



May 11, 2012

The Honorable Charles Bass
U.S. House of Representatives
Washington, DC 20515

Dear Mr. Bass:

On behalf of the 30 million men, women and children affected by one of the 7,000 known rare diseases, I am writing today to express our sincere thanks for your leadership in crafting legislation that will increase the development of humanitarian use devices for adults as well as preserving the pediatric device incentives enacted in 2007. Your commitment to the entire rare disease community is deeply appreciated.

The Humanitarian Use Device (HUD) program was established by Congress in 1990 with the passage of the *Safe Medical Devices Act*. This novel pathway was created to make available medical devices “intended to benefit patients in the treatment or diagnosis of a disease or condition that affects or is manifested in fewer than 4,000 individuals in the United States per year.”

Unfortunately, the one roadblock to increased development of HUDs for the treatment or diagnosis of a rare condition in the adult population continues to be the inability of companies to realize a profit.

Your legislation addresses NORD’s concerns by ensuring that all Americans, both children and adults, have access to life-saving medical devices treating or diagnosing rare conditions. The National Organization for Rare Disorders sincerely thanks you for your dedication to the individuals affected by rare diseases. Please contact Diane Edquist Dorman, ddorman@rarediseases.org, for additional information.

Sincerely,

A handwritten signature in black ink, appearing to read "Peter L. Saltonstall". The signature is written in a cursive style with a prominent initial "P".

Peter L. Saltonstall
President and CEO