Public Health Committee
JOINT FAVORABLE REPORT

Bill No.: HB-6920

Title: AN ACT CONCERNING PATIENT-SPECIFIC EMERGENCY MEDICAL CARE PROTOCOLS FOR PERSONS WITH A RARE DISEASE OR SPECIAL HEALTH CARE NEEDS.

Vote Date: 3/5/2025

Vote Action: Joint Favorable

PH Date: 2/26/2025

File No.:

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SPONSORS OF BILL:

Public Health Committee.

REASONS FOR BILL:

The intent of the bill is to assure that should patients with rare diseases or conditions visit an emergency care facility, the protocols specific to their condition would be used by their healthcare providers to guide them in assisting the patient. Such protocols would have been developed by the providers for the patient, and potentially provided by the patient The requirements of the bill extend to Emergency Medical Services (EMS) personnel. The provisions of the bill would take effect on October 1, 2025.

RESPONSE FROM ADMINISTRATION/AGENCY:

Christine Cohen, Senator, Connecticut General Assembly,
Moira Rader, Representative, Connecticut General Assembly,
Robin Comey, Representative, Connecticut General Assembly:

The above legislators strongly support this bill, which should improve the medical outcomes of individuals living with a rare disease. By requiring providers to utilize patient-specific emergency protocols, this bill addresses a critical gap in the Connecticut healthcare system and ensures that our most vulnerable residents receive the specialized care in emergency situations. The provisions of the bill include emergency department staff as well as EMS personnel requiring these professionals to be equipped to meet the needs of this population.

NATURE AND SOURCES OF SUPPORT:

Linda Alderman, West Hartford, CT:
As a survivor of a rare disease, Ms. Alderman has firsthand experience with providers not having enough information to treat her symptoms effectively and efficiently. As different as rare diseases are from each other, patients frequently don't have the luxury of time in emergency situations for providers to try and accurately diagnose the problems of a person with a rare disease. Patient specific protocols can streamline the process and guide the provider to treat the patient in a more timely, effective manner.

Michele Spencer-Manzone, MD, Associate Chief of Clinical Operations, Yale Genetics:
As a practicing physician for over 20 years, Dr. Manzone has experienced instances where patient-specific protocols for rare diseases have not been followed. Most physicians have little knowledge or training in the care of rare disease patients. Ignoring protocols delays care and negatively affects outcomes. Using patient-specific protocols can prevent devastating complications that can lead to permanent organ system damage. Dr. Manzone believes this bill is a win for all with no downside.

Jordan Scheff, Vernon, CT:
Mr. Scheff writes of multiple bad experiences in some very good institutions suffered by his daughter who has a rare disease. As a parent, he would like to see care recommended by her personal medical team when she is in crisis. Having the emergency team aware of her condition and the medications required to treat her effectively would improve her outcomes and minimize delays in care.

Others in support of this bill:

- Dr. Myrna Watanabe, Harwinton, CT
- Mary Caruso, North Branford, CT
- David Leeds, Avon CT
- Michael Werner, CWCSEO

NATURE AND SOURCES OF OPPOSITION:

Connecticut Hospital Association (CHA):
HB 6920 requires every emergency department provider to follow unvetted, external protocols when caring for a patient with a rare disease or special healthcare needs. Such a law would interfere with the Emergency Treatment and Labor Act (EMTALA) as well as state and federal drug policies and hospital policies, including EMS rules related to medical control. CHA is ready to work with the committee to optimize emergency services for patients with rare diseases that don’t conflict with existing emergency care professional and ethical responsibilities.

Greg Allard, President, Association of Connecticut Ambulance Providers:
Mr. Allard is concerned that this bill will present challenges for EMS staff, particularly requiring them to adhere to protocols specific to patients with rare diseases, which he believes is impractical and dangerous. The bill does not account for the urgent, dynamic nature of an ambulance call. Mr. Allard recommends holding the bill until the Medical Advisory Committee of the CT EMS Advisory Board (CEMSMAC) can review the impact on EMS providers.

Also, in opposition to the bill:

- Marci Pittman, Uphold Justice

Reported by: Dave Rackliffe, Asst. Clerk **Date: March 6, 2025**