

ALBERT EINSTEIN COLLEGE OF MEDICINE OF YESHIVA UNIVERSITY
Parental Permission Form

You are being asked to join a research registry to be used to recruit people for participation in research studies.

The title of the database is: **The Human Clinical Phenotyping Core Database**

Principal Investigator (Research Study Doctor): Sophie Molholm, Ph.D.

Office Address: Albert Einstein College of Medicine, Van Etten, 1C-3C, 1225 Morris Park

Avenue, Bronx, NY, 10461

Telephone #: (718) 862-1823

Protocol #: 2011-320

WHY HAS MY CHILD BEEN ASKED TO TAKE PART IN THIS RESEARCH STUDY?

- You and your clinician are being asked to fill out an enrollment form for your child to be entered into a research registry. This registry is used to compile participants for future research studies. Your information will be stored in this registry, but will only be able to be accessed by HCP personnel. If your child qualifies for a future research study, you will be contacted by HCP personnel and asked if you wish to participate in that study. Even if you are in the registry, you have the right to refuse participation in any study.

DOES MY CHILD HAVE TO TAKE PART IN THIS RESEARCH REGISTRY?

- You do not have to agree to fill out the enrollment form, and you will still have access to any services that are available.

WHAT IS THE PURPOSE OF THIS RESEARCH REGISTRY?

- The research registry is where basic information (such as age, gender, diagnosis, medical conditions) about people is stored. The HCP is a service that investigators use to recruit for their research studies. The registry allows the HCP to have existing information about people to better aide investigators in their recruitment. By filling out the enrollment form, you agree to be contacted by the HCP if you may qualify for a future research study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS RESEARCH REGISTRY?

- By filling out the enrollment form, you agree to be contacted by the HCP when you may qualify for a research study. Active participation is not required by you once you enter the registry. It just means that your information will be on file and you may be contacted in the future to see if you wish to participate in a specific study.

WHO MAY SEE MY CHILD'S RECORDS?

- By filling out the enrollment form, your information will be added to a portion of the research registry that is only accessible to HCP personnel. No one outside of the HCP will be able to see any of your information.

WHO CAN ANSWER MY QUESTIONS ABOUT THE STUDY?

- Researcher’s Name: Margot Gardin B.A. Office Phone: (718) 862-1860
Office Address: Albert Einstein College of Medicine, Van Etten, 1C, 1225 Morris Park Avenue, Bronx, NY, 10461

If any questions arise related to this research database you can call the researcher above. If you have questions regarding your child's rights as a research subject, you may also call the Manager of The Albert Einstein College of Medicine Committee on Clinical Investigations at (718) 430-2253, Monday through Friday between 9 AM and 5 PM.

FOR FUTURE CONTACT, PLEASE INITIAL YOUR CHOICES BELOW:

I consent to have my child's details entered into the registry and to be contacted for participation in future research studies. (Your wish does not constitute a guarantee that you will be contacted.)

I do NOT consent to have my child's details entered into the registry.

FOR INFORMATION SHARING, PLEASE INITIAL YOUR CHOICES BELOW:

I consent to have my child's records shared between his/her clinical team at the CERC or Montefiore and the HCP.

I do NOT consent to have my child's records shared between his/her clinical team at the CERC or Montefiore and the HCP.

Informed Consent Signature Page

The following is a list of items we discussed about this research registry. If you have any questions about any of these items, please call (718) 862-1860 before agreeing to participate.

- What the registry is about.
- Who to contact if I have questions.
- My child can discontinue participating in the registry at any time without penalty.
- I have been given the name of the researcher and others to contact.
- I have the right to ask any questions.

PARENTAL PERMISSION:

I voluntarily give permission for my child to participate in the research protocol.

Printed Name of Parent or Guardian Signature of Parent or Guardian Date

Printed Name of Child (1)

Printed Name of Child (2)