



Dear Caregiver of a Patient with Menkes Disease,

Sentynl Therapeutics, a U.S.-based biopharmaceutical company focused on bringing innovative therapies to patients living with rare disease, is collaborating with researchers at a leading academic medical center to develop a laboratory test that could potentially diagnose Menkes disease at birth.

We are hoping you can help.

It is our aspiration that the test that we are developing becomes part of every state's Newborn Screening Program. In order to make sure this test works, we are inviting you to actively participate in this research by:

1. Obtaining the dried blood spot card for your child from your state's newborn screening lab, if permitted by your state.
2. If your child is living and not currently receiving copper replacement therapy, by also collecting a very small sample of blood to create a new dried blood spot card.
3. OPTIONAL: If possible, obtaining a urine sample to support the development of a rapid bedside test.

These dried blood spot cards and (optional) urine samples will be used to measure levels of specific chemicals that can assist in the early diagnosis of Menkes disease.

We have partnered with a clinical research organization called Serologix to conduct this study. Serologix will work with you to simplify the process to acquire the dried blood spot cards held by your state. You or your physician will need to request that the cards be sent to you.

In the event blood sample collection (and optional urine sample collection) is possible, Serologix can either send a nurse directly to your home for a sample collection or send a kit to your physician's office where the sample can be obtained.

In order to maintain strict confidentiality, Serologix will assign an anonymous code to each blood and urine sample or newborn dried blood spot card to ensure your loved one's information is de-identified. Your child's name, date of birth, or any other identifying information will under no circumstances be provided to either Sentynl Therapeutics, the academic medical center performing the research, or any other entity.

Please contact Maria Middleberg at mmiddleberg@serologix.net or 215-450-9365 if you are interested in participating, have questions about the study, or would like additional information.

Thank you for considering participating in this important research study. Your family could make a significant impact on the early diagnosis of patients with Menkes disease and help change the newborn screening paradigm.

Kind regards,

Maria Middleberg on Behalf of Sentynl Therapeutics

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