For Families Contacted through Outreach

Invitation to enroll in the Waisman Center’s Research Participation Core Research Registry

What is the purpose of the Research Participation Core research registry?

- The Research Participation Core (RPC) serves as a connection between families and research projects at the University of Wisconsin-Madison Waisman Center. The RPC maintains a database (the research registry) of individuals and families who have agreed to be contacted in a confidential manner about opportunities to participate in research studies.

- Enrolling in the research registry will provide you with a confidential way to learn about research studies that meet the characteristics of you and your family.

- **Enrolling in the research registry does not commit you to participate in any particular study.**

- Enrollment in the registry is completely voluntary, and your decision will not affect any services that you or your family receives from the University of Wisconsin-Madison, the Waisman Center clinics or any of their programs. If you enroll in the registry, you can withdraw at any time.

- You will only be contacted about participating in research projects that are approved by a University of Wisconsin-Madison Institutional Review Board. These Institutional Review Boards make sure research studies meet federal regulations for the protection of individuals participating in research.

How will the research registry work?

- The RPC will send you information about studies through the mail or by e-mail for which you might be eligible. In this mailing, we include information about the study and a reply form on which you can indicate if you are interested in participating in the study or not. If you indicate on the reply form you are interested in participating, your name and contact information will be provided to the research team so you can learn more about participating. **Your name and contact information is not disclosed to the researcher unless you indicate interest in the specific study on the reply form, email the RPC, or verbally provide permission to RPC staff.**

- Within 3 weeks of the mailing, a member of the RPC staff may follow up with a phone call and/or email to make sure you received the information packet, answer any questions you may have about the registry, and connect you to the research team if you have questions about the study.

- The RPC keeps records of participation in studies to make sure you are contacted only on an occasional basis. Specifically, once you agree to participate in a study, the RPC will not contact you again for 6 to 12 months, depending on the time commitment of the studies involved.

- The RPC may contact you once a year to update your contact information.

- Although there are no direct benefits to being enrolled in the registry, the RPC may inform you about Waisman Center events. As an act of appreciation to registry members, the RPC occasionally offers free educational programs about child development and developmental disabilities, as well as a newsletter that summarizes research findings and Waisman Center developments. You do not have to participate in a study to receive an invitation to a program or to receive a newsletter.
What information will be recorded in the research registry?

- If you agree to be included in the registry, basic contact information that you provide to the RPC about you and your immediate family members will be recorded. Information can include names of parent(s) or guardian(s), home address, home telephone number, cell phone number and e-mail address; as well as name, gender and birth dates of all children in your family.

- Because research at the Waisman Center focuses on human development, developmental disabilities, and neurodegenerative diseases, the participation of all individuals is very important. This includes those who are typically developing and those with disabilities and special needs. If you and/or anyone in your family have a diagnosis or special needs, it is important that you provide this information to help the RPC better match you to studies that meet the characteristics of you and your family. If applicable, you can provide this information to the RPC in one of the following ways:
  o Provide information about diagnoses and/or special needs on the consent form below.
  o Provide this information on the Family Questionnaire included with this form.

- We also ask families who enroll in the registry to complete the attached family questionnaire. The purpose of this questionnaire is to provide background information about the child(ren) who has special needs, as well as your family. Such information includes the language spoken in your home, race, and ethnicity, for example. This information will also be recorded in the registry. Some families who enroll in the registry prefer to complete the questionnaire with the assistance of RPC staff or at a later date. Therefore, if the RPC does not receive a questionnaire from you, an RPC staff member will call you to ask if you would like to complete the questionnaire over the telephone. Please note that completion of all or part of the questionnaire is optional. You may still enroll in the RPC registry even if you decide not to complete the questionnaire. If you do not wish to complete the questionnaire, return only the consent form.

- All of the information in the registry will be used to determine whether you and/or your family qualify for research studies.

- If you decline our invitation to be notified about research studies and want to receive just our newsletter and announcements, provide only your name and address below.

