

# Barrow Normal Pressure Hydrocephalus Program Patient Handbook



**Dignity Health.**  
St. Joseph's Hospital and  
Medical Center



# Barrow NPH Program Patient Handbook

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# Welcome to the Barrow Normal Pressure Hydrocephalus Program

We are very pleased that you have chosen the Barrow Normal Pressure Hydrocephalus (NPH) Program for your care. Barrow Neurological Institute is committed to providing excellence in clinical care and patient satisfaction, which is based upon our high standard of excellence in personalized healthcare.

In just five decades, Barrow Neurological Institute has grown into a world leader in the neurosciences. Barrow is consistently recognized by US News and World Report as being one of the top 10 centers for quality neurological and neurosurgical care. Barrow achievements have improved the care for individual patients and have also led to changes in the way neurosurgery is practiced around the world.

Our multidisciplinary team of neurosurgeons, neurologists, neuropsychologists, physical therapists, psychiatrists, nurses, 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.

For most patients, dealing with NPH is more of a marathon than a sprint, so we encourage all your friends and family members, not just you, to take care – get enough sleep, nutrition, and exercise to stay as healthy and focused. Step-by-step, our NPH team we will help take you through the treatment process, all the way from your initial appointments and diagnostic examinations, preoperative testing, neurosurgery and beyond. While you will meet many different specialists during this time, rest assured that we are all working in unison on your behalf. If our team feels you will benefit from surgery, care will be provided by a team of doctors and nurses who are NPH experts, and many other helpful staff members.

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 become acquainted with your condition, we assembled this Patient Handbook to provide an accurate framework to better understand NPH. We hope this handbook will help you and your family find up-to-date sources of information and support specific to the Barrow NPH Program.

At the Barrow NPH Program, the treatment plan for each patient is individualized, so not everything described in these pages will necessarily apply to you. Nevertheless, it is always easier to navigate the waters when you know what is in the realm of possibilities. 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 condition.

Maggie Bobrowitz, RN, MBA,  
Barrow NPH Program Coordinator

# Barrow Normal Pressure Hydrocephalus (NPH) Program

The Normal Pressure Hydrocephalus (NPH) Program features a multidisciplinary team at St. Joseph's Hospital and Medical Center designed to provide comprehensive evaluation, diagnostic testing, and treatment for patients with Normal Pressure Hydrocephalus (NPH). The team supports collaboration between clinical and research specialists and facilitates educational programs to advance the diagnosis and treatment of this condition. The Barrow NPH team is dedicated to the continuity of care of each individual throughout the course of treatment, including discharge planning and correspondence with other physicians involved in the care of the patient.

The NPH Program is made up of the following specialists and collaborators:

- Neurology
- Neurorehabilitation
- Neurosurgery
- Neuroradiology
- Neuropsychology
- Neuropathology
- Physical/Occupational/Speech Therapy
- Neuro-certified Nursing
- Physiatry

# International Patient Program

We understand that NPH specialists are few and far between and patients often travel 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 they 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**

**(602) 406-6281**

**BarrowInternationalProgram@DignityHealth.org**

**Visit the website:**

[http://www.stjosephs-phx.org/Patients\\_And\\_Visitors/International\\_Patient\\_Program/index.htm](http://www.stjosephs-phx.org/Patients_And_Visitors/International_Patient_Program/index.htm)



# 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 NPH team members are highly skilled to meet your unique needs. Here are descriptions of the primary specialists who will be involved in your care.

**Physiatrist:** A doctor who specializes in physical medicine and rehabilitation, who restore optimal function to people with injuries to the muscles, bones, tissues, and nervous system.

**Neurologist:** A doctor who specializes in diagnosing and treating non-surgical diseases of the brain and nervous system (e.g., strokes, unusual headaches, seizures).

**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.

**Neurosurgeon:** A doctor who performs surgery to place a shunt device. He or she works with residents (doctors in training) who also provide care while you are in the hospital.

**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.

**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 other doctors in the hospital and clinic with the goal of directing your plan of care and teaching you about your disease.

**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.

# Meet Your Team

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

## Neurosurgeons



David  
Barranco, MD

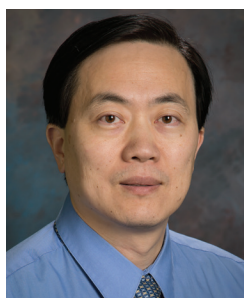


Peter Nakaji, MD



Kris Smith, MD

## Neurologists



Jiong Shi, MD,  
PhD



Terry Fife, MD



Kamala Saha, MD



Marisa Peoples,  
AG-ACNP

## Neuropsychologists



William  
Schultz, PhD



Krista  
Hanson, PhD



Alexander  
Tröster, PhD

## Nurse Coordinator



Maggie Bobrowitz,  
RN, MBA

## Physical Therapist



Sharon Hayden,  
PT, DPT

## NPH Neurology Clinic Coordinator



Deanna  
Hernandez



# NPH Overview

Normal Pressure Hydrocephalus (NPH) is an accumulation of cerebrospinal fluid (CSF) within cavities called ventricles inside the brain. Every day, the average adult produces about one pint of CSF, which cushions the brain from injury and carries nutrients to and waste products away from the brain. In NPH, the CSF pathways become blocked, and CSF builds up, causing the ventricles to become enlarged, usually with little or no increase in pressure.

## What Causes NPH?

The cause for the majority of cases of normal pressure hydrocephalus is unknown. In some cases, NPH can develop as the result of a head injury, brain surgery, brain hemorrhage, meningitis, tumor or cyst, as well as blood clots.

## Signs and Symptoms of NPH

NPH causes three main symptoms: difficulty walking, mild dementia and impaired bladder control. Because these symptoms are also associated with the aging process and other diseases, many people with NPH go undiagnosed or possibly misdiagnosed for years. Symptoms of NPH mirror the signs of Alzheimer's, Parkinson's, other types of dementia, as well as the normal aging process. For this reason the condition is often misdiagnosed.

***Gait disturbances*** – Ranging in severity from mild imbalance to the inability to stand or walk at all. Your gait may be widespread, short, slow and shuffling or you may have trouble picking up your feet. Gait disturbance is often the most pronounced symptom and the first to become apparent.

***Mild dementia*** – Loss of interest in daily activities, forgetfulness, difficulty dealing with routine tasks and short-term memory loss.

***Impairment in bladder control*** – Ranging from urinary frequency and urgency in mild cases to complete loss of bladder control (urinary incontinence) in more severe cases.

## Diagnosing NPH

The Barrow NPH team has designed a screening process which can provide rapid diagnosis and identify those individuals who have great potential to improve with shunt surgery. Whether you have already been diagnosed with NPH or suspect you are suffering from this condition, our team will create a treatment plan designed specifically for you.

The **NPH Screening Clinic** is designed to provide comprehensive evaluation by neurologists who specialize in cognitive and movement disorders in order to determine if patients have NPH and whether surgical intervention is appropriate for them. For those patients felt likely to have NPH after initial consultation, further diagnostic tests and exams are completed to determine if treatment should be pursued. Once the necessary tests are completed, if it is determined that the patient is a candidate for the shunt surgery they are referred to neurosurgery at that time. Patients who are not candidates for surgery are referred to the appropriate specialist.

