brain talk™

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Pituitary Tumor Gave Her a Growth Spurt

"I went from a 7½ to a 10 foot size," Linda recalls. "My bones would pop. My toes would pop. My hands would pop. I would have a glare in my eyesight sometimes, but my eye doctor never did catch it."

Although Linda wasn't diagnosed with a pituitary tumor until much later, she had symptoms while in her early 40s. "I was about 42," she recalls. "My feet were growing. I thought it was middle age."

"Then I started getting skin tags," she says. "My family doctor tried to help me. He thought it was arthritis." When she was 54, her family physician sent her to an endocrinologist. "He was picking up my hands and looking at them," she says. "After he did that I got to thinking, my nephew gave me a pair of gloves and they were small. I used to wear them but couldn't wear them anymore."

"I thought it was all middle age," Linda states.

The endocrinologist sent her for an MRI. She found out in February of 1997 that she had a pituitary tumor. "After the MRI, my husband, Charles, and I had fun with it—joking that I could be taller than him," she says. "I was looking in the mirror one morning and I thought my ears were getting fat—and I always had skinny ears."

"I wasn't all that upset when I found out," she says. "All I was after was to get rid of the thing. I had a good family, they really stuck with me. I mean, my husband really stuck with me."

Linda had a growth hormone-secreting macroadenoma that was 1.7 X 2.2 cm. "It was about like a quarter," she says. She also had acromegaly, a condition in which excess growth hormone causes the hands, feet and jaw to enlarge and soft tissues to swell. Linda's lip protruded from the increased growth hormone secretion. "My family doctor was just amazed—once in a lifetime you see that," she states.

She had surgery at Caraway Methodist Medical Center in Birmingham, Alabama, in April of 1997. "He went through the nose, he got 90% of it," she says. After the surgery, "I lost electrolytes and potassium. But they got it built back up," she says.

"I went to see Dr. Swaid and he sent me for Gamma Knife treatment on July 15, 1997," she says. "I had watched them put that Gamma Knife thing in at Birmingham on television. I watched with my son," Linda recalls, "never knowing that I would have to use it."

Linda was offered five weeks of radiation

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Linda and Husband Charles

Inside:

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Stereotactic Radiosurgery

Stereotactic radiosurgery is surgery using radiation as a scalpel. The skull is never opened. Radiosurgery involves the use of precisely directed 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

Eyesight Often Affected by Pituitary Tumors

Neuro-Ophthalmologists are an indispensable part of the multi-disciplinary physician team that treats patients with pituitary tumors. An eye doctor is often the first doctor consulted by the patient when eye problems develop. Often the patient does not know there is a tumor. Pituitary tumors can cause partial vision loss in both eyes (or occasionally one eye) by compressing the fibers of the optic nerve.

A sharp physician may suspect a pituitary tumor based on the visual loss pattern of the patient. These tumors apply pressure to the point where the optic nerves converge, called the optic chiasm. Typically, the nerves that control the outer half of the visual field are affected by these tumors.

Vision loss caused by pituitary tumors can be extensive. For example, with one eye covered, a patient may not be able to see fingers held on the temporal side of the open eye. However, vision loss is often more subtle and may only be properly determined with peripheral vision tests performed with machines called perimeters. These tests may be computer-assisted and are performed by skilled technicians who use a screen, or more often, a Goldmann machine. Both types of visual field test are used to accurately measure and track peripheral vision changes. Goldmann fields measure the whole field of vision while computer fields generally measure only the central thirty degrees of vision.

Visual fields often improve in patients with pituitary tumors after they undergo treatments to reduce the tumor like radiosurgery, radiation therapy, surgery or medical therapy. Such improvement must be confirmed by a neuro-ophthalmologist with formal visual field testing so that a new baseline may be established after treatment. The baseline visual fields may be compared to subsequent tests, which should give the same results. If visual field deterioration is observed, an MRI to determine whether the tumor has grown or enlarged is recommended.

