

ANNOUNCING A NEWBORN SCREENING PROJECT FOR FRIEDREICH'S ATAXIA AT THE MAYO CLINIC

Population screening for Friedreich's ataxia (FA) has been hampered due to the absence of an effective screening test. This obstacle may be overcome by the implementation of a test developed at Mayo Clinic with collaboration from Friedreich Ataxia Research Alliance researchers that can measure the concentration of frataxin in dried-blood spots. A study to determine frataxin levels in tissue samples from patients with Friedreich's ataxia revealed the ability to distinguish patient results from those of controls, suggesting that newborn screening for Friedreich's ataxia is potentially feasible. An effective newborn screening program would allow diagnosing and treating affected infants prior to the onset of symptoms and development of irreversible damage.

To determine the effectiveness of Mayo's test in identifying neonates with Friedreich's ataxia, Mayo Clinic's Biochemical Genetics Laboratory is now conducting a study on donated samples from Friedreich's ataxia patients, carriers, and unaffected relatives. In particular, Mayo seeks any participants interested in allowing access to their State's newborn screening card and/or interested in donating a tablespoon of blood or fresh dried-blood spot along with filling out a questionnaire about their FA status.

Call for Samples – Participate in Ongoing Research at Mayo Clinic

Members of the Friedreich Ataxia Research Alliance may be able to help in this effort in two ways:

- 1) Provide Mayo Clinic access to any leftover newborn screening samples that may still be available in the newborn screening lab of the state where a Friedreich's ataxia patient was born (see table below to determine if your blood spot sample may still be available). A consent form will need to be signed and sent to the birthing state.
- 2) Donate a tablespoon-sized sample of blood or a fresh dried-blood spot for prospective testing of frataxin. Samples from FA patients, carriers, and unaffected relatives will be accepted. A small questionnaire and consent can be obtained by contacting Mayo by the means below.

Analysis of such precious samples may allow Mayo Clinic's Biochemical Genetics Laboratory to better define a specific range of frataxin values in newborn screening blood spots of FA patients and accelerate the completion of this study. **If you want to participate and a newborn screening sample may still be available, please, call Mayo Clinic's Biochemical Genetics Counselor at (507) 266-8158 or email: biochemicalgenetics@mayo.edu for assistance in**

requesting this sample from the respective newborn screening laboratory and for submitting a blood sample.

See the chart below to find out if your NBS card is available.

STATE	NBS Card Storage Time	STATE	NBS Card Storage Time	STATE	NBS Card Storage Time
Alabama	3 months	Louisiana	2 – 4 weeks	Oklahoma	1 month
Alaska	3 years	Maine	5 years	Oregon	1 year
Arizona	3 months	Maryland	6 months	Pennsylvania	3 months
Arkansas	2 years	Massachusetts	1991 to present	Rhode Island	23 years
California	Indefinitely	Michigan	21.5 years	South Carolina	Parent's choice
Colorado	3 months	Minnesota	7 years	South Dakota	2 months
Connecticut	6 months	Mississippi	2 year minimum	Tennessee	3 months
Delaware	4 months	Missouri	6 months	Texas	6 months
District of Columbia	2 years minimum	Montana	2-6 months	Utah	3 months
Florida	> 5 years	Nebraska	3 months	Vermont	Indefinite
Georgia	6 weeks	Nevada	1 year	Virginia	6 months – 10 years
Hawaii	1 year	New Hampshire	Indefinitely	Washington	21 years
Idaho	Not Given	New Jersey	23 years	West Virginia	3 months
Illinois	2 – 4 months	New Mexico	3 months	Wisconsin	1 year
Indiana	23 years	New York	Indefinitely	Wyoming	Not Given
Iowa	1 month	North Carolina	Indefinite	Virgin Islands	1 year
Kansas	1 month	North Dakota	10 years		
Kentucky	6 months	Ohio	21 years		