



ANA/NJ Newsletter
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***Acoustic Neuroma Association
of New Jersey***

A Non-Profit Corporation

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Epidemiology of VS: Data from Denmark & Minnesota

Reports by epidemiologists in Denmark have been alerting us that the “true incidence” rate of acoustic neuromas (VS) is considerably higher than the estimate of 10/million of population/year presented in 1991 by the U.S. National Institutes of Health *Consensus Statement* for acoustic neuroma.



Danish researchers have had the advantage that data for all patients in Denmark diagnosed with VS has been entered into a national database since 1976. Denmark has a centralized health system. In contrast, the Central Brain Tumor Registry of the U.S., established in 1992, only began to keep records for benign tumors like VS in 2004. In 2015, researchers at the Cleveland Clinic in Ohio used this largest aggregation of population-based data in the U.S. to calculate a 10.9/million incidence of VS. Meantime, however, sequential reports from Denmark presented ever higher rates of incidence: 2.7 in 1997; 17.4 in 2004; 19.4 in 2008; 22.8 in 2010.

The most recent report from Copenhagen in 2019 has now evaluated 40-year data for all patients diagnosed with VS in Denmark since 1976.¹ 3,637 cases of VS were diagnosed during this 40-year period. The annual number of diagnosed VS increased from 14 in 1976 to 193 in 2015. Since the population of Denmark in 2015 was 5.7 million, the “true incidence” of VS was therefore calculated to be 34/million/year (34 x 5.7 million = 193 cases of VS). Maybe the calculations seem confusing, but as the Cleveland Clinic researchers have noted: “Such data are necessary to assess the burden of vestibular schwannomas on varying populations and to inform future research and healthcare planning.”²

The 2019 Danish report states that the main reason for the steady increase over the years in the VS incidence rate in Denmark was improved diagnostics and the increased availability of improved diagnostics. “The first MRI scanner in Denmark was functional in 1989 and by 2015 the number had increased to approximately 100.” Also, “Denmark has a state-funded healthcare system financed through general taxation and every citizen can consult an ENT specialist (and have an MRI if indicated) free of

¹ M.Reznitsky, S-E Stangerup et al, “Epidemiology of Vestibular Schwannomas – Prospective 40-Year Data from an Unselected National Cohort,” *Clinical Epidemiology*, vol. 11 (Nov 2019). Free full text copy available at PubMed.gov.

² V.R.Kshetry et al (Cleveland Clinic), “Incidence of Vestibular Schwannomas in the United States,” *Journal of Neurooncology*, vol.124(2) (Sept 2015).

charge and without a referral.” In addition, the population in Denmark is aging, and as more and more older people began to have MRIs, a large number of previously undiagnosed small tumors was revealed. The Cleveland Clinic also found a higher incidence up to 29.3/million in the 65-74 year old age group.

The Danish report cites other recent studies showing an increasing incidence rate of VS. The Netherlands, for example, reported a rate of 15.5/million (2016); Taiwan has documented an increase to 37.2/million (2018). Perhaps most interesting is the Mayo Clinic study (2018) calculating that the incidence of VS in Minnesota’s Olmsted County increased from 15/million in 1976 to 42/million in 2016.³ The city of Rochester, the home of the Mayo Clinic, is the county seat of Olmsted County.



Mayo Clinic

Olmsted County (ca. 150,000 people) is a pretty small subset of the total U.S. population of 331 million, but county records were used effectively to illustrate how ease of access to medical care contributed to the detection rate of VS. The county “represents a unique geographic region with an economy driven by healthcare. For instance, according to the 2015 American Community Survey by the U.S. Census, the healthcare and social assistance industry accounts for almost 40% of the workforce in Olmsted County compared to approximately 10% of the workforce across the United States. This demographic feature of Olmsted County undoubtedly influences overall health literacy, and the underlying economy facilitates uniquely easy access to medical care and thus advanced diagnostic imaging.” The authors call attention to another such example of a very high incidence of VS (54/million/year!) reported for the affluent municipality of Beverly Hills, CA, where residents enjoy easy access to an advanced level of healthcare.⁴

For Olmsted County, “the incidence rate of VS more than doubled following the introduction of MRI circa 1985.” The authors observe: “Given that MRI is only increasingly being used in recent years, the significant increase in the incidence of VS observed over the past 50 years can most likely be attributed to increased utilization of advanced imaging modalities rather than a true increase in the sporadic development of VS within the Olmsted County population. . . Remarkably, within the most recent decade, almost a quarter of all sporadic VS were diagnosed incidentally after individuals obtained head imaging for unrelated indications.” As in Denmark, the trend in Olmsted County towards an aging population has important healthcare implications for the coming years. Age at tumor diagnosis is increasing. Tumor size overall at diagnosis is decreasing. More cases managed by observation (Wait-and-Watch) are predicted, as has been described in detail in an earlier Mayo Clinic study.⁵

³ J.Marinelli, C.Lohse & M.Carlson, “Incidence of VS over the Past Half-Century: A Population-Based Study of Olmsted County, Minnesota,” *Otolaryngol Head Neck Surg*, vol.159 (Oct 2018).

