Permission to Take Part in a Human Research Study

University at Buffalo
The State University of New York

University at Buffalo Institutional Review Board (UBIRB)
Office of Research Compliance | Clinical and Translational Research Center Room 5018
875 Ellicott St. | Buffalo, NY 14203
UB Federalwide Assurance ID#: FWA00008824

Title of the registry: The Buffalo Research Registry (BRR)

Version Date: 9/1/2022

Investigator: Dr. Laurene Tumiel-Berhalter

Key Information: The following is a short summary of this study to help you decide whether or not to be a part of this study. More detailed information is listed later on in this form.

Why am I being invited to take part in this registry?

You are being invited to take part in the Buffalo Research Registry because you expressed interest in being made more aware of research opportunities at the University at Buffalo.

What should I know about this registry?

- Someone will explain this registry to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

Why is this research being done?

To match researchers who are looking for eligible research volunteers and community members who are interested in participating in research studies at the University at Buffalo. ***How long will the registry be active?***

We expect that you will be in this registry indefinitely.

Will being in this registry help me in any way?

We cannot promise any benefits to you or others from your taking part in this registry. However, possible benefits include being matched to a research study that you are interested in and you may be eligible to participate in.

Is there any way being in this ***registry*** could be bad for me?

There are few risks involved with signing up for the Buffalo Research Registry. The main risks are loss of data privacy and confidentiality. More detailed information about the risks of this registry can be found under ***"Is there any way being in this registry could be bad for me? (Detailed Risks)".***

What happens if I do not want to be in this registry?

Your participation in this registry is voluntary. Your alternate to participating in this registry is to not participate.

Detailed Information: The following is more detailed information about this study in addition to the information listed above.

Who can I talk to?

If you have questions, concerns, or complaints, or think being involved in the registry has hurt you, talk to the research team at ***716-829-2502.*** You may also contact the research participant advocate at 716-888-4845 or researchadvocate@buffalo.edu.

This research registry has been reviewed and approved by an Institutional Review Board ("IRB"). You may talk to them at (716) 888-4888 or email ub-irb@buffalo.edu

If:

- You have questions about your rights as a participant in this registry
- Your questions, concerns, or complaints are not being answered by the Community Engagement Team.
- You cannot reach the Community Engagement Team.
- You want to talk to someone besides the Community Engagement Team.
- You want to get information or provide input about this registry.

What happens if I say yes, I want to be in this registry?

Your signature on the registration form does not promise your participation in any study it simply acknowledges your willingness to be contacted to be given more information about a study which you will use to decide if you are interested in participating. If you agree to be in the registry then you will be asked to complete a registration form. The registration form for the Buffalo Research Registry will ask for your contact information, demographic information and information about your health. Your demographic and health information would be used to match you to research projects that you might be eligible for, although the researchers will only be provided with your name and contact information. No recorded health information will be shared.

What happens if I say yes, but I change my mind later?

You can leave the registry at any time it will not be held against you. All you have to do is call 716-829-2502 and request that your information be removed from the registry.

"Is there any way being in this registry could be bad for me? (Detailed Risks)

There are no physical risks involved in participating in the Buffalo Research Registry. There are, however, risks related to the information you share with the registry. They include:

- Loss of privacy: The Buffalo Research Registry includes contact, personal, and medical information. Information included on the sign-up form will be seen by the individuals who operate the registry. Researcher teams might also, in some instances, have access to your contact information if you meet their study criteria. They do not have access to your health information.
- Break of confidentiality: All information in the BRR is kept in a safe and secure database. There is a small risk that a technological or human error could occur where your email address is shared. Breach of confidentiality will be minimized by using secure technology options and putting quality checks in place. Only key personnel, who are properly trained in the registry technology, will be handling the collection and use of data.

What happens to the information collected for the registry?

Efforts will be made to limit the use and disclosure of your personal information to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB and other representatives of this organization. The information in this registry will be stored in password protected files on the SMBS cloud server. Hard copies will be stored in a locked file cabinet in the Clinical and Translational Research Center. Researchers will need to have IRB approval in their study protocols to be able to access the contact information in the Buffalo Research Registry. Researchers are only provided with your contact information if it is found that you may be a match for their study, none of your health information is provided to them for the registry. Your health information is strictly used as a searching tool for the Community Engagement Team so that you are not contacted about studies that you are ineligible for.

Will I get paid for completing this registration form?
No, you will not be paid for completing this registration form.

Participation
By completing the registration form and by signing the last page of it, you are agreeing to participate in this registry.

BUFFALO RESEARCH REGISTRY

University at Buffalo
Clinical and Translational Science Institute

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