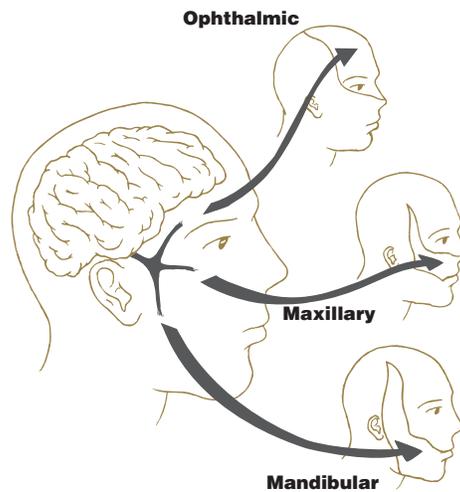




Trigeminal Neuralgia



Trigeminal neuralgia, also called tic douloureux (painful spasm), is a disorder of the 5th cranial nerve. This nerve is the largest of the 12 cranial nerves. There are two trigeminal nerves, one on each side of the head. The trigeminal nerve is responsible for sending impulses of touch, pain, pressure, and temperature to the brain from the face, jaw, gums, forehead, and around the eyes. There are three branches to the trigeminal nerve: the ophthalmic branch, the maxillary branch and the mandibular branch. A brief listing of what is affected by each branch follows.

Ophthalmic: Forehead, frontal portion of scalp, eye and eyebrow. (The upper or 1st branch.)

Maxillary: Cheek, lower eyelid, side of nose, upper lip, upper teeth and upper gum. (The middle or 2nd branch.)

Mandibular: Side of tongue, lower lip, lower teeth, lower gum, and a narrow strip that extends from in front of the ear along the lower jaw to the side of the head. (The lower or 3rd branch.)

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History

Through the years, effective treatments have been developed for trigeminal neuralgia, both medical and surgical. To date, none is 100% successful. Each option has its advantages and disadvantages. Additionally, no treatment has been found to be benign or without side effects or risks. For those treated, even if initial pain relief is achieved, the pain may recur and require further treatments. Most sufferers will have more than one treatment in their lifetime.

We know much of the clinical aspects of this disorder, yet we still know almost nothing about the cause of the condition or the mechanism by which it produces pain. While the pain starts intermittently with long pain free intervals, it soon strikes more frequently with increasing severity of pain and medications soon become ineffective. Finally, the pain is constant.

While Greek and Roman physicians described the pain of trigeminal neuralgia in the writings of Aretaeus in the 1st century AD, the first clear descriptions of the disorder were written by Fehr and Schmidt in 1671. Carvings in Wells Cathedral in England in the 16th century showed the contorted facial expressions of sufferers. Common treatments in these times were bloodletting, caustic chemical dressings and poisons.

Since the 18th century surgical treatments were tried with often destructive results. In the 1930's Walter Dandy noted the frequent occurrence of the close proximity of a blood vessel to where the nerve enters the brain. In the 1960's the neurosurgeon Peter Jannetta with the use of the operating room microscope proposed the idea that a blood vessel compressing the trigeminal nerve could be the cause of the pain. Later Jannetta popularized the surgery microvascular decompression which in experienced surgical hands can be effective for this disease.

Beginning in 1953, the neurosurgeon Lars Leksell was utilizing his recently developed Gamma Knife for the treatment of trigeminal neuralgia. This edition of *brain talk* discusses the merits and results of Gamma Knife surgery for trigeminal neuralgia and therefore offers only a minimal discussion of other treatments. Gamma Knife treatment has been shown to be an effective, low risk treatment of trigeminal neuralgia.



Stereotactic Radiosurgery

Stereotactic radiosurgery is not surgery. The skull is never opened. Radiosurgery involves the use of precisely directed single fractions of radiation to create lesions within the brain or to treat tumors or vascular malformations with minimal damage to surrounding structures or tissues.

This works by delivering a relatively high dose of radiation in one session to the target with scalpel-like precision. The dose is designed to injure or kill the cells or their supporting blood vessels, while minimizing its effect on surrounding healthy tissue. The radiation distorts the cells' DNA, causing them to lose the ability to replicate themselves. The safety and clinical effectiveness of this technique has been established since 1968 in over 200,000 treated individuals.

The benefits include: No risks of infection or anesthesia reactions; virtually no pain; reduced costs; and an immediate return to normal activities.

Radiosurgery may or may not be appropriate for your condition. It may be used as the primary treatment or recommended in addition to other treatments you may need. Only a treating neurosurgeon can make the evaluation as to whether you can be treated. Some of the most common indications for treatment today are:

- Arteriovenous/vascular malformations
- Meningiomas
- Acoustic neuromas
- Pituitary and pineal tumors
- Metastatic tumors
- Glial and astrocytoma tumors
- All other malignant & benign tumors
- Trigeminal neuralgia
- Parkinson's tremors/rigidity
- Functional disorders

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Six Years After Treatment for Trigeminal Neuralgia



Editor's note: this story was kindly contributed by Donna. We are pleased to update her story for those of you who have repeatedly asked how she is doing. Donna's story was printed in the Volume 4, No. 3 Another Perspective issue. When she had the

first pain attacks in her left eye in 1991, she was told she just needed new glasses. After she got a pair of glasses, the pain went away and did not return until late 1995, when she was correctly diagnosed with trigeminal neuralgia.

