



The University of Michigan
Health Systems
Ann Arbor, Michigan 48109-0364

Department of Internal Medicine
Nephrology Division
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The division of Nephrology is dedicated to serving people with kidney disease. There is still much we don't know and here at the University of Michigan we are working hard to improve patient care through research.

We are looking for people who would consider participating in research aimed to improve the health of people with kidney disease.

Through research, doctors and patients can:

- *Learn new information about kidney health and disease*
- *Develop and learn about new ideas for therapy*
- *Increase social contact and support systems*
- *Gain the satisfaction of knowing they may be contributing to the health of others like themselves*

If you would like to be contacted to learn about opportunities to participate in kidney research studies, please fill out the attached form and give it to the clinic staff. Your signature on the form will allow University of Michigan researchers (including faculty and staff members) to put your name and other information you give us on a list of people interested in participating in research. The list is called a registry. The form will also let the researchers look at your University of Michigan medical records to see which studies you might qualify for. An identical copy of the form is printed on the back of this letter for you to keep.

There is no obligation to complete the form or participate in the registry. You can always decide to remove your information from the registry, or not to participate in any specific study. Even if you decide not to sign up for the registry, you still will have the opportunity to be contacted by your health care providers or others about future research studies at the University of Michigan.

If you have questions, please call Kathryn Lindblad, RN @ 734-764-5187. You can also e-mail Lindblad@umich.edu if you prefer.

Thank you!

Nephrology Research Registry
IRB # HUM00000260
University of Michigan, Department of Internal Medicine,
Division of Nephrology

The University of Michigan is involved in many research projects. We have developed a Nephrology Registry to help us find people who might be interested in participating in kidney-related studies. If you fill out and sign this form, your name and the other information you give us will be placed in the registry. More information about the registry and who to contact with questions is provided below.

Authorization to Use Protected Health Information and Consent to Contact

**Items marked with an asterisk must be completed. We also need at least one way to contact you.*

* Full Name (please print): _____

* Date of Birth: _____ Phone _____ E-Mail _____

Address: _____

Race: What race do you consider yourself to be? Select one or more of the following:

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- More than one race

Ethnicity: Do you consider yourself to be Hispanic or Latino? Select only one:

- Yes = Hispanic or Latino
- No = Not Hispanic or Latino
- Unknown

Risks and Benefits: There are no known risks to participate in the research, other than a low risk of breach of confidentiality of your medical information. However, paper records will be kept in a locked file cabinet after they are turned in to the registry manager. The registry itself will be maintained on a secure server and ordinarily, only University of Michigan researchers (faculty and staff) and University officials who oversee research will have access to the registry. There are no expected benefits for you personally from the research. You will not be paid or reimbursed for your participation. However, research can help us learn how better to prevent, diagnose and treat kidney disease. The purpose of the Nephrology Registry is to create a database of people who are interested in participating in clinical research studies on kidney disease. If you complete and sign this form, your name and the other information you give us will be placed in the registry, and you are likely to be contacted by U-M researchers.

Information to be Used or Disclosed: If you sign this form, you will allow the researchers to review the information in the registry and all of your University medical records to see whether you, or others like you, may be eligible to participate in various studies. University medical records may include information about mental health, substance abuse, and communicable diseases such as HIV/AIDS. If the researchers find you are eligible, they may contact you using the information you provide above. Once in a while, government agencies who oversee research compliance may access identifiable information related to a particular project.

Voluntary Participation/Right to Revoke: Participating in the registry is completely voluntary. If you decide not to participate, or if you decide to withdraw your name from the registry, you will not suffer any penalty or loss of benefits to which you otherwise would be entitled. Your treatment at the University will not be affected by your willingness or refusal to participate. If you decide not to participate, or if you withdraw your name from the registry, you still may be contacted about future projects and may participate in those projects.

Duration of Study and Expiration Date or Event: Unless you ask to be removed from the registry, your permission will not expire. We expect to maintain the registry indefinitely.

Privacy Rights: If your information is disclosed to individuals outside the University of Michigan, it may no longer be protected by federal privacy regulations. However, as long as it remains in the University, it will be protected by our own privacy policies and procedures. For more information on our privacy practices, please refer to the University's Notice of Privacy Practices, available at <http://www.med.umich.edu/hipaa/npp.htm>.

Contact Information: To learn more about the registry, contact Kathryn Lindblad, RN at 734-764-5187. For information about your rights as a research subject, write to our institutional review board (IRBMED) at 517 W. William, Argus I, Ann Arbor, MI 48103-4943, or by e-mail at irbmed@umich.edu. You may call the IRB at (734) 763-4768.

* Signature: _____ *Date: _____

* Relationship to Patient/Subject: Self Spouse Parent Adult Child Legal Guardian