



# The Cure SMA Newborn Screening Registry (NBSR)

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is a secure online registry established to collect and analyze information on patients diagnosed with spinal muscular atrophy through newborn screening. This information will help families, health care providers, and researchers learn more about SMA, better manage symptoms over time, and develop new treatments.

We invite you to participate by going to the NBSR website and following the instructions provided. You will be asked to provide details on topics such as diagnosis, treatment, and supportive care.

**To access the NBSR portal or to receive additional information  
visit our website [www.curesma.org/NBSR](http://www.curesma.org/NBSR)**

# Frequently Asked Questions

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## Q. Why should I join the registry?

A: The purpose of the Cure SMA Newborn Screening Registry (NBSR) is to collect and analyze data from SMA patients diagnosed via newborn screening. The goals of the NBSR are:

- Increase understanding of the diagnostic journey of infants diagnosed via newborn screening
- Enable clinicians and researchers to identify trends and generate new insights into SMA and improve treatment and care
- Accelerate the development of treatments for SMA

## Q. Is my information secure?

A: The NBSR has been reviewed and approved by an independent Institutional Review Board (IRB) (Western IRB). The purpose of the IRB is to ensure that human subject research is conducted in accordance with all federal, institutional, and ethical guidelines. Data will be held in compliance with US Health Information Privacy Laws (HIPPA, HITECH, and FISMA) and state privacy laws (where applicable).

## Q. Who will be able to access my information?

The data collected and compiled by this Registry belongs to the Cure SMA community. Cure SMA is the guardian of the information contained within the Registry. Cure SMA staff who are not on the Registry team do not have access to the secure database that holds your names and medical information.

## Q. How we will use and share your data

Your Registry information will be used to review standards of care and treatment for SMA with the goal of improving the quality of care for patients in the future.

Your Registry information will be provided to researchers interested in studying SMA. It is anticipated that the Registry will be a valuable resource for current and future research. A Registry Oversight Committee will ensure proper evaluation of research proposals to use Registry data.

## Q. How long will it take to fill out the survey?

The survey is designed to be completed in 5-7 minutes and can be accessed on a mobile device.

## Q. Where can I get additional information?

If you have any questions while completing the NBSR or encounter any challenges, please contact: [info@curesma.org](mailto:info@curesma.org)

**For more information about Cure SMA and the resources and support services available to patients with SMA, please visit [www.curesma.org](http://www.curesma.org)**