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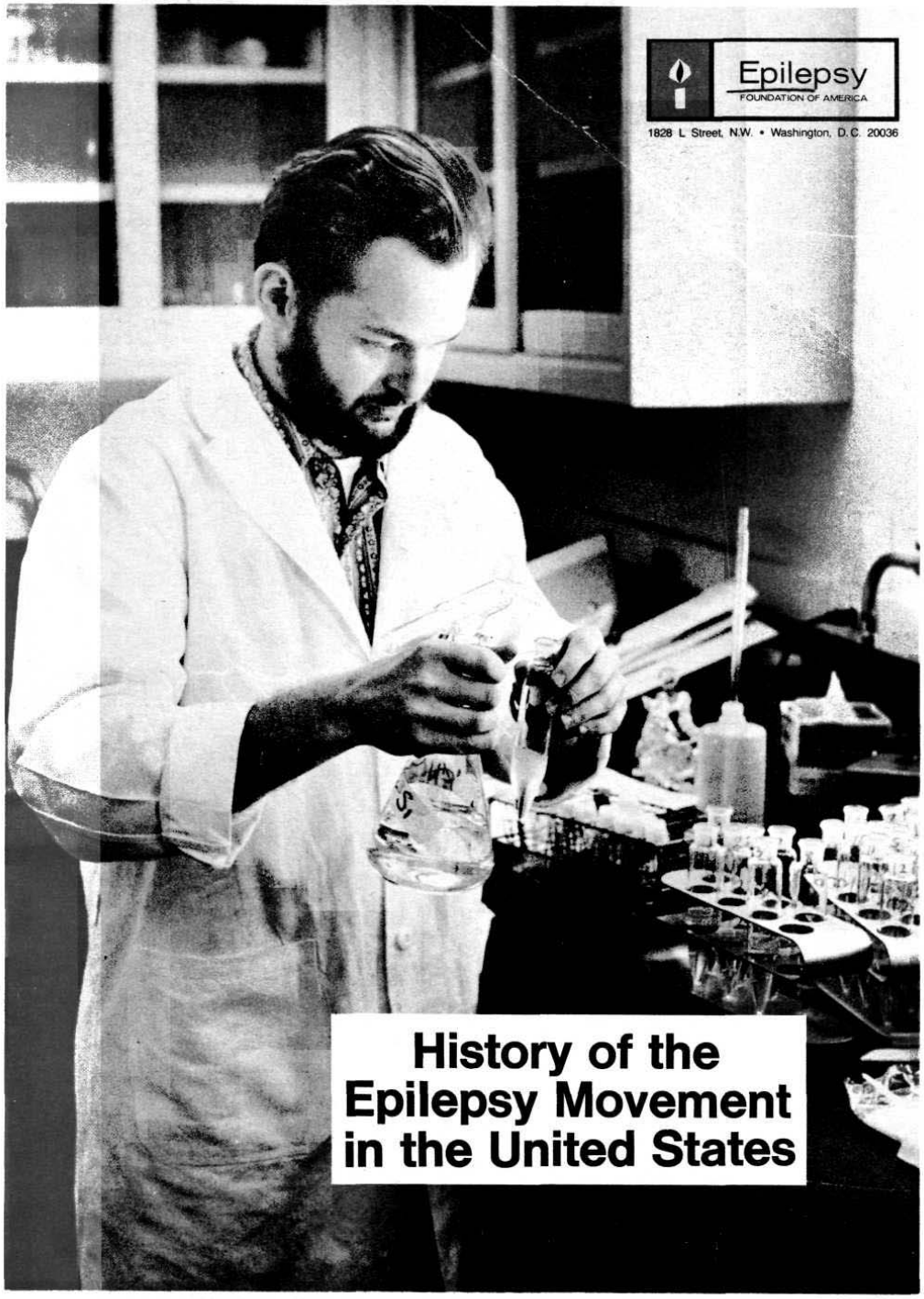

Epilepsy
FOUNDATION OF AMERICA

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History of the Epilepsy Movement in the United States

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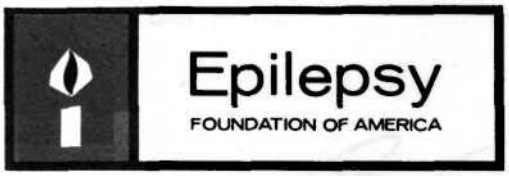

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Introduction

It is appropriate that the History of the Epilepsy Movement in the United States first appeared in 1973, as a series in *National Spokesman,* the monthly publication of the Epilepsy Foundation of America, for 1973 marked the 75th Anniversary of the epilepsy movement in America, and the fifth anniversary of this Foundation.

Many groups of dedicated individuals and organizations devoted countless months and years to the fight against epilepsy and the formation of the present national organization. Difficulties were met and overcome because these loyal volunteers, while defending their own convictions, did so with the recognition and mutual respect of other individuals and groups struggling for the same cause.

The Epilepsy Foundation of America has experienced substantial growth since its formation and is meeting its obligations as never before in serving the nation's 4 million citizens with epilepsy. Their needs, however, continue to outstrip our resources and physical capabilities.

As you will see in the last chapter of this History, much remains to be done. Many old and new goals have yet to be reached. But with continued support and unselfish devotion to our cause, we will meet the challenge.

A. B. Baker, M.D., Ph.D.
CHAIRMAN OF THE BOARD
EPILEPSY FOUNDATION OF AMERICA

Paul D. Holland, Esq.
PRESIDENT
EPILEPSY FOUNDATION OF AMERICA

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Chapter I
Early Instances of Epilepsy (1773-1846)

Epilepsy has run like a thread through American life since the birth of the nation and before. It was regarded by most, as writer Harry Best puts it, "... with wonder, disquietude and dread."

In the early days of our nation it affected the lives of the first "First Family." It even dwelt in the White House as a constant companion to an American First Lady a hundred years later. And it perhaps stayed forever the golden pen of America's most gifted humorist.

Patsy Custis Jean Clemens

Patsy Custis

George Washington's step-daughter, Martha Parke Custis, was an epilepsy victim. A dark-haired, pretty little girl, she was described as a "delicate child."

When Patsy, as she was called, was 12, she suffered an epileptic seizure. The physician who was summoned spent the night at Mount Vernon and in the morning the child seemed well again.

The seizures returned, though, and Martha Washington took her daughter to the best specialists of the day.

But physicians could offer little in the 18th Century. One prescribed an "iron ring" to prevent seizures; another, some "fit drops." A third suggested a visit to Warm Springs in West Virginia, a favorite retreat for ailing members of the Washington family.

In spite of her illness, Patsy was fortunate in that those who loved her encouraged her to live an active life, and there were many young people's parties held at Mount Vernon.

Disapproving doctors of the day frowned on this indulgence; one wrote to Martha to urge regular, moderate exercise for Patsy and a diet including barley water and a kind of weak porridge.

Martha Washington's worst fears were realized in the spring of 1773. The grieving George Washington wrote in his diary: "About five o'clock poor Patsy Custis died suddenly." She was only sixteen.

