

COMMITTEE ON HEALTH, HOSPITAL AND
HUMAN SERVICES

06/29/16-SPECIAL ORDERED TO THE FLOOR

BILL NO. 31-0385

Thirty-first Legislature of the Virgin Islands

June 29, 2016

An Act repealing and reenacting title 19 Virgin Islands Code, chapter 47 relating to the Virgin Islands Central Cancer Registry Program

PROPOSED BY: Senator Almando "Rocky" Liburd

1 *Be it enacted by the Legislature of the Virgin Islands:*

2 **SECTION 1.** Title 19 Virgin Islands Code, chapter 47 is repealed and reenacted with
3 amendments to read as follows:

4 "Chapter 47 Virgin Islands Central Cancer Registry Program

5 **§ 1251. Definitions**

6 In this chapter:

7 (1) "Cancer" means all malignant neoplasms, regardless of the tissue of origin, including
8 malignant lymphoma, Hodgkin's disease, and leukemia.

9 (2) "Health care facility" means hospitals; health care clinics; health centers; skilled nursing
10 facilities; mental health facilities; kidney disease treatment centers, including freestanding

1 hemodialysis units; intermediate care facilities; ambulatory surgical facilities; rehabilitation facilities;
2 health maintenance organizations; and hospice care facilities.

3 (3) "Health care provider" means a person, corporation, facility or institution licensed in the
4 Territory to provide health care or professional, medical services including a medical, osteopathic,
5 chiropractic or naturopathic physician; hospital; dentist; registered nurse, including an advanced
6 practice registered nurse; licensed practical nurse; optometrist; podiatrist; physical therapist;
7 psychologist; paramedical personnel; emergency medical technician; pharmacist and laboratory
8 technician.

9 (4) "Identifying Information" means a patient's name, social security number, address or other
10 information that allows for ready identification of the individual and the name and other identifiers of
11 a health care facility or health care provider.

12 (5) "Pathology Laboratory" means any facility that reports the results of examinations of organ
13 tissue, cells, or blood specimens from the human body for cancer to physicians who use the reports
14 for purposes of diagnosis or patient care.

15 (6) "Registry" means the Virgin Islands Central Cancer Registry Program.

16 (7) "Reportable Neoplasm" means any form of in-situ or invasive malignant neoplasms,
17 carcinomas, with the exception of basal cell and squamous cell carcinoma of the skin; lymphoma,
18 including Hodgkin's disease; sarcoma; leukemia; benign and malignant tumor in the central nervous
19 system, or any other malignant growth or neoplastic disease.

20 (8) "Central Cancer Registry Standard-Setting Organization" means national and international
21 organizations responsible for developing and sometimes implementing standards for cancer reporting
22 for central registries.

23 (9) "Territory" means the Virgin Islands of the United States.

24 **§ 1252. Establishment of the Cancer Registry**

1 (a) There is established within the Department of Health under the division of and
2 supervision of Chronic Disease Prevention Program, the Virgin Islands Central Cancer Registry
3 Program. The Registry serves as the territorial surveillance system and repository of cancer data that
4 includes information regarding incidence, mortality, distribution of the disease, and risk factors and
5 aids in the reduction of cancer incidence and mortality by providing scientific data for the support of
6 cancer research, policy makers and the creation and evaluation of cancer control programs.

7 (b) To accomplish its mandate, the Registry is responsible for collecting information on all
8 reportable neoplasms for which a diagnosis of, or the first course of treatment of, reportable cancer
9 was performed in the Territory, independent of patient's residence

10 (c) The Registry shall establish and regularly convene an advisory committee to assist in
11 building consensus, cooperation, and planning for the Program and to enhance the chronic disease
12 program coordination and collaboration. Representation on the advisory committee includes
13 representatives from the cancer prevention and control field; the chronic disease program; hospitals,
14 clinicians, and cancer oriented community programs.

15 (d) The Registry shall train and certify personnel designated by the reporting entities as the
16 person responsible for reporting information to the Registry.

17 (e) The Health Commissioner shall promulgate administrative guidelines as may be
18 amended from time to time to ensure that the Registry performs its mandate consistent with guidelines
19 of central cancer registries standard-setting organizations.

20 **§ 1253. Participation in program**

21 (a) Each healthcare provider and health care facility shall report in an electronic format or
22 any other format requested by the Registry each new case of a reportable neoplasm to the Registry not
23 later than 180 days after the date of diagnosis or date of first contact with the already diagnosed patient.

24 (b) Private or public pathology laboratories, clinical laboratories, and dermatopathologists
25 shall report to the Registry every pathology, cytology, bone marrow and autopsy report, pathological

1 reviews, tumor markers, molecular studies, and any other report that is consistent with a clinical or
2 pathological diagnosis or contributes to determine the stage of the disease at the time of diagnosis of
3 the reportable neoplasm in an electronic format or in a format requested by the Registry not later than
4 30 days after the diagnosis or test.

5 (c) If an entity fails to provide the required information in the format or within the time
6 specified, or if the data are of unacceptable quality, the Registry may enter the facility to obtain the
7 information. When this happens, the entity shall reimburse the Registry for the cost associated with
8 obtaining and reporting the information.

