

N I H C L I N I C A L C E N T E R

# P A T I E N T H A N D B O O K





# P A T I E N T H A N D B O O K

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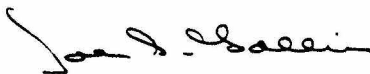
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## WELCOME FROM THE DIRECTOR

Welcome to the Clinical Center at the National Institutes of Health. This is an exciting time for clinical research at NIH. Our new hospital—the Mark O. Hatfield Clinical Research Center—was dedicated in 2004 and is truly a national resource. Individuals from every state in the nation and from countries around the world participate in studies here, research dedicated to better health and health care for all.

Clinical Center staff provide information in this handbook to help you prepare for admission. Look here for answers to some questions you may have about your hospital stay and for information about the practical aspects of your visit, including visiting hours and support services. Some unique features of the Clinical Center are described so that you will have a better picture of a patient's daily routine here at the largest clinical research hospital in the world.

Clinical Center patients are partners in research and your participation is invaluable to advancing medical knowledge. We are committed to making your experiences here as comfortable and satisfying as possible. Thank you for your continued partnership.



John I. Gallin, M.D.  
Director, NIH Clinical Center

### **THE NIH CLINICAL CENTER**

The NIH Clinical Center, the world's largest hospital devoted exclusively to clinical investigation, is the research hospital for the National Institutes of Health. NIH is one of five health agencies of the Public Health Service, which, in turn, is part of the U.S. Department of Health and Human Services (DHHS).

NIH is one of the largest research centers in the world. The principal medical research arm of DHHS, NIH conducts basic, clinical, and applied research related to a broad spectrum of diseases and health problems. It represents the public's commitment to biomedical research and improving the health of its people. Over the years, NIH has supported the work of numerous Nobel Prize winners.

NIH is actually numerous Institutes and Centers created to study cancer; eye disorders; heart, lung, and blood disorders; genome research; aging; alcohol abuse and alcoholism; allergy and infectious diseases; arthritis, musculoskeletal and skin diseases; child health and human development; deafness and other communication disorders; dental and craniofacial disorders; diabetes, digestive, and kidney diseases; drug abuse; environmental health; general medical science; mental health disorders; neurological disorders and stroke; nursing research; information technology; and complementary and alternative medicine.

Patients at the Clinical Center consent to participate in research studies (protocols) and are treated without charge. Unlike most hospitals, the Clinical Center does not routinely provide standard diagnostic and treatment services. Admission is selective: Institute physicians choose patients solely because they have an illness being studied by those Institutes. In addition, numerous NIH guest scientists from around the world collaborate in Clinical Center activities. The Clinical Center also offers training in research medicine for physicians, medical students, and nursing students.

Thousands of patients are admitted yearly to the facility, which houses inpatient wards and outpatient clinics. Healthy people are also admitted every year to serve as clinical research volunteers. Physicians from different Institutes and outside hospitals provide medical care at the Clinical Center, and registered nurses and allied health care professionals provide patient care.

A unique feature of the Clinical Center is the proximity of laboratories to patients. Advances realized in the laboratory are brought to the bedside, and new areas for laboratory investigation are suggested by the health care team's observations of patients. In 2004, a new facility, the Mark O. Hatfield Clinical Research Center, was dedicated to meet new research challenges and to foster this collaboration and exchange of information between basic scientists and clinicians. Indeed, many NIH clinicians are themselves outstanding scientists.

The Clinical Center is fully accredited by the Joint Commission on the Accreditation of Healthcare organizations. The Joint Commission inspects hospitals and accredits only those meeting strict standards of quality.

### **WHY YOU WERE SELECTED**

You were selected as a Clinical Center patient on the basis of medical information provided by your referring doctor and/or by you. You are one of several people with a similar condition who will be invited to take part in a research program. By observing many people with a particular disorder, we hope to find common factors that will help us to better understand the condition.

Some patients at the Clinical Center receive new treatments that offer some potential for alleviating, improving, or curing their conditions. NIH doctors carefully monitor their patients' responses to these new treatments. For other patients, too little is known about their conditions to begin new treatment. These patients are admitted to enable us to gain vital information about their diseases.

### **YOUR RESEARCH PROGRAM**

Whether or not you receive new treatments, you will be admitted under a care and observation plan developed to study your condition. This plan, called a protocol, specifies the information needed about your illness and the procedures that will be followed to obtain this knowledge. The protocol and the status of your health determine how long you will spend at the Clinical Center and whether you will be an inpatient or an outpatient.

### **SPEAK UP FOR YOUR SAFETY**

Everyone has a role in making healthcare safe—physicians, nurses, healthcare executives, and technicians.

You, as the patient and a partner in clinical research, play a vital role in making the care you receive safe. You must be an active, informed, and vocal member of your healthcare team.

*Speak up if you have questions or concerns about your care or the protocol in which you are enrolled. If you don't understand, ask again. You have a right to know!*

- ▶ Don't be afraid to tell the nurse or the doctor if you think you are getting the wrong medication.
  - ▶ Ask about safety. For instance, ask the doctor to mark the area that will be operated on so that there is no confusion.
  - ▶ Don't hesitate to tell your healthcare professional if you think he or she has confused you with another patient.
- Pay attention to the care you receive. Make sure you get the right treatments and medications by the right healthcare professional.*
- ▶ Tell your nurse or doctor if something doesn't seem right to you.
  - ▶ Make sure healthcare workers introduce themselves when they enter your room. Look at their identification badges.
  - ▶ Know what time of day you normally receive a medication. If you don't get it at the usual time, tell your nurse or doctor.
  - ▶ Make sure your doctor or your nurse checks your identification band—or asks your name

and your date of birth—before giving you medications or treatments.

***Educate yourself about your diagnosis, the research protocol in which you are enrolled, and all medical tests you are undergoing.***

- ▶ Ask your doctor about the training and experience that qualifies him or her to treat you.
- ▶ Learn about your disease. Get information from your healthcare team, your library, respected websites, and support groups.
- ▶ Make sure you know about the operation of any equipment that is used in your care.

***Ask a trusted family member or friend to be your advocate.***

- ▶ Your advocate can ask questions that you may not think about when you are under stress.
- ▶ Your advocate can also help remember answers to questions you have asked and can speak up for you if you cannot.
- ▶ Make sure this person understands your advance directives preference—for example, your decisions about resuscitation and life support.
- ▶ Review consents for treatment with your advocate before you sign them. Make sure both of you understand exactly what you are agreeing to.
- ▶ Make sure your advocate understands the type of care you will need when you go home.

***Know the medications you take and understand why you take them.***

- ▶ Ask about the purpose of your medications. Ask for written information about them.
- ▶ If you do not recognize a medication, make sure that it is for you before you swallow it.
- ▶ If you are given intravenous (I.V.) fluids, ask the nurse how long it should take for the liquid to “run out.”

- ▶ Whenever you are to receive a new medication, tell your nurses and doctors about allergies you have.
- ▶ Make sure you can read the handwriting on all prescriptions. If you can't read it, the pharmacist may not be able to, either!

***Understand all informed consent documents or other medical forms you are asked to sign.***

***Participate in all decisions about your care and treatment. You are the center of the healthcare team!***

- ▶ You and your doctors should agree on exactly what will be done during each step of your care.
- ▶ Know that you can stop participation in your research protocol at any time
- ▶ Don't be afraid to ask for a second opinion.
- ▶ Ask to speak to other patients who are on your protocol or who have had the procedure you are undergoing.

**PATIENT REPRESENTATIVE**

The Patient Representative serves as a link between the patient and the hospital. The Patient Representative makes every effort to ensure that patients are informed of their rights and responsibilities and that they understand what the Clinical Center is, what it can offer, and how it operates. We realize that this setting is unique and may generate questions about the patient's role in the research process. As in any large and complex system, communication can be a problem and misunderstandings can occur. If you have an unanswered question or feel there is a problem you would like to discuss, call the Patient Representative. The sooner your concerns are known, the easier they are to address. You may reach the Patient Representative at 301-496-2626. Calls made to this number after 5 p.m. or on weekends or holidays will be returned the following business day.



## PATIENTS BILL OF RIGHTS, PATIENT RESPONSIBILITIES, AND RELATED ISSUES

### Patients' Bill of Rights

Whether you volunteer to participate in a research protocol as a healthy subject or as a patient, you are protected by the Clinical Center Bill of Rights for patients who are volunteer subjects. We, at the Clinical Center, believe that personal concern for every volunteer is indispensable to the quest for knowledge about disease. The most important person in medical research is the patient. The Clinical Center provides hospital facilities and professional care, but the patient is the essential element without which health and disease could not be observed or response to treatment measured.

Clinical Center patients' rights are safeguarded by procedures to ensure that all patients know their medical choices and are aware of any risks from the procedures and understand how research may affect them.

Members of the hospital staff have a responsibility to ensure the following:

- the patient receives information necessary to make decisions about taking part in any research procedures
- care is given in a manner consistent with the patient's beliefs
- those rights basic to human dignity are observed

This Bill of Rights for Clinical Center patients has been adapted from a similar document developed by the American Hospital Association for use by general hospitals.

- 1** The patient has the right to considerate and respectful care.
- 2** The patient has the right to know, by name, the physician responsible for coordinating his or her care at the Clinical Center.
- 3** The patient has the right to obtain from his or her physician complete current information about diagnosis, treatment, and prognosis in easily understandable terms. If it is medically inadvisable to give such information to the patients, it will be given to a legally authorized representative.
- 4** The patient has the right to receive from his or her physician information necessary to give informed consent before starting any procedure or treatment. Except in emergencies this will include, but not necessarily be limited to, a description of the specific procedure or treatment, any risks involved, and the probable duration of any incapacitation. When there are alternatives to therapeutically designed research protocols, the patient has the right to know about them. The patient also has the right to know the name of the person responsible for directing the procedures or treatment.
- 5** The patient has the right to refuse to participate in research, to refuse treatment to the extent permitted by law, and has the right to

be informed of the medical consequences of these actions including possible dismissal from the study and discharge from the institution. If discharge would jeopardize the patient's health, he or she has the right to remain under Clinical Center care until discharge or transfer is medically advisable.

