Rockefeller University Hospital

AUTHORIZATION TO OBTAIN, USE, AND DISCLOSE HEALTH INFORMATION

Participant Name: _____

Participant's MRN: _____

Name of Study: Entrance into the International Fanconi Anemia Registry (IFAR)

Principal Investigator: Agata Smogorzewska, MD, PhD

Sponsor:

Granting Institutions: Starr Foundation, NIH Grant, Doris Duke Clinical Scientist Development Award, Irma T.

The Rockefeller University understands that information about you and your health is personal. We are committed to protecting the privacy of your information. Because of this commitment, we must obtain approval from you before we can obtain, use, or disclose your protected health information for research purposes. This form provides that authorization. This form also helps us make sure that you are informed of how this information will be obtained, used, or disclosed in the future. Please read carefully the information below before signing this form.

Who may obtain, use, and/or disclose your health information?

The following persons and organizations may obtain, use, or disclose health information about you:

- The Principal Investigator named above and persons who assist the Investigator(s) in carrying out the research
- Each research site for this study, including The Rockefeller University, and the research management and support staff and the medical staff at each site
- Health care providers who have provided in the past, or currently provide, health care services to you
- Laboratories and other persons and organizations that will analyze your health information and/or biological samples as part of this study, including Memorial Sloan Kettering Cancer Center, New York-Presbyterian Hospital and Weill Medical College of Cornell University, and entities listed below (if applicable):

  Members and staff and other boards and committees that watch over research at Memorial Sloan-Kettering Cancer Center, Cincinnati Children"s Hospital Medical Center and University of Minnesota.

- Members and staff of the Institutional Review Board and other boards and committees that watch over research at The Rockefeller University
- Members and staff of The Rockefeller University's Office of Sponsored Research
- The sponsor(s) of the research or granting institution(s), as named above, and persons who watch over the research for the sponsor(s)
- The United States Food and Drug Administration, other government agencies, regulatory entities and Rockefeller University consultants that watch over the safety, effectiveness, and quality of research and/or fund The Rockefeller University Hospital
- Others (as described here): _____

_____

What information will be obtained, used, or disclosed?

The persons and organizations listed above may obtain, use, and disclose:

- Information about you that is created or collected during the research study (but not including any HIV-related information)
- Health information in your medical records that is relevant to the research study (but not including any HIV-related information)
- And, if checked below:

☐ HIV-related information (this includes any information indicating that you have had an HIV-related test or have HIV infection, HIV-related illness, or AIDS, as well as information that could indicate you may have been exposed to HIV)

☐ Other information (as described here):

_____

_____

_____

By signing this form, you give permission to the persons and organizations listed above to obtain, use and disclose your health information noted above.

How will your health information be used?

The health information noted above, as well as information shown by the boxes checked above (if any), may be obtained, used, and disclosed to:

- conduct the research study explained to you during the informed consent process; and
- assure the quality, safety, and effectiveness of the research study.

In addition, the Prinicpal Investigator, sponsor, granting institution(s) and The Rockefeller University may obtain, use, and disclose your information as needed for your treatment or as permitted by the informed consent form for the research study.

Please note that the persons and organizations listed above may re-use or further disclose your information if they are permitted by law to do so.

What are your rights?

It is your right to refuse to sign this authorization form. If you do not sign this form, you will not be able to participate in the research study. Your health care outside the study will not be affected. The payment for your health care and your health care benefits will not be affected.

If you sign this authorization form, you will have the right to withdraw it at any time except to the extent that the persons and organizations listed above:

- have already taken action based upon your authorization;
- need the previously collected information to complete analysis and reports of data for this research; or
- will continue to use and disclose previously collected information as permitted by the informed consent form signed by you (except as to HIV-related information, for which disclosure to new persons or organizations will not occur unless permitted by federal or state law).

If you withdraw the authorization, you will not be permitted to continue taking part in the research study. This authorization form will not expire unless you withdraw it. If you want to withdraw this authorization, please write to the Principal Investigator named above.

You have a right to see and copy your health information described in this authorization form in accordance with The Rockefeller University's policies; in certain circumstances where the integrity of the study will be affected, you will not be able to obtain your health records in this study until the study has been completed.

You will receive a copy of this form after you have signed it.

Notice Concerning HIV-Related Information
If you are authorizing the release of HIV-related information, you should be aware that such information may not be shared without your approval unless permitted by federal or state law. You also have a right to request a list of people who may receive or use your HIV-related information without authorization. If you experience discrimination because of the release or disclosure of HIV-related information, you may contact the New York State Division of Human Rights at (212) 480-2493 or the New York City Commission of Human Rights at (212) 306-7450. These agencies are responsible for protecting your rights.

Your Signature

I have read this form, and all of my questions have been answered. By signing below, I acknowledge that I have read and accept all of the information above.

_____ _____

Signature of participant or participant's legal representative

Date

_____ _____

Print Name of Participant

Printed name of legal representative (if applicable)

_____

Representative's relationship to Participant

THE STUDY PARTICIPANT OR HIS OR HER PERSONAL REPRESENTATIVE MUST BE PROVIDED WITH A COPY OF THIS FORM AFTER IT HAS BEEN SIGNED.