Join the Dent Disease Registry

Dent Disease Contact Registry Agreement

Last Updated: 01/14/2011

Please read the following text (download this agreement in pdf format) carefully before joining the Dent Disease Contact Registry. You may wish to print a copy of this document for your files.

What is the Dent Disease Contact Registry?

The goal of the Contact Registry is to gather patients' contact information. Contact Registry will allow us to communicate with Dent disease patients without necessarily sharing medical information. The information from Contact Registry is not part of the Dent Disease Clinical Registry hosted by our Rare Kidney Stone Consortium in Mayo Clinic in Rochester, Minnesota and it will be kept at a separate and secure location at NYU School of Medicine.

POTENTIAL RISKS AND DISCOMFORTS/COMPENSATION FOR INJURY:

There are no identifiable risks to participants. Your privacy will be effectively protected by maintaining your data in an “encrypted” form, in a secure computer at the NYU School of Medicine.

POTENTIAL BENEFITS:

We will send you annual updates on Dent disease and Dent disease Registry. It is our hope that the knowledge gained from the Clinical Registry will be of benefit to you and others in the future. You will not benefit financially.

Who can join?

Anyone with Dent disease can join the Contact Registry as a volunteer. A parent, legal guardian or caretaker may register someone under the age of 18 or an adult that may not be able to enter in their own information.

What do I have to do to join?

If you decide to sign up for the Contact Registry, you will be asked a few questions about yourself, such as your age and contact information. The Contact Registry will not include any information about your disease. If you decide to join the Dent Disease Clinical Registry, which does contain protected medical information, we will mail or email you a separate Informed Consent Form. We will then have you send us copies of your medical records. That information will be stored securely and will be kept
confidential as described in the Registry Privacy Statement. You can join the Dent Disease Contact Registry without joining the Clinical Dent Disease Registry.

**What happens once I register?**

Once you join the Dent Disease Contact Registry, you will be added to the list of patients of Dent disease and receive annual updates on Dent disease and Dent Disease registry.

If you chose to join the Dent Disease Clinical registry, your non-identifiable medical information will become part of a pool of data stored at the Mayo Clinic. We will update your data at least once a year. This database will be used for a better understanding of Dent disease and for the development of research questions, which will lead to future clinical trials. Access to this data, and its use, is limited to members of the Rare Kidney Stone Consortium. All future clinical trials, based on this registry, will undergo a scientific review and approval process.

**How is my information protected?**

Private identifiable information about you may be used or disclosed for the purposes of this research project. The agreement section describes how your information may be used and shared in the research, and the ways in which NYU School of Medicine will safeguard your privacy and confidentiality.

**Who is involved in Contact and Clinical Dent Disease Registry?**

The registry has been developed by Dr. Lada Beara-Lasic and Dr. John Lieske and colleagues from the Rare Kidney Stone Consortium at the Mayo Clinic.

**Does the Dent disease Registry provide health care services?**

No. The Dent Disease Contact Registry, as well as Dent Disease Clinical Registry does not provide any medical or healthcare products, services or advice. If you have any questions about your medical condition or medical care, please see your physician. We will be available to provide medical advice to your physician.

**AGREEMENT**

By reading this Volunteer Agreement and signing up for the Contact Registry, you consent to the use and disclosure of your personal, identifiable information on your Contact Registry profile, as outlined here. You also agree that the Contact Registry may access, keep or share your registration information if required to do so by law or in the good faith belief that it is necessary to:

- Enforce the terms of this Volunteer Agreement or the site's Terms of Use
- Respond to your requests for customer service
- Comply with federal, state or local legal processes

By completing the registration process, you represent and warrant that you are at least nineteen years of age, and that you possess the legal right and ability to enter into this Volunteer Agreement. You agree that if you register with the Contact Registry, you will provide accurate information about yourself. You agree that if any information you provide is inaccurate, NYU School of Medicine may prohibit your access to the Contact Registry. If you register someone who may not be able to register themselves (including individuals under the age of 18 or someone who is unable to register without your assistance), you assert that you are their legal guardian, parent or caretaker and agree to the terms outlined in this agreement. If you agree, your profile will be added to the Dent Disease Contact Registry as soon as you enter and submit your information.

Thank you for learning more about Dent disease!

Questions or concerns?

For general questions, please email Dr. Lada Beara Lasic at Lada.BearaLasic@nyumc.org or visit the Dent Disease Registry page at NYU Langone Medical Center.