**6** The patient has the right to be transferred to another facility when his or her participation in the Clinical Center study is terminated, providing the transfer is medically permissible, the patient has been informed of the needs for and alternatives to such a transfer, and the facility has agreed to accept the patient.

**7** The patient has the right to privacy concerning the medical care program. Case discussion, consultation, examination, and treatment are confidential and will be conducted discreetly. The patient has the right to expect that all communications and records pertaining to care will be treated as confidential to the extent permitted by law.

**8** The patient has the right to routine services whenever hospitalized at the Clinical Center in connection with the active protocol for which he or she is eligible; these services will generally include diagnostic procedures and medical treatment deemed necessary and advisable by the professional staff. Complicating chronic conditions will be noted, reported to the patient, and treated as necessary without the assumption of long-term responsibility for their management. The patient may be returned for long-term or definitive care of these conditions to the referring physician or to other appropriate medical resources.

**9** The patient has the right to expect that medical information about him or her discovered at the Clinical Center, as well as an account of his or her medical program here, will be communicated to the referring physician.

**10** The patient has the right, at any time during the medical program, to designate additional physicians or organizations to receive medical updates. The patient should inform the Ambulatory Care Services Department staff of these additions.

**11** The patient has the right to know in advance what appointment times and physicians are available and where to go for continuity of care provided by the Clinical Center when such care is required under the study for which the patient was admitted.

### **PATIENT RESPONSIBILITIES**

In the spirit of working together toward our common goal, our patients (and their parents, guardians, or surrogates) have certain responsibilities as participants in medical research and as patients at the Clinical Center.

**1** The patient (or his/her parents, guardian, or surrogate) has the responsibility to provide, to the best of his/her knowledge, complete information about his/her current medical condition and past medical history, including current illness, prior hospitalizations, current medications, allergies, and all other health-related matters.

**2** The patient (or his/her parents, guardian, or surrogate) has the responsibility to discuss his/her protocol (study or treatment plan) with the medical/nursing staff, before indicating agreement by signing a consent to take part in it.

**3** The patient (or his/her parents, guardian, or surrogate) has the responsibility to comply with his/her protocol, to cooperate with hospital staff, to ask questions if directions or procedures are

not clear, and to participate in his/her health care decisions. Any patient may withdraw from the study for any reason, but it is desirable to discuss his/her concerns with the attending physician before taking that action. Parents of pediatric patients have the responsibility to indicate if and how they want to be involved in their child's plan of care.

**4** The patient has the responsibility to refrain from taking any medications, drugs, or alcoholic beverages while participating in the protocol, except those that have been approved by an appropriate NIH physician. Smoking is prohibited in the Clinical Center.

**5** The adult patient has the responsibility to inform the medical staff about his/her wishes regarding treatment plans. The patient may provide for a duly authorized family member or spokesperson to make medical decisions on his/her behalf in the event he/she becomes unable to communicate.

**6** The outpatient (or his/her parents, guardian, or surrogate) has the responsibility to report on time for scheduled procedures and to keep all clinic appointments. If unable to do so for any reason, the outpatient (or his/her parents, guardian, or surrogate) has the responsibility to notify the protocol physician, and to cancel and reschedule the appointment.

**7** The patient (or his/her parents, guardian, or surrogate) has the responsibility to report promptly to the medical or nursing staff any unexpected problems or changes in his/her medical condition.

**8** The patient (or his/her parents, guardian, or surrogate) has the responsibility to inform the appropriate staff or the Patient Representative of any concerns or problems with the care and treatment that he/she feels are not being adequately addressed.

**9** The patient (or his/her parents, guardian, or surrogate) has the responsibility to respect the property of the U.S. Government, fellow patients, and others; to follow NIH rules and regulations affecting patient care and treatment; and to respect the rights of other patients and hospital staff. This includes the responsibility of respecting the privacy of other patients and treating information concerning them as confidential.

**10** The patient (or his/her parents, guardian, or surrogate) has the responsibility to provide his/her own transportation to and from the Clinical Center. The outpatient also has the responsibility to pay for all living expenses—except where all or part of these expenses are specifically covered by the protocol and/or authorized by the responsible NIH physician. The patient has the responsibility to advise accompanying escorts or others who travel to and remain in the Bethesda area that they must pay for their own travel and living expenses, except when designated by NIH as a guardian for a patient whose expenses are covered.

**11** The patient (or his/her parents, guardian, or surrogate) has the responsibility for paying all medical or laboratory expenses incurred outside the Clinical Center, except when the patient has been given prior written authorization on the appropriate NIH form to have such expenses billed to NIH.

**12** The patient (or his/her parents, guardian, or surrogate) has the responsibility to provide complete information, so that contacts and communications to schedule visits and monitor health status can be maintained. This information should include the following:

- ▶ the patient’s current address and phone number;
- ▶ the names, addresses, and phone numbers of next of kin or persons to be notified in the event of an emergency; and
- ▶ the names, addresses, and phone numbers of physicians responsible for the patient’s ongoing care, including the patient’s family physician and the physician(s) who referred the patient to NIH.

**13** The patient (or his/her parents, guardian, or surrogate) has the responsibility to obtain medical care and medications from his/her own health care provider for all conditions unrelated to the protocol in which he/she is participating, except while being treated as an inpatient at the Clinical Center.

**14** The patient (or his/her parents, guardian, or surrogate) has the responsibility to return to the care of his/her own health care provider when participation in the protocol is completed or stopped and the patient’s medical condition permits.

### **PAIN MANAGEMENT**

Every patient has the right to appropriate assessment and relief of pain.

### **ADVANCE DIRECTIVES FOR MEDICAL CARE**

The rights of Clinical Center patients to participate in decisions concerning their medical care are preserved even if they lose the ability to communicate directly with their caregivers. One method of exercising these rights is to prepare an “advance directive.”

An advance directive is a document in which a person gives advance directions about medical care or designates who should make medical decisions for that person if he or she loses the ability to make such decisions. There are two types of advance directives: treatment directives, the most common example being the living will, and proxy directives, the most common example being the durable power of attorney for health care.

A treatment directive, such as a living will, is a written statement expressing the forms of medical treatment a person wishes to receive or forego when unable to make decisions in stated medical conditions. Such medical conditions may include irreversible unconsciousness, terminal illness, or severe and irreversible brain disease.

A proxy directive, such as durable power of attorney, is a person’s written statement naming another to make medical decisions for that person if he or she becomes unable to make such decisions. In 1990, Congress approved legislation called the “Patient Self-Determination Act.” This law requires all medical facilities reimbursed by Medicaid and Medicare to educate patients about advance directives and to help them make advance directives if they choose to do so. Although the Clinical Center does not receive such financial reimbursement, there has been, and continues to be, a commitment to consistent and thoughtful attention to the ethical aspects

of patient care, including advance directives. The Clinical Center has guidelines for using durable power of attorney for patients in certain research studies.

The Clinical Center has guidelines for using durable power of attorney for patients in certain research studies. Work is in progress to expand the Clinical Center's ability to educate and help patients make advance directives. If you have any questions about advance directives, please speak with your doctor, your nurse, the Patient Representative (301-496-2626), or the Department of Clinical Bioethics staff (301-496- 2429).

### **DNR (DO NOT RESUSCITATE) ORDERS**

At the Clinical Center of the NIH, all members of the health care team are dedicated to your care and well-being. We believe that one of our most important responsibilities is to preserve and maintain the life and vigor of our patients. We also believe that patients have the right and responsibility to participate in decisions about their health care.

In this hospital, it is understood that if a patient has cardiopulmonary arrest (sudden stoppage of heart or lung function), every effort will be made to restore these vital functions. Cardiopulmonary resuscitation, or CPR, refers to the technique used to restore these functions. These efforts will take place routinely, unless an order to the contrary has been written in the patient's medical record.

When a patient's heart or breathing stops and CPR is started, a multi-step process begins. CPR may include such procedures as chest compression, administration of various medications, electrical shocks to restart the heart, placement of a breathing tube (intubation), and placement on a breathing machine (ventilator). Patients receiving

successful CPR will usually be transferred to an intensive care unit (ICU) for continued treatment and observation.

Although our hope is to restore health in all our patients, there are times when this will no longer be possible. In certain situations, it is important to discuss whether we should even try CPR. CPR may not be appropriate for patients with a progressive and terminal condition from which recovery is no longer possible. Making this decision should be a joint process in which the patient, the physician, the nurse, and the patient's family are involved. Other persons on the health care team experienced in discussing these matters with patients include chaplains, social workers, and the Patient Representative. The decision to write the DNR (do not resuscitate) order, however, rests with the competent patient and his or her physician.

If the patient is not competent, the decision rests with the patient's surrogate and physician.

If the patient, in consultation with his or her attending physician, decides that CPR is not appropriate, at least at that particular time, the attending physician will write a DNR order, or a "No Code," in the patient's records. A DNR or No Code order means that CPR will not be started. It is important to remember two points about a DNR order:

- The DNR order will be reviewed regularly. Entering a DNR order into a medical record does not mean that the DNR order is permanent. A DNR order can be reversed if it becomes medically appropriate. If a patient changes his or her mind about the DNR order, this should be discussed with the attending physician.

- Even if the DNR order is written, this does

not mean that other lifesaving treatments, such as antibiotic administration, will be withheld. All treatments related to pain management, or other treatments agreed to by the patient and the physician, will be given.

We hope this information will help familiarize you with choices related to your health care. We encourage you to discuss this, or any aspect of your care, with your family and your physician and with other members of your health care team.

### **HIV TESTING AND REPORTING OF INFECTIOUS DISEASES**

As a Clinical Center patient, you may be asked to provide a blood sample to be tested for antibodies against the human immunodeficiency virus (HIV), the virus that has been identified as the cause of AIDS (the acquired immune deficiency syndrome). If testing is indicated for you, your primary caregiver at the Clinical Center will ask for your permission to do the test. Further information about HIV testing is available in the booklet "Testing Your Blood for HIV, the Virus That Causes AIDS," and is online. Ask your nurse for a copy.

The Clinical Center may report certain communicable diseases, including HIV infection, to appropriate State and Federal Government agencies. If you have any questions about HIV testing or this policy, you can discuss them with your caregivers in the Clinical Center or the Clinical Center HIV Counseling Coordinator. The HIV Counseling Coordinator may be reached at 301-496-2381 or through the page operator at 301-496-1211.

