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Cure SMA Call for Applications for Funding to Implement Newborn Screening for Spinal Muscular Atrophy

Cure SMA is pleased to announce that we are accepting applications for funding of activities that will enable states to pre-symptomatically identify and treat pediatric SMA patients through the implementation of newborn screening programs.

Funding Overview

- The deadline for submission is May 1, 2019.
- Funding is available for one year up to \$200,000.

Funding Priorities:

Through this funding, Cure SMA intends to facilitate the ability of state laboratories to implement and conduct newborn screening for SMA.

A list of possible funded activities includes, but it is not limited to, the following:

Screening Implementation Support:

- Pilot Screening
- Assay validation
- Additional personnel and staff training
- Equipment needed to perform the assay
- IT resources to perform the assay

Data Gathering/Patient Follow-up and Support:

- Collection of data on infants identified as SMA positive via NBS including, but not limited, collaborations with Cure SMA
- Appropriate personnel/resources to ensure adequate patient referral/counseling.
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Timeline:

Announcement Date: March 13, 2019.

Application Due: **May 1, 2019**

Award Notification: June 1, 2019

Application Process

Applications are due by **May 1, 2019**. Applications should be no longer than 2 pages and be submitted electronically, by email to jackie@curesma.org.

- 1) Describe your state's process for adding a new condition to your NBS panel and describe where SMA is in that process?



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- 2) How will these funds be utilized to accelerate/and or increase your ability to screen for SMA?
- 3) How long do you estimate it will take your state to start screening for SMA with and without this funding?
- 4) How many infants testing positive for SMA do you project identifying in your state each year?
- 5) Do you have funding from another agency, such as the CDC, for SMA NBS?
- 6) Are you willing to collaborate with Cure SMA on NBS follow-up?
- 7) Please provide a brief budget summary detailing how you would use the requested funds.

For more information or if you have questions, please contact Jackie Glascock, Senior Scientific Program Manager at jackie@curesma.org.