Another Perspective

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ACOUSTIC NEUROMA...
ALL IN THE FAMILY

Marjie and Jeff each had an acoustic neuroma. We thank them for sharing their courageous story with us.

Marjie:

This is a story about coincidence and determination. It is a wonderful story for the International Radiosurgery Support Association because it contains all the points of concern that we each face during our unsettling trip through the decisions surrounding how to treat brain tumors.

It begins with me, Marjie, when I started having hearing problems in late 1994. In December of that year I was diagnosed with an acoustic neuroma and began my search for the “right” solution to my problem. In 1994 the medical profession in Columbus, Ohio firmly believed in surgery as the only reasonable treatment for brain tumors, even benign ones such as an acoustic neuroma. My initial search brought me to the “best” and “most knowledgeable” otolinguologist in the city who told me surgery was considered the treatment of choice. I initially thought this was my only option but had concerns after learning about potential post-operative problems. Although each negative outcome represented a small probability, to me the cumulative effect of the problems was too high to ignore. In addition, I still had 94 percent hearing in my right ear and no noticeable balance problems. Surgery did not appear to be the way to ensure the preservation of my hearing and balance.

My husband, Jeff, and I began to investigate the available alternatives. Some of our friends were very knowledgeable about ways to use the Internet (even in 1994) and they helped me discover the Gamma Knife. Since Gamma Knife radiosurgery was not offered in Ohio and much of the current research came from The University of Pittsburgh, I chose to consult with Dr. Dade Lunsford at Presbyterian Hospital, part of The University of Pittsburgh. My procedure was performed on the morning of January 3, 1995. My recovery was immediate with no side effects.

Five years have passed and I have had a very positive result. My hearing was maintained over the first four years, although I have experienced a slight decline recently. I now wear a “state of the art,” almost invisible, digital, programmable hearing aid by Sonnic Innovations called Natura. Radiosurgery had no affect on my balance and trigeminal nerves. My 2.3 centimeter tumor has stopped growing and has begun to shrink. My experience has been so positive that I have shared it with others on the Internet and on television. Five years passed and the acoustic neuroma was no longer part of my daily conscious thought.

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Jeff and Marjie
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 150,000 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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The field of stereotactic radiosurgery has evolved markedly over the decades. In the past we treated simple, spherical pathologies with a simple solitary shot of radiation. Now with increased experience, and improved planning software and technology, we are boldly tackling complex, large, irregularly shaped masses that were once thought to be untreatable.

The successful use of this technology for treating small tumors in dangerous locations has blossomed to near perfection. Recurrent tumors in the pediatric population are now being treated with stereotactic radiosurgery, allowing a young child to avoid a second or third craniotomy. All this has prompted the evolution of a “new era” of radiosurgery.

The radiosurgeon is often faced with a patient who has had multiple open surgeries, saddening complications and a recurrent tumor. I have seen many young children, for example, who have had two or three craniotomies to remove a tumor which is just impossible to remove. Had these patients been seen by the radiosurgeon with a new MRI scan immediately after the initial operation, perhaps they could have been treated and potentially cured with radiosurgery. The problem lies in a relative misunderstanding of the potential of radiosurgery on the part of patients, families and referring physicians.

In the four cases presented on pages 3 and 4, radiosurgery was furthest from the minds of the original treating physicians. The family members did their due diligence in researching their loved ones’ options and often they themselves served as the referral source. Misunderstandings such as “the tumor is too large,” “it is near very critical structures,” or “its shape is too complex to treat” are simply the words of physicians inexperienced with the technique and results of radiosurgery. Only an experienced radiosurgeon is able to make those judgements.

The “new era” of radiosurgery is now upon us. We can now treat pathologies which were once thought untreatable. As we move into the new millennium more and more patients will be helped with stereotactic radiosurgery.

Dr. Christopher Duma is the Medical Director of Hoag/UCI Gamma Knife Center at Hoag Hospital in Newport Beach, California. He can be reached by phone at +949-574-6232, and through e-mail at cduma@hoaghospital.org.
Case number one is a 38-year-old male who was in good health until severe headaches, nausea and vomiting, and visual changes led to an MRI. This revealed a large suprasellar cystic mass and obstructive hydrocephalus. He underwent temporary ventriculostomy and a frontal craniotomy for removal of a craniopharyngioma (a remnant of embryogenesis in the pituitary region). He did well postoperatively and required total pituitary replacement therapy. Months later, the tumor was back, again compressing his optic nerves. The patient refused to have another operation and sought Gamma Knife radiosurgery.

