



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: Clinical and Translational Science Institute's (CTSI) Buffalo Research Registry (BRR)

Version Date: 7/9/2020

Investigator: Dr. Laurene Tumiel-Berhalter

Key Information: The following is a short summary of the registry to help you decide whether or not to participate. 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 (BRR) because you expressed an interest in being made more aware of research opportunities at the University at Buffalo (UB).

What should I know about this registry?

- You will be contacted about research at UB based on your profile
- You will be contacted about educational events or other ways to get involved in research
- Whether or not you take part is up to you
- 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 was this registry created?

The registry was created to connect researchers looking to recruit participants and community members looking to get involved with research. The registry matches volunteers to research studies and then shares the approved study flyers with them. From there, volunteers decide whether or not they wish to participate in a particular study.

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

You will sign up for registry by completing an intake form either on paper or online. The intake form for the registry will ask for contact, demographic and basic health information. The CTSI will use the information you provide to match you to research studies that you might be eligible for. If you are a match for a study, you will receive either an email or mailing from the BRR about the study. We might also share your contact information with research teams so that they may contact you directly about the study.

Your signature on the form does not promise your participation in any study—it simply acknowledges that you want to be contacted and given more information about research studies you may be a match for. Any time you receive information on a study, you will decide if you are interested in participating.

In order to share their study with you, research teams will need to have IRB approval to do so. Please note that research teams are only provided with your contact information. None of your health information is provided to them. Your health information is strictly used by the CTSI as a way to match you to potential studies and to ensure that you are not contacted about studies that you would be ineligible for.

By filling out the registration form and signing it, you are agreeing to participate in this registry.



IRB Approval Period

HRPP Revision Date: September 17, 2015

What happens to the information collected for the registry?

Only key personnel have access to your information, solely to match you with studies. However, we cannot promise complete secrecy. Organizations, like the IRB and other representatives from this organization, may inspect your information. The information in this registry will be stored in a password protected electronic database and files on a secure cloud server. Any paper copies of data will be entered into the electronic database and then stored in a locked file cabinet in the Clinical and Translational Research Center.

How long will the registry be active?

The registry is always recruiting new volunteers and will be active for an indefinite amount of time.

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

❖ ***Breach of confidentiality***

Potential risks of participating in this registry include breach of confidentiality and privacy. 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.

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.

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 or email EngageUB@buffalo.edu and request that your information be removed from the registry.

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

Your participation in this registry is voluntary. If at any time you wish to stop participating, you can call 716-829-2502 or e-mail EngageUB@buffalo.edu and request that your information be taken off the registry.

Who can I talk to?

If you have questions, concerns, or complaints, or think being involved in the registry has hurt you, you can contact the research team at 716-829-2502 or e-mail EngageUB@buffalo.edu.

You may also contact the UB research participant advocate at 716-888-4845 or e-mail researchadvocate@buffalo.edu.

This research registry has been reviewed and approved by an Institutional Review Board (or IRB). You may contact them at (716) 888-4888 or e-mail 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 CTSI.
- You cannot reach the CTSI.
- You want to talk to someone besides the CTSI.
- You want to get information or provide input about this registry.



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