At that time her doctor gave her almost no information on trigeminal neuralgia and a prescription for Tegretol, which caused an adverse reaction. Donna also began experiencing pain on her right side. In early 1996 Donna found Dr. Ronald Young, and had Gamma Knife surgery. She experienced some immediate relief from the surgery but still had some pain. It has been a long process for Donna, but she says she now leads a "very normal, pain-free life," has no numbness and takes no medications. We applaud Donna's bravery and resilience.

(Go to www.IRSA.org, click on "Publications" and "Volume 4, No. 3" to see Donna's original story).

To pick up right where I left off in IRSA's publication in 1999 while we were still in Washington, I had a brief, and quite light, return of pain. This was almost 3 years after my Gamma Knife treatment. It wasn't the same type of pain as before my Gamma Knife procedure, or as bad, but with winter on its way and since cold always seemed to make my TN [trigeminal neuralgia] worse, we decided to move back to Tucson where we lived years ago.

We bought a house in Tucson, sight unseen. (A really stupid thing to do.) We lived there for just a very short time. We managed to get the seller to take that house back and bought another. During that time the TN attacks totally disappeared. It had come on abruptly and left the same way after about a month.

We went house hunting again and found one but didn't think of having a building inspector check it over. Many serious flaws were so well covered that they were invisible. So, we were back to square one, remodeling and repairing again, but



Donna in the Sun

we're very happy with our neighbors and the convenience of our location.

The weather is wonderful, we like desert weather and haven't missed the snow and ice at all. I know warm weather doesn't cure TN, but for those of us who seem to have more, or worse pain, when our faces get cold, a warm climate is wonderful. We're not trapped inside as much. I don't know if a cold face ever caused an attack but I don't worry about it now. This move has really helped me to be outdoors doing the things I always did before my TN began.

My Gamma Knife procedure was slow in stopping my TN pain. There were immediate changes but it took several months to completely go off medications. However, just this summer I read that increasing medications as I did can actually cause TN pain to become worse in some people.

I don't really know if this is true or not but it's an interesting thing to try to find out more about. But, in the six years since my Gamma Knife, outside of two small attacks, one hardly worth mentioning really, I have had a very normal pain-free life. No side effects, no numbness at all, and no medications. There have been occasions when I thought

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Trigeminal Neuralgia and Gamma Knife® Surgery

Trigeminal Neuralgia (TN), paroxysmal triggered face pain, responds very well in most patients to Gamma Knife surgery, which has proven over time to be the least invasive and one of the best standard treatments for this condition.

Symptoms

Trigeminal neuralgia is characterized by sudden bursts (paroxysms) of face pain that are often triggered by light touch around the mouth or face or by talking, eating, or brushing the teeth. The pain sometimes gets worse or better for periods of weeks or months. The pain is in the area supplied by the trigeminal nerve (cheek, jaw, teeth, gums or lips and less often around the eye or forehead). Pain is usually on one side of the face, but in 5 to 10% of patients pain occurs on both sides of the face, although not at the same time. The pain responds to Tegretol (carbamazepine is the generic name and Tegretol is the trade name), but sometimes the dose has to be increased and unpleasant side effects may occur.

Atypical features may coexist with some of the previously described symptoms. These atypical features may include a constant pain which is not always triggered by light touch. Patients with constant pain and TN are sometimes diagnosed as having atypical trigeminal neuralgia. Gamma Knife surgery and other treatments for TN are likely to relieve the sharp, electric-like pains that are triggered by light touch even in these patients, but are less likely to relieve the constant, untriggered pains.

Incidence and Prevalence

Approximately 15,000 new patients will develop TN each year in the United States where about 100,000 patients have the condition. Trigeminal neuralgia is much more common in patients with multiple sclerosis.

Cause

The cause of trigeminal neuralgia is not always certain. Approximately 5% of patients have a tumor press-



Drs. Ron and Michael Brisman

ing on the trigeminal nerve where it leaves the brain.

Approximately 5% of patients with trigeminal neuralgia have multiple sclerosis. Patients with trigeminal neuralgia and multiple sclerosis are usually younger, with an average onset of TN symptoms in their mid-40s. They are more likely to have pain on both sides of the face and often have other neurological abnormalities, such as weakness or numbness of arms or legs, dizziness, unsteadiness, or double vision. Most patients in their 40s or 50s who have trigeminal neuralgia do not have multiple sclerosis. Patients with TN without multiple sclerosis have an average onset of TN symptoms in their mid-50s.

Some patients have a blood vessel that presses on the trigeminal nerve close to the brain. In other patients, the cause cannot be determined.

Diagnosis

In addition to a thorough history and physical examination, magnetic resonance imaging (MRI) of the brain is recommended. This helps identify a brain tumor in the rare cases in which it is present. It may also help diagnose multiple sclerosis. Often when the MRI is done,

some contrast material is injected into the vein so that the appearance of a small tumor, blood vessel, or other structures in the brain can be enhanced and made easier to detect.

Nonsurgical Treatment

There are some patients who have very mild face pain that may subside and even disappear without treatment. For pain that is bothersome, medication, especially carbamazepine (Tegretol), is often highly effective. There are many possible side effects from carbamazepine. Some of the more common ones are sleepiness, forgetfulness, confusion, drowsiness, dizziness and nausea. Carbamazepine can cause more serious problems such as bone marrow suppression, which can cause anemia or a decrease in the number of white blood cells. A low white blood cell count can predispose a person to infection. Rarely are these problems life threatening. Blood counts have to be monitored to lessen the chance of these occurring. Carbamazepine can also harm many other parts of the body, so patients who take this medicine must be under careful medical supervision. Tegretol also interacts with many medicines. Patients must advise their doctor about all their

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Trigeminal Neuralgia and Gamma Knife® Surgery

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medicines. Elderly patients and those with multiple sclerosis are more likely to be bothered by Tegretol.

