Dear Patient,

Welcome to the National Institutes of Health!

We want your visit to go as smoothly as possible. To help with that, we’ve compiled this welcome packet. You will be given a copy of this packet when you arrive at the NIH. The packet contains some important forms for our protocol, as well as some information you may find helpful during your visit. Please take the time to look over the enclosed materials. More detailed information on what is enclosed in this packet is available on the next page.

If you have any questions, comments, or concerns, please do not hesitate to contact us. Our contact information can be found at the end of this packet.

We look forward to seeing you soon!

Sincerely,

Karen T. Adams, CRNP, MSc.  
Program Coordinator

Tory Martucci  
Genetic Screening Coordinator
Welcome Packet Contents

This welcome packet will help orient you to the NIH and prepare you for your visit. Please take the time to read this letter and look over the enclosed materials.

The packet includes:

- A copy of your schedule

You should have received a copy of your schedule via email prior to your visit. **It is very important that you are on time for all scans and appointments, so please look at your schedule carefully.** During the course of your visit, your schedule may be modified or updated, so please be sure we have a contact number where we can reach you during your stay here. Whenever possible, we will also give you a hard copy of the schedule.

- Forms for your visit

In addition to the forms you will (or have already) filled out at Admissions, there are several forms that are required for our protocol. These include:

  a) Protocol consent form (new patients only)

  The protocol consent form explains our protocol, and lists all the testing we can perform on our patients. **Please note that every test will not be performed on every patient.** We will decide which testing is necessary for clinical diagnosis on an individual basis.

  It is important to note that this is a **volunteer study**, which means that you may withdraw at any point if you no longer wish to participate.

  Please take the time to read this consent form carefully. The copy in this packet is yours to keep. A member of our team will bring you a consent form to sign at your first appointment.

  b) Privacy Act letter (new patients only)

  As part of our protocol, we collect blood for genetic testing on all pheo patients. This blood is tested for mutations in the succinate dehydrogenase (SDH) subunit B, C, and D genes. Mutations in these genes are linked to a predisposition to pheochromocytoma/paraganglioma development. This testing is not done in a CLIA-certified laboratory, but is done in a research setting. While the testing is still accurate, the results are not considered official, which means that special permission must be obtained in order to release these results. Please take the time to fill out your address and the date at the top of the page, and sign and print your...
name and birthdate at the bottom. This allows us to send you a letter with your results when they are available. A member of our team will collect this from you at your first appointment.

c) Present Health Questionnaire (all patients)

This form asks about your current health status and any important medical information. A member of our team will go through this form with you and ask you to sign it at your first appointment.

d) Visitor ID Badge Form (all patients)

As a patient or patient visitor, you are entitled to an extended visitor badge, which allows you access to campus via any entrance. More information on this form, as well as instructions, are attached to the form. The badges are active for one year, so if you have received a badge within the last year, you do not need to complete this form.

- Visit information

The left side of this folder contains information that you may find useful during your visit. This includes information about the Safra Family Lodge and the Children’s Inn, maps of the NIH Campus and the Clinical Research Center (Building 10), and NIH shuttle schedules.

If this is your first visit to the NIH, and you have not yet gone through Admissions, please do so upon arrival. It is best to go to Admissions the afternoon or evening before any scheduled tests, as the Admissions process can take over an hour to complete. You must have completed the Admissions process before you can undergo any tests.

More information on our protocol and the NIH is available on our website, https://science.nichd.nih.gov/confluence/display/pheo/Home.
CONSENT TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

MEDICAL RECORD
• Adult Patient or • Parent, for Minor Patient

INSTITUTE: National Institute of Child Health and Human Development

STUDY NUMBER: 00-CH-0093 PRINCIPAL INVESTIGATOR: Karel Pacak, M.D., Ph.D., D.Sc.

STUDY TITLE: Diagnosis, Pathophysiology, and Molecular Biology of Pheochromocytoma and Paraganglioma

Continuing Review Approved by the IRB on 05/25/11
Amendment Approved by the IRB on 07/25/11 (MMM)
Date Posted to Web: 08/20/11

INTRODUCTION

We invite you to take part in a research study at the National Institutes of Health (NIH).

First, we want you to know that:
Taking part in NIH research is entirely voluntary.

You may choose not to take part, or you may withdraw from the study at any time. In either case, you will not lose any benefits to which you are otherwise entitled. However, to receive care at the NIH, you must be taking part in a study or be under evaluation for study participation.

You may receive no benefit from taking part. The research may give us knowledge that may help people in the future.

Second, some people have personal, religious or ethical beliefs that may limit the kinds of medical or research treatments they would want to receive (such as blood transfusions). If you have such beliefs, please discuss them with your NIH doctors or research team before you agree to the study.

Now we will describe this research study. Before you decide to take part, please take as much time as you need to ask any questions and discuss this study with anyone at NIH, or with family, friends or your personal physician or other health professional.

OVERVIEW OF THE STUDY

We are inviting you to participate in this study because we believe you may have pheochromocytoma, a tumor located either in or outside the adrenal gland, or may carry a genetic predisposition towards developing pheochromocytoma. Pheochromocytomas are a surgically correctable cause of chronic high blood pressure. The clinical features and consequences of pheochromocytoma result from release of substances called catecholamines (epinephrine and norepinephrine) by the tumor. We wish to know whether various biochemical and scanning methods will improve our ability to diagnose and localize a pheochromocytoma. In addition, we wish to find out if there are any specific genetic or other markers to predict the course, malignant potential, and recurrence of pheochromocytoma. Some of this testing is not available elsewhere and so may benefit you.

The main goal of this study is to develop new tests to diagnose and find a pheochromocytoma. If a pheochromocytoma is undetected, situations that normally would not pose a hazard, such as surgery, childbirth, or general anesthesia, can evoke catecholamine release by the tumor, with catastrophic results, such as stroke, heart attack, or sudden death. Both the
detection of pheochromocytoma and locating the tumor can be difficult. Commonly used diagnostic imaging methods such as computed tomography (CT scanning) and magnetic resonance imaging (MRI scanning) are very good at locating a mass. Metaiodobenzylguanidine (MIBG), bone, octreotide, and fluorodeoxyglucose (FDG) positron emission tomography (PET) scans are types of nuclear medicine scans that are useful in identifying a pheochromocytoma but are not very sensitive and can miss a tumor. This protocol focuses on a new blood test and new imaging approaches, called fluorodopamine and fluorodopa and fluorothymidine PET/CT scanning.

You will be admitted to the Clinical Center of the NIH for standard medical and imaging tests, to assess whether you have pheochromocytoma. These tests include taking blood through an intravenous (i.v.) tube and collecting urine. You may also stay in a local hotel or guest house during most of this time and return to the Clinical Center for the tests. You must refrain from smoking and from consumption of any alcoholic beverages for 18 hours prior to blood testing and from taking Tylenol™ (generic name acetaminophen) in any form for 5 days prior to blood testing. Water is the only permissible beverage.

If diagnostic tests indicate that you have a pheochromocytoma, you will be offered surgery at the NIH. You may benefit from the detection and removal of a previously unrecognized tumor. If the tumor cannot be found, you may be offered medical treatment, and we will continue to look for the tumor in follow-up evaluations. If surgery is not indicated (e.g., if you have multiple tumors that cannot be removed), then you may have follow-up evaluations to assess the size and number of tumors.

You may be offered genetic testing through the NIH to detect genetic mutations known to cause pheochromocytoma. If the results of the genetic testing indicate that you are positive for a mutation, we may extend the genetic testing opportunity to your first-degree relatives. Those that are positive for the mutation may be invited to the NIH for a history and physical examination, as well as relevant biochemical and imaging studies to detect pheochromocytoma. If pheochromocytoma is detected, the same management outlined above will be offered.

Pheochromocytoma can occur as part of diseases that run in families. At least four familial conditions are associated with pheochromocytoma: multiple endocrine neoplasia type 2 (MEN 2); von Hippel-Lindau (VHL) disease; neurofibromatosis type 1 (NF 1), and alteration of the gene for succinate dehydrogenase (SDHx). If you have an inherited disease that is associated with an increased risk of developing a pheochromocytoma, we will discuss with you the chances of developing this tumor. If appropriate, we will arrange counseling with a genetic counselor.

As part of this protocol, we will be taking photographs of you at your first visit to facilitate facial recognition of patients by our medical team. Your photograph will be secured in a locked room and will only be used by members of our team for recognition purposes.

You will not be paid for your participation in this study. However, all protocol-related tests, procedures, and hospitalization at the NIH are without cost to you.

You are free to withdraw from the study at any time. Should you do so, we will not continue further diagnostic tests and we will not perform surgery at the NIH. Any information obtained up to that time will be made available to you and your physician.

**BLOOD TESTS FOR PHEOCHROMOCYTOMA**

We have found that the measurements of catecholamines and their breakdown products, metanephrines, provide an extremely sensitive way to detect pheochromocytomas. If the blood tests are negative, then you do not have the tumor.

We don't know, however, whether a positive test necessarily means that you do have the tumor. This study considers this problem.
For blood tests you should remain in the lying position, resting, for at least 20 minutes before and during collection of the blood samples (10 cc, about 2 teaspoons). The samples are drawn without a tourniquet, through an indwelling i.v. catheter. No more than 10.5 mL/kg or 550 mL of blood will be drawn over an eight-week period.

You may receive two drugs, glucagon and clonidine, which are used in standard medical evaluation of pheochromocytoma. At least 20 minutes before the test, two i.v. catheters are inserted into your arm veins, and you rest in the lying position. Glucagon and clonidine tests are usually done in the same testing session.

**GLUCAGON STIMULATION TEST (FDA APPROVED)**

This test is used to determine if a suspected pheochromocytoma can be stimulated to produce significant increases in plasma catecholamine levels. You receive 1.0 mg glucagon i.v. over 30 seconds. Blood pressure and heart rate are measured every minute for at least 5 minutes before and for at least 15 minutes after glucagon is given. Five blood samples (10 cc, about 2 teaspoons) are obtained through the i.v. catheter, for levels of catecholamines and metanephrines at intervals 0, 1, 2, 3, and 5 minutes after glucagon is given. In patients with pheochromocytoma, blood pressure and heart rate can increase within 30-60 seconds and last for several minutes after glucagon is given. Severe allergic reactions are very rare, but increased sweatiness, nausea, sometimes vomiting, as well as a feeling of a need to urinate may occur after glucagon administration. A physician will administer glucagon and be present during the entire test. An antidote drug will be immediately available if there is a prolonged, excessive increase in blood pressure.

**CLONIDINE SUPPRESSION TEST (FDA APPROVED)**

This test is used to determine if you have high levels of plasma catecholamines being released from a pheochromocytoma. You receive 0.3 mg clonidine/70 kg by mouth. Blood pressure and heart rate are monitored every 5 minutes for 20 minutes before and every 15 minutes for 3 hours after administration of clonidine. Blood is drawn via an i.v. catheter for levels of catecholamines and metanephrines before and after clonidine is given. Clonidine often causes drowsiness and a fall in blood pressure, regardless of the presence of pheochromocytoma. These effects can last several hours so you will not be allowed to drive or operate machinery until the next day.

**REGIONAL VENOUS SAMPLING**

In some unusual cases, pheochromocytomas may not be located by typical imaging studies. In other cases one or more masses may be found that are suspicious but not identified as pheochromocytomas. In these situations it may be appropriate to do a test called selective vena caval sampling. This is a clinically indicated, not a research, procedure. The testing involves inserting a long intravenous tube into a major blood vessel returning blood to the heart (i.e., the inferior vena cava) to sample blood from veins draining organs in the neck, chest, abdomen, or pelvis. The blood is assayed for levels of catecholamines and metanephrines. Because of the clinical indication for selective vena caval sampling, radiation exposure related to the procedure is not included in the dosimetric estimates for use of radioactivity for research purposes.

**BONE TURNOVER MARKERS**

High levels of catecholamines may contribute to the development of osteoporosis. To screen for such a condition 2 ml of blood will be collected to measure 25(OH) vitamin D, parathormone, alkaline phosphatase, bone-specific alkaline phosphatase, and osteocalcin. Spots and twenty-four hour urine samples will be also collected to measure calcium, phosphorus, hydroxyproline, deoxypyridinoline, and pyridinoline.

**TESTS BASED ON IMAGING**
Clinically indicated imaging tests used in the evaluation of pheochromocytoma will include computed tomography (CT scanning), magnetic resonance imaging (MRI), sonography, bone and octreotide scans, $^{[123]}$I- or $^{[131]}$I-MIBG scintigraphy, and fluorodeoxyglucose (FDG) PET and DEXA scanning. You may undergo imaging studies before and after surgical treatment of pheochromocytoma. Fluorodopamine, fluorodopa and fluorothymidine PET/CT's are considered research procedures.

**STANDARD IMAGING PROCEDURES**

Standard imaging procedures require you to lie still, either in an enclosed tube (the MRI scanner) or in a more open “doughnut” shaped tube (CT scanner). Some patients feel closed in or anxious in the MRI scanner. If this is a problem for you, we may give you a sedative, or use an alternative test. The approximate times for the studies are as follows: CT of neck, chest, abdomen, and pelvis 2 minutes; MRI of neck, chest, abdomen, and pelvis 1-2 hours. If CT is done using intravenous dye, you will be asked not to take any food 4 hours before the test. Occasionally, CT dye can cause hypertensive crisis. You may also have blood sampling done shortly before and immediately after CT scan is completed. A physician from our research team will be drawing blood samples and supervise you during CT scan. FDG scans take up to 2 h total, MIBG scans up to 3-4 hrs over 2 days, octreotide up to 1.5-3 h over 1 or 2 days.

**MIBG SCINTIGRAPHY**

To block thyroid hormone accumulation of radioiodine generated from deiodination of $^{[123]}$I-MIBG or $^{[131]}$I-MIBG, you will be required to take medication called SSKI or potassium perchlorate (if you are allergic to iodides), 1 day before and 3-7 days after $^{[123]}$I-MIBG or $^{[131]}$I-MIBG administration, respectively.

**DEXA SCANNING**

Dual-energy x-ray absorptiometry (DXA) or bone densitometry (DEXA) is an X-ray often performed on the lower spine and hips. During DEXA examination, the patient lies on a padded table. An x-ray generator is located below the patient and an imaging device, or detector, is positioned above. DEXA is quick, lasting from 10-30 min and is painless. DEXA examination is equal to about 30 minutes of background radiation. This test is an excellent standard for measuring bone mineral density and diagnosis of osteoporosis.

**FLUORODEOXYGLUCOSE (FDG) PET SCANNING**

After injection of radioactive fluorodeoxyglucose (FDG), the tumor cells become radioactive, allowing the tumors to be seen on the PET scan. These FDG PET scans will be performed as clinically indicated procedures.

You will not be permitted to eat anything for 6 hours before the test is started, but will be allowed to drink as much water as you wish. If possible, you should drink 2 to 3 glasses of water before the test. The entire study will take about 2 hours. FDG PET scanning is done in the Nuclear Medicine Department of the NIH Clinical Center. You will receive an injection of FDG and after 1 h of resting quietly standard scans will be obtained over portions of your body. During this time you will need to lie very still. If for any reason you feel that you cannot continue the scan once it has begun, the scanning can be stopped and you can be removed from the camera immediately. However, the information from the scan may be lost.

After the scan is finished, you will be asked to empty your bladder every 90 minutes for the next 6 hours to remove the radioactive compound in the urine.

**FLUORODOPAMINE, FLUORODOPA AND FLUOROTHYMIDINE PET/CT SCANNING (RESEARCH SCANS)**
The basis for visualization of pheochromocytoma in this study is PET scanning after injection of a synthetic, radioactive catecholamine called fluorodopamine or a synthetic radioactive catecholamine precursor called fluorodopa. Both radiopharmaceuticals fluorodopamine and fluorodopa offer promise for improved detection and localization of pheochromocytoma.

After injection of radioactive fluorodopamine, it enters pheochromocytoma cells and these cells become radioactive, allowing us to see the tumors on the PET scan. Most cells in the body do not become radioactive after fluorodopamine injection. This means that if we see that a mass takes up the radioactivity and concentrates it, it is likely to be a pheochromocytoma.

