

Tennessee Newborn Screening Long-Term Follow-Up Program

The Newborn Screening Long-Term Follow-Up (LTFU) program collects information about children diagnosed with certain newborn screening disorders¹. The information gathered helps us understand if children and families in Tennessee have access to the support and resources they need. Based on the information collected, we support families by working with healthcare providers and local public health agencies. Information is collected to determine how effective the program is at helping children through early diagnosis and treatment and the impact early diagnosis and treatment have on children as they grow older. We will analyze the information collected throughout the state to identify patterns and ensure that all families in Tennessee have access to needed services. The goal of the LTFU program is to gather data on each child until they are at least ten (10) years old.

What information is collected about children in the LTFU program?

Information collected for the LTFU program includes but is not limited to:

- Demographics such as age, date of birth, sex, address, etc.
- Your child's diagnosis
- Treatment and care received
- Barriers affecting your child's care such as distance from clinics, financial challenges, insurance, etc.
- Support resources utilized such as TN Early Intervention Services, Family Voices, Children's Special Services, WIC, etc.

What does participation in the LTFU program include?

If you choose to participate in the LTFU program, you can expect 1-2 phone calls with a LTFU genetic counselor each year. During these calls, the counselor will collect demographic information, information on your child's health, and any challenges you have experienced related to your child's care. The genetic counselor can also answer any questions about your child's diagnosis and give you resources to help support your child and family.

We will also collect information from your child's healthcare providers. We collect information from the doctors' offices that provide care related to your child's condition diagnosed by newborn screening. This may be a geneticist, endocrinologist, pulmonologist, hematologist, etc. We may also contact your child's primary care provider for additional information.

Participation in the program is voluntary. We are grateful for your choice to participate in this program but understand that you may change your mind. You have the option to opt out of the program at any time.

¹ <https://www.tn.gov/health/health-program-areas/fhw/newborn-screening/dried-bloodspot/for-parents.html>

Who has access to the information we collect?

We take data privacy very seriously. Only Tennessee Department of Health (TDH) employees have access to the data we collect. Representatives from genetics centers across Tennessee have access to data **only for the patients under their care**. Everyone with access to the information in our database completes required training to protect your child's information. Information collected in our database is not public. When information must be reported outside of our team, names, birthdates, and other identifying information are always excluded. We redact all information in accordance with applicable state law.

How long do we keep the information we collect?

Your child's information will be stored in our secure database indefinitely. If you choose to opt out of the program, we will stop collecting your child's data. See RDA 10148.

Newborn Screening Long-Term Follow-Up Program Consent

I hereby give the Tennessee Department of Health (TDH) permission to collect and use my child's healthcare information, both via family phone calls and data collection from medical providers. I grant TDH permission to store my child's information indefinitely and to use my child's information for quality improvement and publication. All information will be de-identified. No identifying information about my child will be shared publicly.

I hereby give the Tennessee Department of Health (TDH) permission to collect and use my child's healthcare information, collected from medical providers only. I do not wish to be contacted directly by TDH regarding my child's healthcare information. I grant TDH permission to store my child's information indefinitely and to use my child's information for quality improvement and publication. All information will be de-identified. No identifying information about my child will be shared publicly.

I do not give permission for my child's healthcare information to be collected and request that my family not be contacted for long-term follow-up.

Child's Name: _____

Child's DOB: _____

Parent/Legal Guardian Signature: _____

Date: _____

Name and Relationship to child: _____

Phone: _() _____

Address: _____

City, State, ZIP: _____