### **INFORMED CONSENT AND PROTECTION OF PRIVACY**

While you receive medical care here, information gained from studying your condition will help us to better understand your illness and to develop or improve treatments or methods of prevention.

Because you consented to take part in research, we have a responsibility to inform you about the procedures we use and what you can expect from your stay.

Your doctors and nurses will explain treatments and tests, and very often, your written consent is required before they are administered. If a treatment is relatively new and not yet generally used, or if it is a test mainly for research and not for your immediate benefit, your doctor will make this clear and will ask for your written consent. However, you may have questions later even after you have given your consent. Please do not hesitate to discuss these questions with your doctor, nurse, social worker, chaplain, or Patient Representative (301-496-2626). We want you to understand exactly what is being done and why.

If at any time you wish to withdraw from the research study, you may do so. The Clinical Center will provide short-term medical care for any physical injury resulting from your participation in research here until such time that the NIH has determined that you can be safely discharged.

Although data from the studies in which you participate may be used widely in medical research, information about you as an individual is confidential. Generally, access to this information is restricted to NIH staff involved in the patient care and research programs. Your doctor and other physicians or organizations you specify will also receive your medical information.

You are entitled to receive a copy of the protocol consent form you signed. Ask for this when you sign the consent form.

### **MEDICAL RECORD INFORMATION**

If you have questions about access to your medical record or the release of information contained in it, please call the Medicolegal section of the Medical Record Department at 301-496-3331 or stop by room 1N216.

### **PHOTOGRAPHING FELLOW PATIENTS**

If you wish to take a photograph of your fellow patients, please ask their verbal permission. You may photograph patients in their rooms or in the unit lounge, solaria, or outside the Clinical Center. Please refrain from taking photographs in gathering places such as cafeterias and lobbies.

### **PHOTOGRAPHS AND RECORDINGS**

Some types of medical information cannot be recorded completely in writing. Photography, tape recording, and other audiovisual methods are sometimes much better. Audiovisual records that could reveal your identity are never made unless you have given your prior written permission on a special form, which states the particular uses that will be made of the records.

### **PROTECTING YOUR PRIVACY**

Patients who give information about themselves or their families to the doctors and other workers in a hospital expect the information to be kept confidential. We will do this to the best of our ability. However, you should be aware that neither the Clinical Center nor any other medical institution can absolutely guarantee confidentiality.

In 1974, the U.S. Congress passed a law called the “Privacy Act.” This law puts strict limits on how Federal agencies may use and disclose personal information, including medical information. It requires every agency to inform each individual why he or she is asked for information and how it will be used.

Physicians and other scientists at NIH conduct research by authority of the U.S. Congress, Section 301 of the Public Health Act (42 United States Code 241). The research in which patients or volunteers participate —clinical research— takes place mainly in the Clinical Center in Bethesda, Maryland.

The medical and other personal information you are asked to give, as well as the information from various tests, is gathered for two purposes: to provide the best care and treatment for you as a patient, and to allow for research to increase understanding of health and illness. Both good treatment and good research depend on accurate and complete information. However, just as your coming to the Clinical Center as a patient is voluntary, your giving the information we request and participating in various tests and research procedures is also voluntary.

**PUBLICATIONS**

Some of the information obtained from you may appear in scientific publications or be presented to professional audiences at meetings. It may be used for the purpose of teaching health professionals or students in the health professions. Under these circumstances, measures are taken to conceal your identity.

**RELEASE OF PATIENT INFORMATION TO THE MEDIA**

Occasionally, we receive media requests for information about patients who are being treated at the Clinical Center. Inquiries may be made especially if a patient is a public figure or celebrity. These requests are handled by the Office of Clinical Center Communications (OCCC), the public affairs office for the hospital. Our primary concern is patient welfare, but we also have an obligation to cooperate with the media.

The only information that may be released to the media without the patient's prior written permission is verification that the person is a current Clinical Center patient.

Medical records, including diagnosis, are confidential and will not be released to the media.

If you are contacted by the media while you are a patient here, or if you have questions about Clinical Center media policies, please call OCCC at 301-496-2563.

**SOCIAL SECURITY NUMBER AND RELIGION**

At the time of your admission, you will be asked to give your social security number and your religion. Giving this information is strictly voluntary, and the admissions clerk will emphasize this.

Knowing your religion enables the hospital chaplains to offer spiritual service, which for many patients is an essential part of their care.

**USES OF INFORMATION AT NIH**

The information needed for care and treatment, and much of the research information, is recorded and stored in your written medical record and in a computer system. In addition, records containing some of the same or similar information are maintained by the many departments and offices essential in a modern hospital. These include admissions, anesthesiology, transfusion medicine, dental clinic, nursing, nutrition, pharmacy, reception desk, recreation therapy, social work, spiritual ministry, and travel office. These also include the departments and offices that perform electrocardiograms, electroencephalograms, metabolic rates, pathological anatomy, pulmonary function, radioisotope studies, and x rays.



NIH scientists and their technical assistants maintain research records in their offices and laboratories. These may be records of clinical research procedures carried out in each laboratory, or they may be compilations of data abstracted from the medical records of many patients, some of whom may have no personal contact with the scientist. Such records are essential in preparing the hundreds of clinical research reports published in scientific journals each year.

Students in the health professions, particularly medicine and nursing, are regularly assigned to the NIH as part of their formal training. They may be unpaid volunteers, but they are under the direct supervision of the NIH staff. They have access to medical information as necessary to carry out their training assignments. For the purposes of the Privacy Act, they are regarded as NIH employees.

### **USES OF INFORMATION OUTSIDE NIH**

Generally, access to medical information is restricted to NIH employees who need it to carry out their official duties. There are, however, occasions when confidential information is shared with individuals or organizations that are not part of the NIH. These are as follows:

- ▶ The physician(s) or organization(s) that the patient specifies to receive reports (which are identified in CRIS) get the following:
  - reports summarizing each patient admission
  - letters dictated by the patient's primary care physician(s)
- ▶ The Social Work Department may share pertinent information with community agencies that may assist the patient. Providers may also be given the information needed for obtaining special individualized devices such as braces, artificial limbs, or cosmetic aids.
- ▶ The travel office may inform public carriers such as airlines of the special requirements of some patients, for example, "heart condition" or "wheelchair required."
- ▶ Information about diagnostic problems or having unusual scientific value may be shared with consultants other than NIH employees. For example, bacterial specimens may be sent to the Centers for Disease Control and Prevention of the Public Health Service in Atlanta; tissue specimens may be sent to the Armed Forces Institute of Pathology in Washington, D.C.; x-rays may be sent for the opinion of a radiologist with extensive experience in a particular kind of diagnostic radiology. Pertinent parts of your medical history may be shared with such consultants. NIH scientists may collaborate with colleagues at institutions such as medical schools. They may share information so that the number of patients under combined study will be sufficient, or they may exchange samples of material such as blood so that samples can be analyzed uniformly in the laboratory best equipped to do so.

- ▶ Representatives of the Joint Commission on the Accreditation of Healthcare Organizations or of the Government's General Accounting Office occasionally have access to representative medical records. Such inspections ensure that the quality of our record-keeping meets established standards.
- ▶ Records may be released to Congress or to committees and subcommittees of Congress for matters within their jurisdiction, and information may be used to respond to congressional inquiries for constituents concerning their admission to the NIH Clinical Center.
- ▶ Certain diseases or conditions, including infectious diseases, may be reported to appropriate representatives of the State or Federal Government as required by law.
- ▶ Records may be released for statistical research or reporting if the information is transferred in a form that does not identify anyone individually. For example, medical information may be disclosed to tumor registries for maintaining health statistics.
- ▶ The DHHS may contract with a private firm for transcribing, updating, copying, or otherwise refining records it uses. Relevant records will be disclosed to such a contractor. The contractor(s) will be required to comply with the requirements of the Privacy Act regarding such records.
- ▶ If a Government employee is involved in a lawsuit, records may be released that facilitate the employee's defense.
- ▶ The Bureau of the Census may request records for census or survey purposes, and records may be released for archival purposes to the National Archives.
- ▶ Records may be released for law enforcement purposes to a law enforcement agency, and records may be released in response to a court order.
- ▶ Whenever medical information about you as an identifiable individual is disclosed to anyone who is not an employee of the DHHS, notation of the reason for the disclosure and the identity of the recipient of the information is made in your medical record. When such disclosures are for one of the reasons described above, or if disclosure is otherwise required by law, the NIH does not seek your written permission to make the disclosure.
- ▶ Except for the uses described here, medical information about a patient is not given to anyone without the specific written permission of the patient or a legally authorized representative. However, there is one additional exception to that rule: if at some later time, a hospital or physician who is caring for you needs information immediately, and if waiting to obtain your written release of the information would endanger your health, the information will be released immediately, and you will be notified of the release later.

## YOUR DOCTORS

### **YOUR DOCTOR AT THE CLINICAL CENTER**

While you are a Clinical Center patient, there are always two doctors who share the responsibility for your care. Your attending physician is responsible for conducting your study (protocol) and for the overall quality of your medical care. Your clinical fellow, a well-trained doctor who has chosen to come to NIH to learn more about medical research, is responsible for the immediate management of your care.

### **THE DOCTOR TO TALK TO REGARDING QUESTIONS ABOUT TREATMENT**

The clinical fellow who evaluates you, orders medications and tests, and sees you often is the doctor who knows you best. The clinical fellow consults with your attending physician. You may, of course, ask to see your attending physician if you have more questions.

### **HOW OFTEN YOU WILL SEE YOUR ATTENDING PHYSICIAN**

This depends on the design of the research protocol, the complexity of the medical problem, and your individual needs.

### **DOCTORS MAY CHANGE**

If you are a Clinical Center patient over a long time, you will not have the same doctors. Clinical fellows are assigned to patient care for fixed periods, so unless you are a short-term patient, your clinical fellow will change from time to time. You may retain the same attending physician, but on many patient care services, these responsibilities rotate among a group of senior doctors who also rotate on a fixed schedule. Any time you are transferred from one Institute or branch to another, both your clinical fellow and your attending physician will change.

The NIH consists of many Institutes, most of which conduct research in a specific field of medicine. Within each Institute are several branches where studies are being done on specific conditions within the general field covered by the Institute. Many patients have problems of interest to more than one Institute or branch. Each Institute and branch has its own team of doctors.