Another PET agent that can be used in the localization of pheochromocytoma is fluorodopa. The compound dopa is an amino acid. Amino acids are present in our body and are used to build proteins and transmit signals. Fluorodopa enters pheochromocytoma cells, they become radioactive and the PET scanner detects them. Also most cells in the body do not become radioactive after fluorodopa injection. You will receive a single oral administration of 200 mg of carbidopa 60 minutes prior to fluorodopa injection. This procedure increases the amount of fluorodopa in tumor. Carbidopa is a drug that is often used in the treatment of Parkinson disease.

You will not be permitted to eat anything for about 6 hours before these tests are started, but will be allowed to drink as much water as you wish. If possible you should drink 2 to 3 glasses of water before the test. Fluorothymidine (FLT) is another PET agent given intravenously can be used in conjunction with the tumor localization methods to evaluate the biologic activity of the tumors. Thymidine is taken in by proliferating cells and used for DNA synthesis. A radiolabeled thymidine ([18F] FLT) detected by the scan will be used. The scan will monitor the rate of thymidine uptake into the tissue. This will provide information on the proliferative behavior of the tumor.

The PET/CT scanning is done in the PET Department of the NIH Clinical Center. The scanner is shaped like a doughnut, and the part of your body being scanned is in the hole. You are placed in the scanner, with the head, neck, chest, abdomen, pelvis, or extremities in the field of view. Initial scanning consists of transmission/attenuation CT scanning and is done for the purpose of correcting the imaging data for the density of different organs as well as determining the localization of the abnormalities. A plastic catheter is inserted into an arm vein for injection of drugs (fluorodopamine, fluorodopa and fluorothymidine). The investigational drugs are tested by a quality control facility just prior to use. The injection of fluorodopamine, fluorodopa and fluorothymidine lasts 3 minutes. During the injection you should feel nothing unusual. The PET/CT scanning can last up to about 2 hours. You will also be asked to get up and empty your bladder prior to getting into the scanner. Throughout the PET/CT scanning, you will be monitored by a physician or Research Nurse.

After the scan is finished, you will be asked to empty your bladder every 90 minutes for the next 6 hours to remove the radioactive compound in the urine.

Fluorodopamine, fluorodopa and fluorothymidine PET/CT scans are research tests. We, therefore, do not know whether the results of these PET/CT scans will benefit you directly.

**ADDITIONAL DIAGNOSTIC TESTING**

**URINE TESTING**

<table>
<thead>
<tr>
<th>PATIENT IDENTIFICATION</th>
<th>CONTINUATION SHEET for either:</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIH-2514-1 (10-84)</td>
<td>NIH-2514-2 (10-84)</td>
</tr>
<tr>
<td>NIH-2514-2 (10-84)</td>
<td>P.A.: 09-25-0099</td>
</tr>
</tbody>
</table>
Urine for biochemical diagnosis of pheochromocytoma will be collected and sent to the Department of the Laboratory Medicine at the NIH Clinical Center. Any of several medications can interfere with the test results and, therefore, all medications you are taking must be reviewed.

**GENETIC TESTING**

Pheochromocytoma can be associated with a genetic change called a mutation. If all your genetic information (DNA) were a book, the genes would be words, and a mutation would be a typographical error in one of the words. To detect such a genetic typo, we will collect 3-7 ml of your blood and extract the DNA. We may compare the DNA in your blood cells with that from people who do not have a pheochromocytoma or with the DNA in tumor cells.

Samples of your blood cells or genetic material (DNA) will be used either for the diagnosis or for research about your medical condition. The genetic testing will be performed either by a CLIA certified laboratory or a non-certified laboratory (e.g. research laboratory). Even though the sensitivity and quality of the test parallel that of a certified laboratory, the results from a non-certified laboratory will be classified as research and are not official. You may pursue genetic testing at a CLIA certified laboratory at your own cost. We may invite your family members to participate in the pheochromocytoma study based on the research test results or the CLIA certified results. The research may be done at the NIH. No other genetic testing will be done using your DNA unless you give specific permission, as indicated below. Genetic test results performed at a research laboratory can only be provided to you or those with whom you intend to share the results, under the Privacy Act of 1974, after you indicate your desire by signing a separate permission form.

There are certain risks from tests run on genetic samples. Instances are known in which a patient has been required to furnish genetic information as a precondition for application for health insurance and/or a job. There are ways your life could be affected by information that may be discovered by genetic testing. Another factor to consider in thinking about whether or not to participate in this study includes the potential effects on your psychological well-being. In other words, how might you feel about yourself if information is provided to you about risks that could affect your own future health or that of your children? Some individuals may feel anxious or depressed or suffer additional stress as a result of learning genetic information about themselves or their children. You may experience similar feelings. We will try to help you or refer you to someone if you experience these feelings.

**BIOPSY**

The biopsy will determine if you have pheochromocytoma. This is especially important in a situation such as when your fluorodopamine scan is positive but your plasma catecholamine and metanephrine levels are normal or if you have metastatic pheochromocytoma. The biopsy will be performed after you are given appropriate medicine to prevent the action of catecholamines released from a possible pheochromocytoma during the biopsy. The medicine includes alpha and beta blockers given for at least 3-5 days prior to the biopsy. The biopsy will be done either by a surgeon or by an interventional radiologist under local anesthesia. There will be an anesthesiologist and endocrinologist at the bedside during the biopsy.

**CELL CULTURE**

If you have a pheochromocytoma removed surgically, we may try to grow the cells in a cell culture. We believe that pheochromocytoma research would benefit from the establishment of a human pheochromocytoma cell line. Having available a human pheochromocytoma cell line should help us study the potential for malignancy or recurrence, develop and test new imaging techniques, and evaluate potential new treatments.

**HAZARDS, RISKS, INCONVENIENCES, AND DISCOMFORTS**
Pain Inserting an i.v. catheter can cause local discomfort, clotting, bleeding, or infection. There is a slight, but definite risk of entering an artery, rather than a vein, and this could result in bleeding, bruising, or communication between the artery and vein. We have a sound wave detector available that enables us to "see" the vein even in difficult cases. We estimate less than a 1% risk of local complications other than bruising. Bruising or mild discomfort can last for several days following the procedure. These complications are generally transient and permanent damage is extremely rare.

Biopsy Although our surgeons and interventional radiologists have vast experience with biopsies of various organs or bones, inserting a needle in the area of interest can cause local discomfort, bleeding, or infection. Discomfort will be treated with standard pain medication, usually Tylenol or Tylenol with codeine. A few stitches might be placed to close the skin wound.

Allergy Some people are allergic to iodinated radiographic contrast agents. If you have any allergy to those agents, you must let us know to ensure that alternative imaging studies are used, appropriate pre-treatments are given, and to ensure that appropriate allergy medications are made immediately available.

Pregnancy If you are a woman of child-bearing age, we will perform a urine or blood test for pregnancy within 24 hours before any test involving radioactivity. If you are pregnant, imaging studies such as fluorodopamine, florodopa, fluorothymidine PET/CT, MIBG, octreotide, and bone scans and contrast CT will be not performed. If you are more than 26 weeks pregnant, you cannot be studied in the NIH Clinical Center.

Blood sampling No more than 310 ml (about 11 ounces) of blood will be taken for this study. You will not be accepted into the study if the total amount of blood required for all testing is more than the recommended NIH guideline amount for research subjects (550 ml over any eight-week period).

Unexpected findings Because of the investigational nature of this study, we may not understand the significance of all findings. For instance, PET or MIBG scanning may identify abnormalities that are not tumors. Such results are called false positive results. If unexplained or unusual findings occur we may recommend other tests to help explain these findings to determine their significance.

We will not recommend surgery if only the fluorodopamine/DOPA PET, MIBI or MIBG scans are positive. We require that at least one of the conventional imaging tests (CT or MRI) also be positive to be recommended for surgery. Thus, some patients with positive imaging will have surgical confirmation of pheochromocytoma while others will not.

Follow-Up You may return for follow-up conventional imaging or PET scanning at a later date, such as after surgery. The completeness of tumor resection will be evaluated by biochemical testing 1-2 months after the operation. You will be followed on a yearly basis thereafter. If pheochromocytoma recurs, or if you are not cured by initial surgery, you will be offered re-evaluation to localize the residual tumor or recurrence. In such cases, the clinical, biochemical, and imaging tests may be repeated. This would take place only with your additional, separate consent. If no pheochromocytoma is found, you will be referred back to your primary physician.

Bladder catheter For your comfort and convenience, and at your request, you may have a bladder catheter inserted during the research testing. The use of a bladder catheter may be associated with local discomfort and an increased risk of urinary tract infection.

RADIATION

This study involves the use of radiation from PET scanning with fluorodopamine, florodopa, fluorothymidine, the associated attenuation CT scans and DEXA scan. Please note that this radiation exposure is not necessary for your medical
care and is for research purposes only. Other radiographic and nuclear medicine studies are performed as part of standard clinical care. You may not participate in this study if you are pregnant or nursing. Unborn or nursing children are more sensitive to radiation than adults and children.

**FLUORODOPAMINE, FLUORODOPA AND FLUOROTHYMIDINE PET/CT’s**

Within 1 year, this research study may involve exposure to radiation from: 3 fluorodopamine PET scans using 1 mCi fluorodopamine per scan; 2 fluoroDOPA PET scans using 12 mCi fluorodopa per scan; 2 Fluorothymidine PET scans using 5 mCi fluorothymidine per scan as well as the radiation associated with the attenuation CT scans that are used to help generate the PET images and localize the abnormalities. The radiation exposure associated with the PET/CT scans is not necessary for your medical care and is for research purposes only.

Radiation dose is commonly expressed in units called rem. The amount of radiation an adult would receive during this study in one year is 5.3 rem if all studies are performed. Based on the guidelines of NIH Radiation Safety Committee, the maximum radiation dose per year for adult research subjects is 5 rem, hence the amount of radiation received in this study exceeds the dose guidelines. The radiation exposure in this protocol was deemed to be an acceptable risk and necessary to obtain the desired research information by the NIH Radiation Safety Committee.

The average person in the United States receives a radiation exposure of 0.3 rem per year from natural sources, such as the sun, outer space, and the earth's air and soil. If you would like more information about radiation, please ask the investigator for a copy of the pamphlet “An Introduction to Radiation for NIH Research Subjects”.

The effects of radiation exposure on humans have been studied for over 60 years. In fact, these studies are the most extensive ever done of any potentially harmful agent that could affect humans. In all these studies, no harmful effect to humans has been observed from the levels of radiation you will receive by taking part in this research study. However, scientists disagree on whether radiation doses at these levels are harmful. Even though no effects have been observed, some scientists believe that radiation can be harmful at any dose – even low doses such as those received during this research.

One possible effect that could occur at these doses is a slight increase in the risk of cancer. This change in risk is very small and cannot be measured directly. Compared with other everyday risks, such as flying in an airplane or driving a car, this increase is considered negligible.

One concern some people may have about radiation exposure is the effect on fertility or on the possibility of causing harm to future children (i.e., genetic risk). The doses received in the research study are well below the levels needed to affect fertility.

If you are pregnant you will not be permitted to participate in this research study. If you are breast feeding and the protocol involves injection of radioactive material you will not be permitted to participate. It is best to avoid radiation exposure to unborn or nursing infants since they are more sensitive to radiation than adults.

The fluorodopamine, fluorodopa and fluorothymidine that you receive are administered under an Investigational New Drug approval from the US Food and Drug Administration (FDA), with Peter Herscovitch, M.D. as the Sponsor. Both Sponsor and the FDA have access to the medical records of research subjects.
Please let us know if you have participated in research studies at the NIH or other institutions that have involved the use of radiation, to ensure that the total radiation dose from all studies is not excessive. Examples of such studies include X-ray studies, cardiac catheterization, fluoroscopy, or nuclear medicine studies.

**CONTRAST AND DRUG DYE EFFECTS**

Fluorodopamine, fluorodopa and fluorothymidine administered at the approved doses should not exert detectable pharmacological effects.

Glucagon testing can provoke attacks due to catecholamine release by a pheochromocytoma. These attacks are generally milder and of much shorter duration than spontaneous attacks and usually require no treatment. In the rare instance of an extremely large or sustained release of catecholamines, the blood pressure can be controlled readily by means of i.v. drugs (phentolamine and metoprolol). These drugs are always immediately available for emergency use.

We, and many others, have used glucagon as a provocative test for pheochromocytoma for many years without significant adverse effects. Glucagon administration can also cause transient nausea, vomiting, or allergic reactions.

Clonidine often causes sedation and a decrease in blood pressure. Sometimes it produces a headache, dizziness, or generalized weakness. In such a situation, the patient is positioned in bed with the head down or legs up, and normal saline can be given i.v.

**OTHER GENERAL ISSUES RELATED TO THIS PROTOCOL**

1. **Unanticipated medical information.** During the course of this or future investigations, it is possible (although not likely) that we may obtain unanticipated information about your health or genetic background. If this information is considered to be relevant to your health care, we will provide it either to you or to your referring physician.

2. **Release of medical records.** In the course of applying for certain types of insurance (e.g., medical insurance, life insurance, or disability insurance), people are often asked to sign forms that authorize insurance companies to obtain their medical records. If you sign such a release form at some point in the future, it is possible the insurance company would present this signed release form to the Clinical Center of the (NIH). In that event the NIH would comply with your request to provide the insurance company with your medical record. It is possible that the information contained in your medical record might affect the willingness of the insurance company to sell you insurance.

3. **Family relationships.** During this study or in future studies, we may learn information about relationships within the family that are medically relevant. We will not ordinarily provide this type of information to any family member or the referring physician. However, we may make exceptions under an extraordinary circumstance if this information were required for the medical care of the individuals involved. If we are convinced that this is necessary, we will provide the information to the physician providing medical care to the patient.

4. **Participation in other research studies.** This consent form specifically refers to your participation in the research protocol described above. In the future, we may invite you to participate in other studies. Even if you sign this consent form, you are not obligated to participate in these other research protocols. If you are asked to participate in these other studies, you will be provided with additional consent forms. As stated in the Introduction to this protocol, you are free to withdraw from any or all research studies at any time without penalty or loss of any benefits to which you are otherwise entitled.

5. **Collection, research and storage of biologic material.**
During your participation in this protocol, samples of your body fluids (e.g., blood, urine) and tissues (e.g., tumor tissue taken at surgery) may be collected and stored for ongoing and future research purposes. Data about your condition will also be collected. The research carried out on these samples and the data collected will help in understanding how pheochromocytomas develop and how different forms of these tumors, including those that have become malignant, might be better diagnosed and treated. Much of this research using stored human specimens and data will be carried out by NIH investigators under the direction of the Principal Investigator of the protocol. However, some research involving your samples and data collected under the protocol may also be carried out as part of collaborations with investigators at centers outside of the NIH. In the latter situation, your samples will be coded so that your identity as the source of those samples will be protected and remain confidential to the non-NIH investigators directly involved in the research. Any data that is shared will also have identifying information removed before it can be used for collaborative research with investigators at centers outside the NIH.

Samples we collect from you will be used only for research to search for an underlying genetic association with your medical condition. No other testing or research will be conducted on your body, blood and urine samples unless you specifically give permission (as stated above).

The DNA and plasma collected from your blood and urine will be stored in freezers contained in a secured building on the NIH campus. The samples will be inventoried and stored by codes defined by us.

Researchers within the NIH, as well as from outside the NIH, may be involved or interested in using the samples of your DNA to help us pursue our objectives or their own individual research projects. The use of any DNA samples can be controlled by those who provide them, namely you. Therefore, we ask your guidance and concurrence concerning future use of your DNA samples.

I give permission to use my blood cells or DNA sample(s) in future research studies, under the following conditions:

___________ I give my permission to use my blood cells or DNA sample(s) in future research studies about known or suspected pheochromocytoma or neurocardiologic disorders as judged important by the investigators.

___________ I wish to be re-contacted if future research studies are considering using my blood cells or DNA sample(s). After the study has been explained, I will then decide if I want my samples to be included in the study.

___________ Under no circumstances shall my blood cells or DNA sample(s) be used in future research studies.

The Principal Investigator will not share any genetic test results unless you give us permission to do so by signing a separate permission form.