Diagnostic tests may include the following:

***MRI CINE Flow Study:*** MRI of the brain that evaluates the flow of cerebrospinal fluid around the brain, brainstem and/or spinal cord. This test is safe and painless and will take approximately 30 minutes or longer. MRI uses radio signals and a very powerful magnet to create a picture of the brain. It will be possible to detect if the ventricles are enlarged as well as evaluate the CSF flow and provide information about the surrounding brain tissues. The MRI provides more information than the CT, and is therefore the test of choice in most cases.

***Lumbar puncture or spinal tap:*** Under local anesthesia, a thin needle is passed into the spinal fluid space of the low back. Removal of CSF is performed to see if symptoms are temporarily relieved. Improvement of symptoms suggests that the patient will respond positively to shunt surgery.

***Physical Therapy Evaluation:*** This examination is performed by a physical therapist (specializing in balance disturbances) in the early stages of the diagnostic process to obtain a baseline assessment of the patient's gait, balance, level of functional ability and fall risk. The same exam is performed before and immediately after the lumbar puncture (L/P) is completed to document improvements in mobility and to assist in determining if the procedure was beneficial from a functional mobility standpoint.

***Neuropsychological test:*** This test involves asking a series of questions used to determine if there is a loss of brain function due to hydrocephalus.

## Treating NPH

There is no known way to prevent or cure hydrocephalus. Fortunately, NPH can often be successfully treated with a special shunt that drains excess CSF away from the brain to another part of the body, usually the abdominal cavity, where it can be absorbed. This shunt is programmable, meaning that the rate of flow can be adjusted using a special magnet without requiring additional surgeries. The shunt tube is about 1/8 inch in



diameter and is made of a soft and pliable plastic that is well tolerated by body tissues. Shunt systems come in a variety of models but have similar functional components.

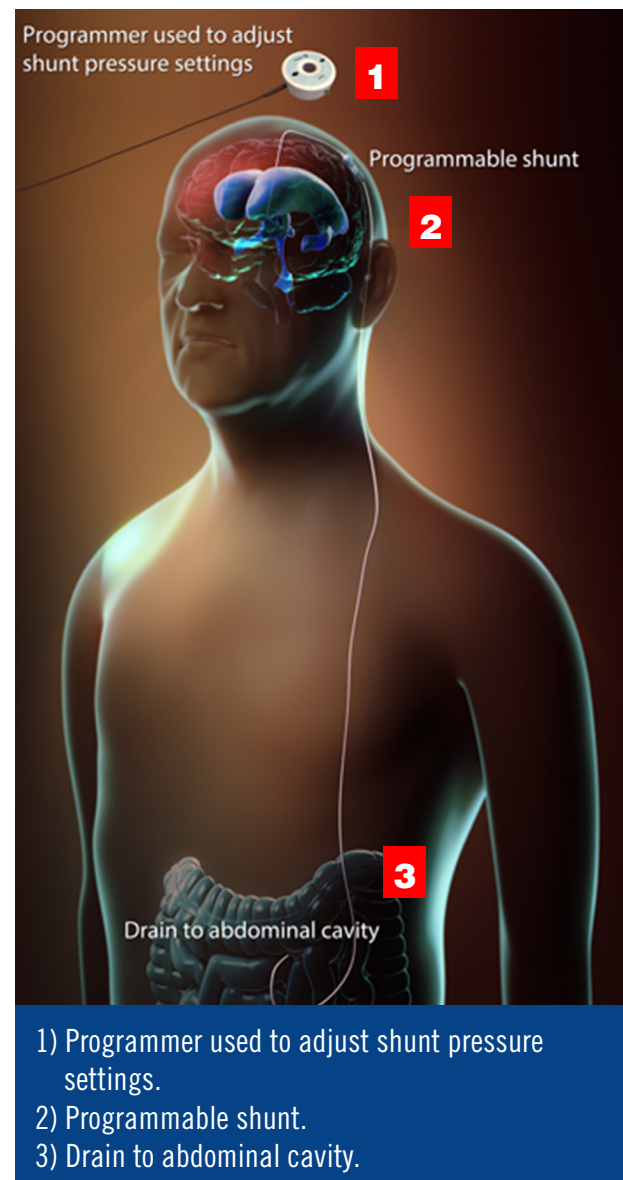
A programmable shunt is typically used for patients with NPH. The settings on this type of shunt can be adjusted to allow more or less CSF to be drained from the brain, and thus, maximize the potential benefit of the shunt for each individual.

## Possible Complications with Surgery

Although shunt surgery is a relatively simple neurosurgical procedure, the decision to undergo insertion of a shunt should not be taken lightly. The operation should be undertaken only if the potential benefits outweigh the risk of complications.

The potential complications of shunt surgery should be viewed as those related to the actual operation, and those which may occur days to years later. A complication can be thought of as any unwanted event related to the surgical procedure itself or the presence of the shunt. The risks of shunt surgery itself include those of general anesthesia and actual placement of the shunt. These risks include death, coma, stroke, hemorrhage, and infection. Fortunately, the risk of serious life changing complications are relatively small. Your neurosurgeon will discuss these risks with you and answer your questions.

Unlike many other operations in which the surgical risks are highest during the operation itself, many of the common and serious problems associated with shunting can occur weeks to years after the surgery. The most common problem with shunt systems is that they can become obstructed (clogged). This can occur hours or years after the operation. For patients with NPH, a shunt obstruction is usually discovered



when the original symptoms recur. Fortunately, shunt obstructions in NPH are relatively rare and do not often result in serious problems.

The most serious complication that can occur following insertion of a shunt is a subdural hematoma (blood clot). Because most shunts drain CSF from the center of the brain (the ventricles), this may cause the surface of the brain to pull away from the skull, thus stretching and tearing blood vessels on the surface of the brain. The symptoms of a subdural hematoma vary from increasing headache to paralysis or even coma or death. Shunt-related subdural hematomas most commonly occur following a fall, even one involving only a minor bump to the head. Therefore, a patient with NPH should not hesitate to seek medical attention if abnormal symptoms develop.

## Outcome & Recovery

Higher success rates have been reported from medical centers with greater experience in treating this condition. It is important to note that if initial success is followed by a recurrence of symptoms, it may be due to a shunt or shunt failure or the need for shunt pressure re-programming.

## Rate of Improvement

The symptoms of gait disturbance, mild dementia and bladder control problems may improve within days of shunt surgery, or may take weeks to months to mend. However, there is no way to predict how fast, or to what extent, this improvement will occur. In addition, this improvement may range from mild to dramatic. It is also not possible to make general predictions of how long the improvement will last, as the course of clinical improvement varies for each patient. Some patients seem to reach a plateau, while others improve for months but then seem to decline again. Unfortunately, there are no guarantees.

Generally, patients with an implanted shunt system are not restricted in their daily activities, except those involving great physical exertion. Your doctor will discuss with you any restrictions that may be advisable. Most patients with hydrocephalus can look forward to a normal future. Shunts are expected to perform reliably over a long period of time. However, because hydrocephalus is an ongoing condition, patients do require long term follow-up care by a doctor. Having regular medical checkups at intervals determined by the neurologist is strongly recommended.

