

1                                    AMENDMENT TO HOUSE BILL 2284

2                    AMENDMENT NO. \_\_\_\_\_. Amend House Bill 2284 on page 1, by  
3 inserting the following after line 5:

4                    "Section 5. Policy declaration. The General Assembly  
5 finds that epilepsy is a devastating health condition that  
6 afflicts 2,300,000 United States citizens, over 125,000 of  
7 whom reside in Illinois. The General Assembly also finds  
8 that epilepsy afflicts its victims at all ages, but is  
9 particularly devastating to children and the elderly. It is  
10 the opinion of General Assembly that epilepsy can cause  
11 serious financial, social, and emotional hardships on the  
12 victims and their families of such a major consequence that  
13 it is essential for the State to develop and implement  
14 policies, plans, programs, and services to alleviate such  
15 hardships.

16                    It is the intent of the General Assembly through  
17 implementation of this Act to establish a program for the  
18 conduct of education and research regarding the cause, cure,  
19 and treatment of both the physiologic and psychosocial  
20 aspects of epilepsy. Additionally, it is the intent of the  
21 General Assembly, through the establishment of regional  
22 epilepsy centers and a comprehensive, statewide system of  
23 regional and community-based services, to provide for the

1 identification, evaluation, diagnosis, referral, and  
2 treatment of victims of such health problems.

3 Section 10. Definitions. As used in this Act:

4 "Epilepsy" means a disorder characterized by  
5 recurring attacks of motor, sensory, or psychic  
6 malfunction with or without unconsciousness or convulsive  
7 movements.

8 "Regional epilepsy center" means a postsecondary  
9 higher educational institution having:

10 (1) a medical school in affiliation with a  
11 medical center;

12 (2) an established education and outreach  
13 initiative to provide assistance to both children  
14 and adults with epilepsy; and

15 (3) full-time educators, advance practice  
16 nurses, epileptologists treating both children and  
17 adults, social workers, psychologists, and  
18 researchers involved in exploring both the  
19 pathophysiologic and psycho-social aspects of  
20 epilepsy.

21 "Primary epilepsy provider" means a licensed  
22 hospital, a medical center under the supervision of a  
23 physician licensed to practice medicine in all of its  
24 branches, or a medical center that provides medical  
25 consultation, evaluation, referral, and treatment to  
26 persons who may be or who have been diagnosed as victims  
27 of epilepsy.

28 "Epilepsy Advisory Committee" or "Advisory  
29 Committee" or "Committee" means the Epilepsy Disease  
30 Advisory Committee created under Section 20 of this Act.

31 "Department" means the Illinois Department of Public  
32 Health.

33 "Director" means the Director of Public Health.

1 Section 15. Development of standards for a service  
2 network; designation of regional centers and primary  
3 providers. By January 1, 2002, the Department, in  
4 consultation with the Advisory Committee, shall develop  
5 standards for the conduct of research and for the  
6 identification, evaluation, diagnosis, referral, and  
7 treatment of victims of epilepsy and their families through  
8 the regional centers. The standards shall include the  
9 following:

10 (a) A description of the specific populations and  
11 geographic areas to be served.

12 (b) Standards, criteria, and procedures for  
13 designation of the Regional Centers that will ensure the  
14 provision of quality care to a broad segment of the  
15 population through on-site facilities and services  
16 available within the service area defined by the  
17 Department. At least one regional center shall be  
18 conveniently located to serve the Chicago metropolitan  
19 area and at least one regional center shall be  
20 conveniently located to serve the balance of the State.  
21 The regional centers shall provide at least the  
22 following:

23 (1) Comprehensive diagnosis and treatment  
24 facilities and services that have (i) professional  
25 medical staff specifically trained in neurology and  
26 the detection, diagnosis, and treatment of epilepsy,  
27 (ii) sufficient support staff who are trained as  
28 caregivers to victims of epilepsy,  
29 (iii) appropriate and adequate equipment necessary  
30 for diagnosis and treatment, (iv) transportation  
31 services necessary for outreach to the service area  
32 defined by the Department and for assuring access of  
33 patients to available services, and (v) such other  
34 support services, staff, and equipment as may be

1 required;

2 (2) Consultation and referral services for  
3 victims and their families to ensure informed  
4 consent to treatment and to assist them in obtaining  
5 necessary assistance and support services through  
6 primary epilepsy providers and various private and  
7 public agencies that may otherwise be available to  
8 provide services under this Act;

9 (3) Research programs and facilities to assist  
10 faculty and students in discovering the cause of and  
11 diagnosis, cure, and treatment of epilepsy;

12 (4) Training, consultation, and continuing  
13 education for caregivers, including families of  
14 those who are affected by epilepsy;

15 (5) Centralized data collection, processing,  
16 and storage that will serve as a clearinghouse of  
17 information to assist victims and families and to  
18 facilitate research;

19 (6) Programs of scientific and medical  
20 research in relation to epilepsy that are designed  
21 and conducted in a manner that may enable the center  
22 to qualify for federal financial participation in  
23 the cost of such programs.

24 Section 20. Epilepsy Advisory Committee. There is  
25 created the Epilepsy Advisory Committee consisting of the  
26 Director or his or her designee, who shall serve as a  
27 non-voting member and who shall be the chairman of the  
28 Committee and 11 voting members appointed by the Director.

29 The appointed members shall include persons who are  
30 experienced in research and the delivery of services to  
31 victims of epilepsy and their families. Such members shall  
32 include 4 physicians licensed to practice medicine in all of  
33 its branches experienced in the diagnosis and treatment of

1 epilepsy, at least 3 of whom shall be physicians who are  
2 board certified in neurology; one representative of a  
3 postsecondary educational institution that administers or is  
4 affiliated with a medical center in the State, one  
5 representative of a licensed hospital, one nurse, one social  
6 worker, one representative of an organization established  
7 under the Illinois Insurance Code for the purpose of  
8 providing health insurance, and 2 victims of epilepsy or  
9 members of their families.

10 Each member appointed by the Director shall serve for a  
11 term of 2 years and until his or her successor is appointed  
12 and qualified. Members of the Committee shall not be  
13 compensated, but shall be reimbursed for expenses actually  
14 incurred in the performance of their duties. No more than 7  
15 members may be of the same political party.

16 Vacancies shall be filled in the same manner as original  
17 appointments.

18 Section 25. Regional Epilepsy Center grants-in-aid.  
19 Pursuant to appropriations made by the General Assembly, the  
20 Department shall provide grants-in-aid to regional epilepsy  
21 centers for necessary research and for the development and  
22 maintenance of services for victims of epilepsy and their  
23 families. The Department shall adopt rules and procedures  
24 governing the distribution and specific purposes of such  
25 grants."