Mrs. William McKinley

Just a hundred years later, another prominent family struggled with the problem of epilepsy. At the age of 28, Mrs. William McKinley, whose husband was to be the 25th president of the U.S., began to have seizures. And though never publicly acknowledged, it was soon discovered that Mrs. McKinley was a victim of epilepsy.

Nevertheless, she proved an inspirational figure for her friends and husband, who was now climbing the political ladder. She traveled with him extensively, and took great pains to always be at his side.

Mrs. McKinley was 53 when she became First Lady, and had suffered from epilepsy for 25 years. Her seizures were so frequent and severe that she was confined at most times to a wheelchair. Yet she carried on the duties of a presidential wife.

During dinners, and other functions, over many of which she presided, President McKinley kept a handkerchief at the ready in case his wife, seated to his left, should have a seizure.

In that case he would carefully place it across her face and explain to guests that she had suffered another "fainting spell."

In September, 1901, President McKinley fell to the bullet of assassin Leon Czolgosz.

Legend has it that his first words, upon being mortally wounded, were, "My wife, be careful how you tell her, oh, be careful!"

Jean Clemens

On Christmas night in 1909, Samuel L. Clemens (Mark Twain), despondent, grieving, and ill, turned to his close friend and biographer, Albert Bigelow Paine, and said, "I shall never write anymore." The reason was epilepsy, which had caused the death of his beloved daughter Jean.

As early as 1899, Twain, having found no relief for Jean in America, took her to Europe. There, he and his daughter journeyed to Sanna, Sweden, and Dr. Heinrich Kellegren's clinic.

Twain had great faith in Dr. Kellegren, and hoped "that osteopathic treatment would avail where others have failed."

Jean had been in a sanitorium from 1907 to 1909, but was at the New York dock to greet her father when he returned from a Bermuda trip on December 20, 1909.

Since returning home, Jean had busied herself with the duties of housekeeping, managing their small farm in Elmira, N.Y., and acting as her father's secretary.

"If I wished to show a student the difficulties of getting a truth from medical experience, I would give him the history of epilepsy to read."

Oliver Wendell Holmes

Twain thought he could see signs of improvement in her overall health after her sanitorium stay.

Four days later, Jean was dead, having apparently suffered a seizure while bathing in a cold tub.

Twain felt too ill to attend the funeral and, one biographer wrote, on Christmas night, 1909, he "considered his autobiography, and his career finished."

These three women were, in a sense, symbolic of the medical inadequacies of the time, yet they were all active people whose families involved them in the world and society. Not all were so lucky.

It was common to shut people with epilepsy away — in private homes, and too often, in mental institutions and insane asylums.

Yet the 19th Century saw the beginning of a new concern as well as a new concept of care which would dominate this country for half a century. It was the rise of the "colony," begun first in Europe in 1846, and extended to this country when the first U.S. institution for epilepsy patients was opened in Baldwinsville, Mass., in 1882.

Chapter II
First Efforts at Treatment (1857-1914)

Treatment with Bromides

In May 1857, at a meeting in London of the Royal Medical and Chirurgical Society, Sir Charles Locock first reported the use of a bromide formula in treating an epileptic woman.

Bromides were to remain the standard medication for epilepsy for more than 50 years, despite many reports of unpleasant side effects.

All in all, the 1850's saw a bewildering variety of treatments for epilepsy. Some physicians recommended cauterization of the limbs or skull, tracheotomies and even amputation of various limbs.

They were all, of course, groping for the still elusive "cure" and some, in particular a certain Scottish doctor named John Hughlings Jackson, believed that an understanding of the cause was the starting point from which to begin to seek a cure.

Dr. Hughlings Jackson, a pioneer in modern thinking about this ancient disorder, was a mild mannered philosopher, his education only fair, who was subject every so often to attacks of vertigo.

Born in 1835, he married a cousin who was a writer and a victim of epileptic seizures. Historians feel that his wife's condition, as well as his own severe spells of dizziness, led to his interest in epilepsy.

Through clinical studies, Jackson arrived at a definition of epilepsy which, in many ways, differs little from those proposed today. Jackson wrote, "Epilepsy is the name for occasional, sudden, excessive, rapid and local discharges of the gray matter."

At the same time two German physiologists — G. Fritsch and E. Hitzig — were assembling the data to support it in laboratory experiments. They identified the brain's motor cortex and produced unilateral focal motor seizures through electrical shock.

The pace of research quickened as, at approximately the same time, in Germany, a certain type of lesion involving a portion of the brain's temporal lobe was identified as a cause of epilepsy. Thus, various disciplines in various nations merged toward a common idea that seizures originate from an identifiable, localized area of the brain.

By the end of the century, Dr. Jackson had also described a form of seizure that still bears his name, Jacksonian Epilepsy, and had identified a link between lesions in a portion of the temporal lobe and a complex "dreamy state" epilepsy.

The First Colonies

The nineteenth century saw the opening of a number of colonies and residential institutions for people with epilepsy, many of them supported by the state.

Europe was the leader in establishing these

colonies. A home was founded in Bordeaux, France in 1846, and the Bethel Colony was established in Germany in 1867.

In 1868, an "asylum for epileptics" was proposed in Gallipolis, Ohio. Some 23 years after the idea was suggested the Ohio legislature finally established the nation's first public institution for those with epilepsy. It was named so there would be no mistake about its purpose: it was the Ohio Asylum for the Epileptic and Epileptic Insane.

Nine years earlier, in 1882, the first American institution of any kind for those with epilepsy had been opened. A private home, it was situated in Baldwinsville, Massachusetts.

In 1892, a year after the Ohio Asylum was founded, the New York legislature set up the Craig Colony, near Sonyea, New York, in Livingston County.

Monson State Hospital, near Palmer, Mass., followed in 1895. In 1896, Oakburne Hospital near Philadelphia, Pa., was created through a merger of St. Clements Hospital for Epileptics and the Pennsylvania Epileptic Hospital.

Skillman, N.J., was the site of the next facility for those with epilepsy. The State Village for Epileptics, later known as the Skillman Colony, was begun there in 1898. All in all, some thirteen colonies were established.

The First Voluntary

Something else happened in these closing years of the 19th century. In 1898 a spark was struck in New York which eventually grew into the flame we know as the American epilepsy movement.

It began inconspicuously enough, when an attorney and a physician called a public meeting of those interested in epilepsy in New York City.

Dr. Frederick Peterson and William Pryor Letchworth were gratified to find some 75 people waiting when they entered the New York City Medical Library on May 24, 1898.

Before the meeting ended they had organized the National Association for the Study of Epilepsy and the Care and Treatment of the Epileptic, the first voluntary society for epilepsy.

Mr. Letchworth was elected president of the new organization, and in that capacity visited most of the camps and colonies for epilepsy patients in America and Europe.

The group was active for a time, holding its first scientific sessions in Washington, D.C., on May 14 and 15, 1901. At the meetings, reports were given on the public care of epilepsy victims in the United States and abroad.