The patient and his/her family must be responsible for follow-up care. Regular visits will help the neurologist identify subtle changes that may identify a shunt problem. Patients and their caregivers should become familiar with the signs and symptoms of shunt malfunction as described below.



## Shunt Adjustments

At the Barrow Neurological Institute all of the neurosurgeons use programmable shunts for the treatment of NPH. These shunt valves have the ability to be easily adjusted to control the amount of fluid (CSF) that is drained. Not enough drainage prevents improvement in symptoms while too much drainage can lead to headaches and increase the risk of complications. As noted earlier, one or more shunt adjustments are typically required to obtain maximum benefit of this device while minimizing the risks of over drainage.

The adjustment procedure is a simple, non-invasive, procedure that uses an external device placed over the shunt valve to change the shunt setting. This can be done in the physician's office. Both your neurosurgeon and neurologist have been trained to make these changes.

## Shunt Revisions

Occasionally, patients with shunt systems require revisions. A revision is a surgical procedure to modify, repair or replace a shunt system due to complications or changing patient conditions. In those cases where a change in shunt pressure is needed, a patient with a programmable shunt system will simply require their shunt to be externally (without surgery) re-programmed.

## Symptoms of Shunt Malfunction

- Headache
- Vision problems
- Difficulty speaking
- Irritability/personality change
- Mild dementia
- Extreme sudden fatigue
- Difficulty in waking up or staying awake
- Loss of coordination or balance
- Return of gait disturbance
- Incontinence

This list of symptoms is for your reference only, and is not intended to be used as a diagnostic tool. If you are in doubt about your/your family member's condition, consult your physician immediately or go to the nearest emergency room.



# Just Diagnosed with NPH, Now What?

Once a diagnosis of NPH is confirmed by one of our neurologists in the screening clinic and it is determined that you would benefit from having a shunt implanted, you will be referred to one of our neurosurgeons who specialize in NPH. You may also be referred to one of our team neuropsychologists to obtain a baseline assessment of your cognition or ability to understand and process information. This type of testing is performed to provide realistic expectations of cognitive function after surgery.

## Your Doctor's Visit

During the initial appointment with your neurosurgeon, the treatment and recovery process will be discussed with you and your family in detail. 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?
- Who manages my medications and supplements after surgery?
- What medications should I stop taking 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 (MRI study, EKG, Chest x-ray)?
- Discuss my allergies to food, medications, or products (i.e. latex)
- Do I follow up with the surgeon, neurologist, or both?

If your surgeon and you agree to move forward with surgery a date will be selected. Since this is a progressive condition the surgery is typically not considered urgent. Your surgeon understands, however, that once you have been given an opportunity

to improve your quality of life, you want to feel better immediately. His/her office will make a great effort to accommodate your schedule and desire to move forward quickly. In addition to the surgeon's busy schedule there are other factors that influence the timeline of surgery. Since most of our NPH patients are over 60 years of age, many have other specialists (cardiologist, pulmonologist, etc.) who will need to provide clearance for surgery prior to setting this date. Your surgeon's office will discuss this with you.

# Surgery is Recommended

First, understand that the 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.

Once you come to the Barrow NPH Program you are part of the Barrow family. We care about you!

## 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-Operative Department. This may include specific lab work, chest x-ray, MRI or CT studies, EEG 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 this handbook and any other paperwork you received from our doctors, with you to your pre-operative 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, & 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, etc.; anticonvulsants (Depakote); anti-inflammatory drugs including Anaprox, Dolobid, Feldene, Motrin, Ibuprofen, Naprosyn, Toradol, Vioxx, Aleve, Advil, etc.; natural supplements such as Vitamin E; and herbal medications such as ginkgo 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. Although a typical stay for NPH surgery is one night, if any of the specialists on our team have concerns or want to keep a closer eye on any area of your body they will keep you in the hospital longer.

- Identify a companion to help you for a few days after you arrive home
- Arrange transportation to and from the hospital. Discharge usually takes place by 11:00 a.m.
- 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
- Consider creating a webpage on social media, such as CaringBridge (<https://www.caringbridge.org/>) to update your friends and extended family of your recovery. Be selective in a site that offers privacy controls.
- 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 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, air-conditioned 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](http://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.

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 “The Pantry”**

Breakfast: 6:30am until 9:30am

Lunch: 10:30am until 2:30pm

Dinner: 4:00pm until 7:30pm

### **Starbucks™**

Monday thru Friday: 5:30am until 8:30pm

Saturday and Sunday: 6:00am until 12:00pm

## **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.

## **Front Desk Services**

Wireless internet is available in most areas of the hospital. To access the wireless network please contact the front desk at 602.406.4949 for a voucher. The front desk is located just inside the main hospital entrance. The desk is staffed Monday through Friday 7 a.m. until 5 p.m. Wireless internet is available in most areas of the hospital.

## **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**

NPH Program	(602) 406-7585
Barrow ResourceLink	(800) 227-7691
Concierge Services	(602) 406-4949
Registration	(800) 643-1219
Main hospital	(602) 406-3000
Preoperative Center	(602) 406-3192
Hospital Security	(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 health. 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 mark the side of the body he/she will be entering during. An intravenous catheter may be placed in your arm to administer medication to relax you before you are taken to the operating room.

At this time you will also meet the nurse program coordinator if you haven't met her already. She will discuss the treatment and recovery guidelines designed by the team to ensure your recovery is a positive experience.

*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.

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 condition you have as well as your symptoms. If you meet the criteria for one of these research projects you will be 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 NOT to sign a research consent form without feeling the need to explain your decision.

*Your care is not affected if you chose not to sign the research consent form.*



## 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. You will be asked to state your name and to answer other questions to assess your mental status. You will be

connected to a cardiac monitor, pulse oximetry machine (measures the oxygen in your blood), temperature gauge, and oxygen mask.

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 few days 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.

You may have a variety of intravenous and arterial lines, which may remain in place for a few days or until hospital discharge.



# While in the Hospital

## Intensive Care Units (ICU)

The hospital has many different ICU(s). You may be assigned to an 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 to help avoid complications associated with temporary immobility such as gas pains, bed sores, decreased lung capacity, and blood clots. You will be asked to reposition your body by turning over or moving your arms and legs, to take deep breaths, and to use an incentive spirometer to flush anesthetic agents from your lungs. Showers are permitted after your surgeon provides a written order.



Your nurse assesses your neurological status at predetermined times to ensure that you recover as expected. Your assessment includes being asked various questions to test your alertness. You also may be asked to move specific parts of your body. Food and liquids are introduced slowly, beginning with ice chips and advancing to more substantial foods as tolerated. At this point, you may need treatment to assist with your recovery such as speech, occupational, and physician therapy. These services may continue throughout your hospital stay and after hospital discharge in an outpatient setting.

Social work, case management, and pastoral services are available on request. Tubes that drain fluid from the surgical site may remain in place for as long as 4 days and are removed at the discretion of your surgical team. Tests such as radiographic studies (MRI, CT) and laboratory tests may be performed in the days after your surgery.

## General Nursing Units

Your surgeon may determine that your condition does not require ICU monitoring. If this is the case you will be admitted to the general nursing floor. Private and double rooms are available in these areas.

