



June 9th is International Batten Disease Awareness Day

What is Batten Disease?

Scan to make a
difference today!



Batten disease, or Neuronal Ceroid Lipofuscinosis (NCL), is a family of rare diseases caused by genetic mutations, which disrupts cells' ability to dispose of waste in the brain. It is estimated that 2-4 babies per 100,000 are born in the U.S. with Batten disease.

Children and adults with Batten disease suffer progressive neurological impairment because of their damaged cells, including visual and ambulatory impairment, as well as seizures, and premature death.

No One Battles Batten Alone

The Batten Disease Support, Research, and Advocacy Foundation (BDSRA) is the largest support and research organization dedicated to all forms of Batten disease in North America. They have created a community of caring by providing essentials like:

- [Grant funding](#) for families in need
- [Virtual support programs](#)
- An [Annual Family Conference](#)
- [A Director of Family Support](#) to help families from the moment of their diagnosis through the rest of their Batten journey.

They also offer world-class Batten disease knowledge by:

- Convening [Clinical Centers of Excellence](#)
- Sharing vital information about [Batten disease clinical research](#)
- Providing [expert programming and updates](#) on all CLN types
- Having [a Science Officer](#) provide monthly research & clinical updates

BDSRA just announced more than \$320,000 in research grants with partners in the [Batten Disease Global Research Initiative](#). They are making strides toward treatments and cures!

My Community Needs You

In recognition of International Batten Disease Awareness Day, I am asking you to give to the BDSRA Foundation because someone I know, and love has Batten Disease. It's easy to donate [online](#) here, or by scanning the QR code above. Thank you for joining my battle against Batten Disease.