



**35TH LEGISLATURE OF THE VIRGIN ISLANDS
COMMITTEE ON HEALTH, HOSPITALS AND HUMAN SERVICES**

The Honorable Ray Fonseca
Chair of Committee

Testimony Presented By
The Honorable Justa Encarnacion, RN, BSN, MBA/HCM
Commissioner of Health

**Bill No. 35-0207-An Act amending Title 19 Virgin Islands Code, part I, adding chapter 6a
to create the Territorial Chronic Kidney Disease and Diabetes Registry**

1 Good day, Honorable Senator Ray Fonseca, Chairperson of the Committee on Health, Hospitals,
2 and Human Services; Honorable Kenneth L. Gittens, Vice Chair, Committee Members, and all
3 Non-committee members, and the viewing and listening audience. I am Justa “Tita” Encarnacion,
4 Commissioner for the Virgin Islands Department of Health. Present with me today are Dr. Tai
5 Hunte-Cesar, Medical Director, and Dr. Lyña Fredericks, Director of the Division of Chronic
6 Diseases.

7 We are here to testify on Bill No. 35-0207, an Act amending Title 19 Virgin Islands Code, part I,
8 adding chapter 6a to create the Territorial Chronic Kidney Disease and Diabetes Registry. This
9 registry will serve as a pivotal shift in our approach to medical management of chronic kidney
10 disease and diabetes within our territory. These conditions are interlinked, with diabetes being a
11 leading cause of chronic kidney disease. Diabetes and chronic kidney disease are precursors to
12 End Stage Renal Disease (ESRD), which requires dialysis or a kidney transplant for survival. Type
13 II diabetes, although often preventable and manageable, when combined with Type I diabetes, is
14 the 6th leading cause of death in the U.S. Virgin Islands and currently affects 15.93% of the
15 population or approximately 11,161 persons. Chronic kidney disease affects 1.5% of the
16 population. In 2016, the USVI diabetes prevalence was 12.7% affecting approximately 10,382
17 persons. The prevalence of these diseases is increasing at an alarming rate, posing significant
18 health, economic, and social challenges. These prevalence data were captured from the Behavioral
19 Risk Factor Surveillance System, which is self-reported data. Although these data are useful, they
20 do have their limitations. A Chronic Kidney Disease and Diabetes Registry will give the ability to
21 corroborate and strengthen the existing data, enable comparisons with other jurisdictions, and
22 forge a way to truly quantify the burden of disease in the territory.

1 Disease registries have long been recognized as useful tools to aid health system professionals and
2 leaders track chronic disease and diabetes morbidity in populations. Chronic kidney disease and
3 Type II diabetes are two preventable conditions that contribute significantly to the disease burden
4 in the US. A disease registry is a centralized database for the collection of data on a specific
5 disease. Currently, the VI Department of Health operates the Virgin Islands Central Cancer
6 Registry as part of the network of National Program of Cancer Registries funded through the
7 Centers for Disease Control and Prevention. The cancer registry functions as an epidemiologic
8 surveillance system designed to collect information regarding the incidence, distribution, risk
9 factors, and mortality of the disease. This data is essential to public health professionals,
10 researchers, the medical community, and policymakers in understanding and addressing the cancer
11 burden in the territory. Also, the VI Department of Health is currently preparing to launch the
12 Sickle Cell Disease Voluntary Patient Registry in the next few months. This registry will collect
13 longitudinal data on persons living with sickle cell disease to increase understanding of how
14 clinical characteristics predict outcomes and affect quality of life. The creation of a dedicated
15 registry to track and analyze chronic kidney disease and diabetes is urgent and necessary.

16 The registry will have many benefits to the Virgin Islands community. It will serve as a critical
17 resource for policymakers and public health officials, offering data-driven insights to shape
18 preventive public health strategies. It can identify high-risk populations, guide resource allocation,
19 and evaluate the impact of public health interventions. Further, it will inform infrastructure
20 planning to ensure the Territory is prepared and equipped to care for persons diagnosed with these
21 diseases. The registry can also function as a quality improvement tool in healthcare organizations
22 allowing clinicians to audit their practice patterns and standards of care across systems.

1 Another benefit is the increased capacity to foster research and collaboration. Currently, the VI
2 Department of Health partners with several higher education institutions such as the University of
3 the Virgin Islands, Louisiana State University, the University of Utah, and John Hopkins
4 University to implement and manage its disease registries and surveillance systems. This registry
5 will be an added, invaluable resource for research, fostering collaborations with academic
6 institutions and research organizations. By understanding the epidemiology and treatment
7 outcomes of chronic kidney disease and diabetes, we can drive innovations in medical research
8 and healthcare delivery.

9 The registry will also strengthen community engagement and knowledge. Empowering patients to
10 become active self-managers in their care is essential to the reduction of morbidity and mortality.
11 The registry will support community-based initiatives, educational programs, and outreach efforts
12 empowering our citizens with knowledge and resources to manage their health better.

13 Moreover, the VI Department of Health acknowledges that the successful implementation of this
14 registry will require collaboration and cooperation of healthcare systems, healthcare providers, and
15 the members of the community. Therefore, we pledge to ensure the privacy and security of
16 protected health information. In establishing this registry, our commitment to patient privacy and
17 data security is paramount. We will adhere to the highest standards of data protection, ensuring
18 compliance with HIPAA (Health Insurance Portability and Accountability) and other relevant
19 privacy laws. Building on the legacy of the provisions in the USVI Central Cancer Registry that
20 speaks to the reporting requirements by providers, this legislation will provide the support needed
21 to collect data from the appropriate sources seamlessly.

1 In conclusion, disease registries have proven effective in healthcare locally and globally. They
2 encompass a value-based approach that prioritizes and tracks outcomes important to patients and
3 healthcare providers such as sociodemographic factors, treatment protocols, quality of care,
4 survival rates, and healthcare costs, as well as providing the evidence that can be leveraged to
5 support prevention and health promotion efforts.

6 The establishment of the Territorial Chronic Kidney Disease and Diabetes Registry is a step
7 towards a healthier future for our islands. It will enable us to tackle the twin challenges of chronic
8 kidney disease and diabetes with the precision and effectiveness that these serious health issues
9 demand. We are committed to the successful implementation and ongoing development of this
10 registry and are eager to collaborate with all stakeholders in this endeavor.

11 Finally, The Virgin Islands Universal Data Warehouse (Data Warehouse), funded by a \$2 million
12 ARPA (American Rescue Plan Act) grant, will integrate medical, pharmacy, and dental claims
13 data from public and private payers. This robust database can serve as a foundation for disease
14 registries like the proposed Chronic Kidney Disease/Diabetes Registry. The Data Warehouse
15 population-level insights on prevalence, costs, outcomes, and disparities would power impactful
16 surveillance and interventions. The Data Warehouse puts us at the forefront of health data
17 analytics. We want to maximize this opportunity to enable evidence-based policies and initiatives
18 like the CKD/Diabetes Registry.

19 The VI Department of Health is committed to reducing health risks, increasing access to quality
20 healthcare, and enforcing health standards. The Department commits to continued collaborative
21 efforts with the members of the 35th Legislature. We stand ready to respond to any questions you
22 may have.