On general nursing floors, your activity will be increased to avoid muscle weakness and other complications of immobility. Some patients are out of bed the same day as surgery. Services such as physical therapy, speech therapy, and rehabilitation may be provided.

Diet is advanced as tolerated. Small, frequent, balanced meals will help you heal faster and regain your normal energy level.

While you are in the hospital many different types of doctors from different specialties (areas of medicine) may visit you. These include your surgeon, internal medicine doctor, etc.



A typical hospital admission for patients undergoing NPH surgery is one overnight stay which may be in the intensive care unit (ICU) or the regular nursing floor. 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.

The hospital's case management department and social workers are available to help you identify needs that you may have after discharge from the hospital. These needs may range from renting wheelchairs to arranging home health care and outpatient therapies. Please ask your physician to order a consultation with a social worker or case manager to help you with this before the day of discharge.

If you have a specialist who is NOT affiliated with our team, it is important that you let him/her know that surgery is planned and that you schedule an appointment in his/her office within a timeframe determined by that specialist.

# Discharge from the 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 by 11a.m. It is helpful to notify your ride the night

before your anticipated discharge to ensure a timely pick-up. If your ride is unavailable before 11a.m., you will be taken to the Discharge Lounge to wait for your 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.

Taking baths or submersion of your incisions into any body of water (hot tubs, pools, etc) is 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.

The hospital's case management department and social workers are available to help

you identify needs that you may have after discharge from the hospital. These needs may range from renting wheelchairs to arranging home health care and outpatient therapies. Please ask to speak to one of these individuals before the day of discharge.

Remember to take all of your belongings with you and to tell your friends and family that you have been discharged from the hospital.

## Discharge Lounge

After you are discharged we will escort you to our discharge lounge. 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. 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 arrives at the circle entrance they can check in at the front desk or contact the discharge lounge from their vehicle at (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

Please note that the appointments above have been coordinated with specific attention to the timeframe between hospital discharge and follow-up with your providers. If you reschedule any of these appointments please ensure that there are at least **two to three weeks between the appointments** with your neurosurgeon and your neurologist. Adjustments made to your shunt valve must be done slowly over time to avoid complications of over drainage. If you see the neurologist, less than two to three weeks after your neurosurgeon makes an adjustment to your shunt, your neurologist will NOT be able to make another adjustment to your shunt during this visit.



You neurosurgeon will ensure your recovery is going as expected. Your neurologist will manage your shunt long-term and only refer you back to your neurosurgeon if there is a problem with the shunt down the road. Often times when we have a foreign device placed in our body we attribute new symptoms to this device. Your neurologist is specifically trained to evaluate any new symptoms that arise after surgery and determine if it is shunt related or caused by an unrelated condition.

Your appointment with Sharon Hayden, PT, or one of her colleagues, has been made to evaluate your gait/balance after surgery and to make recommendations for on-going physical therapy. Once Sharon completes this assessment she will provide your neurologist with recommendations for therapy. Although we understand that it may be more convenient for you to seek therapy at a facility closer to your home, if you would like to continue on-going care with Sharon she will be happy to schedule you in her clinic.

If you are receiving therapy at another facility please **ask your therapist to provide you with a progress note** to bring with you to your follow-up appointment with your neurologist. This can assist him/her in making decisions regarding your shunt adjustments.

Keep in mind that if you begin therapy at another facility (in the home, rehab, skilled nursing facility or at another out-patient setting) prior to your appointment with Sharon, **your insurance carrier may not allow you to see her during for this follow-up visit. If this is the case please contact Deanna in the NPH clinic to cancel your appointment with her at least one week in advance to allow for another patient to accept that appointment time. She can be reached at (602) 406-4784.**

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



## At Home After Surgery

While specific instructions will be provided to you at the time of hospital discharge this document is intended to give you general guidelines and prepare you for recovery. Although shunt operations do not work for everyone with NPH, many people experience substantial symptom relief, which may range from mild to dramatic. These symptoms including gait disturbance, mild dementia and incontinence may resolve within days to weeks following a shunt procedure.

Some patients may require significantly more time to improve. There is no way to predict perfectly who will benefit and who will not. It is also not possible to make general assumptions of how long the improvement will last, as the course of clinical improvement varies for each patient. Some patients seem to reach a plateau, while others improve for months but then seem to decline again. A small percentage of patients experience worsening symptoms immediately after surgery followed by gradual improvement. Unfortunately, there are no guarantees.

Caring for patients with NPH 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

Post-operative **nausea** may be related to your pain medications. If possible, take your pain medication with food. Eating small, frequent meals and avoiding spicy or fried food may decrease feelings of nausea.

It may take **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. It is helpful to increase water, fresh fruits and vegetables, fiber and bran in your diet. Also, take over-the-counter docusate sodium tablets, 100 mg (1 to 2 times per day) to keep your stools soft. You may decrease the amount taken if your stools become too soft.

If constipation is not relieved with these measures, you may take Milk of Magnesia, 1 to 2 tablespoons every 12 hours. If this doesn't work, it is recommended that you use a Fleet enema or rectal suppository to assist with evacuation of the rectum. This is preferred over heavy straining. If an enema or rectal suppository is not successful, please notify us.

### Here are some tips to keep your bowels moving:

What to do	How often
<b>Prevent constipation with these:</b>	
Drink more water	Every day
Eat fresh fruits and vegetables	Every day
Walk	Every day
Senokot (8.6 mg tablet)	Daily 1-2 times per day until your bowel movements return to normal
<b>If constipation is not relieved with these measures, you may take:</b>	
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
<b>If these do not work or if you have not had a bowel movement in 3 days, try:</b>	
An enema or rectal suppository	Once; an enema or rectal suppository is preferred over straining

## Wound Care

- Keep the dressing on your abdominal incision clean and dry. You may have some itching at your abdominal incision as this is normal healing.
- Do not apply ointments, lotions, or creams to your incision unless advised to by your surgeon.
- Showers are typically approved by your surgeon within a day or two after surgery.
- Baths, hot tubs, and swimming pools are not allowed until your surgeon says you can.
- Avoid peroxide for incisions closed with absorbable suture, as it will cause too rapid of breakdown of suture. Clean with soap and running water.
- Keep incision free of dried blood, crusting or scabbing to decrease risk of infection and minimize the scar.

- Begin daily hair washing with mild shampoo and conditioner (to ease the tangles) when cleared by surgical team, usually three days post-operatively.
- Use caution when the combing hair. Vigorous rubbing can disrupt the sutures.
- If a nylon suture is used for the skin closure the surgeon will remove them during the post-operative visit to the clinic after hospital discharge (within ten to fourteen days following surgery).

## Avoid Infection

Keep fingernails trimmed short to decrease risk of incision irritation and infection from scratching as healing occurs. Contact your surgeon immediately if any of the following occur:

- Sudden increase in swelling at the surgical site after the swelling had begun to subside
- Fever or chills, colored drainage from incision
- 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.

## Activity

Patients recover at different rates from neurosurgical procedures and are encouraged to honor their physical and emotional limitations. 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. Get plenty of rest.

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

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.

Resume **normal daily activities** (including sexual activity) after six weeks unless otherwise advised by your surgeon.

Do not to lift, push, or pull more than **10 pounds** for 12 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 great physical exertion.

