

1 AN ACT concerning lupus.

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 Lupus Erythematosus Registry Act.

6 Section 5. Legislative findings. The General Assembly  
7 finds that:

8 (1) More complete and precise statistical data than is  
9 presently available is necessary to evaluate lupus  
10 erythematosus treatment and prevention measures than is  
11 currently available.

12 (2) The creation of the Lupus Erythematosus Registry  
13 will provide a vital foundation for a concerted State effort  
14 to reduce the incidence of lupus erythematosus in this State.

15 Section 10. Definitions. For the purposes of this Act,  
16 unless the context requires otherwise:

17 "Lupus" means lupus erythematosus, as defined by the  
18 Centers for Disease Control or the National Institutes of  
19 Health.

20 "Department" means the Illinois Department of Public  
21 Health.

22 "Director" means the Director of Public Health.

23 "Registry" means the Lupus Erythematosus Registry.

24 Section 15. Lupus Erythematosus Registry.

25 (a) The Department shall establish and maintain a Lupus  
26 Erythematosus Registry consisting of a record of cases of  
27 lupus that occur in Illinois and any other information  
28 concerning the cases as it deems necessary or appropriate.  
29 These cases shall be used to conduct thorough and complete

1 epidemiological surveys of lupus in Illinois and to evaluate  
2 existing control and prevention measures. Cases included in  
3 the Registry shall be identified by a code rather than by  
4 name. To the extent feasible, the Registry shall be  
5 compatible with other national models so as to facilitate the  
6 coordination of information with other data bases.

7 (b) To facilitate the collection of information relating  
8 to cases of lupus, the Department shall have the authority to  
9 require physicians, hospitals, laboratories, and other  
10 facilities that diagnose such conditions to report cases of  
11 lupus to the Department, and to require the submission of  
12 such other information pertaining to or in connection with  
13 the reported cases as the Department deems necessary or  
14 appropriate for the purposes of this Act. The Department may  
15 promulgate rules specifying the types of information  
16 required, requirements for follow up of patients, frequency  
17 of reporting, methods of submitting the information, and any  
18 other details deemed by the Department to be necessary or  
19 appropriate for the administration of this Act. Nothing in  
20 this Act shall be construed to compel any individual to  
21 submit to a medical examination or supervision.

22 (c) The Director shall by rule establish standards for  
23 ensuring the protection of information made confidential or  
24 privileged under law.

25 Section 20. Funds. The Department shall have the  
26 authority to accept, receive, and administer on behalf of the  
27 Registry grants, gifts, loans, or other funds made available  
28 to the Registry from any source for the purposes of this Act.

29 Section 25. Annual report. The Department shall file an  
30 annual report to the General Assembly that shall include  
31 information on the progress of the Registry, as well as  
32 descriptions of any related studies that are underway or have

1     been completed.

2             Section 30. Confidentiality.

3             (a) The Department may not release information gathered  
4 pursuant to this Act unless (i) it is in a statistical form  
5 that does not identify the reporting entity, physician, or  
6 patient in any way, including by address; or (ii) the release  
7 or transfer is to an Illinois local public health department  
8 or to a registry or health department of another state, and  
9 is of information concerning a person who is residing in that  
10 jurisdiction.

11            (b) All data obtained directly from medical records of  
12 individual patients shall be for the confidential use of the  
13 Department and those entities authorized by the Department to  
14 view those records in order to carry out the purposes of this  
15 Act.

16            (c) The identity of any person whose condition or  
17 treatment has been studied, or any facts that are likely to  
18 reveal the identity of the person, shall be confidential and  
19 shall not be revealed in any report or any other matter  
20 prepared, released, or published. Researchers may, however,  
21 use the names of persons when requesting additional  
22 information for research studies approved by the Department;  
23 provided, however, that when a request for additional  
24 information is to be made, the Department must first obtain  
25 authorization from the patient or the patient's legally  
26 authorized representative.

27            (d) No liability shall attach to any hospital,  
28 physician, or other facility submitting information pursuant  
29 to this Act based upon a claim that the hospital, physician,  
30 or facility reported information that may be confidential.

31             Section 35. Rules. The Department may promulgate rules  
32 for the implementation of this Act.