

**ACT No. 373**

2017 Regular Session

HOUSE BILL NO. 483

BY REPRESENTATIVES JACKSON, BAGNERIS, BILLIOT, BOUIE, TERRY BROWN, COX, GISCLAIR, JIMMY HARRIS, HUNTER, JEFFERSON, JENKINS, JOHNSON, JORDAN, LEBAS, LYONS, MARCELLE, NORTON, PIERRE, POPE, RICHARD, SMITH, AND STAGNI AND SENATORS PEACOCK AND THOMPSON

1 AN ACT

2 To amend and reenact R.S. 40:1105.10(B) and to enact R.S. 40:5.12, 1105.8.1, and 1105.8.2,  
3 relative to maintenance and reporting of data on cancer by the Louisiana Tumor  
4 Registry of the Louisiana State University System; to provide authorizations and  
5 restrictions concerning reporting of data by the registry; to provide relative to  
6 requests for registry data by the office of public health of the Louisiana Department  
7 of Health; to provide for cooperation between the registry and the office of public  
8 health in certain functions; to provide for state cancer investigation and intervention  
9 functions; to establish procedures for processing of data requests submitted to the  
10 registry; to provide for duties of the research committee of the registry; to provide  
11 for annual reports of cancer data to designated parties; to provide for electronic  
12 notifications and reports concerning cancer data; and to provide for related matters.

13 Be it enacted by the Legislature of Louisiana:

14 Section 1. R.S. 40:1105.10(B) is hereby amended and reenacted and R.S. 40:5.12,  
15 1105.8.1, and 1105.8.2 are hereby enacted to read as follows:

16 §5.12. Cancer investigation and intervention

17 A. Cancer control is hereby declared to be an urgent public health priority  
18 of this state.

19 B. The state health officer and the office of public health of the Louisiana  
20 Department of Health are hereby authorized to operate a program of cancer  
21 investigation and subsequent intervention if sufficient funding is available for this  
22 purpose.

1           C. The source of monies for the cancer investigation and intervention  
 2           program provided for in this Section may be any appropriation by the legislature,  
 3           including appropriations of federal funds; appropriations from the Health Excellence  
 4           Fund created by Article VII, Section 10.8(A)(2) of the Constitution of Louisiana, and  
 5           appropriations from the Louisiana Fund created by Article VII, Section 10.9(A) of  
 6           the Constitution of Louisiana; any public or private donations, gifts, or grants from  
 7           individuals, corporations, nonprofit organizations, or other business entities; and any  
 8           other monies which may be provided by law.

9           D. The state health officer and the office of public health of the Louisiana  
 10           Department of Health shall engage and collaborate with the Louisiana Tumor  
 11           Registry, the Louisiana Cancer Research Center, and the Louisiana Advisory  
 12           Committee on Populations and Geographic Regions With Excessive Cancer Rates  
 13           in administering the cancer investigation and intervention program provided for in  
 14           this Section.

15           E. The program provided for in this Section shall be conducted in addition  
 16           to the activities of, and shall not replace or supplant, the Louisiana Cancer  
 17           Prevention and Control Programs of the School of Public Health of the Louisiana  
 18           State University Health Sciences Center-New Orleans.

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20           §1105.8.1. Louisiana Tumor Registry; research committee; disclosure of registry  
 21           data

22           A. The Louisiana Tumor Registry, referred to hereafter in this Section as the  
 23           "tumor registry", shall provide diagnostic, treatment, and follow-up information  
 24           concerning a patient, if requested, to a physician or medical facility diagnosing or  
 25           treating the case as authorized pursuant to 45 CFR 164.506.

26           B.(1) The tumor registry shall collaborate with the National Cancer Institute,  
 27           the Centers for Disease Control and Prevention, the North American Association of  
 28           Central Cancer Registries, the International Agency for Research on Cancer, and any  
 29           other national or international cancer surveillance program it may designate in  
 30           providing cancer data and participating in cancer studies.

1           (2) The tumor registry shall cooperate with the office of public health of the  
2           Louisiana Department of Health, referred to hereafter in this Section as the "office  
3           of public health", in evaluating programs and investigating cancer concerns and other  
4           cancer-related issues through activities including, without limitation, cooperating  
5           with the office of public health in implementing the program of cancer investigation  
6           and intervention provided for in R.S. 40:5.12. Because the tumor registry data are  
7           an integral part of national and state cancer prevention and control programs, the use  
8           of registry data by office of public health officials and registry-designated national  
9           cancer surveillance programs shall be considered an in-house activity and shall be  
10           processed expeditiously.