**Smoking** delays healing and can cause a wound infection. Reducing this activity or stopping completely will improve your chance of a speedy recovery.

**Driving** *is not* 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

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

## Nutrition

Eat frequent small meals (4–6 per day) are suggested with a moderate amount of protein in each to assist in healing process. Specific instructions will be communicated to you while in the hospital. Avoid straining hard for bowel movements for 3 months. Use stool softeners immediately after surgery and include plenty of fluids (6-8 cups of water) and fiber (fruits & vegetables) in diet. Contact your primary care physician to help manage constipation problems.

## 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. Surgeon's preferences vary from waiting 10 days to 4 weeks after surgery.
- Keep in mind
  - ~ Pain pills are strong medicine.
  - ~ They can only be filled and refilled with a paper Rx.
  - ~ They cannot be called in to the pharmacy by a doctor or NP.
  - ~ Some of the pain pills also have acetaminophen (Tylenol®) mixed in them and others do not.
  - ~ Vicodin and Percocet both contain acetaminophen (Tylenol). Do not take Tylenol while you are taking these medications because taking more than 4000 mg of Tylenol in a 24-hour period can lead to liver damage. Avoid drinking alcohol, driving, and operating heavy machinery while taking medication for pain.

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

When you feel that you no longer need your strong pain pills, you may take ibuprofen or acetaminophen (Tylenol) as directed by your surgeon.

Acetaminophen (Tylenol) is over the counter—no Rx needed.

Caution: Taking too much acetaminophen (Tylenol) can damage the liver.

Take your pain pills with food, and only as needed to avoid side effects such as nausea, vomiting, or constipation.

Do not drink alcohol or drive when taking prescription pain pills.

## MRI Studies

Depending on the type of shunt that is implanted during your surgery, it may or may not be MRI *resistant*. All shunts we use are compatible with MRI machines meaning they do not prevent you from having an MRI study in the future and will not affect the results of this test.

Some shunts are also MRI *resistant*. This means that the magnet in the MRI machine will not interfere with the shunt valve setting. The valves in programmable shunt devices are adjusted using a handheld programmer containing a magnet. These adjustments are done in small increments by your neurosurgeon or neurologist to ensure it is done safely. Some shunt manufactures indicate that an MRI study may inadvertently change the shunt setting to slow down or speed up the rate at which the fluid is drained from your brain.

If you have a device that is not MRI *resistant* please contact our program coordinator or team neurologist prior to completing an MRI study in the future. Your shunt can be examined after the MRI is completed (with advanced notice) to ensure the setting has not changed. You can ask your surgeon at the time of surgery which type of shunt device was used and if it is MRI *resistant*.

## Call your Neurosurgeon or go to the Emergency Room if any of these occur:

Complications of NPH surgery include infection, bleeding, and over drainage. Feelings of depression are temporary and common following any surgical procedure. 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 (noted above) are thought to be present
- Fever of 101 degrees or greater, especially within the first three months of surgery
- Persistent or worsening headaches not relieved with over the counter medication and/or a nap.
- Jerking/twitching of face arms or legs (seizure activity)
- Difficulty or discomfort in moving your neck, face, arms or legs
- Significant changes in behavior, ability to think, confusion, difficulty concentrating
- Depression or severe anxiety
- Excessive sleepiness or dizziness
- Significant fatigue that doesn't improve
- Abdominal stitches come apart
- Redness, swelling, odor or drainage at your abdominal incision
- Severe abdominal pain
- Loss of bowel/bladder control
- Nausea and vomiting
- Constipation lasting 3 days and not helped with over the counter pills

# Community Support & Resources

## Barrow NPH Program

The Barrow NPH Program Support Group is a national support group which provides information, education, and support to those affected by NPH; 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 NPH. Support group meetings are held throughout the year in addition to bi-annual full-day patient education conferences.

Maggie Bobrowitz, RN, MBA

Office: (602) 406-7585

[margaret.bobrowitz@dignityhealth.org](mailto:margaret.bobrowitz@dignityhealth.org)

**[www.barrowneuro.org/pituitaryprogram](http://www.barrowneuro.org/pituitaryprogram)**

## 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 & Medical Center

350 W. Thomas Road

Phoenix, AZ 85013

## Hydrocephalous Association

### **Our Mission**

The mission of the Hydrocephalus Association (HA) is to promote a cure for hydrocephalus and improve the lives of those affected by the condition.

We will accomplish this by collaborating with patients, caregivers, researchers and industry, raising awareness, and funding innovative, high-impact research to prevent, treat and ultimately cure hydrocephalus.

### **Our Vision**

A world without hydrocephalus. We provide one-on-one support, so please feel free to contact us:

Our toll free hotline: (888) 598-3789

E-mail: [Info@hydroassoc.org](mailto:Info@hydroassoc.org)

Website: [www.hydroassoc.org](http://www.hydroassoc.org)

### **Who We Are**

The Hydrocephalus Association (HA) Founded in 1983 by parents of children with hydrocephalus. At a time when there was little to no information about the condition, we provided support services and educational resources to individuals and their families. Today we have grown into a national organization and have expanded to include four program areas: support, education, research, and advocacy.

### **Support**

Our staff shares knowledge that comes from personal experience with hydrocephalus and from talking to people with the condition.

Our Medical Advisory Board is comprised of clinicians and scientists eager to answer your questions, speak to your concerns and share their knowledge of hydrocephalus.

Our local Community Network and WALK events provide opportunities for you to get involved and connect at a local level to your peers. Expect a listening ear from staff and access to informed and current resources to help you understand and deal with the complexities of hydrocephalus.

### **Education**

We produce numerous free publications, host webinars, and a biennial national conference with leading experts, providing you with current, relevant information about research, medical technologies, and educational resources. We are committed to supporting and providing you with accurate information through this journey.

### **Research**

Our Research Initiative funds innovative, high- impact research to prevent, treat and ultimately cure hydrocephalus. We are the largest private funder of hydrocephalus research in the country and sustain the pediatric-focused Hydrocephalus Clinical Research Network (HCRN) and the Adult Hydrocephalus Clinical Research Network (AHCRN).

## **Advocacy**

Our Hydrocephalus Action Network (HAN) empowers our community to assure that the federal government is investing adequate funds to support hydrocephalus research for improved treatments and cures as well as appropriate programs that support those affected with hydrocephalus.

## **Mental Health Resources**

American Association of Marriage and Family Therapists

**[www.aamft.org](http://www.aamft.org)**

American Psychological Association

**[www.apa.org](http://www.apa.org)**

Health Resources and Services Administration

**[www.hrsa.gov](http://www.hrsa.gov)**

# Understanding NPH, You're Not Alone

Dear Patients and Caregivers:

When a family member or loved one is diagnosed with normal pressure hydrocephalus (NPH) it can cause mixed emotions. The diagnosis process is complex and frustrating. NPH symptoms like gait disturbance, mild dementia and bladder incontinence also occur with other conditions that affect people over 60 years of age often making diagnosis confusing. On the other hand, receiving a diagnosis of NPH can create change for the better. It can trigger emotions ranging from solace to sadness, anger to acceptance. It's a sigh of relief; we finally know what the problem is and why. We are frustrated; why did he or she go undiagnosed for so long? These emotions encompass grief.

