

## Batten's Disease Information



**Bee For Battens  
The Saoirse Foundation  
Castledrum  
Keel  
Castlemaine  
Co Kerry  
Ireland**

Email: [info@beeforbattens.org](mailto:info@beeforbattens.org)

[www.beeforbattens.org](http://www.beeforbattens.org)

Registered As A Charity In Ireland CHY 19226



**Battens Disease** is a fatal brain disease which mainly affects young children.

**The Saoirse Foundation** is working to find a cure and raise awareness. Please do what you can to help!

There are numerous ways to support our goals, you can:

- Donate Online
- Send a Postal Donation
- Recycle your old mobile phones and printer cartridges in the home, office or school
- Take part, support or run a fundraising event for us!

Find out more on our website:  
[www.beeforbattens.org](http://www.beeforbattens.org)

Join us on  or follow us on  & 

For Postal Donations please fill in this form, detach & Send to :



**Bee For Battens  
The Saoirse Foundation,  
Castledrum, Keel, Castlemaine,  
Co. Kerry, Ireland.**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Donation \_\_\_\_\_ **Thank You So Much!**

If you or someone you know is in any way affected or concerned about Battens Disease , or if you wish to learn more, then please feel free to contact us.

Email us : [support@beeforbattens.org](mailto:support@beeforbattens.org)

Alternatively write to us at the address listed. We are here to help. Confidentiality is assured.

We provide a call back service so please provide a date / time which is convenient, and a contact number of course!

## Batten's Basic's

Batten disease (Neuronal Ceroid Lipofuscinoses) is an inherited disorder of the nervous system that usually manifests itself in childhood. Batten disease is named after the British paediatrician who first described it in 1903. It is one of a group of disorders called neuronal ceroid lipofuscinoses (or NCLs).

Although Batten disease is the *juvenile* form of NCL, most doctors use the same term to describe all forms of NCL.

Early symptoms of Batten disease (or NCL) usually appear in childhood when parents or doctors may notice a child begin to develop vision problems or seizures. In some cases the early signs are subtle, taking the form of personality and behaviour changes, delayed speech, slow learning, clumsiness or stumbling.

Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Children become totally disabled and eventually die.

Batten disease is not contagious nor, at this time, preventable. To date it has always been fatal.

There are three main types of Battens Disease, including a very rare form that affects adults. The symptoms of all types are similar but they become apparent at different ages and progress at different rates. While most symptoms are presented in a "Classical" way, occasionally variants of each type are encountered.

## Batten's Type's

**Infantile Battens Disease:** begins between about 6 months and 2 years of age and progresses rapidly. Patients usually die before age 5, although some have survived a few years longer.


**Late infantile Battens Disease:** begins between ages 2 and 4. The typical early signs are loss of muscle co-ordination (ataxia) and seizures that do not respond to anticonvulsant drugs. This form progresses fairly rapidly and children live to between the ages 6 and 12.

**Juvenile Battens Disease:** begins between the ages of 5 to 10. The most frequent beginning symptom is visual failure, less common are seizures. After a slowly progressive course patients usually live to late teens, early 20's or more rarely, into their 30's.

**Other Types & Variants :** Some children who definitely have Batten disease don't fall into any of the patterns described above. About 1 in 10 cases are not typical of any of these groups of children.

## Who We Are!

Bee For Battens is operated & funded by The Saoirse Foundation, a Non Profit Volunteer Based Charitable Organisation for Battens Disease. Our Support & Research activities completely rely on fundraising & donations from the public and private business sectors.

Also why not visit our  group events page where our most up to date activities are shown, even better still: create your own event!

## What We Do!



We maintain an informative website and provide a family contact network within Ireland & Worldwide.

Our Support Programme for Families and Communities will provide:

Newly diagnosed family information packs

State-wide Resource Information For Health Care & Specialist Support Organisations

Maximise the opportunities of persons affected by Batten disease

Ongoing contact, not only with the family but their extended family, friends, field specialists and general public

Educate all concerned about the special needs required

Liaise with international counterparts regarding family support, patient participation & with funding research projects working towards a treatment and cure

Bereavement support

We will also act as the national registry for NCL researchers throughout the world and endeavour to support their work.

**We put the FUN in FUNdraising!**