⁴ M.Schwartz & L. Fisher, “Incidence and Clinical Characteristics of Acoustic Neuroma in Beverly Hills,” *Skull Base*, vol.16 (June 2006).

⁵ M.Carlson, M.Link et al, “The Changing Landscape of VS Management in the United States – A Shift Toward Conservatism,” *Otolaryngol Head Neck Surgery*, vol. 153 (Sept 2015). See ANA/NJ Newsletter (March 2019).

Notices

- ANA/NJ is very pleased to announce that Dr. Anthony L. D'Ambrosio has joined our Medical Advisory Board. Dr. D'Ambrosio is Director of Neurosurgery and Co-Director of the Gamma Knife Program at Valley Hospital in Ridgewood, NJ. He is President of the New Jersey Neurological Society. He specializes in the treatment of brain tumors and trigeminal neuralgia. Dr. D'Ambrosio is listed in the March 2020 issue of the ANA/NJ Directory of patients and providers.
- Professor Brian Hare (see "Hearing Dogs," below) is an evolutionary anthropologist and Director of the Canine Cognition Center at Duke University in Durham, NC. With his research scientist wife, Vanessa Woods, he has published two popular studies, *The Genius of Dogs* (2013) and *Survival of the Friendliest* (2020). For an excellent review of how Prof. Hare, his wife, and other scientists are studying dog behavior as never before, see Jeff Macgregor's excellent article, "Evolution of a Friendship," in the *Smithsonian* (December, 2020).
- National Institutes of Health (NIH) has posted an advisory (March 23, 2020) for forthcoming over-the-counter (OTC) hearing aids, making clear that they are intended for adults who believe they have mild-to-moderate hearing loss. You will be able to buy them directly in stores and online. OTC hearing aids are not meant for children or for adults who have severe hearing loss or significant difficulty hearing. OTC aids will be regulated as medical devices by the U.S. Food and Drug Administration. (<https://www.nidcd.nih.gov/health/over-counter-hearing-aids>)
- From an interesting report by doctors at Beaumont Hospital in Dublin, Ireland: "We present a case of spontaneous 79% regression in the size of a vestibular schwannoma (VS). A 41-year old lady with a large (36mm) VS underwent serial follow-up MRI scans which demonstrated the shrinkage over 9 years; the highest relative spontaneous regression recorded in the literature for vestibular schwannoma of this size." That would be a shrinkage from 36mm to 8mm. (See Michael Amoo et al, "The Shrinking Vestibular Schwannoma," *British Jour Neurosurgery* (March 4, 2019). PubMed abstract.

Hearing Dogs

Those who attended our April 2018 mini-conference at JFK Medical Center will probably still recall being greeted by two very friendly 'Hearing Dogs,' brought to the meeting by Melanie Riordan. Everyone wanted to meet the Golden Retrievers and ask Melanie about their special training.

Hearing dogs are assistance dogs for people who are deaf or hard of hearing. They are "Canine Companions for Independence," which is the name of the leading assistance dog nonprofit in the United States. Founded as a small venture in 1975 in Santa Rosa, CA, Canine Companions for Independence (CCI) is now a large and well-organized nonprofit with impressive volunteer support working in collaboration with major health associations and university canine cognition research centers. A CCI North East Regional Training Center is located in Medford, NY, and there's an affiliated New Jersey Volunteer Chapter in Edison, NJ. For general information, visit www.cci.org or call 1-800-572-BARK.

On the CCI website, the main page for information about Hearing Dogs states:

Canine Companions for Independence hearing dogs are specially bred Labrador and Golden Retrievers who alert partners to key sounds by making physical contact such as nudging the leg or arm. Among the many

sounds hearing dogs can be trained to recognize and respond to can be the sound of a doorbell, alarm clock, someone calling a name or a smoke alarm.

Partnering with a Canine Companions hearing dog can increase feelings of security and self-confidence by heightening awareness of environmental sounds.

After being placed in the home, the graduates “customize” the dog’s alerting pattern to their own particular environment and needs. Examples include: alerting to incoming e-mail messages at work, timers on microwaves, dryers and other appliances, and dropping keys.



In order to be eligible for a hearing dog, the applicant must:

- *Be deaf or hard of hearing*
- *Be 18 years of age or older*
- *Be independent in mobility*
- *Be able to demonstrate the ability to safely and effectively control, manage and care for a dog*
- *Have adequate vision to observe and manage a dog’s behavior*
- *Be willing to attend a two-week Team Training class only in Santa Rosa, CA, or Orlando, FL*
- *Be willing to participate in an on-going Canine Companions training and graduate support program*

Canine Companion hearing dogs and follow-up services are free of charge.

