

HOW WILL MY PRIVACY BE PROTECTED?

Healthcare providers who participate in the **UCD Pregnancy Registry** with you, their staff and Hyperion—the company sponsoring the registry—respect all patients' privacy. Please see the Informed Consent Form for a complete description of how your health information will be used and protected.

If you have questions about your treatment, contact your healthcare provider.

For more information:
www.THRIVEregistry.com/pregnancy-registry

855-UCD-2595
(855-823-2595)

Learn More About

UCD (urea cycle disorders) PREGNANCY REGISTRY





THRIVE



WHAT IS THE UCD PREGNANCY REGISTRY?

The **UCD Pregnancy Registry** is a voluntary, observational study, or “registry”. The study was created to collect information about the effects of **BUPHENYL**® (sodium phenylbutyrate) or **RAVICTI**™ (glycerol phenylbutyrate) Oral Liquid on women and their babies who took one of these medicines just before or during pregnancy.

Hyperion Therapeutics, Inc., the maker of RAVICTI, designed this registry because pregnant women were excluded from clinical trials during the development of RAVICTI. So, there is limited information available about pregnant women taking RAVICTI or about their babies.

WHO CAN PARTICIPATE IN THE UCD PREGNANCY REGISTRY?

You may be able to participate in this Registry if you are pregnant, have a confirmed or suspected diagnosis of UCD and have taken at least one dose of BUPHENYL or RAVICTI just before or during your pregnancy.

WHY SHOULD I PARTICIPATE IN THE UCD PREGNANCY REGISTRY?

Your participation will provide important information that may be used by healthcare providers and future patients when weighing the benefits and risks of taking BUPHENYL or RAVICTI during pregnancy.

*If you are taking **BUPHENYL** or **RAVICTI**, talk to your doctor right away if you are pregnant or plan to become pregnant.*

WHAT DOES PARTICIPATION INVOLVE?

Because the **UCD Pregnancy Registry** is observational, there is no additional medicine, office visits, or special tests required. Once enrolled in the registry, you and/or your healthcare providers will be asked to provide some information a few times during and after your pregnancy:

- Upon enrollment
- At each trimester
- Within 4 weeks after your delivery
- Follow-up until the baby is 8-12 weeks old

Information may be collected directly from you or from healthcare providers who are caring for you during your pregnancy or caring for your baby. Healthcare providers who may be contacted can include your general practitioner, obstetrician/gynecologist, pediatrician and even genetic counselors.

HOW CAN I ENROLL?

To learn more about the **UCD Pregnancy Registry** and to find out if you qualify for enrollment you may:

- Contact a **UCD Pregnancy Registry** Team member toll-free at 855-UCD-2595 (855-823-2595), 8:00a.m. – 5:00p.m. Eastern Time.
- Visit www.THRIVEregistry.com/pregnancy.
- You may also ask your healthcare provider to enroll you.

If you are eligible and would like to participate, you will be asked to read and sign an **Informed Consent Form**. The Informed Consent describes the registry and any potential risks or benefits to you or your baby. Signing this form says that you understand what the **UCD Pregnancy Registry** is and that you want to participate in the registry. It also includes notification of your rights under the Health Insurance Portability and Accountability Act (HIPAA).

Participation in the **UCD Pregnancy Registry** is entirely voluntary, and you may stop at any time by telling the doctor who enrolled you, or by calling the **UCD Pregnancy Registry** Team directly.

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