A complex treatment plan, with “plugging” of certain collimator holes in order to keep the dose of radiation away from the optic nerves, was administered using the Gamma Knife. As you can see from the images above the tumor began shrinking within two months and by one year, the tumor was gone. The patient avoided a second craniotomy, which invariably would have resulted in yet another incomplete resection, and he is currently in perfect post-Gamma Knife condition.

The patient is a very bright, alert and intelligent 10-year-old young lady, who at age two underwent a biopsy of a hypothalamic lesion. This was considered an astrocytoma at the time (a low grade, benign tumor). She underwent 18 months of chemotherapy and radiation therapy. She did well until the tumor began to grow again, changing from two cm in diameter to about three cm in diameter over six months. Even an inexperienced viewer can see from the images shown here that the tumor in this bright, intelligent and fully functional patient is not resectable by surgical techniques. She underwent Gamma Knife radiosurgery with a complex 11-shot plan with tight margins, and on the seven-month follow-up there are already signs of shrinkage and necrosis of the tumor. She is doing great.
A bright nine-year-old boy presented with symptoms of elevated intracranial pressure and gait disturbance and failure to thrive in March of 1995. The original surgery was aborted by the surgeon because the tumor felt “like a piece of wood.” In a second operation two years later, the surgeon was only able to perform a biopsy. He underwent 14 months of chemotherapy but no XRT (external beam radiation therapy). After a third craniotomy with similar dismal results, the patient was referred by his pediatric neurosurgeon who felt that the tumor might be managed with Gamma Knife. In March 1999 the patient underwent a complex Gamma Knife treatment involving multiple isocenters for precise conformal planning. His nearly one-year follow-up MRI images are seen below, with a near miraculous result. Had it not been for the educated referring neurosurgeon the child would not have made it to radiosurgical treatment.

A lot has been said about the deadly brainstem gliomas. Open craniotomy for these tumors can be performed if the tumor does not completely involve the brainstem, but it is never enough. Because of the involvement of the important brainstem, average life expectancy is on the order of only a few months. We have now treated a number of patients with both low grade astrocytomas and anaplastic and the higher grade astrocytomas with astounding results. Figure 4 is an eight-month follow-up of a 10-year-old boy treated with surgery and Gamma Knife radiosurgery. He is currently steroid-dependent, but his tumor is shrinking. This is one of the first times this has been attempted, and the results are promising.
Editor’s Note: The diagnosis of Glioblastoma Multiform has always been considered a death sentence. Patients are routinely told that they have six to twelve months to live. However, as Charlie has found out, after the initial treatments and the side effects, life does go on. Charlie and Joanne aggressively sought all treatment modalities, surgery, chemotherapy, radiation therapy and radiosurgery with the Gamma Knife. Research is now suggesting that those whose diagnosis is timely and who receive adjunct treatments, may survive with quality of life and minimal effects. We believe that the ‘spirit’ of Charlie and Joanne has also promoted his well being. Charlie and Joanne have learned to overcome the difficulties and to move on with life. We are pleased to update their story for those of you who have repeatedly wanted to know how they are doing.

Charlie is a familiar sight around his neighborhood in Marmora, New Jersey, USA. Riding his electric scooter with his golden retriever companion dog at his side, he runs errands and does chores around the house.

This 61-year-old former administrator is no quitter. Not even the “tumor stroke” could stop him.

Sometime in 1990, Charlie started experiencing focal seizures in his right arm. “It would take on a life of its own, flailing,” says his wife, Joanne.

Charlie worked as a school monitor for the New Jersey Department of Education and was involved in rating school districts. He drove 75 miles from his home to his office in the morning and 75 miles back in the evening. He started having seizures in his right arm during his commute.

“I would just get over to the side of the road and stop and wait till it passed,” Charlie recalls. “It was a pain in the neck. It was scary.”

“We thought it was a muscular thing,” says Joanne. “His cousin, a nurse, recommended a neurologist.” This doctor thought Charlie had meningioma, a benign tumor on the protective coverings of the brain. “The neurologist said 90 percent of the time, it’s benign and in a little sac and they pop them out,” Joanne says.

