



HUNTER'S HOPE

July 21, 2006

The Honorable Hilary Clinton  
United States Senate  
476 Senate Russell Office Building  
Washington, DC 20510

Dear Senator Clinton,

On behalf of the Hunter's Hope Foundation, I respectfully submit this letter as our full and complete support for the bill titled "Screening for Health of Infants and Newborns (SHINE Act)".

The Hunter's Hope Foundation was established in 1997 by Pro Football Hall of Fame member and former Buffalo Bills Quarterback, Jim Kelly, and his wife, Jill, after their infant son, Hunter, was diagnosed with Krabbe (Crab ā) Leukodystrophy, an inherited, fatal, nervous system disease.

The Foundation's mission is to:

- increase public awareness of Krabbe disease and other leukodystrophies,
- support those afflicted and their families,
- identify new treatments, and ultimately find a cure.

Since 1997, Cord Blood Transplant (CBT) has become a viable treatment for Krabbe disease as well as a few other leukodystrophies. But, CBT is only effective if the child is treated before the disease inflicts irreversible damage to the brain and nervous system. There are many other treatable diseases that if not treated early will cause irreversible damage. And, the number of such diseases continues to increase with advancements in science and technology. We must establish an infrastructure in our country that not only addresses the immediate need, but also creates a system for expansion. The SHINE Act will accomplish this.

Hunter passed away August 5, 2005. Like thousands of other children, if he had been screened at birth, he may be living a healthy life today. Please help these children and their families and pass this bill. We implore you to expedite the passing and implementing of this bill. With each day that passes, children are suffering and dying needlessly.

Thank you from the bottom of our hearts.

Sincerely,

Jacque Waggoner  
Board of Directors, Chair