The Melissa Froio Foundation

In searching for information about Batten Disease, Melissa's family found the Batten Disease Support and Research Association (BDSRA), an organization dedicated to providing support to families affected by Batten Disease. The BDSRA also provides financial assistance to researchers who are trying to find a cure for Batten Disease. Melissa's family and friends partnered with the BDSRA and formed the **Melissa Froio Foundation** in order to increase public awareness and raise money to help find a cure for Batten Disease. A secondary goal of the **Melissa Froio Foundation** is to provide financial assistance to Melissa's special needs school - St. John of God Community School.

The **Melissa Froio Foundation** sponsors a number of fundraising events each year, including the Annual Golf Tournament, Night at Camden Riversharks, and several other events throughout the year.

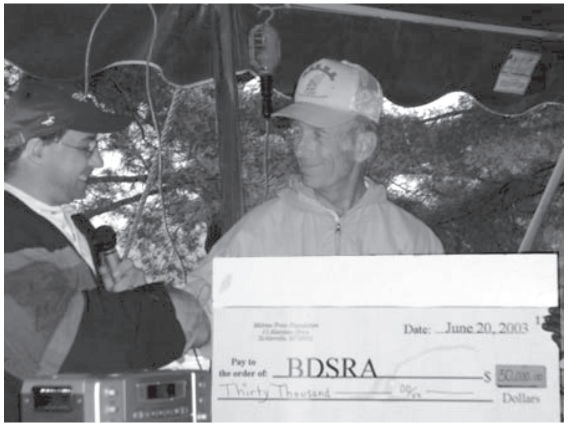
Our Mission

The **Melissa Froio Foundation** was formed to increase public awareness and to raise money to help find a cure for Batten Disease. A secondary goal is to provide financial assistance to Melissa's special needs school - St. John of God Community School.

The **Melissa Froio Foundation** is a 501C(3) not-for-profit tax-exempt charitable organization. All donations to the Foundation are fully tax deductible.

Please visit the Foundation's
web site at:
www.melissafroio.org

Melissa Froio Foundation
25 Aberdeen Drive
Sicklerville, NJ 08081
(856) 435-0212



Help Finding A Cure For Batten Disease

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25 Aberdeen Drive
Sicklerville, NJ 08081
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Melissa Lynn Froio

The **Melissa Froio Foundation** is named in honor of Melissa Lynn Froio. Until the fall of 1998, Melissa was progressing normally and was as active as any other four-year old girl. Suddenly, she began having seizures and developmental problems. Melissa began receiving medical services from The Children's Hospital of Philadelphia and had to undergo a number of medical procedures and two minor operations to determine the cause of her seizures.

In April of 1999, Melissa was diagnosed with the Late Infantile variant of Batten Disease.

Melissa has since lost most of her fine motor skills including her ability to see, eat, walk, and talk and has become completely dependent on others for her care. Melissa is enrolled at the St. John of God Community School in Westville, NJ, where she receives expert care even as Batten Disease progresses and limits her ability to fully participate in the school's curriculum and activities.

Batten Disease

Batten Disease is the common name for a group of diseases known as neuronal ceroid lipofuscinosis, or lysosomal storage disorder. It is an inherited degenerative neurological disease that mostly affects young children. At this time there is no cure or treatment to stop the progression of the disease. Unfortunately, this disease always results in the death of the child at a relatively young age. Batten Disease is often called the orphan disease as it affects mostly children and comes in four types:

- Infantile (onset under age 2)
- Late Infantile (onset at age 2 - 4)
- Juvenile (onset at age 7 - 14)
- Adult (adult onset)

One in 100,000 people carry the defective, recessive gene for Batten Disease. A child must inherit a copy of the bad gene from both parents in order to be affected. A child that inherits a bad copy from just one parent will be a carrier.

Batten Disease is rarely diagnosed immediately and is often mistaken for epilepsy, mental retardation, or retinitis pigmentosa. Onset is characterized by beginning vision loss, seizures, clumsiness, and personality and behavior changes.