Charlie had a craniotomy in early 1991. Instead of a meningioma, doctors found a glioblastoma - fast-growing, highly malignant brain tumor - on the left side of his cerebral cortex. It was 3.5 to 4 centimeters in size and had tentacles.

“They did a biopsy, sewed him back up (with more than 100 stitches) and recommended radiation,” Joanne says. “It pretty much had a negative prognosis. Radiation was a shot in the dark. They were hoping that would stall the (tumor’s) growth.”

After seven weeks of radiation treatment, Charlie’s glioblastoma shrank to 2 cms.

“Right after the surgery, he had a lot of seizures but they stopped within a month,” Joanne says. “He was on medication and he kept working through this. My husband has an extremely positive attitude.”

When New Jersey offered an early retirement program that year, Charlie took it.

By January 1992, a year after the craniotomy, Charlie started to suffer seizures again and his right arm and leg were weak. By June, he couldn’t use them. MRIs showed the tumor was growing.

Their doctors had given them no hope, Joanne says. They had not even arranged physical therapy for Charlie. “With prayers to God, we were led to the right doctors,” she says.

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They went to the University of Pittsburgh Medical Center in October 1992. With his right side paralyzed, Charlie was in a wheelchair. Dr. Douglas Kondziolka, stereotactic neurosurgeon at Pittsburgh, asked Charlie, “What do you want us to do?” Charlie said he just wanted to “live as normal a life as possible.” Dr. Kondziolka said this was also his goal.

Doctors at Pittsburgh found that Charlie had 4 cms of scar tissue from the brain surgery. They recommended experimental chemotherapy treatment - BCNU and Cisplatin delivered intravenously continuously for three days - beginning in January 1993. The couple spent one week a month in Pittsburgh for four straight months. Today, Joanne jokes about how they spent the early 1993 holidays in the Steel City - their anniversary in January, Valentine’s Day in February, St. Patrick’s Day in March and Easter in April.

Each time, Charlie received chemotherapy for 72 hours at Pittsburgh Cancer Institute. “We’re 10 hours from Pittsburgh (driving time) so we would fly there,” Joanne says. “Then he would need a couple of days to get back on his feet” before they could fly back to New Jersey.

The experience was “unbelievable,” Charlie says. He used meditation, which he taught himself, to make it through the treatment. “It works,” he says.

While he was being treated, Joanne stayed at a Family House facility. This non-profit organization provides an inexpensive “home away from home” for patients with life-threatening illnesses and their families. Joanne praises the program and its volunteers. “They are life savers for anyone who has to travel from a distance to Pittsburgh for treatments.”

The goal of the chemotherapy was to shrink Charlie’s tumor down enough for the Gamma Knife.

“He usually had one day of upset stomach afterward but they gave him a lot of medication to combat that,” Joanne recalls. “By the second week at home, he was feeling weak and tired,” but still kept up with his physical therapy. “By the time he was feeling well again, it was time to go back to Pittsburgh” for the next round of chemo.

In the meantime, a visiting nurse saw Charlie three times a week. He was on “all kinds of minerals and vitamins.” “God was with us,” Joanne believes. “He was injecting strength into us each time.”

At the end of the third session, Charlie says he knew the treatment had worked. His body felt different and “I had a feeling that it was over.”

In April, tests showed the experimental chemotherapy had indeed done its job: Charlie’s tumor had shrunk enough that he could have the Gamma Knife. He was treated in May 1993.

Since then, MRIs have shown no significant growth in Charlie’s glioblastoma. He has the MRI done near his home in New Jersey and it’s sent immediately to Pittsburgh.

“Dr. Kondziolka and his staff have been always kind, caring and extremely sensitive to our needs through all these years,” Joanne says. “They truly are a class act,” and continue to follow Charlie even now 10 years later.

His right side is still partially paralyzed, but Charlie uses a partial walker and his electric scooter to get around. He continues to work in physical therapy to keep his right side active, moving and in good shape.

Besides physical therapy, Charlie works on exercises to assist his memory in recalling letters and numbers. “You have to keep working on it and the skills return,” Joanne says. “He reads a lot. But writing is a problem.”

Charlie’s speech was also affected. He can formulate ideas in his mind but can’t always express them, or the words come out backwards. “It’s very frustrating because he knows what his mouth wants to say but he can’t always say it,” Joanne says.

