## WRITTEN SUBMITTED TESTIMONY FROM DONNA M. CHRISTENSEN, MD

## The Committee on Health, Hospitals and Human Services Of the 35th Legislature of the Virgin Islands On Bill No. 35-0207, An Act Amending Title 19of the VI Code, Part I, Adding Chapter 6a to Create the Territorial Diabetes and Chronic Kidney Disease Registry

February 7, 2024

Good Morning, Chairman, Senator Ray Fonseca, Vice Chair, Senator Kenneth Gittens, members of the Committee, other Senators present, staff, fellow testifiers and inperson, radio and tv audiences, Thank you for the opportunity to submit this brief written testimony.

I am testifying on my own behalf, but as a long time family physician and health care administrator here in the Virgin Islands, and as a Board member of both the Virgin Islands Diabetes Center of Excellence and the American Kidney Fund (a national organization) I felt it important to do so.

I am in support of the registries. Several states have established them and found them valuable in understanding the prevalence of the diseases which they monitor as well as in their distribution and trends. This information is critical to being able to effectively plan how to lessen the adverse impact of the diseases on communities.

The mission of VIDCOE is to prevent diabetes and reduce its complications through health promotion, patient education, treatment, and research. The prevalence of diabetes in the Virgin Islands requires this kind of surveillance and the actions that it will demand.

Likewise, the increasing number of patients on dialysis is unsustainable and requires early diagnosis and management of diabetes and other risk factors of chronic kidney disease. The mission of AKF is to eliminate preventable kidney disease, accelerating innovation for the dignity of the patience experience and dismantling structural inequities in kidney care dialysis and transplantation. I serve on their Boards because the work of these two entities is important to me and to the wellbeing of our residents.

There is much that can be done in terms of prevention, delay of onset of severe or harder to control disease, in management and hopefully in avoiding the several complications which can be devastating.

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But without the key information the registries can provide, we will be moving blindly, unable to adequately and successfully do what is needed to address these predominant causes of morbidity and mortality in our community.

Moreover, we cannot ignore the higher costs to patients who may have limited resources, and all the other barriers - social determinant of health - that make relying on personal responsibility, impossible, no matter how hard they may try.

Two concerns that are top of mind:

CONFIDENTIALITY: the bill seems to provide the possibility to use identifiers other than names. I suggest that an identifier be used.

PENALTIES: I do not support penalties for failure to report.

At the very least there should be a transition period while this is being implemented before any penalty be imposed. In fact, successful registries utilize electronic health records where the data is actually reported automatically through a Health Information Exchange or some similar electronic method. I believe the Data Warehouse can do that if properly developed ( and I have confidence in the DOH to do that).

As a former busy practicing physician who struggled to ensure I reported what was required, it would be better to plan to gather the information from a carefully designed electronic source than depend on individual providers and burden them with yet another task.

Not being in government at this time, it was at the last minute that I happened to see that 35-0207 was in committee tomorrow. With more time, it might have been a more detailed testimony, but I trust I have clearly convey my strong support for the Registries and the concerns I feel need to be addressed on behalf of patients/consumers and providers .

Thank you again for the opportunity to submit my written testimony.

Respectfully submitted

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