Barrow Pituitary Center Patient Handbook





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Welcome to the Barrow Pituitary Center

Dear Patient and Loved Ones,

We are very pleased that you have chosen the Barrow Pituitary Center for your care. The team at Barrow Neurological Institute is committed to helping you and your loved ones by developing a personalized treatment plan for you.

More pituitary patients seek care at Barrow Neurological Institute than at any other brain tumor center in the Southwest United States. Our multidisciplinary team of neurosurgeons, neuroendocrinologists, otolaryngologists, radiation oncologists, neuro-ophthalmologists, nurse specialists, neuropsychologists, psychiatrists, and social workers is dedicated to providing you with state-of-the-art clinical care so that you can get back to your daily life as soon as possible.

At Barrow Neurological Institute, the treatment plan for each patient is individualized, so not everything described in these pages will necessarily apply to you. By consolidating the latest information in a single booklet, we hope this knowledge will help you make informed decisions as we work in partnership to diagnose and treat your pituitary tumor.

For most pituitary tumor patients, dealing with a tumor is more of a marathon than a sprint, so we encourage all your friends and family members to take care – get enough sleep, nutrition, and exercise to stay as healthy and focused. Step-by-step, our pituitary team we will help take you through the diagnostic and treatment process, from diagnosis to treatment to recovery. While you will meet many different specialists during this time, rest assured that we are all working together on your behalf.

As you will soon learn, research and technology play central roles in modern-day pituitary tumor management. During your care, you may learn about next-generation neurosurgical techniques, advanced brain imaging studies, cutting-edge medications, and precision radiation therapies, if needed.

You will be comforted to know that the Barrow Pituitary Team is constantly pushing boundaries to develop new treatments that specifically target your tumor. Barrow has an active research program including clinical trials designed to develop next generation treatments for people just like you.

While your case is certainly not our first time dealing with this diagnosis, we recognize that it is yours. To help you and your family familiarize yourselves with your situation, we assembled this Patient Handbook to provide a reliable source of information about pituitary tumor treatment. This handbook provides patients and families up-to-date sources of information and support specific to the Barrow Pituitary Center. We hope this will be helpful as you learn about your pituitary tumor.

Barrow Pituitary Team

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The Pituitary Center at Barrow Neurological Institute provides comprehensive care in a multidisciplinary approach to patients with disorders of the pituitary, hypothalamus, sella, and skull base. Established in 2007, The Pituitary Center is comprised of an experienced multidisciplinary team of doctors and nurses that combine medical and surgical expertise to offer patients with pituitary disease the most advanced level of care. Physicians at The Pituitary Center have treated over 2000 patients with pituitary and skull-based tumors over the past 20 years. The team emphasizes state-of-the-art technology, research, and minimally invasive surgical techniques to improve patient outcomes, comfort, and reduce the length of hospital stay.

Common Pituitary Disorders Treated at The Pituitary Center

- Pituitary adenomas including micro and macroadenomas
- Hormone producing tumors Cushing's Disease, Acromegaly, Prolactinoma, TSH Secreting Adenoma
- Pituitary apoplexy
- Radiation induced hypopituitarism
- Craniopharyngioma
- Rathke's cleft cyst
- Lymphocytic hypophysitis
- Meningioma
- Germ cell tumors

Treatment

Treatment is determined by the size and type of tumor, hormone function or dysfunction, symptoms, previous treatment, associated conditions, and patient preference. At The Pituitary Center, a multidisciplinary team of surgeons and medical specialists evaluate the treatment of each patient. Treatment may involve medication, surgery, radiation treatment/surgery, and/or observation. Our team of physicians also specialize in minimally invasive approaches to treatment such as transnasal transsphenoidal approach, expanded endoscopic endonasal surgery, and stereotactic radiosurgery (i.e., Gamma Knife or CyberKnife).

Research

One goal of The Pituitary Center is to investigate new frontiers in pituitary disease. From Phase 3 clinical trials of new medical treatments not yet available to the general public to developing knowledge of diseases and treatment of issues facing pituitary tumor patients, The Pituitary Center is vigorously involved in ongoing research. For example, The Barrow Pituitary Outcomes Project is enrolling patients to better understand the natural history of pituitary adenomas and the long-term outcomes of surgically and medically treated patients. Researchers are also designing ways to improve post-operative care and shorten hospital stays. Developing insight into the powerful role genetics may play in pituitary tumors is also a focus of study both on a molecular and clinical level.

Educational Centers

The Pituitary Center and Barrow Neurological Institute are proud to host educational programs for medical students, residents, fellows, and practicing physicians specifically interested in pituitary disorders. Monthly Neuroendocrine and Skull Base Conferences discuss challenging and rare patient cases. Other educational programs and rotations currently train physicians from the University of Arizona, Creighton University, St Joseph's Hospital and Medical Center, University of Arizona College of Medicine-Phoenix Endocrinology and Metabolism Fellowship Program, and numerous international sites. The Institute also sponsors an active schedule of conferences and practical courses on neurological and neurosurgical topics. For more information on the educational curriculum at Barrow Neurological Institute go to BarrowNeuro.org/Education.

We understand that pituitary specialists are few and far between and patients often travel from out of state to receive the specialized care they need. Patients from other states and countries are encouraged to contact our program coordinator to help find lodging, discuss the treatment process, and answer any questions you may have.

The *International Patient Program* is committed to making your treatment at St. Joseph's Hospital and Medical Center and Barrow Neurological Institute[®] as easy and stress-free as possible. The international team will serve as your personal guide to St. Joseph's world-class medicine. During your stay at St. Joseph's, we will seamlessly blend your medical needs, individual preferences and cultural, linguistic and religious expectations into a tailored experience that makes St. Joseph's feel as close to home as possible.

Our team is here to help you before, during and after your treatment and can help you with the following:

- Schedule clinic appointments and diagnostic tests
- Make hotel or lodging arrangements
- Assist with hospital admission and insurance verification
- Assist with financial estimates and payments
- Communicate with hospital physicians and staff before and after your stay
- Find a local worship/religious center

For more information about our International Patient Program, please contact International Patient Navigator 1 (602) 406-3867 BarrowInternationalProgram@DignityHealth.org

Visit our webpage: https://www.barrowneuro.org/patient-care/support-resources/international-patients/

Members of Your Barrow Treatment Team

You may be seen by a number of doctors and staff during your stay in the hospital. Some of them may become members of your treatment team. Our physicians and other health care professionals work with each patient to provide caring and comprehensive health care. From specialized care to routine follow up visits, our pituitary team members are highly skilled to meet your unique needs.

Neurosurgeon: A doctor who performs surgery to remove the pituitary tumor. He or she works with residents (doctors in training) who also provide care while you are in the hospital.

Radiation Oncologist: A doctor with special training and treats tumors with radiation. This doctor will follow your care during radiation treatments and follow up with you after treatment.

Endocrinologist: A doctor who treats patients with hormonal and electrolyte imbalances and ensures hormonal function is stable. This doctor may prescribe supplements before and/or after surgery.

Nurse Practitioners (NP): The NPs at Barrow have special training in the neuroscience field. Their role is to work with doctors and serve as the main contact person on your care team while you are in the hospital. An NP works closely with your neurosurgeon and endocrinologist with the goal of directing your plan of care and teaching you about your disease.

Nurse Navigator/Coordinator: A nurse who is a contact person and helps bring you together with your care team before and after you leave the hospital. This person can also help you connect with other support resources and provide information to you regarding your condition and the treatment you require.

Psychiatrist: A doctor with special training in helping people with emotional challenges including anxiety, depression, and general stress management. Health care concerns can present in psychiatric symptoms which can interfere with relationships with their partners, children, friend, co-workers and daily acquaintances. If you need this doctor's help, you would get an appointment to meet them before surgery or after you leave the hospital.

Neuro ophthalmologist: A doctor who specializes in eye conditions related to neurological disorders. This person focuses on diseases of the nervous system that affect vision and control of eye movements and will perform visual field testing as well as general visual assessments.

Neuropsychologist: A doctor with special training in helping people with trouble with their thinking and memory issues. If you need this doctor's help, you would get an appointment to meet them before surgery after you leave the hospital.

Meet Your Team

To learn more about our team of pituitary experts or to request at appointment, please call **(602) 406-7585**.

Neurosurgeon



Andrew Little, MD Surgical Director, Barrow Pituitary Center

Neurologist



Kerry Knievel, DO

Endocrinologists



Kevin Yuen, MD Medical Director, Barrow Pituitary Center & Barrow Neuroendocrine Clinic

Pediatric Endocrinologist



Kajalben Buddhdev, MD



Garineh Ovanessoff, MD, MPH



Monica Rodriguez, MD



Oliver Oatman, DO

Otolaryngologists



John Milligan, MD



Ryan Rehl, MD



Griffin Santarelli, MD

Radiation Oncologists



Igor Barani, MD



William Kennedy, MD

Nurse Practitioner



Thomas Rowe, FNP-C

Clinical Nurse Navigator



Terry Maxwell, RN, BSN

Pituitary Gland Overview

The **pituitary gland** (hypophysis) is a very small gland of major importance to the functioning of the human body. It is located directly in a bony cavity behind the eyes and below the front of the brain. It is about the size of a pea and secretes hormones directly into the bloodstream.

Despite its size, the pituitary gland is responsible for producing hormones that regulate very critical body organs and glands. Some of these include



the thyroid gland, the adrenal glands, the ovaries, and the testicles. It is because of this control of other body systems that the pituitary gland is known as the "master" gland. The pituitary hormones include:

Anterior Pituitary Gland

- Adrenocorticotropic hormone (ACTH)
- Growth hormone (GH)
- Prolactin
- Thyroid-stimulating hormone (TSH)
- Luteinizing
- Hormone (LH) and follicle stimulating hormone (FSH)

Posterior Pituitary Gland

- Oxytocin
- Vasopressin

Regulating growth hormone is what people commonly associate with the pituitary gland. Too large an amount of these hormones causes gigantism, a condition where facial features, hands, etc. become abnormally large. Too little causes dwarfism, where the overall stature of a person is very small.

While the pituitary gland is responsible for regulating growth hormone, it also sends signals to the thyroid gland, adrenal glands, ovaries and testes, directing them to produce thyroid hormone, cortisol, estrogen, testosterone, and many more. These hormones have dramatic effects on metabolism, blood pressure, sexuality, reproduction, and other vital body functions, including prolactin for milk production.

An analogy to help understand it's critical function is to compare the pituitary gland to a symphony. It takes great care and skill to choreograph and direct one hundred musicians on brass, string, percussion and woodwind instruments. Conductors give numerous cues and signals as they help to transform potential noises into beautiful melodious music. The same can be said for the relationship of the pituitary gland to the endocrine system. This masterful gland stands center stage at the base of the brain as it takes on the immense responsibility of regulating the activity of the six other major endocrine glands that release hormones integral for growth and development.

What Causes the Pituitary Gland to Fail?

Tumors (typically benign/non-cancerous), inflammation, infections and injury can cause the gland to fail, as well as spread of other tumors to the pituitary (but this is very rare). Radiation therapy to the brain can also cause normal pituitary cells to malfunction.

A **pituitary tumor** is an abnormal growth in the pituitary gland. Up to 20% of people have pituitary tumors. Many of these tumors do not cause symptoms and are never diagnosed during the person's lifetime.

Most tumors of the pituitary gland are non-cancerous (benign). "Functioning" tumors produce hormones. Those that do not produce hormones are called "non-functioning" tumors.

As a pituitary tumor grows, the normal hormone-releasing cells of the pituitary may be damaged. This results in the pituitary gland not producing enough of its hormones. This condition is called hypopituitarism.

If you have a tumor of the pituitary gland, it is <u>unlikely</u> to be cancerous. Cancerous pituitary tumors are extremely rare.

Signs and Symptoms of a Pituitary Tumor

There are many possible signs and symptoms of a pituitary tumor, including:

- Extra hormones in the blood
- Flushing of the face
- Weak muscles and bones
- High blood pressure
- Irregular heartbeat
- Headache
- Vision loss
- Large hands and feet (acromegaly)
- Breast milk even if not pregnant
- Lack of milk when breastfeeding
- Menstrual cycle changes
- Lower sex drive
- Impotence
- Loss of body hair
- Delayed sexual development and growth in children
- Weight gain
- Bruising easily
- Irritability, anxiety, depression
- Nausea, vomiting
- Dizziness
- Confusion
- Seizures
- Runny nose due to cerebrospinal fluid leaking into the nose

<u>Keep in mind that individuals can experience any of these symptoms</u> without having a pituitary tumor. Many other conditions can cause problems associated with hormonal abnormalities. This is why a thorough examination by a pituitary expert is important.

Some pituitary tumors produce too much of one or more hormones. As a result, symptoms of one or more of the following conditions can occur:

- Hyperthyroidism (extremely rare)
- Cushing syndrome
- Gigantism or acromegaly
- Hyperprolactinemia



Diagnosing Pituitary Tumors

Being diagnosed with a pituitary tumor or pituitary disorder may send many questions racing through your mind. Because pituitary tumors and the diseases they cause are rare, many people have no idea what to expect when they are diagnosed, or where to turn next.