Oxcarbazepine (Trileptal) is another anticonvulsant that is similar to carbamazepine and also works very well for trigeminal neuralgia. Trileptal has fewer side effects. Unlike Tegretol, oxcarbazepine does not cause bone marrow suppression or liver toxicity, and has fewer interactions with other medicines. About 25 to 30% of patients who have a rash from Tegretol will have a rash when they take oxcarbazepine. It may cause dizziness, drowsiness, headaches, fatigue, impaired balance, nausea or vomiting. It is more likely than Tegretol to cause low levels of sodium in the blood especially when taken with excessive amounts of water or other medicines, such as diuretics, which also can lower the sodium. Low sodium in the blood often occurs without symptoms, but can cause lethargy, seizures, or loss of consciousness. Blood tests are needed to determine the level of sodium in the blood. Oxcarbazepine is taken twice a day and the dose is 50% more in milligrams than carbamazepine.

There are other medicines that can be used either alone or in combination. These are usually less effective than Tegretol. They include baclofen (Lioresal), phenytoin (Dilantin), clonazepam (Klonopin), gabapentin (Neurontin), or lamotrigine (Lamictal). The generic name is listed before the trade name, which is in parentheses. All of them, except baclofen, are also used to prevent seizures.

Surgical Treatment

A surgical procedure is recommended for patients who continue to be bothered either by pain or side effects of medicines. In the past, when surgical procedures had higher risks, patients with TN did not consider neurosurgical options until pain or medicines became unbearable. As surgery has become safer, and especially with Gamma Knife, which is not only highly

effective but also safer than any of the other procedures, patients no longer have to wait to be in agony in order to undergo neurosurgical intervention.

There are five important neurosurgical procedures. Each is often, but not always effective and sometimes may have to be repeated. They are: Gamma Knife surgery, radiofrequency electrocoagulation (RFE), glycerol injection (GLY), balloon microcompression (BMC), and microvascular decompression (MVD). All of these treat the trigeminal nerve at about the same place, close to where it leaves the brain.

Gamma Knife Surgery

Gamma Knife surgery is the least invasive neurosurgical treatment for trigeminal neuralgia. It is least likely to cause a major (or minor) complication, and is least likely to cause discomforting new facial sensations (dysesthesias). In a consecutive series of 400 Gamma Knife procedures for trigeminal neuralgia by this set of authors, there have been no significant complications and most have had relief of pain. Currently, we offer Gamma Knife at two locations, the Columbia Presbyterian Medical Center, New York, NY, (Ronald Brisman, M.D.) or the Long Island Gamma Knife at South Nassau Communities Hospital, Long Island, NY (Michael Brisman, M.D.).

What Is Gamma Knife Surgery?

This is a method for treating certain problems in the brain without making an incision. Two hundred and one beams of cobalt⁶⁰ radiation are focused precisely on a specific region in the brain. In the case of trigeminal neuralgia, the target area is the trigeminal nerve, just where it leaves the brain. The Gamma Knife is a neurosurgical machine that is specialized and manufactured for the precision to treat only within the brain. The treatment does not require general anesthesia. The patient may be outpatient or have a one-day hospital stay.

Who Is a Candidate for Gamma Knife?

Any patient with trigeminal neuralgia who has pain or is bothered by medicines used to relieve the pain is an excellent candidate for Gamma Knife. The patient's age or medical condition does not affect the decision to have Gamma Knife. Even the elderly or medically infirm can undergo this treatment. Patients who are receiving anticoagulation for other medical conditions do not have to stop or reverse the anticoagulation prior to surgery. Those who have had previous procedures for trigeminal neuralgia may also undergo Gamma Knife. Patients who are concerned about the possibility of bothersome numbness are particularly good candidates for GKRS, because the chance of this occurring is very small or transient. Patients who poorly tolerate medicines given for sedation and relief of pain during a procedure are also very suitable for this procedure because these medicines are not necessary.

What are the Expected Results with Gamma Knife?

Excellent or good pain relief occurs in approximately 82% of patients. Onset of pain relief may occur from one day to four months after the procedure. About half of patients will obtain pain relief within four weeks. Sixteen percent of patients with typical TN have required an additional procedure for recurrent pain. Patients with TN and multiple sclerosis are less likely to respond to Gamma Knife than those without multiple sclerosis, although they also may be helped by it. Gamma Knife can be repeated, but not until at least six months after the original procedure. Patients who have had other invasive procedures before a Gamma Knife procedure may not have as positive a result as when Gamma Knife is chosen as the first and primary treatment. This could be a result of damage caused by the initial procedure the patient has already undertaken.

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Meningioma on the Trigeminal Nerve Causes Severe Pain



PATIENT STORY

Editor's note: this story was kindly contributed by Clarence, Amelia's husband.

Amelia is a “young” lady who happens to be 84 years old. She is always interesting to be around because she maintains a very positive attitude and rolls with the punches.

I started playing trumpet in dance bands at age 13 and continued until I started dating Amelia in 1937. Amelia and I first met when she was a “date” of a friend of mine—on December 30, 1936—and we all went to a big ballroom dance in Boston. She was a junior in high school at the time and I was a sophomore at Northeastern University. We got married on September 2, 1939.