No matter the treatment given for the pituitary tumor, patients should have their visual fields tested regularly throughout life. It is important that a neuro-ophthalmologist be a part of the multi-disciplinary team that treats and manages the patient. Other vision problems may be involved, including cataracts and macular degeneration, which is a progressive disease of the retina. A good examination by a neuro-ophthalmologist will be vital in understanding the cause of a visual problem in a pituitary tumor patient.

Pituitary tumor patients may need to have formal visual field tests on a regular basis for many years.

Fast Facts
Pituitary Tumors:

- Make up 10-15% of all intracranial tumors
- Are usually benign
- Median age at diagnosis is 49
- In a 1938 Mayo Clinic study of 1000 autopsies, 22.4% had pituitary tumors at death
- About 75% are hormone secreting
- About 25% do not secrete hormones
- Vision disturbance and headaches are common symptoms
- May cause peripheral vision loss by compressing optic nerves
- Pituitary may produce less hormones because of the tumor, causing symptoms such as:
  - Hypothyroidism (weight gain, cold intolerance)
  - Hypogonadism (infertility, amenorrhea, loss of libido)
  - Hypoadrenalism (easy fatigability)

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Gamma Knife Radiosurgery for Pituitary Tumors

Background

Tumors arising from the pituitary gland are the third most commonly treated tumor of the central nervous system (behind gliomas and meningiomas) and account for at least 15% of all intracranial tumors (over 20% in African-Americans). Each year almost 15 individuals per 100,000 population are diagnosed with a pituitary tumor. Interestingly, this represents only a small fraction of people who actually harbor an asymptomatic tumor. This is because 20-25% of unselected autopsy cases have shown evidence of pituitary microadenomas (diameter < 1 cm).

Patients with pituitary tumors come to medical attention for a variety of reasons, but their presenting signs and symptoms can be grouped into three main categories: excess hormone production (hypersecretion), loss of normal hormone production (hypopituitarism) and compression of adjacent structures. In addition, with the wider availability of advanced imaging modalities (CT and MRI), an increasing number of patients are being diagnosed with incidental pituitary tumors. Some of these are large enough to warrant surgical intervention while others may be causing unrecognized pituitary insufficiency or signs of mass effect. However, many are small enough to allow observation rather than surgery or hormonal therapy.

Hyperfunctioning Tumors

Acromegaly (excess growth hormone production) is probably the most well-known syndrome and is responsible for the easily recognizable features of a well-known professional wrestler and a James Bond nemesis. ACTH-secreting tumors (which result in Cushing's disease or excess adrenocortical cortisol production due to the tumor's excessive ACTH production) and prolactinomas (excess PRL secretion) are the other two most common hyperfunctioning pituitary tumors. Tumors that secrete TSH can also occur, resulting in excessive thyroid hormone production by the thyroid gland. TSH-secreting tumors account for approximately 5% of all pituitary adenomas. A story in the November 1997 issue of the publication *Another Perspective* describes one patient's experience with surgery and GKRS for this rare tumor (www.IRSA.org/publications/).

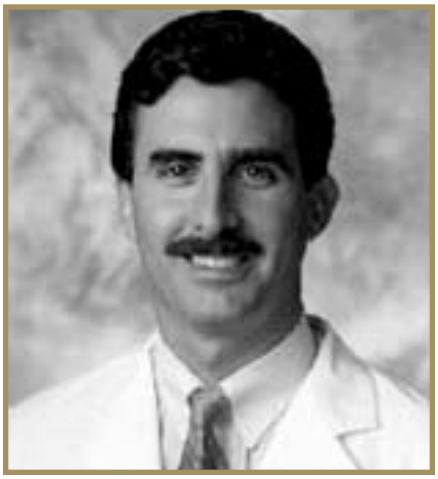
Gonadotropin-secreting adenomas are relatively common tumors that comprise 10-15% of all pituitary tumors. However, these tumor cells are inefficient producers of LH and FSH (the gonadotropins) and can lead to a wide array of symptoms related to abnormal secondary sex hormone (e.g., testosterone, estrogen and progesterone) production depending upon the patient's age and sex. Therefore, these tumors are rarely recognized for their hypersecretion and usually present with either symptomatic compression of adjacent structures and/or hypopituitarism.