If you're reading this, you've turned to the right place. At the Barrow Pituitary Center, our specialists believe that patient education and involvement form a vital foundation for the successful treatment of pituitary tumors and disorders. And, because our doctors and nurses treat more people with pituitary disorders than any other team in the Southwest, you can rest assured that you will be in experienced hands as you decide on a course of treatment.

The problem with pituitary disorders is that they are hard to diagnose because they can cause a wide spectrum of symptoms, and are often confused with other disorders. Due to its location near the brain, symptoms may appear both hormonal and neurological, making diagnosis of pituitary disease difficult. Diagnosis is dependent on analyzing symptoms, signs on examination, blood tests and MRI findings as direct access to the pituitary can only be reached via surgery.

Too often pituitary gland dysfunction is not suspect, and tumors can go undetected until the individual has developed debilitating or life-threatening symptoms of heart disease or adrenal (uncommon), gonadal and/or thyroid insufficiency, visual impairment or blindness.

Exams and Tests

Your health care provider will perform a physical examination. The provider will note any problems with double vision and visual field, such as a loss of side (peripheral) vision or the ability to see in certain areas. Blood and urine tests can be used to determine hormone levels. MRI or CT scans can detect tumors in the pituitary gland.

Tests to check endocrine function may be ordered, including:

- Cortisol levels: dexamethasone suppression test, urine cortisol test
- Follicle-stimulating hormone (FSH) levels
- Insulin growth factor-1 (IGF-1) levels
- Luteinizing hormone (LH) levels
- Serum prolactin levels
- Testosterone/estradiol levels
- Thyroid hormone levels: Free T4 test, TSH test
- Tests that help confirm the diagnosis include the following:
- Visual field testing
- MRI of brain and pituitary gland

Treating Pituitary Tumors

There are many treatments for pituitary tumors including medicine, surgery, radiation, or a "wait and see" approach. Your pituitary team will develop an individualized treatment plan specifically for you.

Surgery

Surgery to remove the tumor is sometimes needed, especially if the tumor is pressing on the optic nerves (nerves that control vision) or causing other severe symptoms.

Most of the time, pituitary tumors can be removed surgically through the nasal passages without making a visible incision. If the tumor cannot be removed this way, it is removed through the skull (transcranial).



After you are placed under general anesthesia, your surgeon may place a retractor or camera in your nose. The surgeon then identifies the sphenoid sinus, which is an air-filled space in the back of your nose. Your surgeon will expose your sella turcica and dissect it to visualize your pituitary gland and tumor.

The pituitary gland and brain are covered by a thick tissue called the dura. Your dura is opened and its layers are peeled back.

The tumor is then removed using a combination of instruments to separate the tumor from the normal pituitary gland, which is usually pushed over to the side of the sella turcica. The tumor is removed off of the carotid arteries on either side of the tumor. The tumor is then also removed from the underside of the optic nerves, thus taking pressure off of the nerve. Once the tumor has been removed, your surgeon will inspect the tumor cavity with endoscope or microscope to ensure as much tumor as is possible has been removed. The goal of surgery is to preserve the function of the pituitary gland.

The final step of the surgery is to reconstruct the base of the skull. A packing material is placed in the sella turcica, and medpore implant or septal bone is placed in the hole created in your sella turcica.

In some cases, tumors are small and easy to remove from nearby tissue, which makes complete removal possible. In other cases, tumors cannot be removed from the nearby tissue, or are next to sensitive areas in your brain. In these cases your neurosurgeon may try to safely remove as much of the tumor as possible.

Possible Complications with Surgery

Surgery to remove a pituitary tumor carries certain risks that you should be aware of. Although low probability, these risks include infection, bleeding, and CSF (cerebro-spinal) leak. Other possible complications are felt to be rare such as blindness and stroke. This can occur if the optic nerve or a major blood vessel is seriously damaged. The tumor or its removal may cause permanent hormone imbalances. The affected hormones may need to be replaced, and you may need to take medicine for the rest of your life.

Surgery can sometimes damage the posterior pituitary (back part of the gland). This can lead to diabetes insipidus (DI), a condition with symptoms of frequent urination and extreme thirst which is easily treated with medication.

Radiation (Radiosurgery: Gamma Knife and Cyberknife)

This type of treatment may be used to shrink the tumor for people who cannot have surgery. It may also be used if the tumor returns after surgery or couldn't be completely removed during surgery.

Radiation therapy is planned on an individual basis, depending on the tumor location and type. It is usually performed in an outpatient setting. Side effects of radiation therapy depend on the type and dose.



Stereotactic radiosurgery is not a form of surgery in the traditional sense. Instead, radiosurgery uses multiple beams of radiation to give a highly focused form of radiation treatment to kill the tumor cells in a very small area. By itself, each beam of radiation is not particularly powerful, but at the point where all the beams meet—the pituitary tumor—a very large dose is delivered, killing the tumor cells.

Radiosurgery is most often an outpatient procedure. The procedure is not invasive and requires no surgical incision. Side effects may include fatigue, headache and nausea. Patients usually go home the same day but may be admitted to the hospital for closer observation if necessary.

Barrow offers two forms of stereotactic radiosurgery. Each form is usually referred to by their specific names, Gamma Knife and Cyberknife.

If you are a candidate for radiation you will be referred to one of our radiation oncologists to discuss what type of radiation is best for you.

Just Diagnosed with a Pituitary Tumor, Now What?

Take a breath! The vast majority of pituitary tumors are benign. This means it is NOT likely to be cancer.

Many pituitary tumors do not need to be removed surgically. Often times, you can take medicine to shrink the tumor and/or stop it from causing your symptoms.

Once you are diagnosed with a pituitary tumor one of our pituitary specialists will look at your MRI study as well as your medical records. He/she will determine what happens next. Some tumors cause symptoms that require urgent attention and others can wait.

There are many factors that influence the urgency that is placed on your condition. The size of the tumor as well as the involvement of the surrounding structures in the brain such as blood vessels, nerves, etc, help the doctors determine



how quickly you should be treated. Your symptoms also play a factor in this decision. Some tumors affect the amount of hormones your body secretes. Too much or too little affects your body's daily functions. If your symptoms don't respond to medicine, you can't tolerate the feelings you get when you take the medicine, or the tumor is too large, surgery may then be recommended for you.

After your records are reviewed by our specialists you will be seen by one of our endocrinologists for further evaluation. You may also be scheduled with our neurosurgeon if your condition requires a surgical discussion.

If you have already established care with an endocrinologist in the community it is not necessary to see one of our team endocrinologists unless your current physician prefers you to be managed by a pituitary specialist.

If you are being managed by our endocrinologist he/she will order lab work and determine what supplements and/or medications you need to feel better. If you don't improve after being on medication for a specific amount of time or you can't tolerate the effects of the medication you may be referred to the neurosurgeon to discuss surgical treatment options. The endocrinologist and surgeon will work closely together to make sure you receive the treatment that will is best for you.

You may be referred to another specialist on our team if your symptoms warrant it. These specialists <u>may</u> include a neuropsychologist, psychiatrist, otolaryngologist, neurologist, or neuro-ophthalmologist. Evaluations from these specialists give us more information about your condition and help us design a treatment plan specifically for you.

Your Doctor's Visit

Remember that some pituitary tumors require surgery and others are best treated with medication. Sometimes the recommendation is to perform MRI studies every 6 to 12 months to determine the speed of tumor growth. If the tumor is found to be growing rapidly and causing an increase in symptoms the surgeon may recommend surgery at that time. If surgery is recommended remember to ask your surgeon the following questions:

- Reason for my surgery
- How urgent is my surgery
- Description of the surgery
- What are the possible complications of my surgery
- What should I expect during the recovery process
- How long should I take off of work/school
- Who manages my medications and supplements after surgery
- What medications (you are currently taking) should I stop before surgery
- Will any of my other medical problems affect my recovery or length of stay in the hospital
- Will any recent testing done be repeated before surgery (EEG test, MRI study, chest x-ray)
- Discuss my allergies to food, medications, or products (i.e. latex)
- Do I follow up with the surgeon, endocrinologist, or both

Surgery is Recommended... What Happens to Me NOW?

First, understand that Barrow Neurological Institute is an internationally renowned medical center that offers care for people from throughout the world with brain and spine diseases, disorders and injuries. We perform more neurosurgeries annually than anywhere in the United States. U.S. News & World Report routinely lists Barrow at St. Joseph's Hospital as one of the best hospitals in the nation for neurological and neurosurgical care.

Your medical team including the staff in the operating room, intensive care unit, and regular nursing floor are highly skilled individuals who strive to provide care with dignity and compassion. The Barrow Neuroscience Tower is a 430,000 square foot tower dedicated solely to treating neurological and neurosurgical patients. We care!

Once you come to the Barrow Pituitary Center you are part of the Barrow family.

Testing before Surgery

Once a date has been set for surgery your surgeon's office will schedule a time for you to come in and complete testing in our Pre-Test Department. This may include specific lab work, chest x-ray, MRI or CT studies, EKG tests, and an examination by one of our hospitalists for medical clearance. The tests are deliberately selected to allow us to take care of you in the best manner possible.

The hospitalist will ask you questions about your health and perform an examination. If you have



had some of these tests completed recently please send the reports to your surgeon's office. Some of them may not have to be repeated if they were done within an acceptable timeframe the hospital allows for such tests. The results of these tests sometimes uncover other medical problems that are unknown to you and may need to be addressed prior to surgery. We want to ensure you are as healthy as possible before surgery is performed.

The pre-operative nurse will interview you, obtain your medical history,

review your patient care record, and answer any questions you have at this time. Make sure you bring a list of your current medications (with their dosages) even if you have already provided this list to your surgeon's office. This list should include prescription as well as over the counter medications.

Hospital registration may take place at this time. Remember to provide them with your email address so you can be sent an invitation to our *Patient Portal*. This portal allows you to retrieve medical records from your hospital stay for you to keep as well as share with your other doctors. If your other doctors are not affiliated with our hospital they will not have access to crucial records that can help them take care of your other medical problems. The registration department staff is responsible for sending you the invitation to this link.

Bring paperwork you received from our doctors, with you to your pre-test appointment.

Preparing for Surgery

Diet

Weeks before your surgery, begin eating a balanced diet if you are not already on a specific plan. Include protein, fruits, vegetables, and dairy in each meal. Eat 3-4 meals a day.

Decrease your intake of alcohol, caffeine and cigarettes weeks or months prior to your surgery if possible. It is not recommended that you abruptly stop smoking days before surgery. Doing so can have an adverse effect on your breathing passages.

Medications

Notify your surgeon if you are currently taking the following medications: hypoglycemics (insulin or oral agents); anti-coagulants/anti-platelets such as Aspirin, Excedrin, Coumadin, Plavix, Heparin, Lovenox, Pradaxa, Xarelto, etc.; anticonvulsants (Depakote); anti-inflammatory drugs including steroids, Anaprox, Dolobid, Feldene, Motrin, Ibuprofen, Naprosyn, Toradol, Vioxx, Aleve, Advil, etc.; immunosuppressant, natural supplements such as Vitamin E; CoQ10, fish oil, and herbal medications such as gingko and St. John's wort. Your surgeon may ask you to discontinue some medications before surgery because many of these substances contain ingredients that interfere with normal body functions and can increase the risks of complications during surgery.

Planning

Plan your discharge ahead of time. Make sure you have taken care of the following tasks that can make your recovery at home much easier.

- Identify a companion to help you for a few days after you arrive home
- Arrange transportation to and from the hospital.
- Stock your refrigerator
- Prepare meals in advance
- Contact your insurance company to determine your benefits regarding outpatient therapy or medical devices such as walkers and shower chairs that you may need once you are home
- Remove all loose area rugs in walking paths
- Move any loose cords and/or wiring and clear the walking paths inside your home
- Move essentials to the top drawers/lower shelves of upper cabinets (between shoulder & waists level) making them easy to reach without bending over past your waist
- Notify family and friends when you are expected to be discharged from the hospital to avoid gift deliveries after you have left
- Ask friends & family not to visit you once home if they suspect anyone in their family may have a cold or flu
- If you will not have help when you go home make sure you:
 - ~ Stock your food and pantry cabinet before your surgery
 - ~ Fill prescriptions medications in advance when possible. Keep in mind, pain medication prescriptions may not be given to you until discharge

Day before Surgery

Remove nail polish, jewelry, and body-piercing jewelry.

Your surgeon may request that you take a shower with Chlorhexidine the night before and morning of surgery, from the neck down, giving special attention to the area of surgery.

You may also be asked to shampoo your hair with your shampoo of choice when you shower as instructed above. **Do not** use hair spray, other styling products, lotions, or perfumes.

Traditionally, patients are advised not to eat or drink (after midnight) the day before your surgery.



Please consult your surgeon for the restrictions that apply to your specific case.