11           (3) Requests by the office of public health for case-specific data shall require  
12           annual approval by the institutional review board of the Louisiana State University  
13           Health Sciences Center-New Orleans, referred to hereafter in this Section as the  
14           "LSUHSC-New Orleans". Additionally, the office of public health shall comply  
15           with all applicable confidentiality standards of the tumor registry.

16           C.(1) Subject to the limitations of Subsection F of this Section, the tumor  
17           registry shall release case-specific data to persons or organizations for the purposes  
18           of cancer prevention, control, and research in accordance with Paragraph (2) of this  
19           Subsection. However, no such data shall include information collected for special  
20           studies or other research projects. The tumor registry shall have and shall reserve the  
21           right to prioritize its responses to data requests.

22           (2) Requests from persons or organizations for case-specific tumor registry  
23           incidence data, including data linkages, shall be submitted in writing and shall be  
24           reviewed and approved by the tumor registry research committee following the  
25           established policies of the registry. These policies shall require, without limitation,  
26           all of the following:

27           (a) Approval from the LSUHSC-New Orleans institutional review board and  
28           compliance with the LSUHSC-New Orleans HIPAA research policy.

29           (b) Approval from the researcher's institutional review board and compliance  
30           with that institution's HIPAA research policy.

1           (c) Execution of the tumor registry's form entitled "Agreement to Maintain  
2           Confidentiality of Data", or any successor form, by each investigator who will have  
3           access to the data indicating agreement by the investigator to adhere to the tumor  
4           registry confidentiality provisions and prohibiting the disclosure of tumor registry  
5           data in any civil, criminal, administrative, or other proceeding.

6           (d) Provision of a copy of the complete protocol for the project.

7           (e) Completion of all requirements provided in the document entitled  
8           "Louisiana Tumor Registry: Researchers' Requests for Data", or any successor  
9           document.

10          (f) Prior to contacting a patient or his next of kin, notification to the patient's  
11          physician, if required.

12          (g) Destruction or return of data once the research is completed.

13          (3) If a request for data submitted in accordance with the provisions of this  
14          Subsection is denied by the LSUHSC-New Orleans institutional review board, the  
15          institutional review board shall provide to the requestor notice in writing of the  
16          reason for the denial electronically or by postal mail.

17          D.(1) The director of the tumor registry or his designee shall coordinate the  
18          research committee of the tumor registry. The research committee shall include,  
19          without limitation, the following members:

20               (a) The director of the tumor registry.

21               (b) A qualified representative selected from each of the following entities:

22                   (i) The LSUHSC-New Orleans.

23                   (ii) The office of public health.

24                   (iii) The Louisiana Cancer and Lung Trust Fund Board.

25          (2) The research committee shall verify that the researchers are able to  
26          execute the proposal, in terms of both financial support and professional  
27          qualifications; that the study has scientific and ethical merit; and that the researchers  
28          will obtain appropriate consent.

1           E.(1) In determining the order of processing requests for data, the tumor  
2           registry shall give priority to requests for data from the office of public health for use  
3           in responding to concerns about threats to the public health.

4           (2) Subject to the provisions of the Public Records Law, R.S. 44:1 et seq.,  
5           the tumor registry shall process requests for aggregate data other than those provided  
6           for in Paragraph (1) of this Subsection in the order of receipt. The tumor registry  
7           shall respond to any public request in a timely manner, as resources permit, if the  
8           request meets the applicable requirements of R.S. 40:3.1 and 1105.8.

9           (3) The tumor registry may assess a charge to a requestor of data for actual  
10          costs of compiling and providing the data, and may require payment before  
11          proceeding to fulfill the data request.

12          (4) The tumor registry shall not be required in any instance to perform  
13          original work to create data not currently in existence.

14          F.(1) The tumor registry shall not release data in cases in which such data  
15          would disclose the identity of any person to whom the data relate and thus violate the  
16          requirements of the Health Insurance Portability and Accountability Act relating to  
17          uses and disclosure of protected health information (45 CFR 164.514). In such  
18          situations, the tumor registry may combine more years of cancer data together at the  
19          census tract level or suppress the data according to the suppression rule of the United  
20          States Cancer Statistics program.

21          (2) In considering for approval or denial a request for aggregate data, the  
22          research committee of the tumor registry shall determine whether the request  
23          complies with applicable state and federal laws relating to privacy of health  
24          information. If the research committee finds that disclosure of data in response to  
25          the request would violate any such law, then the committee shall collaborate with the  
26          requestor to revise the request in order to preclude such violation.

27          (3) In collaborating with a requestor as provided in Paragraph (2) of this  
28          Subsection, the research committee shall employ methods for de-identifying  
29          case-specific data as defined by the Centers for Disease Control and Prevention and  
30          any other de-identification or statistical methods for disclosure protection.