NPH can cause a ripple effect, impacting not only the person with the condition, but family, friends and loved ones. The challenges of living with a chronic illness or caring for a chronically ill parent or spouse are stressful for all involved. Adults with NPH may resent their dependence on a spouse, child or other family member. It's important to remember there are no right or wrong emotions. Acknowledging emotional responses to this chronic and potentially disabling condition can help all those involved.

You may have a lot of questions and concerns: What is NPH? Will treatment work? How will this change our life? The unknown can be frightening and make you feel powerless. Educating yourself on your condition will empower you to make informed decisions. Take a deep breath. Now is the time to take charge and understand next steps and ongoing management of care. You're not alone and we are here to support you throughout your journey.

The Hydrocephalus Association (HA) is deeply committed to providing innovative programs and comprehensive resources to meet the diverse needs of the community. We offer high quality support services and free, personalized information to help each individual process the diagnosis or navigate the daily challenges and uncertainties that accompany a chronic condition.

Through our website, [www.hydroassoc.org](http://www.hydroassoc.org), publications, webinars, videos, mobile app (HydroAssist), and educational events, we are providing the latest and most accurate information about research, medical technologies and protocols, and educational resources. Our programs and services provide reliable information to answer your questions and address concerns that are specific to the needs of the entire community.

Please contact our support staff to help you understand and manage this complex condition.



# Glossary of Common Terms

**Acquired Hydrocephalus** – Of or relating to a disease, or condition, that is not congenital but develops after birth.

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

**Adult Onset Hydrocephalus** – Any hydrocephalus which appears in adulthood from any cause, including head injury, stroke, meningitis, or unknown cause (idiopathic).

**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.

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

**Anxiety** – A feeling of apprehension and fear

**Atrophy** – A wasting away

**Blood clots** – Blood that has been converted from a liquid to a solid state

**Brain** – The portion of the central nervous system that is located within the skull.

**Catheter** – Small, flexible tube (part of the shunt system) inserted into the body part (i.e. ventricle), which allows the passage of the Cerebrospinal Fluid.

**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 water-like fluid that bathes the brain and spinal cord. The fluid provides nourishment, carries away any debris (such as excess protein cells), and protects us from injury. It is in constant production, circulation and absorption. The body makes almost a pint of CSF daily.

**Cerebral Ventricles** – Four chambers of the brain that produce the CSF, located near the center of the brain. (There are two lateral ventricles, one on each side of the hemisphere, the fluid then flows into the third ventricle, which is located in the center and onto the fourth ventricle, located in the back, near the skull.) Each chamber produces CSF.

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

**Cisternogram (Cisternography)** – Radiographic study of the basal cisterns of the brain after the introduction of an opaque contrast.

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

**Cognitive** – Having to do with thought, judgment, or knowledge.

**Communicating Hydrocephalus** – Also referred to as “non-obstructive.” A type of hydrocephalus where the pathways and ventricular system are not obstructed, however, the problem appears to be that of re-absorption of the used CSF.

**Congenital Hydrocephalus** – A child diagnosed in utero or after birth as having hydrocephalus.

**Contrast Agent/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.

**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.

**CT Scan (Computed Tomography)** – Scan of the head using an X-ray beam, which passes through the head allowing the computer to make a picture of the brain in slices. A CT Scan will show if the ventricles are enlarged or if there is a blockage.

**Dementia** – Deterioration of intellectual faculties, such as memory, concentration, and judgment. Dementia can also be caused by a head injury, medication, stroke, or another medical condition (such as Alzheimer's or Hydrocephalus).

**Drain** – A device for removing fluid from a cavity or wound.

**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.

**Endoscopic Third Ventriculostomy (ETV)** – A surgery in which a hole is made in the floor (bottom) of the third ventricle. This allows a new pathway for the CSF to be absorbed (and discarded) by the body.

**External Ventricular Drain (EVD)** – This device is somewhat similar to a shunt, although it is on the outside of the body. A catheter is implanted into the brain to drain the excess CSF. The flow can be regulated by either raising or lowering the bag where the fluid is emptied into.

**Fixed Shunt** – A type of shunt that has a valve preset for high, medium, or low pressure (within the brain). The pressure setting cannot be changed without further surgery.

**Gait** – A manner of walking.

**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.

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

**Hydrocephalus** – Is an abnormal buildup of cerebrospinal fluid (CSF) in the ventricles of the brain. The fluid is often under increased pressure and can compress and damage the brain. Hydrocephalus can arise in utero, at the time birth, or any time afterward.

**Incontinence** – Inability to prevent discharge of urine, and sometimes feces. Urinary urgency or incontinence is a common symptom of Normal Pressure Hydrocephalus.

**Intraventricular Hemorrhage (IVH)** – A bleed within the ventricular system of the brain (also referred to as a brain bleed).

**Lateral Ventricles** – There are two, one on each side of the brain (near the center of the brain) – see Cerebral Ventricles.

**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.

**Lumbar Drain** – A lumbar drain is used in a variety of circumstances including testing whether a person might be a candidate for long-term shunting of (CSF) fluid. In patients diagnosed with NPH, prior to placing a permanent shunt, a lumbar drain can be used to gauge if the patient will respond to the shunt. This is a procedure done in the hospital (it may take 1 to 4 days to complete).

**Lumbar Puncture** – See Spinal Tap.

**Lumbar Tap** – See Spinal Tap.

**Memory** – The ability to recover information about past events or knowledge.

**Meningitis** – Inflammation of the meninges, the three membranes that envelop the brain and spinal cord.

**MRI** – (Short for) Magnetic Resonance Imaging. This is a non-invasive test which uses radio signals and a powerful magnet to show the anatomical structures of the brain. It can reveal enlarged ventricles and evaluate the CSF Flow.

**Nausea** – Stomach queasiness, the urge to vomit.

**Non-invasive** – Denoting a procedure that does not require insertion of an instrument or device through the skin or a body orifice for diagnosis or treatment.

**Normal Pressure Hydrocephalus (NPH)** – A form of hydrocephalus where the ventricles are enlarged, but there is no obstruction within the ventricular system. The cause appears to be that the used CSF is not being absorbed (and discarded).

**Over-Drainage** – Is a condition where too much CSF has been withdrawn from the cerebral ventricles. Usual symptoms are noticed after being upright for a while and usually include a severe headache in the morning with in about ½ hour to an hour after getting out of bed. Can be combined with nausea, dizziness, and vomiting. Over draining can result in “Slit Ventricle Syndrome.”

**Peritoneal Cavity** – The area of the abdomen, below the diaphragm where the intestines are located.

**Prognosis** – A forecast as to probable outcome.

**Programmable Shunt** – Type of shunt where the physician can raise or lower the amount of CSF taken from the brain. To change the setting by means of a magnetic device placed over the shunt. NO surgery is involved.