ALTERNATIVES TO PARTICIPATION IN THIS STUDY AND RIGHTS UPON REFUSAL OR WITHDRAWAL FROM THIS STUDY

The choice to enter or not enter this study is entirely voluntary. Before you decide to enter or not, you should understand what the doctor has explained and what you have read about the research study. If you decide not to participate your enrollment in any other NIH protocol will not be affected. If you choose to begin this study you have the right to withdraw at any time.

As noted above, many other physicians and centers are experienced in the evaluation and treatment of patients with pheochromocytoma. These centers will commonly rely on many of the same tests that we use to determine the cause of
your symptoms. While some tests that we perform are not widely available (such as fluorodopamine PET scanning) they may not be critical to your specific case.

We cannot predict which patients will benefit from the additional tests offered in this study. If you are not sure that you wish to participate in this study, let us know at any time, and we will refer you to other physicians and medical centers experienced in the evaluation and treatment of patients with pheochromocytoma.
OTHER PERTINENT INFORMATION

1. **Confidentiality.** When results of an NIH research study are reported in medical journals or at scientific meetings, the people who take part are not named and identified. In most cases, the NIH will not release any information about your research involvement without your written permission. However, if you sign a release of information form, for example, for an insurance company, the NIH will give the insurance company information from your medical record. This information might affect (either favorably or unfavorably) the willingness of the insurance company to sell you insurance.

The Federal Privacy Act protects the confidentiality of your NIH medical records. However, you should know that the Act allows release of some information from your medical record without your permission, for example, if it is required by the Food and Drug Administration (FDA), members of Congress, law enforcement officials, or authorized hospital accreditation organizations.

2. **Policy Regarding Research-Related Injuries.** The Clinical Center will provide short-term medical care for any injury resulting from your participation in research here. In general, no long-term medical care or financial compensation for research-related injuries will be provided by the National Institutes of Health, the Clinical Center, or the Federal Government. However, you have the right to pursue legal remedy if you believe that your injury justifies such action.

3. **Payments.** The amount of payment to research volunteers is guided by the National Institutes of Health policies. In general, patients are not paid for taking part in research studies at the National Institutes of Health. Reimbursement of travel and subsistence will be offered consistent with NIH guidelines.

4. **Problems or Questions.** If you have any problems or questions about this study, or about your rights as a research participant, or about any research-related injury, contact the Principal Investigator, Karel Pacak, M.D., Ph.D., D.Sc.; Building 10, CRC, Room 1E-3140, Telephone: 301-402-4594 or Karen T. Adams, CRNP; Building 10, CRC, Room 1E-3140, Telephone: 301-402-7785.

You may also call the Clinical Center Patient Representative at 301-496-2626.

5. **Consent Document.** Please keep a copy of this document in case you want to read it again.

<table>
<thead>
<tr>
<th>COMPLETE APPROPRIATE ITEM(S) BELOW:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A. Adult Patient’s Consent</strong></td>
<td><strong>B. Parent’s Permission for Minor Patient.</strong></td>
</tr>
<tr>
<td>I have read the explanation about this study and have been given the opportunity to discuss it and to ask questions. I hereby consent to take part in this study.</td>
<td>I have read the explanation about this study and have been given the opportunity to discuss it and to ask questions. I hereby give permission for my child to take part in this study. (Attach NIH 2514-2, Minor’s Assent, if applicable.)</td>
</tr>
<tr>
<td>Signature of Adult Patient/Legal Representative</td>
<td>Signature of Parent(s)/Guardian</td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
</tr>
<tr>
<td>Print Name</td>
<td>Print Name</td>
</tr>
<tr>
<td><strong>C. Child’s Verbal Assent (If Applicable)</strong></td>
<td></td>
</tr>
<tr>
<td>The information in the above consent was described to my child and my child agrees to participate in the study.</td>
<td></td>
</tr>
<tr>
<td>Signature of Parent(s)/Guardian</td>
<td>Date</td>
</tr>
<tr>
<td><strong>THIS CONSENT DOCUMENT HAS BEEN APPROVED FOR USE FROM MAY 25, 2011 THROUGH MAY 24, 2012.</strong></td>
<td></td>
</tr>
<tr>
<td>Signature of Investigator</td>
<td>Signature of Witness</td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
</tr>
<tr>
<td>Print Name</td>
<td>Print Name</td>
</tr>
</tbody>
</table>
Dear Dr. Karel Pacak,

I was tested for a mutation in the genes, succinate dehydrogenase, subunit B, C, D (SDHB/C/D) by the National Institute of Child Health and Human Development (NICHD) under protocol #00-CH-0093. I would like to request that my research genetic testing results be sent to the address above through the Privacy Act of 1974.

Sincerely,

____________________________________
Signature

____________________________________
Full Name:

____________________________________
Date of Birth:
CONSENT TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

INSTITUTE: National Institute of Child Health and Human Development

STUDY NUMBER: 00-CH-0093

PRINCIPAL INVESTIGATOR: Karel Pacak, M.D., Ph.D., D.Sc.

STUDY TITLE: Diagnosis, Pathophysiology, and Molecular Biology of Pheochromocytoma and Paraganglioma

We invite you to take part in a research study at the National Institutes of Health (NIH).

First, we want you to know that:

Taking part in NIH research is entirely voluntary. You may choose not to take part, or you may withdraw from the study at any time. In either case, you will not lose any benefits to which you are otherwise entitled. However, to receive care at the NIH, you must be taking part in a study or be under evaluation for study participation.

You may receive no benefit from taking part. The research may give us knowledge that may help people in the future.

Second, some people have personal, religious or ethical beliefs that may limit the kinds of medical or research treatments they would want to receive (such as blood transfusions). If you have such beliefs, please discuss them with your NIH doctors or research team before you agree to the study.

Now we will describe this research study. Before you decide to take part, please take as much time as you need to ask any questions and discuss this study with anyone at NIH, or with family, friends or your personal physician or other health professional.

OVERVIEW OF THE STUDY

We are inviting your child to participate in this study because we believe that your child may have pheochromocytoma, a tumor located in the adrenal gland or outside the adrenal gland, or that your child may carry a genetic predisposition towards developing pheochromocytoma. Pheochromocytomas are a surgically correctable cause of chronic high blood pressure. The clinical features and consequences of pheochromocytoma result from release of substances called catecholamines (epinephrine and norepinephrine) by the tumor. We wish to know whether various biochemical and scanning methods will improve our ability to diagnose and localize a pheochromocytoma. In addition, we wish to find out if there are any specific genetic or other markers to predict the course, malignant potential, and recurrence of pheochromocytoma.

PATIENT IDENTIFICATION

NIH-2514-1 (07-09)
P.A.: 09-25-0099

File in Section 4: Protocol Consent (5)
The main goal of this study is to develop new tests to diagnose and find a pheochromocytoma. If a pheochromocytoma is undetected, situations that normally would not pose a hazard, such as surgery, childbirth, or general anesthesia, can evoke catecholamine release by the tumor, with catastrophic results, such as stroke, heart attack, or sudden death. Both the detection of pheochromocytoma and locating the tumor can be difficult. Commonly used diagnostic imaging methods such as computed tomography (CT scanning) and magnetic resonance imaging (MRI scanning) are very good at locating an unusual mass but are not good at deciding whether a mass is a pheochromocytoma. Metaiodobenzylguanidine (MIBG), bone scans, octreotide scans and fluorodeoxyglucose (FDG) positron emission tomography (PET) scans are types of nuclear medicine scans that are useful in identifying a mass as a pheochromocytoma but are not very sensitive and can miss a tumor.

Your child will be admitted to the Clinical Center of the NIH for standard medical and imaging tests, to assess whether your child has pheochromocytoma. These tests include taking blood through an intravenous (i.v.) tube and collecting urine. Your child may also stay in a local hotel or guest house during most of this time and return to the Clinical Center for the tests. Your child must refrain from smoking and from consumption of alcoholic beverages for 18 hours prior to blood testing and from taking Tylenol™ (generic name acetaminophen) in any form for 5 days prior blood testing. Water is the only permissible beverage.

Some of this testing is not available elsewhere and may benefit your child. If diagnostic tests indicate that your child has a pheochromocytoma, your child will be offered surgery at the NIH. Your child may benefit from detection and removal of previously unrecognized tumor. If the tumor cannot be found, your child may be offered medical treatment, and we will continue to look for the tumor in follow-up evaluations. If surgery is not indicated (e.g., if your child has multiple tumors that cannot be removed), then your child may have follow-up evaluations to assess the size and number of tumors.

You child may be offered genetic testing thru the NIH to detect genetic mutations known to cause pheochromocytoma. If the results of the genetic testing indicate that your child is positive for a mutation, we will extend the genetic testing opportunity to the first-degree relatives. Those that are positive for the mutation may be invited to the NIH for a history and physical examination, as well as relevant biochemical and imaging studies to detect pheochromocytoma. If pheochromocytoma is detected, the same management outlined above will be offered.

Pheochromocytoma can occur as part of diseases that run in families. At least four familial conditions are associated with pheochromocytoma: multiple endocrine neoplasia type 2 (MEN 2); von Hippel-Lindau (VHL) disease; neurofibromatosis type 1 (NF 1), and alteration of the gene for succinate dehydrogenase (SDHx). If your child has an inherited disease that is associated with an increased risk of developing a pheochromocytoma we will discuss with you and your child the chances of developing this tumor. If appropriate, we will arrange counseling with a genetic counselor.

Your child will not be paid for participation in this study. However, all protocol-related tests, procedures, and hospitalization at the NIH are without cost to your child.

Your child is free to withdraw from the study at any time. Should he/she do so, we will not continue further diagnostic tests and we will not perform surgery at the NIH. Any information obtained up to that time would be made available to you, your child and his/her physician.
BLOOD TESTS FOR PHEOCHROMOCYTOMA

We have found that the measurements of catecholamines and their breakdown products, metanephrines, provide an extremely sensitive way to detect pheochromocytomas. If the blood tests are negative, then your child does not have the tumor. We don't know, however, whether a positive test necessarily means that your child does have the tumor. This study considers this problem.

For blood tests your child should remain in the lying position, resting, for at least 20 minutes before and during collection of the blood samples (10 cc, about 2 teaspoons). The samples are drawn without a tourniquet, through an indwelling i.v. catheter. No more than 9.5 mL/kg of blood will be drawn over an eight-week period and no more than 5 mL will be drawn in one day.

Your child may receive two drugs, glucagon and clonidine, which are used in standard medical evaluation of pheochromocytoma. At least 20 minutes before the test, two i.v. catheters are inserted into your child’s arm veins, and your child will rest in the lying position. Glucagon and clonidine tests are usually done in the same testing session.

GLUCAGON STIMULATION TEST

This test is used to determine if a suspected pheochromocytoma can be stimulated to produce significant increases in plasma catecholamine levels. Since its low sensitivity, this test will only be used in patients in whom the clonidine test is equivocal or catecholamine and metanephrine levels are near the upper reference limit despite the high clinical suspicion of the presence of pheochromocytoma. Your child will receive 1.0 mg glucagon i.v. over 30 seconds. Blood pressure and heart rate are measured every minute for at least 5 minutes before and for at least 15 minutes after glucagon is given. Five blood samples (10 cc, about 2 teaspoons) are obtained through the i.v. catheter, for levels of catecholamines and metanephrines at intervals 0, 1, 2, 3, and 5 minutes after glucagon is given. In patients with pheochromocytoma, blood pressure and heart rate can increase within 30-60 seconds and last for several minutes. Severe allergic reactions are very rare, but increased sweating, nausea, sometimes vomiting, as well as a feeling of a need to urinate may occur after glucagon administration. A physician will administer glucagon and be present during the entire test. An antidote drug will be immediately available if there is a prolonged, excessive increase in blood pressure.

CLONIDINE SUPPRESSION TEST

This test is used to determine if your child has high levels of plasma catecholamines being released from a pheochromocytoma. Your child will receive 0.3 mg clonidine/70 kg by mouth. Blood pressure and heart rate are monitored every 5 minutes for 20 minutes before and every 15 minutes for 3 hours after administration of clonidine. Blood is drawn via an i.v. catheter for levels of catecholamines and metanephrines before and after clonidine is given. Clonidine often causes drowsiness and a fall in blood pressure, regardless of the presence of pheochromocytoma. These effects can last several hours so your child will not be allowed to drive or operate machinery until the next day.

REGIONAL VENOUS SAMPLING

In some unusual cases pheochromocytomas may not be located by typical imaging studies. In other cases one or more masses may be found that are suspicious but not identified as pheochromocytomas. In these situations it may be appropriate to do a test called selective vena caval sampling. This is a clinically indicated, not a research, procedure. The testing involves sending a long intravenous tube into a major blood vessel returning blood to the heart (i.e., the inferior vena cava) to sample blood from veins draining organs in the neck, chest, abdomen, or pelvis. The blood is assayed for levels of catecholamines and metanephrines. Because of the clinical indication for selective vena caval sampling, radiation exposure related to the procedure is not included in the dosimetric estimates for use of radioactivity for research purposes.
TESTS BASED ON IMAGING

Clinically indicated imaging tests used in the evaluation of pheochromocytoma will include computed tomography (CT scanning), magnetic resonance imaging (MRI), sonography, bone and octreotide scans, \([^{123}\text{I}]\)- or \([^{131}\text{I}]\)-MIBG scintigraphy, and fluorodeoxyglucose (FDG) PET scanning. Your child may undergo imaging studies before and after surgical treatment of pheochromocytoma.

STANDARD IMAGING PROCEDURES

Standard imaging procedures require your child to lie still, either in an enclosed tube (the MRI scanner) or in a more open “doughnut” shaped tube (CT scanner). Some patients feel closed in or anxious in the MRI scanner. If this is a problem for your child, we may give your child a sedative, or use an alternative test. The approximate times for the studies are as follows: CT of neck, chest, abdomen, and pelvis 30 minutes; MRI of neck, chest, abdomen, and pelvis 1-2 hours. If CT is done using intravenous dye, your child will be asked not to take any food 4 hours before the test. Occasionally, CT dye can cause hypertensive crisis. Your child may also have blood sampling done shortly before and immediately after CT scan is completed. A physician from our research team will be drawing blood samples and supervise during CT scan. FDG scans take up to 2.5 hr total, MIBG scans up to 3-4 hrs over 2 days, octreotide up to 1.5-3h over 1 or 2 days.

MIBG SCINTIGRAPHY

To block thyroid hormone accumulation of radioiodine generated from deiodination of \([^{123}\text{I}]\)-MIBG or \([^{131}\text{I}]\)-MIBG, your child will be required to take medication called SSKI or potassium perchlorate (if your child is allergic to iodides), one day before and three-seven days after \([^{123}\text{I}]\)-MIBG or \([^{131}\text{I}]\)-MIBG administration, respectively.

FLUORODEOXYGLUCOSE (FDG) PET SCANNING

After injection of radioactive fluorodeoxyglucose (FDG), the tumor cells become radioactive, allowing the tumors to be seen on the PET scan. These FDG scans will be performed as clinically indicated procedures.

Your child will not be permitted to eat anything for 6 hours before the test is started, but will be allowed to drink as much water as he/she wishes. If possible, he/she should drink 2 to 3 glasses of water before the test. The entire study will take about 2 hours. FDG PET scanning is done in the Nuclear Medicine Department of the NIH Clinical Center. Your child will receive an injection of FDG and after 1 h of resting quietly, standard scans will be obtained over portions of his/her body. During this time your child will need to lie very still. If for any reason he/she feels that they cannot continue the scan once it has begun, the scanning can be stopped and they can be removed from the camera immediately. However, the information from the scan may be lost.

After the scan is finished, your child will be asked to empty his/her bladder every 90 minutes for the next 6 hours to remove the radioactive compound in the urine.
ADDITIONAL DIAGNOSTIC TESTING

URINE TESTING

Urine for biochemical diagnosis of pheochromocytoma will be collected and sent to the Department of the Laboratory Medicine at the NIH Clinical Center. Any of several medications can interfere with the test results and, therefore, all medications your child is taking must be reviewed.