Day of Surgery

Hospital Information You Should Know

Parking

The closest parking for surgical patients is in the 6th avenue garage. Additional parking may be available in the 3rd avenue garage. Upon request, hospital security will escort you to your car and may be available to shuttle you to and from nearby hotels. Valet services are available from 6:00 a.m. to 8:00 p.m. Fees for valet services as well as the parking garage are available at the hospital information desk.

Getting Around

The Barrow neuroscience inpatient tower is located on 3rd Avenue, just north of Thomas road in Phoenix. It is about a 20-minute cab ride from Sky Harbor Airport and about a 30-minute drive from Scottsdale's private airport. In the event of a prolonged visit, airconditioned Valley Metro buses make it easy for patients and families to travel around town. Most outpatient services, including the Barrow physician offices, are located in buildings adjacent to the patient Neuroscience Tower. Campus maps and directions to the most common locations on the hospital campus can be downloaded from the website thebarrow.com. Visitors can park in the 3rd Avenue Garage or the 6th Avenue Garage, both located just a block north of Thomas Road and an easy walking distance from most inpatient and outpatient services. Trolleys and wheelchairs are available to patients and visitors who need help moving about the hospital campus.



Insurance

Although the hospital and the Barrow physicians accept most insurance plans, patients are advised to check with their insurance company before their visit to determine which hospital and professional diagnostic and treatment services will be covered. Also, your surgeon's office will verify insurance coverage prior to your hospital admission. The ResourceLink staff can check the insurance information of a Barrow physician to determine if the specialist accepts a particular insurance. However, patients are advised to check with their treating physician's office to verify insurance coverage. Patients who plan to receive elective services but who lack health insurance must make payment arrangements with the hospital and physician before treatment is provided. The physician's billing office provides the necessary forms and hospital contact information.

Contacting Patients in the Hospital

Family and friends can call the hospital 24 hours a day at (602) 406-3000 to reach a patient who has been admitted. Because of governmental regulations, information about a patient's condition can be shared with no one but those individuals legally designated by the patient. Patients can

contact friends and family by phone from their room or via the Care Pages e-mail system provided by the hospital. Care Pages is a virtual "gathering place" that provides emotional support, patient updates, pictures and messages using a personal and secure program that is web-based. Many patients choose to identify a contact person who can provide family and friends with updates about the patient's condition. Several locations in the hospital have wireless internet access for family members and visitors to use.

Tobacco-Free Campus

For the health and well-being of its patients, visitors, and employees, St. Joseph's Hospital and Medical Center is proud to announce that it is a tobacco-free campus. As a national healthcare leader, St. Joseph's believes that it is important for the hospital to promote good healthcare practices. A tobacco free environment follows the hospital's mission of delivering high-quality services while protecting patients, staff, and visitors from exposure to second-hand smoke. Tobacco use is not allowed in the hospital's buildings, grounds (including outdoor areas), parking areas, or walkways.

Visiting Guidelines and Hours

St. Joseph's is dedicated to providing excellent care in a safe, patient- and family-friendly environment utilizing an open visitation policy on all patient units. This means that the patient decides who and when others may visit. The hours of 10 p.m. to 6 a.m. are considered "quiet hours" for all units. Visitation is not restricted during this time, however it is expected that all staff, patients and visitors will maintain a quiet environment. (*Please ask about our current visitation policies as these are subject to change*)

Children may visit patients but must be accompanied by and remain with an adult at all times. Patient care areas such as intensive care units have age-related visitor restrictions. In certain situations, St. Joseph's reserves the right to limit the number and time of visits. We ask for your cooperation if a staff member requests a visitor to leave the room. This will allow us to fully concentrate on the patient's care and needs. The visitor will be allowed back into the room as soon as it is safe to do so.

Cafeteria

Breakfast: 6:30 - 9:30 a.m. Lunch: 10:30 a.m. - 2 p.m. Dinner: 5 - 7 p.m.

Starbucks™

Monday thru Friday: 5:30 a.m. - Midnight Saturday and Sunday: 5:30 a.m. - Noon

Patient Safety

In the interest of safety for our patients, anyone who has symptoms of a cold, including a runny nose, fever, sneezing, and coughing, should not visit hospitalized patients.

Patient Relations

We want our patients to be highly satisfied during their stay at St. Joseph's. If you have any concerns regarding your care, please speak with the nurse manager. If you feel that your concerns have not been addressed please contact Patient Relations at (602) 406-6200.

Hospital Phone List

(602) 406-BPIT (2748)
(602) 406-3410
(602) 406-4949
(800) 643-1219
(602) 406-3000
(602) 406-3192
(602) 406-6954
(602) 406-3363



What Do I Bring to the Hospital with Me?

Do not bring the following items to the hospital:

- Unnecessary valuables or jewelry
- Medications from home. The hospital policy prohibits patients from receiving medication from outside the hospital for safety precautions.

Do bring the following to the hospital:

- Complete list of medications that you take at home, including dosages and frequency
- Insurance card and means to pay hospital co-payment
- Identification
- Test results:
 - If you have had a chest x-ray within the last year, notify your surgeon to avoid unnecessary testing the morning of surgery. Also tell your physician if you have had an EKG (electrocardiogram) test completed within the last month. Your surgical team will want to see the results of this test. Give these documents to your surgeon's office before surgery or bring them with you the morning of surgery.
 - ~ If you have experienced any medical challenges such as cardiac, renal, or respiratory conditions, please make sure that your specialist is aware of your upcoming surgery. These physicians must "clear" you for surgery; that is, they must provide a written release stating that your condition does not prohibit you from undergoing surgery.
- Living wills and advance directives

Pre-Operative Department (2nd floor of the Neuroscience Tower)

You will be asked to arrive at the hospital hours before the surgery is scheduled to begin. You will receive the specific time of arrival when you come in for pre-testing or from your surgeon's office. This time allows the hospital staff and physicians to ensure everything is in place for your surgery and answer last minute questions you or your family has.

You will be asked to remove your eye glasses, contact lenses, and dentures. Your dentures may be placed back into your mouth in the recovery room when you are awake and alert. You will be asked to remove all jewelry. Hearing aids will not be removed until you have arrived at the operating room to ensure that you can communicate with the surgical team until you drift off to sleep.

You will meet many individuals during the time before your surgery. Your surgeon and his assistant will check in with you to see how you are feeling and complete all hospital tasks. These tasks include explaining the procedure, answering all questions, and obtaining consent forms.



In addition to the surgeon, you will meet the rest of the surgical team including the resident surgeon assisting your surgeon, OR nurse and anesthesiologist. It may seem like everyone is asking you the same questions over and over again but we do this to ensure nothing has been overlooked and everyone understands your medical condition and overall heath. The surgical team also has requirements to carry out such as asking you what procedure you expect to be performed. The surgeon or his assistant will either mark the side of the nostril he will be entering during surgery **OR** he will place a wrist band on that side. Surgeons have this option which they select base on their preference. Both are equally acceptable.

Our research nurse may introduce herself to you at this time if you are being considered for a research project. Determining factors in participation in these projects include the type of tumor you have as well as your symptoms. If you meet the criteria for one of these research projects you will asked to sign a consent form after a thorough explanation of the project is discussed. Doctors improve surgical techniques, develop new technology, and identify safe medical therapy through research studies. These research studies may not help you personally or affect your hospital experience, but may in fact help others in the future. You always have the right <u>NOT</u> to sign a research consent form without feeling the need to explain your decision. *Your care is not affected if you chose not the sign the research consent form.*

An intravenous catheter may be placed in your arm to administer medication to relax you before you are taken to the operating room.

Neurosurgical Waiting Room

While you are in surgery, your family and friends may wait in the neurosurgical waiting room. A hospital pager, which only functions on the hospital grounds, will be given to your contact person.

The volunteer in this area should be notified if your contact person wishes to leave the premises in case a member of the surgical team wishes to speak with them. After the surgery is completed, a member of the surgical team will speak to your contact person. Children are welcome to visit once



you have been admitted to the general nursing floor. Neurosurgical procedures tend to be longer than other procedures. The lengthy wait can be challenging for young children who require constant attention in the waiting room.

Operating Room

You will be in the operating room a couple of hours longer than the actual time for surgery. The anesthesiologist needs time to care for you before and after surgery. It is best to tell your family this



so they don't worry. Our surgeons take their time. Once the surgery is completed your surgeon will talk to your family about how the operation went.

Recovery Room

Your personal contact in the waiting room will be notified once you are transferred to the recovery room from the operating room and again when you are to be transferred to your room. Visitors may be

permitted in the recovery room at the discretion of the recovery room staff. You will remain in the recovery room for one to two hours while you are waking up from anesthesia. Delays in transfer to your hospital room sometimes occur when the hospital admissions reach capacity. Great effort is made to avoid any such delays.

The nurses monitor your neurological status and vital signs.

Medication may be ordered to control your pain and to assist in your recovery process. Our team is strongly committed to pain management. Please ask for this medication when you feel uncomfortable, especially during the first day after surgery. If you wait until the pain is extraordinarily strong, the medication ordered by your doctor may not be able to control your pain. If you are concerned about becoming dependent on narcotics, please discuss this fear with your surgeon before surgery. Non-narcotic medication is available and is often sufficient to *control pain*.

Please notify your nurse if your pain is not adequately addressed. Because many patients feel nauseated after a surgical procedure, medications are given in the recovery room to help prevent this unpleasant side effect.

While in the Hospital

Intensive Care Units (ICU)

The hospital has many different ICU(s). You will be assigned to a specific ICU, designed for patients with similar problems, when you enter the recovery room. ICU(s) are available to patients who require close monitoring such as those recovering from a surgical procedure or who are critically ill. In this department there is usually one nurse for every two patients.

Visiting hours vary among the different ICUs. Flowers and live plants are not permitted in these areas. Please check with your unit for specific policies.

In the ICU you will be encouraged to increase your activity level as tolerated. Showers are permitted the day after surgery.

Food and liquids are introduced slowly, beginning with ice chips and advancing to more substantial foods as tolerated. Small, frequent, balanced meals will help you heal faster and regain your normal energy level.



Social work, case management, and pastoral services are available on request. Tests such as radiographic studies (MRI, CT) and laboratory tests may be performed the day after your surgery.

If you use a CPAP devise it may be used while in the hospital. This will be at the discretion of your surgeon.



While you are in the hospital many different types of doctors from different specialties (areas of medicine) may visit you. These include your surgeon, endocrinologist, internal medicine doctor, etc. The endocrinologist who sees you in the hospital may not be the same person you met prior to surgery but rest assured they will be in close contact to discuss your condition.

A typical hospital admission for patients undergoing pituitary surgery lasts 1 to 2 days. The length of stay

in the hospital as well as the need for ICU is ultimately determined by your surgeon and based on your overall health and any existing medical concerns. Once you are ready to leave the hospital remember to take all of your belongings with you and to tell your friends and family that you have been discharged.

Discharge from Hospital

Your physician will let you know the day you are expected to be discharged from the hospital in advance so you can arrange transportation.

Prescriptions for pain control and other medications are provided prior to discharge. You may not feel that it is necessary to have these prescriptions filled right away, but it is important that your medications be available if the need arises.

Discuss the possible interactions between various medications that you are taking with your physicians. Avoid drinking alcohol, driving, and operating heavy machinery while taking medication for pain.



On the day of discharge, you will receive your paperwork and be ready for discharge. It is helpful to notify your ride the night before your anticipated discharge to ensure a timely pick-up. If your ride is unavailable at the time of discharge, you will be taken to the Discharge Lounge to wait for you ride. Home medical equipment, prescriptions and lunch boxes can be delivered to this area if necessary.

Honor your physical limitations. Allow sufficient time to recover before you resume normal daily

activities. Ask your surgeon for specific limitations on lifting weight based on the procedure that you had. Exercise gradually with activities such as walking rather than aggressive gym activities. Discuss this process with your surgeon.

Baths and swimming are discouraged until your incision is healed, typically at least 14 days after surgery. Wound care is prescribed by your surgeon.

Small frequent meals, including foods rich in protein, are encouraged to promote healing. Smoking inhibits the healing process by hindering blood flow to your organs and tissues and should be avoided.

A successful surgical outcome is not only dependent on the expertise of the surgeon. The effort of the patient to follow recovery instructions is just as crucial in having a smooth recovery experience.

Although our recommendations for recovery may appear restrictive please be patient and understand it is our experience in treating thousands of patients just like you that influenced these instructions.

Discharge Lounge

After you are discharged you may possibly be taken to our discharge lounge if needed. Our lounge offers a quiet and comfortable healing environment with the following amenities:

- Water, coffee, and light snacks
- Comfortable chairs
- Television
- Phone
- Bathroom
- Lockers

Enjoy the amenities while you wait for your family to pick you up. If you have chosen to utilize our pharmacy for your discharge medications, they will be delivered to you. The pharmacist will review your discharge medications and answer any questions you may have. And if you are being discharged with any medical equipment, this will also be delivered to you in the discharge lounge.

