



**BATTEN
DISEASE**
SUPPORT & RESEARCH
ASSOCIATION
A LIGHT IN A WORLD OF DARKNESS

For Immediate Release

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CHICAGOLAND AREA FAMILY BATTLING BATTEN DISEASE RECEIVES EARLY EASTER GIFT FROM THE WHITE HOUSE

(Chicago, IL, April 22, 2011) The VanHoutan Family from Downers Grove, IL received tickets for their family to the White House Easter Egg Roll and plan to attend the event on Monday, April 25 with their three children, two of which, Noah (7 years old) and Laine (5 years old and a fraternal twin) who are fighting for their lives since being diagnosed with a terminal disease, known as Batten disease.

Batten disease is the most common form of a group of disorders called neuronal ceroid lipofuscinosis (or NCLs). Although Batten disease is usually regarded as the juvenile form of NCL, it has now become the term to encompass all forms of NCL. The forms of NCL are classified by age of onset and have the same basic cause, progression and outcome. The outcome being fatal as there is no treatment, there is no cure.

Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Eventually, children with Batten disease / NCL become blind, bedridden and unable to communicate. Eventually it robs the children of their life. *"This is a very special Easter for us,"* said Jennifer VanHoutan, mother of No, *hopefully we will be able to spread more awareness about this fatal disease while making memories on the lawn of the White House that will last a lifetime."*

The White House Easter Egg Roll will feature live music, sports courts, cooking stations, storytelling and, of course, Easter egg rolling. The White House will open its South Lawn for children aged 12 years and younger with their families. The tradition of inviting guests from across the United States to participate in The White House Easter Egg Roll dates back to 1878.

You can find more information about Batten disease at www.bdsra.org or on the VanHoutan family at www.noahshope.com.

A Deadly Disease Without a Cure

Batten disease is a rare, genetic neurological disorder that primarily affects children and adolescents. Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Eventually, children with Batten disease become blind, bedridden, and unable to communicate. Presently, there is no effective treatment for the disease and the disease is always fatal.

About the Batten Disease Support and Research Association

The Batten Disease Support and Research Association (BDSRA), a 501(c)(3) nonprofit, is the largest support and research organization in North America for families that have children with the disease. Continued research efforts hold the key to the future for these children.

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