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Introduced and read first time: February 7, 2001

Assigned to: Environmental Matters

## A BILL ENTITLED

## 1 AN ACT concerning

## 2 Maryland Tumor Registry for Cranial and Central Nervous System Tumors

- 3 FOR the purpose of establishing a certain tumor registry; specifying the purpose of
- the registry; providing for the administration of the registry; establishing 4
- 5 certain reporting requirements; specifying that the Community Public Health
- Administration shall administer the registry; providing that the registry shall 6
- 7 be part of a certain computerized data system; specifying certain duties of the
- 8 Secretary of Health and Mental Hygiene concerning the registry; authorizing
- the Secretary to employ certain personnel subject to budget restrictions; 9
- 10 requiring the Secretary to charge certain fees for certain data; authorizing the
- Secretary to enter into certain collaborative agreements; providing 11
- 12 confidentiality for certain individuals; authorizing the release of certain
- 13 information under certain circumstances; providing a certain immunity;
- 14 providing a penalty for a violation of this Act; requiring the Secretary to adopt
- 15 certain regulations; and generally relating to a tumor registry for cranial and
- 16 central nervous system tumors.
- 17 BY adding to
- Article Health General 18
- 19 Section 13-1601 through 13-1607, inclusive, to be under the new subtitle
- "Subtitle 16. Maryland Tumor Registry for Cranial and Central Nervous 20
- System Tumors" 21
- Annotated Code of Maryland 22
- (2000 Replacement Volume) 23
- 24 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF
- 25 MARYLAND, That the Laws of Maryland read as follows:

1	Article - Health - General
2	SUBTITLE 16. MARYLAND TUMOR REGISTRY FOR CRANIAL AND CENTRAL NERVOUS SYSTEM TUMORS.
4	13-1601.
5 6	IN THIS SUBTITLE, "REGISTRY" MEANS THE MARYLAND TUMOR REGISTRY FOR CRANIAL AND CENTRAL NERVOUS SYSTEM TUMORS.
7	13-1602.
8 9	THERE IS A MARYLAND TUMOR REGISTRY FOR CRANIAL AND CENTRAL NERVOUS SYSTEM TUMORS IN THE DEPARTMENT FOR THE PURPOSE OF PROVIDING:
	(1) ACCURATE AND UP-TO-DATE INFORMATION RELATING TO THE INCIDENCE, DIAGNOSIS, AND TREATMENT OF BENIGN AND MALIGNANT CRANIAL AND CENTRAL NERVOUS SYSTEM TUMORS; AND
13 14	(2) INFORMATION THAT WILL REDUCE THE MORBIDITY AND MORTALITY RATES ASSOCIATED WITH CRANIAL AND CENTRAL NERVOUS SYSTEM TUMORS.
15	13-1603.
17 18 19	THE REGISTRY SHALL RECEIVE, COMPILE, ANALYZE, AND MAKE AVAILABLE EPIDEMIOLOGICAL AND AGGREGATE CLINICAL CASE INFORMATION COLLECTED FROM ALL HEALTH CARE PROVIDERS AND ALL HEALTH CARE FACILITIES IN THE STATE THAT DIAGNOSE OR TREAT CRANIAL OR CENTRAL NERVOUS SYSTEM TUMORS. 13-1604.
21	(A) THE REGISTRY SHALL:
22 23	(1) BE ADMINISTERED BY THE COMMUNITY HEALTH ADMINISTRATION IN THE DEPARTMENT;
24 25	(2) BE PART OF THE COMPUTERIZED DATA SYSTEM UTILIZED BY THE MARYLAND CANCER REGISTRY; AND
26 27	(3) COLLECT STATEWIDE DATA ON EACH BENIGN OR MALIGNANT PRIMARY CRANIAL AND CENTRAL NERVOUS SYSTEM TUMOR.
28 29	(B) ALL CASES OF CONFIRMED BENIGN OR MALIGNANT CRANIAL OR CENTRAL NERVOUS SYSTEM TUMORS SHALL BE REPORTED TO THE REGISTRY.
30	13-1605.
31 32	(A) TO ACCOMPLISH THE PURPOSES OF THIS SUBTITLE, THE SECRETARY SHALL:
33	(1) ESTABLISH A UNIFORM STATEWIDE REPORTING SYSTEM;

