# Clinical Center Patients' Bill of Rights

The Clinical Center Patients' Bill of Rights protects you when you volunteer to participate in clinical research as a patient or as a healthy subject. We believe that concern for every research volunteer is linked closely to the successful conduct of clinical research. The Clinical Center provides hospital facilities and professional care; you, the research participant, make it possible for us to observe health and disease and to measure response to treatment.

Your rights and safety are protected by procedures that provide an awareness of your medical choices, of any risks or benefits, and of possible consequences of participating in research. The list summarizes your rights as a research participant at the Clinical Center.

You have the right:

- To safe, considerate and respectful care, provided in a manner consistent with your beliefs;
- To expect that all communications and records pertaining to your care will be treated as confidential to the extent permitted by law;
- To know the physician responsible for coordinating your care at the Clinical Center;
- To receive complete information about diagnosis, treatment, and prognosis from the physician, in terms that are easily understood. If it is medically inadvisable to give such information to you, it will be given to a legally authorized representative;
- To receive information necessary for you to give informed consent prior to procedure or treatment, including a description of the procedure or treatment, any potential risks or benefits, the probable duration of any incapacitation, and any alternatives. Exceptions will be made in the case of an emergency;
- To receive routine services when hospitalized at the Clinical Center in connection with your protocol. Complicating chronic conditions will be noted, reported to you, and treated as necessary without the assumption of long-term responsibility for their management;
- To know in advance what appointment times and physicians are available and where to go for continuity of care provided by the Clinical Center;
- To receive appropriate assessment of and treatment for pain;
- To refuse to participate in research, to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of these actions, including possible dismissal from the study and discharge from the Clinical Center. If discharge would jeopardize your health, you have the right to remain under Clinical Center care until discharge or transfer is medically advisable;
- To be transferred to another facility when your participation in the Clinical Center study is terminated;

- To expect that a medical summary from the Clinical Center will be sent to your referring physician;
- To designate additional physicians or organizations at any time to receive medical updates.

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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