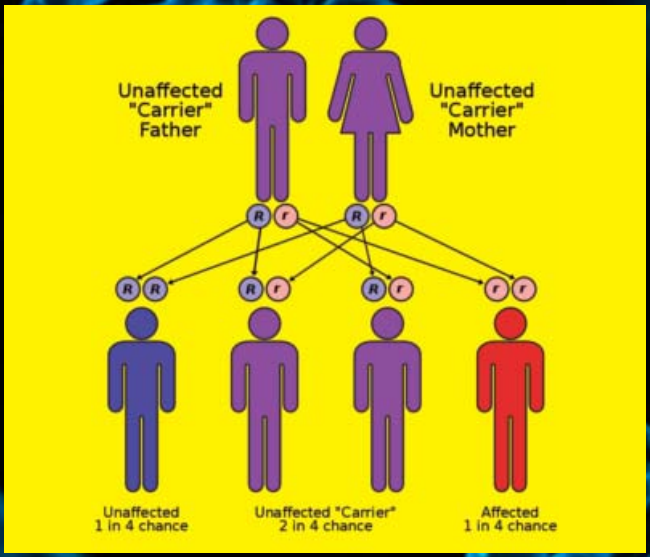
Batten Disease (CLN3)



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Researchers at the National Institutes of Health (NIH), in Bethesda, Maryland, seek individuals with CLN3 (Juvenile Neuronal Ceroid Lipofuscinosis, Batten disease) and their family members to participate in a research study. CLN3 is a neurodegenerative disease, with typical onset seen in children. Individuals with CLN3 may have symptoms such as visual impairment/blindness, seizures, personality and behavioral changes, dementia and loss of motor skills. The main purpose of this research study is to identify markers of disease to better detect, monitor, and understand CLN3.

Who can participate in this study?

- Any person who has been diagnosed with CLN3 (Juvenile Neuronal Ceroid Lipofuscinosis, Batten disease)
- Family member who is a carrier of the CLN3 gene variant
- Children with CLN3 must have parents/guardian for consent

What is involved?

- Contact the study team if your child has CLN3 and was born in one of the below states/regions.[1]
  - California
  - New York
  - Maryland
- Provide consent for the state laboratory to send us a portion of the stored dried blood spots.
- There is no cost or procedure involved for the collection of dried blood spots.

[1]Not all states store dried blood spots collected from newborns or make them available for research.

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