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- 1 (2) DETERMINE THE SPECIFIC DATA TO REPORTED; AND
  2 (3) DETERMINE THE DEADLINE FOR REPORTING DATA.
  3 (B) SUBJECT TO THE BUDGET, THE SECRETARY MAY EMPLOY:
- 4 (1) A DIRECTOR OF THE REGISTRY; AND
- 5 (2) ANY OTHER STAFF SUFFICIENT TO CARRY OUT THE PURPOSE OF 6 THIS SUBTITLE.
- 7 (C) (1) THE SECRETARY SHALL CHARGE A FEE WHEN DATA IS REQUESTED 8 FROM THE REGISTRY.
- 9 (2) FEES ARE TO BE BASED ON THE ACTUAL COST OF PRODUCING THE 10 DATA.
- 11 (D) THE SECRETARY MAY ENTER INTO COLLABORATIVE AGREEMENTS WITH 12 OTHER STATE REGISTRIES OR FEDERAL AGENCIES TO:
- 13 (1) OBTAIN COMPLETE INFORMATION ON MARYLAND RESIDENTS WHO 14 ARE DIAGNOSED OR TREATED IN OTHER STATES; AND
- 15 (2) PARTICIPATE IN A PROGRAM WITH ANOTHER STATE OR A FEDERAL 16 AGENCY FOR TREATMENT AND PREVENTION OF CRANIAL OR CENTRAL NERVOUS 17 SYSTEM TUMORS.
- 18 13-1606.
- 19 (A) INFORMATION IN THE REGISTRY THAT COULD IDENTIFY A PATIENT 20 SHALL BE KEPT STRICTLY CONFIDENTIAL.
- 21 (B) AN ANALYSIS, RESEARCH STUDY, REPORT, OR COMPILATION OF DATA 22 BASED ON INFORMATION IN THE REGISTRY MAY NOT DISCLOSE THE IDENTITY OF
- 23 ANY INDIVIDUAL WITH A TUMOR.
- 24 (C) CONFIDENTIAL INFORMATION MAY BE RELEASED BY THE DEPARTMENT 25 ONLY:
- 26 (1) UPON THE WRITTEN REQUEST OF THE INDIVIDUAL PATIENT WHO IS 27 THE SUBJECT OF THE INFORMATION OR THE PATIENT'S AUTHORIZED
- 28 REPRESENTATIVE; OR
- 29 (2) TO PERSONS AUTHORIZED BY THE SECRETARY TO CONDUCT 30 RESEARCH STUDIES.
- 31 (D) AN INDIVIDUAL DOES NOT HAVE ANY CLAIM OR CAUSE OF ACTION
- 32 AGAINST ANOTHER INDIVIDUAL, A HEALTH CARE FACILITY, OR A HEALTH CARE
- 33 PROVIDER WHO PARTICIPATES IN GOOD FAITH IN THE REPORTING OR RECEIVING OF
- 34 INFORMATION FOR THE REGISTRY.

- 1 (E) THE LICENSE OF A HEALTH CARE FACILITY OR A HEALTH CARE PROVIDER
- 2 MAY NOT BE DENIED, SUSPENDED, OR REVOKED FOR THE GOOD FAITH DISCLOSURE
- 3 OF CONFIDENTIAL OR PRIVILEGED INFORMATION IN THE REPORTING OF TUMORS TO
- 4 THE REGISTRY.
- 5 (F) A PERSON WHO DISCLOSES CONFIDENTIAL INFORMATION IN VIOLATION
- 6 OF THIS SUBTITLE IS GUILTY OF A MISDEMEANOR AND UPON CONVICTION IS
- 7 PUNISHABLE BY A FINE NOT EXCEEDING \$1,000, IMPRISONMENT FOR NOT MORE
- 8 THAN 6 MONTHS, OR BOTH.
- 9 13-1607.
- 10 THE SECRETARY SHALL ADOPT REGULATIONS TO IMPLEMENT THE PROVISIONS
- 11 OF THIS SUBTITLE.
- 12 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect
- 13 October 1, 2001.