ANA NJ
ACOUSTIC NEUROMA ASSOCIATION of NEW JERSEY

ANA/NJ Newsletter
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Acoustic Neuroma Association
of New Jersey
A Non-Profit Corporation

Fall Meeting, Berkeley Heights
October 15, 2017

Our Fall meeting on October 15, 2017, was held at the Summit Medical Group facility, Lawrence Pavilion, in Berkeley Heights. Dr. Jed Kwartler, otologist and neurotologist with SMG, was present at the beginning of the meeting to welcome everyone to the facility and to introduce our speaker, Dina Leyden, PT. Dina is also a member of SMG and has special certification in vestibular rehabilitation. Her topic for the day was "Acoustic Neuroma and Balance Issues." Twenty-seven acoustic neuroma patients and caregivers were in attendance.

This was a really great meeting. Both the speaker and attendees were in top form. Dina began by reviewing briefly how the normal balance system works. The importance of the VOR, vestibular-ocular-reflex, was explained clearly. She then began to give examples of balance issues, which resulted in an outpouring of questions and descriptions of personal experiences from the audience. We heard about, and Dina commented on: age as well as AN as a factor in balance; the discomfort and risks of 'over-stimulating' environments (as in Walmart or Costco); the balance value of a cane, shopping cart, spouse or friend; the value of sit-stand & demi-squat balance stabilization exercises, as demonstrated; the impor-

tance of our brain's plasticity in correcting imbalance with the help of vestibular therapy; how stress and anxiety affect balance adversely; how quick motions can be problematic for 'motion-intolerant' persons; that acupuncture can help in some cases, but copper bands, not likely; how basic yoga and tai chi can help; the importance for proper balance of good footwear and good vision; the danger of walking in the dark on uneven surfaces; how sitting on the edge of the bed for a minute or two before getting up is a good idea; and much more.

Dina ended the meeting by giving brief sample lessons in yoga and meditation. She received a good round of applause for an overall wonderful and helpful presentation.

Save the date!

NJ-NY Joint Mini-Conference
Sunday, April 22, 2018

Notices

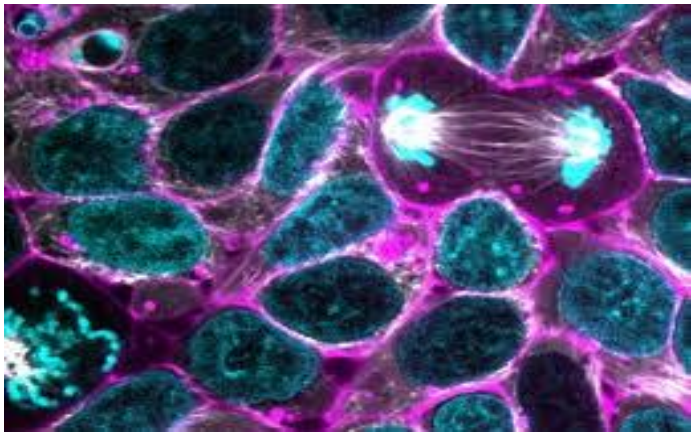
● ANA/NJ is happy to be able to provide a limited number of "scholarships" for AN patients who need financial assistance for fees and/or other expenses for attendance at biennial Mini-Conferences. For information and to apply, please contact Jane Huck at 908-725-0233 or email janehuck@msn.com.

● The transcript for "NF2 – Your Questions Answered" (ANA Live, January 16, 2018) is available in ANAUSA's online Webinar Library. Drs. Gustavo Pradilla and Esther Vivas, at the Emory University Medical Center, describe how the symptoms and treatment for Neurofibromatosis Type 2 (NF2) differ from those for sporadic acoustic neuroma.

● Doctors in the Department of Neurological Surgery at the University of Virginia have compared the costs of Gamma Knife radiosurgery and open surgery for acoustic neuroma at their institution over a recent 3-year period. Follow-up costs for at least 12 months after treatment were included. The study found that the average total cost for open surgery was $67,538, compared to $37,840 for radiosurgery. On average, Gamma Knife radiosurgery was 44% of the cost of open surgery. (See *Jour Clinical Neuroscience*, 22, January 2015)

● The newest model Gamma Knife, called *Icon*, is currently in use at RWJ in New Brunswick (Dr. Danish) and at Valley Hospital in Paramus (Dr. D'Ambrosio). *Icon* will be installed at JFK in Edison (Dr. Landolfi) by Spring/Summer 2018. (See the notice for *Icon* in the March 2017 issue of the Newsletter).