Nonfunctioning Tumors

Pituitary Insufficiency

Nonfunctioning pituitary adenomas are endocrinologically inactive and may present with symptomatic pituitary insufficiency (hypopituitarism) and/or mass effect on adjacent structures. The development of pituitary insufficiency is usually insidious and can result in a variety of symptoms that are specific to each hormone. A list of pituitary hormones and their associated deficiencies follows.

- **TSH** (Central Hypothyroidism)
  Fatigue, weakness, excessive need for sleep, impaired mentation, weight gain, cold intolerance, and constipation



Dr. Alan Appley

- **ACTH** (Adrenal Insufficiency)
  Malaise, fatigue, anorexia, nausea, weight loss, arthralgias, myalgias, pale sallow skin complexion, and loss of body hair
  Acute illnesses or severe stress can lead to a marked worsening of symptoms as well as vomiting and orthostatic hypotension
- **PRL** (Prolactin)
  Prolactin deficiency is only clinically significant in women attempting to breastfeed since breast milk production depends upon normal prolactin secretion
- **GH** (Growth Hormone)
  Children and adolescents may show short stature due to delayed skeletal maturation
  Adult deficiencies are easy fatigability, poor exercise tolerance, muscle weakness, weight gain and impaired psychosocial skills
- **Vasopressin** (Diabetes Insipidus or DI)
  Rarely seen before pituitary surgery
  Postoperative DI occurs transiently in up to 25% of patients, but is permanent in only 2% of patients Causes polyuria (large amounts of very dilute urine) that, in turn, leads to polydipsia (increased drinking due to increased thirst)

Mass Effect

Patients with pituitary macroadenomas (> 1 cm) often have symptoms due to compression of structures adjacent to the pituitary gland.

Headaches are common in this group of patients and, when due to the tumor itself, are often longstanding and slowly progressive. These headaches can be due to:

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Abbreviations

GKRS	Gamma Knife® radiosurgery
GH	growth hormone
XRT	conventional fractionated radiotherapy
PRL	prolactin
MRI	magnetic resonance imaging
ACTH	adrenocorticotropic hormone
CT	computerized tomography
TSH	thyroid-stimulating hormone
ICA	internal carotid artery
LH	luteinizing hormone
FSH	follicle-stimulating hormone

Radiosurgery for Pituitary Tumors...

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- Stretching of the dura (or diaphragma sellae) above the tumor
- Invasion into the cavernous sinuses on either side of the tumor
- Bone invasion below, in front and to the sides of the tumor
- Increased pressure inside the head (increased intracranial pressure)
- Various hormonal imbalances

While headaches often improve (and may resolve completely) after pituitary surgery, it is not uncommon for headaches to be unrelated to the pituitary tumor and relief of headaches should not be guaranteed by the treating physicians.

Pituitary apoplexy is an uncommon event characterized by the sudden onset of headache, nausea, vomiting and neurologic changes (usually visual loss and difficulty with various eye movements) caused by hemorrhage into a pituitary tumor. Infarction and necrosis (loss of blood supply leading to cell death) in a pituitary tumor can also lead to pituitary apoplexy.

Visual loss from compression of the optic nerves and/or optic chiasm above the tumor can be insidious and quite advanced before a patient seeks medical attention.

Double vision can also occur from involvement of the cranial nerves controlling eye movements that travel through the cavernous sinuses on either side of the normal pituitary gland.

Facial pain from involvement of the trigeminal nerve (which also travels through the cavernous sinus) can be severe and is a relatively uncommon presenting complaint of patients with pituitary macroadenomas.

Gamma Knife Radiosurgery

Stereotactic radiosurgery with the Leksell Gamma Knife® (GKRS) is an alternative treatment option for patients with pituitary tumors who do not require rapid normalization of excessive hormone production and whose tumors are not in close proximity to the optic apparatus. This would include many patients who have residual or recurrent nonfunctioning pituitary tumors, as well as selected patients who are unable or unwilling to undergo transphenoidal microsurgery. In addition, GKRS is probably now the preferred treatment modality for patients with continued hormone hypersecretion or residual tumor after microsurgery.