Despite his physical problems, she says, “he has good quality of life.” When he can, Charlie works three days a week for their county diagnostic training center. “It’s a boost to his morale,” Joanne says. The center provides employment opportunities for people with disabilities.

In late 1998, Charlie needed dental surgery. His physician recommended a quick hospitalization to prevent problems. However, Charlie contracted an infection, and then developed blood clots in his leg and had to have a vascular bypass surgery on his leg. After the surgery, Charlie was admitted to a rehab facility for five months to regain the use of his leg. Complications continued when he had to deal with a pressure wound from the knee stabilizer he was required to wear. Through all of this Joanne says that Charlie maintained a good attitude and a great sense of humor. It was especially hard on her when Charlie was not at home.

Charlie’s constant companion, his golden retriever, Heather, had to be ‘put down’ as she was found to have had cancer throughout her body. This was especially hard for the McGuires. They now have a new golden retriever named ‘Sweet Dreams’ which they lovingly call ‘Sweety.’ Sweety roams the neighborhood everyday with Charlie who uses his scooter. Joanne states that Sweety is quite a hand full at a year and a half of age and is very playful.

Prior to 1990, Charlie was very active in his church and the community. He served as an emergency medical technician and was in the National Guard. So tumor or no tumor, “he was absolutely determined to get out,” Joanne says.

“Everybody in our town knows him. He goes everywhere with the scooter and the dog.”

Charlie adds: “It’s a nice feeling. The neighbors are a big help.”

He still does what he can, raking leaves and taking out the garbage one-handed.

Charlie and Joanne go out to eat, have friends over and travel to Florida on vacation. They have two grown children: Jeff, 34 and Julie 28. “It’s a good life,” Charlie says. “I’ve been lucky to have Joanne.”

For her part, Joanne says, “He’s a more positive person than I have ever been so I’ve learned a lot from him. We don’t look at this negatively at all. There are no pity parties here.

“If at first the idea is not absurd, then there is no hope for it.”

– Albert Einstein
Magnetic resonance imaging (MRI or MR), in contrast to other types of imaging modalities for brain tumors (PET scans, CT scans and angiography), utilizes no ionizing radiation to acquire the data for the images. Instead, MR utilizes magnetic fields and radio frequencies (radio waves). Tissues in the body are composed of a large portion of water. One of the building blocks of water is an element called hydrogen, and the nuclei (or centers) of hydrogen contain protons. Normally protons are in constant motion and randomly aligned. When a magnetic field is applied, the protons all align and spin in the same direction. When radio waves are then applied, they knock these protons out of alignment. Once the radio waves are turned off, the protons realign themselves and emit radio signals. The radio signals are then transformed by a computer into an image. MR can create an image in all three dimensions.

Magnetic strength is measured in units called “Teslas.” Routine clinical MR units utilize a magnetic strength of 1.5 Tesla. The Ohio State University Medical Center / Arthur James Cancer Hospital and Richard Solove Research Institute have constructed an ultra high field MR for clinical use with a strength of eight Tesla. A 4.2 Tesla unit is operational at Columbia University and a seven Tesla MR is under development at the University of Minnesota. With these high field MR units, more detail of the brain is possible. A temporary side effect of being imaged at these high strengths is vertigo (dizziness). It is caused by stimulation of the inner ear with motion and ceases after being removed from the magnet.

The first clinical application of this magnet at Ohio State will be the imaging of the most aggressive brain tumor, glioblastoma multiforme, before and after administration of a radiosensitizer called Gadolinium Texaphyrin (Pharmacyclics Inc., Sunnyvale CA). This type of tumor can be difficult to image completely with lower Tesla units. The patient will receive the radiosensitizer three hours prior to a Gamma Knife radiosurgery boost (after five weeks of conventional radiotherapy). The patient’s tumor must be four cm in greatest dimension and must be one cm from the optic chiasm and brainstem. If the tumor becomes four cm after debulking surgery, the patient is still eligible for the study. Additional information regarding the Gadolinium Texaphyrin trial, which is sponsored by the National Cancer Institute, can be obtained by calling 1-614-293-4562. This high strength magnet will also be utilized to image patients with multiple sclerosis. Another area of investigation in magnetic resonance imaging is called functional MRI. Functional MRI can be performed with a 1.5 Tesla unit. Signal changes are detected by alterations in local blood oxygenation levels. Some accomplishments of functional MRI include mapping areas of the brain responsible for finger and thumb movements, receptive language, and tinnitus (perception of sound in the absence of external stimuli).