When your family or caretaker arrive at the circle entrance they can check in at the Information Desk or they can contact the discharge lounge from their vehicle by calling (602) 406-2616.

Once your family or caretaker has arrived our Discharge Lounge staff will escort you and your belongings to your waiting vehicle.

If you need help arranging a Taxi to transport you home, the Discharge Lounge staff will assist you!

Follow Up with Your Doctors

An appointment should be scheduled with your neurosurgeon approximately 1 week after surgery to assess your recovery.

- Write down any instructions that your physician gives you at that time such as the need for an annual checkup, future x-rays, or other time-sensitive tests.
- Before the appointment write down any questions you may have to ensure that all of your concerns are addressed.

You should be seen by our endocrinologist within onetwo weeks after surgery to determine if you need to take supplements. You will be advised at this time to have lab tests completed. These labs are often ordered to be drawn while **fasting** and by **9 am** to obtain specific blood levels. This appointment should not be postponed as hormonal and electrolyte abnormalities can interrupt your recovery and cause another hospital admission. If



you have an endocrinologist who is NOT affiliated with our team, it is important that you let him/her know that surgery is planned and that you schedule a follow up appointment in his/her office within 1-2 weeks after surgery. Surgery can affect your hormones and electrolytes (sodium, potassium) and you may need supplement after being discharged from the hospital. The endocrinologist is the best suited to help you through this period. Left untreated, these imbalances can become serious and cause harm to your health. Symptoms of these imbalances will be discussed with your before you leave the hospital.

These appointments are typically set up prior to surgery to help you arrange transportation to the physician's offices. If you <u>do not</u> have these appointments set up in advance *contact your program coordinator*.

• Special accommodations can be made for patients traveling from out of state to ensure your appointments with the neurosurgeon, endocrinologist or other specialist are scheduled within the same timeframe for your convenience.

At Home After Surgery

Although specific instructions will be provided to you at the time of hospital discharge, the information in this handbook is intended to give you general guidelines and prepare you for recovery. Often times caring for patients with pituitary conditions requires a team of physicians rather than an individual surgeon. For this reason it can be difficult to determine which physician to contact with questions and concerns throughout the treatment and recovery process. Please contact the program coordinator to triage these concerns and ensure you are referred to the appropriate team member in a timely manner.

You May Experience the Following after Surgery

Nasal drainage: You should have a small amount of bloody nasal drainage after surgery typically lasting 3 weeks. When you start to blow your nose, **6 weeks after surgery**, you will notice drainage of mucous and blood. This is normal. Secretions will pool in your sinuses overnight so you may have more drainage in the mornings. **Some patients experience less drainage if you keep your head elevated at least 30 degrees for 10 days after surgery**.

Sinus congestion is common after surgery. Nasal sprays, such as Ocean Nasal Spray, can help relieve some of the crusting in the nasal passages and is recommended 5 times per day as needed to clear nasal passages. Nasal washes help drain your sinuses and are advised to start 4 weeks after surgery. Ask your surgeon before taking antihistamines as they may cause excessive dryness. **Do not insert anything else into your nose for 3 months.**

Decreased sense of smell and taste may continue for a few weeks to a few months following surgery.

Contact your surgeon if you notice sudden changes such as blurry or double vision or diminished peripheral vision.

It may take **4 to 6 weeks or more for your energy level to return to normal**. You will probably feel fatigued for the first 2 weeks then notice a gradual increase in energy thereafter. If you experience extreme **fatigue** notify your doctor as he/she may order blood tests to evaluate your hormonal levels.

Constipation is a common problem after surgery due to anesthesia, inactivity, and prescription pain pills.

Here are some tips to keep your bowels moving...

What to do	How often	
Prevent constipation with these:		
Drink more water Eat fresh fruits and vegetables Walk	After fluid restrictions are lifted Every day Every day	
Senokot (8.6 mg tablet)	Daily 1-2 times per day until your bowel movements return to normal	
If constipation is not relieved with these measures, you may take:		
Dulcolax (10 mg pill)	Once a day until you have a successful bowel movement	
MiraLAX powder (1 capful dissolved in 8 ounces of water)	Drink once every day until you have a bowel movement	
If these do not work or if you have not had a bowel movement in 3 days, try:		
An enema or rectal suppository	Once; an enema or rectal suppository is preferred over straining	

Activity

Patients recover at different rates from neurosurgical procedures. It is, however, important to get out of bed and move as soon as possible after surgery to avoid developing problems such as blood clots or pneumonia. Walk with help if you feel unsteady.

Start **light activity** for the first few days you are home and then gradually increase activity with short walks. Get plenty of rest

Do not to lift, push, or pull more than **10 pounds** or **bending past your waist** for 6 weeks after surgery.

Do not do anything that would put you at **risk of head trauma for 3-4 months** after surgery (such as skiing, snowboarding, biking, contact sports, etc.).

Ask your surgeon for specific limitations on **weight lifting**, swimming and any other activity involving physical exertion.

Plan to be away from **work** for 2-4 weeks if you have a sedentary job and 6 weeks if you have an active job.

Sleeping with your head elevated on pillows may help decrease headaches. Some individuals find it easier to sleep with the head of bed elevated at least 30 degrees for 10 days after surgery. Use a humidifier at night to keep your nasal membranes moist if needed.

Bathing: Showering is appropriate upon discharge from the hospital. Do not immerse the surgical sites on your head or abdomen into any body of water until the sutures are removed and cleared by your surgeon (bath, pool, hot tub, etc).

Smoking delays healing and can cause infections at the wound and in the brain. Reducing this activity or stopping completely will improve your chance of a speedy recovery.

Driving is <u>not</u> recommended until you have:

- Stopped taking narcotic pain medications
- Experienced no visual problems that affect your ability to drive
- Complete awareness of your surroundings
- Total control over your fine motor movement and regained your strength

Nutrition

Small frequent meals (4–6 per day) are suggested with a moderate amount of protein to assist in healing process. You may be instructed to eat a high salt diet and restrict your fluid intake upon leaving the hospital. This will depend on your lab results while in the hospital and clear instructions will be communicated to you prior to discharge. This is typically 1.5 liters of fluid per day for anywhere from 7-10 days.

Medicines at Home

Prescriptions for pain control and other medications are provided at discharge. You may not feel that it is necessary to have these prescriptions filled right away, but it is important that your medications be available if the need arises. Keep in mind that it is easier to control pain while the intensity is minimal to moderate. If you wait until the pain is significant the dose you have been prescribed may not be sufficient to manage the pain. Decrease the frequency of the pain meds once the pain subsides. You should transition to over the counter medications within a few days following surgery.

- Discuss the possible interactions between various medications that you are taking with your physicians.
- Make certain that you take your medications with food as many cause nausea on an empty stomach.
- Many pain medications cause constipation so stool softeners may be beneficial. See "Diet" section for more information on this.
- Ask your surgeon before taking medications that contain anticoagulant properties (blood thinning) such as ibuprofen or aspirin.

Oxycodone/Acetaminophen (Percocet, Endocet)	DO NOT TAKE EXTRA
hydrocodone/acetaminophen (Vicodin, Norco)	acetaminophen with these 2 types of pain pills. (Tylenol®)
Oxycodone	N/
Hydrocodone	You can also take 650 mg of
Hydromorphone (Dilaudid)	4 to 6 hours if needed with these
Codeine	5 types of pain pills.
Tramadol	

Call your Neurosurgeon if any of these occur:

Complications of pituitary surgery include infection, bleeding, and cerebrospinal leaks (fluid in the brain). Feelings of depression are temporary and common following any surgical procedure. You may develop hormonal deficiencies weeks, months, or years following your surgery therefore regular follow-up appointments with the Barrow Pituitary Specialists is strongly encouraged. The symptoms below warrant a call to your surgeon. If you are calling outside of normal business hours and can't reach your surgeon in a timely manner, please contact the nearest emergency room.

- Dramatic vision changes (blurred, double, loss of peripheral)
- Signs of infection are thought to be present (sudden increase in swelling at the surgical site after the swelling had begun to subside, fever or chills, colored drainage from incision, and temperature greater than 101 degrees without other signs of illness)
- Pink skin is indicative of the healing process where as deeply reddened areas may be a sign of infection.
- Fever of 101 degrees or greater, especially within the first three months of surgery
- Continuous faucet-like nasal drip (clear)
- Continuous nosebleed spotting is normal
- Persistent or worsening headaches not relieved with over the counter medication and/or a nap.
- Significant changes in behavior, ability to think, confusion, difficulty concentrating
- Extremely clear and large amounts of urine
- Excessive thirst
- Depression or severe anxiety
- Excessive sleepiness or dizziness
- Significant fatigue that is worse than when you first arrived home
- Abdominal stitches come apart
- Redness, swelling, odor or drainage at your abdominal incision
- If you have severe abdominal pain
- Nausea and vomiting
- Constipation lasting 3 days and not helped with over the counter pills

Communication with your Medical Team

It is recommended that you notify your primary care physician and other medical specialists, currently involved in your care; about your surgical procedure as he/she may want to see you and review your medical records from this hospital stay (especially is you are visiting us from out of town).

Barrow Brain Tumor Research

Doctors, scientists, nurses, and coordinators at the Barrow Brain Tumor Research Center (BBTRC) carry out research studies in special research labs and also in people. Studies done with people are called 'clinical trials.' Research studies help us to better understand how brain tumors grow and behave with certain treatments. Clinical trials help discover better ways to diagnose and treat patients with brain tumors. The main goal is to find a cure for brain tumors. We may offer you a clinical trial as part of your treatment.

The Barrow Brain Tumor Research Center is dedicated to developing new treatments for brain tumors, improving the care of patients with brain tumors and, ultimately, finding a cure. Barrow Neurological Foundation supports our important work by funding research, medical education and patient care at our center.

For information on how you can make a gift to benefit our center, please visit **https://giveto. supportbarrow.org/donate**, or call Barrow Neurological Foundation at (602) 406-3041. The Foundation is a non-profit 501(c)(3) organization. Contributions are tax deductible as allowed by law.

Standard Treatment versus Clinical Trials

Standard treatment is what is known as the "best" treatment(s) for most types of brain tumors right now. Standard treatments change over time as doctors learn from research. Standard treatment depends on the kind of tumor you have.

Clinical trials test new drugs, equipment, treatments that the FDA has not yet approved or new surgery techniques. Clinical trials also may test a new drug with standard treatment that is an already FDA approved. We offer clinical trials to people who have new tumors as well as those whose tumor has returned. For most up to date information on clinical trials offered around the country, please visit **www.clinicaltrials.gov**.

Community Support

Barrow Pituitary Center

The Barrow Pituitary Center Support Group is a national support group which provides information, education, and support to those affected by pituitary tumors; including patients, caregivers, and friends. Group members have the chance to meet others with similar issues, discuss problems, ask questions and learn new information about topics related to pituitary tumors. Support group meetings are held throughout the year in addition to bi-annual full-day patient education conferences.

Clinical Nurse Coordinator (602) 406-5954 www.barrowneuro.org/pituitary

Caregivers Support Group at Barrow

This support group provides information, resources and help for those who care for others with illnesses or disabilities (stroke, brain or spine injury, brain tumor, other).

Outpatient Rehabilitation Building near St. Joseph's Hospital 114 West Thomas Road, Phoenix, AZ 85013 Call (602) 406-6688 for more information

Grief Support Group

St. Joseph's Hospital hosts a grief support group every other Wednesday in the Mercy Conference Room. The group is led by a chaplain. Please call (602) 406-3275 for times and dates.

St. Joseph's Hospital and Medical Center 350 W. Thomas Road Phoenix, AZ 85013

Acromegaly Community

Acromegaly Community- Empowering patients to be their best advocates!

It is the mission of the Acromegaly Community to provide an emotional and communal support network for people touched by the disease.

www.acromegalycommunity.com

Cushing's Support and Research Foundation (CSRF)

The CSRF was started in 1995 by Louise Pace, in Boston, MA, who herself, endured Cushing's. Louise was astounded that there was not a foundation to provide education and support for this rare, but devastating disease. Patients are often misdiagnosed for many years and the recovery process can be long and extremely difficult. Since Cushing's is not well known, patients can feel very alone and support and information is highly valuable. The CSRF maintains a website, provides patient networking services, responds to emails, publishes a newsletter, holds local support group

meetings in the US and has members in many different countries. The CSRF also strives to increase awareness of Cushing's in the medical community and general public. The CSRF maintains a Medical Advisory Board of expert physicians and is an associate member of NORD.

cushinfo@csrf.net, www.csrf.net

The MAGIC Foundation

This organization is the global leader in endocrine health, advocacy, education, support, and events. We began our mission in 1989 as a foundation for parents whose children were affected with growth disorders but as our children grew into the affected adults, so did our mission. We now provide resources for patients with Adult GHD / Panhypopituitarism and Cushings Syndrome. With an annual convention for patient education, bi-annual newsletters, Facebook chat groups, and more.

