DeLauro Announces Jeffrey Modell Foundation Wins CDC Grant

Friday, July 20, 2012

Successful Public-Private Partnership Has Raised Awareness

WASHINGTON, DC—Congresswoman Rosa DeLauro (D-CT) announced today that the Jeffrey Modell Foundation has been awarded a $5 million, five-year grant from the Centers for Disease Control (CDC). The grant will go to combating primary immunodeficiency diseases by educating physicians and increasing public awareness of the ailments. The most well-known of these conditions is Severe Combined Immune Deficiency (SCID), or "bubble boy" syndrome, where a child is born without an effective immune system. Last year Connecticut adopted a law advocated for by the Jeffrey Modell Foundation and others ensuring that all newborns are now screened for such diseases.

"Fred and Vicki Modell have been heroes to so many families since their son Jeffrey passed away from an immunodeficiency disorder," DeLauro said. "The Jeffrey Modell Foundation is at the center of cutting edge research and education and this grant will help ensure that work continues. I am proud Connecticut has been a leader in this area, saving lives and bringing us closer to a day where no family has to go through what the Modells endured."

"Congresswoman Rosa DeLauro has been a champion for nearly a decade to assure that patients with diseases are diagnosed early and have access to appropriate treatment," said Fred and Vicki Modell, who lost their son to complications from primary immunodeficiency and co-founded the Jeffrey Modell Foundation. "The Congresswoman has been a champion of children with immunodeficiency diseases and truly fought to make sure they can thrive in life. We look forward to working closely with her for years to come."

Connecticut, just the ninth state in the country to require SCID screening, has already seen families benefit from the law. Health and Human Services Secretary Kathleen Sebelius announced SCID’s addition to the group of disorders the federal government recommends newborn screening for in 2010.

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