GENETIC TESTING

Pheochromocytoma can be associated with a genetic change called a mutation. If your child’s genetic information (DNA) were an encyclopedia, the genes would be words, and a mutation would be a typographical error in one of the words. To detect such a genetic error, we will collect 3-7 ml of your child’s blood and extract the DNA.

Samples of your child’s genetic material (DNA) will be used either for the diagnosis or for research about your child’s medical condition. The genetic testing will be performed either by an officially certified laboratory or a non-certified laboratory (e.g. research laboratory). The results from a non-certified laboratory will be classified as research and are not official but it can be provided to your child and you under the Privacy Act of 1974, after you indicate your desire by signing a separate permission form. If we find that you have a genetic change, or a mutation, we may invite your family members to participate in this protocol.

There are ways your child’s life could be affected by learning information discovered by genetic testing. Instances are known in which a patient has been required to furnish genetic information as a precondition for application for health insurance and/or a job. Another factor to consider in thinking about whether or not to participate in this study includes the potential effects on your child’s psychological well-being. Some individuals may feel anxious or depressed or suffer additional stress as a result of learning genetic information about themselves. Your child may experience similar feelings. We will try to help your child or refer your child to someone if your child experiences these feelings.

CELL CULTURE

If your child has a pheochromocytoma removed surgically, we may try to grow the cells in a cell culture. We believe that pheochromocytoma research would benefit from establishment of a human pheochromocytoma cell line. Having available a human pheochromocytoma cell line should help us study the potential for malignancy or recurrence, develop and test new imaging techniques, and evaluate potential new treatments.
HAZARDS, RISKS, INCONVENIENCES, AND DISCOMFORTS

Pain. Inserting an i.v. catheter can cause local discomfort, clotting, bleeding, or infection. There is a slight, but definite risk of entering an artery, rather than a vein, and this could result in bleeding, bruising, or communication between the artery and vein. We have a sound wave detector available that enables us to "see" the vein even in difficult cases. We estimate less than a 1% risk of local complications other than bruising. Bruising or mild discomfort can last for several days following the procedure. These complications are generally transient and permanent damage is extremely rare.

Allergy. Some people are allergic to X-ray dye. If your child has any allergy to X-ray dye, you/your child must let us know to ensure that alternative imaging studies are used, appropriate pre-treatments are given, and to ensure that appropriate anti-allergy medications made immediately available.

Pregnancy. If your child is a female of child-bearing age, we will perform a urine or blood test for pregnancy within 24 hours before any test involving radioactivity. You and your child will be notified about pregnancy test results. If your child is more than 26 weeks pregnant, she cannot be studied in the NIH Clinical Center and we will inform you and your child about this situation.

Blood Sampling. No more than 280 ml (about 10 ounces) of blood will be taken for this study. Your child will not be accepted into the study if the total amount of blood required for all testing is more than the recommended NIH guideline amount for research subjects (9.5 mL/kg over any eight-week period).

Unexpected Findings. Because of the investigational nature of this study, we may not understand the significance of all findings. For instance, imaging tests may identify abnormalities that are not tumors. Such results are called false positive results. If unexplained or unusual findings occur, we may recommend other tests to help explain these findings and determine their significance. Your child will not be offered surgery at the NIH if results of conventional imaging studies are equivocal or negative, but biochemical studies are positive, because of the possibility of false-positive results. Some patients with positive imaging will have surgical confirmation of pheochromocytoma while others will not.

Follow-Up. Your child may return for follow-up conventional imaging, including after surgery. The completeness of tumor resection will be evaluated by biochemical testing 1-2 months after the operation. Your child will be followed on a yearly basis thereafter. If pheochromocytoma recurs, or if your child is not cured by initial surgery, your child will be offered re-evaluation to localize residual tumor or recurrence. In such cases, the clinical, biochemical, and imaging tests may be repeated. If no pheochromocytoma is found, your child will be referred back to his/her primary physician.

Drug Effects. Glucagon testing can provoke attacks due to catecholamine release by a pheochromocytoma, with its attendant complications as noted above. These attacks are generally milder and of much shorter duration than spontaneous attacks and usually require no treatment. In the rare instance of an extremely large or sustained release of catecholamines, the blood pressure can be controlled readily by means of i.v. drugs (phentolamine and metoprolol). Both drugs are always immediately available for emergency use. We, and many others, have used glucagon as a provocative test for pheochromocytoma for many years without significant adverse effects. Glucagon administration can also cause transient nausea, vomiting, or allergic reactions.

Clonidine often causes sedation and a decrease in blood pressure. Sometimes it produces a headache, dizziness, or generalized weakness. In such a situation, your child is positioned in bed with the head down or legs up, and normal saline can be given via an i.v. catheter.
OTHER GENERAL ISSUES RELATED TO THIS PROTOCOL

1. **Unanticipated medical information.** During the course of this or future investigations, it is possible (although not likely) that we may obtain unanticipated information about your child’s health or genetic background. If this information is considered to be relevant to your child’s health care, we will provide it either to you or your child’s referring physician.

   Genetic information about your child may be discovered during this project. There are many aspects of life that may be affected by knowing this type of information. These include potential effects on your child’s well-being; in addition, it has been reported that relationships with other family members may be affected as a result of participation in genetic studies. Finally, you, your child, and/or other family members may experience anxiety, depression, or other feelings related to finding out a potentially serious diagnosis for your child and/or you. Results from DNA testing may alter knowledge about family relationships (e.g. false paternity).

   Family Relationships. In the course of this study, it is possible that we may learn information about relationships within the family. For example, it is possible that we might learn that a family member is not the biological child of the parents with whom he/she lives (for example, because of adoption). We will not ordinarily provide this type of information to any member of the family or the referring physician. However, we may make exceptions under extraordinary circumstances if this information is required for the medical care of the individuals involved. If we are convinced this is necessary, we will provide the information to the physician providing medical care to your child.

2. **Release of medical records.** In the course of applying for certain types of insurance (e.g., medical insurance, life insurance, or disability insurance), people are often asked to sign forms that authorize insurance companies to obtain their medical records. If you/your child signs such a release form at some point in the future, it is possible the insurance company would present this signed release form to the Clinical Center of the NIH (NIH). In that event the NIH would comply with your request to provide the insurance company with your child’s medical record. It is possible that the information contained in your child’s medical record might affect the willingness of the insurance company to sell your child insurance.

3. **Family relationships.** During this study or in future studies, we may learn information about relationships within the family that are medically relevant. We will not ordinarily provide this type of information to any family member or the referring physician. However, we may make exceptions under an extraordinary circumstance if this information were required for the medical care of the individuals involved. If we are convinced that this is necessary, we will provide the information to the physician providing medical care to the patient.

4. **Participation in other research studies.** This consent form specifically refers to your child’s participation in the research protocol described above. In the future, we may invite your child to participate in other studies. Even if you sign this consent form, your child is not obligated to participate in these other research protocols. If your child is asked to participate in these other studies, you and your child will be provided with additional consent forms. As stated in the Introduction to this protocol, your child is free to withdraw from any or all research studies at any time without penalty or loss of any benefits to which your child is otherwise entitled.

5. **Collection, research and storage of biologic material.** During your child’s participation in this protocol, samples of your child’s body fluids (e.g., blood, urine) and tissues (e.g., tumor tissue taken at surgery) may be collected and stored for ongoing and future research purposes. Data about your child’s condition will also be collected. The research carried out on these samples and the data collected will help in understanding how pheochromocytomas develop and how different forms of these tumors, including those that have become malignant, might be better diagnosed and treated. Much of this research using stored human specimens and data will be carried out by NIH investigators, under the direction of the Principal Investigator of the protocol. However, some research involving your child’s samples and data collected under the protocol may also be carried out as part of collaborations with investigators at centers outside of the NIH. In the latter
situation, your child’s samples will be coded so that your identity as the source of those samples will be protected and remain confidential to the non-NIH investigators directly involved in the research. Any data that is shared will also have identifying information removed before it can be used for collaborative research with investigators at centers outside the NIH.

Samples we collect from your child will be used only for research to search for an underlying genetic association with your child’s medical condition. No other testing or research will be conducted on your child’s body, blood and urine samples unless you specifically give permission (as stated above).

The DNA and plasma collected from your child’s blood and urine will be stored in freezers contained in a secured building on the NIH campus. The samples will be inventoried and stored by codes defined by us.

Researchers within the NIH, as well as from outside the NIH, may be involved or interested in using the samples of your child’s DNA to help us pursue our objectives or their own individual research projects. The use of any DNA samples can be controlled by those who provide them, namely you and your child. Therefore, we ask your guidance and concurrence concerning future use of your child’s DNA samples.

I give permission to use my child’s blood cells or DNA sample(s) in future research studies, under the following conditions:

_______ I give my permission to use my child’s blood cells or DNA sample(s) in future research studies about known or suspected pheochromocytoma or neurocardiologic disorders as judged important by the investigators.

_______ I wish to be re-contacted if future research studies are considering using my child’s blood cells or DNA sample(s). After the study has been explained, I will then decide if I want my samples to be included in the study.

_______ Under no circumstances shall my child’s blood cells or DNA sample(s) be used in future research studies.

The Principal Investigator will not share any genetic test results unless you give us permission to do so by signing a separate permission form.

ALTERNATIVES TO PARTICIPATION IN THIS STUDY AND RIGHTS UPON REFUSAL OR WITHDRAWAL FROM THIS STUDY

The choice to enter or not enter this study is entirely voluntary. Before your child decides to enter or not, your child should understand what the doctor has explained and what you have read to your child about the research study. If your child decides not to participate, your child’s enrollment in any other NIH protocol will not be affected. If your child begins this study, your child has the right to withdraw at any time.

As noted above, many other physicians and centers are experienced in the evaluation and treatment of patients with pheochromocytoma. These centers will commonly rely on many of the same tests that we use to determine the cause of your child’s symptoms.
We cannot predict which patients will benefit from tests offered in this study. If you are not sure that your child wishes to participate in this study, let us know at any time, and we will refer your child to other physicians and medical centers experienced in the evaluation and treatment of patients with pheochromocytoma.
OTHER PERTINENT INFORMATION

1. **Confidentiality.** When results of an NIH research study are reported in medical journals or at scientific meetings, the people who take part are not named and identified. In most cases, the NIH will not release any information about your research involvement without your written permission. However, if you sign a release of information form, for example, for an insurance company, the NIH will give the insurance company information from your medical record. This information might affect (either favorably or unfavorably) the willingness of the insurance company to sell you insurance.

   The Federal Privacy Act protects the confidentiality of your NIH medical records. However, you should know that the Act allows release of some information from your medical record without your permission, for example, if it is required by the Food and Drug Administration (FDA), members of Congress, law enforcement officials, or authorized hospital accreditation organizations.

2. **Policy Regarding Research-Related Injuries.** The Clinical Center will provide short-term medical care for any injury resulting from your participation in research here. In general, no long-term medical care or financial compensation for research-related injuries will be provided by the National Institutes of Health, the Clinical Center, or the Federal Government. However, you have the right to pursue legal remedy if you believe that your injury justifies such action.

3. **Payments.** The amount of payment to research volunteers is guided by the National Institutes of Health policies. In general, patients are not paid for taking part in research studies at the National Institutes of Health. Reimbursement of travel and subsistence will be offered consistent with NIH guidelines.

4. **Problems or Questions.** If you have any problems or questions about this study, or about your rights as a research participant, or about any research-related injury, contact the Principal Investigator, Karen Pacak, M.D., Ph.D.; Building 10, CRC, Room 1E-3141, Telephone: (301) 402-4594 or Karen T. Adams, CRNP; Building 10, CRC, Room 1E-3141, Telephone (301) 402-7785.

   You may also call the Clinical Center Patient Representative at (301) 496-2626.

5. **Consent Document.** Please keep a copy of this document in case you want to read it again.

<table>
<thead>
<tr>
<th>COMPLETE APPROPRIATE ITEM(S) BELOW:</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. <strong>Adult Patient’s Consent</strong></td>
</tr>
<tr>
<td>I have read the explanation about this study and have been given the opportunity to discuss it and to ask questions. I hereby consent to take part in this study.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature of Adult Patient/Legal Representative</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Print Name</td>
<td></td>
</tr>
</tbody>
</table>

| B. **Parent’s Permission for Minor Patient.** |
| I have read the explanation about this study and have been given the opportunity to discuss it and to ask questions. I hereby give permission for my child to take part in this study. |

<table>
<thead>
<tr>
<th>Signature of Parent(s)/Guardian</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Print Name</td>
<td></td>
</tr>
</tbody>
</table>

| C. **Child’s Verbal Assent (If Applicable)** |
| The information in the above consent was described to my child and my child agrees to participate in the study. |

<table>
<thead>
<tr>
<th>Signature of Parent(s)/Guardian</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Print Name</td>
<td></td>
</tr>
</tbody>
</table>

**THIS CONSENT DOCUMENT HAS BEEN APPROVED FOR USE FROM MAY 25, 2011 THROUGH MAY 24, 2012.**

<table>
<thead>
<tr>
<th>Signature of Investigator</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Print Name</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature of Witness</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Print Name</td>
<td></td>
</tr>
</tbody>
</table>
Dear Dr. Karel Pacak,

My child was tested for a mutation in the genes, succinate dehydrogenase, subunit B, C, D (SDHB/C/D) by the National Institute of Child Health and Human Development (NICHD) under protocol #00-CH-0093. I would like to request that my child’s research genetic testing results be sent to the address above through the Privacy Act of 1974.

Sincerely,

____________________________
Parent Signature

Parent’s Full Name: ______________________________

Child’s Full Name: ______________________________

Child’s Date of Birth: ____________________________
Patient Visit Questionnaire
To be filled out at first appointment in the presence of a team member

**Current Health Problems**

Within the last few days, have you had/experienced, or do you currently have:

- A fever? Yes _____  No _____
- Palpitations? Yes _____  No _____
- Shortness of breath? Yes _____  No _____
- Chest pain? Yes _____  No _____
- Severe constipation? Yes _____  No _____
- Severe abdominal pain? Yes _____  No _____
- Severe issues with your blood pressure? Yes _____  No _____
- Severe issues with your heart rate? Yes _____  No _____
- Visits to the emergency room? Yes _____  No _____

**Important Medical Information**

- Are you allergic to iodine? Yes _____  No _____
- Do you have any allergies? Yes _____  No _____
  If yes, please list them below.

List any medications you are currently taking:

Is there any other information you feel we should know for your visit?

Signature: 

Printed Name: 

Date: 

Team Member Signature: 
ID Badge Form Instructions

As a patient or patient visitor, you are eligible for an extended visitor ID badge. These picture ID badges allow you to enter through any gate on campus and are good for one year.

To obtain an ID badge, please fill out the attached form, entitled “The National Institutes of Health Extended Visitor ID Badge Application.” Please print your last name, first name, social security number, date of birth, and contact number on the indicated lines. Then sign and date on the appropriate lines. If the patient or patient visitor is under 18, a parent or guardian must also sign where indicated. The badge effective date is the date you will be turning in the form.

A member of our team will complete the bottom portion of the form.

Once the form has been completed, you must bring it and a current photo ID to the badge issuing station. The badge issuing station is located in the main lobby of the Clinical Research Center, on the right side immediately before you exit the building through the main doors. There is a sign reading “Patient Identification Services.” The badge issuing station is open Monday to Friday, from 8:00 a.m. to 4:00 p.m.
THE NATIONAL INSTITUTES OF HEALTH
EXTENDED VISITOR ID BADGE APPLICATION

Privacy Act Notification:
Collection of this information is authorized under 5 U.S.C. 301 and 302; 40 U.S.C. 121 (d),k 1315; Delegation of Authority, 33 FR 6044 (January 17, 1968); 42 U.S.C. 216; 44 U.S.C. 3101 and 3102; and 45 CFR Part 3. The primary use of this information is to determine the suitability or eligibility for access to the National Institutes of Health (NIH) facilities. For NIH security purposes, your name will be checked against the National Crime Information Center (NCIC) and other applicable law enforcement databases prior to the issuance of an affiliate NIH identification and campus access pass. This may result in information being disclosed to law enforcement officials regarding past arrests, outstanding warrants, criminal convictions, or your inclusion on the FBI watch list. As a result of that disclosure, and if warranted, possible legal action and/or arrest could occur. Submission of this information is voluntary; however, in order for the NIH Police to determine your suitability to receive a government-issued NIH identification card and campus access pass, you must complete all fields.

