 170 paid members.

We know that we have made a difference in the lives of many acoustic neuroma patients and their family members. You can help to make a difference, too. Thank you for your understanding and continued support.

Sincerely,

Wilma Ruskin, for the Executive Board
July 15, 2004

Choosing Between Surgery and Wait-and-Watch

Dr. Tina Tos and colleagues at the Gentofte University Hospital of Copenhagen, Denmark, have compared the long-term socio-economic impact for acoustic neuroma patients who were either operated on (716 patients) or chose to wait-and-watch (226 patients). The aim of the study was to be able to inform AN patients of the socio-economic and quality of life changes they might face after surgery or during observation. Tables 1-3 (see p.5) present the main findings of this valuable study.

For the wait-and-watch group, the median age at diagnosis was 59.8 years (range 21.4-95.2). The patients responded to a questionnaire at a median of 3.7 years after diagnosis (range 1.1-18.1). The tumors in this group of 226 patients were mostly below 2.0cm and were evaluated as the less aggressive type. Surgical intervention at the treating center was standard for tumors larger than 2.0cm with documented growth verified by MRI.

For the 716 surgery patients, the median age at operation was 53 years (range 24.6-83.4). The patients responded to the questionnaire at a median of 11.5 years after surgery (range 1.1-26.6). Ninety-five per cent of the patients were operated on by the translabyrinthine approach and 5% by either the middle fossa or retrosigmoid approach.

As seen in Tables 1-3, the most frequent complaint by both wait-and-watch and surgery patients were a decrease in social ability. "Social ability" was not defined in the study, but is considered to involve problems in going out socially, self-image, being handicapped physically.

Over 50% of surgery patients and 37% of wait-and-watch patients reported increased fatigue. This is a higher figure for fatigue than reported in the 1998 ANA Survey.

"Regardless of tumor size, the change in social ability, concentration and fatigue was worse in the group of operated patients."

For headache, 20% of the wait-and-watch patients reported a worsening of headache during observation, whereas 17% of operated patients with large tumors and 7% with small tumors had relief after surgery.

Depression worsened for 27% of wait-and-watch patients and over 30% of surgery patients. Patients operated on for a small tumor experienced depression more than the other groups.

The study reported no really significant difference between the groups for intellect, irritability and libido. However, attention was called to the 3% improvement in libido for surgery patients with large tumors.

The patients for this study were also asked about their ability to handle daily chores following surgery or during the observation period. No decreased ability was reported by 76% of the wait-and-watch group, 62% of the small tumor group and 55% of those with large tumors (>2.0cm).

The 716 surgery patients were also asked when they had resumed their daily chores. Only 59% responded to this question: 70-84% said they resumed chores within 4-6 months, while 17% of the large tumor group and 10% of the small tumor group said that they never resumed chores.

Regarding impact on employment, although a majority of all patients 60 years or younger reported no job consequences, the category "Had to stop working" was marked "Yes" by 28% with large tumors, 22% with small tumors, and 18% for wait-and-watch.

The study concluded: "It has to be realized that surgery of even small tumors has consequences worse than those of observation, concerning psycho-social well-being, ability to handle daily chores and vocational status. This clearly justifies a policy of observation and repetitive MRI of the increasing number of intra-meatal and small tumors, at least until growth is documented."

Table 1: Changes for 226 Wait-and-Watch Patients*
(Tumor Size < 2.0 cm)

Change	Better	Unchanged	A Little Worse	Much Worse
Social Ability	--	101 (50%)	66 (33%)	35 (17%)
Fatigue	--	126 (64%)	47 (24%)	25 (13%)
Concentration	--	132 (66%)	54 (27%)	14 (7%)
Irritability	1 (0.5%)	121 (61%)	59 (30%)	17 (9%)
Depression	--	142 (72%)	42 (21%)	12 (6%)
Headache	--	155 (79%)	30 (15%)	10 (5%)
Intellect	--	168 (87%)	20 (10%)	6 (3%)
Libido	--	175 (90%)	9 (5%)	11 (6%)

Table 2: Changes for 316 Surgery Patients*
(Tumor Size < 2.0 cm)