Contact us: adultghd@magicfoundation.org, cushings@magicfoundation.org, (800) 3MAGIC3 (362-4423), (630) 836-8200

Growth Hormone Research Society

The Growth Hormone Research Society (GRS) was founded in 1992 to provide a forum for the study and exchange of ideas on all aspects of growth hormone physiology, and diseases involving abnormalities of the GH axis. With over 400 members from more than 30 countries, the society represents a unique international body composed of clinicians, scientists, educators, and students.

The mission of the GRS is to promote scientific research and clinical advancement in the fields of growth hormone (GH) and insulin-like growth factors (IGFs).

www.ghresearchsociety.org

Histiocytosis Association

This organization is dedicated to raising awareness about histiocytic disorders, providing education and emotional support, and funding research leading to better treatments and a cure. https://www.histio.org/?gclid=CLyO1rWy8rMCFUIxQgodDIsAYA

Mental Health Resources

American Association of Marriage and Family Therapists **www.aamft.org**

American Psychological Association **www.apa.org**

Health Resources and Services Administration **www.hrsa.gov**
Pituitary Network Association (PNA)

The PNA is an international non-profit organization for patients with pituitary tumors and disorders, their families, loved ones, and the physicians and health care providers who treat them.

The PNA was founded in 1992 by a group of acromegalic patients in order to communicate and share their experiences and concerns. The PNA has rapidly grown to become the world's largest and fastest growing patient advocacy organization devoted to the treatment and cure of pituitary disorders.

Our mission is to support, pursue, encourage, promote and where possible, fund research on pituitary disorders in a sustained and full-time effort to find a cure for these illnesses. Contact us at (805) 499-9973 or membership@pituitary.org.

Message to Patients & Caregivers

Pituitary Network Association

When a family member is diagnosed with a pituitary disorder the family system will be affected. No one lives in isolation; the people in this person's life will need to make adjustments. In order for the family to remain intact and interconnected there are some steps each member can take to ensure that their relationship stays strong and positive.

One of the most important things a family member can do is to educate themselves about the disorder with which their loved on has been diagnosed. We all know some of the effects of paralysis, or cancer, but the pituitary creates a set of symptoms understood by very few. If a family member truly wants to help, they need to find a way to try to understand.

To better serve patients the PNA, along with guidance and generous support from a PNA Member has developed a place for families to get information to help them understand the daily struggles that pituitary patients face. While these struggles are not evident on the outside, what these patients go through is real and can be very debilitating.

The Pituitary Network Association has developed a Pituitary Family Resource Center to help the families of pituitary patients get answers to their questions and have a place to turn that does not put an added burden on the patient. In conjunction with our Family Resource Center I wrote this message for family members and friends of pituitary patients. Pituitary patients, feel free to share this letter with the people that care about you. It could help explain to them what you go through on a regular basis.

Dear Pituitary Families and Friends,

For your sake and the sake of your loved one, we ask that you take a few minutes to read this article. You may think pituitary patients are difficult and tend to complain a lot, but please let us explain. One of the hardest things for pituitary patients is the fact that there are a lot of unknowns. There are multiple symptoms that may (or may not) occur. The symptoms may subside for a while, only to come back unexpectedly, much worse than before.

Exhaustion, fatigue, weakness in limbs, loss of libido, infertility, headaches, excessive sweating, apathy, anger, rage, depression, mood swings, uncontrollable weight gain, diabetes, and visual disturbances. These are just some of the symptoms of a pituitary disorder. Taken individually, these symptoms can be debilitating, but together they can be devastating. Can you imagine the burden on the patient if they also lose support from the people they depend on the most?

Symptoms such as the ones listed above can adversely affect the family unit. The apathy for example, can make family members feel like the person is disconnected or doesn't care what is happening with everyone else. Because of the disease, the patient may not even recognize that he or she is behaving this way. In addition, anger, depression and uncontrollable rage can also make the family feel like they are under siege: abused, unloved, unappreciated and unneeded. The fact is, this is when pituitary patients need their family the most. It's understandable to want to pull away and retreat emotionally, but that just ends up isolating the patient even more. These are the times that your loved one needs you to stand by him or her and try to understand that the disease is controlling the bad behavior. If your loved one had cancer would you accuse that person of being lazy or making up the symptoms? Of course not, but this happens regularly to pituitary patients. We all know that cancer is a frightening disease that does horrible things to patients. Many people do not know about pituitary/ hormonal disorders and the negative effects it has on a person's everyday life.

In times of crisis, the family dynamics become magnified. Patients dealing with a diagnosis of an unknown intruder in their body need the support and understanding of their family more than ever. Now imagine that the intruder is unseen (have you ever tried to make sense of those MRIs?) and not clearly definable. When people hear that their loved one has a pituitary tumor, but that it is not cancerous or terminal, they are relieved and think that everything is going to be okay. Unfortunately, what they don't know is that the pituitary issue will affect every aspect of the patient's life, possibly indefinitely.

When people hear about a tumor, they don't think about how it diminishes the patients' mental health, their quality of their life, or their ability to accomplish everyday tasks. Pituitary tumors are usually benign, but they do cause some severe symptoms and they can require a lifetime of treatment and monitoring. Cancer is something that you can fight and BEAT, but for most pituitary patients, the battle goes on and on and on.

Understanding and acceptance truly comes from knowledge. The more you know about the disorder, the better prepared you are to support your loved one through his or her daily struggles. It can be very frustrating to have to care for someone who is ill, to have to pick up the slack with the daily chores they used to be able to do. When a patient is diagnosed with a pituitary or hormonal disorder, it is important that the family comes together to develop a plan of attack. Someone faced with a chronic illness will be able to handle it much better if they have the necessary support. The first and most important thing that any loved one can do is get educated about their loved one's disorder. Read the information contained on our website www.pituitary.org, purchase our Pituitary

Patient Resource Guide, and learn as much as you can from trusted sources. Our information is compiled from the world's renowned experts in pituitary medicine.

The more you are aware of up front, the better equipped you will be to make decisions. Your family will have to make adjustments. This is not going to be easy, but it can be made less stressful. Within the immediate family/household, all roles need to be assessed and redefined if necessary. For example, the person with pituitary disease may not be strong enough to carry out their regular household chores or do the same amount of driving. They may be too scattered to effectively manage the family's finances or schedules. Their emotions may get out of control at home or at work.

If you know going in what changes to expect, they are much easier to accept and adapt to. One thing that is very important to note; if family and friends are not supportive, if they do not believe the patient when he or she reports struggles caused by this disorder, it can exacerbate your loved one's symptoms. The fatigue and strain that they go through will be amplified if they have to justify their symptoms to people. Sometimes people are accusatory and assume that the patient is just lazy. Patients are told that they'd probably feel better if they just ate a little less and exercised a little more. This kind of attitude undermines the patient's treatment. There is a medical explanation for their symptoms and for their inability to live a normal life. It is not just another excuse. They did not choose this illness. They do not want to miss out on family functions; they don't like that they can't do their part. They cannot control their symptoms, so they need your understanding. Thank you for everything that you do to be supportive. The PNA is here to support you in your quest for information. Please contact us with your questions and we will be happy to point you in the right direction.

Glossary of Common Terms

Adenoma: A benign tumor that arises in or resembles glandular tissue which may or may not produce hormones in excess. Presence may affect normal glandular function.

ADH: A hormone stored in the posterior pituitary gland in the brain, which regulates water levels in the body. ADH interacts with the kidneys to increase total body water increasing blood volume and blood pressure. After pituitary surgery, there may be short-term deficiency or an excess of ADH, which must be recognized and treated promptly. More rarely, there may be permanent deficiency of ADH, which is a condition called Diabetes Insipidus (DI).

Acromegaly: A disease caused by the overproduction of growth hormone by the pituitary gland. Acromegaly occurs in 2.6 % of the pituitary patient population but is difficult for some doctors to detect and treat. Acromegaly affects both men and women. In almost all cases, acromegaly is not inherited and cannot be passed on to children.

Acute: An illness or symptom that happens suddenly and for a short time. It is the opposite of chronic.

Adhesion: Union of two tissue surfaces which can also refer to scar tissue which forms in the area of a previous operation. Surgery, inflammation, or injury can cause tissues to bond to other tissue or organs, similar to the forming of scar tissue.

Adrenal Glands: A pair of endocrine glands which produce small quantities of vital hormones. The adrenal glands sit on top of the kidneys and are controlled by the pituitary gland. They produce aldosterone which regulates salt and potassium balance, cortisol which is a stress hormone, and weak sex steroids.

Amenorrhea: The failure of a woman to menstruate. Amenorrhea is the absence of a menstrual period. Primary amenorrhea refers to a young woman who has not yet had a period by age 16. Secondary amenorrhea describes someone who used to have a regular period but then it stopped for at least three months due to pregnancy or other factors.

Analgesic: A medicine used to reduce pain. Analgesics include aspirin, acetaminophen, and ibuprofen. Every pain medicine has benefits and risks. Specific types of pain may respond better to one medication over another. Results also vary from patient to patient.

Anosmia: Absence of the sense of smell.

Anterior: Pertaining to being in front of another structure - toward the front of the body.

Anterior pituitary: The front portion of the pituitary. Hormones secreted by the anterior pituitary influence growth, sexual development, skin pigmentation, thyroid function, and adrenocortical function (ACTH, GH, LH, FSH, Prolactin, TSH). These influences are exerted through the effects of pituitary hormones on other endocrine glands except for growth hormone which acts directly on cells. The effects of under-function of the anterior pituitary include growth retardation (dwarfism) in childhood and a decrease in all other endocrine gland functions normally under the control of the anterior pituitary (except the parathyroid glands). The results of over-function of the anterior pituitary include overgrowth (gigantism) in children and a condition called acromegaly in adults.

Anticoagulant: Drugs that helps prevent blood clots from forming and are externally administered (IV, oral). They are also called blood thinners.

Apnea: This is a common sleep disorder characterized by brief interruptions of breathing during sleep. Episodes usually last 10 seconds or more and occur repeatedly throughout the night. People with sleep apnea will partially awaken as they struggle to breathe, but in the morning they will not be aware of the disturbances in their sleep. The most common type of sleep apnea is obstructive sleep apnea (OSA); caused by relaxation of soft tissue in the back of the throat that blocks the passage of air. Central sleep apnea (CSA) is caused by irregularities in the brain's normal signals to breathe. Most people with sleep apnea will have a combination of both types. The hallmark symptom of the disorder is excessive daytime sleepiness. Additional symptoms of sleep apnea include restless sleep, loud snoring (with periods of silence followed by gasps), falling asleep during the day, morning headaches, trouble concentrating, irritability, forgetfulness, mood or behavior changes, anxiety, and depression. Not everyone who has these symptoms will have sleep apnea, but it is recommended that people who are experiencing even a few of these symptoms visit their doctor for evaluation. Sleep apnea is more likely to occur in men than women, and in people who are overweight or obese.

Arachnoid cyst: Cerebrospinal fluid-filled sacs which are located between the brain or spinal cord and the arachnoid membrane, one of the three membranes that cover the brain and spinal cord.

Primary arachnoid cysts are present at birth and are the result of developmental abnormalities in the brain and spinal cord that arise during the early weeks of gestation. Secondary arachnoid cysts are not as common as primary cysts and develop as a result of head injury, meningitis, or tumors, or as a complication of brain surgery.

Asymptomatic: To have a disease condition without showing obvious outward symptoms. Many pituitary patients however, do have mild symptoms that are simply not recognized by treating physicians.

Benign: Not malignant/cancerous. In reference to a tumor; an abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumors may be benign (not cancerous), or malignant (cancerous).

Biopsy: Examination of a small amount of tissue surgically removed from the patient's body to make a diagnosis and examined by a pathologist. This test is done during pituitary surgery to help your doctors identify the best treatment plan for you.

Bromocriptine: An example of a dopamine agonist commonly used to treat Prolactinomas. These drugs suppress prolactin production and secretion and can lead to tumor shrinkage.

Cabergoline: A medication used to treat hyperprolactinemia, a condition characterized by high levels of prolactin — a natural substance in the body that helps breastfeeding women produce milk. Too much prolactin can cause health problems in men, and in women who aren't breastfeeding. Cabergoline can help treat symptoms associated with irregular menstruation, unwanted breast milk production, infertility, bone loss, and sexual problems. People with pituitary gland tumors may produce too much prolactin.

Cancer: General term frequently used to indicate any of various types of malignant tumors. Most cancers invade surrounding tissues, may metastasize to several sites, and may recur after attempted removal.

Carotid Artery: The arteries which carry blood up through the neck, eventually supplying the brain with its major blood supply. These vessels are also found within the cavernous sinus.

Catheter: A tubular devise to allow passage of fluid from or into a body cavity. Examples of use include; heart or urinary catheterization.

Cavernous Sinus: Area adjacent to the sphenoid sinus containing several vital nerves and blood vessels. The cavernous sinus is an important structure because of its location and its contents which include the third cranial (oculomotor) nerve, the fourth cranial (trochlear) nerve, parts 1 (the ophthalmic nerve) and 2 (the maxillary nerve) of the fifth cranial (trigeminal) nerve, and the sixth cranial (abducens) nerve.