Penalties to Inaccurate or False Statements:
Title, 18 Section 1001, United States Code (USC) provides that knowingly falsifying or concealing a material fact is a felony punishable by a fine(s) of up to $10,000, or 5 years imprisonment, or both. Additionally, Federal agencies generally fine, deny grant access, or disqualify individuals who have materially and deliberately falsified these forms, and this fact remains a part of the permanent record for consideration of future placements.

Authorization:
Although this process may have been done prior to the date of this application, I authorize any appropriate member of the National Institutes of Health Division of Police to periodically conduct appropriate checks against the National Crime Information (NCIC) and other applicable law enforcement databases to obtain information relating to my past history. I understand that the information released by record custodians, and sources of information is for official use by the NIH only for the purposes of determining my suitability or eligibility for access to NIH facilities, and may be disclosed by the NIH only as authorized by law.

Print Last Name ________________________________ Print First Name ________________________________
Social Security Number ______________ Date of Birth _________
Contact Number ________________________________ Date ________________________________
Applicant Signature ________________________________
Date ________________________________ Badge Effective Date ________________________________
Print Parent/Guardian Signature (If applicant under 18)

EXTENDED VISITORS (UP TO ONE YEAR)
☐ Board Member
☐ Blood Donor
☐ Child Care Center
☐ Community Liaison
☐ Construction Worker
☐ Grounds Maintenance
☐ Service Provider/Vendor ______________ (company name)
☐ Tenant
☐ Transportation Visitor
☐ Volunteers / Others
☐ Clinical Rotators
☐ Extended Visitor
☐ Patient/Patient Affiliates

SHORT TERM VISITORS (6 MONTHS OR LESS)
☐ Fellows
☐ Summer Students
☐ Volunteers/Others
☐ Retiree/Alumni

All applicants, other than Service Providers, must have a NIH employee sponsor, i.e. spouse, department or institute coordinator sign this document before a badge is issued.

Sponsor Signature ________________________________ Date ________________________________
Contact Number ________________________________
Print Sponsor Name ________________________________

This pertains to applicants outside of the Clinical Center only:
Applicant can personally hand carry or fax this form to (301) 480-7840 (Security Assistants). Service providers/Vendors can also fax this form to the same number but must be accompanied with a letter from your company on company letterhead stating your business at NIH. It may take up to 5 business days to process your request. After the 5th business day, you can go directly to the Badge Station at Bldg. 31, Room B3B04 and/or the Gateway Visitors Center. You must present government approved photo identification such as a driver's license, passport, work permit, school identification card, etc. when obtaining your badge.

For additional information please contact the Security Assistants office at (301) 435-5095.

☐ NCIC check completed

Revised 7/09
Visitor Information

This side of your folder contains information you may find helpful during your visit.

This information includes:

1. **Campus map**
   
The numbers for the important buildings on the map, the Safra Family Lodge, Children's Inn, and Clinical Research Center, are listed at the bottom of the map.

2. **Map of the Clinical Research Center**
   
The map of the first floor of the Clinical Research Center provides you with a general idea of the layout of the building. Important points on the map are indicated. Written directions to important locations in the Clinical Research Center are attached to the map.

3. **Lodging Information about the Safra Family Lodge and Children's Inn**
   
This section lists check-in and check-out times for the Safra Lodge and Children's Inn, as well as their rules and policies.

4. **Food and Dining Information**
   
This contains information about the cafeterias located in the Clinical Center, and provides websites for information about local dining options.

5. **Security Information**
   
All visitors must go through security in order to enter campus. This gives a brief overview of the security process.

6. **Admissions Information**
   
New patients must go through the admissions process before they can be treated. Some new patients may have gone through this process off-site. If you have any questions about whether you need to go through admissions, please contact the team member scheduling you. More information on the admissions process can be found on this page.

7. **What to Expect as a Patient**
   
This page gives a general overview of what to expect during your visit.
8. Information About Diagnostic Tests

This page lists information about the biochemical and imaging tests we perform, including specific fasting requirements and scan lengths.

9. Medication, Food, and Exercise Restrictions

This lists the medication, food, and exercise restrictions for patients. A copy of this should have been provided to you before your visit.

10. NIH Medications

Depending on your schedule, you may need to pick up a prescription while you are here at the NIH. If you require any medications, it will be indicated on your schedule. A brief summary of when to pick up your medications and where the pharmacy is located can be found on this page.

11. Release of Medical Information to You or Your Physician

If you would like to have a copy of your results sent to you or your physician(s) after your visit, you must contact the Medicolegal Department. More information can be found on this page.

12. Gift Donations

If you are interested in making a donation to our research study, please see this page for information.

13. Emergencies/Urgent Medical Attention

This page contains information on how to reach Suburban Hospital, located across from the NIH campus, if you need urgent medical attention while at the NIH.

14. NIH Campus Shuttle Schedules

The NIH has many shuttles that run to various buildings on campus. The shuttle schedules provided in this packet are the NIH Campus Route, which runs to many buildings on campus, including the Clinical Research Center (Building 10 North) and Metro stop, the NIH Campus Limited Route, which runs to fewer stops, but also includes the Clinical Research Center (Building 10 North) and the Metro, and the Building 10 After Hours Route, which runs to very limited stops, including the Safra Lodge, Children’s Inn, and Building 10 between 6:00 PM and 12:00 AM. The shuttle stop (Building 10 North) is located just outside the main entrance to the Clinical Research Center.

When available, maps of the shuttle route are attached after the route schedule.
More information on the shuttle schedules, including additional shuttle routes, can be found online at http://dtts.ors.od.nih.gov/NIHShuttle/scripts/shuttle_map_live.asp.

15. NIH Airport Shuttle Schedules

The NIH runs shuttles to and from the three major nearby airports, Baltimore-Washington International (BWI), Dulles International (IAD), and Reagan National (DCA). These shuttles run every day except Saturday.
Building Index

<table>
<thead>
<tr>
<th>Building</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Warren G. Magnuson Clinical Research Center</td>
</tr>
<tr>
<td>62</td>
<td>Children's Inn</td>
</tr>
<tr>
<td>65</td>
<td>Safra Family Lodge</td>
</tr>
</tbody>
</table>
Navigating the Clinical Research Center

Getting to Admissions

New patients who have not been through the admissions process will need to first go to admissions upon arrival to the CRC. If you drove to the NIH and are coming in from the garage, take the South Elevators to the first floor. Exit the elevators and take a left. Take a right at the main corridor (do not go through the sliding glass doors). The Admissions Office will be the first area on your left.

If you took a shuttle or walked to the CRC and entered through the main lobby, continue through the lobby. Stay to the right of the tables in the café area. The Admissions Office will be on your right just after the Central Elevators.

Getting to 5 South West Day Hospital

To get to 5 South West Day Hospital (5SWDH), take the Central Elevators (just outside of Admissions) to the 5th floor. Exit the elevators and turn away from the glass windows overlooking the lobby. With your back to the glass windows, go to the right, toward signs for the West Corridor and 5 SW Inpatient Unit. Take a left into the main hallway, and 5SWDH will be ahead on your right – there should be a sign from the ceiling to direct you.

Getting to 1 North West Day Hospital (pediatric patients)

To get to 1 North West Day Hospital (1NWDH), take a right into the first hallway after you enter through the Main Entrance. 1 North West Day Hospital will be in front of you.

Getting to phlebotomy, nuclear medicine, or radiology

To get to phlebotomy, nuclear medicine, or radiology, follow the main corridor outside of the Admissions Office to the sliding glass doors (away from the main lobby). Phlebotomy will be in front of you once you pass through the sliding glass doors, and nuclear medicine and radiology are down the hallway to your right.

Getting to OP9 Clinic

To get to OP9 clinic, take the South Elevators to the 9th floor. Upon exiting the elevator, turn toward the large glass windows. When facing the windows, take a left. OP9 Clinic is to the left.
Lodging Information

Safra Lodge Information

Check In: After 3:00pm
Check Out: Before 11:00am on the last day of your scans

****GUEST ROOMS AT THE FAMILY LODGE ACCOMMODATE 4 PEOPLE
MAXIMUM PER ROOM AND ONLY ONE ROOM PER FAMILY

Guest Policies

Guests must be referred by the Institute/Center conducting the patient's clinical research study.

Guests:
- Must be a family member, caregiver, or loved one supporting an adult patient at the NIH Clinical Center. Under special circumstances, adult patients may be Lodge guests.
- Must live more than 50 miles from the NIH campus in Bethesda, Maryland
- Must be over 18 years of age (unless accompanied by an adult).
- May stay up to 27 consecutive nights

Registration priority:

The following are the registration priority guidelines:
1. Guests of inpatients in intensive care
2. Guests of inpatients who are receiving palliative or end-of-life care
3. Guests of inpatients who are undergoing inpatient surgery or who are admitted for a length of stay of equal to or greater than one week
4. Discharged inpatients transitioning to home (and their guests)
5. Outpatients

WHAT YOU SHOULD KNOW PRIOR TO ARRIVAL
AT THE SAFRA FAMILY LODGE
AT THE NATIONAL INSTITUTES OF HEALTH (NIH)

- Check-in time is 3:00 PM- If you arrive earlier in the day, and a room is available, we will arrange an early check-in. Our guest rooms accommodate a maximum of 4 people. The Institutes authorize only one guest room per family.
• Check-out time is 11:00 AM. Keys are to be returned to the Front desk at checkout.
• A Photo ID, that includes a current address, is required to be presented at check-in.
• This is a non-smoking facility. There is a comfortable and pleasant smoking area outside of the lodge.
• Alcohol and any illegal substances are not permitted on the NIH campus.
• We provide a fully equipped kitchen for your use. However, you are responsible for the purchase of your food. Provisions have been made for you to store perishable and non-perishable food in individual containers. More information on our guidelines and rules is provided upon arrival.
• There is no Concierge Service provided at the Lodge.
• Each guest room floor has a laundry room for your use. We provide detergent and softener at no charge to you.
• Free local and long distance telephone service (within the continental U.S.) is available.
• Shuttle Service is provided between the Lodge, the Clinical Center and the Metro.
• Free parking is provided at the Lodge and you will be given a permit to park in the Lodge parking lot.
• All of the guest rooms are equipped with cable TV.
• Each guest room has a safe, however, we encourage you to limit the number valuables you bring with you. The Family Lodge is not responsible for lost or stolen items.
• The Lodge has a Business Center. It is equipped with several computers (that have free Internet access), a fax machine and a printer.
• The Lodge also has a library and a fitness room provided for your enjoyment.

The Safra Family Lodge is a communal environment. We request that all guests be respectful of their fellow guests and of our staff. It is our mission to make your stay with us as comfortable as possible.

**Safra Lodge House Rules**

Please be aware that the Edmond J. Safra Family Lodge is a Federal facility and all rules and regulations governing Federal facilities apply here.

1. This is a NON SMOKING FACILITY including the garden areas and gazebos, too. Smoking is permitted only in one designated area, which is the patio outside rooms 114 and 116.*

2. Alcohol and drug use is forbidden in the Lodge. No weapons of any type may be brought to the NIH campus and into the Lodge.*
3. All items in the Lodge, including furniture and furnishings, decorative items, dishware and silverware, televisions, radios, etc., are the property of the United States government and removal of these is a Federal offense.*

4. Food is **not permitted** in your guest room, living room, library, business center, exercise room, second and third floor lounges. **All food is to be consumed in the kitchen or in the patio areas.**

5. Please be respectful of other guests and keep the volume of your TV and/or radio lowered. Also, when walking in the guest room corridors keep your voices down so as not to disturb guests in their rooms. All visitors to guests must leave the second and third floor by 10:00 p.m. Visit may be continued on first floor until 11:00 p.m.

6. You must not give your card key to someone not registered at the Lodge. You must sign in and sign out (at the main lobby desk) each time you arrive or leave.

7. Proper attire must be worn when not in your guest room. Please no robes, bare feet or pajamas outside of your guest room.

8. Guests are responsible for securing their personal property. Room safes have been provided in each guest room; please use these to secure valuables. The NIH, the Clinical Center and the Safra Family Lodge will not be responsible for lost or stolen items.

*Offenses against these rules will call for the immediate removal of a guest from the Lodge.*
Children’s Inn Information

Check In: Before 7:00pm
Check Out: within 24 hours of last appointment (48 hours for international patients)
Phone Number: 301-496-5672

How YOU Can Help The Inn: Rules for your “place like home”

During your stay at The Children’s Inn you are expected to comply with the following policies. Failure to do so may result in forfeiture of your privilege to stay at The Inn.

Sign In/Sign Out
All guests are required to sign out and sign in at the Resident Log located in the Welcome Desk area. This is important, so that staff may locate you in the event that a message needs to be relayed to you, or in the event of an evacuation.

Supervision of Children
Parents are responsible for their children at all times. All children 16 and under must be supervised by a parent or guardian and supervision must be within direct line of sight. Children under the age of 18 may not be left without a parent present at The Inn. If you need to leave The Inn and wish to leave your child in the care of another Inn resident, you and the temporary caregiver must discuss the arrangement with the Manager on Duty (MOD).

Activity Supervision
During structured or unstructured activities, you are responsible for your child. If another adult will be supervising your child during an activity, please see the MOD. Residents 16 and older may use the fitness room after signing a waiver, but younger children must be accompanied by a guardian.

Security Cameras
The Inn has closed circuit security cameras installed both inside the building and around the outside perimeter. These cameras are to increase the safety and security for you and our facility. They are not located in any spaces that are considered private. Although they record around the dock, the cameras are not continuously monitored.

Visitors of Residents
All visitors not residing at The Inn must sign in at the Visitor Log in the Welcome Desk area and present photo identification for security purposes. Guests must let the Welcome Desk volunteers know when they arrive and when they leave. Guests with cold or flu symptoms or exposure to chickenpox, shingles, or measles will be
asked to come back at another time.

**Quiet Hours**
Please be considerate of other guests by keeping noise at a very low level from 9:00 p.m. to 8:00 a.m.

**Keys**
You will receive one or more key cards for entrance to your room. You will also have a mailbox and a pantry key located on a ring in your room. To prevent loss of keys, please keep these keys on the designated hook in your room when you are not using them. If you require a key to the medical refrigerator, please see the Welcome Desk.

**Illegal Drugs/Alcohol/Smoking**
Illegal drugs and alcohol are prohibited at all times in or around The Inn. Smoking is permitted only on the A/B patio.

**Firearms and Weapons**
Firearms or weapons of any kind are prohibited in or around The Inn.

**Evacuation**
If you must evacuate The Inn, please calmly proceed to the nearest evacuation door and gather at the far end of the parking lot in front of The Inn. In the event of a known fire, pull the fire alarm and exit immediately, notifying others of the fire as you evacuate. Please cooperate with Inn staff if an evacuation becomes necessary by immediately exiting the building.

**Housekeeping/Room Checks**
Families are responsible for keeping their rooms, including the bathroom, clean at all times. There are vacuum cleaners and cleaning kits available in the used linen room. Families are also responsible for cleaning dishes, pots and kitchen utensils immediately after use and placing all items properly in the dishwasher for thorough cleaning. Please keep food out of resident rooms and carpeted areas. Routine room and kitchen checks will be performed by Inn Housekeeping staff during our INNhouskeeping Service.

*NOTE: Housekeeping staff is not responsible for cleaning up after families residing at The Inn.*

**Waste**
Dispose of any biohazardous waste—waste coming from the human body—in MPW boxes in the used linen room. Diapers, latex gloves, and bandages also should be disposed of in the MPW boxes.

**Maintenance**
If your room requires maintenance (A/C or heat failure, toilet or shower problems, etc.), please report the problem to the Manager on Duty immediately. Please be aware that NIH maintenance or Inn staff may enter your room to perform the
requested maintenance or to remedy problems reported before your arrival.

