Children's Hospital of Philadelphia
RESEARCH INSTITUTE

BECKWITH-WIEDEMANN SYNDROME REGISTRY

WHAT IS THE BECKWITH-WIEDEMANN SYNDROME REGISTRY?

Here at Children's Hospital of Philadelphia we have a patient registry to improve our understanding and management of Beckwith-Wiedemann syndrome (BWS), hemihypertrophy and other epigenetic and growth disorders.

WHAT IS THE PURPOSE OF THE REGISTRY?

While we understand the genetic and epigenetic causes of BWS, we have many questions that we currently do not know the answer to. Other growth and epigenetic disorders are not well understood. This registry provides an opportunity to gather information on these rare disorders as well.

WHAT ARE THE GOALS OF THE REGISTRY?

Our goal is to answer some of these unanswered questions. With the registry, we hope to increase our understanding about how genes affect growth, clarify clinical guidelines, and improve current diagnosis and treatment methods.

WHAT WILL I BE ASKED TO DO IF I JOIN THE REGISTRY?

- Sign our consent form
- Share medical records
- Share samples (optional)
- Share pictures (optional)
- Update information about every six months

WHAT WILL YOU DO WITH MY INFORMATION?

We will look at your medical records to identify common features in children with growth disorders and work to develop better treatments. We will also study your leftover samples in the lab.

HOW IS MY INFORMATION PROTECTED?

- Replace all identifying information with unique code number
- Password-protected servers
- HIPAA
- Certificate of Confidentiality

WHAT IS A REGISTRY?

This study consists of a registry and biorepository that will help us examine how genes affect growth.

- **Registry**: collection of medical records
- **Biorepository**: collection of samples

The information and samples you share will be examined along with other patients' data to learn more about growth conditions.

WHO CAN JOIN THE REGISTRY?

Any patient with a suspected or diagnosed growth condition can join the registry. We also invite family members to join. You do not have to be a patient at CHOP to participate.

HOW CAN I PARTICIPATE?

- Talk to a study team member
- Sign a consent form to join
- Share your medical records and samples

WHO IS FUNDING THE REGISTRY?

This research is funded by a variety of institutions and foundations including Children's Hospital of Philadelphia, National Institutes of Health, St. Baldrick's Foundation, Alex's Lemonade Stand Foundation, Margaret Q. Landenberger Research Foundation, and University of Pennsylvania's Orphan Disease Center.

THE BWS STUDY TEAM

The BWS study team is a group of individuals dedicated to improving the understanding and management of BWS. We are here to answer any questions you have and help educate families and physicians about BWS.

CONTACT US!

If you are interested in learning more about this exciting project, please contact us at **BWS@chop.edu**.

http://www.chop.edu/pages/beckwith-wiedemann-syndrome-research

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