A research news brief on the website notes how CCI is currently collaborating with the Canine Cognition Center at Duke University for a study of puppy rearing methods most likely to improve the behavior and cognitive development of assistance dogs. “Becoming an assistance dog is like going to college,” says Prof. Brian Hare, the director of the center. “It’s tough to get in and not everyone graduates. The goal of the project is to increase the supply of assistance dogs and to see more dogs graduate and serve more people. To do that we need to understand what experiences they need early in life to be successful.”

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The Earwax Problem

Earwax buildup can be a special concern in particular for acoustic neuroma patients who develop single-sided deafness (SSD) and worry about any small decline in hearing in the good ear. The waxy buildup is particularly common in older people. As we age, this normally helpful lubricant becomes dryer and harder and moves more slowly out of the ear canal as it picks up debris. There’s a clogging possibility. A hearing aid can also block the outward flow of earwax, and the device itself can become damaged in the process. The aids need to be cleaned daily and checked out frequently to see if they’re in good working order.

The paragraph above is in large part gleaned from a recent article by Barbara Stepko for the AARP Hearing Center (www.aarp.org/hear). The article (April 7, 2020) offers handy advice for “What to do When Earwax Becomes a Problem.”

First off there’s a warning: “It might be tempting to poke a cotton swab, bobby pin, pencil or finger into your ear to get the gunk out, but don’t go digging. Yes, it’ll remove some of the wax, but it may also push the rest deeper into the ear canal. There’s also the risk of injuring the eardrum.”

Better would be to give your ears a gentle cleansing each day. “After washing your face or stepping out of a steamy shower, cover one finger with a damp washcloth and wipe around your outer ear. Declogging the most external exit will help with [the natural migration of the earwax].”

For an abundance of earwax, a softening agent (a drop or two of baby oil or mineral oil) might be tried using an eyedropper and tilting the head appropriately.

There are over-the-counter products to loosen small amounts of wax. But be careful. Not recommended fully is syringe flushing the ear with warm water. An infection in the ear canal could be a consequence.

There are times when you’ll need professional help. You’ll need experienced assistance to remove a serious blockage. A primary physician may be able to do the job. But “If the ear is impacted with a hard, stubborn chunk of wax that’s really lodged in there, it’s time to bring out the big guns – namely, an ear, nose and throat doctor (that is, an otolaryngologist [ENT]). This specialist has an arsenal of precise tools to go deep, without harming the delicate eardrum.” Dr. Yu-Lan Mary Ying, ENT at Rutgers NJ Medical School in Newark, for example, uses a surgical microscope and suction to dislodge the wax.



Barbara Stepko’s article concludes, encouragingly: “And a clean ear can make a world of difference. One study found that 35 percent of hospitalized patients over age 65 had impacted earwax and 75 percent of those had improved hearing after it was removed. Some experts estimate that removing an earwax plug can improve hearing by 10 decibels. (The difference between whispering and normal conversation is around 20 decibels.) Better hearing isn’t the only benefit. There may also be an improvement in your balance [observes Dr. Mark Vaughan, director at the Auburn Medical Group in Auburn, CA]. Some patients actually feel as though their lives have changed.”

Note: NIH’s Institute on Aging (www.nia.nih.gov; see ‘Health Topics/Hearing’) advises that something as simple as a piece of earwax blocking the ear canal can cause tinnitus.

GIFTS & DONATIONS to ANA/NJ

January 1, 2019 – January 31, 2021

The Executive Board of ANA/NJ gratefully acknowledges those who have contributed to ANA/NJ in support of its mission to provide information, encouragement and support to acoustic neuroma patients and their families.

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ANA/NJ Virtual Support Meeting

Sunday February 28, 2021

2:00 to 4:00 p.m. EST

TOPIC:

Caring, Sharing, Networking and Support

Space is limited Sign up soon

Currently and out of an abundance of caution regarding COVID-19, the Acoustic Neuroma Association of New Jersey (ANA/NJ) is limiting its sharing and educational meetings to virtual opportunities. Future meetings may offer a speaker. Please mark your calendars and plan to join our first Zoom virtual support meeting.

Care & Share meetings provide a nurturing, non-judgmental environment with individuals who have shared acoustic neuroma experiences and can provide emotional support and encouragement through the stages of the AN journey.

You do not need to be a resident of New Jersey or a particular area in New Jersey or a member of ANA/NJ to participate, but **you do need to register** [registration information below]. Family members, caregivers, friends, and interested persons are welcome to attend as well. Bring your questions and join peers for this interactive opportunity.

In order to receive a confirmation email with detailed instructions to join our Zoom meeting, send an email to Dave Belonger at dbelonger@verizon.net requesting attendance at the February 28th ANA/NJ Care & Share meeting.

We look forward to welcoming you!