Length of Stay
The Children’s Inn at NIH is a temporary home for pediatric patients enrolled in research protocols and their families during trips to the NIH. Pediatric patients and their families will be provided with accommodations at The Inn for up to 120 consecutive days based on medical need. Exceptions to this policy are considered by a committee in extraordinary medical circumstances.

FAQs about the Children’s Inn

Q: Who can stay at The Children’s Inn at NIH?
A: Patients enrolled in pediatric protocols at the National Institutes of Health who are 25-years-old or younger and their families are eligible to stay at The Children’s Inn.

Q: How can I book a reservation to stay at The Inn?
A: If this is your first visit to The Children’s Inn, an NIH Clinical Center representative must submit a referral form for a patient/family’s first visit before the family can stay at The Inn. The medical team will then send a referral form to The Inn. All first visit residents need to be referred to The Inn by someone from the Clinical Center.
If you are a returning resident, you may call us at 800-644-4660 or make your reservation online.

*We kindly ask that families be aware of the fragile health of those who stay at The Inn. Should you—or anyone else coming to The Inn—develop cold or flu symptoms, or become exposed to chicken pox or shingles, please reschedule your visit or make alternate accommodations. Please contact someone from your medical team if you need assistance.*

Q: How much does it cost to stay at The Inn?
A: There is no charge for families to stay at The Inn.

Q: What time should I plan to arrive?
A: Residents may come to The Inn no more than 24 hours before their FIRST appointment and may stay no longer than 24 hours after their final clinical appointment. For international residents, it is 48 hours before and after their appointments. New families should arrive at The Inn no later than 7 p.m. on the day they are scheduled to arrive to receive an orientation tour of The Inn. Returning families should arrive no later than 9 p.m.

Q: What time does The Inn close?
A: The Children's Inn never closes. We operate 24 hours a day, 7 days a week. A Manager on Duty (MOD) is always onsite and available to answer questions or assist you with anything that you need.
Q: Is The Inn ever full?
A: Families are encouraged to make reservations as soon as they know their child’s appointment date to prevent the chance of The Inn being full.

Q: What happens if I call to make my reservation and The Inn is already booked?
A: If The Inn is full, families are referred to their social worker, who will assist in making alternative arrangements.

Q: Does The Children’s Inn have shuttle service?
A: Yes. The Children’s Inn shuttle runs Monday through Friday from 7 a.m. to 11:49 p.m. On weekends, the shuttle is available from 7 a.m. to 3:30 p.m.

Q: Is food service provided?
A: The Inn is a self-help “place like home” which does not provide an in-house food service. There are however, three large communal kitchens for residents to cook their family’s favorite foods. Each kitchen has community refrigerators, stoves, microwaves, dishwashers and “help yourself” pantries for all residents to use. Local organizations and community groups donate supper for the entire Inn one or two nights a week.

Q: How can I get to a grocery store?
A: The Inn provides shuttle service to local grocery stores four times a week. Residents may sign-up for these trips at our Welcome Desk. Local grocery stores are also metro accessible.

Q: Do you have wireless Internet?
A: There is wireless Internet access in all public spaces at The Inn. Internet access is also available via Ethernet in your room.

Q: Are there TVs in the rooms?
A: There is a television in each sleeping room. DVD players are also available, on loan for a 24-hour time period, at our Welcome Desk.

Q: Do I need to bring a stroller/car seat for my child?
A: The Inn has strollers/car seats for families to checkout. Please see the Welcome Desk for assistance.

Q: If I have any questions or concerns regarding my stay, what should I do?
A: You may contact The Children’s Inn at 800-644-4660 or by emailing our Resident Services team at tcireservations@mail.nih.gov.
Food and Dining

There are two cafeterias located in the Clinical Research Center, as well as a café in the main lobby. Information about these options is listed below.

**Au Bon Pain Café, Main Atrium**

**Hours:** Monday through Friday, 6:30 a.m. to 8:00 p.m.

**Directions:** The Au Bon Pain café is located in the main atrium of the CRC, to the left of the large area with the tables and chairs.

**Second Floor Cafeteria**

**Hours:** Monday through Friday, 6:30 a.m. to 8:00 p.m.
- **Breakfast:** 6:30 a.m. to 9:30 a.m.
- **Lite Fare:** 9:30 a.m. to 11:00 a.m.
- **Lunch:** 11:00 a.m. to 3:00 p.m.
- **Evening Service:** 3:00 p.m. to 8:00 p.m.

**Weekends and Holidays:** 8:00 a.m. to 6:00 p.m.
- **Breakfast:** 8:00 a.m. to 10:00 a.m.
- **Lite Fare:** 10:00 a.m. to 11:00 a.m.
- **Lunch:** 11:00 a.m. to 6:00 p.m.

**Directions:** To get to the second floor cafeteria, take the South Elevators to the second floor. Take a right out of the elevator area, and a right into the main hallway. The cafeteria is ahead of you, through the tiled sitting area.

**B1 Level Cafeteria**

**Hours:** Monday through Friday, 6:30 a.m. to 2:30 p.m.

**Directions:** To get to the B1 cafeteria, take the hallway to the left of phlebotomy toward Masur Auditorium. When you are almost at the end of the hallway (in front of Masur Auditorium), you will see a set of elevators. Take these elevators downstairs to the B1 level. There will be signs to the cafeteria when you exit the elevators.

**Off-Campus Dining**

The following websites contain information about restaurants in the Bethesda area:

http://www.bethesda.org/dining-guide
Security Information

This section has three parts: general security information, information for patients arriving by car, and information for patients who will not be driving to campus.

General Security Information

Visitor vehicles must be inspected before entering campus, and all visitors must go through security.

All visitors over 15 years of age must present a valid government-issued photo ID, such as a driver's license or passport. Patients under 16 years of age must be accompanied by an adult. Visitors will be asked to walk through a metal detector, and all bags will be scanned.

Please note that the following items are prohibited on the NIH campus: firearms, explosives, archery equipment, dangerous weapons, knives with blades over 2 ½ inches, alcoholic beverages and open containers of alcohol.

Please note: Depending on the time of day and the amount of visitors, the security process can take as long as 30 minutes to 1 hour, so please plan accordingly.

The following three pages of this section contain information for patients arriving by car. If you will not be driving to the NIH, please see the last page for more specific security information.
**Information for Patients Arriving by Car**

If you are arriving by car and do not have an NIH-issued extended visitor ID badge, you must enter the campus at a designated visitor vehicle entrance. **Once you have been issued an extended visitor ID badge, you can enter through any entrance by swiping your badge.** Information on these entrances, as well as on parking, is available below.

**Weekday entrance**

There are two entrances for patients and patient visitors who arrive via car on weekdays.

The Gateway Center Vehicle Inspection facility is open from 5 AM to 10 PM, Monday to Friday. It is located on Rockville Pike (Route 355). After turning into Gateway Drive, please continue straight ahead to one of the lanes for campus access (either lane is fine). Do not park in the visitor parking lot located on Gateway Drive. You will be directed by security personnel into a lane for vehicle inspection. You will need to turn your car off, unlock your vehicle, and open your trunk. Exit the vehicle and take all bags and personal belongings with you into the badge issuing station. Once inside the badge issuing station, your bags will be scanned. You will be asked to pass through a metal detector and present your government-issued ID. Once these steps have been completed, you will be given a visitor ID badge and can return to your vehicle.

The Patient and Patient Visitor Entrance is open from 7 AM to 7 PM, Monday to Friday. It is located at the intersection of Cedar Lane and West Drive. Visitors will be assisted by Clinical Center Hospitality Staff. You will need to exit your vehicle and proceed to the badge issuing station with all your bags and personal belongings. Once inside the badge issuing station, your bags will be scanned and you will need to pass through a metal detector. You will then be asked to present your government-issued ID. Once these steps have been completed, you will be given a visitor ID badge and can return to your vehicle.

**Weekend and After-Hours Entrance**

Vehicles entering on weekends or between 10 PM and 5 AM on weekdays must enter via the Commercial Vehicle Inspection Facility, located on Rockville Pike (Route 355). Your vehicle will be inspected by security personnel, so you must unlock all doors and open your trunk. You will be asked to exit the vehicle and proceed to a badge issuing station, where you will need to present your government-issued ID. Once you have received your visitor ID badge, you may return to your vehicle.

**Parking**

Visitor parking is extremely limited at the NIH, so we recommend patients take public transportation if possible. Free parking is available at the Safra Family Lodge and the Children’s Inn. Please talk to the staff at the Lodge or the Inn about receiving a permit for these parking areas.
For patients who are not staying on campus, visitor parking is available in the on the P1 level of the garage located under the CRC. You will need a ticket to park between 7 AM and 7 PM, and your vehicle may be inspected again. **PARKING IN THE GARAGE IS FREE FOR PATIENTS AND PATIENT VISITORS, BUT YOU WILL NEED TO GET YOUR TICKET VALIDATED.** Validation is done at the desk just inside the doors on the P1 level of the garage (near the South Elevators). If you arrive before 7 AM and do not have a ticket, please inquire at the desk about the procedure for parking validation.

**A map of the visitor vehicle entrances, including their hours, is available on the next page.**
**1 West Drive Patient Entrance**: Use weekdays 7am-7pm

**2 Main Public Vehicle Entrance**: Use when the West Drive Patient Entrance is closed.

**3 After Hours Entrance**: Use when the Public Entrance is closed.
Information for Patients Who Are Not Driving to the NIH

For Pedestrians/Metro Riders

If you are walking to campus or taking the Metro and do not have an NIH-issued extended visitor badge, you must go through the Gateway Center to get a visitor ID. Once you have been issued an extended visitor ID badge, you can enter through any entrance by swiping your badge. The Gateway Center is open to pedestrians from 6 AM to 10 PM on weekdays. Between 10 PM and 6 AM and on Saturdays and Sundays, pedestrians must go through the Commercial Vehicle Inspection Facility.

For Shuttle Riders

Several area hotels offer shuttle services to the NIH for guests. There are also NIH shuttles that run to several stops off-campus, as well as around the NIH campus. If you are taking a shuttle to campus, the shuttles will stop at the entrance to campus. All visitors without NIH-issued badges will be required to disembark the shuttle and go through security before entering campus.

For Patients Taking a Taxi

If you are taking a taxi to campus, the taxi may drop you off at the Gateway Center (you will then need to walk or take a campus shuttle to get to the CRC), or the taxi may go through Visitor Vehicle Security and drop you off at the CRC. If you are arriving after hours or on the weekend, make sure to have the taxi drop you off at or go through the Commercial Vehicle Inspection Facility. See the information for patients arriving by car for more detail.
Admissions

All new patients must go through the admissions process before their appointments. The admission process can take up to an hour and the patient will be required to fill out forms and meet with an admissions counselor. If you arrive at the NIH over the weekend you must go through admissions over the weekend to be ready for testing on Monday morning.
What to Expect

At the National Institutes of Health, we offer a very comprehensive team approach to our patients’ evaluation. We have many disciplines on our team, including surgery, oncology, interventional radiology, and radiation oncology.

Patients will have a concise evaluation. The evaluation is supervised by our chief and principal investigator, Dr. Karel Pacak.

Patient evaluations are done as an outpatient. We admit patients into the CRC (Clinical Research Center) for surgery and treatments.

For patients with known or suspected pheochromocytoma/paraganglioma

If you are known or suspected to have a pheochromocytoma or paraganglioma, plan to spend approximately ten days at the NIH. Typically, new patients arrive on Sunday and go to the Admissions Office. It is extremely important that new patients go through the admissions process before any scheduled labs or scans. Admissions can take up to an hour, so we recommend going to the Admissions Office the day before any scheduled labs. In some cases, patients may have gone through Admissions off-site. If this is the case, you do not need to go to Admissions upon arrival. Please ask the team member scheduling you if you have any questions about whether you need to go through Admissions.

Patients are usually scheduled for labs on their first day at 7:00 AM at 5 South West Day Hospital. On Tuesday mornings, patients are typically scheduled for an appointment at our endocrine clinic. Depending on disease status and tumor location, patients may also be scheduled for other clinic appointments during the week. In addition to biochemical tests and clinical appointments, patients with a known or suspected pheo/para will be scheduled for several imaging scans throughout the week.

For surgical patients

Surgery patients are typically admitted as an inpatient 1-3 days before surgery. You will need to go to Admissions to be registered as an inpatient, at the date and time listed on your schedule. All surgical patients must have a chest X-ray, EKG, and pre-anesthesia consult before surgery. No appointments are needed for the chest X-ray or EKG. Depending on the procedure, you will typically be at the NIH for several days to a week after surgery before discharge, and may require several weeks of recovery after you are discharged before you can return to work.

For patients who are undergoing screening for pheochromocytoma/paraganglioma

If you are a patient who has a history of pheo/para or has a known genetic predisposition to pheo/para who is undergoing screening, plan to spend one to two days at the NIH. If you are a new patient, it is extremely important that you go to the Admissions Office before any
scheduled labs or imaging studies. Since labs are often scheduled for 7:00 AM and the admissions process may take up to an hour, it is recommended that you go through Admissions the day before any scheduled studies. Screening patients will be scheduled for labs at 5 South West Day Hospital. You may also be scheduled for a history and physical with a member of our team. Screening patients are typically also scheduled for an imaging study, usually a whole body CT scan.

For patients who are undergoing genetic testing

If you are a patient who has a family history of pheo/para-related genetic mutations, plan to spend a morning at the NIH. You will need to go to the Admissions Office before getting your blood drawn. The Admissions process can take up to an hour, so please plan accordingly. After you have gone through Admissions, you will need to go to phlebotomy to have your blood drawn for the genetic testing.
Information about Diagnostic Tests

We recommend that you arrive at your appointments (except for the day of your CT scan) well hydrated. When patients are well hydrated IV insertion is much quicker and less painful. Please increase your fluid (water, juices, milk) intake a few days before your first appointment to ensure proper hydration.

Biochemistry/Blood Tests

When coming to the NIH you will be required to have your blood drawn for research purposes. A plastic catheter/IV will be placed in your arm and you will be asked to lie still in a dark room for 30 minutes prior to the blood draw. Blood draws ALWAYS take place at 5 South West Day Hospital (adult patients) or 1 North West Day Hospital (pediatric patients) unless otherwise noted. You may also be sent to 3 South West North Procedure Unit to have a plastic catheter/IV placed before your blood draw. Please do not go to Phlebotomy for your blood draw unless specified on your calendar.

Imaging

*For imaging tests-Please let us know if you have any metal implants or a pacemaker as you are not to be scanned.*

All metal jewelry, piercings, belts, etc., need to be removed prior to any scanning.

*If you are claustrophobic please let us know in advance. We have medication available that will relax the body allowing you to undergo the needed scans.*

It is the requirement of the radiology department that within seven days of any imaging studies (scan) you will be required to have your blood drawn. This is to ensure that your kidneys are functioning well enough to filter the contrast dyes from the scans. The blood that is taken on your first day at the hospital will be valid for seven days, after that however, you will be required to get your blood drawn again before more imaging can be done.

Magnetic Resonance Imaging (MRI)

**Food:** There are no food restrictions with the MRI however we recommend you eat lightly prior to the scan to allow the contrast to disperse throughout the body

**Time:** 1 hr – Scan is split up by body part. Ex. An MRI of the neck will be done at a different time than an MRI of the chest. Each scan takes about an hour

**Injection:** There will be no injection

**Scan:** Long tube. Entire body will be in tube
Computed Tomography (CT) Scan

**Food:** Fasting; No eating or drinking water after midnight the night before (must be dehydrated)
**Time:** 2 hr – 1 hr to drink oral barium contrast and 1 hr scan
**Injection:** There will be no injection – only contrast dye to be ingested
**Scan:** Doughnut shaped machine. The body part being scanned will remain inside the tube

**Preparation for CT Scanning**

- No Metformin (anti-diabetic drug) 24 hours prior to CT scan.

**** 48 hours after scan need to check BUN and creatinine levels to see if levels are normal in order to restart Metformin.

**** If you are not at the NIH 48 hours after CT scan, it is your responsibility to contact your physician to follow up with your BUN and creatinine levels in order to restart your Metformin medication.