Amelia and I raised two children. Christine graduated from Boston University and works for the ethics committee in the Capitol building in Washington, D.C. One year she won the women's national championship award in dart throwing. Bruce went to M.I.T. and got his B.S. and M.S. degrees in chemical engineering. He's very active with his own consulting firm in the environmental area.

When Amelia was about 45 years old, she decided that she wanted to play golf and so I bought her a nice set of golf clubs to encourage her to play. Three years later, she started to beat me at the game. I started to play serious golf when I was 14 years old—I played every day while working at caddie camp with coaching from professional golfers. (I was the camp bugler: a fun experience.) Amelia is also regarded as a very good duplicate bridge player.

Amelia loves to travel and so do I, and so we did a lot of it. We made two trips each to Alaska and Mexico, four to Hawaii, five to Canada, one each to Japan, Australia, Fiji, New Zealand, England and Peru, and 12 other visits to the various islands in the Caribbean. We also made an extended trip to the Mediterranean by



Clarence & Amelia

ship and by land that included inland jet plane visits to France, Spain and five other countries. Amelia loved the inland trips because she got seasick during the periods on board the ship. At home, although she got seasick readily, we belonged to a yacht club with our 30-foot cabin cruiser and 21-foot sail boat.

Amelia continued to be active until she came down with rheumatoid arthritis. It was her last game of golf until we moved to Florida and played at least three times a week. In Florida, for some reason, the rheumatoid arthritis went into remission.

Amelia has tolerated trigeminal neuralgia, to various degrees, since August 1996. It is only recently that she has permitted me to take any pictures of her because, in her words, she looks horrible. I personally think that she looks great.

Amelia experienced a very common start of the problem. The first sign of it occurred in August 1996 while we were on vacation in Maine. She had three episodes of extreme jaw pain in one day and then the pain disappeared.

In November of 1996, Amelia experienced two TIAs [transient ischemic attacks]. This was an upsetting experience because her twin brother had just experienced a severe stroke and passed away. An MRI was run to determine if there had been any brain damage. There was no thought that there might be

brain tumor involvement. At that time, there was no sign of any jaw pain and the entire focus was on the possible brain damage due to the TIAs.

It was originally reported that a 1.5 centimeter acoustic neuroma was present. Later on, I consulted a brain surgeon and he stated that it was a meningioma. We were told to ignore the meningioma because they grow so slowly that Amelia will likely die from some other cause. There was no comment about its proximity to the trigeminal nerve.

In February of 1997 the jaw pain returned with a vengeance. There was no thought of the meningioma being a cause of the problem and so the emphasis was in the dental area. The jaw pain came back again in April 1997. The dentist said that he could find no dental cause for the jaw pain problem but would refer Amelia to an oral surgeon. The net result of this visit was a very expensive root canal job and then a decision to extract the tooth five days later because of the extreme jaw pain that still existed. This extraction did not solve the problem and he then suspected two other teeth in that same jaw area and extracted those too.

The jaw pain continued and so these extractions were not related to the jaw pain. The oral surgeon then said that he had done all that could be done in the dental area, and Amelia left with both the jaw pain and the significant bill for the dental work. It was very upsetting to us to subject Amelia to the trauma of the dental work and to still have the same degree of jaw pain.

It was the family doctor who referred her to the neurologist in April of 1998, not the oral surgeon, by saying, “If it is not dental, then a neurologist is the next stop.” As soon as Amelia started to discuss the jaw pain with the neurologist, it took him all of five minutes to say that she had a trigeminal neuralgia condition that was probably related to the meningioma impinging upon the nerve. He then ordered another

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Treatments for Trigeminal Neuralgia

Medications

- ◆ Often first line of defense
- ◆ Effectiveness may diminish over time
- ◆ Several medications may be used:
 - Dilantin (phenytoin)
 - Klonopin (clonazepam)
 - Lamictal (lamotrigine)
 - Lioresal (baclofen)
 - Neurontin (gabapentin)
 - Tegretol (carbamazepine)
- ◆ Tegretol is the main medication used to treat TN
- ◆ Tolerance may develop to Tegretol
- ◆ Common side effects of Tegretol and Dilantin:
 - Drowsiness
 - Forgetfulness
 - Dizziness
 - Unsteadiness
 - Nausea

Glycerol Rhizotomy

- ◆ Glycerol is injected into the trigeminal ganglion, to damage “pain fibers”
- ◆ Also known as glycerol injection
- ◆ Alleviates or eliminates pain
- ◆ Procedure may be repeated
- ◆ 80 to 85% attain pain relief
- ◆ Pain relief may last no more than 2 years
- ◆ Greater than 50% will ultimately experience some facial sensory loss
- ◆ Outpatient Treatment
- ◆ May lead to loss of sensation in eye

LINAC Radiosurgery

- ◆ Closed-skull surgery
- ◆ Outpatient Treatment
- ◆ No controlled studies
- ◆ Lack of sufficient clinical research
- ◆ May damage other facial nerves
- ◆ Most machines lack needed targeting preciseness

Microvascular Decompression

- ◆ Open-skull surgery
- ◆ Teflon pads inserted between blood vessels and nerve
- ◆ Immediate relief often experienced
- ◆ 70% attain complete, long-term relief
- ◆ Risk of surgical complications
- ◆ Permanent deafness possible
- ◆ Also known as the Jannetta procedure
- ◆ Lower risk of dysesthesias than with other percutaneous procedures

