

Patient Responsibilities

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

You have the responsibility:

- ▶ To provide, to the best of your knowledge, complete information about your current medical condition and past medical history, including current illness, prior hospitalizations, current medications, allergies and all other health-related matters;
- ▶ To discuss your protocol (study or treatment plan) with the research staff before indicating agreement to take part in it by signing a consent;
- ▶ To comply with your protocol, to cooperate with hospital staff, to ask questions if directions or procedures are not clear, and to participate in your health care decisions. You may withdraw from the study for any reason, but it is desirable to discuss your 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;
- ▶ To refrain from taking any medications, drugs, or alcoholic beverages while participating in the protocol, except those approved by an NIH physician; smoking is prohibited in the Clinical Center.
- ▶ To adhere to the no-smoking policy of the NIH;
- ▶ To inform the medical staff about your wishes regarding treatment plans. You may provide for a duly authorized family member or spokesperson to make medical decisions on your behalf in the event that you become unable to communicate;
- ▶ To report on time for scheduled procedures and to keep all clinic appointments. If unable to do so, you have the responsibility of notifying the protocol physician and canceling and rescheduling the appointment;
- ▶ To report promptly to the medical or nursing staff any unexpected problems or changes in your medical condition;
- ▶ To inform the appropriate staff or the Patient Representative of any concerns or problems with the care and treatment that you feel are not being adequately addressed;
- ▶ To respect the property of the U.S. government, fellow patients and others; to follow NIH rules and regulations affecting patient care and treatment; 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;
- ▶ To pay all medical or laboratory expenses incurred outside the Clinical Center, except when you have received written authorization on the appropriate NIH form to have such expenses billed to the NIH;

- ▶ To obtain medical care and medications from your own health care provider for all conditions unrelated to the protocol in which you are participating, except while being treated as an inpatient at the Clinical Center;
- ▶ To provide your own transportation to and from the Clinical Center and to pay living expenses except when all or part of these expenses are covered by the protocol or authorized by the responsible NIH physician; to advise accompanying escorts or others who travel to and remain in the Bethesda area that they must pay for their travel and living expenses except when designated by NIH as a guardian for you when your expenses are covered;
- ▶ To provide complete information, so that contacts and communications to schedule visits and monitor health status can be maintained. This information should include: (1) your current address and phone number; (2) the names, addresses, and phone numbers of next of kin or persons to be notified in the event of an emergency; and (3) the names, addresses, and phone numbers of physicians responsible for your ongoing care, including your family physician and the physician(s) who referred you to the NIH

- ▶ To return to the care of your own health care provider when participation in the protocol is completed or stopped and your medical condition permits.

If you have questions about your rights, you may contact the Clinical Center Patient Representative at 301-496-2626.

This information is prepared specifically for persons taking part in clinical research at the National Institutes of Health Clinical Center and may not apply to patients elsewhere. If you have questions about the information presented here, talk to a member of your health care team.

Products/resources named serve as examples and do not imply endorsement by NIH. The fact that a certain product/resource is not named does not imply that such product/resource is unsatisfactory.

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Questions about the Clinical Center?
<http://www.cc.nih.gov/comments.shtml>
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