● "Top 10 Emerging Technologies of 2017," a special report in *Scientific American* (Dec 2017), calls our attention to the Human Cell Atlas (HCA), the ambitious project launched in 2016 by a global consortium of leading scientists (19 institutions across 10 countries) to create a comprehensive reference map of all human cells – the fundamental units of life. "The consortium's long-term goal is to profile at least 10 billion cells covering all tissues, organs and systems, representing healthy tissues as well as those affected by particular diseases and conditions." (See www.humancellatlas.org; also O.Rozenblatt-Rosen et al, "The Human Cell Atlas: From Vision to Reality," *Nature* (Oct 18, 2017).



ACOUSTIC NEUROMA TODAY

From Traditional Radiotherapy to Stereotactic Radiosurgery: Excerpts from "An Interview with David Larson, MD, PhD, FASTRO" (Fellow of the American Society for Radiation Oncology)

Dr. David Larson is professor emeritus of radiation oncology at the University of California, San Francisco. He is past-president of ASTRO (2000-2001) and recipient of the Jacob Fabricant award by the International Society of Radiosurgery and the 2016 Pioneers in Radiosurgery award by the Leksell Gamma Knife Society. The interview, available in full at the ASTRO website, was conducted for the History Committee of ASTRO on July 1, 2016, by Drs. Theodore Phillips and Arjun Sahgal. Some reordering of excerpts has been done for purposes of chronology and topicality.

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"My medical school [after graduate study in particle physics at the University of Chicago] was the University of Miami School of Medicine. I graduated [in 1981] after two years, at the age of 41, having not slept much for two years. The school's motivating idea at the time was that America needed more scientists in medicine in order to accelerate scientific progress, i.e, 'Let's select people who have a PhD, put them through medical school quickly, and get them out there in academic institutions'. [For my internship year] "I chose radiation oncology with Sam Hellman at the [Harvard] Joint Center for Radiation Oncology. . . That's certainly where I developed my interest [in radiosurgery]. I noticed Wendell Lutz and [neurosurgeon] Ken Winston working together late every evening. They were modifying a linac [linear accelerator] to do radiosurgery, something that seemed to be at odds with the 4 R's of radiobiology [See below, Table 1]. After residency, when I joined the UCSF faculty, I asked Wendell if he'd share his linac radiosurgery design plans, and he did without hesitation. So with the help of UCSF physicists. . . we put together a radiosurgery linac. . . and we used the system from 1988 until 1991. UCSF was one of the initial radiosurgery programs in the country.

"I attended the first U.S. Radiosurgery Congress in December, 1987, in Boston, which had over 100 attendees even though only three of them, Ladislau Steiner, Jay Loeffler and Dade Lunsford, had treated anybody with X-ray [linac] or gamma ray radiosurgery. I saw my first radiosurgery patient soon thereafter, in March of 1988, a patient with . . .a left parietal arteriovenous malformation [AVM] referred by neurosurgeon Charlie Wilson.

"I ended up treating somewhere around 120 patients between 1988 and 1991, over three years. So not a huge number of patients but enough so that I could be on top of potential single fraction complications, of which we had very few, as it turned out. I was pretty much plugged into other radiosurgery departments around the world. I and many other radiosurgeons favored radiosurgery dose distributions over standard radiotherapy dose distributions, given the latter's unneeded large margins, especially unneeded for non-infiltrating targets such as meningiomas, acoustic neuromas, brain mets [metastatic tumors] and AVMs.

"Fractionated dose distributions and immobilization techniques used at that time were rudimentary by today's standards. I knew that the 4 R's argued for multiple fractions, but I also knew that most radiosurgery targets have no normal tissue within them, and thus two of the 4 R's (repopulation and repair of sublethal damage) must be of lesser importance given good radiosurgery dose distributions and good immobilization. Nevertheless, clinical affirmation of potential radiosurgery advantages had to develop over time.