Nuclear Medicine Scans

**Fluordopamine (FDA) PET Imaging (Research Scan)**

**Food:** No eating 8 hours prior to scan; drinking water is encouraged
**Time:** 3 hr – after 2 hr will be asked to empty bladder
**Injection:** A plastic catheter/IV will be placed in the arm for contrast injection
**Scan:** Doughnut shaped machine. The body part being scanned will remain inside the tube

**Fluorodopa (FDOPA) PET Imaging (Research Scan)**

**Food:** No eating 8 hours prior to scan; drinking water is encouraged
**Time:** 1 hr
**Injection:** A plastic catheter/IV will be placed in the arm for contrast injection
**Scan:** Doughnut shaped machine. The body part being scanned will remain inside the tube

**Fluorodeoxyglucose (FDG) PET/CT Imaging**

**Food:** No eating 6 hours prior to the scan; drinking water is encouraged
**Time:** 2 hr – rest 1 hr after injection and 1 hr scan
**Injection:** A plastic catheter/IV will be placed in the arm for contrast injection
**Scan:** Doughnut shaped machine. The body part being scanned will remain inside the tube
**99mTc-MIBI Imaging (Research Scan)**

**Food:** No eating 3 hours prior to the scan  
**Time:** 1.5 hr – 2 phases: 30 min 1st phase and 45 min 2nd phase  
**Injection:** A plastic catheter/IV will be placed in the arm for contrast injection  
**Scan:** Doughnut shaped machine. The body part being scanned will remain inside the tube

**Bone Scan**

**Food:** No food restrictions prior to scan  
**Time:** After injection wait 3 hours, come back for 1 hour scan.  
**Injection:** A plastic catheter/IV will be placed in the arm for contrast injection  
**Scan:** Camera moves around body

**Octreotide Scan**

**Food:** No food restrictions prior to scan  
**Time:** After injection wait 4 hrs, 1 hr scan. Will be required to return the following day for 1 hr scan  
**Injection:** A plastic catheter/IV will be placed in the arm for contrast injection  
**Scan:** A machine that specifically detects the radioisotope will be used

**I-123 Meta-Iodobenzylguanidine Scintiscan (MIBG)**

**Food:** No food restrictions prior to scan  
**Time:** 1-2 hr – 15 minute injection on day one; must come back in 24 hrs for a 1-2 hr scan; may have to come back in 48 hrs for another 1-2 hr scan  
**Injection:** A plastic catheter/IV will be placed in the arm for contrast injection  
**Scan:** A machine that specifically detects the radioisotope will be used

**Genetic Testing**

Genetic testing for mutations in the succinate dehydrogenase (SDHx) gene is provided through a collaboration with the Mayo Clinic. The NIH provides genetic testing for patients and family members affected with pheochromocytoma. If you or any family members would like to have genetic testing done, or if you have any questions or concerns about genetic testing, please contact Tory Martucci (victoria.martucci@nih.gov), who is our genetic screening coordinator.
Medication, Food, and Exercise Restrictions

Fasting and medication restrictions are listed below. Specific fasting information should also be available on your schedule.

Some medications can interfere with some of the testing we do at our facility, so some patients may need to adjust their medications. If you are taking any of the medications listed on this page, please contact your physician or a member of our team for advice on adjusting or stopping medications.

**Do not discontinue any medications without first discussing with either your physician or a member of our team.**

The following medications MUST BE STOPPED 14 days prior to your visit to the NIH:

- All H2 Blockers: (for stomach/digestive problems) Nexium, Pepsid, Zantac, Prevacid, Prilosec, Gaviscon, Axid (Nizatidine), Tagamet, Tums
- Tricyclic and other antidepressants, such as Amitriptyline (Elavil), Imipramine (Topfranil), Nortriptyline (Aventyl)
- Anxiolytics (for anxiety) such as Xanax, Valium, Trazodone, Ativan, and other anti-anxiety medications.
- Sleep aids such as Ambien and Lunesta
- Monoamine oxidase inhibitors (deprenyl), Phenelzine (Nardil), tranylcypromine (Parnate), Selegiline (Eldepryl)
- Blockers (selective) such as Doxazosin (Cardura), Terazosin (Hytrin), Prazosin (Minipress)
- Antihistamines (for allergies) and cold/decongestant medications such as Benadryl, Dimedrol, Nytol, Unisom, Guaifenesin (Robitussin), Loratadine (Claritin), Fexofenadine (Allegra), Cetirizine (Zyrtec and Reactine)
- DDC inhibitors (for Parkinson's disease) such as Carbidopa/levodopa, Sinemet, Parcopa, Atamet
- Stimulants (for attention-deficit hyperactivity disorder) including Adderall, Dexedrine, Cylert, Ritalin

Other Medication Restrictions

- **All Tylenol/acetaminophen products**, including Excedrin, Percocet and hydrocodone, must be stopped a **minimum** of 5 days prior to your visit to the NIH.
- Labetolol** MUST BE STOPPED** for **6 weeks** prior to your visit to the NIH.
Food Restrictions

- No caffeine or decaf products for **a minimum of 24 hours** prior to your visit
- No spicy foods, bananas, cheese, and citrus fruits for **a minimum of 24 hours** prior to your visit
- **NO ALCOHOL** for **24 hours** prior to your visit
- **NO SMOKING (cigarettes or marijuana)** for **24 HOURS** prior to your visit
- No food after midnight on the days of your appointments; please drink water except on the day of your CT scan (you must be dehydrated for the CT scan, you get a much more accurate reading)
- No gum, mints or candy when fasting (appointment days)

Preparation for Blood Draw (5SWDH or 1NWDH appointments)

- No food after midnight prior to blood draw

Preparation for CT Scanning

- No Metformin (anti-diabetic drug) 24 hours prior to CT scan.

***** 48 hours after scan need to check BUN and creatinine levels to see if levels are normal in order to restart Metformin.

***** If you are not at the NIH 48 hours after CT scan, it is your responsibility to contact your physician to follow up with your BUN and creatinine levels in order to restart your Metformin medication.

Exercise Restrictions

If you have been diagnosed with a pheochromocytoma or paraganglioma, no exercise until your lesion/tumor has been removed and your catecholamines are down to a normal level. Exercise increases catecholamine production.

Please take your medications even when fasting unless otherwise instructed

ALLERGIES

If you have an allergy to contrast dyes, please let us know at least 2 weeks prior to your scheduled appointment. We can order the blockade (medication), for you to start the night before the scan, which will prevent you from having an allergic reaction to the contrast dye.

If you have a pacemaker, any metal implants or cannot have an MRI scan for any reason, please let us know as soon as possible.
NIH Medications

If you have certain types of scans on your schedule (MIBG scans or FDOPA/FDA PET scans), you will need to take certain medications, as described on your schedule. Please follow all instructions on your schedule and on your prescriptions.

It is important to note that if you are scheduled to receive medications while at the NIH, your prescriptions cannot be picked up until after you have gone through the admissions process. If you are a new patient, please wait 2-4 hours after going through admissions before attempting to pick up any prescriptions at the pharmacy.

The pharmacy is located on the first floor, across from Admissions.
Release of Medical Information to You or Your Physician

MEDICAL RECORD DEPARTMENT
Phone: 301-496-3331
Toll Free: 1-888-790-2133
Fax: 301-480-9982

*If you would like to have a copy of your medical records sent to yourself or your physician(s), you must contact the NIH Medicolegal Department.* They will send your reports to whomever you wish. We are not allowed to forward medical information to anyone.

The medical record department will not automatically send medical records to your physician if you are an outpatient. Please call them to update any recent information or new visits to the NIH.
Gift Donations

Many patients and family members have asked how to donate financially to our pheochromocytoma/paraganglioma research protocol. If you wish to make a donation, checks should be made payable to "NICHD Pheo Research Program" with an accompanying letter stating this money is being donated for the sole purpose to be used for pheochromocytoma/paraganglioma research.

If you wish a further explanation as to where your donation can be best utilized, i.e., genetics research, treatment research, fellowship/staff salaries, we would be happy to provide that information, and requests are welcome. Please forward the check to:

Karen T. Adams/NICHD
10 Center Dr., Bldg. 10
Room 1E-1-3140
Bethesda, Maryland 20892.
If you have an emergency/need urgent medical attention while on campus:

The Clinical Research Center does NOT have an emergency room. Please seek urgent medical attention at Suburban Hospital, which is located across the street.

Suburban Hospital
8600 Old Georgetown Road
Bethesda, MD 20814
Main Number: 301-896-3100

Map:
Red Line - NIH Campus Shuttle
Effective April 23, 2009 (For Government Use Only)

Click on the PRINT button from the menu bar to print the schedule.
<table>
<thead>
<tr>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>4:40PM</td>
<td>4:41PM</td>
<td>4:43PM</td>
<td>4:45PM</td>
<td>4:48PM</td>
<td>4:49PM</td>
<td>4:50PM</td>
<td>4:52PM</td>
<td>4:56PM</td>
<td>4:59PM</td>
<td>5:01PM</td>
<td>5:02PM</td>
<td>5:03PM</td>
<td>5:04PM</td>
<td>5:05PM</td>
<td>5:07PM</td>
<td>5:12PM</td>
</tr>
<tr>
<td>4:54PM</td>
<td>4:55PM</td>
<td>4:57PM</td>
<td>4:59PM</td>
<td>5:02PM</td>
<td>5:03PM</td>
<td>5:04PM</td>
<td>5:06PM</td>
<td>5:10PM</td>
<td>5:13PM</td>
<td>5:15PM</td>
<td>5:16PM</td>
<td>5:17PM</td>
<td>5:18PM</td>
<td>5:20PM</td>
<td>5:23PM</td>
<td>5:25PM</td>
</tr>
<tr>
<td>5:28PM</td>
<td>5:29PM</td>
<td>5:31PM</td>
<td>5:33PM</td>
<td>5:36PM</td>
<td>5:37PM</td>
<td>5:38PM</td>
<td>5:40PM</td>
<td>5:44PM</td>
<td>5:47PM</td>
<td>5:49PM</td>
<td>5:50PM</td>
<td>5:51PM</td>
<td>5:52PM</td>
<td>5:54PM</td>
<td>5:58PM</td>
<td>6:01PM</td>
</tr>
<tr>
<td>5:42PM</td>
<td>5:43PM</td>
<td>5:45PM</td>
<td>5:47PM</td>
<td>5:50PM</td>
<td>5:51PM</td>
<td>5:52PM</td>
<td>5:54PM</td>
<td>5:58PM</td>
<td>6:01PM</td>
<td>6:03PM</td>
<td>6:04PM</td>
<td>6:05PM</td>
<td>6:06PM</td>
<td>6:08PM</td>
<td>6:11PM</td>
<td>6:13PM</td>
</tr>
</tbody>
</table>

For questions or comments regarding Shuttle Information, please contact davislou@ors.od.nih.gov

## NIH Campus Limited

Effective April 11, 2011 (For Government Use Only)

**Click on the PRINT button from the menu bar to print the schedule.**

<table>
<thead>
<tr>
<th>METRO (Depart)</th>
<th>Bldg.45</th>
<th>Bldg.38A</th>
<th>Lot41B</th>
<th>Bldg.10 (South)</th>
<th>Bldg.10 (North)</th>
<th>Bldg.31A</th>
<th>METRO (Arrival)</th>
</tr>
</thead>
<tbody>
<tr>
<td>12:49PM</td>
<td>12:53PM</td>
<td>12:55PM</td>
<td>12:58PM</td>
<td>1:02PM</td>
<td>1:04PM</td>
<td>1:07PM</td>
<td>1:10PM</td>
</tr>
<tr>
<td>1:10PM</td>
<td>1:14PM</td>
<td>1:16PM</td>
<td>1:19PM</td>
<td>1:23PM</td>
<td>1:25PM</td>
<td>1:28PM</td>
<td>1:31PM</td>
</tr>
<tr>
<td>1:31PM</td>
<td>1:35PM</td>
<td>1:37PM</td>
<td>1:40PM</td>
<td>1:44PM</td>
<td>1:46PM</td>
<td>1:49PM</td>
<td>1:52PM</td>
</tr>
<tr>
<td>1:52PM</td>
<td>1:56PM</td>
<td>1:58PM</td>
<td>2:01PM</td>
<td>2:05PM</td>
<td>2:07PM</td>
<td>2:10PM</td>
<td>2:13PM</td>
</tr>
<tr>
<td>2:34PM</td>
<td>2:38PM</td>
<td>2:40PM</td>
<td>2:43PM</td>
<td>2:47PM</td>
<td>2:49PM</td>
<td>2:52PM</td>
<td>2:55PM</td>
</tr>
<tr>
<td>2:55PM</td>
<td>2:59PM</td>
<td>3:01PM</td>
<td>3:04PM</td>
<td>3:08PM</td>
<td>3:10PM</td>
<td>3:13PM</td>
<td>3:16PM</td>
</tr>
<tr>
<td>3:58PM</td>
<td>4:02PM</td>
<td>4:04PM</td>
<td>4:07PM</td>
<td>4:11PM</td>
<td>4:13PM</td>
<td>4:16PM</td>
<td>4:19PM</td>
</tr>
</tbody>
</table>

For questions or comments regarding Shuttle Information, please contact davislou@ors.od.nih.gov
**Bldg. 10 After Hours Shuttle**

Effective April 23, 2009 (For Government Use Only)

**NOTE:**
1. Between 6:00 PM and 12:00 AM, the schedule below will be in effect. During this time the driver will not be available by pager.
2. The driver will take passengers to their vehicles at Lots 41-B, NIH Metro Shelter and Children's Inn.
3. Stops at Lot 41 only when requested.

This shuttle does not leave the campus at any time.

Please wait by the NIH Shuttle sign outside the North Lobby of the Clinical Center (Building 10) or designated waiting areas.

Click on the PRINT button from the menu bar to print the schedule.

<table>
<thead>
<tr>
<th>Bldg.10 (North) (Depart)</th>
<th>Lot41B</th>
<th>METRO</th>
<th>Children's Inn</th>
<th>Family Lodge</th>
<th>Bldg.10 (North) (Arrival)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:00PM</td>
<td>6:03PM</td>
<td>6:06PM</td>
<td>6:09PM</td>
<td>6:12PM</td>
<td>6:15AM</td>
</tr>
<tr>
<td>6:20PM</td>
<td>6:23PM</td>
<td>6:26PM</td>
<td>6:29PM</td>
<td>6:32PM</td>
<td>6:35AM</td>
</tr>
<tr>
<td>6:40PM</td>
<td>6:43PM</td>
<td>6:46PM</td>
<td>6:49PM</td>
<td>6:52PM</td>
<td>6:55AM</td>
</tr>
<tr>
<td>7:00PM</td>
<td>7:03PM</td>
<td>7:06PM</td>
<td>7:09PM</td>
<td>7:12PM</td>
<td>7:15PM</td>
</tr>
<tr>
<td>7:20PM</td>
<td>7:23PM</td>
<td>7:26PM</td>
<td>7:29PM</td>
<td>7:32PM</td>
<td>7:35PM</td>
</tr>
<tr>
<td>7:40PM</td>
<td>7:43PM</td>
<td>7:46PM</td>
<td>7:49PM</td>
<td>7:52PM</td>
<td>7:55PM</td>
</tr>
<tr>
<td>8:00PM</td>
<td>8:03PM</td>
<td>8:06PM</td>
<td>8:09PM</td>
<td>8:12PM</td>
<td>8:15PM</td>
</tr>
<tr>
<td>8:20PM</td>
<td>8:23PM</td>
<td>8:26PM</td>
<td>8:29PM</td>
<td>8:32PM</td>
<td>8:35PM</td>
</tr>
<tr>
<td>8:40PM</td>
<td>8:43PM</td>
<td>8:46PM</td>
<td>8:49PM</td>
<td>8:52PM</td>
<td>8:55PM</td>
</tr>
<tr>
<td>9:00PM</td>
<td>9:06PM</td>
<td>9:09PM</td>
<td>9:12PM</td>
<td>9:15PM</td>
<td></td>
</tr>
<tr>
<td>9:20PM</td>
<td>9:26PM</td>
<td>9:29PM</td>
<td>9:32PM</td>
<td>9:35PM</td>
<td></td>
</tr>
<tr>
<td>9:40PM</td>
<td>9:46PM</td>
<td>9:49PM</td>
<td>9:52PM</td>
<td>9:55PM</td>
<td></td>
</tr>
<tr>
<td>10:00PM</td>
<td>10:06PM</td>
<td>10:09PM</td>
<td>10:12PM</td>
<td>10:15PM</td>
<td></td>
</tr>
<tr>
<td>10:20PM</td>
<td>10:26PM</td>
<td>10:29PM</td>
<td>10:32PM</td>
<td>10:35PM</td>
<td></td>
</tr>
<tr>
<td>10:40PM</td>
<td>10:46PM</td>
<td>10:49PM</td>
<td>10:52PM</td>
<td>10:55PM</td>
<td></td>
</tr>
<tr>
<td>11:00PM</td>
<td>11:06PM</td>
<td>11:09PM</td>
<td>11:12PM</td>
<td>11:15PM</td>
<td></td>
</tr>
<tr>
<td>11:20PM</td>
<td>11:26PM</td>
<td>11:29PM</td>
<td>11:32PM</td>
<td>11:35PM</td>
<td></td>
</tr>
<tr>
<td>11:40PM</td>
<td>11:46PM</td>
<td>11:49PM</td>
<td>11:52PM</td>
<td>11:55PM</td>
<td></td>
</tr>
</tbody>
</table>

For questions or comments regarding Shuttle Information, please contact davislou@ors.od.nih.gov

Disclaimer | Privacy | FOIA | Accessibility

http://dtts.ors.od.nih.gov/NIHShuttle/scripts/new_shuttle_print_schedule_live.asp?route='Route_1'
National Institutes of Health – Airport Shuttle Service

Baltimore Washington International Thurgood Marshall Airport (BWI)

Please Note: This schedule is subject to change. If you have any questions, please contact the NIH Transportation Desk at (301) 496-1161, available 24 hours a day, 7 days a week.