In the past, conventional fractionated radiotherapy (XRT) has played an important role in the management of similar patients' pituitary tumors. However, advances in imaging (e.g., MRI) and computer science have dramatically improved our ability to precisely target abnormal tissue (i.e., tumors) as well as limit the radiation dose to critical structures such as the optic apparatus and normal pituitary gland.

Normalization of Hormone Production

The major factor in predicting a patient's chance of biochemical remission after surgery for a hyperfunctioning pituitary tumor is the tumor's size. Patients with macroadenomas generally have a significantly lower chance of biochemical cure than do those with microadenomas. With surgery alone, biochemical remission can be expected in 80-90% of patients with microadenomas, while only 50-60% of patients with macroadenomas can expect this result. If it is to occur, the normalization of hormone production after surgery for these tumors is immediate. However, recurrence of excessive hormone production can occur many years after presumably successful surgery in as many as 40% of patients, depending on tumor type and size.

For those patients with persistent or recurrent hormone hypersecretion, both XRT and GKRS can be effective treatment modalities. However, there has been a lack of consistency in reporting "normal" results after treatment of pituitary tumors. In addition, the definition of biochemical cure varies widely from one institution to another. Because of this, there has been wide variation in the reported results from all types of treatment (medical therapy, surgery, XRT, and GKRS) for hyperfunctioning pituitary tumors.

Nonetheless, using modern definitions of biochemical remission, GKRS has now been shown to be effective in leading to biochemical remission in a significant number of patients with hypersecretory pituitary tumors refractory to

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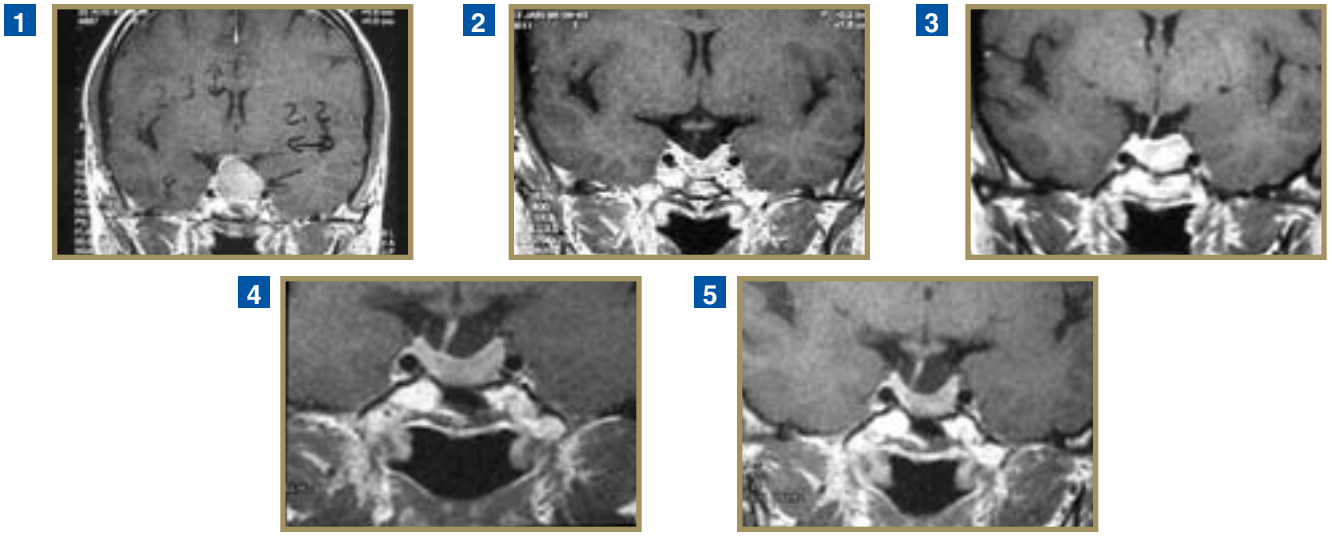

Female patient presented in her 20s with a non-functioning pituitary tumor. Scan No. 1 shows the tumor before microsurgery. Scan 2 shows the tumor reduced at six months after surgery. At one year (scan 3) the tumor has begun to grow and show an increased in size. The patient then had Gamma Knife® surgery. At six months after GKRS (scan 4) there is reduction in the tumor and at one year post GKRS (scan 5) the tumor is still decreasing in size.