"At UCSF the transition from non-CT [computed tomography] based to CT-based treatment planning for brain tumors took place in 1981, well before we were doing radiosurgery. . . There had been several

publications from UCSF and other institutions that the local recurrence rate after radiation therapy for meningioma was somewhere around 20-30 percent. That seemed pretty high, and when we looked at our data we found that the recurrence rate was indeed 20-30 percent at five years for patients planned and treated before 1981, but only 2 percent if treated in the CT-based planning era after 1981. So we

Table 1: The 4 R's of Radiobiology[1]	
Reoxygenation	Tumor cells with an inadequate oxygen supply are resistant to radiation. Splitting the radiation dose into fractions assists in reoxygenation of hypoxic tumor cells so that they can be killed.
Repair	By using low dose fractions, normal tissue cells are allowed to repair sublethal radiation damage during the times between the delivery of each fraction.
Redistribution	Fractionation provides for radiation through all phases of the cell cycle. Given time, some tumor cells will have left the resistant phase and be in a more sensitive phase, allowing them to be killed more easily.
Repopulation	Repopulation refers to increase in cell division in normal and tumor cells following radiation. On average, it takes about 4 weeks for a tissue to start repopulating after radiation exposure. Repopulation of normal tissues is highly desirable.

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published that, and got quite a number of phone calls from colleagues around the U.S. saying that that couldn't possibly be true. But those data were soon replicated by many groups. Of course, in retrospect it makes no sense that you could have low recurrence rates without good targeting. So that was a great lesson for all of us. . .We used only CT-based planning during our linac SRS [stereotactic radiosurgery] period, 1988-1991. We began using a Gamma Knife in 1991. I suppose we used MRI planning for SRS in the early 1990's.

"Bob Cassidy called me up and asked me if I would give an educational course at ASTRO in 1988. At the time, they didn't call them educational courses; they called them refresher courses. So I gave the first SRS refresher course in 1988, in a room crowded with 400 attendees, standing room only. Everybody was interested in SRS. But the word 'refresher' was a bit of a misnomer because since there was so little known about SRS, how could you refresh anybody? I also gave the same course in 1989, when there was more information available, so the first two ASTRO SRS educational courses were done by me, and there was great individual clinical interest and great ASTRO societal interest in this new thing called SRS.

"There was initially the notion that it's not 'radiosurgery' if you do more than one fraction.[2] If you do two fractions you can't call it radiosurgery. So everybody at first was doing one fraction, despite the 4 R's, and despite some criticism. What we're learning now is that for large tumors you are much better off doing perhaps three fractions. Large tumors, I think, usually have a fair amount of hypoxia. If you have hypoxic tumors, you're probably better off with two or three fractions rather than one. Reoxygenation

[1] The 4 R's were then guidelines generally in support of traditional radiotherapy with its approximate fields of radiation and multiple-session low dose procedure. With some revision, they are still taught, and a 5th R has since been added, thus: **Radiosensitivity - There is a difference in radiosensitivity for different cell types.** An easy to read description of "The Five R's of Radiotherapy" is online at www.RadicalRadiationRemedy.com.

[2] Lars Leksell (1907-1986), the 'father of radiosurgery,' defined it as "the destruction of intracranial targets without opening the skull using single high doses of ionizing radiation in stereotactically directed narrow beams." See "Introducing New ideas in Medicine: Stereotactic Radiosurgery," ANA/NJ Newsletter (October 2011).

makes sense. . . Now, all the radiosurgery apparatus manufacturers build SRS apparatus in such a way that one can accurately deliver more than one fraction. I think as time goes by we are going to see more and more patients get perhaps two or three fractions [hypofractionated radiosurgery].[3] Whether you'd do even better with ten fractions is an open question. My guess is probably not much better, at least for brain and spine. For example, clinical outcomes for small meningiomas are the same for 30 fractions or 1 fraction.

"Well, if you're asking me to reflect a little bit on future oncology directions, what I would say is that right now we're just at the starting point of targeted therapy and immunotherapy. . . and there will be a great need to know how you should integrate those therapies with radiation in different areas of the body. This is exciting, and great research opportunities for young faculty.

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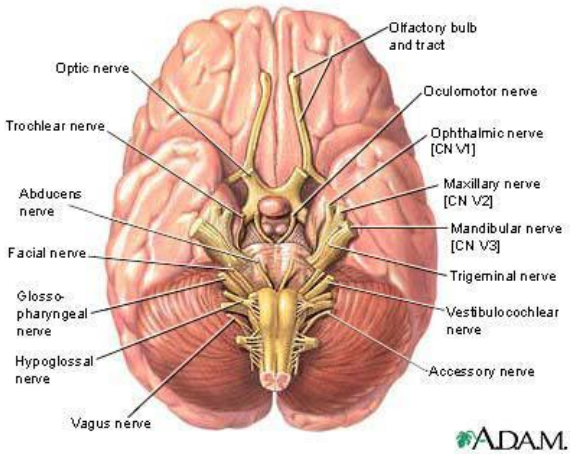
Facial Nerve Preservation after Gamma Knife Radiosurgery