Gamma Knife Surgery

- ◆ Closed-skull surgery
- ◆ Facial sensations usually preserved
- ◆ Complications rare
- ◆ 80 to 85% pain relief
- ◆ 54% are pain-free after the radiosurgery
- ◆ Relief usually experienced within 1 to 3 months
- ◆ Trigeminal nerve root damaged
- ◆ Outpatient or one day stay
- ◆ May be permanent
- ◆ Repeatable if necessary
- ◆ Substantial long-term clinical research

Balloon Compression

- ◆ Tiny balloon threaded through the trigeminal ganglion, then inflated to compress and damage nerves which transmit light touch sensations.
- ◆ Corneal reflex nerves may be damaged
- ◆ Risk of dysesthesias
- ◆ Mild to moderate numbness may result
- ◆ 26% pain recurrence rate
- ◆ Repeatable if necessary
- ◆ Outpatient Treatment

Radiofrequency Electrocoagulation

- ◆ Also known as radiofrequency rhizotomy or radiofrequency thermocoagulation
- ◆ Electrode heats nerve to destroy “pain fibers”
- ◆ Outpatient Treatment
- ◆ High rate of initial pain relief
- ◆ Light touch sensation usually preserved
- ◆ May lead to loss of sensation in eye
- ◆ Facial sensory loss common
- ◆ 25% pain recurrence rate, after 14 years
- ◆ Repeatable if necessary

Resources

- ◆ **IRSA**
www.IRSA.org
- ◆ **National Institute of Neurological Disorders and Stroke**
http://www.ninds.nih.gov/health_and_medical/disorders/trigeminal_doc.htm
- ◆ **Facial Neuralgia Resources**
<http://facial-neuralgia.org/>
- ◆ **Trigeminal Neuralgia Association**
<http://www.tna-support.org/>

Astrocytoma, Bowling and Faith

Conrad says he'd "like to get back to work soon, and bowling another perfect .300 wouldn't be bad either." Getting treatments and going to doctor's appointments have become a routine part of his life in the past two years. On Sunday, June 5th, 2000, after a busy day doing chores at home, Conrad went to bed feeling tired.

In the middle of the night, his wife Sonia awoke to find her husband experiencing a facial seizure. Alarmed, Sonia quickly called rescue that transported him to the hospital. There, emergency room doctors suspected Conrad had a small stroke and placed him on medication. Months later however, Conrad experienced another seizure, and this time the family decided to consult with their family doctor who recommended they see a neurologist.

Once there, his MRI revealed a shadow in his brain but no definitive lesion with a clear form could be seen. Months later, still experiencing seizures on the left side of his face, Conrad received a PET Scan, a more sophisticated imaging



Sonia, Marios, Conrad and Dr. Wolf

test, which revealed he did indeed have a brain tumor on his right frontal lobe. "It is the kind of news," Conrad says, "you just know will change everything in your life."

Fearful but with plenty of guidance from his devoted wife, Conrad went to see Dr. Aizik Wolf, a neuro-

surgeon with offices in Coral Gables and Key West, Florida. Dr. Wolf performed a brain biopsy and diagnosed Conrad with a grade three astrocytoma.

Astrocytomas are the most common primary central nervous system tumors and represent about half of all primary and spinal cord tumors. They are called "astro" cytomas because their cells are shaped like a star. A grade three astrocytoma grows faster than lower grade tumors and often invades nearby healthy tissue, making it difficult to completely remove with traditional surgery.

"You hate to bring news like this to such a young family, but Conrad and Sonia were exceptional in their approach to this condition," says Dr. Wolf. "They asked a lot of questions, they understood the risks and their expectations were realistic -- I could not ask for a better patient to go into battle with," continued Wolf.

The battle for Conrad so far has included a biopsy, microsurgery to resect the tumor and make it smaller, surgery with the Gamma Knife, and chemotherapy. Conrad has also had brain mapping to isolate the cortical area in his brain responsible for the seizures. Surviving all of these "scary treatments," says

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Current Research: Refractory Trigeminal Neuralgia and Radiosurgery



The effects of repeat Gamma Knife surgery on 31 patients with refractory (failed other treatments) trigeminal neuralgia (TN) were studied. Twenty-seven patients were available for followup. Most patients had previously undergone several other types of surgery for TN. After the first radiosurgery, 13 patients experienced complete relief, 3 experienced complete relief with medication, 7 experienced more than 50% relief, and 4 experienced less than 50% relief. Despite initial pain relief, some patients with refractory TN had a recurrence of pain. After the second radiosurgery, 5 patients experienced complete relief, 8 experienced complete relief with medication, 10 experienced more than 50% relief with medication, and 4 experienced less than 50% relief. The radiation dose was slightly reduced in the second radiosurgery to lower the risk of facial sensory loss. New sensory symptoms were experienced by 2 patients after the first radiosurgery and 3 patients after the second radiosurgery. After the second radiosurgery, 85% of patients with refractory TN experienced complete or partial relief.

— from Neurosurgery 2002;50(3):494-502.

Meningioma on the Trigeminal Nerve Causes Severe Pain

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MRI the next day, which indicated no change in the position or size but was now interpreted as a meningioma pressing against the trigeminal nerve.

The neurologist put Amelia on Tegretol and said that if Tegretol did not solve the problem, the only other option was a craniotomy. I found this remark to be very disturbing because Amelia was in her 80s and age had to be a factor. Later, I found out that he had no knowledge at all about other procedures such as the Gamma Knife.

After several months on Tegretol, it became obvious that Tegretol was a very effective medication to minimize the pain of TN but Amelia was slowly losing all her energy and ability to walk. She ended up spending most of the day in bed in an exhausted condition. We reported the problem to the neurologist who then advised us to select a brain surgeon for surgical removal of the meningioma, by craniotomy.