Headache & Vision Problem First Sign of Tumor

"Being a grandma is my number one priority right now," states Monica, 55. She and her husband Rick have three children: Nicole, Daniel and Scott. In addition, they have two grandchildren: Colin, 2.5 yrs, and Owen, eight months; two more grandchildren will arrive in the spring. "My family is very important to me; my children and their families, and my grandchildren," she adds. "They mean a great deal to us."

Monica's family was very supportive while she coped with her pituitary tumor. Her first symptom was a headache. "In September of 1998, on a Thursday, I had an appointment at church with one of our ministers, and I remember thinking, 'hmm, I have a headache,'" she recalls.

"It just continued. The weekend came, and I developed double vision and my right eye started to protrude," she adds. "I couldn't see. I couldn't read newspapers—like the fine print."

"This all went through Tuesday, when my husband said, 'this is not right,' she continues. Rick is a family physician who is now the chief of staff of the health center at Western Illinois University. Monica is an outpatient cardiac rehabilitation nurse.

Monica went to see her family doctor that afternoon, who referred her to an eye doctor. "He called up and I went right up to see the ophthalmologist. He ordered a CT scan for the next morning," she says.

"The next afternoon, on Wednesday, my husband came with my family doctor to the hospital to tell me, he felt like it was a pituitary tumor—very big," she relates. "He said, typically, if it's a pituitary tumor, they are benign."

After Rick and her family physician left, Monica went to the office and told her coworkers. "It's in God's hands now," she told them. "He will guide us."

The same week, she saw a surgeon about the tumor. "On Friday I had an appointment in St. Louis, a good 3.5 hour drive," she tells us. "We saw the surgeon and he looked at the CT scan, and he gave me a neurological exam and told me what he thought needed to be done." She then had an MRI.

"My daughter came back from St. Louis with us and she just sort of took over," Monica says. "Then we all drove back to St. Louis for the surgery on Tuesday, September 29th," she recalls. "Our children were really shaken."

Monica and Grandson Owen (7 months)

"I wanted to wait to have the surgery because my second son, Scott, was getting married on October 10th. But the doctor said it had to be now," she remembers.

Monica's pituitary tumor was benign and non-hormone secreting. It was removed through a transphenoidal approach, in which surgeons access the pituitary gland by entering through the nose, or in Monica's case, the roof of the mouth. "I had a bad-looking face afterwards, hence, the anxiety since this wedding was coming up," she says.

"My oldest son, Daniel, bought masks that only cover half the face," she recalls. "He thought if I looked rough, they would all wear the masks and look the same." She and her family later had photos taken of the group wearing the masks.

Before the surgery, Monica had been training for a half marathon, which she believes helped her recovery. "Because of that, I was in pretty good shape," she says. "I'm a very dedicated exerciser."

Fortunately, she was able to go to Scott's wedding. "I came home from the hospital on Monday," she recalls. "The next weekend my Mom came and we flew out to the wedding."

"We love to dance," Monica says of herself and Rick. "I could only do some slow dances at the wedding. I don't remember a lot of it."

Half of Monica's tumor was removed during surgery. "The other half was entwined around the internal carotid artery and facial nerves. It still is," she says. "The surgeon recommended radiosurgery in hopes of stopping the tumor's growth and shrinking it." In February of 1999 she had Gamma Knife radiosurgery at Barnes-Jewish Hospital in St. Louis, Missouri. "I had eight or nine shots of radiation," she says. "They told me the previous surgeon had done a very good job of clearing the tumor away from the optic nerve."

The summer after she had radiosurgery, Monica experienced some new problems. "It started in May, I think; I just generally wasn't feeling good," she remembers. "My hands were extremely painful and swollen, I was hungry but I had no appetite and I was cold all the time. The swelling in my hands was just awful. It was hard to drive a car—hard to hold the wheel."