The association boasted as many as 270 members at one time, most of them medical men. Dr. William G. Lennox was from the first the driving force behind the group.

A Philosophy of Retreat

Meanwhile, more colonies and hospitals for those with epilepsy were opened, including, in 1905, the Indiana Village for Epileptics at New Castle, Ind.

Now known as the New Castle State Hospital, it is the last surviving trace of the colony system in America.

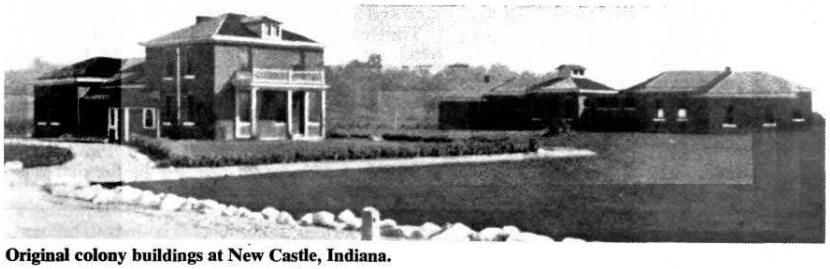
Just what did the colonies do? They showed the concern of society for the person with epilepsy and recognized that special facilities were necessary for their care. The aim, moreover, was to allow patients to live a relatively normal life, produce some sort of goods, and at the same time contribute materially to the colony's support.

It was hoped that patients would get a better brand of therapy doing healthy work on the farm, under carefully supervised medical care, shielded from the prying eyes and mocking laughter of strangers.

The late Carroll Lunt, founder and former president of the California Epilepsy Society, in his book, *How to Live With Epilepsy* (Twayne Publishers, New York City, 1961), described the now defunct Craig Colony at Sonyea, New York, as the "most extensive" in the United States.

Craig boasted 1,900 acres of fields, orchards and "market gardens," along with 30 buildings that included residences, barns and a variety of shops. In addition, wrote Lunt, there were stone quarries, brick-clay deposits and stands of timber on the grounds.

Efforts were made to establish a similar one in California, but that dream was never realized, partly due to a shortage of funds. Lunt wrote that the California group had envisioned a "self-supporting, 50-acre, produce-growing section for young epileptic men, plus a 500-acre, coeducational colony for 600 eligible epileptics.



Original colony buildings at New Castle, Indiana.

"This would have given to many . . . work and recreation and a purpose for living," he wrote.

Yet, idyllic as it sounds, the colony concept was essentially a retreat from the world, better by far than the "snake pits" of mental institutions, but offering no real hope of patient progress or restoration to society.

In short, they were very different from the modern multi-disciplinary treatment center to which patients in several European countries are now referred for temporary stay, diagnostic testing, therapy, and even, in some cases, job training. Today the goal of such institutions is a hopeful one: improvement in the medical condition and return to society.

End of the Beginning

The year 1914 was not a happy one for a world on the brink of war—nor was it auspicious for the young epilepsy movement. What turned out to be the last meeting for the National Association for the Study of Epilepsy and the Care and Treatment of the Epileptic was held in the spring of that year. The rigors of wartime, combined with low morale, finally scattered its members.

Why did it fail? The best answer perhaps is that, while it had expertise and guidance from the medical community in abundance, it represented few businessmen or other segments of society. Its support was not sufficiently broad-based to provide adequate funds.

These were mistakes that leaders of its successor tried to avoid.

The 1920's were America's Jazz Age and the 1930's saw the nation plunged into the depths of depression and then catapulted headlong into the Second World War.

But for epilepsy patients the two decades brought a startling parade of progress and discovery. Achievements in anticonvulsant therapy and the slow development of social understanding gave the person with epilepsy greater seizure control and enabled him to lead a more normal life.

Chapter III
The "Miracle" Drugs (1920-1941)

Phenobarbital

The first report of the anticonvulsant properties of phenobarbital reached America in 1920. It became a basic tool in controlling seizures.

Nine years later, American scientists first learned of the work of Dr. Johannes (Hans) Berger, a German physiologist and psychiatrist who had published a paper dealing with the variations of electrical current recorded through the closed skull.

The German scientist — whose discoveries were taken up in the U.S. much more rapidly than in his homeland — had performed experiments with the forerunner of what we know today as the electroencephalograph (EEG), or brain wave machine. He had demonstrated the brain's electrical discharges by placing electrodes on the scalps of patients and recording the electrical activity on moving strips of paper.

Dr. Berger's work won him the accolade "the father of electroencephalography" — but he did not live to see it.

An early victim of the Second World War, he committed suicide in Germany on June 1,1941, at the age of 68. Friends said he was deeply depressed at the advance of the Nazis, who were destroying everything in their path.

His work, however, lived on. The relationship between epilepsy and the brain's electrical activity was studied painstakingly here in the United States.

Among the most noted EEG experimenters in the United States were Dr. and Mrs. Frederic A. Gibbs, and Albert M. Grass, along with Dr. William G. Lennox.

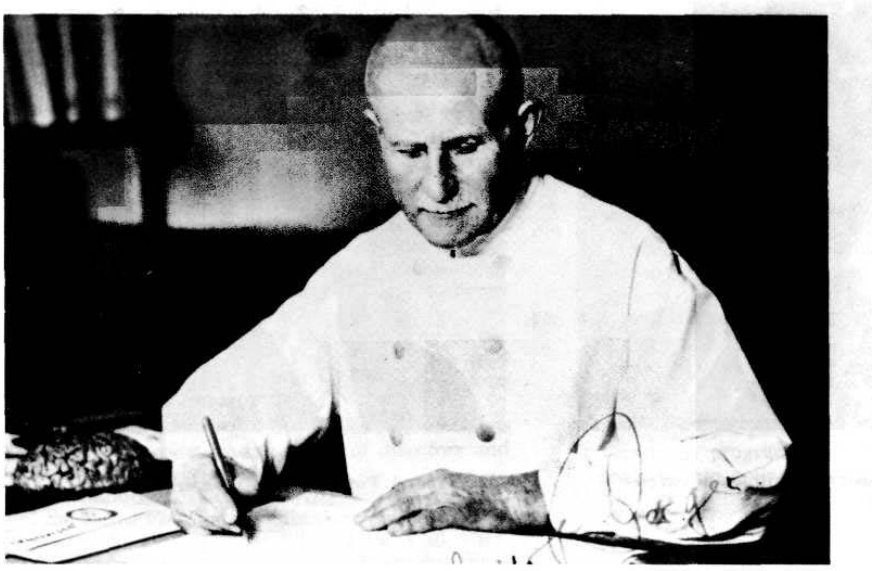
As the Gibbses, Albert Grass and Dr. Lennox carried out their experimentation with rudimentary EEG facilities in Massachusetts, there was another development in the rolling countryside north of Baltimore, Maryland. Although it attracted little attention at the time, it would later have a profound effect on the goals of the movement.

In 1933, Henry L. Bowditch, M.D., organized the Bowditch School in Ruxton, Maryland. A suburb of Baltimore now, Ruxton was green farmland and horse country in the early 1930's.

