

KRABBE DISEASE

By the numbers



EARLY
DIAGNOSIS
IS THE KEY

09

Only 9 states
across the US
screen for Krabbe
Disease

1 in
100,000

Krabbe Disease
affects only 1 in
100,000 people
in the US

60

The Recommended Uniform
Screening Panel (RUSP) a
national panel for newborn
screening mandated in the
United States tests for over
60 conditions in infants

Our Vision:

A day in which each patient
receives an early diagnosis, has
access to state-of-the-art care,
and lives a life free of Krabbe
Disease

Contact Us

KrabbeConnect
(651)252-4117
info@krabbeconnect.org

Newborn Screening

What You Need To Know



Only 9 states across the country screen for Krabbe Disease

What Is It?

The testing for multiple conditions in newborns shortly after birth

What is RUSP?

The Recommended Uniform Screening Panel (RUSP) is a national panel recommended in the United States.

What does it test for?

The RUSP screens for over 60 different conditions.

Krabbe Disease on the RUSP?

Despite early diagnosis being crucial for treatment and quality of life, Krabbe Disease is not on the RUSP.

Please call with any questions regarding Newborn Screening or Krabbe Disease

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How to get Legislation in Motion



1) Approach your representative to sponsor your idea.

2) Sponsor introduces it to the House of Reps, then drafted into a legal form known as a bill.

3) The bill is read and sent to review committee.

4) A committee signs off, amendments printed, and it is sent back to the House for a 2nd hearing.



5) Once approved by the House, its sent to Senate for 3rd hearing.

6) Sent to the Senate committee, amendments sent to the House for approval. Revised until approved

7) Signed, sent to Governor - signed or not, becomes law; vetoed needs Congress approval



8) Becomes law on Jan. 1 the year after approval and given a number.

★ Remember to check state legislature website to see your bill's progress ★