Change	Better	Unchanged	A Little Worse	Much Worse
Social Ability	1 (0.4%)	85 (30%)	98 (35%)	95 (34%)
Fatigue	2 (1%)	118 (42%)	93 (33%)	68 (24%)
Concentration	1 (0.4%)	132 (48%)	100 (37%)	40 (15%)
Irritability	4 (2%)	141 (53%)	79 (30%)	43 (16%)
Depression	4 (2%)	159 (60%)	65 (25%)	37 (14%)
Headache	18 (7%)	168 (64%)	35 (13%)	41 (16%)
Intellect	2 (0.8%)	199 (80%)	33 (13%)	16 (6%)
Libido	--	206 (81%)	25 (10%)	24 (9%)

Table 3: Changes for 400 Surgery Patients*
(Tumor Size > 2.0 cm)

Change	Better	Unchanged	A Little Worse	Much Worse
Social Ability	10 (3%)	99 (28%)	132 (37%)	117 (33%)
Fatigue	14 (4%)	142 (41%)	119 (34%)	70 (20%)
Concentration	15 (4%)	170 (48%)	130 (36%)	42 (12%)
Irritability	17 (5%)	173 (51%)	107 (32%)	40 (12%)
Depression	13 (4%)	211 (63%)	81 (24%)	32 (10%)
Headache	58 (17%)	214 (64%)	40 (12%)	24 (7%)
Intellect	11 (3%)	240 (73%)	64 (19%)	16 (5%)
Libido	11 (3%)	250 (75%)	43 (13%)	28 (8%)

*Reference: Tina Tos et al, "Long-term Socio-economic Impact of Vestibular Schwannoma for Patients under Observation and after Surgery," *Journal of Laryngology & Otology*, vol. 117 (Dec. 2003).

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Special Notices

◆The Internet address for ANA/NJ, the Neuroma Association of New Jersey, will be

www.ananj.org

Please visit often for news about meetings activities, our newsletters past and membership renewals, links to other acoustic sites, and much more.

Many thanks go to board member Dave B. for arranging for our new place on the Internet and overseeing the design of the new website.

◆ANA/NJ's brochures have been updated and copies will be mailed to members and to area physicians for distribution to acoustic neuroma patients.

High-Tech Healthcare

A recent special report in *U.S. News & World Report* (August 2, 2004) examined the high-tech innovations being adopted in a growing number of U.S. hospitals. Things like: CPOE (computerized physician order entry) for prescriptions, lab tests and special diets); digital health records that patients can access online through a secure website; image transfer technology for sending CT and MRI scans anywhere over high-speed Internet connections; and eICUs, electronic intensive-care units, where highly trained "intensivists" monitor critical-care patients. The innovations are intended to improve the quality of hospital care, facilitate communications between doctors and patients, reduce healthcare costs and, most importantly, save lives.

By logging on to the Internet and going to "How's Your Health, New Jersey," you can check on ways in which NJ hospitals are responding to this high-tech challenge. This new website (www.howsyourhealthnj.org) is currently rating NJ hospitals for three practices: 1) CPOE, computerized drug orders; 2) ICU staffing with trained physician specialists; and 3) proven outcomes or extensive experience with high risk treatments.

The new website also allows visitors to take a ten-minute "How's Your Health Survey" and have their survey entries analyzed by a clinical team from New Jersey's Health Care Quality Institute. The results are returned in an "Action Form" that can be

printed out to share with your doctor. Users are assured that the personal data provided will not be stored or shared electronically.

In addition, the website can be used to check on HealthGrades' Report Cards for hospitals, physicians, nursing homes and home health agencies in NJ, NY and PA. And there is a Patient Safety Reporting System that patients and healthcare professionals can use to report on incidents involving patient safety in the medical arena.

"How's Your Health, New Jersey" is sponsored by New Jersey's Health Care Quality Institute in cooperation with the New Jersey Chamber of Commerce, the State of New Jersey, and the New Jersey Health Care Payers Coalition. Financial support is by the Commonwealth Fund and the Robert Wood Johnson Foundation.

Acoustic Neuroma and Fatigue

(Editor's note: Part IV of this article, "How can I cope with long-term fatigue?" is still under preparation and is now scheduled to appear in the next issue of the newsletter. We apologize for the delay!

Meeting

"Radiosurgery and Radiotherapy"

Dr. Michael Schulder

Associate Professor and Vice-Chairman
Department of Neurosurgery, UMDNJ-New Jersey Medical School
Co-Director, Center of Stereotactic Radiosurgery

October 10 1 PM Conference Rm 4

Overlook Hospital, Summit, NJ

Discussion Social Time Refreshments