### **KNOWING YOUR INSTITUTE AND BRANCH**

It is very useful to know your Institute and branch. If you should ever need assistance when your own doctor is not available, knowing your Institute and branch will make it easier to locate the person best able to help you.

**SEEING NIH DOCTORS OUTSIDE  
YOUR INSTITUTE AND BRANCH**

You may see a number of other NIH doctors who have been asked to examine you because they are specialists in medical fields other than those familiar to your attending physician or clinical fellow.

**WHY SO MANY PEOPLE ARE  
INVOLVED IN YOUR CARE**

Because of the complexity of medicine, it is impossible for one person to know all that can be known, or all that needs to be known, about a medical problem. Doctors with special training provide expert opinions, perform tests, and operate advanced medical equipment. Other health care professionals are also trained to perform certain procedures or monitor your condition.

The continuity of your care rests with a team or group of doctors. Even though members of the team or group may change, they all communicate through the same channel: your clinical fellow and attending physician. You should always be informed when changes occur. If you ever have questions, do not hesitate to contact your clinical fellow or attending physician so that you understand the situation to your satisfaction.

## PATIENT INFORMATION

### THE ADMISSIONS PROCESS

Admissions handles registrations for all new inpatients and outpatients as well as previously registered patients who are scheduled for inpatient admission to the hospital. If you are a new patient, you will be interviewed by an admissions clerk. You will be asked to review and sign a general consent form stating that you have agreed to take part in biomedical research. You will also be asked to review and sign an information practices form. This form states that the Clinical Center will do its utmost to protect your privacy and identifies situations when the Clinical Center may share information about you (as discussed in Section 2 in this booklet under the heading “Uses of Information Outside NIH”).

Except for an emancipated minor, only a parent, legal guardian, or legally authorized representative may sign for a patient who is a minor (less than 18 years of age). If you have any concerns about your research program or informed consent, ask for assistance. There are many people available to address your concerns.

When the admissions process is completed and you have signed the required forms, you will be directed to the patient care unit or outpatient clinic.

### BANKING

An array of financial services is available to you from the NIH Federal Credit Union (NIHFCU). The Credit Union has provided financial services to the NIH community for over 60 years. It is a federally insured, member-owned and -operated cooperative.

You do not have to be a member of the Credit Union to cash personal checks (though some restrictions apply). But you may join the Credit Union to take advantage of membership benefits such as low-cost loans, savings and checking accounts, and convenient account access.

With a \$25 deposit in a savings account, you can join NIHFCU. You will also need a valid photo ID, such as a driver’s license or passport, and verification of your affiliation with NIH (such as an NIH identification badge). You may remain a member as long as you like—even after you leave NIH.

The NIHFCU Clinical Center Branch is located on the B1 level and is open at these times:

**Monday through Thursday:** 8 a.m. to 4 p.m.

**Friday:** 8 a.m. to 6:30 p.m.

**Saturday:** 8:30 a.m. to 1 p.m.

**Note:** *Extended hours on Friday and Saturday are for the Teller Department only.*

**ATM:** *A full-service ATM is located at the top of the escalators near the second-floor cafeteria. An additional ATM is located just outside the B1 level Cafeteria. Both are available 24 hours a day.*

For more information about NIHFCU membership or products and services, visit its Web site at [www.nihfcu.org](http://www.nihfcu.org) or call its Telephone Service Center at 1-800-877-6440, TDD 301-881-5822.

### **BUSINESS CENTER**

As a part of the ongoing efforts to meet the needs of patients and their families, the Clinical Center has opened a Business Center, located on the first floor of the Hatfield Center, Room 1-2480.

Five computers in the Clinical Center's new business center help patients and their families keep up with work and personal responsibilities, which is especially useful during long hospital stays. Available are Internet connections, telephones, a copier, and FAX.

Located just inside the front door of the Hatfield Center, the business center is open Monday through Friday, from 8 a.m. to 5 p.m. Hospitality staff stationed in the main north lobby of the Hatfield Center provide access to the center.

### **CASHIER**

The cashier's office processes voucher payments Monday-Friday, 8:30 a.m.-5 p.m. It is located near the Admissions desk off the main lobby of the Hatfield Center.

### **DEPARTMENT OF CLINICAL BIOETHICS**

The Department of Clinical Bioethics helps maintain high ethical standards in patient care and research. Bioethicists are specially trained to help you and your providers make medical decisions that reflect your values and beliefs. Bioethicists participate on review boards that review all research studies involving patients at the Clinical Center, to ensure that they meet the ethical standards.

There is a bioethics consultation service. Members come from both the Clinical Center's ethics committee and the Department of Clinical Bioethics. During your stay, you will make many decisions about your care and participation in research. These decisions may be hard to make. The bioethics consultation service can help you balance your needs with those of others as you deal with the impact of illness.

Some questions you might want to discuss with a bioethics consultation team include:

- How do I mesh my medical situation with my values about life and the future?
- How might I decide about treatment options or side effects?
- How might I think about a power of attorney or a living will?
- What about my concerns for privacy and confidentiality?
- What might I do about family arrangements or inconveniences?

A bioethics consultation team is available 24 hours a day to help you think about issues regarding your health care and participation in research.

Please feel free to call the Department of Clinical Bioethics at 301-496-2429 if you have questions or concerns about your part in biomedical research.

## **DEPARTMENT OF TRANSFUSION MEDICINE**

The Clinical Center supplies vital blood and blood components for patients with cancer, heart disease, and blood disorders. This blood comes solely from volunteer blood donors.

Families and friends of patients at the Clinical Center can help the Department of Transfusion Medicine continue to provide this “gift of life.”

Giving blood is easy and takes less than 30 minutes. Donation is safe and there is little discomfort. Every donation helps patients at the Clinical Center. Contact the department at 301-496-1048 or 301-496-1049 to ask how you can help.

## **DOCTORS’ ROUNDS**

NIH doctors as well as nurses, consultants, specialists, students, and trainees periodically make group visits to the patient care units to review patients’ health status. During these visits, called “rounds,” doctors may want to examine you and talk with you. Rounds may occur every day, once a week, or special rounds may be scheduled less often. Check with your nurse for the times of rounds on your patient care unit. You will probably be asked to be in your room for rounds.

## **DRESS**

Unless your doctor or nurse tells you otherwise, you are urged to be up and dressed during the day. If you are not confined to your bed, you should plan to wear casual street clothes and comfortable walking shoes. If you prefer to go out of your room in night clothes, please wear your bathrobe. At night, you will probably prefer to use your own night clothing, robe, and slippers. However, the Clinical Center can supply free, standard hospital nightwear. Please remember always to wear shoes or slippers.

## **ELECTRICAL APPLIANCES/ MEDICAL DEVICES**

To ensure a safe environment on the patient care units and throughout the hospital, we have a policy about electrical appliances patients may bring. Small personal appliances such as electric razors, hair dryers, or laptops are okay, but they should require standard 110-volt electricity and should not show signs of damage (frayed cords). Irons, portable heaters, heating pads, hot plates, toasters, hot oil popcorn poppers, and other kitchen appliances used to heat and prepare food are not permitted. Because of concerns for the operation of medical equipment, we restrict the use of cellular phones and other transmitting devices in some patient care areas.

If you have any questions about the appliances or equipment you may bring, be sure to ask your nurse.

If you own or rent a medical device that you routinely use, you may bring it to the Clinical Center. When you are admitted, our staff will tell you whether this device can be used. When possible, we will try to accommodate your special needs and you will be allowed to use the device. However, the Clinical Center reserves the right to substitute another device for yours if it is determined necessary for your protocol or for your care at the Clinical Center.

If it is okay for you to use your medical device at the hospital, the device must be in good working order. Since we may not have your device at the Clinical Center, you should also bring a supply of disposable items (e.g., special tubing or bags), instructions for use, as well as any reports on the testing and performance of the equipment.

### **EXERCISE ROOM**

The 14th floor gymnasium in the Magnuson Center has an exercise room for patients and their guests. Equipment includes treadmills, recumbent exercise bicycles, an elliptical trainer and Stairmaster, as well as Universal - type equipment and free weights. Before patients can use the exercise room, their NIH doctors must sign a medical clearance form. Patient's guests are asked to sign a waiver of liability release form. A recreation therapy staff member must orient patients and their guests to the equipment before the equipment can be used. Hours: 1-3 pm Monday - Thursday. A personal trainer is available 10-11 am on Tuesday, Thursday, and Friday. For more information, contact the recreation therapy staff at 301-402-0271.

### **FOOD AND LODGING FOR COMPANIONS**

#### **Food**

#### *Cafeteria on B1 Level (Magnuson Center)*

This is a full service cafeteria, open to the public. Hours of operation are posted outside the cafeteria.

#### *Cafeteria on 2nd Floor (Magnuson Center)*

This is a full service cafeteria, open to the public. Hours of operation are posted outside the cafeteria.

**Café (Hatfield Center)** Beverages and light fare are available in the café, located right off the Atrium on the 1st floor in the Hatfield Center. Hours of operation are posted and the café is closed on weekends.

Food may also be purchased in vending machines throughout the Clinical Center. There are also restaurants in Bethesda, located about 2 miles from the hospital.

#### **Lodging**

There are several hotels near NIH, and the Clinical Center admissions section can provide you with a list of local accommodations and may help arrange for temporary housing. Rooms are also available in private homes registered with the admissions desk. Some of these homeowners will accept roomers for a night or two; others will accept them only for a stay of a week or longer. These rooms are only available to relatives of inpatients.

**Edmond J. Safra Family Lodge**—The Edmond J. Safra Family Lodge at NIH offers a home-like place of respite for families and loved ones of adult patients who are receiving care at the NIH Clinical Center, the nation's premier clinical research hospital. Patients from across the nation and throughout the world visit NIH to participate as partners in medical discovery. Often they are experiencing serious illness and undergoing intensive medical treatments. It's important and necessary for patient families and loved ones to be nearby during these difficult and often stressful times. The Safra Family Lodge provides a home away from home by providing space for solitude, family meetings and supportive fellowship.



The facility includes 34 guest rooms (most have two double beds), a library, a generously equipped business and telecommuting center, a fitness center, a home-style kitchen where guests are encouraged to cook their meals (food must be provided by each guest), and comfortable social areas. There are two fully equipped laundry rooms for guests to use.