The school was an organization formed by a handful of interested citizens, searching for ways to help the epileptic child lead a normal life.

Mrs. Bowditch once said, "It was in the early 1930's that my husband first became interested in epilepsy. The field was then practically untouched. Dr. Bowditch often said in those early years that he wanted to clear up the fog that was 'besmirching epilepsy.' "

We shall see how, years later, Dr. Bowditch's school grew from its humble beginnings to become the National Children's Rehabilitation Center,



National Library of Medicine

Dr. Hans Berger, "father of electroencephalography"

which today serves emotionally disturbed children with epilepsy.

Meanwhile, the International League Against Epilepsy, which had fallen victim to the First World War, was reorganized at the 1935 Congress of Neurologists meeting at Lingfield Colony near London. Thirty-two physicians, representing 14 nations, revived the group on July 31, 1935, electing Dr. Lennox president.

Dilantin

Now the year was 1937 and the night lamps burned brightly and late in the laboratories of Boston City Hospital.

Tracy Jackson Putnam, M.D., a Bostonian who headed Harvard's neurological service at the hospital, was working hard on a "hunch" that would make history. Dr. Putnam felt that a chemical preparation with a certain formulation would have anticonvulsant values.

At the same time, a South Carolinian physician named Hiram Houston Merritt worked painstakingly along the same path. Since barbiturates had proved successful in controlling seizures, but often over-sedated the patient, Dr. Merritt reasoned that what he needed was a barbiturate that didn't sedate — in other words, a barbiturate "failure." He asked the Parke Davis Co. to give him preparations which their laboratories had rejected from their own research into better sedatives. And, sure enough, he found one that worked.

Doctors Merritt and Putnam both discovered that a barbiturate formulation with the chemical name of sodium diphenlhydantoin was the most effective anti-seizure drug producing the fewest side-effects and the least sedation.

They reported their findings to the American Neurological Association in 1937, and in 1938 presented the results of testing with actual patients to the American Medical Association.

Their discovery is known as Dilantin, still the most commonly used anticonvulsant drug.

Thus, in a span of less than 20 years, the epilepsy movement had been spurred by the first U.S. use of phenobarbital, the beginnings of electroencephalography to aid diagnosis, and the discovery of Dilantin.

Small wonder then, that laymen began to take new hope, to feel the need to communicate with one another about mutual problems and experiences, and to feel that strength lay in cooperation. After centuries of neglect, rejection and hopelessness, something positive could now be done to aid the epilepsy patient, and restore him to the possibility of a normal life.

With the aid of such interested parties as Dr. Lennox and Mrs. Eleanor Roosevelt, who served as a director, the Laymen's League Against Epilepsy was born in Boston in 1939. Mrs. Francis Riggs was the first president. By 1941, the League had 700 members in 43 states and Canada. And in the same year, the educational bulletins of the Laymen's League were gathered into a book, *Science and Seizures,* by Dr. Lennox (Harper & Bros., New York), who stipulated that all royalties from its sale were to go to the League.

The future looked bright. There was what appeared to be national interest on the lay level at last.

No one could have predicted the arduous road which waited ahead.

Dr. H. Houston Merritt, co-discoverer of Dilantin

National Library of Medicine

Dr. Tracy J. Putnam, co-discoverer of Dilantin

Chapter IV
Impetus During World War II (1943-1945)

Where was the epilepsy movement going in the 1940's? It had already survived World War I and the Great Depression—but would mankind's worst war stop it cold?

The answer was an emphatic "no," because during the 1940's and through the 1950's the movement only gained impetus. By 1960, several semi-national organizations had been formed which would become the Epilepsy Foundation of America.

The Laymen's League Against Epilepsy, sparked by the indefatigable William Lennox, M.D., grew in the early 1940's under the presidency of Mrs. Francis Riggs. In 1943, the league's budget was $1,300—a good sized sum in pre-inflation days.

The next year, 1944, the name of the organization was changed to the American Epilepsy League to better reflect what was hoped would evolve into a group that would be national in scope. Mrs. Brooks Potter succeeded Mrs. Riggs as president in the same year.

Meanwhile, a New York physician, Jerry C. Price, who had been a patient in Boston, helped

Franklin D. Roosevelt Library (Harris and Ewing)

Eleanor Roosevelt, director, Laymen's League Against Epilepsy

to organize a branch of the league in New York City.

He was joined by Tracy J. Putnam, M.D., the co-discoverer of Dilantin, at the New York Neurological Institute and, together, they succeeded in forming a vigorous anti-epilepsy group.

NACE Organized

But, the New York branch objected to paying a part of its income to the parent organization in Boston, and so Drs. Putnam and Price founded the National Association to Control Epilepsy (NACE).

NACE was chartered by the University of the State of New York in 1944. Its president was Fred Markham, of California, and Dr. Price served as vice president.

H. Houston Merritt, M.D., joined his colleagues in NACE, serving on the board of directors and the medical advisory board.

An important NACE activity was sponsorship of the Baird Foundation Clinic, an epilepsy clinic situated on East 93rd Street in New York City. Dr. Price directed the clinic. A staff member there was Harry Sands, Ph.D., a practicing psychologist who currently serves as director of program planning and evaluation for EFA. Dr. Sands also would serve as director of the Committee for Public Understanding of Epilepsy, and director of United Epilepsy Association in New York City.

As the National Association to Control Epilepsy was getting organized and under way, the Epilepsy Association of New York was founded in 1945 with little fanfare. It would play an important role later.

At about this time too, an article about Mrs. Potter, president of the Boston-based league, appeared in a national magazine. It precipitated such a flood of mail that it was deemed wise for the league to undertake a much larger program.

Survey Commissioned

Accordingly, a New York City public relations firm was paid $3,500 to survey the league's status, possibilities, and make recommendations. The firm advised that a national program be launched, with a yearly administrative budget of $50,000, and projects to cost over $200,000. The "kickoff" for this plan was to come in the form of a $3,000 donation from each director of the league.

The seeming hopelessness of finding this sort of cash—and enough people willing to contribute —led to discouragement among members of the league. And when Mrs. Potter resigned as president in 1946, headquarters were shifted to Chicago, Ill.

With new offices in Chicago came a new president: Mrs. Ruth McCormick Miller, the granddaughter of famed GOP chieftain Mark Hanna, and the niece of Bertie McCormick, owner of the influential *Chicago Tribune.*

Although former league supporters in Boston organized a New England Branch, the territory they attempted to cover was just too large, and the branch closed within less than two years.

At the same time, the nation had discovered with alarm that World War II was sending back to the United States a steady stream of wounded and injured veterans—men with head trauma who were developing convulsive disorders, most often epilepsy.

Veteran's Center Established

Realizing the need for action, the Veterans Administration developed the National Veterans Epilepsy Center, first at Cushing VA Hospital in Framingham, Mass., and later at Boston. Jerome K. Merlis, M.D., was named to oversee the project.