9 (d) Each report submitted to the Registry must contain:

10 (1) the patient's name: first, middle and last; social security number; address at time
11 of diagnosis; date and place of birth; sex; race; ethnicity; marital status; usual occupation and
12 industry;

13 (2) the date of diagnosis;

14 (3) topography;

15 (4) histology; including the type involved in the reportable neoplasm;

16 (5) characteristic of the reportable neoplasm – the behavior, differentiation grade,
17 size; stage of the reportable neoplasm at the time of diagnosis;

18 (6) the cancer directed first course of treatment;

19 (7) the name of the health care facility or health care provider; and

20 (8) other information required by any of the Central Cancer Registry Standard-
21 Setting Organizations.

22 § 1254. Confidentiality

23 (a) All cancer case data provided to the Registry must be kept confidential. No information
24 reported to the Registry which identifies or could lead to the identification of an individual cancer

1 patient may be disclosed to any person or entity; except that the identifying information may be
2 disclosed to another state cancer registry and territorial health officers.

3 (b) State cancer registries, cancer researchers or federal cancer control agencies that
4 receive cancer case data from the Registry which includes identifying information shall enter into an
5 agreement with the Registry before receiving the information agreeing to keep the information
6 confidential.

7 (c) All Registry employees and researchers shall sign a confidentiality agreement agreeing
8 to keep all information regarding the data received at the Registry confidential. These agreements
9 remain effective after the employee or researcher no longer has a relationship with the Registry.

10 § 1255. Disclosure

11 (a) Cancer case data that may include identifying information may be disclosed to cancer
12 researchers or federal cancer control agencies for the purposes of cancer prevention, control, and
13 research upon the submittal of documentation to the Registry demonstrating that research in cancer
14 prevention or control is ongoing or approval for such research has been granted. If applicable, the
15 Registry shall also request evidence of compliance with the requirements of 45 CFR Part 46.

16 (b) The Registry may use statistical compilations of the cancer case data that do not include
17 identifying information or provide the statistical compilations to state cancer registries, federal cancer
18 control agencies, or to other persons or organizations for either of the following:

19 (1) to perform studies on the sources and causes of cancer;

20 (2) for evaluation of the cost, quality, efficacy, and appropriateness of the
21 diagnostic, therapeutic, rehabilitative, and preventative services;

22 (3) for programs relating to cancer; and

23 (4) for any other clinical, epidemiological, or other cancer research.

24 25 § 1256. Liability

1 (a) No person who in good faith discloses privileged or confidential information or
2 provides cancer case reports to the Registry or allows the Registry access to a cancer case report is
3 liable in any civil action.

4 (b) The protection from liability provided in subsection (a) does not apply to the
5 unauthorized disclosure of confidential or privileged information when the disclosure is due to gross
6 negligence or willful misconduct.

7 (c) The license of a health care provider or a health care facility's may not be suspended
8 or revoked for the disclosure of information provided to the Registry pursuant to this chapter.

9 **§ 1257. Penalties**

10 (d) Any person who violates the reporting provisions of this chapter or regulations or
11 orders pertaining to the reporting of information to the Registry is subject to a civil fine of not less
12 than \$1,000 per case but not more than \$5,000 per case. Before assessing the fine, the Commissioner,
13 or the Commissioner's designee, may conduct a hearing with the person or entity to ascertain the
14 reason for noncompliance and determine if an adjustment in the fine is warranted. Funds collected
15 pursuant to this subsection must be deposited in an account established by the Department of Health
16 within the Department of Finance. The monies in this account must be used exclusively to assist in
17 the funding of the Cancer Registry Program.

18 **§ 1258. Program Funding**

19 The Registry must be funded through appropriations from the Legislature, Federal agencies
20 and through donations from private entities.

21 **§ 1259. Annual Report**

22 The Registry shall publish an annual statistical compilation that does not include identifying
23 information showing the incidence of cancer in the Territory.”

24 **BILL SUMMARY**

1 This bill repeals and reenacts the Virgin Islands Central Cancer Registry Program. The chapter
2 was reenacted to include provisions to make Registry eligible to receive National Program of Cancer
3 Registries funding. Section 1251 adds definitions for healthcare facility, health care provider,
4 identifying information, pathology laboratory and reportable neoplasm. Section 1252 provides for the
5 establishment of the Cancer Registry within the Department of Health under the direction and
6 supervision of the Chronic Disease Prevention Program. Section 1252 also provides that the Registry
7 may establish and convene an advisory committed to provide input to the Registry; that the Registry
8 will train and certify personnel responsible for reporting information to the Registry; and grants the
9 Commission of Health the authority to promulgate administrative guidelines for the Registry.

10 Section 1253 lists what entities must report cancer information to the Registry, what information
11 must be provided and when it must be provided, the consequences for failure to provide the information,
12 and what information each report must contain.

13 Section 1254 provides that all information provided to the Registry is confidential and sets forth
14 the circumstances under which the Registry may share the confidential information and to which
15 entities. It also provides that employees and researchers must execute confidentiality agreements that
16 bounds them to keep Registry information confidential even after they are no longer associated with
17 the Registry.

18 Section 1255 provides that the Registry may disclose information to cancer researchers or
19 federal cancer control agencies for the purposes of cancer prevention, control, and research upon the
20 entity's showing that the research is ongoing or has been approved. It also sets forth the circumstances
21 when the Registry can disclose non-identifying information.

22 Section 1256 sets forth the instances when the Registry, employees of the Registry and entities
23 required to provide information to the Registry are not be liable for performing acts pursuant to this
24 legislation.

1 Section 1257 sets forth the penalties for failing to comply with the requirements of this
2 legislation. Section 1258 provides how the Registry will be funded and section 1259 provides that the
3 Registry must publish an annual statistical compilation of the instances of cancer in the community.
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