Just steps away from the NIH Clinical Center, the Safra Family Lodge was designed as an early 1900 English Arts and Crafts manor. Surrounding gardens offer a spacious patio, quiet walking paths and serene seating areas.

#### ***Safra Family Lodge Referrals and Contacts***

For more information on The Edmond J. Safra Family Lodge, including details on referrals and use of the facility, call 301-496-6500 or email [cc-famlodge@cc.nih.gov](mailto:cc-famlodge@cc.nih.gov).

Guests must be referred by the institute conducting the patient's clinical research study. The Safra Family Lodge does not accept self-referrals.

In general, 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 days

**Registration priority:** In the event that the Safra Family Lodge is operating at full capacity, the following are guidelines for registration priority:

- 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 Inpatients (and guests) transitioning to home Outpatients (and guests).

The Edmond J. Safra Family Lodge follows the same infection control rules as the Clinical Center. Any patient who is on isolation is not permitted to visit or stay at the Safra Family Lodge. The Safra Family Lodge staff may ask you questions when you check in to ensure that you do not have any infections that could be spread to other patients or families. If you are infectious, you may be temporarily relocated.

For more information on The Edmond J. Safra Family Lodge, including details on referrals and use of the facility, call 301-496-6500 or email [cc-famlodge@cc.nih.gov](mailto:cc-famlodge@cc.nih.gov). Information is online at <http://www.cc.nih.gov/familylodge/index.shtml>

**Children's Inn**—The Children's Inn at NIH is a family-centered residence on the NIH campus serving pediatric patients and their families who travel here for treatment at the Clinical Center. The Inn provides a home-like atmosphere of private sleeping rooms with baths, common living areas, playrooms, kitchen and laundry facilities, a computer room, and a library. The Inn operates on a self-help basis with the resident children and their families helping themselves and each other. Family members do their own shopping, cooking, laundry, and supervise their children as they would at home. The first reservation to stay at the Children's Inn must come to the Inn through the patient's social worker. Thereafter, returning patients may call the Inn directly for reservations at 301-496-5672 or toll free at 1-800-644-4660. Go online for more information at <http://www.childrensinn.org/>

Pediatric patients and their families may also visit the Inn as day visitors during their stay at NIH even though they are not residents.

The Children's Inn follows the same infection control rules as the Clinical Center. Any patient who is on isolation is not permitted to visit or stay at the Inn. The Inn staff may ask you questions when you check in to ensure that you do not have any infections that could be spread to other patients or families. If you are infectious, you may be temporarily relocated.

### **GIFT SHOPS**

**1st Floor (Hatfield Center)** The Gift shop is located off the Atrium on the 1st floor of the Hatfield Center. Open Monday-Friday, its hours are posted outside the shop.

**Gift Shop B1 Level (Magnuson Center)** Another gift shop is located on the B1 level of the Magnuson Center. Its hours are posted outside the shop.

**Concession Stand B1 Level (Magnuson Center)** A concession stand for food, snacks, sundries, newspapers is on the B1 Level of the Magnuson Center, near the Cafeteria on B1. Open Monday-Friday, its hours are posted outside the stand.

### **GUIDELINES FOR CHILDREN VISITING**

Children are encouraged to visit during regular Clinical Center visiting hours. Children under age 14 must be accompanied and supervised by a familiar, responsible adult. At the discretion of the nurse, adolescents between the ages of 14 and 18 may visit unaccompanied. Visitors may visit in the unit and common rooms (lounges, cafeterias, playrooms) within the Clinical Center and in the room of the patient they are visiting.

Visitors who have been recently exposed to an infectious disease (for example, impetigo, chickenpox, tuberculosis, hepatitis) may not visit. Visitors with cold or flu symptoms are discouraged from visiting. Any visitor who becomes disruptive may be asked to leave.

### **HAIR GROOMING**

A barber shop and a beauty shop are on the B1 level of the Magnuson Center, right outside the B1 Cafeteria. They are open Monday through Friday.

### **INFORMATION KIOSK**

To help find their way in the Clinical Center, patients, families, and visitors can use information kiosks located in high traffic areas throughout the Hatfield Center. The steel and granite kiosks feature a touch-screen computer and mapping software. After locating the desired destination on screen, the family can print out a map showing them how to get from that kiosk to the Blood Bank, or wherever else they need to go that day. They can also pick up a courtesy phone, which automatically dials hospitality staff who are available 6:30 a.m.-5 p.m. weekdays for assistance.

### **HOSPITAL DISCHARGE**

When your part in the research is completed and your health permits, you will be discharged to the care of your referring doctor. If you need help to make arrangements, a doctor, nurse, or social worker can assist you.

If you need continued medical or nursing care after you leave, members of our staff will help you locate appropriate community resources. Social workers may be particularly helpful in making these arrangements.

The length of your hospital stay will be determined by the needs of your research protocol. Some patients may be studied by their NIH doctor for months or years after leaving the hospital. You may be asked to return to the outpatient clinic for examinations from time to time. Your NIH doctor will explain the procedures if he or she wants you to return. If you cannot keep appointments for return visits, please notify your physician promptly.

We hope that you will want to stay with the study until your part is complete. By participating in clinical research at NIH, you help many others who are ill. The contribution you make is an essential part of medical research.

### **HOSPITAL VOLUNTEERS**

Hospital volunteers serve in many ways to make your stay at the Clinical Center more pleasant. They can introduce you to the hospital, answer general questions, or act as language interpreters. Others can shop for you, accompany you to appointments, or just spend time visiting. Volunteers in recreation help you with crafts, special events, and go on scheduled trips. Red Cross volunteers provide a variety of hospitality services to make patients feel welcome and more comfortable.

Volunteers are here because they understand how important it is to share time with patients who are away from home and family.

If you would like a helpful hand or have a special need, call the volunteer program office at 301-496-1807 or visit in room 2-3581. The office hours are from 7:30 a.m. to 4 p.m. Monday through Friday.

**HOSPITALITY SERVICES**

Hospitality information desks are located at the entrances to the hospital and in other key locations. Hospitality staff members are available Monday through Friday to assist you with directions, questions, wheelchairs, escorts, and in any other way that they can. Hours for the desk at the main lobby of the Hatfield Center are 6:30 a.m.-5 p.m.

**IDENTIFICATION BADGE**

Patients and family members may ask of their health-care team about getting an NIH Patient Identification Badge (also called an Extended Visitor Pass). There is an application form that must be signed by your doctor or nurse to authorize issuance of the badge. This badge expedites the security screening process.

Take the completed application to the Hatfield Center Badging Station, located on the B1 Level (take the South Elevators to B1) next to the Hospitality Desk. Hours are 7:30 a.m.-4:30 p.m., Monday through Friday.

**IDENTIFICATION BRACELET**

On admission to an inpatient unit, you will receive an identification bracelet to wear on your wrist. Please keep it on at all times, even while bathing or when going home on weekend pass.

This bracelet will serve as identification when you go through security checks at NIH.

**INFORMATION SERVICES AND PATIENT INFORMATION**

If you would like to have more information about the activities of the National Institutes of Health or any of its Institutes or Divisions, OCCC staff may be able to help. Call 301-496-2563 if you would like to obtain some material.

The hospital also produces a variety of patient information materials on many of the conditions and procedures under study at the Clinical Center. Feel free to ask your doctor or nurse whether there is any literature available about a topic of interest to you.

**LANGUAGE INTERPRETER**

Interpreting services are available for some languages on a limited basis. Call the volunteer office for information at 301-496-1807 from 7:30 a.m. to 4 p.m. Monday through Friday. Evenings, after 4 p.m., or on weekends, call the admissions office at 301-496-3315. Contact the on-call social worker by calling the page operator at 301-496-1211. Sign language interpretation for the hearing impaired may also be obtained.

**LAUNDRY**

Washers and dryers are available for your use at no cost. They are located adjacent to some inpatient units. Ask at the nursing desk for directions. Additionally, a dry cleaning service is available through the Gift Shop on the B1 level of the Magnuson Center.

**LEAVING THE UNIT**

Before leaving the unit or clinic, please sign a check-out sheet at the nurses' station and inform a staff member. This enables the medical and nursing staff to locate you if necessary. Check with your nurse to see if you are scheduled for any tests or medications.

**LUGGAGE STORAGE**

Patients can store their luggage in the transportation area located off the Main Lobby entrance to the Hatfield Center. The luggage lockers are available for use 24 hours a day. The transportation staff are not responsible for possessions which are either lost or damaged.

**MAIL**

Mail is usually delivered to your unit at least once a day Monday through Friday. Special delivery and registered mail will be distributed as soon as it arrives.

Provide this address to your friends and relatives:

*Patient Name*  
*NIH Clinical Center*  
*National Institutes of Health*  
*Building 10 Patient Care Unit \_\_\_\_\_*  
*10 Center Drive MSC \_\_\_\_\_*  
*Bethesda, MD 20892-\_\_\_\_\_*

To make sure your mail reaches you quickly, relatives and friends should write "patient mail" on the envelope. Also, ask for the ZIP-plus-4 code for your unit.

**MEAL SERVICE**

**Inpatients**—The Clinical Center Nutrition Department's mission is to provide the best nutrition and service to you during your stay. In order to accomplish this goal, we offer room service to our patients. Using the room service menu located at each bedside, you can order a meal from 6:30 a.m. to 6:30 p.m. We also have the following special Room Service menus available in the Nutrition Department:

- Spanish Menu
- Pediatric Menu
- Kosher Menu

For medical or research reasons, some patients must follow restricted diets that are not part of the room service program. In these cases you may be asked to select meals from a paper menu. If your study requires a special diet, you may speak with a registered dietitian. The dietitian will be happy to talk to you about this diet. Please let your nurse or doctor know if you want to speak to a member of our staff.

Family and friends may purchase food in any of the cafeterias, vending machines, and shops throughout the Clinical Center.

**MEDICINES**

Give all your own medicines (even aspirin or vitamins) to your nurse. If NIH doctors prescribe medicine for you, it will be dispensed to your unit and administered by your nurse. Please plan to be on the patient care unit at medication time.

Medications prescribed at discharge or in your clinic, are dispensed at the Outpatient Pharmacy.