The VA first set up laboratories for research into head injury, and then established wards where selected patients were treated. As the need —and the program—grew, various VA research projects into epilepsy were organized throughout the U.S.

Chapter V
Epilepsy and the Government (1949-1952)

In 1948, three years after the hearings in Washington, Mr. and Mrs. Fred Markham persuaded leaders of the National Society for Crippled Children and Adults (Easter Seal Society) to make epilepsy and cerebral palsy main causes.

The Society agreed, but it was stipulated that the American Epilepsy League (AEL) and the National Association to Control Epilepsy (NACE) must first disband and form a new united group.

NEL Formed in Chicago

This was done, and in 1949, the National Epilepsy League (NEL) was born. The old AEL charter, granted in Boston, was used to incorporate NEL, which set up headquarters in Chicago. It remains there today.

But other requirements set by the Easter Sea group could not be met, and cerebral palsy was taken over by a distinct group bearing that name

The National Society for Crippled Children and Adults to this day maintains epilepsy-aid programs in many areas of the nation. While epilepsy is not their main interest, a few chapters retain a particular interest in programs for epileptic children.

New Efforts in Congress

In the spring of 1945, after years of inactivity, there were stirrings on Capitol Hill which indicated the U.S. Congress was at last going to take a look—no matter how cursory—at epilepsy.

The Subcommittee on Aid to the Physically Handicapped of the Committee on Labor was holding lengthy hearings on a House of Representatives resolution in the 79th Congress.

The resolution authorized the full committee "to conduct an investigation of the extent and character of aid now given by the federal, state, and local governments and private agencies to the physically handicapped . . ."

Epilepsy was Part 11 of the hearings, held May 24 and 25, 1945, and Dr. William Lennox, in his unceasing battle on behalf of those with epilepsy, was present to offer eloquent testimony. Some of his words still apply today:

"Of all the handicaps which you and your committee are studying, epilepsy without doubt is the least understood by both the medical and general public and is the most neglected. Like the lepers of ancient times, epileptics still 'dwell without the city' of public understanding and philanthropy."

After noting the paucity of funds available for epilepsy research—both public and private—he proceeded to unfold for the panel an ambitious plan for the care of epilepsy patients.

Here is what Dr. Lennox proposed in May of 1945:

(1) A grants-in-aid program.

(2) A national institute for neuropsychiatric research, with epilepsy sharing in the programs.

(3) Diagnostic, treatment, and training centers.

Dr. Lennox Calls for Centers

These centers were denned in terms of function and form:

"First, a diagnostic clinic where patients from near and far would come for a complete examination and recommendations for continued treatment by their local physicians—a sort of epilepsy Mayo Clinic.

"Second, a hospital would provide bed care for perhaps 20 or 30 patients who required more extended examination or treatment. . .

"Third, laboratories for examinations and studies, equipped with apparatus, such as the electroencephalographs (EEGs), especially used in studies of epilepsy. Workers in the laboratories would be of a quality to qualify for grants-in-aid . . .

"Fourth, a training center for doctors, nurses, social workers, and research students interested in the problems of epilepsy.

"Fifth, the headquarters of lay organizations concerned with the education of the public and with social aids for the epileptic."

So, perhaps coincidentally, but more likely with an eye toward the successful facilities he had seen in pre-World War II days in Europe, Dr. Lennox had passed on a blueprint for an Epilepsy Center, or "Center of Excellence." It would be years before that idea gained prominence in this nation again. And still more before they are built.

Key Witnesses Testify

Michael J. Shortley, director of the U.S. Office of Vocational Rehabilitation, and Wilfred B. Johnston, a private safety consultant and instructor in safety engineering at Northeastern University, Boston, testified next.

The fourth witness that spring day in 1945 was an eloquent one. Frank D. Ashburn, headmaster of Brooks School, North Andover, Mass. He settled into a chair facing the panel and began speaking:

"Epilepsy throws a shadow on the soul. It marks a child as a strange being, and it shuts on him the doors and windows of life."

Pausing to let these words find their mark, Headmaster Ashburn continued:

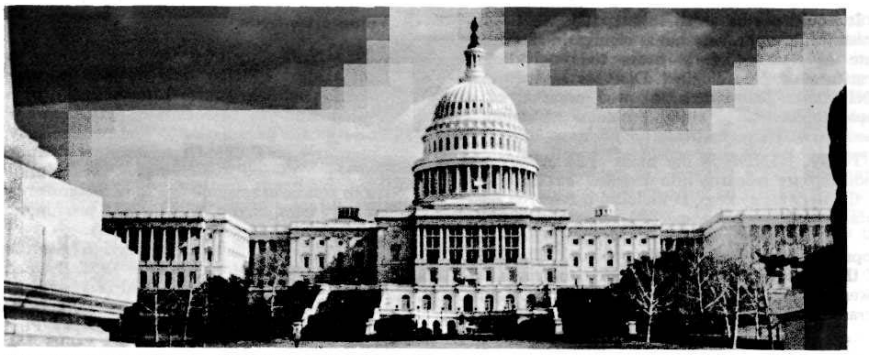
"It is a sad but true fact that the danger of ignorance is greater in almost exact proportions to the lack of general education. That is why the matter (epilepsy) concerns not only every school, but also every labor union, every industry, every person with human instincts in the United States."

The congressmen heard, too, from Dr. A. L. Van Horn, director of health services of the children's bureau. He reminded them that a national commission had recommended the appropriation of more federal funds to be spent for children with conditions such as epilepsy.

Dr. Jerry Price appeared to describe a four-point program which had been proposed for the care of epilepsy patients at Tiffin State Institute, Ohio. Plans called for education, vocational training, research and diagnosis.

The congressmen listened attentively—and that was all. There was, despite heroic individual efforts and personal pleas, no congressional action on epilepsy.

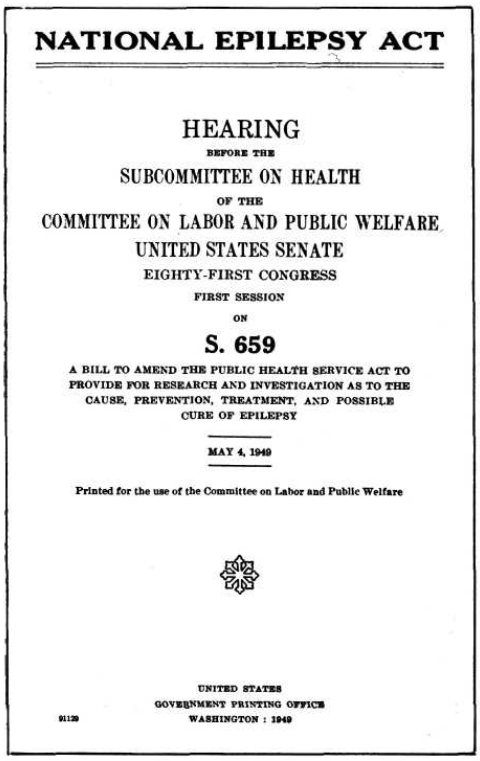
Had a united national movement existed then, the story might have been different. Subsequently, leaders in the vanguard of the epilepsy movement intensified their efforts to find allies and support among related causes.