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Fast Facts

Radiosurgery offers many advantages including:

♦ Requires no overnight hospital stay or one-day stay.
♦ Fewer side effects than conventional brain surgery.
♦ No risk of bleeding or infection and general anesthesia is not necessary.
♦ Results in little or no pain.
♦ Offers a rapid return to normal activities without physical therapy or other rehabilitation.
♦ Is covered by insurance companies and Medicare.
Your Medical Records...

The Association assists patients with insurance denials by writing to insurance companies, working with the insurance utilization review contact person and the medical director.

We provide up-to-date research, contact neurosurgeons and act as a liaison where needed between the insurance company, your treating site and you. However, you as the patient play an important part when it comes to obtaining insurance approval for treatment.

Maintaining control of your medical records and their contents is important in securing further treatment approvals. Medical records are also utilized for employment criteria and life and disability insurance approvals. Denials of insurance coverage may be erroneous, incomplete or both. In any case, however, they are still the only “record” of what has transpired. A more accurate rendition of what goes on in the medical setting should be kept by patients themselves. Patients need to be in control of their medical records. Physicians are busy, distracted and sometimes do not know what an insurance company is looking for.

To maintain your own records, you can begin by taking notes when you visit your doctors and asking for copies of each clinic visit record generated by the doctor. All documents should be reviewed for accuracy and completeness. Patients can request that more information be added to their record or corrections be made if they note anything missing or incomplete. Always make sure your physical condition and problem were described completely at each visit. Insurance companies look for full descriptions of how a condition affects you, how long it has been a problem and what non-surgical interventions were tried.

You can be a powerful force in decisions made about your medical care. Accurate records may establish medical necessity when a physician may be reluctant to declare it. Well maintained records serve to increase the likelihood of the medical consumer prevailing in a dispute with the doctor or insurance company.

If you are having problems with insurance approvals, you should review your medical records yourself. Ask for information to be modified or added to the record if needed. Also, consider requesting your record from MIB (for a small fee) and request any corrections that may be needed.

To request your MIB records:

In USA: MIB, PO. Box 105, Essex Station, Boston, MA 02112, or phone 1-617-420-3660.

In Canada: MIB, 330 University Avenue, Toronto, Ontario, Canada M5G 1R7, or phone 1-416-597-0590.

Additionally, a record of some non-medical conditions such as an adverse driving record or participation in hazardous sports are maintained.

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Before calling a treating site, it will be helpful if you have the following information available:

- Your diagnosis as stated by your physician.
- A list of all previous treatments and their dates.

Include surgery; types of chemotherapy (chemical and doses); radiation therapy (record of total dose received); and the physician and site where you received them.

- Names, addresses and phone numbers of all treating physicians and institutions. Include endocrine lab studies within the past six months.
- Dates and places where all scans or angiograms were completed. You will probably need copies of the most recent scans.
- Current symptoms and problems, especially those related to memory, speech and communication, ability to care for self, work level, personality changes, physical mobility and mental comprehension.

- Health insurance card(s).
- A list of all other medical conditions such as heart or thyroid problems, diabetes, high blood pressure, etc.
- A primary contact person (other than yourself) with address and phone number.

Writing all of this information on paper will enable you to mail or fax it immediately to a medical professional or treatment facility.

Have You Peaked?

We are up and running – with more to be done. Send your comments and suggestions to us by email. Visit the patient forum today.
KEVIN HAD INDEED SUFFERED A LARGE HEMORRHAGE - FROM WHAT, DOCTORSCouldn't tell. They thought it was probably an aneurysm.

"Maybe it was just mother's intuition, but I suspected an AVM," Beth says.

Because Kevin was so young and his condition was so serious, he was flown by helicopter to Children's Hospital in Pittsburgh. The family drove there in their car.

By the time they arrived, Kevin was already in the operating room getting an extra-ventricular drain to remove the blood and decrease the intracranial pressure. Doctors had also done an angiogram, which showed the hemorrhage (a major stroke) was caused by an AVM in the basal ganglia - nerve clusters deep within the cerebrum above the brain stem.