**METRO SUBWAY**

Metro, a mass transit service operating in the Washington, D.C., area, provides transportation to the heart of Washington, D.C., and the immediate area surrounding the city. You may obtain a Metro subway schedule from the Hospitality desk. The stop closest to the Clinical Center is “Medical Center” on the Red Line located on the NIH campus near the National Library of Medicine. You may contact Metro for information by calling 202-637-7000. The NIH campus shuttle makes routine stops at the Metro Station.

**MONEY AND VALUABLES**

When you are admitted, valuables such as money or jewelry should be taken to the cashier’s office located on the first floor where they will be placed in a locked vault. You will receive a receipt. Cashier’s hours are 9 a.m. to 5 p.m. Monday through Friday. If you expect to be discharged on a weekend, evening, or holiday, withdraw your valuables in advance. You may call the cashier’s office at 301-496-2654. If you are going to be discharged before 9 a.m., be sure to remove your property before 5 p.m. the previous day. At other times, the admissions staff will accept valuables to keep in the safe and turn them over to the cashier for you. Be sure to safeguard your property and belongings.

**NEWSPAPERS**

Newspapers are available in the gift shop located off the Atrium on the 1st floor of the Hatfield Center and at the concession stand on B1.

**NOTARY**

Public notaries are available to witness signatures and certify documents. The Patient Representative can provide you with information about notary services.

**NURSE CALL SYSTEM**

Each bed has call systems that signal the nurses’ station. Your nurse will explain how to use the devices to summon a staff member.

**NURSING STAFF**

You will get to know the nursing staff. They will provide much of your day-to-day care and will be a link to other hospital staff. Your primary nurse will coordinate all of your nursing care. He or she will assist you and your family and see that your medications, tests, and treatments are carried out. You will become familiar with the unique and special features of your unit.

**PARKING FOR PATIENTS AND PATIENT VISITORS**

There are two options for parking and both are free.

**► *Parking your own vehicle***

If you choose to self-park, go to the Patient Parking garage (P1), which is on the west end of the building off Convent Drive. Parking attendants will be available to assist you. You’ll enter the new hospital through a new lobby on the lower (B1) level. Stop by the Hospitality desk to validate your parking ticket. The South Elevators serve the parking garages.

**► *Valet parking***

If you prefer to use the valet parking service for patients and visitors, drive to the Clinical Center’s new main entrance on Center Drive. Valet parking is available Monday through Friday, 7 a.m. -10 p.m. (excluding federal holidays). When you arrive, have your valet claim ticket validated at the Hospitality desk.

**SPECIAL NOTES**

- Parking is always available for patients and their visitors in the garage.
- On weekends and nights, you can park easily on the P1 level of the Clinical Center garage. At those times, it is not necessary to get a ticket for validation.
- When you are inside the garage, you can also get assistance from the staff at the parking attendant's booth or from Hospitality staff.

**PASS**

You will need permission from your doctor if you wish to go outdoors. Many patients are also permitted to leave the campus for an evening or weekend. Obtain a pass from your doctor and check with your nurse to make sure no tests are scheduled when you plan to be away. Your nurse will obtain any medicine that you will need, and he or she will notify the kitchen about your missed meals. Because units may have slightly different procedures, you may want to check with your nurse.

**PATIENT COMPUTERS**

There is a combination television and computer (with Internet access) at each patient's bedside. The computers provide patient's access to games, personal email via the Internet and *Starbright World*, an interactive website for pediatric patients. These computers also provide a direct link to the Clinical Center Home page in which patients can access various patient education documents in both English and Spanish.

**THE PATIENT CARE UNIT**

Your stay on the patient care unit will have some routine features. Meals, sleep, doctors' visits, and medicines are usually scheduled at regular times. Occasionally, you may be referred to other departments for treatment and care. You may have special tests or perhaps treatments, but usually your entire day will not be filled.

You may take advantage of patient recreation programs as much as your condition and doctor permit. Dress in casual clothing and engage in your favorite crafts, or check out a book from the patient library. You may also get a pass from your doctor to go outdoors to enjoy the NIH campus. Wheelchairs, other special aids, and staff are available to help you in all activities, including excursions outside. You may wish to explore Bethesda and Washington, D.C., whenever possible.

You may also enjoy becoming acquainted with other patients. They come from many different backgrounds but share the common experience of participating in clinical research at a government research hospital.

**THE PATIENT EMERGENCY FUND**

For more than 25 years, the Clinical Center Patient Emergency Fund (PEF) has helped financially strained patients and their families meet emergency expenses. PEF helps patients who come to the Clinical Center to take part in research.

Clinical Center patients come from all over the U.S. and the world. Many patients and their families deplete their savings traveling to the Clinical Center and have difficulty affording basic necessities, lodging, and food. Others suffer

financial hardship due to illness prior to their participation in research. The Clinical Center PEF is used to help in emergency circumstances and with unexpected incidental expenses.

PEF is administered by the Social Work Department. To receive PEF funds, patients must contact their social worker. For information about PEF, contact your social worker or:

***Patient Emergency Fund***  
***National Institutes of Health, PHS, DHHS***  
***Social Work Department, NIH Clinical Center***  
***10 Center Drive, Room 2-3581***  
***Bethesda, MD 20892***

### **PATIENT ESCORT SERVICES AND WHEELCHAIRS**

Patient Escort Services provide wheelchair transport or personal escort for patients to tests and procedures. These services are arranged as needed for you by the patient care staff.

Wheelchairs are available at the entrance to the hospital and at the patient parking garage entrance. Upon arrival, Hospitality staff are available if needed to transport you or personally escort you safely to your destination. Wheelchairs are also provided in treatment and patient care areas.

### **PATIENT ENTRANCE: CAMPUS ENTRANCE FOR PATIENTS AND FAMILIES**

The West Drive Patient Entrance at the intersection of West Cedar Lane and West Drive, eases access to NIH for patients and their visitors by providing one-stop security screening. Individuals 16 and older need a photo ID. This entrance is open from 7 a.m. until 7 p.m. weekdays (except holidays). At other times visitors enter through the main public entrance at Metro, which is located at Rockville Pike and South Drive. There is no exit from the West Drive Patient Entrance.

### **PATIENT LIBRARY**

A well-stocked library is located in the 7<sup>th</sup> floor. There are more than 4,000 books, including a selection of current best-sellers, reference, foreign language, large-print, picture, and audio books. A special section featuring selections on health and coping is also included. Music CDs, with choices ranging from classical to hip hop, are available. Books may be checked out for 2 weeks to inpatients, outpatients, and their family members. The library subscribes to some 30 magazines, the Washington Post, The New York Times, and The Wall Street Journal. If you are not able to go to the library yourself, magazine selections may be made from the cart that is brought to your patient care unit each week. Call the library to find out the day and time. A hospital volunteer or member of the library staff will also bring books, CDs, or other library material to you between cart visits.



The library offers instruction in basic computer skills (how to access the Internet, send and receive e-mail, and explore) so that you may better use the computer in your room. Special items such as CD players, guitars, and special visual aids such as talking books, book holders, and “bed specs” (prism glasses that allow you to read lying down) are also available. You may return books to the library yourself, or you may call library staff for pick-up. Drop by the library to browse or contact a hospital volunteer or nurse for information. Also watch the monthly patient activities schedule for partial lists of new acquisitions.

The library is open Monday through Friday from 11 a.m. to 7 p.m. and Saturdays from 11 a.m. to 6 p.m. On Federal holidays it is open from 11 a.m. to 4 p.m. You may call the library at 301-451-7603 for assistance or information.

### **RECREATION SERVICES**

The recreation therapy section provides recreation, library services, in-hospital entertainment, and maintains a movie channel on your room TV (stations 90, and 92 are in English; 91 and 93 are in Spanish). Helping patients cope with the stress of hospitalization and maintaining their quality of life in the face of chronic disease and experimental treatment are the section’s objectives. Available to all patients and their families, most programs are held on the first floor of the hospital and may include arts and crafts, music, games and sports, social events, and exercise. The gymnasium has a game room and a well-equipped exercise room.

Instruction in coping skills such as relaxation, enhanced communication, and stress management is available.

Trips are taken into the community for entertainment and sightseeing. Wheelchairs can be accommodated on all trips.

Children and their families are welcome in the playroom. At least one special event for children is held each month. Occasionally, special visitors entertain the children during these events. When time permits, entertainers may visit patients in their rooms.

The playroom has an aquarium and two resident guinea pigs. As part of the animal-assisted therapy program, children are encouraged to hold and play with the guinea pigs.

Twice a month, several dogs are brought in to visit both adult and pediatric patients. These visits are voluntary and closely follow hospital infection control procedures.

For more information about recreation services for both children and adults, check the patient activities calendar. This calendar is available on the unit, in the Patient Library, and from your therapeutic recreation specialist.

### **RELIGIOUS SERVICES AND MINISTRY**

The hospital has a Department of Spiritual Ministry. The chaplaincy staff supports your spiritual needs. Chaplains are available for personal visits with you and your loved ones. Catholic, Jewish, Islamic, and Protestant chaplains hold regular services in the Inter-Faith Chapel. If your faith is not represented within the staff, the chaplains will contact your faith group representative on your behalf. Scriptures and religious literature of most faiths are available upon request.

Religious services are scheduled at these times:

■ **Catholic:** Daily at 11:15 a.m.

Holy Communion is distributed at the bedside upon request. The Blessed Sacrament is reserved in a small chapel on the 7<sup>th</sup> floor.

This chapel is open 24 hours a day for meditation.

■ **Islamic:** Monday through Friday at 1:30 p.m.

■ **Protestant:** Sunday at 10 a.m., devotions on Thursday at 12:30 p.m. Holy Communion is distributed on the first Sunday of each month. Bedside Communion is available upon request.

■ **Jewish:** Jewish patients wishing to celebrate Shabbat and other Holy days may contact the Spiritual Ministry Department to coordinate arrangements.

Special services and changes in the regular schedule are announced by special notice and in the patient activities schedule available at the nurses' station.

Escorts can be arranged through the nursing staff to take patients in wheelchairs to the chapel. To contact a chaplain, call 301-496-3407, or ask the nurse or social worker to help you.