Amelia felt like she was being poisoned by the Tegretol and that she would soon die. The neurosurgeon finally, grudgingly, gave her a prescription for Dilantin and his parting words were: "Dilantin will not do the job."

It was clear that Dilantin was doing a better job for Amelia. After being on Dilantin for several months, the jaw pain disappeared. Amelia returned to the neurologist to report the disappearance of the trigeminal neuralgia. He then said, "The tumor could not have been pressing directly upon the nerve because such a condition could never go into remission. However, sooner or later, the meningioma will increase in size and you will still be faced with having a craniotomy."

Gradually, Amelia reduced the Dilantin dose to zero. On rare occasions, she felt a reminder of the jaw pain and would take one 100mg pill and the problem would go away—like taking an aspirin. I really doubt if just one pill taken during these long time intervals had that much effect. Anyway, it worked for Amelia.

She had another series of TIAs in April 2000. These are frightening to have without any known cause. She had no jaw pain at all. The doctors ran another MRI to search for possible brain damage. No damage was found and the meningioma was reported as being stable compared to the original MRI (no change in size).

We own a small cottage on a pond in Maine. At first, it was just one room, no electricity, oil lamps and a one-holer for outside plumbing. Gradually, we succumbed to the new inventions. If I was to name the one place that Amelia enjoys most, I would have to say that the original camp was it. Amelia's health prevented us from making the 1723-mile trip from Florida up to Maine last year, but we were able to go this year.

In July 2000, on the long car trip up to Maine, the jaw pain very gradually returned and Amelia started taking 400mg of Dilantin per day. Very suddenly, the pain became very severe a few days after arriving at our cottage in Maine. She tried up to 500mg a day of Dilantin plus a prescription narcotic given by the local doctor to "tide Amelia over" until she got back to Florida; however, it had practically no beneficial impact. At that point, Amelia started to live on Ensure. She could not chew food, it was even painful to sip liquid and to move her mouth to speak. We rushed back to Florida to visit the neurosurgeon.

He said that something must be done right away because the meningioma must have increased the degree of pressure on the nerve, and he said that it looked like a craniotomy must be performed. I asked about the possibility of the Gamma Knife instead of a craniotomy. He had no knowledge of the Gamma Knife but was aware of a procedure called radiofrequency rhizotomy.

He called a neurosurgeon that specializes in the radiofrequency rhizotomy approach, who said that the rhizotomy method would not work because the needles could not reach the impingement area.

This neurosurgeon recommended Gamma Knife surgery in Orlando. We got an immediate office appointment with Dr. Appley. Ten days later, on November 20, 2000, Gamma Knife radiosurgery was performed on the meningioma.

About six months after the Gamma Knife, the severity of the jaw pain increased very abruptly. This was more than the 500mg of Dilantin plus the additional courses of prednisone could handle. Dr. Appley had moved out of Florida and had given her medical file to another doctor. I tried to get an early appointment with the new doctor because Amelia could no longer chew food, even had trouble drinking fluids and could hardly speak at all. There was no place to run because medication no longer could cope with the problem. I was told that there was no opportunity, at all, to get an early appointment.

IRSA and Dr. Wolf, in Coral Gables, Florida, assisted us and in less than a week, he had examined Amelia's previous MRI, scheduled an office visit and performed Gamma Knife surgery on the trigeminal nerve (on July 19, 2001). This prompt action was uplifting from an emotional point of view and from a prompt action point of view. Amelia and I will always appreciate the performance of IRSA on our behalf.

More than 50% of the intensity of the pain had disappeared within the first two weeks after the Gamma Knife. Dr. Wolf is very pleased with Amelia's progress. Again, as to Dr. Wolf and his staff, especially Roselin Gallardo, they were all extremely pleasant and helpful to Amelia and to me.

From that time until the end of June 2002, there was a steady but very slow improvement in the reduction of pain. This can best be measured by knowing that before

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Astrocytoma 24 Years Later



Editor's Note: We are always encouraged by life stories of those who are determined to survive and live a quality life. There always seems to be a positive person involved with a supportive family. Jim came to us with his story.

"I'm a 24-year survivor since diagnosis," Jim says. "I'm very fortunate—I'm off the charts, statistically. It's nice to be alive."

Jim, a retired taxonomic botanist, was working towards his Ph.D. in 1978 when he discovered the brain tumor. "I was doing field work for the Pacific Northwest Experiment Station in southern Oregon, about 13 miles from Ashland," he recalls. "I was out there 10 hours a day, four days a week. This was my first experience using botany in the woods. I was doing some fence building and helping a friend. There were several plots under the canopy [of trees] and in the clearout area. I was going between the canopy and the clearout, and I had a sensation much like someone taking your picture with a flashcube. I thought my eyes could not adjust between the intense shade and sunlight."

"I went to see a clinician and then a neurologist," he says. A CT scan showed that Jim had a tumor. He was 36, and had a grade II astrocytoma. "I was frightened for my life," he recalls.

"After the first craniotomy, I was given the option of radiation treatment," he relates. "I was scared to death, but I knew I had to treat it aggressively. The tips of my ears on both sides were crispy red from the radiation, and the hair follicles never grew back in that area, which was 3 to 4 inches wide."

"I could have made a wonderful punk rocker," he jokes. "I ended up just shaving my head."