"There was not much hope for Kevin that night and we were told to prepare for the worst," Beth recalls. "The doctors told us he had no brain stem reflexes on admission." But overnight, Kevin started to show some improvement. "To the amazement of his doctors and nurses, by the sixth day, he was weaned from the ventilator," transferred out of the intensive care unit and moved to a neurosurgical floor, Beth says.

She knew they had a long road ahead of them. Kevin's left side was weak and he suffered short-term memory loss and some expressive aphasia (an inability to express himself verbally) and facial droop.

However, his mother notes, "We were just so thankful that he was alive."

The neurosurgeon told the family that because of its size and location, the only way to treat Kevin's AVM was with radiosurgery.

The couple met with Dr. Lunsford at the University of Pittsburgh. He explained how her radiosurgery machine worked and what the procedure would involve. Kevin could not be treated until he was able to go home the next day.

"We had yearly follow-ups with Dr. Lunsford, consisting of an MRI and neurological exam," Beth says.

"Kevin was doing well," she adds. His facial droop had gone away as did his left side weakness. He was left-handed prior to the hemorrhage, but was now using his right hand for most every-

dothing. He was in first grade and doing all the things any 7-year-old would do."

But tragedy struck again four years later. It was a cold winter day and the boys were playing outside in the snow with their radio-controlled bulldozer. Beth told Kevin and Eric not to stay out too long and promised to make hot chocolate for them when they came in.

"Kevin was the first to come bounding in the back door, taking off his coat and yelling, 'Hot chocolate, Mom!'" Beth relates. "He sat down at the table and started to sip his cocoa. I noticed he was rubbing the back of his neck. He said, 'I've got a stiff neck, Mom.'"

Fear came over her and Beth's stomach churned. Kevin started to hold the back of his head and said he was getting a headache.

"I knew what was happening but didn't want to believe it," Beth says. "I was nauseated and shaking. I had to quickly compose myself. I told Dave we were going to take Kevin over to the emergency room." As Dave put Kevin's shoes on, the boy turned pale and started to vomit. Beth called out the window for Eric, telling him Kevin was sick again and had to be rushed to the hospital.

"Kevin's level of consciousness was decreasing rapidly as we sped over to the hospital," Beth says. She told the emergency room physician what was wrong.

Kevin was placed on basic life support and flown to Children's Hospital for further treatment. This time around, while Kevin's neurological condition steadily improved during his hospital stay, he suffered several infections, including ones affecting his spinal fluid and blood.

But Kevin "rallied through all the adversities," Beth says, and was discharged on his eighth birthday, March 21, 1994.

Since this was Kevin's second major hemorrhage, Dr. Lunsford again consulted with a physician who specialized in resecting difficult AVMs. However, this specialist urged the family to pursue further radiosurgery for Kevin instead. Brain surgery, they were told, would likely leave Kevin with permanent deficits, including probable paralysis.

So he was treated a second time with Gamma Knife in May, 1994.

In October 1996, he had a follow-up angiogram that showed the AVM had shrunk and there was "significant reduction" in its blood flow.

Today, Kevin is a healthy, happy 14-year-old who is developing normally with no complications. He has undergone two tendon transfers in his left foot to correct a type of foot drop he developed after the second hemorrhage and surgery to his left arm. His Dad says that you can hardly tell there was a problem with his foot.

Kevin has some mild spatial perception problems as a result of his damage from his original stroke. This does not affect his love of computers and music. He is a great fan of Britney Spears! While restricted from contact sports, he still loves fishing and camping. He digs his own bait and enjoys walking in the woods.

"We are continually faced by great opportunities brilliantly disguised as insolvable problems."  

--- Lee Iacocca
Acoustic Neuroma

Continued from page 1

Until December 1999! My husband Jeff experienced a sharp hearing reduction in his right ear and went to his ear, nose & throat doctor for a check-up. It wasn’t a cold or stuffed ear, and the hearing test indicated that an MRI was required to rule out an acoustic neuroma. I’ll let Jeff tell the rest of the story.

Jeff:
I was unconcerned about my hearing loss in the early days. I participated in Marjie’s discovery of her acoustic neuroma and subsequent search for the appropriate medical solution. The odds of having an acoustic neuroma are one in 100,000. I had a COLD with a stuffed ear; the probability of us both having the same is incalculable. I received the results of the MRI in mid-December: I had an acoustic neuroma in my right ear, .8 centimeter by 1.2 centimeters. I did not experience any swelling or headaches, and on Saturday morning we drove back to Columbus. Two days later I jogged five miles and then worked out with weights.

