

Public Health Committee JOINT FAVORABLE REPORT

Bill No.: SB-166

AN ACT ADDING AMNIOTIC FLUID EMBOLISM TO THE LIST OF ADVERSE EVENTS A HOSPITAL IS REQUIRED TO REPORT TO THE DEPARTMENT OF

Title: PUBLIC HEALTH.

Vote Date: 3/19/2018

Vote Action: Joint Favorable Substitute

PH Date: 2/28/2018

File No.:

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SPONSORS OF BILL:

Public Health Committee

REASONS FOR BILL:

This bill requires the Department of Public Health to establish a registry of incidents of amniotic fluid embolism (AFE) by January 1, 2019. The registry will contain non-personally-identifiable data. Each hospital must make available, data on the diagnosis and treatment of AFE incidents at the hospital. The Department of Public Health and researchers authorized by the Department may use the data to evaluate potential treatments for AFE. All data on the registry is not disclosable under the Freedom of Information Act.

RESPONSE FROM ADMINISTRATION/AGENCY:

Raul Pino, M.D. M.P.H, Commissioner, Department of Public Health (DPH)

The definition of an adverse event includes specific events in Connecticut and any event listed on the National Quality Forum (NQF) list of serious reportable events. According to Connecticut law, a hospital is required to report an adverse event within seven days after the adverse event. The primary purpose of reporting adverse events is to ensure that patients are protected from injury while being treated in the hospital. Adverse events are often situations that were largely preventable. There currently exists a category of adverse events that are associated with death or injury to a mother or child during a delivery that occurred during an otherwise low-risk pregnancy.

The DPH monitors every adverse event, conducts an investigation if necessary, and also releases a yearly report that lists all adverse events that were reported to the Department.

AFE is a condition which is often fatal but, also a complication of pregnancy that is unpreventable and unpredictable. To require the reporting of AFE events is not in line with current posting of adverse preventable clinical events.

Rep. Mitch Bolinsky

Rep. Bolinsky was made aware of the seriousness of Amniotic Fluid Embolism (AFE) through his constituents Frank and Joan Bonacci whose daughter Diana Masulli suffered a near fatal experience two years ago. Internationally, AFE is considered a leading contributor to maternal deaths.

The intent of this bill is to require hospitals in Connecticut to include AFE in the list of serious reportable events to protect patients from injury while receiving care helping individuals such as Diana.

Rep. Bolinsky supports this bill and urges it be voted out of committee.

NATURE AND SOURCES OF SUPPORT:

Tina Boldini:

Ms. Boldini tells her personal experience with AFE during childbirth at St. Francis Hospital in Connecticut. As a result of this AFE event, she went into cardiac arrest involving an 8-day hospital stay with two surgeries and numerous blood transfusions. Her newborn daughter also suffered health setbacks. This traumatic experience was devastating to her family and contributed to the end of her marriage. She urges the Public Health Committee to pass this legislation that would require incidents of AFE to be reported and tracked as a serious life-threatening event.

Kenneth Borkowski, DO, Women's Health Connecticut

AFE (also referred to as Anaphylactic Syndrome of Pregnancy or ASP) is still regarded as an unpreventable and unpredictable complication during delivery of a child, and is often a fatal complication of pregnancy.

Mandating the reporting of these catastrophic incidences will lead to a more accurate and accessible database. This registry will provide information that will allow for ongoing review and research to better understand AFE/ASP.

During my career, two of my patients experienced this unfortunate event which they both survived. Although they suffered the emotional and physical consequences associated with AFE, their outcomes are an exception. If this bill will help researchers to better understand this issue, I ask the Public Health Committee to favorably report this bill.

M. Regina Cram, Glastonbury, CT

My experience with Amniotic Fluid Embolism (AFE) was at Saint Francis Hospital. Patients who have experienced AFE can suffer pulmonary failure, cardiac arrest, massive hemorrhaging, strokes, and organ failure.

It is known that death can occur within one hour after experiencing AFE and survivors often suffer from prolonged health issues. Because Connecticut does not require the reporting of AFE, my case and many others are not documented anywhere. Knowing that the United States is in the highest rating of maternal mortality in the western world, mandating the reporting of AFE is the right thing to do.

Miranda Klassen, Founder and Executive Director, AFE Foundation

After nearly a century, Amniotic Fluid Embolism (AFE) still remains an unpreventable, unpredictable and oftentimes a fatal complication of pregnancy. This is the most feared complication for all labor and delivery clinicians because there are no warning signs or proven risk factors. AFE is often fatal even with rapid medical responses and that is why it is still regarded as a leading cause of maternal mortality and morbidity in the United States.

For the last decade the AFE Foundation, led by several respected AFE experts, has been at the forefront of this issue and is leading the charge for more research in order to provide accurate information. The biggest barrier is the lack of data because there is no uniform reporting system for these adverse events.

These events typically result in high financial costs for providing appropriate health care. The average cost of providing care for a mother and baby can run as much as \$1 million.

The passage of this bill will benefit the state without placing a burden on the hospitals. This will reaffirm our commitment made in the Healthy Connecticut 2020 initiative and will save lives.

Carla DeSantis, MD; Women's Health Group: Dr. DeSantis is a physician who provides care at St. Francis Hospital and is a partner and provider at Women's Health. Dr. DeSantis in her testimony tells of two patients in her care who experienced AFE and were fortunate to have survived this condition which is most often unpredictable, unpreventable and often fatal.

Dr. DeSantis supports this legislation which would provide valuable information to help in further researching this condition.

The following individuals support this legislation and presented testimony sharing personal experiences with Amniotic Fluid Embolism:

- Diana Masulli
- Frank & Joan Bonacci
- Patricia Shea
- Diane Fortin

NATURE AND SOURCES OF OPPOSITION:

Reported by: Kathleen A. Panazza

Date: 3/31/18