Jim had two more craniotomies, the last in 1981. "I had convinced my doctor to be very aggressive, as aggressive as his conscience would allow," he says of the third craniotomy. "He saved me—he went



Jim and his family

into good tissue. It really hit me hard. I'm sure he saved my life."

"I retired on disability after the third craniotomy," he adds.

Jim has also used alternative therapies to combat the cancer. "I did a number of nontraditional treatments," he says. "I threw the kitchen sink at it. At the time, the only source of information I had was the college. I did anything I encountered that decreased cancerous growth in the brain."

To try to counteract the cancer, Jim used visualization, meditation, herbs, nutritional supplements and vitamins. "I ate massive amounts of soy every day," he says. "Hot sauce made it taste better. I guess you could call me a health nut."

"I visualized attacking the tumor," he adds. "I became very adept at it, and ended up teaching a couple of classes at the college in that subject."

"It was the meditation that got me here," Jim believes.

What has happened since Jim's last surgery in 1981? "I truly don't know," he says. "Somehow, the tumor stopped." He had no chemotherapy or radiation treatments after the third craniotomy. "I did all these nontraditional things," he adds. "The literature did not say if you have 'x,' do 'y.' It was alternate stuff."

"Not many people get the chance to look back and say they've retired their neurosurgeon," he says.

Recently, in March, Jim had two

transient ischemic attacks (TIAs). "I was totally blind for 24 hours," he recalls. "I had accepted that I was going to be blind. I was in the hospital for five days."

"Now I take Plavix, which is a slippery platelet drug," he explains. "My small blood vessels are quite frail as a result of radiation." He reports that he has no problems with bruising.

Jim's sight has been affected by the radiation treatments. Now, he requires much more light to focus. "The eyes are giving up the ghost," he says.

"I've lost my ability to spell and some math capabilities," he adds. "The thing that was most significant was my short-term memory. While I could remember classes I've taken, I couldn't remember what I did 15 minutes ago." E-mail is the best way for Jim to keep track of contacts.

"I suspect three craniotomies led to a decrease in serotonin," he states. "I'm on an SSRI—Wellbutrin. I'm not ashamed of it, I realize that in our society there's a stigma... but it's just another disease, like diabetes, that can be treated."

"Life is beautiful," he says. "Every day is so precious. I am fortunate to have the help of Wellbutrin. The organic source of my depression is very real. I suspect there is a tendency towards

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Six Years After Treatment for Trigeminal Neuralgia

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it might be getting ready to start again but it turned out to be nothing. Maybe the nerve tries to regenerate at times?

In the years since my first attack of TN, I've talked to so many people and read everything I could get my hands on, and I know I am so lucky to have had the option of Gamma Knife. Since the worst, most unbearable electric shock pain was in my left eye, my nose and the roof of my mouth, any other procedure could have been a disaster. Microvascular decompression would have been useless because I have something unidentifiable in my brain stem, which is almost certainly causing pressure on the trigeminal nerve root. This is not operable or treatable and was probably the product of an accident.

Everyone agreed that nothing would have worked but Gamma Knife. I know there are neurologists and doctors who still don't know Gamma Knife exists and this worries me. I learned of it through an article sent to me by the Trigeminal Neuralgia Association.

My neurologist never mentioned it as an option. I now carry a small flat portfolio with hundreds of pages of information about the TN Assn. and the Gamma Knife and leave them on tables in dentists' and doctors' and neurologists' offices and hope this has helped get some information to people. Every one has to choose for themselves, but they need to do good research in order to make an informed decision.

This is what I did, I read a lot and researched all possible options and I am so glad I chose as I did because Gamma Knife was a miracle for me. I will always feel so grateful to all those who helped me to learn about all that was available to me.

I would love to hear from any Gamma Knife patients, and anyone interested in having Gamma Knife. And, I would like to hear from those who had Gamma Knife prior to 1995 and 1996. I would like to resume contact with people I've lost track of and hear from anyone

with TN. Try me again if I fail to answer. I would love to help anyone who might have questions. I'll do my best to help in the same manner others helped me.

Astrocytoma, Bowling...

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Conrad, was made much easier by the support he has received from his physicians, family, friends and the "terrific" co-workers at his office at BellSouth. Sonia's office started a fund to cover his travel expenses.

Conrad is not working currently and misses his co-workers a lot. He hopes to be seizure-free for two years, so he can return to doing what he loves best — being a Facility Technician for BellSouth. Until then, Conrad is continuing his chemotherapy, taking medications and getting in an occasional bowling game at the Navy Base whenever he can.

Sonia, now a well-informed person on the subject of brain tumors, is acutely aware of what an ordeal a brain tumor diagnosis can be for the patient and the family. She is considering initiating a support group in her home area with the guidance of some local professionals, so that others with brain tumors can receive the much needed support and information needed to win the battle against brain tumors.

TN Triggers

- ◆ Breeze
- ◆ Cold
- ◆ Eating
- ◆ Brushing Teeth
- ◆ Talking

Astrocytoma

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this in my family."

"I tell you, I'm one happy, happy, happy person," Jim says.

He and his wife Deb have two children: Meghan, 17, and Peter, 22. The couple live in Ashland, Oregon. "She's a heck of a cook," says her husband. "She loves to cook, and I'm the benefactor here."

"Meghan is very responsible and serious," says Jim. "She's going to the University of Oregon on scholarship. And Peter developed a nine-man *capella* group out of the University of Oregon," he adds proudly. Peter is majoring in music and has two music scholarships.

