



ULSTER COUNTY LEGISLATIVE NEWS

OFFICE OF ULSTER COUNTY LEGISLATURE
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FOR IMMEDIATE RELEASE

June 16, 2015

Ulster County Legislator Backs HHT Diagnosis and Treatment Act

(Kingston, NY) Legislator Kevin Roberts sponsored two resolutions at tonight's Ulster County Legislature meeting in order to bring awareness to a genetic disease called hereditary hemorrhagic telangiectasia and support a related federal bill.

HHT is a genetic disease that causes malformed blood vessels that lead to sudden and extreme bleeding throughout the body. Without the proper treatment, HHT can result in stroke, brain hemorrhage, heart failure and death. There is currently no cure.

"I bet if we knocked on every door and asked people if they have heard of HHT, they would probably say no," said Paula Roberts, a Modena resident who is planning a Paint in the Park event on Aug. 16 to benefit Cure HHT. "We had never heard of it until a recent diagnosis in the family."

The resolutions will increase local awareness efforts through the disseminating of HHT Clinical Guidelines to all Ulster County medical providers as well as push for New York state representatives to co-sponsor the HHT DATA Act.

"These resolutions are for the thousands of people suffering from the disease who don't know they have it," said Legislator Roberts, who has a family member recently diagnosed with the disease.

Cure HHT, the only US nonprofit organization that supports HHT patients and their families, is honored to have the support of the Ulster County Legislature during HHT Awareness Month efforts to further the HHT DATA Act and improve the 10% diagnosis rate.

The HHT DATA Act HR 1849, co-sponsored by Ed Royce (R-CA) and Jim Himes (D-CT), would be the first of its kind to create a Federally led and financed initiative for early diagnosis and appropriate treatment of hereditary hemorrhagic telangiectasia.

"The hope is to make it so the one in every 5,000 people who have HHT are diagnosed and receive the correct treatment," said Cure HHT Executive Director Marianne Clancy. "Currently, nine out of every 10 people with HHT don't know they have it," she added.

"We depend on people like Kevin and Paula to spread the word of Cure HHT so people know they have somewhere to turn," Clancy said.

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About Cure HHT:

Cure HHT has become the epicenter of the national and global effort to advocate for HHT patients and families, raise awareness, sponsor critical research and advance treatments. However, research remains woefully underfunded. The National Institutes of Health (NIH) currently spends only half-a-million dollars on HHT research, but spends as much as \$75 million a year each on other rare diseases that affect a similar number of people, such as ALS, Cystic Fibrosis and Huntingtons.

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