



Congressman Tim Bishop

FIRST DISTRICT -- NEW YORK

NEWS RELEASE

JULY 11, 2005

FOR IMMEDIATE RELEASE

CONTACT: JON SCHNEIDER
(631) 696-6500

BISHOP OFFERS RESOLUTION HONORING LOCAL GIRL FIGHTING RARE SKIN DISEASE

Congressman Hopes to Raise Nation's Conscience of Epidermolysis Bullosa

Holtsville, NY- Congressman Tim Bishop hosted a press conference today to announce legislation (H. Res. 335) Bishop hopes will raise the nation's awareness of Epidermolysis Bullosa (EB). Bishop held the press conference at the Holtsville home of Karen and Michael Peshkur; the couple's 3-year-old daughter Grace suffers from EB.

Bishop introduced the legislation with Congressman Peter King reserving the last week of October as National Epidermolysis Bullosa Awareness Week. Senators Charles Schumer and Hillary Rodham Clinton are introducing companion legislation in the Senate.

"We need to raise awareness of Epidermolysis Bullosa so that it is properly diagnosed to prevent suffering, and to build support to research a cure," Bishop said. "Grace Peshkur deserves to live a normal, full life, that must be our goal."

EB is a rare disease characterized by the presence of extremely fragile skin that results in the development of recurrent, painful blisters, open sores, and in some forms of the disease, in disfiguring scars, disabling musculoskeletal deformities, and internal blistering. Writing, eating, walking, and seams of clothing can trigger painful reactions and skin irritations making the lives of the family and children almost intolerable. The disease affects approximately 12,500 individuals in the United States. There is no cure for EB.

Grace Peshkur suffers from the worst possible form of EB (Recessive Dystrophic). Her condition is so rare that the medical community has difficulty treating it at times. Grace has blisters all over her body as well as internal problems. She has special bandages that must be wrapped around most of her body twice every day. The "dressing" changes require 4 adults and last anywhere from one to two hours. Because Grace needs constant care, Grace's mother is unable to work.

The community has been very active in supporting the Peshkurs, including fundraising to build a new home for Grace.

"I am proud of the way our community rallies together to help one another," Bishop said. "It is one of the things that make this area a great place to live."

#