### **SHUTTLE SERVICE & PUBLIC TRANSPORTATION**

Shuttles leave from the main entrance of the Hatfield Center. Shuttle service is available for patients and families who wish to go to:

- Children's Inn
- Safra Family Lodge
- Nearby hotels
- Airports:
  - Baltimore-Washington International (BWI)
  - Dulles International (IAD)
  - Ronald Reagan National (DCA)
- Metro
- Other NIH Buildings

Shuttle schedules are available at the Hospitality Desk located at the main entrance to the Hatfield Center. Hospitality staff can assist you.

Taxi cabs are also available at your own expense, leaving from the main entrance of the Hatfield Center. To arrange a cab pickup, visit the Transportation desk located at the main entrance or call 301-496-1161.

### **SMOKING POLICY**

As the nation's leading medical research center, the NIH Clinical Center is committed to ensuring a healthy and safe environment for patients, visitors and staff. Patients who would like information about smoking cessation help should talk with a member of their care team. Medical Executive Committee policy permits patient smoking under certain strictly controlled circumstances. Talk with your principal investigator if you need more information.

### **SOCIAL WORK SERVICES**

If you or members of your family have difficulties or concerns during your stay, social workers are here to provide information and counseling. In most patient units and outpatient clinics, new patients are routinely screened by social workers.

You are encouraged to speak with a social worker to explore your concerns or any other issues that have an impact on your coping with treatment and illness. These include anxiety, depression, concerns about family, work, and adjustment to the Clinical Center. Social workers are available to support you with issues related to your taking part in protocols at NIH. They can also help connect you to valuable resources, support organizations, and public and private agencies that address personal, financial, and health care problems.

Many patients need special assistance with discharge from the hospital, and your social worker will work with staff to set up services, supplies, special equipment, or rehabilitation at home.

There are several ways to obtain social work services:

- ▶ See the social worker on your patient care unit.
- ▶ Call the Social Work Department at 301-496-2381 and ask for a visit from a social worker.
- ▶ Ask your doctor, nurse, family member, or a friend to ask for a meeting with your social worker.

### TELEPHONES

On most units, there are telephones in each room for local calls.

- ▶ To call a number within the hospital, press 9 plus the 10 digits of the number.
- ▶ To call local outside numbers:
  - press 9-202 for Washington, D.C.
  - press 9-301 for Maryland
  - press 9-301 or 9-410 for Maryland

For long-distance calls, you may use your patient extension to call collect or to bill charges to a credit card. It is not possible to charge calls to your room extension or accept incoming collect calls.

On each patient care unit, a telephone is provided for long-distance calls at no expense to you. Calls may be placed from 6 a.m. to 8 a.m. and from 6 p.m. to midnight. We urge you to limit your calls to 10 minutes in consideration of your fellow patients who may also need access to the telephone. If you cannot get to this telephone, ask your social worker to authorize a long-distance call from your room telephone.

Family and friends may call you directly. If they do not have your number, they can reach you through the NIH operator at 301-496-4000. As a courtesy to other patients, please ask family and friends to call before 10 p.m. There are also pay telephones located throughout the hospital.

### TRAVEL

If you need help with travel plans, the travel agency staff can assist you and your family. The staff can obtain plane, train, bus, and airport shuttle information; make reservations or changes for you; and secure tickets. For further information and assistance, call or visit the travel office on the first floor weekdays between 8 a.m. and 5:30 p.m. The telephone number is 1-866-227-9339.

### TVS AND RADIOS

TVs are available without charge. You may bring your own small radio.

### UNIVERSAL PRECAUTIONS/ ISOLATION PRECAUTIONS

*Universal precautions*—One of the goals of the Clinical Center is to provide a safe and healthy environment for patients and staff. Universal precautions are used to reduce the risk of transmission of blood-borne infections, as well as infections from moist body substances. If exposure to a patient's blood, body fluids, or other infectious materials is likely, hospital staff members will use some type of personal protective equipment.

Gloves are the most frequently used personal protective equipment, but the actual equipment used will depend on the procedure involved. You may notice health care members wearing gloves while drawing your blood. Masks, gowns, and protective eyewear might also be used when performing a procedure where blood or other infectious materials might splash on a health care worker's skin, eyes, or mouth. Housekeeping staff wear gloves and gowns when changing soiled linens and wear gloves when handling trash. Hospital staff should observe universal precautions with all Clinical Center patients.

**Isolation precautions**—Universal precautions are not always enough to prevent the transmission of all infectious diseases. Some infectious diseases may require additional protective measures to prevent the spread to others. If hospital staff suspect that a patient has one of these infections, that patient is placed on isolation. Gloves, gowns, masks, and protective eyewear are used more frequently by staff caring for patients on isolation. Patients who are on isolation should limit the amount of time they spend out of their rooms. They should not visit busy, crowded areas and are not permitted to visit with other patients in the hospital.

If you require isolation, a sign will be placed on the door to your room. The sign reminds staff which additional protective equipment they should wear. The sign also instructs visitors to check with nursing staff for more information before entering your room. If you require isolation, your nurse or doctor will explain this to you. To protect patient confidentiality, isolation signs do not identify the patient's infection.

During cold and flu season, it is important to let your doctor or nurse know at once if you have a cough, sore throat, runny nose, or congestion. Visitors with these symptoms should avoid coming to the Clinical Center until their symptoms resolve.

You can receive more information about universal precautions or isolation precautions through your unit staff, who will contact the Hospital Epidemiology Service at 301-496-2209.

## **VISITING HOURS**

Visiting hours are generally from 9 a.m. to 9 p.m. On some units hours may vary, and there may be age restrictions for visitors.

## **VISITOR'S PASS**

Due to heightened security measures, patients and visitors arriving at the main entrance to the Clinical Center will be asked for a valid photo ID (driver's license, state ID, passport, high school/college ID, etc.). Bags and luggage will be inspected. You will be issued a Visitor Pass that should be worn at all times in the Clinical Center and while on the campus. If you are unable to wait in line for this procedure, please inform the security staff who will notify a member of the Clinical Center's Hospitality Staff to come and assist you.

## SUPPORT SERVICES FOR PATIENTS AND FAMILIES

### **SOCIAL WORK SERVICES**

**Barber and beautician services**—Barber and beautician services are available to patients and their visitors. An appointment should be made for using these services. Call 301-496-3019 for the barber shop; call 301-496-2765 for the beauty shop. For patients in financial need, a social worker may provide a voucher that meets the cost. For patients confined to their patient care unit, the barber or beautician will come to the patients.

Your social worker can help you obtain the following services:

**Family Friend program**—Assistance with child care is available through the Clinical Center Family Friend program, a child care service staffed by trained volunteers. The program may be used by

- parents who need respite while caring for children who are pediatric patients, and
- parents who are outpatients but have no other means of child care, such as family members or friends.

Arrangements must be made in advance and can be made by the social worker or the protocol's research nurse.

**Inpatient relative/guardian program**—Some Institutes have programs that assist relatives/guardians to stay in the area while the patient is hospitalized. Contact your social worker for information about these programs.

**Medic-Alert and stainless steel bracelets and necklaces**—The Clinical Center will help patients whose medical problems warrant them obtain stainless steel Medic-Alert bracelets and necklaces. Contact your social worker to obtain the order form for this identification. To ensure the accuracy of the information on the bracelet or necklace, you should talk with your doctor about how to state your medical condition.

**Outpatient voucher program**—There is a voucher program, supported by some Institutes for patients on specific protocols, to help defray the cost of participating in research at the Clinical Center. You will be notified concerning your eligibility, or you can check with your health care staff.

**Social Security Administration**—A Social Security Administration field representative visits the Clinical Center on the third Friday every month between 8:30 a.m. and 4 p.m. Inpatients can meet with this field representative. Call your social worker to make an appointment with the representative and to receive helpful brochures and applications.

**Wigs for patients**—The Clinical Center Social Work Department processes wig requests for patients who have hair loss during treatment. Upon receipt of a request, a social worker authorizes a voucher to buy a wig from a contractor hired by the Clinical Center. Ambulatory patients may take their authorizations to room 2-3581 to get a wig voucher. When they have the voucher, patients may contact the wig contractor and make

an appointment, either at the contractor's place of business or in the Clinical Center.

### **OTHER SERVICES**

**Clinical Center galleries**—Looking around the first floor of the Clinical Center, you will notice art galleries. These galleries, on view 24 hours a day, feature artwork by artists from the Washington, D.C., area, with occasional exhibits from around the country. Each artwork sale benefits patients with a 20 percent donation contributed to the Patient Emergency Fund (PEF). Since 1995, these galleries have raised over \$25,000 for the PEF. Price lists and other information about the galleries are available from the Office of Facility Management (B1L410) between 9 a.m. and 4:30 p.m. Monday through Friday. Art may be bought by contacting the Office of Facility Management at 301-496-2862. Feel free to browse through the galleries to enjoy the current display and, perhaps, to purchase a favorite piece.

**Friends of the Clinical Center**—Founded in 1984, the Friends of the Clinical Center (FOCC) is a nonprofit, charitable organization located in the Clinical Center. It provides emergency financial assistance to NIH patients and their families. Illness often causes stress—both emotional and financial—for patients and family members. In addition to the concerns of finding a successful treatment, lost income over a period of time often has severe financial impact.

FOCC can help by providing emergency funding on a case-by-case basis to those in need during these stressful times. FOCC often assists with payment of rent and mortgages, utilities, car payments, transportation costs to and from NIH, medical bills, and other types of expenses. Patients desiring consideration for funding from FOCC should speak with their social worker.

