



Blood Clot Pulmonary Embolism Policy (BCPEP)

Meeting Minutes

Date: April 17, 2024
Time: 10:00 AM to 12:00 PM
Location: GoToWebinar

Members Present: Ali Ataya, M.D., Christopher Pittman, M.D., Leslie Lake, Giovanni Betta

Presenters: Dr. Ataya, Leslie Lake, Dr. Christopher Cogle, Dr. Emma Spencer (DOH), Melissa Jordan (DOH)

Agency Staff Present: Jaime Bustos, Krischell Weston, Susan Slappey, Marnita Anderson, Nancy Tamariz

Meeting Materials: Copies of meeting materials are posted on: [Blood Clot and Pulmonary Embolism Policy Workgroup \(myflorida.com\)](https://myflorida.com/Blood-Clot-and-Pulmonary-Embolism-Policy-Workgroup)

Welcome: Jaime Bustos

Call to Order and Roll Call: Dr. Ataya called roll.

Action Items and Status Updates: The Agency continues to work on scheduling guest speakers.

Summary of Charles Rochester Blood Clot Prevention and Treatment Act:

Presenter Leslie Lake discussed the potential Bill which has been introduced via the Energy and Commerce Committee in Congress. Charles Rochester passed away in 2014 from a blood clot caused by a torn achilles playing basketball. This Bill would improve patient awareness for blood clot risks including educating healthcare providers and hospitals on signs and symptoms, develop a national detection and treatment system for patients, and ultimately save lives. Requirements would be for the Centers for Disease Control and Prevention (CDC) to conduct a nationwide public awareness campaign with an advisory committee that will provide information, recommendations, and advice to the Secretary of Department of Health and Human Services (HHS). This committee would include government agencies, clinicians, and patient advisory groups. A financial ask for this bill is \$100 million dollars and a request of over a 5-year period (\$20 million per year) dedicated to this bill. Approximately 30 organizations are in support.

State Registries: Melissa Jordan, Assistant Deputy Secretary of Health at the Florida Department of Health (FDOH) presented on State Registries. Her overview included information on public health epidemiology, data sources, public health authority for collecting data, and data



dissemination strategies. There was an emphasis on the importance of having a variety of data sources in a registry. Dr. Emma Spencer, Division Director at FDOH touched on considerations for developing a disease or health condition registry and current available data sources. The first step in developing a disease registry should be defining the goals, purpose, and scope. Other steps include engaging stakeholders, ensuring data security, and continuous quality improvement. Dr. Spencer also shared some blood clot data pulled from the Bureau of Vital Statistics and the Agency for Health Care Administration. Dr. Ataya asked about the possibility of collaborating with an existing registry to create a more comprehensive registry.

Guest Speaker Dr. Christopher Cogle: Dr. Cogle is the Chief Medical Officer for Florida Medicaid and a professor at the University of Florida. He discussed his experience with participating in various work groups and advisory bodies. Building a system within a system of current established registries was recommended. Dr. Christopher Pittman asked if the State of Florida was open to sponsorship. Dr. Cogle advised that the efforts of the BCPEP Workgroup and the finalized report could be used to leverage a grant application.

BCPEP Workgroup Discussion - Needs for Surveillance: Dr. Ataya went over some VTE Statistics. He then discussed the need for surveillance, defining the populations at risk, and the recommended steps for moving forward. Dr. Pittman mentioned the missed VTE diagnoses when tracking ICD data. Many practitioners miss the diagnosis due to current tracking procedures. He wants to look at how the group can find the overlooked incidences.

Public Comments: Doug Adkins thanked the workgroup members for the discussions during the meeting. He wants to see Assisted Living Facilities (ALFs) and nursing home front line staff trained in how to respond in the appropriate way when a patient is facing a blood clot or pulmonary embolism. Dr. Jeff Cline, a PE Researcher, asked the group to determine if they would like to receive patient level data. He suggested a subcommittee be formed to establish the case definition and data sources. Giovanni Betta made a point that funding may be more palatable when associated with existing practices.

Meeting Summary and Next Steps: One of the first goals of the workgroup is to determine how the data will be collected, who will be the partner of the project, and what data should be included in the surveillance system. Dr. Ataya questioned how the FDOH could help the workgroup leverage the current systems in place to begin developing a blood clot registry. A suggestion was made to arrange some in-person meetings to help move the workgroup goals along quicker and more efficiently.

New Action Items	Owner
The AHCA team will send out recommended monthly meeting dates to the members.	AHCA
The AHCA team will work with the Chair to coordinate and schedule an in-person meeting.	AHCA



With no further business to discuss, moved to adjourn, with no objections. The committee adjourned.

DRAFT