Preserving facial (7th cranial) nerve function has been a major goal of radiosurgery since the first acoustic neuroma was treated by Lars Leksell in 1969. By 1987, the year Dade Lunsford brought the Gamma Knife from Sweden to the University of Pittsburgh, the recommended minimum radiation dose to the tumor margin for this purpose was 20 Gy.[4] This was the usual dose selected for the first patients treated at Pittsburgh. Since that time, beginning mostly about 1991-92, the marginal tumor dose has been gradually decreased to the current rate of 13 Gy (range 12-14 Gy). This low radiation dose has been found to be about right also to control tumor growth and improve hearing preservation.

In 2009, researchers in the Department of Neurological Surgery at the University of California, San Francisco, reported that "a facial nerve preservation rate of 96.2% can be expected after Gamma Knife

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[3] See John D. Lipani, MD, "Hypofractionated Stereotactic Radiosurgery for Acoustic Neuroma: The CyberKnife," ANA/NJ Newsletter (June 2013). The current CyberKnife protocol at Stanford University for treating acoustic neuromas is three fractions delivered in daily sessions. The newest Gamma Knife model, the *Icon*, provides flexibility to do fractionated treatment, which enables treatment of large tumors. (See www.careforthebrain.com).

[4] G.Noren et al, "Stereotactic Radiosurgical Treatment of Acoustic Neurinomas," in L.D.Lunsford (ed), *Modern Stereotactic Neurosurgery* (1988).

radiosurgery for vestibular schwannoma."[5] This rate was based on an analysis of facial nerve outcomes data for 2,204 patients reported on in a total of 23 published studies from multiple GK centers. The analysis noted: "Patients receiving less than or equal to 13 Gy of radiation at the marginal dose had a better facial nerve preservation rate than those who received higher doses. . . Patients with a tumor volume less than or equal to 1.5 cm(3) [i.e., less than or equal to 1.42 cm in diameter] had a greater facial nerve preservation rate [99.5%] . . . Superior facial nerve preservation was also noted in patients younger than or equal to 60 years of age."

In 2012, a report by the Dept of Neurologic Surgery, Mayo Clinic, evaluated the efficacy of Gamma Knife radiosurgery for tumors larger than 2.5cm. Twenty-two patient records were reviewed. Tumor diameter sizes were 2.5-3.8cm. The median margin dose was 12 Gy. The 3-year rate of freedom from new facial weakness was 92%; the 5-year rate was 85%.[6]

For large tumors, Gamma Knife radiosurgery has become an important part of a 'facial nerve-sparing' technique whereby subtotal surgeries are followed by radiation treatment for 'residuals,' as needed. University hospitals in Lausanne, Switzerland, have most recently reported on the success of this technique for 32 patients whose presurgical tumors averaged 2.87cm in diameter. The mean GK marginal dose for residuals was 12Gy. The mean duration between surgery and Gamma Knife treatment was 6.3 months. The report states: "Our functional results [for facial nerve and hearing] with this approach in large [vestibular schwannomas, VS] are comparable with those obtained with GKRS alone in small- and medium-sized VS."[7]

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Patient Survey, 2014

ANAUSA's 2014 online survey of acoustic neuroma patients was responded to by 846 patients. Data from earlier patient surveys (2012, 2007-08, 1998, 1983) were included in the report, so that, in total, "The report contains the responses of 4,172 AN patients who completed a survey and indicated a treatment modality (microsurgery, SRS, FSR or Wait-and-Watch)."

The following data are excerpted from the report:

Tumor Size at Diagnosis
(% of respondents)

Size	2014 (n. 846)	2012 (n. 1,394)
1.5 cm or less	47	47
1.6 – 2.5 cm	28	26
Larger than 2.5 cm	19	22

[5] I.Yang et al, "Facial Nerve Preservation after Vestibular Schwannoma Gamma Knife Radiosurgery," *Jour Neuro-oncology*, vol 93(1) (May 2009). PubMed abstract.
[6] B.Milligan et al, "Long-term Tumor Control and Cranial Nerve Outcomes following [Gamma Knife] Surgery for Larger-Volume Vestibular Schwannomas," *Jour Neurosurgery*, vol 116(3) (March 2012).
[7] R.T.Daniel et al, "Preserving Normal Facial Nerve Function and Improving Hearing Outcome in Large VS with a Combined Approach," *Acta Neurochir* (*Wien*), vol 159(7) (July 2017).