How will my rights and privacy be protected?

- Members of the RPC staff follow strict federal, state and university guidelines to safeguard individual rights and privacy. Information in the registry is stored and handled with strict regard for confidentiality. A University of Wisconsin–Madison Institutional Review Board reviews registry procedures annually to ensure we meet requirements that protect the rights of individuals involved in research.

- All information contained in the registry is considered private and confidential. Access to information in the registry is restricted to authorized RPC personnel. All data are stored in a secure location with physical, electronic, and procedural safeguards. No information is disclosed to outside parties except, as indicated above, when you indicate interest on the study reply form, or email or verbally provide permission to RPC staff. We want to inform you that there is the slight possibility that your contact information could accidentally become known to researchers without your prior consent; however, we do not expect this to happen and staff members of the RPC take every precaution to avoid a breach of confidentiality.

- In some cases, your information could be reviewed by representatives of the UW, research sponsors, or government agencies for purposes of quality control or safety. It is also possible, but not likely, that there may be instances in which information must be disclosed as required by state or federal law.
Finally, the privacy rules that apply to your medical records as required by HIPAA (the Health Insurance Portability and Accountability Act) do not apply to the health information collected by the RPC for the registry. Regardless, the RPC will handle your personal health information (information about diagnosis) with the utmost concern for your privacy.

If I enroll in the registry, how long will my permission last? Can I change my mind?

- The signed RPC consent form is considered valid until you request to withdraw from the registry.

- To withdraw from the research registry, simply notify the RPC by mail at Waisman Center, 1500 Highland Avenue, Room 467, Madison, WI 53705. Or, you can reach us via telephone at our toll free phone number 1-800-965-9205, or via e-mail at rpc@waisman.wisc.edu.

Will I receive any compensation for being in the research registry? Will it cost anything?

- You will not receive any payments or other compensation for enrolling in the registry. However, some researchers do provide compensation for participating in their studies. There will be no costs to you for enrolling in the registry.

What if I have questions?

- If you have any questions about the research registry, contact the RPC at 1-800-965-9205, or via e-mail at rpc@waisman.wisc.edu.

- If you have questions about your rights as a research participant or concerns about any research projects, contact the University of Wisconsin-Madison Social and Behavioral Sciences Institutional Review Board at 608-263-2320.

If you would like to enroll in the research registry, please read and sign the attached consent form and return it in the postage-paid envelope provided, or send to

Waisman Center
1500 Highland Avenue, Room 467
Madison, WI 53705
For Families contacted through Outreach

Consent Form for Enrollment in

the Waisman Center’s Research Registry

I have read the information provided here, had my questions answered, and I voluntarily give permission for the Research Participation Core (RPC) to enroll my family in the research registry for the purpose of being contacted about participation in future research studies at the Waisman Center. I understand that I can withdraw this permission at any time by notifying the RPC, Waisman Center, 1500 Highland Avenue, Room 467, Madison, WI 53705, 1-800-965-9205 or rpc@waisman.wisc.edu.

- I understand that I will be sent a copy of this signed consent document.

Signature of Parent or Guardian_____________________________ Date ______________

Please print your name_____________________________________________________________

Relationship to Child(ren) (e.g. parent, guardian)______________________________

Please complete the following with respect to the children you would like to enroll in the registry:

To match your family with studies for which you may be eligible, it is helpful to know the nature of your child(ren)’s medical condition or special needs. Please list your child(ren)’s condition or diagnosis as well.

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<thead>
<tr>
<th>Child’s name</th>
<th>birth date</th>
<th>gender</th>
<th>diagnosis/special needs</th>
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Family Contact Information:

Address _______________________________

Street                                                                                      City          State      Zip

Home Phone (______)_________________h Cell Phone (______)_________________h

E-mail address_____________________________________

☐ Please check here if you would like to receive the Waisman Center newsletter. To receive just the newsletter, check this box and provide only your name and address.