



**STATE OF TEXAS
OFFICE OF THE GOVERNOR**

The difficulties associated with the diagnosis of a critical disease are only exacerbated when the disease in question qualifies under the umbrella of a “rare disease.” People afflicted with a “rare” disorder — technically a disorder affecting fewer than 200,000 Americans — face a tougher climb with fewer resources, reduced treatment options and an increased likelihood of a delayed or entirely incorrect initial diagnosis.

Many of these diseases, such as Batten Disease — a fatal affliction of the nervous system — first manifest themselves in childhood via any number of symptoms, many of them quite subtle. In the case of Batten Disease, general clumsiness and vision impairment herald the beginning of a degenerative process that will culminate in seizures, blindness and dementia. This affliction typically takes the lives of its victims by their late teens or early twenties.

Ironically, in their solitude, those affected by rare diseases are many. Nearly 7,000 rare diseases afflict Americans. While only a fraction share symptoms, they all share the difficulties inherent in nursing a family member with a rare disorder.

An awareness campaign is underway to not only spread the word about rare diseases like Batten Disease, but also garner the resources needed to help ease the burden on these patients, their families and their friends. At this time, I urge all Texans to learn more about the special challenges affecting these patients, take advantage of emerging diagnostic tools and do all they can to combat these afflictions.

Therefore, I, Rick Perry, Governor of Texas, do hereby proclaim February 28, 2009,

Batten and Rare Disease Day



in Texas, and urge the appropriate recognition whereof.

In official recognition whereof, I hereby affix my signature this the 27th day of February, 2009.

Rick Perry
Governor of Texas