"My husband's cousin is an endocrinologist, and he suggested that I get some tests," she says. Monica went to an endocrinologist in Springfield. "He told me, 'considering the size of the tumor, and the surgery, and the radiation, the pituitary gets batted around.' He put me on prednisone morning and night—it's so good to feel good again."

Now, Monica goes every two years for an MRI. "The last MRI showed the tumor is the same size, just sitting in there," she says. "I have visual fields done yearly now. I had one done this month—the doctor was pleased."

Monica keeps herself very active. "I work a very busy part-time," she says. She is also president of the women's organization in her church. "I love being a grandmother. I also like to garden. I enjoy my friends, and I like meeting them for lunch. I love to take pictures," she adds. "My husband and I have been married 34 years, and I am on album 49."

"I'm just grateful for the type of tumor it was," she says. "And it's not going to end my life like some brain tumors do."

Those interested in contacting Monica Iverson may write to her at 536 Meadow Dr., Macomb, IL 61455.

Radiosurgery for Pituitary Tumors...

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medical therapy and surgery. This modality is most effective in patients with Cushing's disease (residual or recurrent ACTH-secreting tumors) where 70% or more of these patients can expect remission.

Patients with recurrent or residual acromegaly can expect a 30-40% chance of remission. Refractory prolactin-secreting tumors are the least responsive in that only 11% of patients can expect a cure. However, since prolactin-secreting tumors are the most responsive to medical therapy, a significant number of patients may achieve normal hormone levels with medication after GKRS when this was not possible after surgery alone.

The normalization of excessive hormone production is a slow process and can take many months to several years to occur. While XRT has also been shown to be somewhat effective for these tumors, GKRS appears to result in hormone normalization significantly faster than XRT. Because of the damaging effects of hormone hypersecretion on various body systems, the pace at which this treatment induces normalization of hormone levels is important.

The average time to normalization of hormone production after GKRS varies, but ranges from 16 months for patients with Cushing's disease to 28 months for patients with acromegaly. Therefore, it is imperative that patients continue follow-up indefinitely with their endocrinologist to be monitored both for hormone response as well as pituitary insufficiency (discussed in an earlier section).

The timing of medical therapy prior to GKRS is probably the most significant recent finding in this group of patients. It has been shown that patients who receive somatostatin analogues (for acromegaly) or dopamine agonists (for prolactinomas) at the time of radiosurgery have a significantly lower chance of a biochemical cure after GKRS. Therefore, most surgeons now will withhold medical therapy (stop medication) for these tumors for at least six weeks prior to radiosurgery and for a number of weeks after GKRS. While these medications seem to be radioprotective for these tumors, the mechanism of action is unknown and the optimal time to withhold or resume these medications still needs to be determined.

Control of Tumor Growth

Another goal of GKRS for pituitary tumors is control of tumor growth. Radiosurgery has been shown to produce an excellent growth control rate of 90-100%. However, Nelson's syndrome (recurrent ACTH-secreting pituitary tumor after adrenalectomy) does not respond quite as well and is likely due to the more biologically aggressive nature of these tumors.

Complications Vary among Treatments

Besides not achieving the aforementioned goals of radiosurgery (normalization of hormone production and control of tumor growth), there are several other potential risks of this treatment, which should be weighed among risks of all available treatments, that can be divided into five main categories:

1. Cranial Neuropathy

While the risk of optic nerve or chiasm injury (which results in visual loss to some degree) has been low for XRT (1-3%), the risk is even lower with GKRS (< 1% risk of visual loss). The advantage of GKRS is that sophisticated beam-blocking techniques can be utilized to reshape the eventual dose plan to allow effective maximum and minimum doses to the tumor while limiting the optic structures to a safe level of radiation. This technique was described in more detail in the November 1997 issue of the publication *Another Perspective* (www.IRSA.org/publications/).

Injury to the nerves of the cavernous sinus is even less common with GKRS. The risk of damage to the nerves responsible for eye movement (the third, fourth and sixth cranial nerves) is 0.4% and facial numbness (trigeminal neuropathy) has been described in only 0.2% of cases.

