

The Connecticut General Assembly



REP. KIM ROSE ADVOCATES FOR SUFFERERS OF RARE DISEASE

State Representative Kim Rose (D-Milford) joined activists and families affected by rare disease at a press conference in support of a bill she introduced to establish an advisory council to make recommendations on legislation concerning the issue.

“Rare disease affects over 300,000 state residents and accounts for 40% of our children's health care costs. Among the most frightful news a person or a parent can receive is that they or their child is suffering from a disease that is not identified and the possibility that it could be fatal,” **Rep. Rose** said. “Unfortunately, this is a grey area in medicine as people are left scrambling for diagnosis and treatment, many times having to go to several doctor’s offices to find out what they are afflicted with and many times coming up empty.

“Our rare disease community would like to thank the legislators that came to listen to our stories, struggles, and successes. We demonstrated the importance of a strong collaboration between patients, research, biopharma, physicians and government can improve the lives of one in every 10 people in our state and advance knowledge for all. Thank you to all the brave families and advocates that bring a human face to the daily struggles of the rare diseases community,” said **Dominic Cotton, advocate and supporter of the legislation.**

“Lack of an appropriate treatment places an enormous physical, emotional, social, and financial burden on rare disease patients, their families, and our community,” said **Lesley Bennet, volunteer with the National Organization for Rare Disorders (NORD)**. “The Connecticut Rare Disease Community needs help from members of the Connecticut General Assembly to raise awareness of these medical conditions so that we can improve the health of these patients and lower the healthcare costs associated with managing rare diseases.”

[House Bill #6009](#), An Act Establishing A Rare Disease Advisory Council, focuses research and council of those affected with rare disease, the agencies that are involved with these families, and the legislature as well as the medical community.

“With the proper sharing of information, we can start to make improvements on the efficiency and speed that patients receive proper diagnosis and treatment,” **Rep. Rose** added.

The bill, which is in the Public Health Committee, had a public hearing on February 22nd and is awaiting further action by the Committee.

Rep. Rose is serving her fourth legislative term. She is co-chair of the Women's Caucus, House vice chair of the legislature's Housing Committee, Assistant Majority Whip and a member of the Internship and Veterans Affairs Committees.

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