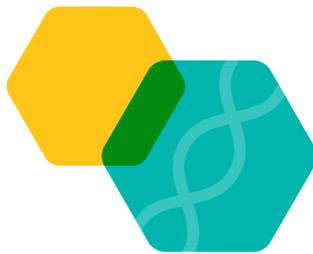


# Who WE ARE



## OUR MISSION

BDSRA is determined to provide unwavering support, fund progressive research, and be a source of steadfast advocacy for all CLN types. Founded in 1987, Batten Disease Support, Research, & Advocacy Foundation (BDSRA) is the largest international nonprofit organization in North America. Our long-term vision is a world without Batten disease.



**BATTEN DISEASE** is a rare, fatal inherited disorder of the nervous system and has no known cure. Those affected with Batten disease often suffer progressive neurological impairment, seizures, blindness, and loss of speech and motor skills. Batten Disease, or Neuronal Ceroid Lipofuscinosis (NCL), is a family of lysosomal storage disorders which cause the build-up of fats and proteins (lipofuscins) in the body, causing cell death. There are 13 identified forms of the disease (CLNs), which are most commonly diagnosed between infancy and school age. Kufs, Parry and ANCL disease are known adult forms of Batten.

Hundreds of families cope with the diagnosis of Batten Disease every year through education, hope, and a shared determination to find a cure.



Did you know?  
International Batten Disease Day is June 9 annually.

To learn more about BDSRA Foundation, email us at [info@bdsrafoundation.org](mailto:info@bdsrafoundation.org)

Though recent improvements in genetic testing have made diagnosing Batten disease much quicker and more reliable, many families experience long diagnostic journeys. Autism, seizure disorder, epilepsy, Pervasive Developmental Disorders, and others are common among roughly 30 early misdiagnoses. According to the Centers for Disease Control, 2–4 births per 100,000 in the U.S. are affected by Batten disease, though some researchers in the field suggest these numbers are low.





# Family GRANTS

Scan the QR code to apply:



## BATTEN FAMILY HELP GRANT

BDSRA is committed to supporting families in all aspects of their fight against Batten, including the financial challenges they face. We offer grants to help cover the costs associated with battling Batten disease, such as emergency travel, loss of employment, hospital bills, and other challenges our families might face.

## BDSRA EQUIPMENT EXCHANGE GRANT

This program provides families the opportunity to gift used equipment to fellow Batten families who are in need. The equipment is gifted to families free of charge, and BDSRA will cover the shipping costs. BDSRA hosts an annual Facebook Swap Party on Earth Day to connect Batten families who want to participate.

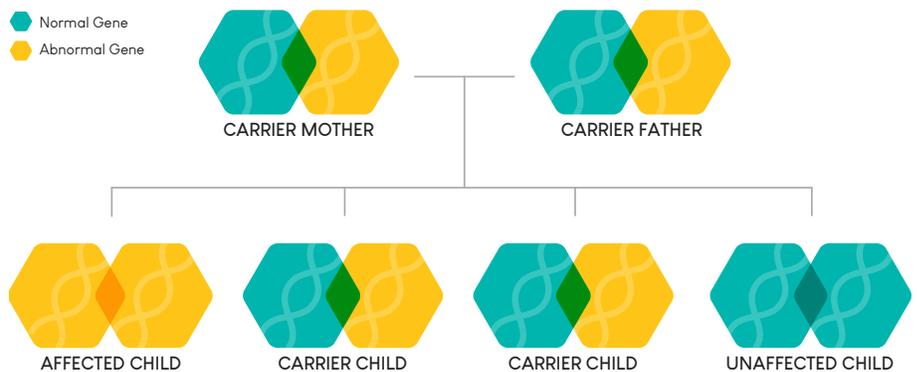
## FORE THE JOURNEY GRANT

Families cherish all the moments that bring their children happiness in their challenging journey with Batten disease. That's why BDSRA and the ForeBatten Foundation collaborated to create the Fore The Journey Fund. This grant is dedicated to providing happy moments to Batten families through experiences, gifts, and memberships. We consider any request, no matter how unique, that will bring much-needed smiles to your family.



# The Genetics of BATTEN DISEASE

Batten disease, for the most part, is an autosomal recessive disease. Autosomal recessive diseases require two copies of an abnormal gene to be passed down in order for the disease to develop. This means that both parents must be carriers in order to have the possibility of their child inheriting a recessive condition. The figure below illustrates the different inheritance possibilities.



When two carriers have children, **at each pregnancy** there is a one in four chance that the child will be born with autosomal recessive Batten disease.

If the child receives both abnormal genes

**25%**

chance this child is affected with the disease

If the child gets a normal gene from one parent and an abnormal gene from the other parent

**50%**

chance this child is not affected but is a carrier of the disease

If the child receives both normal genes

**25%**

Chance this child is not affected and is not a carrier