We are both thankful that we live in a time in which medical science has advanced to a point where diseases such as ours can be discovered and “cured” without invasive treatment. More importantly, we look forward to the day when referring doctors will cast aside their biases toward surgery and inform newly diagnosed patients of this spectacular option.

Another Perspective

The following exerts were presented at the 10th International Meeting of the Leksell Gamma Knife® Surgery Society, April, 2000, Squaw Valley, California.

Obesity:
Researchers at the University of Virginia treated obesity in rats with Gamma Knife radiosurgery. They irradiated the hypothalamus, which controls body weight, of obese rats. Rats treated with two doses of 40 Gy experienced significant weight reductions beginning nine weeks after treatment and lasting until the end of the study, at 34 weeks.

–also presented at the 1999 annual meeting of the Congress of Neurological Surgeons in Boston, Mass.

Pain:
Researchers at Yale University School of Medicine treated three patients with intractable pain of benign origin associated with monopolar depression with Gamma Knife radiosurgery. A closed stereotactic cingulotomy was performed on each with doses of 140 Gy for two patients and 180 Gy for the remaining patient. To date only the patient receiving 180 Gy has benefited from the intervention.

Glaucoma:
Twelve patients were treated with Gamma Knife radiosurgery at the Hospital Na Homolee, Prague, Czech Republic, for advanced stages of glaucoma (blind or very diminished vision with pain). All patients received alleviation of ocular pain and the intraocular pressure was reduced or normalized. There were no early side effects. Dosages in the first group were 28 Gy with 14 Gy to the 50% isodose, and for the second group 40 Gy with 20 Gy to the 50% isodose curve.

Research in Progress

The International Radiosurgery Support Association is an independent organization dedicated to providing information through personal contact and educational materials, encouraging research and promoting patient options about radiosurgery treatment and its availability.

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This publication is not intended as a substitute for professional medical advice and does not address specific treatments or conditions specific to any patient. All health and treatment decisions must be made in consultation with your physician(s), utilizing your specific medical information.
More About MRIs

An MRI (magnetic resonance imaging) is a diagnostic technique that allows us to look inside the body without using X-rays. The pictures are so precise that doctors can often get as much information from an MRI as they would from looking directly at the brain tissue itself.

A large magnet, radio waves and a computer are used to make the MRI pictures. The magnet creates a strong, steady magnetic field that causes the body’s protons, which normally spin randomly, to line up together and spin in the same direction.

A radio frequency signal is beamed into the magnetic field. The signal makes the protons move out of alignment. When it stops, the protons fall back into their aligned position and release energy. A receiver measures the energy released by the disturbed protons and the time it takes for them to return to their aligned position with the magnet. These measurements indicate the type of tissue that’s been scanned and its condition. The computer takes this information and constructs an image on a TV screen. These images can be recorded on film or magnetic tape for a permanent record.

Unlike X-rays, the magnetic fields used in an MRI aren’t known to be harmful to us. We do not know if there are short or long-term side effects at this time.

During the scanning, you may hear some loud thumping sounds. With newer MRI equipment, there is only a very minor sound and you can watch videos or listen to music. Credit cards and watches should not be taken into the scanner as information will be erased and batteries drained.

The MRI scans through bone while clearly defining soft tissue. The images are especially valuable for diagnosis of tumors, abnormal fluid, stroke, cancer and traumatic injuries. While there is a large “bore” MRI available for those who do not like small places, technicians say the small “bore” gives the best definition and clear outline when looking at brain tumors and lesions. Contrast agents (dyes) make many tumors and lesions even clearer.

For the best results with your disorder, always schedule your MRI as requested by your doctor. Early detection of changes in any condition are vital to early treatment and eventual survival.

Editor's note: On a molecular level, all things – people, plants, rocks, etc. – are composed of atoms. These in turn include even tinier particles such as protons.

Here are questions to ask when seeking treatment

The Association encourages patients seeking treatment to ask the following questions:

♦ Will a neurosurgeon direct my treating team?
♦ Does this facility use radiosurgery to treat at least 75 patients for brain tumors and disorders annually?
♦ Has your equipment been modified in its targeting ability since it was manufactured?
♦ Are you a participating member of the International Radiosurgery Support Association?