2. Pituitary Insufficiency

The development of hypopituitarism (pituitary insufficiency) following XRT for residual or recurrent pituitary tumors is well documented, although the reported incidences vary widely. However, it is widely accepted that at least 50-75% of patients who receive XRT for pituitary tumors will develop some degree of pituitary insufficiency and require lifelong hormone replacement therapy.

With GKRS, the normal pituitary gland can often be visualized and excluded from the prescribed radiosurgical treatment volume. Because of this, at least two-thirds of patients should retain normal pituitary function after GKRS for residual or recurrent pituitary tumors.

Newer imaging techniques have contributed greatly to this feature of GKRS.

In addition, a new surgical technique has been developed by Dr. William Couldwell at the University of Utah whereby the normal pituitary gland is actually pushed away from the proposed treatment field during the initial surgery for invasive pituitary tumors. This technique may allow a higher treatment dose to be delivered (leading to better tumor and abnormal hormone control) while decreasing the chance of developing hypopituitarism.

As with normalization of hormone hypersecretion after treatment of functional tumors, pituitary insufficiency resulting from GKRS involving normal pituitary tissue can occur long after the treatment has been completed. Therefore, lifelong follow-up should be expected after treatment of pituitary tumors.

3. Brain Injury

In patients who have had surgery for pituitary tumors, XRT has been shown to contribute to the development of cognitive dysfunction.

Less than 1% of patients are at risk of injury to adjacent brain tissue from GKRS. Most of these patients had previously received XRT as well and most centers will consider using a relatively lower dose during GKRS in patients who have previously undergone XRT.

4. Vascular Injury

Narrowing of the internal carotid artery (ICA) in the cavernous sinus after GKRS is rare and has been reported in three patients, only one of whom actually developed a neurologic deficit.

5. Secondary Tumors

For conventional fractionated radiotherapy, the development of a new radiation-induced tumor within the prescribed radiation field has been described to occur in up to 3% of cases. However, this has not been described in any patient who has received Gamma Knife radiosurgery.

Conclusion

Stereotactic radiosurgery with the Leksell Gamma Knife can be a very safe and effective tool in the multidisciplinary treatment of patients with recurrent or residual pituitary tumors. This modality offers the best chance for preservation of both neurologic and hormonal function. Growth control is excellent and, for many patients, normalization of hormone hypersecretion occurs more rapidly than with conventional fractionated radiotherapy.

Dr. Appley, a neurosurgeon, is the Medical Director of the Gamma Knife® Center at Terrebonne General Medical Center in Houma, LA, USA. He also holds an appointment as Clinical Assistant Professor of Neurosurgery at Tulane University of Medicine. Dr. Appley has participated in a number of clinical trials and multi-institutional protocols. He may be reached at: +(337) 235-7743.

Growth Spurt...

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as a treatment by another physician, “but I wanted to try the Gamma Knife,” she says. "Dr. Swaid is the best, in my opinion. I am all for the Gamma Knife. I would have that any day. His team was great—I mean they were super. They were the greatest." Linda was the 400th person to receive treatment on the Gamma Knife unit she watched being installed on television.

"Sometimes I feel down, but my husband lifts my spirits up," she says. "My son and his wife have been real, real good too." Linda's and Charles' son Jimmy is 38. "He lives right next door with his wife, Kristi," his mother says. Jimmy and Kristi are foster parents for two teenagers. "They're 13 and 14," Linda says. "The boy is in football and the girl in band. They're really enjoying them. They just came to live here last May."

"David was blind," Linda says of their other son. He attended the Alabama Institute for Deaf and Blind in Talladega, Alabama and learned a trade after high school. He suffered from hydrocephalus when he was 29. "We lost David in 1996," she recalls. "He had a job and he was a very happy person. He loved to keep busy, out with the public. He was very outgoing. People really liked him." Linda's husband Charles comments that it was not easy on them to have Linda have severe health problems just four months after losing their son. But, he says that she has done great.