Current schedules can also be found on-line at: http://dtts.ors.od.nih.gov/patient_shuttles.htm

*Shuttle Pick-Up and Drop Off Location at BWI*

Pick-Up Location:
- **Concourse D** - Upper Level - Inside Curb Area – Door #14 - Exiting Air Tran Airlines.
- Vehicles will be marked "NIH."

Please arrive at the pick up area 5 minutes before the departure time. The driver can only wait a short period of time and cannot leave the Shuttle Bus unattended for any reason.

The Information Desk is located in the terminal lobby between door #’s 13 and 14, Concourse D, and can assist passengers in finding the boarding locations for the shuttle. You can reach the Transportation Desk for NIH at 301-496-1161 for assistance.

For transportation back to the airport, please wait by the transportation desk located in the North Lobby of the NIH Clinical Research Center (Bldg. 10) the shuttle driver will announce “BWI” and escort passengers to the shuttle.

### Monday through Friday

<table>
<thead>
<tr>
<th>Depart NIH Bldg 10 N</th>
<th>Depart BWI Concourse D</th>
<th>Arrive NIH Bldg 10 N</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00 AM</td>
<td>11:17 AM</td>
<td>12:15 PM</td>
</tr>
<tr>
<td>12:30 PM</td>
<td>1:47 PM</td>
<td>2:45 PM</td>
</tr>
<tr>
<td>3:30 PM</td>
<td>4:47 PM</td>
<td>5:45 PM</td>
</tr>
<tr>
<td>6:00 PM</td>
<td>7:32 PM</td>
<td>8:30 PM</td>
</tr>
</tbody>
</table>

### SUNDAY ONLY

<table>
<thead>
<tr>
<th>Depart NIH Bldg 10 N</th>
<th>Depart Childrens Inn</th>
<th>Depart BWI Concourse D</th>
<th>Arrive Childrens Inn</th>
<th>Arrive NIH Bldg 10 N</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:00 AM</td>
<td>11:05 AM</td>
<td>12:17 PM</td>
<td>1:10 PM</td>
<td>1:15 PM</td>
</tr>
<tr>
<td>1:30 PM</td>
<td>1:35 PM</td>
<td>2:47 PM</td>
<td>3:40 PM</td>
<td>3:45 PM</td>
</tr>
<tr>
<td>4:15 PM</td>
<td>4:20 PM</td>
<td>5:32 PM</td>
<td>6:25 PM</td>
<td>6:30 PM</td>
</tr>
<tr>
<td>6:45 PM</td>
<td>6:50 PM</td>
<td>8:02 PM</td>
<td>8:55 PM</td>
<td>9:00 PM</td>
</tr>
</tbody>
</table>

### HOLIDAY SCHEDULE  (Open: MARTIN LUTHER KING JR DAY - PRESIDENT'S DAY - COLUMBUS DAY - VETERANS DAY. Closed: MEMORIAL DAY - JULY 4th - LABOR DAY - THANKSGIVING - CHRISTMAS - NEW YEARS DAY)

<table>
<thead>
<tr>
<th>Depart NIH Bldg 10 N</th>
<th>Depart Childrens Inn</th>
<th>Depart BWI Concourse D</th>
<th>Arrive Childrens Inn</th>
<th>Arrive NIH Bldg 10 N</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00 AM</td>
<td>10:05 AM</td>
<td>11:17 PM</td>
<td>12:10 PM</td>
<td>12:15 PM</td>
</tr>
<tr>
<td>12:30 PM</td>
<td>12:35 PM</td>
<td>1:47 PM</td>
<td>2:40 PM</td>
<td>2:45 PM</td>
</tr>
<tr>
<td>3:30 PM</td>
<td>3:35 PM</td>
<td>4:47 PM</td>
<td>5:40 PM</td>
<td>5:45 PM</td>
</tr>
<tr>
<td>6:00 PM</td>
<td>6:05 PM</td>
<td>7:32 PM</td>
<td>8:25 PM</td>
<td>8:30 PM</td>
</tr>
</tbody>
</table>
Please Note: This schedule is subject to change. If you have any questions please contact the NIH Transportation Desk at (301) 496-1161, available 24 hours a day, 7 days a week.

Patient Shuttles are for exclusive use of patients and patient family members ONLY

Current Schedules can also be found on-line at: http://dtt.s.o.rs.od.nih.gov/patient_shuttles.htm

- Pick-up location: Curbside at the Lower Level, 2H baggage claim
- Vehicles will be marked “NIH”. Please be at the pick-up location ready to board at the times scheduled below

For transportation back to the airport, please wait by the transportation desk located in the North Lobby of the NIH Clinical Research Center (Bldg. 10). The shuttle driver will announce “DULLES AIRPORT” and escort passengers to the shuttle.

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>NIH B</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10 N</td>
<td>D</td>
<td></td>
<td>2H</td>
<td>A</td>
<td></td>
<td>10 N</td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>10:30 AM</td>
<td>10:30 AM</td>
<td></td>
<td>11:25 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>11:30 AM</td>
<td>12:30 PM</td>
<td></td>
<td>1:25 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1:30 PM</td>
<td>2:30 PM</td>
<td></td>
<td>3:25 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3:30 PM</td>
<td>4:30 PM</td>
<td></td>
<td>5:25 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5:30 PM</td>
<td>6:30 PM</td>
<td></td>
<td>7:25 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>S</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NIH B</td>
<td>C</td>
<td></td>
<td>D</td>
<td>C</td>
<td></td>
<td>D</td>
<td>2H</td>
</tr>
<tr>
<td>D</td>
<td>10 N</td>
<td>12:00 PM</td>
<td></td>
<td>12:05 PM</td>
<td>1:00 PM</td>
<td></td>
<td>1:50 PM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2:30 PM</td>
<td></td>
<td>2:35 PM</td>
<td>3:30 PM</td>
<td></td>
<td>4:20 PM</td>
<td>4:25 PM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4:30 PM</td>
<td></td>
<td>4:35 PM</td>
<td>5:30 PM</td>
<td></td>
<td>6:20 PM</td>
<td>6:25 PM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6:30 PM</td>
<td></td>
<td>6:35 PM</td>
<td>7:30 PM</td>
<td></td>
<td>8:20 PM</td>
<td>8:25 PM</td>
</tr>
</tbody>
</table>

H (Open: MARTIN LUTHER KING JR DAY - PRESIDENT'S DAY - COLUMBUS DAY - VETERANS DAY.
Closed: MEMORIAL DAY - JULY 4th - LABOR DAY - THANKSGIVING - CHRISTMAS - NEW YEARS DAY)

<table>
<thead>
<tr>
<th></th>
<th>NIH B</th>
<th>C</th>
<th></th>
<th>D</th>
<th>Curbside 2H</th>
<th>Arrive Children’s Inn</th>
<th>Arrive NIH Bldg. 10 N</th>
</tr>
</thead>
<tbody>
<tr>
<td>D</td>
<td>10 N</td>
<td>12:00 PM</td>
<td></td>
<td>12:05 PM</td>
<td>1:00 PM</td>
<td>1:50 PM</td>
<td>1:55 PM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2:00 PM</td>
<td></td>
<td>2:05 PM</td>
<td>3:00 PM</td>
<td>3:50 PM</td>
<td>3:55 PM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4:00 PM</td>
<td></td>
<td>4:05 PM</td>
<td>5:00 PM</td>
<td>5:50 PM</td>
<td>5:55 PM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6:00 PM</td>
<td></td>
<td>6:05 PM</td>
<td>7:00 PM</td>
<td>7:50 PM</td>
<td>7:55 PM</td>
</tr>
</tbody>
</table>
Please Note: This schedule is subject to change. If you have any questions please contact the NIH Transportation Desk at (301) 496-1161, available 24 hours a day, 7 days a week.

Patient Shuttles are for exclusive use of patients and patient family members ONLY

Current Schedules can also be found on-line at: http://dtts.ors.od.nih.gov/patient_shuttles.htm

Pick-up locations:
- Terminal A (Upper Level): Curbside at the NIH Shuttle Booth (outside lane)
- Terminal B & C (Lower Level): Curbside at the NIH stop, located between Doors #5 & 6 (inside lane)

Vehicles will be marked “NIH”. Please be at the pick-up location ready to board at the times scheduled below.

For transportation back to the airport, please wait by the transportation desk located in the North Lobby of the NIH Clinical Research Center (Bldg. 10) the shuttle driver will announce “NATIONAL AIRPORT” and escort passengers to the shuttle.

### MONDAY THROUGH FRIDAY

<table>
<thead>
<tr>
<th>DEPART NIH BLDG. 10 N</th>
<th>DEPART AIRPORT TERMINAL A (Upper Level)</th>
<th>DEPART AIRPORT TERMINAL B &amp; C (Lower Level)</th>
<th>ARRIVE NIH BLDG. 10 N</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 AM</td>
<td>8:30 AM</td>
<td>8:40 AM</td>
<td>9:25 AM</td>
</tr>
<tr>
<td>9:30 AM</td>
<td>10:30 AM</td>
<td>10:40 AM</td>
<td>11:25 AM</td>
</tr>
<tr>
<td>11:30 AM</td>
<td>12:30 PM</td>
<td>12:40 PM</td>
<td>1:25 PM</td>
</tr>
<tr>
<td>2:30 PM</td>
<td>3:30 PM</td>
<td>3:40 PM</td>
<td>4:25 PM</td>
</tr>
<tr>
<td>4:30 PM</td>
<td>5:30 PM</td>
<td>5:40 PM</td>
<td>6:25 PM</td>
</tr>
<tr>
<td>6:30 PM</td>
<td>7:30 PM</td>
<td>7:40 PM</td>
<td>8:25 PM</td>
</tr>
</tbody>
</table>

### SUNDAY ONLY

<table>
<thead>
<tr>
<th>DEPART NIH BLDG. 10 N</th>
<th>DEPART CHILDREN'S INN</th>
<th>DEPART AIRPORT TERMINAL A (Upper Level)</th>
<th>DEPART AIRPORT TERMINAL B &amp; C (Lower Level)</th>
<th>ARRIVE CHILDREN'S INN</th>
<th>ARRIVE NIH BLDG. 10 N</th>
</tr>
</thead>
<tbody>
<tr>
<td>12:00 PM</td>
<td>12:05 PM</td>
<td>1:00 PM</td>
<td>1:10 PM</td>
<td>1:50 PM</td>
<td>1:55 PM</td>
</tr>
<tr>
<td>2:00 PM</td>
<td>2:05 PM</td>
<td>3:00 PM</td>
<td>3:10 PM</td>
<td>3:50 PM</td>
<td>3:55 PM</td>
</tr>
<tr>
<td>4:00 PM</td>
<td>4:05 PM</td>
<td>5:00 PM</td>
<td>5:10 PM</td>
<td>5:50 PM</td>
<td>5:55 PM</td>
</tr>
<tr>
<td>6:00 PM</td>
<td>6:05 PM</td>
<td>7:00 PM</td>
<td>7:10 PM</td>
<td>7:50 PM</td>
<td>7:55 PM</td>
</tr>
<tr>
<td>8:00 PM</td>
<td>8:05 PM</td>
<td>9:00 PM</td>
<td>9:10 PM</td>
<td>9:50 PM</td>
<td>9:55 PM</td>
</tr>
</tbody>
</table>

### HOLIDAY SCHEDULE (Open: MARTIN LUTHER KING JR DAY - PRESIDENT'S DAY - COLUMBUS DAY - VETERANS DAY
Closed: MEMORIAL DAY - JULY 4th - LABOR DAY - THANKSGIVING - CHRISTMAS - NEW YEARS DAY)

<table>
<thead>
<tr>
<th>DEPART NIH BLDG. 10 N</th>
<th>DEPART CHILDREN'S INN</th>
<th>DEPART AIRPORT TERMINAL A (Upper Level)</th>
<th>DEPART AIRPORT TERMINAL B &amp; C (Lower Level)</th>
<th>ARRIVE CHILDREN'S INN</th>
<th>ARRIVE NIH BLDG. 10 N</th>
</tr>
</thead>
<tbody>
<tr>
<td>12:00 PM</td>
<td>12:05 PM</td>
<td>1:00 PM</td>
<td>1:10 PM</td>
<td>1:45 PM</td>
<td>1:50 PM</td>
</tr>
<tr>
<td>2:00 PM</td>
<td>2:05 PM</td>
<td>3:00 PM</td>
<td>3:10 PM</td>
<td>3:45 PM</td>
<td>3:50 PM</td>
</tr>
<tr>
<td>4:00 PM</td>
<td>4:05 PM</td>
<td>5:00 PM</td>
<td>5:10 PM</td>
<td>5:45 PM</td>
<td>5:50 PM</td>
</tr>
<tr>
<td>6:00 PM</td>
<td>6:05 PM</td>
<td>7:00 PM</td>
<td>7:10 PM</td>
<td>7:45 PM</td>
<td>7:50 PM</td>
</tr>
</tbody>
</table>
Contact Information

If you have questions, or would like additional information about our protocol, please see our website, [http://pdeo.nih.gov](http://pdeo.nih.gov), or contact Karen Adams or Tory Martucci using the information listed below.

**Karel Pacak, M.D., PhD, DSc**
Professor of Medicine  
Senior Investigator  
Head, Section on Medical Neuroendocrinology  
Program in Reproductive and Adult Endocrinology

10 CRC, Room 1E-3140  
10 Center Drive, MSC 1109  
Bethesda, MD 20892-1109

Telephone: (301) 402-4594  
Fax: (301) 402-4712  
Email: [karel@mail.nih.gov](mailto:karel@mail.nih.gov)

**Karen T. Adams, CRNP, MSc**
Section on Medical Neuroendocrinology  
Program in Reproductive and Adult Endocrinology

10 CRC, Room 1E-3140  
10 Center Drive, MSC 1109  
Bethesda, MD 20892-1109

Telephone: (301) 402-7785  
Fax: (301) 402-4712  
Email: [adamskt@mail.nih.gov](mailto:adamskt@mail.nih.gov)

**Tory Martucci**
Section on Medical Neuroendocrinology  
Program in Reproductive and Adult Endocrinology

10 CRC, Room 1E-3140  
10 Center Drive, MSC 1109  
Bethesda, MD 20892-1109

Telephone: (301) 496-9992  
Fax: (301) 402-7344  
Email: [victoria.martucci@nih.gov](mailto:victoria.martucci@nih.gov)