The congressmen listened attentively—and that was all.

Epilepsy Act Introduced

In 1949 Dr. Lennox returned to Capitol Hill. And stakes were higher than they had ever been for those affected by or concerned with epilepsy, for the Senate Subcommittee on Health, a unit of the Committee on Labor and Public Welfare, was considering the National Epilepsy Act.



NATIONAL EPILEPSY ACT

HEARING
BEFORE THE
SUBCOMMITTEE ON HEALTH
OF THE
COMMITTEE ON LABOR AND PUBLIC WELFARE
UNITED STATES SENATE
EIGHTY-FIRST CONGRESS
FIRST SESSION
ON
S. 659
A BILL TO AMEND THE PUBLIC HEALTH SERVICE ACT TO PROVIDE FOR RESEARCH AND INVESTIGATION AS TO THE CAUSE, PREVENTION, TREATMENT, AND POSSIBLE CURE OF EPILEPSY
MAY 4, 1949
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The National Epilepsy Act proposed a broad variety of programs, including training of workers and postdoctoral fellows in epilepsy; coordination of many epilepsy-related activities, including research and education; establishment of a federal epilepsy information center; construction of facilities for research and admission of voluntary patients for treatment; and awarding of grants-in-aid.

In addition, the act proposed establishment of a National Epilepsy Council, consisting of governmental and private experts, including at least one person with epilepsy.

Strong opposition to a facility or agency devoted solely to epilepsy already had come from two men in government, J. Donald Kingsley, acting administrator of the Federal Security Agency; and F. J. Lawton, assistant director of the Bureau of the Budget.

Dr. Lennox urged "that epilepsy should not be squeezed out by being given a definite allotment."

"Epilepsy," he asserted, "is not obvious. It has been neglected. It needs a place in the sun."

The doctor again had put his finger on the pulse of the problem. But the senators would not, in turn, put their votes there, and so the National Epilepsy Act went the way of other epilepsy proposals.

Neurological Institute Founded

What Congress *did* do—in response to the clamor and demands of several voluntary national health groups—was to establish the National Institute of Neurological Diseases and Blindness (NINDB) in 1950.

President Harry S. Truman signed the bill—-Public Law 81-692—on Aug. 15, 1950, creating a single federal research institute to probe all of the neurologic, muscular and sensory diseases.

An arm of the National Institutes of Health, NINDB was situated in Bethesda, Md., just north of Washington, D.C.

It would not be until August, 1968, that Congress would approve a name change in the institute to that which it bears today—National Institute of Neurological Diseases and Stroke (NINDS). The switch followed creation of a separate facility to study problems of vision— the National Eye Institute.

Today, NINDS is the main U.S. agency responsible for research into diseases and disorders of the nervous system. It includes a research hospital which accepts some 500 volunteer patients for treatment and study. In addition, there are approximately 1,100 laboratory units. The bulk of the institute's budget is allotted to grants for research and training at medical centers and universities throughout the nation.

Chapter VI
First Steps Toward Unity (1953-1958)

Members of the American epilepsy movement had good reason to cheer in 1950 when President Truman signed into law the bill creating what would eventually become the National Institute of Neurological Diseases and Stroke (NINDS).

Yet it was a year that would be marked with sadness, too, for in October, Dr. Jerry C. Price, one of the most tireless workers for the cause of epilepsy, died.

As director of the Baird Foundation Clinic in New York City, Dr. Price had initiated what was then a revolutionary program of care for the epilepsy patient, combining medical, social, psychological, and psychiatric services in approximately equal proportions.

Each patient completed the circuit of services before plans for his treatment were drawn, and the treatment covered all aspects of the patient's life.

Although the voluntary movement was growing in 1952, there were setbacks. For example, that year a wealthy patient offered $100,000 to be used by a New York group called "The Committee for Public Understanding of Epilepsy." But the plans never got translated into action.

Five years later, Dr. Lennox would caustically tell an epilepsy workshop in New York City that it had cost $5,000 and a year of precious time to have a public relations firm submit a program for using the money. By that time, he said, "the donor and the bulk of the funds went out the window."

Voluntaries Grow

New York City now had three groups in the fight against epilepsy, and in 1953-54, they decided to pool their efforts. Merged under the name United Epilepsy Association (UEA) were the Variety Club Foundation to Combat Epilepsy, the Committee for Public Understanding of Epilepsy, and the Epilepsy Association of New York. The major source of revenue was to be a commerce and industry campaign. Carl Marks, a prominent foreign securities broker, headed UEA.

The epilepsy movement seemed to be gathering steam as never before when, in 1954, the Federal Association for Epilepsy was incorporated in Arlington, Va. This was the organization which would become known as The Epilepsy Foundation (TEF).

The founders included Mrs. Marvin T. Broyhill, an Arlington realtor and socialite, and the mother of U.S. Rep. Joel T. Broyhill (Virginia); and Harold Babbitt, an Arlington businessman who now serves on EFA's board of directors.

Including the National Epilepsy League in Chicago, in 1955 the nation had three epilepsy-interest organizations. Their members recognized even then the potential for national strength through unity—but that goal was still in the future.

The Search for Unity Begins

However, key discussions in 1955 between Mrs. Fred Markham and Madison Thomas, M.D., served as another spur to the movement's search for accord.

The occasion for their meeting was a program planning session for the Western Institute on Epilepsy, of which Dr. Thomas served as secretary. But the conversation soon turned to the confusion created by the existence of three epilepsy organizations, each claiming to be national in scope.

Mrs. Markham asked Dr. Thomas to attempt to arrange a meeting of physicians to determine what might be done about the duplication of effort.

As a result of their conversation, a meeting was held in April, 1955, at the American Academy of Neurology sessions in Houston, Tex. Among those attending were Dr. A. B. Baker, now chairman of EFA; and Drs. Pearce Bailey, Francis Forster, John Otto, and Russell DeJong.

Each expressed concern, and Dr. DeJong, then president of the American League Against Epilepsy (afterwards renamed the American Epilepsy Society), named Dr. Thomas to head a committee which would study the problem. The panel recommended a survey to learn what lay organizations existed and their interest in a national meeting.

It was determined that the various groups desired such a meeting, and so the professional group passed a resolution recommending that the representatives of all known epilepsy organizations in the U.S., and their medical advisors, be invited to a workshop to explore mutual problems.

TEF Telethon

Meanwhile, TEF was working on a project to help severely handicapped children with epilepsy.

On Feb. 9, 1957, with the help of prominent residents, TEF began a 17-hour fund-raising "telerama," originating from Washington's Shore-ham Hotel. Washington businessmen Morris L. Kraft and Milton S. Kronheim served as co-general chairmen of the telethon, which was seen in Maryland, Virginia, West Virginia, and Washington.

When it was all over at 3:30 p.m. the next day, the appeal for funds had raised some $70,000.