**Progressive** – Increasing in scope or severity, advancing, or going forward.

**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.

**Recurrence** – The return of symptoms.

**Reservoir** – Part of the shunt where the CSF is stored and then released periodically.

**Revision** – An operation is performed to replace one part of the shunt, or the entire system (of the shunt).

**Rule out** – Term used in medicine, meaning to eliminate or exclude something from consideration for diagnosis.

**Shunts** – A mechanical device implanted that drains excess CSF to another part of the body where it can be absorbed and discarded. There are many types and the neurosurgeon will choose the one he feels will benefit the patient the best ~ and of course, depending on type (where the blockage is or if it is a communicating type of hydrocephalus). The most commonly used shunts are: Ventriculoperitoneal (VP) Shunt, Ventriculoatrial (VA) Shunt, Ventriculopleural (VPI) shunt, and Lumboperitoneal (LP) shunt.

**Spinal Tap** – (Also called a Lumbar Puncture and/or Lumbar Tap.) The insertion of a hollow needle to remove some of the CSF either for pathological testing (i.e. for infection), or to relieve some pressure and see if the patient improves.

**Symptom** – Any subjective evidence of disease.

**Under Draining** – This occurs when not enough of the CSF is taken. Symptoms usually come about when the patient is reclining or laying down. The patient may wake up with a headache which generally disappears after the patient has been upright for 45 minutes to an hour.

**Unsteadiness** – Loss of one's equilibrium in regard to the environment.

**Urinary** – Having to do with the function or anatomy of the kidneys, ureters, or bladder.

**Urinary incontinence** – The unintentional loss of urine.

**Valve** – Mechanical device (in the shunt) which regulates the flow by opening and closing.

**Ventricles** – See Cerebral Ventricles.

**Ventriculopleural Shunt (VPI)** – Type of shunt where the distal catheter drains in the pleural space that surrounds the lungs.

# 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 (877) 621-8014.

## 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 <input type="checkbox"/> Yes <input type="checkbox"/> No	Part B <input type="checkbox"/> Yes <input type="checkbox"/> 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	Insured 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: \_\_\_\_\_

## Barrow Treatment Team Clinics

### **Maggie Bobrowitz, RN, MBA**

#### **NPH Program Coordinator**

Barrow Neurological Institute  
350 W. Thomas Rd  
Phoenix, AZ 85013

**Office** (602) 406-7585  
**Fax** (602) 728-9003  
**Email** [margaret.bobrowitz@dignityhealth.org](mailto:margaret.bobrowitz@dignityhealth.org)

## Neurology

### **Terry Fife, MD**

Normal Pressure Hydrocephalus Clinic  
240 W. Thomas Road, Suite 301  
Phoenix, Arizona 85013

**Office** (602) 406-4784  
**Fax** (602) 798-9963  
**Contact** Deanna Hernandez

### **Kamal Saha, MD**

Normal Pressure Hydrocephalus Clinic  
240 W. Thomas Road, Suite 301  
Phoenix, Arizona 85013

**Office** (602) 406-4784  
**Fax** (602) 798-9963  
**Contact** Deanna Hernandez

### **Jiong Shi, MD, PhD**

#### **Medical Director, Barrow NPH Program, Normal Pressure Hydrocephalus Clinic**

Normal Pressure Hydrocephalus Clinic  
240 W. Thomas Road, Suite 301  
Phoenix, Arizona 85013

**Office** (602) 406-4784  
**Fax** (602) 798-9963  
**Contact** Deanna Hernandez

### **Maria Peoples, AG-ACNP**

Normal Pressure Hydrocephalus Clinic  
240 W. Thomas Road, Suite 301  
Phoenix, Arizona 85013