Central Nervous System (CNS): Pertaining to the brain, cranial nerves and spinal cord. It does not include muscles or peripheral nerves. The central nervous system (CNS) is made up of the spinal cord and brain. The brain receives nerve impulses from the spinal cord and cranial nerves. The spinal cord contains the nerves that carry messages between the body and the brain.

Cerebral: Of or relating to the brain or the intellect.

Cerebrospinal Fluid (CSF): The clear fluid made in the ventricular cavities of the brain that bathes the brain and spinal cord. It circulates through the ventricles and the subarachnoid space. Analysis of this substance involves the removal of a small amount of the fluid that protects the brain and spinal cord. The fluid is tested to detect any bleeding or brain hemorrhage, diagnose infection to the brain and/or spinal cord, identify some cases of multiple sclerosis and other neurological conditions, and measure intracranial pressure.

Cerebrum: The largest area of the brain, the cerebrum occupies the uppermost part of the skull. It consists of two halves called hemispheres. Each half of the cerebrum is further divided into four lobes: frontal, temporal, parietal and occipital. The forebrain is the largest and most highly developed part of the human brain; it consists primarily of the cerebrum and the structures hidden beneath it. The cerebrum sits at the outermost part of the brain and is the source of intellectual activities. It holds memories, allows you to plan, and enables you to imagine and think, to recognize friends, read books, and play games. The cerebrum is split into two halves (hemispheres) by a deep fissure. Despite the split, the two cerebral hemispheres communicate with each other through a thick tract of nerve fibers that lies at the base of this fissure. Although the two hemispheres seem to be mirror images of each other, they are different. For instance, the ability to form words seems to lie primarily in the left hemisphere, while the right hemisphere seems to control many abstract reasoning skills.

Chronic: An illness or symptom which persist for a long time or constantly recurring.

Clinical: That which can be observed in patients. Research which uses patients to test new treatments, as opposed to laboratory testing or research in animals is considered a clinical trial. This either directly involves a particular person or group of people or uses materials from humans, such as their behavior or samples of their tissue that can be linked to a particular living person. (The process of clinical research, however, protects personal data.)

Congenital: Existing before or at birth; acquired during development in the uterus and not through heredity.

Contrast Agent, Contrast Medium: Substances used in radiography that allow visualization of certain tissues. This substance is injected through an IV that is placed shortly before the test.

Cranial Cavity: This is also known as the skull which is the boney structure that contains the brain; the largest portion of the central nervous system.

Craniectomy: Surgery performed on the skull where pieces of bone are removed to gain access to the brain which is not replaced.

Craniopharyngioma: Intracranial tumors that are typically both cystic and solid in structure. They occur most commonly in childhood and adolescence and in later adult life after age 50 years. They account for 2-4% of primary brain tumors.

Craniotomy: Surgery performed on the skull where a portion of bone is removed to gain access to the brain, and the bone is put back in its place.

CRH (Corticotropin): A hormone which is produced by the hypothalamus and stimulates ACTH release by the pituitary gland.

CT or CAT Scan (Computerized Axial Tomography): Also known as a CT scan, it is a noninvasive, painless process used to produce rapid, clear two-dimensional images of organs, bones, and tissues. Neurological CT scans are used to view the brain and spine. They can detect bone and vascular irregularities, certain brain tumors and cysts, herniated discs, epilepsy, encephalitis, spinal stenosis (narrowing of the spinal canal), a blood clot or intracranial bleeding in patients with stroke, brain damage from head injury, and other disorders. Many neurological disorders share certain characteristics and a CT scan can aid in proper diagnosis by differentiating the area of the brain affected by the disorder.

Cyst: A closed sac having a distinct membrane and developing abnormally in a body cavity or structure.

Debulk: A surgical procedure performed to decrease mass effect by removing a portion of a tumor or dead tissue.

Decadron (Dexamethasone): A glucocorticoid medication used to reduce brain tissue swelling. In low doses, it is also used to treat adrenal insufficiency.

Desmopressin (DDAVP): A medication used to control the symptoms of a certain type of diabetes insipidus, a condition in which the body produces an abnormally large amount of urine). Desmopressin is also used to control excessive thirst and the passage of an abnormally large amount of urine that may occur after a head injury or after certain types of surgery. Desmopressin is in a class of medications called hormones and works by replacing vasopressin, a hormone that is normally produced in the body to help balance the amount of water and salt.

Diabetes Insipidus (DI): A problem with water balance in the body causing excess urine production and great thirst, due to pituitary/hypothalamic damage. This may be a temporary condition after pituitary surgery or long-term and may require treatment with medication called Desmopressin (DDAVP).

Diabetes Mellitus: Insufficient insulin production by the pancreas in which long-term complications include development of disorders of the nervous system, eyes and kidneys; generalized degenerative changes in large and small blood vessels, and increased susceptibility to infection. Two types of a highly variable disorder in which abnormalities in the ability to make and/or use the hormone insulin interfere with the process of turning dietary carbohydrates into glucose, the body's fuel. Type I is known as insulin dependent diabetes mellitus, and type II is known as non-insulin dependent diabetes mellitus.

Diplopia: A vision disorder, in which two images of a single object are seen, caused from unequal action of the eye muscles

Dopamine Agonists: Medications with predominant effects on pituitary cells that harbor receptors for the chemical transmitter dopamine. Examples include Bromocriptine and Cabergoline.

Dura Mater: The outermost, toughest, and most fibrous of the three membranes (meninges) that cover the brain and spinal cord. The brain is made up of the dura mater, arachnoid mater, and pia mater. The dura, or inner layer, lines the inside of the skull and creates small creases or sections in which parts of the brain are protected and secured.

Dysfunctional: Working improperly or abnormally.

Edema: An accumulation of an excessive amount of watery fluid in cells, tissues, or serous cavities (swelling). Edema may be brought on by eating too much salt, surgery, sunburn, heart failure, kidney disease, cirrhosis of the liver, pregnancy, lymph node disorder, medicines, and exercise in warm temperatures. Diuretics may be given as medication for edema.

Emesis: Vomiting, stomach upset, or nausea is a complex, coordinated reaction orchestrated by the brain responding to signals coming from the mouth, stomach, intestines, bloodstream, balancing systems in the ear (motion sickness), or due to unsettling sights, smells or thoughts.

Encapsulated: Confined to a specific, localized area and surrounded by a thin layer of tissue. It can refer to a tumor that is wholly confined to a specific area, surrounded by a capsule.

Endocrine Glands: Those parts of the body which produce and secrete (release) hormones. Examples include pituitary, thyroid, adrenal, testicles, ovaries, parathyroid glands, etc.

Endocrine System: The endocrine system is an integrated system of small organs that involve the release of molecules known as hormones. The endocrine system is instrumental in regulating metabolism, growth, development and puberty, tissue function, and also plays a part in determining mood. Endocrine glands regulate your body chemistry by releasing hormones directly in to the blood system, which stimulate or inhibit activity in cells. They are like remote-control devices for your body's many cells and systems.

Endocrinology: The study of the endocrine glands and their hormones. A science dealing with the ductless glands that secrete substances (hormones) which are released directly into the circulation and which influence metabolism and other body functions.

Erectile dysfunction (ED): Defined as the consistent inability to achieve or maintain an erection.

Etiology: The study of the cause of a disease or abnormal condition.

FIPA (Familial Isolated Pituitary Adenoma): Rarely pituitary adenomas can occur in families. If no other abnormality is associated then this condition is called Familial Isolated Pituitary Adenoma. Most often family members have acromegaly, prolactinoma, or other types of adenomas. Some of these families carry a mutation in the AIP gene. Patients who have childhood onset acromegaly/ gigantism can also carry a mutation in AIP gene even if they do not have a known family history of the disease. Please see further information and possibility to have tested at http://www.fipapatients. org.

FSH (Follicle Stimulating Hormone): A gonadotrophin secreted by the pituitary gland, the hormone promotes fertility in men and helps to regulate the menstrual cycle in women

Gadolinium: A metal element that is used in magnetic resonance imaging (MRI) and other imaging methods. It is a contrast agent, which helps show abnormal tissue in the body during imaging with a special machine

Generic: Nonproprietary, or not protected by trademark registration. A drug not protected by a trademark is also the scientific name as opposed to the proprietary or brand name

GH (Growth Hormone): Secreted by the pituitary gland; the major hormone responsible for height growth. Also plays a role in maintenance of bone density in adults, body composition in that it builds muscle and breaks down fat, regulates lipids, and may play a role in cardiovascular health.

GHRH (Growth hormone releasing hormone: Regulates the synthesis and secretion of growth hormone in the anterior pituitary gland. The growth hormone (GH) stimulation test measures the level of growth hormone (GH) in the blood after you receive arginine or GH-releasing hormone. The test measures the ability of the pituitary gland to release GH.

GHRIH (Growth hormone release inhibiting hormone (same as SRIF): Somatostatin inhibits growth hormone release in response to GHRH

GHRP (Growth hormone releasing peptide (GHRP-6): A synthetic hexapeptide which specifically stimulates secretion of growth hormone

GH: Growth Hormone, secreted by the pituitary gland; the major hormone responsible for height growth. Also plays a role in maintenance of bone density in adults, body composition in that it builds muscle and breaks down fat, regulates lipids, and may play a role in cardiovascular health.

Gland: An organ of the body that produces hormones released into the bloodstream, such as the pituitary or pineal gland. Hormones influence metabolism and other body functions. Endocrine glands include the Adrenals, Hypothalamus, Islets of Langerhans in the pancreas, Ovaries, Parathyroids, Pineal, Pituitary, Testes, and Thyroid.

Glucagon Test: Glucagon is a hormone that is produced by cells in the pancreas the function of which is to raise blood sugar. An alternative to the insulin tolerance test; used to test for normal function of the hypothalamus and pituitary gland; glucagon increases blood sugar levels, causing a number of hormones (e.g., growth hormone and cortisol) to be released in response.

Glucocorticoids: Medications used to decrease swelling around tumors and duplicate the effects of cortisol. They are often used to treat adrenal insufficiency.

Glucose: A type of sugar found in the blood and an important source of energy in the body.

GnRH (Gonadotropin Releasing Hormone): A hormone secreted by the hypothalamus and stimulates the release of LH and FSH from the pituitary gland. It must be secreted in a coordinated fashion for LH and FSH to be secreted properly and then to stimulate gonads. Patients with Kallmann's syndrome have a deficiency of this hormone.

Gonadotrophin: A hormone which regulates the function of the gonads. The two main gonadotrophins; LH and FSH; are released from the pituitary gland and secreted in a regulated fashion with minute-to-minute variations that are important for gland function.

Growth Factor: A substance made by the body that functions to regulate cell division and cell survival. Some growth factors are also produced in the laboratory and used in biological therapy. It is produced by normal cells during embryonic development, tissue growth, and wound healing. Tumors, however, produce large amounts of growth factors.

Gynecomastia: A usually harmless female-like enlargement of one or both breasts in males; occurs commonly in teen-aged boys, but may be a characteristic of some hypogonadal males. It consists of excessive development of the male mammary glands, even to the functional state; the development of abnormally large breasts in males. May occur in one or both breasts and begins as a small lump beneath the nipple and the breasts often enlarge unevenly. Developing gynecomastia during puberty is common and usually recedes over a period of months. Gynecomastia can also be caused by chronic liver disease, exposure to anabolic steroids or estrogen, kidney failure, genetics, marijuana use, testosterone deficiency, or side effects from some medications. In rare instances an overactive thyroid, or genetic defects or tumors may be the cause.

HCG (Human Chorionic Gonadotrophin): A hormone which behaves like LH; made by the placenta, hCG may be extracted and used together with hMG to treat hypogonadism. This is what is measured in a pregnancy test.

HCG/HMG Therapy (Human Chorionic Gonadotropin / Human Menopausal Gonadotropin): This is a type of therapy for hypogonadal patients who wish to become fertile.

Hemianopsia: Loss of one half of the field of vision (the area that can be seen by each eye when staring straight ahead). This can occur in isolation or affecting both eyes. The most common form of vision loss due to pituitary tumors is loss of the outer half of vision in both eyes.

Hereditary: Transferred via genes from parent to child; also called genetic. Transmitted from parent to child by information contained in the genes.

Heterogeneous: Composed of varied cell types. Made up of elements or ingredients that are not alike.

HMG (Human Menopausal Gonadotropin; Human Menopausal Gonadotropin): Derived from the urine of post-menopausal women, hMG not only contains LH but also FSH.

Homogeneous: Composed of identical cell types; of uniform composition or structure.

