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Newborn Screening Program  
Wadsworth Center  
New York State Department of Health  
120 New Scotland Avenue  
Albany, NY 12208

nbsinfo@health.ny.gov  
(518) 473-7552

[www.wadsworth.org/LTFU](http://www.wadsworth.org/LTFU)

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# New York State Newborn Screening Patient Registry

Learning From Your Experience  
for a Brighter Future

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## What is the New York State Newborn Screening Patient Registry?

A project to collect health information from children with one of the conditions identified by newborn screening in New York State.

## Why is the New York State Newborn Screening Patient Registry Important?

- Each individual disorder on the newborn screening panel is rare.
- It will give health care providers a chance to study information for a larger group of patients than they treat in their clinic.
- The information will help health care providers learn more about the diseases on the newborn screening panel and the best treatment.
- It will improve newborn screening for all babies in New York State!

## What information is being collected?

- Updates to your child's diagnosis
- How often your child is seen in clinic
- What other types of health care providers your child sees
- Your child's hospital visits
- Your child's developmental milestones and education
- Your child's insurance type (i.e. no insurance, private insurance, state insurance, federal insurance)
- Your education level
- Your child's treatment plan

## How will the information be collected?

Your child's health care provider will enter the information into a secure online system. The data will be maintained by the New York State Newborn Screening Program.

## What will happen to the information?

- Health care providers across New York State will be able to submit a request to receive de-identified information, which means no names or information that directly identifies your family will be given out.
- The information will only be released to the health care providers if they plan to use it to learn about the diseases on the newborn screening panel and the best treatments.
- Health care providers can learn from the experience of your child and others with the same condition for a better future for everyone!

## How does my child participate in the registry?

- Your child can only participate in the registry if you give permission.
- Your child's health care provider will give you a consent form.
- If you would like your child to participate, sign the form and give it back to your child's health care provider.
- The health care provider will send the form to the Newborn Screening Program and begin entering information into the secure online system.

## How long will my child be enrolled?

- Your child will be enrolled until 18 years of age. When they turn 18 years old, we will ask their permission to continue in the project until age 21.
- You may request that we stop collecting information about your child at any time. Information will not be collected from the date your request is received.
- You may also withdraw your child from the project. The information that has been collected will be removed from the registry and no more information will be collected.

Written requests should be mailed or faxed to:

Sarah Bradley, MS, CGC  
Newborn Screening Program  
Wadsworth Center  
New York State Department of Health  
120 New Scotland Avenue  
Albany, NY 12208  
Fax: (518) 474-0405