With the money, TEF, spearheaded by Harold Babbitt, Washington attorney Thomas E. Jenks, and others, completed the purchase of a 211-acre estate along Rt. 7, a mile west of Leesburg, Va., which they planned to turn into a hospital-school for children with epilepsy. It had been owned first by W. C. Hibbs and, after his death, by his daughter, Mrs. Edgar Legg.

They took title to the property on behalf of TEF on July 30, 1957, and in September, 1957, moved into the former estate.

It is the site of the National Children's Rehabilitation Center (NCRC), for children between the ages of 7 and 18. The center is still the only one of its kind in the nation devoted entirely to the care and rehabilitation of children whose epilepsy is accompanied by severe emotional problems.

Mr. Jenks, Mr. Babbitt, and Mrs. Broyhill were all members of NCRC's first board of directors.

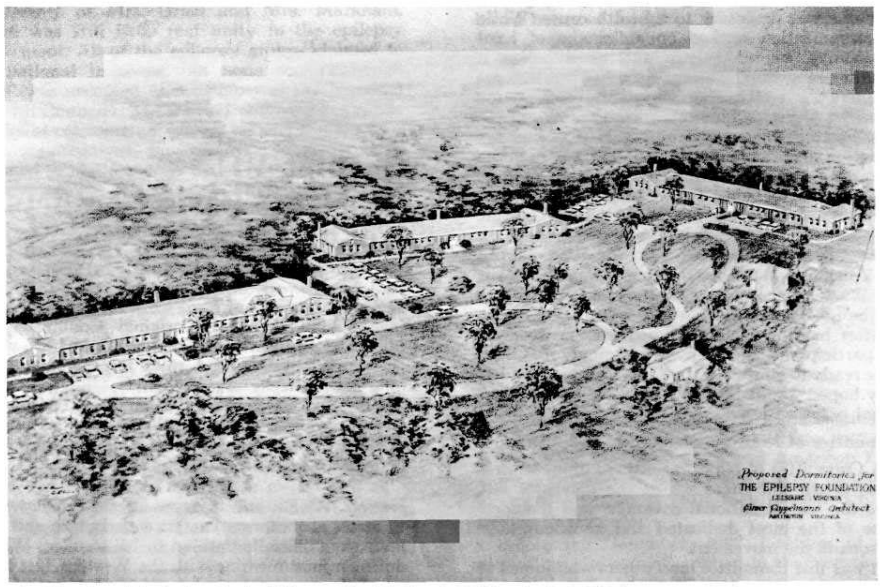
Dr. Henry L. Bowditch, who had been running a school for epileptic children in nearby Maryland, was named its educational director. Marvin C. Korengold, M.D., a consultant in neurology to the National Institutes of Health, was named to a similar post at NCRC. Dr. Korengold is today a member of EFA's professional advisory board. Also during the fifties, with the strong support and leadership of Mr. Babbitt, a mail solicitation campaign was designed, not only to aid the center, but to support other TEF activities. Today, EFA is still supported in large part by its mail fund raising campaign.

Federal Agencies and Philanthropies

By the summer of 1958, philanthropy had become a $6 billion business. However, the development of uniform Federal, state and local guidelines for philanthropic accounting standards, operating principles and reporting procedures had not kept pace with philanthropy growth. Many states, for example, had no legislation applicable to solicitations, giving restrictions and donations.

A Subcommittee of the House Committee on Government Operations held hearings on the subject to "determine whether government agencies concerned were performing their duties efficiently and effectively." Officers of the fledgling Federal Association for Epilepsy were asked to testify at the hearings and did so, extensively and with complete candor, for five days in July, 1958.

Major information about F.A.E.'s operations



Architect's original plan for buildings at the National Children's Rehabilitation Center in Leesburg, Va.

was provided by Mrs. Nellie M. Broyhill, president, and Harold Babbitt, V.P. Their testimony, along with that of others in the newly organized association, did much to inform the subcommittee about the complexities and basic difficulties faced by a small but dedicated group of volunteers in the national health picture.

It is entirely probable that the testimony of Mrs. Broyhill and others contributed greatly to the development of many of the guidelines that volunteer health organizations follow today.

First Epilepsy Organization Workshop

Just two months after TEF took possession of the Virginia center, the first national conference of epilepsy groups finally took place in New York. In December, 1957, the various independent groups which had been polled by the American League, Against Epilepsy gathered at the Shelton Towers Hotel on Lexington Avenue to discuss mutual problems.

Madison H. Thomas, M.D., today a member of EFA's national board, served as chairman of the meeting, formally known as the Epilepsy Organization Workshop.

William G. Lennox, M.D., spoke briefly on the last half-century of epilepsy progress, and the delegates—representing 26 of 39 independent organizations—split into groups to discuss fund raising, organizational concepts, educational programs, and "action" programs.

One guest was Dr. Gunnar Dybwad, executive director of the National Association for Retarded Children (NARC), who spelled out for the delegates how a national organization operated, and why one was necessary to a health cause. While his organization worked on a "maxim of local autonomy," he said, there was, nevertheless, a "dual membership" concept. In other words, local chapters belonged to state groups and state groups belonged to the national organization.

Admitting that at the outset NARC had set aside too little money for the national group, Dr. Dybwad pointed out that, "If you want to deal with the Advertising Council of America, you have got to be a national organization. If you want to get on a national network, you have got to work on that basis, and so on.

"You have got to have the proper representation (in Washington) so that matters concerning you can be taken care of."

After hearing reports from discussion leaders, the participants decided overwhelmingly that they were ready to start in motion the machinery which they hoped would lead to some kind of truly national organization.

Committee of Nine

A Committee of Nine was elected, representing those geographic areas which the delegates felt gave the widest national coverage, and included some of the most dedicated and knowledgeable persons in the movement.

It was this committee, and others who joined it along the way, which undertook a two-year "labor of love," as Dr. Thomas has described it, in an effort to hammer out the guidelines and by-laws for a national epilepsy organization.

Members included Frank Risch, Ph.D., project director, Epi-Hab Los Angeles, Inc., Los Angeles, Calif., chairman; Meade P. Brown, executive director, United Epilepsy Association (UEA), New York City, vice chairman; Mrs. T. C. Thoelecke, Illinois Epilepsy League, Chicago, secretary; Louis P. Simons, Epilepsy Information Center, Boston; Raymond D. Dennerll, executive director, Michigan Epilepsy Center, Detroit; Mrs. Eli Tash, president, Wisconsin Epilepsy League, Milwaukee; Mrs. Evelyn Gain, president, Greater Kansas City Epilepsy League, Kansas City, Mo.; Mrs. M. T. Broyhill, president, The Epilepsy Foundation (TEF), Washington, D. C; and Mrs. Ellen R. Grass, of Boston.

Chapter VII
Resolving Basic Conflicts (1959-1963)

With two years of hard work and many meetings behind them, the original Committee of Nine and those who had joined since 1957 were ready with by-laws and rules for the formation of a new epilepsy organization.