For information about FOCC, you may call 301-402-0193, or view its Web site at <http://www.FOCCcharity.org>

**The NIH Children's School**—While they are patients at the Clinical Center, children are expected to attend the NIH Children's School, a satellite school of Montgomery County. The school is staffed by teachers who instruct students in grades kindergarten through 12. Teachers also come to the bedside when patients are unable to attend school. Children should bring their textbooks and current assignments. The NIH teachers will keep the local school apprised of the child's progress. Studies for the graduate equivalency program (GED) and English spoken as the other language (ESOL) are also provided to those who meet a certain criterion. The school can be contacted by

- ▶ phone: 301-496-2077
- ▶ email: [hmays@mail.cc.nih.gov](mailto:hmays@mail.cc.nih.gov)
- ▶ fax: 301-402-9202

## OTHER USEFUL INFORMATION

**FIRE** .....911**SECURITY** .....911**HANDY TELEPHONE NUMBERS****Key Numbers**

NIH Main Operator & Directory Assistance  
 ..... 301-496-4000

Visit NIH Telephone and Services Directory at  
<http://teledirectory.nih.gov/>

Admissions .....301-496-3141

Blood Bank .....301-496-1048

Patient Representative .....301-496-2626

Patient Volunteers  
 (toll-free) .....1-800-411-1222  
 (TTY) .....1-866-411-1010

Healthy Volunteers (local) .....301-496-4763  
 (TTY) .....1-800-892-3276

**General Numbers**

Bank (NIH Credit Union)  
 (toll-free) .....1-800-877-6440  
 (TDD) .....301-881-5822

Barber Shop .....301-496-3019

Beauty Shop .....301-496-2765

Bioethics Consult Service .....301-496-2429

Cashier's Office .....301-496-2654

Children's Inn .....301-496-5672

Children's School .....301-496-2077

Children's Playroom .....301-496-4730

Edmond J. Safra Family Lodge .....301-496-6500

General Information .....301-496-2563

Gift Shop .....301-496-1262

Hospitality Services  
 (South Lobby) .....301-594-3301  
 (Mid-Lobby) .....301-451-7228

Medicolegal Services (Medical Records)  
 (local) .....301-496-3331  
 (toll-free) .....1-888-790-2133

Metro (Washington, D.C. Mass Transit)  
 .....202-637-7000

Office of the Director .....301-496-4114

Outpatient Pharmacy .....301-496-2866

Patient Library .....301-451-7603

Radiology .....301-496-7700

Recreation Therapy .....301-496-2278

Red Cross hospitality .....301-496-5891

Social Work Department  
 (local) .....301-496-2381  
 (toll-free) .....1-888-676-5668

Spiritual Ministry .....301-496-3407

Transportation Services .....301-496-1161

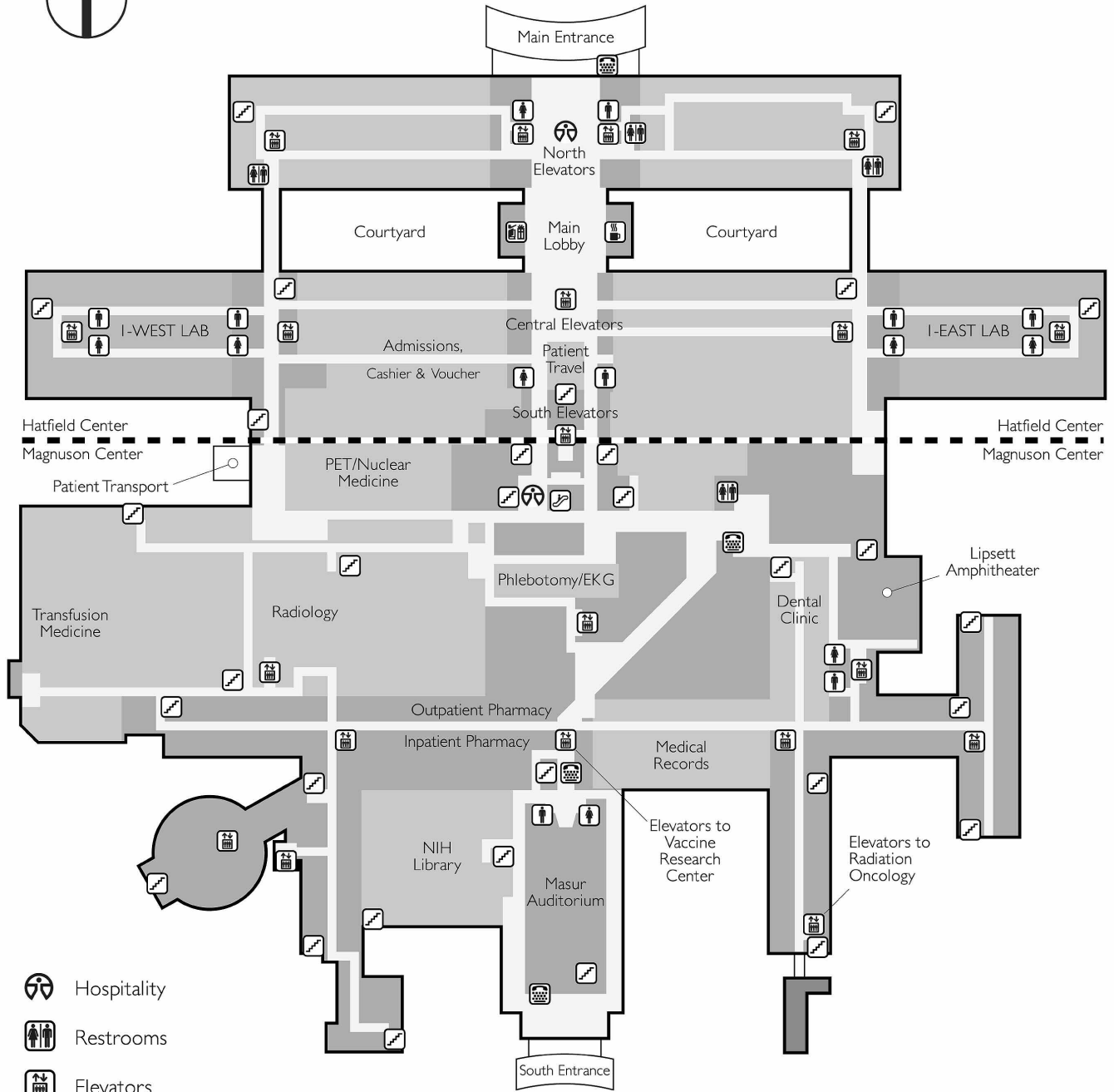
Travel Services  
 (local) .....301-496-6676  
 (toll-free) .....1-866-227-9339








Volunteers Services and Language Interpreters Program  
 .....301-496-1807

Voucher Office  
 (main) .....301-496-7632  
 (patient) .....301-496-4903



The Mark O. Hatfield Clinical Research Center



-  Hospitality
-  Restrooms
-  Elevators
-  Stairs
-  Escalators
-  TDD Phone
-  Coffee Shop

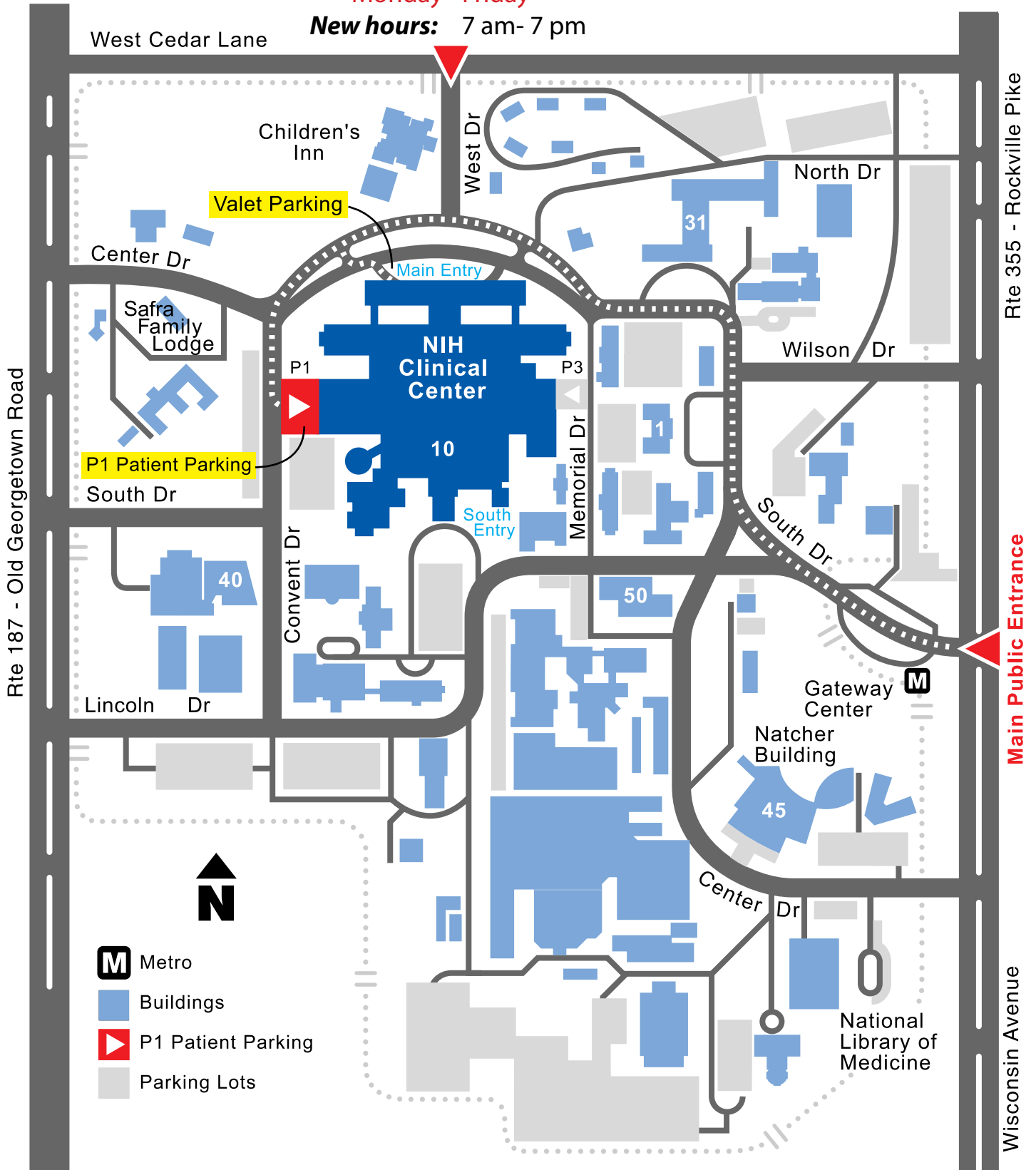
The Warren Grant Magnuson Clinical Center



**Entrance for Patients and Families**

Monday - Friday

**New hours:** 7 am - 7 pm









National Institutes of Health



U.S. Department of Health and Human Services

June 2006