"I have four brothers and a sister," she continues. "We always try to meet the second Sunday in December." Everyone brings their families and a covered dish. It was held at her house last year, and Jimmy counted 68 people in attendance.

"The tumor is still active, but they can't find it on the MRI," Linda says. "They figured I was about 40 when it started."

“I do have a deep voice, a very deep voice," she says. "It's better now, but I'd get real upset when they called me 'sir' at the drive-through.”

"I'll be on the somatostatin medication for the rest of my life," she continues. Linda, now 60, takes Sandostatin, a somatostatin analogue. "I take three shots a day."

"Sometimes I do forget things, little memory lapses," she states. "But they do come back to me. My memory just went blank on me right after the tumor was removed. When my husband first let me go to the mall by myself, I got in and I thought I'd gotten lost. When I got back to the car, I thought, 'I'll never go back to that place again.' Now, I think nothing of it."

Linda and Charles enjoy going to yard sales and flea markets. After Charles retired from the post office, the couple traveled to Holland, Michigan, and to Pennsylvania to visit the Amish country. "I really enjoyed all those flowers [in Holland, Michigan]," she says. "It was beautiful!"

"One thing that gave me hope... my sister-in-law had Cushing's disease," she says. "They told her if she made it 10 years, she'd be good. It's been 10 years now and she's doing well."

A delight to speak with, Linda has a very good outlook on life and is very positive. "You have to be," she says.

Those interested in contacting Linda Bardon may write to her at 12117 Highway 82 East, Duncanville, AL 35456.

Disclaimer

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.

This Publication is designated as educational material.

Fast Facts Functional Pituitary Tumors:

- 40-50% produce prolactin
  More common in women
- 15-25% produce growth hormone
  More common in men
- 5% produce ACTH
  More common in women
  These tumors may cause Cushing's Disease
- Excess growth hormone may lead to acromegaly
- Some produce both growth hormone and prolactin
- Rare pituitary tumors produce: TSH, LH, and FSH

(Abbreviations on page 3)

brain talk

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Growing Up with an AVM

PATIENT STORY

Editor's note: Kevin's story was printed in the Spring 1998 issue. We are pleased to update his story for those of you who have repeatedly asked how he is doing.

Kevin's experience with AVM (arteriovenous malformation, a tangle of blood vessels in the brain) began in July of 1990 at the age of four, when he had a terrible headache. His parents drove him the mile to a nearby hospital where they worked. He was immediately flown to Children's Hospital in Pittsburgh where he received an extra-ventricular drain to lower intracranial pressure.

After the AVM bleed, Kevin had weakness on the left side, short-term memory loss and had to re-learn how to walk, but he was fortunate to be alive. In October of 1990, he had Gamma Knife radiosurgery with Dr. Lunsford at University of Pittsburgh Medical Center Presbyterian. Over time his facial droop and left-side weakness disappeared. However, in February of 1994, the AVM bled again. Kevin caught several infections while in the hospital but recovered from them all, and had a second radiosurgery two months later. A 1996 angiogram showed that the AVM had diminished in size and less blood was flowing through it.

However, an October 2002 angiogram showed that the AVM may have become larger. "Dr. Lunsford thought that the AVM had gotten larger," says his mother Beth. "He thought the AVM grew because of the growth spurt."

"On December 15, 2002, he had another hemorrhage," she recalls. "It bled into his ventricles." Beth was at work when Kevin had the bleed. "He knew when the headache started. They did a CT scan right away and flew him to Pittsburgh."

Radiosurgery was scheduled before the bleed but had to be postponed because of the hemorrhage. "After the bleed he did not have more weakness," Beth recalls. Kevin was hospitalized until two days before Christmas. "He did not require a ventricular drain this time, but he had a spinal tap to release the pressure."

Kevin had a third radiosurgery in January of 2003. "Dr. Lunsford thought he got good target points," his mother recalls. By the end of the month, Kevin was back in school. "He got back to school real quick," she says.

His last MRI was in September. "The small vessels were starting to be obliterated!" says his mother. "He is a senior in high school now—he just started. He's doing just fine, doing everything a senior in high school should be doing."

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