Hormone (Adj. Hormonal): A chemical "messenger" which is made and secreted by an endocrine gland and which targets one or more parts of the body, modifying its structure or changing the way it works. Hormones are chemical substances having a specific regulatory effect on the activity of a certain organ or organs, especially substances secreted by various endocrine glands and transported in the bloodstream to the target organs. Hormones are your body's chemical messengers that travel in your bloodstream to tissues or organs. They affect the body's processes such as growth and development, metabolism, sexual function, reproduction, and mood. Hormones are produced by endocrine glands. The major endocrine glands are the pituitary, pineal, thymus, thyroid, adrenal glands and pancreas. Men will produce also hormones within the testes and women produce hormones in the ovaries. Hormone balance is regulated by the pituitary. Tiny shifts cause large changes to cells or throughout the entire body. Hormone levels are measured in your blood, urine or saliva.

Hormone Replacement Therapy: The name given to a form of treatment in which missing or deficient hormones can be replaced, the body being encouraged to behave normally as if it were making the hormones naturally. Doses are designed to mimic normal blood levels and vary depending on the patient.

Hyperparathyroidism: A condition where the parathyroid glands, located in the neck near the thyroid gland, make too much parathyroid hormone. The excess amounts of parathyroid hormone act on the kidney, bones, and vitamin D metabolism to raise blood calcium levels. Patients often get osteoporosis, kidney stones, and a number of different symptoms of the high calcium including fatigue, weakness, excessive urination, dehydration, depression, and abdominal pain. A small proportion of patients with pituitary tumors have an inherited defect in a gene that can also cause hyperparathyroidism. This condition is called MEN-1. Patients may also get pancreatic tumors that produce insulin or gastrin.

Hypogonadism (Adj. Hypogonadal): The inability of the gonads to function normally which can be due to pituitary dysfunction or else dysfunction of the glands (ovaries and testicles).

Hypogonadotropic Hypogonadism: The inability of the gonads to function normally because of subnormal levels of the gonadotropins LH and FSH which can be due to pituitary disease or a disorder of the hypothalamus.

Hyponatremia: Serum sodium concentration and serum osmolarity normally are maintained under control involving stimulation of thirst, secretion of antidiuretic hormone (ADH), and renal handling of filtered sodium.

Hypophysis (Pituitary gland): The hypophysis or pituitary is a small, pea-sized gland located at the base of the brain that functions as "The Master Gland." From its lofty position above the rest of the body it sends signals to the thyroid gland, adrenal glands, ovaries and testes, directing them to produce thyroid hormone, cortisol, estrogen, testosterone, and many more. These hormones have dramatic effects on metabolism, blood pressure, sexuality, reproduction, and other vital body functions. In addition, the pituitary gland produces growth hormone for normal development of height and prolactin for milk production.

Hypothalamic-Pituitary-Gonadal Axis: The system designed to produce sex steroids in proper amounts. Involves coordinated production of GnRH, LH, FSH, and sex steroids (testosterone and estrogen).

Hypothalamus: A thumbnail-sized part of the brain located just above the pituitary gland to which it is connected. The hypothalamus normally contains cells which make and release hormones that influence pituitary function.

IGF-1 or IGF-I (Insulin-like growth factor-1): Produced by the liver, formerly known as somatomedin-C, and is a marker of the amount of GH secreted over time.

IGFBP-3 (Insulin-like growth factor binding protein-3): One of the proteins that carries IGF-1 thru the bloodstream

Invasive: Refers to a tumor that invades healthy tissues. The opposite of encapsulated. Also called diffuse or infiltrating. Procedures that violate the body are also called invasive.

Lethargy: Sluggishness, drowsiness, indifference. A condition marked by drowsiness and an unusual lack of energy and mental alertness. It can be caused by many things, including illness, injury, or drugs.

LH (luteinizing hormone): A gonadotropin secreted by the pituitary gland, the hormone promotes masculinity in men and helps to regulate the menstrual cycle in women in conjunction with FSH.

LHRH (Luteinizing Hormone Releasing Hormone): another name for GnRH. Luteinizing hormonereleasing hormone - Decapeptide hormone released by the hypothalamus which stimulates the synthesis and secretion of both follicle stimulating hormone (FSH) and luteinizing hormone (LH) from the pituitary gland. Androgens can cause the growth of prostate cancer cells. Luteinizing hormone-releasing hormone agonists may lessen the amount of androgens made by the body.

Macroadenoma: Pituitary tumor 1 cm (10mm) or larger.

Malignant: In reference to an abnormal tissue growth neoplasm (cancer), having the property of locally invasive and destructive growth and metastasis (spreading). Semantics prevail. For example, invasive pituitary tumors are not thought to be malignant.

Microadenoma: Pituitary tumor less than 1cm (10mm).

MRI: A non-invasive diagnostic procedure which uses a magnetic field and radio waves to create detailed images of the organs and tissues within your body.

Nervous System: The entire integrated system of nerve tissue in the body; the brain, brain stem, spinal cord, nerves and ganglia

Noninvasive: Denoting a procedure that does not require insertion of an instrument or device through the skin or a body orifice for diagnosis or treatment.

Olfactory Nerves: Nerves which connect to the nostrils to provide one's sense of smell. These nerves carry impulses for the sense of smell from the nose to the brain. The olfactory nerve is the first cranial nerve.

Optic Chiasm: Area where optic nerves cross over, located just above the pituitary gland, which can be compressed by pituitary tumors and hinder eyesight. At the optic chiasm, nerve fibers from half of each retina cross over to the opposite side of the brain. The fibers from the other half of the retina travel to the same side of the brain. Because of this junction, each half of the brain receives visual signals from the visual fields of both eyes.

Optic Nerves: Nerves which connect to the eyes providing one's sense of sight. The optic nerve connects the eye to the brain.

Paresis: Muscular weakness involving partial or incomplete paralysis..

Paresthesia: Abnormal sensations, such as burning, prickling, tingling and numbness, or loss of sensation on the skin having no direct cause and usually associated with irritation or injury to a sensory nerve or nerve root; and sometimes identified by sensory loss,

Medical conditions causing paresthesias include: carpal tunnel syndrome, diabetes, migraines, multiple sclerosis, seizures, stroke, TIA or transient ischemic attack, underactive thyroid, or Raynaud's phenomenon.

Paresthesias can also be caused by; remaining in the same position for prolonged periods, injury to a nerve, pressure on the spinal nerves (disk herniation), lack of blood supply to an area of the body, abnormal levels of calcium, potassium or sodium, lack of vitamin B12 or other vitamins, certain medications, toxic agents such as lead, alcohol or tobacco, radiation therapy.

Pituitary Gland (Hypophysis): A small, pea-sized gland located at the base of the brain that functions as "The Master Gland." From its lofty position above the rest of the body it sends signals to the thyroid gland, adrenal glands, ovaries and testes, directing them to produce thyroid hormone, cortisol, estrogen, testosterone, and many more. These hormones have dramatic effects on metabolism, blood pressure, sexuality, reproduction, and other vital body functions. In addition, the pituitary gland produces growth hormone for normal development of height and prolactin for milk production.

Pituitary Stalk: A tiny structure which connects the hypothalamus to the pituitary gland composed of blood vessels that carry hormones from the brain to the pituitary and also nervous tissue which transports the hormone ADH to the posterior pituitary.

Posterior: Pertaining to being behind another structure - toward the back of the body. Posterior pituitary: The back portion of the pituitary, a small gland in the head called the master gland.

The posterior pituitary secretes the hormone oxytocin which increases uterine contractions and antidiuretic hormone (ADH) which increases reabsorption of water by the tubules of the kidney. Underproduction of ADH results in a disorder called diabetes insipidus characterized by inability to concentrate the urine and, consequently, excess urination leading potentially to dehydration. The urine is "insipid" (overly dilute).

Primary Amenorrhea: The inability to menstruate, caused by a failure of sexual maturation and function. Specifically refers to patients who have not had any menses whatsoever. Concern arises if menses have not developed prior to age 14. Secondary amenorrhea is loss of menses in a patient who previously had menses. Progesterone helps to build up the endometrium during the menstrual cycle.

Prognosis: A forecast as to probable outcome.

Progesterone: A sex hormone which is made in the ovaries and during pregnancy, by the placenta as well. Progesterone helps to build up the endometrium during the menstrual cycle.

Prostate Gland: An organized cluster of cells functioning as a secretory or excretory organ around the chestnut-shaped body, surrounding the beginning of the urethra in the male. The secretion of the glands is a milky fluid that is discharged by excretory ducts into the prostatic urethra at the time of the emission of semen.

Quality of Life: Refers to the level of comfort, enjoyment, ability to pursue daily activities. The term, quality of life is often used in discussions of treatment options.

Radiation Therapy (Irradiation, Radiotherapy): The use of radiation energy to interfere with tumor growth. See irradiation. The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body.

Radiographic: Of or relating to radiography. Referring to the examination of any part of the body for diagnostic purposes by means of x-rays or other diagnostic modalities (MRI, CT, PET, etc).

Recurrence: The return of symptoms or the tumor itself, as opposed to a remission. A tumor that has recurred (grown back), usually after a period of time following removal of the tumor

Remission: The disappearance of symptoms; the disappearance of the tumor. A decrease in or disappearance of signs and symptoms of a tumor or cancer. In partial remission, some, but not all, signs and symptoms have disappeared. In complete remission, all signs and symptoms have disappeared, although still may be present in the body.

Resection: Surgical removal of a tumor or organ; a procedure that uses surgery to remove tissue or part or all of an organ.

Residual: Remaining tumor; tumor cells that remain after attempts to remove the tumor have been made.

RGH (Recombinant growth hormone, somatropin): This is often referred to as hGH or human Growth Hormone and used to treat growth hormone deficiency and short stature.

Sella Turcica: Bony structure at the base of the skull in which the pituitary gland rests; a depression in the middle line of the upper surface of the sphenoid bone in which the pituitary gland is lodged.

Speculum: An instrument for enlarging the opening of any canal or cavity in order to facilitate inspection of its interior.

Sphenoid Sinus: Either of two irregular cavities in the body of the sphenoid bone that communicate with the nasal cavities. Sinus (cavity lined with mucosa) that lies directly behind the nose and in front of the pituitary gland - the back wall of which makes up the anterior wall of the sella turcica.

Spinal Fluid (Cerebrospinal Fluid): The clear fluid made in the ventricular cavities of the brain that bathes the brain and spinal cord. It circulates through the ventricles and the subarachnoid space. Analysis of this substance involves the removal of a small amount of the fluid that protects the brain and spinal cord. The fluid is tested to detect any bleeding or brain hemorrhage, diagnose infection to the brain and/or spinal cord, identify some cases of multiple sclerosis and other neurological conditions, and measure intracranial pressure.

SRIF (Somatotropin release inhibiting factor; same as GHRIH): Often referred to as somatostatin. A number of drugs to treat GH excess act like this native hypothalamic hormone.

Stalk: A stem. Usually refers to the pituitary stalk that connects the pituitary gland to the hypothalamus.

Steroids (Glucocorticosteroids, Corticosteroids, Glucocorticoids: Corticosteroids steroids are similar to hormones that the adrenal glands produce to fight stress associated with illnesses and injuries; reducing inflammation and having a positive affect the immune system. Corticosteroids are used to treat autoimmune diseases such as lupus and multiple sclerosis, skin conditions, arthritis, asthma and some cancers.

Steroids in high doses should be taken for as short duration as possible as they can produce side effects such as, infections, hypertension, diabetes, osteoporosis, avascular necrosis, myopathy, cataracts, and glaucoma. The body can also become dependent on high doses. <u>Steroid use cannot be stopped abruptly</u>. Tapering the drug gives the adrenal glands time to return to their normal patterns of secretion. Sudden withdrawal from steroids can cause weakness, fatigue, decreased appetite, weight loss, nausea, vomiting, diarrhea, and abdominal pain.

STH (Somatotropin): Growth Hormone, GH

Syndrome of Inappropriate Antidiuretic Hormone Secretion (SIADH): Impaired water excretion resulting from inappropriate, continued secretion or action of the hormone ADH despite normal or increased plasma volume. This can lead to a low serum sodium level and can be dangerous if left untreated.

Systemic: Circulating throughout the body which affects the entire body rather than a single organ or body part. Systemic disorders such as high blood pressure and systemic diseases such as influenza affect the entire body. A systemic infection is an infection in the bloodstream. A localized infection is only affecting one body part or organ.

T3 (Triiodothyronine): The active metabolite of thyroxine. T4 is converted to T3. T3 is also produced by the thyroid gland.

T4 (Thyroxine): The principal product of thyroid secretion.

Thyroid Gland: An endocrine gland normally situated in the lower part of the front of the neck which secretes, stores, and releases the iodine dependent thyroid hormones, Thyroxine and Triiodothyronine. Both of these hormones play a major endocrine role in regulating metabolic rate. An underactive thyroid is called hypothyroidism where as an overactive thyroid is referred to as hyperthyroidism.

Tissue: A group of similar cells united to perform a specific function

Transnasal: Surgical approach through the nostril providing access to the sphenoid sinus and pituitary gland

Transseptal: Surgical approach through a portion of the central partition of the nose to access the sphenoid sinus (exposed either transnasally or through a sublabial incision)

Transsphenoidal Surgery: A surgical approach through the nostril and sphenoid sinus permitting access to the pituitary gland which must be performed by experienced neurosurgeons.

