

# HB6134



## 99TH GENERAL ASSEMBLY

### State of Illinois

2015 and 2016

HB6134

Introduced 2/11/2016, by Rep. Litesa E. Wallace

#### SYNOPSIS AS INTRODUCED:

New Act

Creates the Illinois Alzheimer's Disease Registry Act. Provides for the creation of the Illinois Alzheimer's Disease Registry under the authority of the Illinois Department of Public Health. Provides that the Registry shall provide a database of individuals with Alzheimer's disease and related dementias. Provides the Department of Public Health with rulemaking powers to establish and operate the Registry in accord with specified responsibilities. Requires the Department of Public Health to provide staff and resources for the Registry. Contains provisions concerning data privacy. Defines terms. Effective immediately.

LRB099 19796 MJP 44195 b

FISCAL NOTE ACT  
MAY APPLY

A BILL FOR

1 AN ACT concerning health.

2 **Be it enacted by the People of the State of Illinois,**  
3 **represented in the General Assembly:**

4 Section 1. Short title. This Act may be cited as the  
5 Illinois Alzheimer's Disease Registry Act.

6 Section 5. Legislative purpose. Due to the increasing rate  
7 of those living with Alzheimer's disease, the devastating  
8 health effects on its sufferers, and the growing financial  
9 burdens on taxpayers, the General Assembly finds it to be  
10 beneficial for the State to better understand the full scope of  
11 Alzheimer's disease in Illinois. Therefore, for the  
12 advancement of research opportunities and to properly address  
13 and serve the needs of this population, the General Assembly  
14 authorizes the creation of the Illinois Alzheimer's Disease  
15 Registry.

16 Section 10. Definitions. In this Act:

17 "Department" means the Department of Public Health.

18 "Registry" means the Illinois Alzheimer's Disease  
19 Registry.

20 Section 15. Department responsibilities.

21 (a) The Department shall establish procedures and adopt

1 rules for the establishment and operation of the Registry. Such  
2 procedures and rules shall provide for:

3 (1) collecting and evaluating data regarding the  
4 prevalence of Alzheimer's disease and related disorders in  
5 Illinois, including who shall report the data to the  
6 Registry;

7 (2) determining what information shall be maintained  
8 in the Registry and the length of time that data will be  
9 available;

10 (3) sharing of data for policy planning purposes;

11 (4) disclosing non-identifying data to support  
12 Alzheimer's disease and related disorder research;

13 (5) the methodology by which families and physicians of  
14 persons who are reported to the Registry shall be contacted  
15 to gather additional data; and

16 (6) information about private and public resources.

17 (b) The Department shall provide staff from existing  
18 resources to implement and operate the Registry.

19 Section 20. Registry purpose and function.

20 (a) The purpose of the Registry shall be to assist in the  
21 development of public policy and planning relative to  
22 Alzheimer's disease and related disorders.

23 (b) The Registry shall provide a central database of  
24 individuals with Alzheimer's disease and related dementias.

1           Section 25. Registry data privacy.

2           (a) The data collected in the Registry shall be  
3 confidential, and all persons to whom the data is released  
4 shall maintain patient confidentiality. No publication of  
5 information, biotechnical research, or medical data shall be  
6 made that identifies any patient by name.

7           (b) The Registry shall be established and regulated to the  
8 requirements of the federal Health Insurance Portability and  
9 Accountability Act of 1996.

10           Section 99. Effective date. This Act takes effect upon  
11 becoming law.