"Every Monday, Wednesday and Friday I walk down the hill, in the woods, to the university and go swimming," Jim relates. "I used to be able to swim 3000 yards per day. But now, I think because of long-term radiation exposure, I've lost vigor—both strength and cognitive." Now, Jim swims 1000 to 1500 yards per day, and gets up about 5:30 a.m. to go to the pool.

"Swimming and walking back up the hill is my main exercise," he says. "I stopped counting at 4500 trips up the hill."

"I have a couple of junkyard dogs," he states. "They're my best friends." Rose and Lil are Rottweiler mixes, each weighing around 80 pounds. "They're good little girls," he says. "They don't pull on the leash. I feed them flaxseed oil, which is a nontraditional source of omega-3 fatty acids. I also feed them some cottage cheese."

"When they wag their tails, they clear off the table," he adds.

"I'm so very fortunate," Jim, 57, says. "My life is so full. I'd love to be able to be involved in helping someone. I hope this helps someone. I just want to let someone know that they can survive and give them hope."

"I'm not giving up. I'm not going down without a fight."

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What Are Complications from Gamma Knife?

Major complications have not been reported. Additional numbness in the face or new facial sensations occur in about 14% of patients. This is infrequently bothersome and often improves (transient). Complications such as brain damage or brain tumor, have not been reported to occur in any of the patients treated for trigeminal neuralgia.

Gamma Knife surgery for trigeminal neuralgia was originally performed in Sweden in the 1950's, but there were few patients treated. It has been used in the USA for 15 years. Thousands of patients have been treated in this country and throughout the world and many have been followed by their physicians for an extended period of time. The data consistently indicate that Gamma Knife is not only effective but also very safe.

Linear Accelerator Radiosurgery

There is another form of technology, called LINAC (linear accelerator) radiosurgery which may be confused with Gamma Knife. LINAC uses high-energy X-rays delivered by a sequence of arcs, and is very different from Gamma Knife. LINACs are manufactured to have the flexibility to treat within the whole body where the precision that is needed for brain treatment is not necessary.

Only a limited number of cases of trigeminal neuralgia have been treated with LINAC. There are no reports of LINAC peer-reviewed journals articles on trigeminal neuralgia treatment. This is in contrast to Gamma Knife treatments which are supported by a significant amount of published peer-reviewed research articles. Unlike Gamma Knife, LINAC has not been demonstrated to be an effective and safe treatment for trigeminal neuralgia at this time. Additionally, there are many types of LINAC machines with each having a different targeting and dosing mechanism.

In general, LINAC technology does not have the targeting preci-

sion to treat disorders such as trigeminal neuralgia without a higher risk of complications and long term damage such as permanent numbness to the face.

Needle Procedures

Radiofrequency electrocoagulation, glycerol injection, and balloon microcompression are procedures which are performed through a needle that is inserted into the face and directed, under X-ray guidance, toward the nerve. Each procedure results in partially damaging the trigeminal nerve. Facial numbness is a common side effect of these procedures, which is occasionally very painful and bothersome. Major complications, such as bleeding or infection in the brain, although rare, can be devastating when they occur.

Fast Facts

- ◆ TN is rarely (4%) suffered in the upper branch
- ◆ Right side is more frequently affected than left
- ◆ A small percentage suffer pain in both sides of the face
- ◆ Most common in the middle and lower branches
- ◆ 15,000 new cases annually in USA
- ◆ 1 in 2,500 suffer TN
- ◆ More frequent in women
- ◆ Most sufferers are over 40 years old
- ◆ Estimated 5% family history
- ◆ Also called *tic douloureux*
- ◆ May be caused by a tumor pressing on the nerve

Microvascular Decompression

Microvascular decompression is a major neurosurgical procedure in which the skull is opened. It requires general anesthesia. During the operation, the surgeon sees the nerve. If he finds a blood vessel pressing on the nerve, he places a soft piece of material between the blood vessel and the nerve, thus lifting the blood vessel away from the nerve. This operation carries

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TN and Gamma Knife Surgery

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greater risks than the other procedures, and these risks, although infrequent, include possible death, stroke, bleeding, infection, inflammation of the surface of the brain, anesthesia problems, facial weakness and numbness, hearing loss and pain. In the hands of a skilled neurosurgeon who regularly performs this procedure the risks are less or minimal. However, open surgery always carries more risk to the patient.

Summary

Gamma Knife surgery is a major advance in the treatment of trigeminal neuralgia, an otherwise agonizing condition characterized by paroxysmal, triggered face pain. Gamma Knife surgery not only relieves the pain in most patients, but it is least invasive and has the smallest risk of complications when compared to the available treatments for this disorder.

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Alternatives Used to Treat Pain

- ◆ Acupuncture
- ◆ Acupressure
- ◆ Biofeedback
- ◆ Capsaicin Cream
- ◆ Exercise
- ◆ Meditation/creative visualization
- ◆ Self-hypnosis
- ◆ Vitamins

Meningioma on the...

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the Gamma Knife on the trigeminal nerve, 400mg, Dilantin a day was not enough to quiet down the nerve so that Amelia could move her jaws. Now, the jaw pain has disappeared—it has been gone since July 18, the date she discontinued the Dilantin.

Amelia had been gradually reducing the usage over a period of months with many flare-ups of pain during the reduction process. Lesson learned: one must allow enough time for the full impact of the Gamma Knife to be realized. We were tempted last May to request a second Gamma Knife on the trigeminal nerve, but hesitated with the message of “give it more time” from Dr. Wolf and IRSA.

Although Amelia continues to have a high degree of fatigue, she can talk with ease, she can brush her teeth now, and she can chew most of her food.