For more definitions of common pituitary terms, click on the link below to the PNA website. http://pituitary.org/frontpage/glossary-2

Patient Resource Guide

The Patient Resource Guide is designed to help you take an active role in your care, keep your medical information organized in one centralized location, communicate your health information to your healthcare providers clearly, efficiently, and accurately as well as make the most of your doctor's appointments.

Filling out your Patient Resource Guide may take some time initially, but it will save you time in the future because you will have all of your medical information in one centralized location. If you do not have all of your health information, just start with what you have. Take your notebook with you to all appointments, procedures and hospital visits.

The more information you can provide for your doctors during your appointment, the better your doctors can understand your healthcare needs and the more information they can usually give you.

Keep in mind that St. Joseph's Hospital provides access to your medical records through a Patient Portal. Once you provide your email address to the hospital staff in the Registration Department, you will receive an invitation to access the Patient Portal. Questions regarding hospital records can be addressed by calling (602) 406-3350.

Medical Records

Use this section to keep copies of your medical records that include:

- X-ray (radiology) reports
- Operative (surgery) reports
- Pathology reports
- Laboratory results
- Consultation reports
- Reports or records pertaining to your health

Most medical facilities require written consent signed by the patient to release medical records.

Keep in mind that St. Joseph's Hospital provides access to your medical records through a Patient Portal. Once you provide your email address to the hospital staff in the Registration Department, you will receive an invitation to access the Patient Portal. See next two pages for details. Questions regarding hospital records can be addressed by calling (602) 406-3350.

The Dignity Health Online Patient Center — Getting Started

The Dignity Health Online Patient Center provides a convenient, secure, and electronic way to access your hospital health information and communicate with your Dignity Health care team. All you need is Internet access and an e-mail address.

It's as easy as 1-2-3!

- 1. Provide your e-mail address when you register or during your hospital stay.
- 2. Check your e-mail for an invitation to enroll in the Online Patient Center, and click on the link provided.
- 3. Follow the quick, easy steps to complete your enrollment and start managing your hospital health records online!

Need Assistance?

Once you've enrolled, the Dignity Health Online Patient Center offers support 24 hours a day, seven days a week by telephone, toll-free at 877.621.8014, or on the web at <u>DignityHealth.org/Patients</u>, and select your hospital from the drop down menu in your geographic region.

Accessing the Online Patient Center works best with Microsoft Internet Explorer 8 and 9, Mozilla Firefox, and Google Chrome. For ease of access, bookmark the login page as a "favorite" in your browser.



Access Your Patient Records Online

Dignity Health now offers an Online Patient Center for our hospital patients! You or a designated family member can view your health records and send them to your personal physician.

	Dashb	card TO-SJH1 BEN •- Sign Out	
💏 Dignity Health.		Health Record Appointments	5
Health Profile	Welcome to your personal health record. The Learn N page wiht information about medications.	lore link on this page will take you to a	
A Results	No medications recorded	Learn Mon	е
Documents	[⊉] ≣ Immunizations		
Procedures	Flu vaccine	Date Received: Jan. 1, 2014	
Visit Summaries	B Current Allergies		
	Eggs	Reactions: Rash	
	Seafood		

Features of the Online Patient Center:

- View lab results
- Read and download discharge instructions
- See a list of your procedures and conditions
- Review your medications and allergies
- View upcoming appointments and add them to your personal calendar
- Read a summary of your visit



Making the Most of Your Doctor's Appointments

Making the appointment

- Confirm the location of the office when scheduling the appointment. Many doctors have more than one office.
- Confirm that the office accepts your insurance, even if you have seen the doctor previously.
- Ask whether you need to arrive early to fill out or update paper work.
- Ask if you need to bring your radiology exams (MRI, CT, etc) to your appointment. It is usually necessary to bring all available exams to the first consultation. If the doctor recently ordered an exam, he or she will often have a copy of the report but they may not have seen the actual exam study (pictures).

Preparing for your appointment

Use this handbook to write down information; to keep tract of appointments, phone numbers, questions, instructions, medications; and to collect business cards in a centralized place. Take it with you to every appointment.

Put the following information in this handbook:

- All of your surgeries, including the name of the operation, the date, the name of the doctor and hospital.
- Allergies to foods and medications and the type of reaction.
- All medications you are currently taking. Include the dosage of the medication and the frequency that you take it.
- Your pharmacy information: name, address, phone number and fax number. If your pharmacy is not open 24 hours, keep the name of a 24-hour pharmacy handy in the event that you need a prescription after regular business hours.
- A copy of your radiology exam reports, medical test results, or other medical information. If your doctor needs the information for their records, ask them to make a copy always keep the original copies.
- Business cards for all of your specialists and any facilities or hospitals where you receive care.

Write your questions down before your doctor's appointment, leaving a space between the questions.

Remember that the more information you can provide for your doctor during your appointment, the more information your doctor can give you.

The appointment

Take another person with you to the appointment. It is often difficult to hear, understand, and remember everything the doctor tells you, especially when you are nervous, anxious or not feeling well.

Take your notebook, list of questions, and radiology exams (including reports).

During the appointment, briefly jot down answers (key words) to your questions.

Collect a business card from each specialist or medical facility.

Ask the front desk staff for your medical record number or account number, and record it in your notebook. Each medical facility maintains a specific medical record number or account number for each patient. Providing this number when you request records or radiology exams, inquire about a bill, or even make an appointment will help you get through the system much easier.

My Information

Name	Date of Birth	Blood Type	Height	Weight
Address	Home Phone		Work Phone	
	Cell Phone		Fax Number	
	Email Address			
Social Security Number	Medicare Number		Part A □ Yes □ No	Part B □ Yes □ No

Primary Insurance		Secondary Insurance	
Plan Name		Plan Name	
Address		Address	
Phone		Phone	
Group #		Group #	
Policy #		Policy #	
Insured Name		Insured Name	
Insured Employer		Insured Employer	
Insured SSN	nsured Date of Birth	Insured SSN	Insured Date of Birth

Emergency Contacts Name & Relationship	Address	Phone

My Barrow Treatment

My neurosurgeon is:	
Dr	Office Phone:
My endocrinologist is:	
Dr	Office Phone:
My radiation oncologist is:	
Dr	Office Phone:
My neurophthalmologist is:	
Dr	Office Phone:
My neuropsychologist is:	
Dr	Office Phone:
My psychiatrist is:	
Dr	Office Phone:
My neurologist is:	
Dr	Office Phone:
Other contact:	
Dr	Office Phone:

Finding My Barrow Treatment Team Clinics

Office

Office

Fax

Fax

(602) 406-5954

(602) 294-5931

(602) 406-2596

(602) 294-4492

Surgical Director, Barrow Pituitary Center

Clinical Nurse Coordinator

Barrow Neurological Institute 350 W. Thomas Road Phoenix, Arizona 85013

Neurosurgery

Andrew Little, MD F. David Barranco, MD Thomas Rowe, FNP-C Barrow Brain and Spine 2910 N. 3rd Avenue Phoenix, Arizona 85013

Phoenix, Arizona 85013

Endocrinology

Kevin Yuen, MD Medical Director, Barrow Pituitary Center Monica Rodriguez, MD **Barrow Neuroendocrine Clinic** Office (602) 406-BPIT (2748) 2910 N. 3rd Ave., Suite 420 (602) 406-2770 Fax Phoenix, Arizona 85013 Kajalben Buddhdev, MD Garineh Ovanessoff, MD **Dignity Health Medical Group** (602) 406-3300 Office 500 W. Thomas Road, Ste 900B Fax (602) 406-3978 Phoenix, Arizona 85013 Pediatric Endocrinology Oliver Oatman, DO Phoenix Children's Hospital Office (602) 933-0935 1920 E Cambridge Avenue, Suite 301 Fax (602) 933-0610 Phoenix, Arizona 85006 Neurology Kerry Knievel, DO Barrow Neurological Institute (602) 406-6262 Office 240 W. Thomas Road, Suite 400 Fax (602) 406-8099

Otolaryngology

Griffin Santarelli, MD **Otolaryngologist, Director, Barrow Sinus Program** Barrow Neurological Institute Department of Otolaryngology and Skull Base Surgery Office (602) 406-8811 222 West Thomas Road, Suite 307 (602) 406-8810 Fax Phoenix, Arizona 85013 John Milligan, MD Arizona Otolaryngology Consultants Office (602) 264-4834, (480) 948-2056 2222 E. Highland, Suite 204 (602) 257-1269 Fax Phoenix, Arizona 85016-4872 Ryan Rehl, MD Arizona Sinus Center (602) 258-9859 Office 926 E. McDowell Road, Suite 207 Fax (480) 214-9859 Phoenix, Arizona 85006

Radiation Oncology / Cyberknife / Gamma Knife

Igor Barani, MDWilliam Kennedy, MDEmma May FNP-CEva Duran, FNP-CSt. Joseph's HospitalRadiation Oncology Dept.350 W. Thomas RoadPhoenix, Arizona 85013

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Tumor Diagnosis

Tumor diagnosis can also be referred to as tumor pathology. At the time of surgery, your neurosurgeon will send a tumor sample to the pathology laboratory. The sample will be examined by a neuro-pathologist, and a preliminary diagnosis will be determined while you are still in the operating room. This preliminary diagnosis can also be referred to as a frozen section diagnosis. It will require more time for more testing before a final tumor diagnosis is made.

Your final tumor diagnosis can take an average of 3 to 5 days from your surgery date. For this reason, it is not uncommon to be discharged from the hospital before you receive information on your final tumor diagnosis. Your neurosurgeon or oncologist will discuss your tumor diagnosis at your post-operative office visit.

My preliminary diagnosis is: _____

My final diagnosis is: _____

Contacts

Obtain business cards from or list contact information for your healthcare providers and facilities where you receive care. Keep track of your medical record number or account number at each office, hospital or medical facility where you receive treatment to make it easier when you request x-rays, medical records, inquire about a bill and make appointments.

Healthcare Provider or Facility	Address	Phone Number & Contact Person	Office Hours	Medical Record Number or Account #
EXAMPLE Dr. James Rogers - Neurologist CRS Clinic, St. Joseph's Hospital	124 W. Thomas Road Phoenix, AZ 85013	602-406-6400 Ext 102 Mary - nurse	8am - 4:30pm	061-3P-R349

Pharmacy Information

It is recommended that you list at least one 24-hour pharmacy if possible.

Pharmacy	Hours	Pharmacy	Hours
Phone	Fax	Phone	Fax
Address		Address	

Pharmacy	Hours	Pharmacy	Hours
Phone	Fax	Phone	Fax
Address		Address	

Prescription Insurance Information

Insurance Name	ID#	Group #
Address	Phone	Fax
Insured Name	Employer	
Insured Social Security Number	Insured Date of Birth	
Benefits, Co-pays, and Deductibles		

Allergies

Allergies to food, medication, and environment	Reaction
EXAMPLE Penicillin	Hives

Medications

Current Medication and reason you take it	Dosage	How often you take it	Prescribed by
EXAMPLE Tegretol - seizures	200 mg	Twice a day	Dr. Martin Brown

Health Problems

List significant past and present health problems.

Date	Health Problem & Illness	Treatment

Radiology Information

There are many types of radiology exams (also called radiographic studies). Radiographic studies are evaluated by a radiologist, who then dictates a report about their findings. It is recommended that you always obtain a copy of the radiology report for your records.

If you need to obtain your exams, call the healthcare facility and ask for the radiology file room. Request your exams be copied to a CD so that you can pick them up. Ask to have a copy of the radiology report included. Your will be asked to provide your name, date of birth, date of the exam, and medical record number (if you have it). You may be asked to sign a release form when you pick up the CD. If you are picking up CDs for a family member, you may be asked to show identification and have written permission from the patient to pick up the radiology studies.

Type of radiology study (MRI, CT, angiogram, ultrasound, nuclear medicine study, etc.)	Date of Exam	Healthcare Facility Address & Phone Number	Medical Record Number	Do hav copy radio rep	you e a of the ology ort?
				Y	Ν
				Y	Ν
				Y	Ν
				Y	Ν
				Y	Ν
				Y	Ν
				Y	Ν
				Y	Ν

Treatment Information

Include surgeries, radiation, and chemotherapy.

Date	Treatment	Doctor's Name	Hospital/Facility

Appointments

Date	Time	Name of Healthcare Provider or Facility & Specialty	Address	Phone Number & Contact Person	Special Instructions or Directions
EXAMPLE 3/22/02	10:15am	Dr. Robert Jones Phoenix Children's Hospital Neurologist	1919 E. Thomas Road Phoenix, AZ 85016	(602) 933-1000 Brenda	Arrive 15 minutes early to fill out new patient paper work.

Appointments

Date	Time	Name of Healthcare Provider or Facility & Specialty	Address	Phone Number & Contact Person	Special Instructions or Directions
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Questions for my Doctor

Date of Appointment	Name of Doctor	Questions	Answers
Questions for my Doctor

Date of Appointment	Name of Doctor	Questions	Answers