Type of Treatment
(% of respondents)

Treatment	2014 (n. 846)	2012 (n. 1394)
Microsurgery	51	54
SRS (radiosurgery)	17	18
FSR (radiotherapy)	12	10
Wait-and-Watch	20	20

Type of Surgery
(% of respondents)

Type	2014 (n. 846)	2012 (n. 1394)
Translab	23	28
Retrosigmoid	18	16
Middle Fossa	8	7

▪ Notice that for both the 2012 and 2014 surveys, 47% of patients reported **tumor size at diagnosis** of 1.5 cm or less. For the earliest survey in 1983, this figure was only 17%.

▪ The primary **symptoms** of AN reported by patients for 2014 remained the same as for earlier surveys, with hearing loss, tinnitus, fullness in ear and balance disturbances (including vertigo) still leading the list. The 2014 percentages for patients reporting symptoms of fatigue, memory difficulties, headaches and eye problems were all lower than for the 2012 and 2007-08 surveys.

▪ Patients were asked about their reasons for choosing a **type of treatment**. For patients who chose surgery, 83.4% said they followed their doctor's advice; 57.4% said it was a personal choice. For patients who chose radiosurgery, 63.5% said they followed their doctor's advice; 72.3% said it was a personal choice. For FSR patients, the percentages were 56.2% and 78.3%. For Wait-and-Watch patients, the percentages were 77.2% and 22%; and size of tumor less than 1.5 cm was the reason chosen by 63.0%.

▪ Seven percent of AN patients reported on "Post-Treatment **Rehabilitation** Therapies" they received:

Balance	27%
Facial Movement	13%
Dizziness	8%
Facial Weakness	7%

▪ Regarding post-treatment **Quality of Life**, patients reported the following:

Able to continue regular employment	--	87%
Still employed in the same capacity	--	73%
Symptoms better after treatment	--	31%
Q of L better after treatment	--	24%

NJ/NY Joint Mini-Conference

"Preserving Quality of Life for Acoustic Neuroma Patients"

Sunday, April 22, 2018 9:00 a.m. – 4:00 p.m.
Conference Center at JFK Medical Center
65 James Street, Edison, NJ

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Registration & Coffee	9:00-10:00
Welcome by Wilma Ruskin, President ANA/NJ Miranda Sacharin, NYCity AN Support Group Dr. Joseph Landolfi, JFK Medical Center	10:00
Doctors' Panel: "Wait-and-Scan, Partial Removals, Fractionated Radiation: Exploring the Pros and Cons" •Dr. Jed A. Kwartler (Summit Medical Group), Moderator •Dr. Joseph C. Landolfi (JFK) •Dr. John G. Golfinos (NYU Langone) •Dr. Philip E. Stieg (Weill Cornell) •Dr. Christopher J. Farrell (Thomas Jefferson Univ)	10:15-12:00
Lunch …….	12:15-1:00
Presentation with Q&A: "Balance Issues and Vestibular Therapy" •Dr. Michael Rosenberg (NeuroScience Institute, JFK) •Dina Leyden, PT (Summit Medical Group)	1:15-2:15
Presentation with Q&A: "Tinnitus Issues and Hearing Devices" •Dr. Virginia Toth (Manager, Audiology Programs, JFK)	2:30:3:30

Directions to JFK

From Newark & north: GSPkwy South to Exit 131. Exit right onto Route 27 South to light at James St (Dunkin Donuts on the right). Turn right onto James St to the JFK Med Center. **Note**: The Conference Ctr bldg & separate parking area are on the **right** side of James St, just opposite from the main complex. Turn right to park and look for the **ANA/NJ sign**.

From south: NJ Turnpike to Exit 10 to Rt 1 North. At the Menlo Park Mall area, exit right off Rt 1 on the jughandle for **Parsonage Rd**. Follow Parsonage Rd past the mall and thro the underpass to the traffic light at Rt 27 (landmark is Dunkin Donuts on far right). Go across Rt 27 (Parsonage Rd now becomes James St) and follow to the JFK Med Center. **Note:** The main JFK Center will be on the left, but the Conference Center bldg is just opposite on the other side of James St. Turn right for the Center and its separate parking area. Look for the **ANA/NJ sign.**

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