

1 AN ACT in relation to 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 Epilepsy Disease Assistance Act.

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

18 It is the intent of the General Assembly through
19 implementation of this Act to establish a program for the
20 conduct of education and research regarding the cause, cure,
21 and treatment of both the physiologic and psychosocial
22 aspects of epilepsy. Additionally, it is the intent of the
23 General Assembly, through the establishment of regional
24 epilepsy centers and a comprehensive, statewide system of
25 regional and community-based services, to provide for the
26 identification, evaluation, diagnosis, referral, and
27 treatment of victims of such health problems.

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

29 "Epilepsy" means a disorder characterized by
30 recurring attacks of motor, sensory, or psychic

1 malfunction with or without unconsciousness or convulsive
2 movements.

3 "Regional epilepsy center" means a postsecondary
4 higher educational institution having:

5 (1) a medical school in affiliation with a
6 medical center;

7 (2) an established education and outreach
8 initiative to provide assistance to both children
9 and adults with epilepsy; and

10 (3) physicians licensed to practice medicine in
11 all of its branches, full-time educators, nurses,
12 epileptologists treating both children and adults,
13 social workers, psychologists, and researchers
14 involved in exploring both the pathophysiologic and
15 psycho-social aspects of epilepsy.

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

24 "Epilepsy Advisory Committee" or "Advisory
25 Committee" or "Committee" means the Epilepsy Disease
26 Advisory Committee created under Section 20 of this Act.

27 "Department" means the Illinois Department of Public
28 Health.

29 "Director" means the Director of Public Health.

30 Section 15. Development of standards for a service
31 network; designation of regional centers and primary
32 providers. By January 1, 2002, the Department, in
33 consultation with the Advisory Committee, shall develop

1 standards for the conduct of research and for the
2 identification, evaluation, diagnosis, referral, and
3 treatment of victims of epilepsy and their families through
4 the regional centers. The standards shall include the
5 following:

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

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

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

32 (2) Consultation and referral services for
33 victims and their families to ensure informed
34 consent to treatment and to assist them in obtaining

1 necessary assistance and support services through
2 primary epilepsy providers and various private and
3 public agencies that may otherwise be available to
4 provide services under this Act;

5 (3) Research programs and facilities to assist
6 faculty and students in discovering the cause of and
7 diagnosis, cure, and treatment of epilepsy;

8 (4) Training, consultation, and continuing
9 education for caregivers, including families of
10 those who are affected by epilepsy;

11 (5) Centralized data collection, processing,
12 and storage that will serve as a clearinghouse of
13 information to assist victims and families and to
14 facilitate research;

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

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

25 The appointed members shall include persons who are
26 experienced in research and the delivery of services to
27 victims of epilepsy and their families. Such members shall
28 include 4 physicians licensed to practice medicine in all of
29 its branches experienced in the diagnosis and treatment of
30 epilepsy, at least 3 of whom shall be physicians who are
31 board certified in neurology; one representative of a
32 postsecondary educational institution that administers or is
33 affiliated with a medical center in the State, one

1 representative of a licensed hospital, one nurse, one social
2 worker, one representative of an organization established
3 under the Illinois Insurance Code for the purpose of
4 providing health insurance, and 2 victims of epilepsy or
5 members of their families.

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

12 Vacancies shall be filled in the same manner as original
13 appointments.

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