**Office** (602) 406-4784  
**Fax** (602) 798-9963  
**Contact** Deanna Hernandez

## Neurosurgery

### **Peter Nakaji, MD**

Barrow Brain & Spine  
2910 N. 3rd Avenue  
Phoenix, AZ 85013

**Office** (602) 406-4808  
**Fax** (602) 406-3257  
**Contact** Ann Suter, Diane Dorsey,  
Edna Ramirez

### **F. David Barranco, MD**

Barrow Brain & Spine  
2910 N. 3rd Avenue  
Phoenix, AZ 85013

**Office** (602) 406-4760  
**Fax** (602) 406-6112  
**Contact** Cassie Houselog

### **Kris Smith, MD**

#### **Surgical Director, Barrow NPH Program, Barrow Brain & Spine**

Barrow Brain & Spine  
2910 N. 3rd Avenue  
Phoenix, AZ 85013

**Office** (602) 406-7750  
**Fax** (602) 406-6398  
**Contact** Alma Viniegra,  
Bonnie Burroughs

## Clinical Neuropsychology

### **Alexander Troster, PhD**

Barrow Neurological Institute  
222 W. Thomas Road Suite 315  
Phoenix, AZ 85013

**Office** (602) 406-3671  
**Fax** (602) 406-6115  
**Contact** Mary Henry

### **Krista Hanson, PhD**

Barrow Neurological Institute  
222 W. Thomas Road Suite 315  
Phoenix, AZ 85013

**Office** (602) 406-3671  
**Fax** (602) 406-6115  
**Contact** Mary Henry

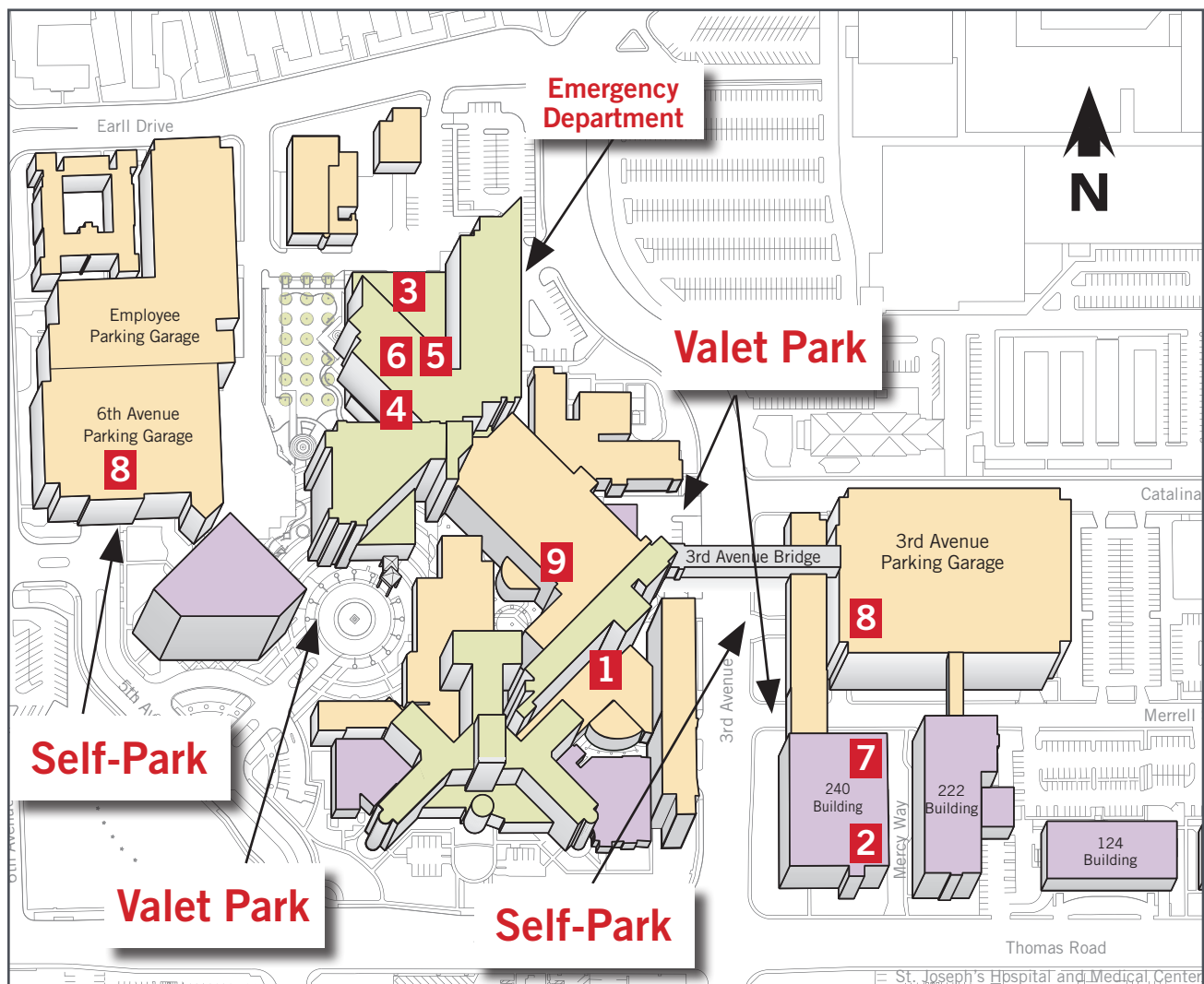
### **Wil Schultz, PhD**

Barrow Neurological Institute  
222 W. Thomas Road Suite 315  
Phoenix, AZ 85013

**Office** (602) 406-3671  
**Fax** (602) 406-6115  
**Contact** Mary Henry

## Key indicates the following areas:

1. Barrow Brain and Spine (1st floor, Heart & Lung Tower)
2. Department of Neurology (3rd and 4th floors, 240 Building)
3. Neurosurgery (2nd floor, Neuroscience Tower)
4. Neurosurgical Waiting Room (2nd floor, Neuroscience Tower)
5. PACU (post-anesthesia care unit - "recovery room") (2nd floor, Neuroscience Tower)
6. Preoperative Center (2nd floor, Neuroscience Tower)
7. Neuro-Rehabilitation (2nd floor, 240 Building)
8. Parking Structures (6th and 3rd Avenues)
9. Cafeteria & ATM machine (1st floor, Ancillary Building)



# 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 #
<i>EXAMPLE Dr. James Rogers - Neurologist CRS Clinic, St. Joseph's Hospital</i>	<i>124 W. Thomas Rd Phoenix, AZ 85013</i>	<i>602-406-6400 Ext 102 Mary - nurse</i>	<i>8am - 4:30pm</i>	<i>061-3P-R349</i>

## Pharmacy Information

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

<b>Pharmacy</b>	Hours
Phone	Fax
Address	

<b>Pharmacy</b>	Hours
Phone	Fax
Address	

<b>Pharmacy</b>	Hours
Phone	Fax
Address	

<b>Pharmacy</b>	Hours
Phone	Fax
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
<i>EXAMPLE</i> <i>Penicillin</i>	<i>Hives</i>

## Medications

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



# Health Problems

List significant past and present health problems.

Date	Health Problem & Illness	Treatment

# 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 (877) 621-8014.

# 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?

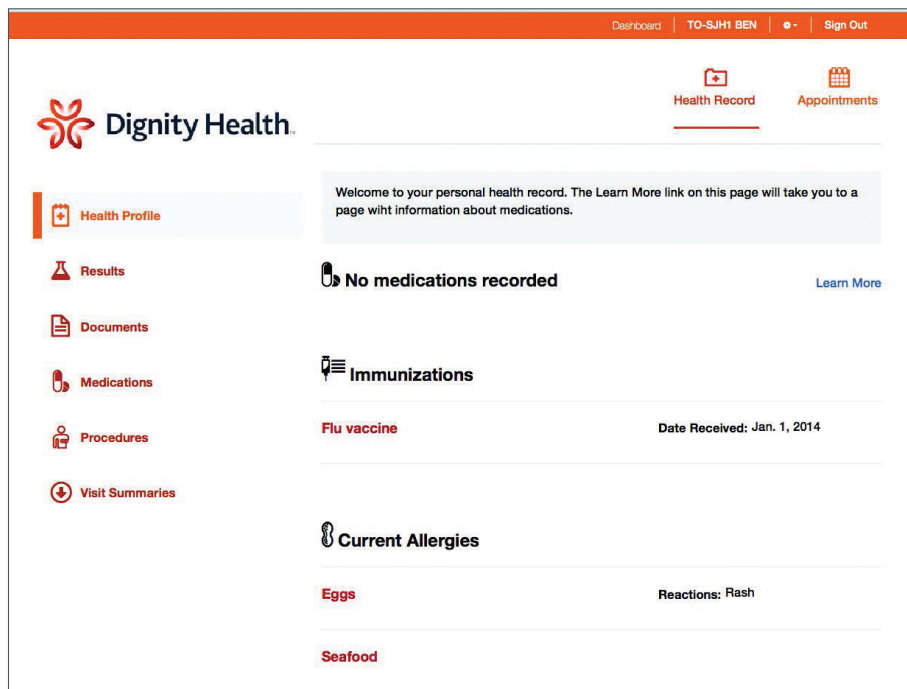
Once you've enrolled, the Dignity Health Online Patient Center offers support 24 hours a day, seven days a week by telephone, toll-free at 877.621.8014, or on the web at [DignityHealth.org/Patients](http://DignityHealth.org/Patients), and select your hospital from the drop down menu in your geographic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



## 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



**Dignity Health™**

## 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. Call the healthcare facility and ask for the radiology file room to request a copy of the radiology report.

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. You 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 you have a copy of the radiology report?
				Y   N
				Y   N
				Y   N
				Y   N
				Y   N
				Y   N
				Y   N

# Treatment Information

Include surgeries, radiation, and chemotherapy.

Date	Treatment	Doctor's Name	Hospital/Facility

# 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 track 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.

If you need to obtain your radiology exams, call the hospital or radiology facility and ask for the radiology file room. They will need to know your name, date of birth, date of the exam, and medical record number if you have it. Ask for your exams to be burned on a

CD so that you can pick them up. Ask to have a copy of the radiology report included. You may be asked to sign a release form when you pick up the CDs.

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.



# Appointments

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

# Appointments

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

## Questions for my Doctor

Date of Appointment	Name of Doctor	Questions	Answers

# Questions for my Doctor

Date of Appointment	Name of Doctor	Questions	Answers

## Information & Instructions

As you receive information about your health, treatments, and follow-up care, store it in this handbook to refer to as needed. You may want to review the information before and after surgery, share it with a friend or relative, or discuss it with your doctor.

Record instructions and follow-up care information below.

Date	Instructions	Instructions received from:

# Information & Instructions

As you receive information about your health, treatments, and follow-up care, store it in this handbook to refer to as needed. You may want to review the information before and after surgery, share it with a friend or relative, or discuss it with your doctor.

Record instructions and follow-up care information below.

Date	Instructions	Instructions received from:

## Notes

[illegible]



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St. Joseph's Hospital and  
Medical Center