National Center for Research Resources
NATIONAL INSTITUTES OF HEALTH

The Clinical Research Office is supported by the National Center on Research Resources . The Clinical Research Support Office reports to the Principal Investigators of the Rockefeller University Center for Clinical and Translational Science.

The Clinical Research Officer fulfils the role of Research Subject Advocate by ensuring that the safety monitoring plan approved by the Institutional Review Board and the Advisory Committee of Clinical and Translational Science is carried out appropriately.

Summary

- ☑ *As a research volunteer, you have the right to receive adequate information about the study. You also have the right to withdraw from a study at any time, for any reason.*
- ☑ *The Clinical Research Officer advocates for your rights and can meet with you to discuss your concerns related to a study.*
- ☑ *All conversations with the Clinical Research Officer are kept confidential.*

My Questions & Notes:

Questions about my rights:

Questions about the study:

Questions for the Clinical Research Support Office:

The Rockefeller University Hospital
1230 York Avenue
New York, NY 10021

THE ROCKEFELLER UNIVERSITY HOSPITAL 1910

The Clinical Research Support Office

The Clinical Research Support Office was founded in 2001 as the Clinical Research Office to advocate for the rights of research volunteers. The office oversees the safety of research studies, develops educational programs to foster an environment sensitive to the values and rights of research volunteers, and serves as a link between the hospital and volunteers.

The Rockefeller University
Clinical Research Office

Partners in Research

Volunteers are important partners in research.

Volunteers are important partners in research. They contribute to obtaining new knowledge that can improve the health of millions of individuals.

The Rockefeller University values this partnership and the open communication and respect on which it is based. In order to involve you in the study as much as possible, we are committed to giving you the information you need to understand your role and make decisions about your participation.

This brochure has two goals:

1.) To share with you your rights as a research volunteer. Volunteers who are knowledge about their rights are more active and informed study participants;

and

2.) To introduce you to the Clinical Research Office, which advocates for your interests

What should I know about being a research volunteer?

While you are enrolled in a research study, there are laws that protect your well-being. As a patient, you are protected by the New York State Patients' Bill of Rights. These rights are posted in the clinic and included in the Patient Information Brochure you received when you enrolled in the study. As a research volunteer, you have additional, important rights.

You are entitled to:

1. Learn the nature and purpose of the research study.
2. Receive an explanation of the procedures and any drug or device to be used.
3. Receive a description of any discomforts and risks that you could experience from the study.
4. Learn about any benefits you might expect from the study.
5. Learn about the risks and benefits of any other available procedures, drugs or devices that might be helpful to you.
6. Learn what medical treatment will be made available to you if you are injured because of the study.
7. Ask questions about the study or the procedures involved.
8. Quit the study at any time. Your decision will not be used as an excuse to hold back necessary medical treatment.
9. Receive a copy of the signed and dated consent form.
10. Decide to consent or not to consent to a study without feeling forced or obligated.

You may exercise these rights at <u>any time</u> during the study.

The Rockefeller University encourages you to have all of your questions answered before you sign the consent form or begin a procedure and continue to ask new questions as they arise during the study.

Who can I talk to about my rights?

The Clinical Research Office advocates for the rights of research volunteers.

There may be times when you wish to speak with someone who is not involved in your medical care. The Clinical Research Officer or attending Research Subject Advocate are available to meet with you in a confidential setting to discuss your concerns. The Clinical Research Office advocates for you by overseeing the safety of research studies and the integrity of the informed consent process, improving the research environment for research volunteers, and educating research staff. When issues arise about study conduct or a volunteer's rights, often the Clinical Research Office can help sort things out.

If you would like to learn more about your rights or have a concern related to a study or visit, please contact the Clinical Research Office to schedule a time to talk. We are committed to maximizing your safety and well-being, and helping you explore choices that reflect your values and needs.

The Clinical Research Office is located in Room 107, on the first floor of The Rockefeller University Hospital. The Clinical Research Officer, or another research subject advocate, is available Monday through Friday, from 9am-5pm. For urgent issues outside of regular hours, the head nurse can contact the Clinical Research Officer for you.

Clinical Research Office: (212) 327-8408 or 327-7408.