Led by the tireless Mrs. Ellen Grass of Quincy, Mass., who is today an EFA senior vice president, the fourth modern group in America's growing epilepsy movement was founded.

It was known as the American Epilepsy Federation (AEF), and it represented 23 affiliates in 11 states at its formation. Its constitution and bylaws were officially ratified in Milwaukee, Wisc, during a joint meeting with the Western Institute on Epilepsy, in September, 1959. Articles of Incorporation were filed in Nebraska.

AEF's Goal — Unity

The ultimate goal of this new organization was, Mrs. Grass said, "Unity of all societies now concerned in the common cause of epilepsy."

Mrs. Grass, the first AEF president, was later succeeded by Mrs. Fred Markham, who was later to be a senior vice president, and is now an honorary life director of EFA. At this point the head office of the new Federation was moved from Boston to Mrs. Markham's home in California.

Mrs. Markham also served as California Epilepsy Society president for two years, then vice president, secretary, and still serves as a board member.

She and her husband, the late Fred S. Markham, are widely recognized as generous philanthropists and vigorous leaders in the epilepsy movement.

Mr. Markham, who died in 1962 at the age of 76, was a charter member of the National Association to Control Epilepsy (NACE), and later was vice president of the National Epilepsy League (NEL).

In addition, Fred Markham was instrumental in forming the Jerry Price Seizure Clinic of Children's Hospital, Los Angeles; was a co-founder of the Western Institute on Epilepsy; a founding member of Epi-Hab Los Angeles and Epi-Hab U.S.A.; a former vice president of the California Epilepsy Society (CES); and a 10-year-member of the CES board of directors.

No Truly National Group

Although the American Epilepsy Federation grew, slowly but surely, behind the unwavering leadership of Mrs. Grass and Mrs. Markham, there was still little real unity in the epilepsy movement. All of the epilepsy groups claimed to be national in scope, but none was (although AEF was accepted as a member of the National Health Council). Merger and unity were common topics of conversation among members of the four key organizations, but the way to get it done seemed to elude everybody.

And, as time passed, some of the early crusaders in the movement passed, too.

Dr. Lennox, who wrote occasional items for the AEF publication "Epi-Vox," and who had donated all royalties from his monumental work, *Epilepsy and Related Disorders* (Little, Brown and Co., 1960) to the Federation, suffered a stroke in June, 1960, and died.

Carl Marks, the New York securities broker who had led the United Epilepsy Association, died in January, 1961.

Then in July, 1961, came what must be regarded as one of the major turning points of the movement. The American Epilepsy Federation requested the National Health Council's aid in unifying the epilepsy groups.

The Council agreed, and with what it termed an "unprecedented action" on its part, said it would form a committee for the task. The council also secured endorsement of the American Epilepsy Society, the nation's professional body, which agreed to join in the efforts.

. . . unwavering leadership

Mrs. Markham Mrs. Grass

Epilepsy Committee Named

The council named an epilepsy committee in the spring of 1962, with James H. Sterner, M.D., a member and former president of its board of directors, as chairman. Others on the committee included the chairman of the American Medical Association's Committee on Voluntary Health Agencies; a representative of the American Epilepsy Society; and three executives of national voluntary health agencies. Peter Meek, NHC executive director, served as staff member to the panel.

A consulting firm, Laurin Hyde Associates, was employed, after each of the four epilepsy groups agreed to donate $2,500 to support the work of the Committee.

Laurin Hyde reported its findings regarding the boards of the four major organizations this way:

American Epilepsy Federation (AEF) —The only major group requiring a portion of the membership of its board to be elected by a broadly based house of delegates. Members came from a wide geographic area.

National Epilepsy League (NEL)—Board members were drawn from the midwest and east, but most activities centered on Chicago.

The Epilepsy Foundation (TEF) and United Epilepsy Association (UEA) —Board members of these groups came primarily from the headquarters' cities of Washington, D.C., and New York City, respectively.

Each group had a medical or professional advisory board, and all made use of advisors from time to time. None met the criteria for NHC membership.

With Laurin Hyde's report in hand, the council scheduled a meeting of representatives of the four bodies for December, 1962.

First Sessions Held

The first sessions of the newly formed epilepsy committee had proved one thing to the co-sponsoring National Health Council and American Epilepsy Society — the deep desire among members for merger and unity. But they needed help in getting there.

Before the December, 1962, meetings of the committee, the council applied to the Vocational Rehabilitation Administration (now the Social and Rehabilitation Service) for a grant, in view of

the financial hardship which protracted negotiations might work on some of the participants.

The grant — for $13,940 — was approved by the late Mary E. Switzer, commissioner of the administration. (At the time of her death in 1971, Miss Switzer was a member of EFA's professional advisory board.)

When the meeting began, William Caveness, M.D., of the American Epilepsy Society, and NHC's Rome Betts were elected to preside.

Merger Discussed

Dr. Caveness' first action was to present a society resolution reiterating its strong desire for a single lay group in the epilepsy field and supporting NHC's activities in working toward this end.

Then the committee's representatives launched into discussions of (a) structure and membership; (b) finance; and (c) program.

Four hours later, there were still vital questions to be answered. One was whether a new, merged group should have a general membership. Another unresolved factor was the method of electing board members and officers.

Other questions revolved around special programs developed by individual groups. There was TEF's support of the National Children's Rehabilitation Center (NCRC), for example, and NEL's drugs-by-mail program. A fourth subcommittee was appointed at the end of the meeting to consider a name for the proposed organization and a headquarters site.

Six weeks later, in February, 1963, the committee met again — but this time UEA delegates were absent. The United Epilepsy Association had resolved in January that it felt the executives of each group should have a greater role in the committee's work. As it stood, they said, chief officers had been excluded from the decision-making process and from serving on subcommittees.

However, the four executives had been acting as advisors and, after the February meeting, they were asked to recommend ways of implementing decisions reached by the subcommittees.

The consternation caused by the absence of the UEA representatives led the committee members to dispatch two delegates to appear before UEA to explain what had been accomplished — and what problems remained.

Debt is Obstacle

For instance, one point of contention had been the debt incurred by NEL, totaling some $65,000. The epilepsy committee agreed that NEL should do all it could to liquidate the obligation but, failing this, the debt would be a matter for study by the merged group's board.

A month after the presentation of committee agreements to United Epilepsy Association, three UEA resolutions were received by National Health Council. They (1) empowered UEA's executive director to meet with other executives to explore the possibility of merger; (2) stipulated that the merged group be headquartered in New York City; and (3) suggested that a name for the new organization be studied.

The National Health Council, somewhat taken aback by this turn of events, commented, "Apparently the UEA board had not understood the scope of the presentation (on committee agreements) made to them, judging by the fact that they had not answered the major points."

TEF Board Opposes Merger

And there was more bad news. TEF's board of directors did not agree, and so stated.

But despite setbacks, efforts for unity went on.

At a March, 1963, meeting of the epilepsy committee, its members, undaunted, asked Laurin Hyde to come up with a "blueprint" for a strong, national voluntary organization.

The plan would then be submitted to the committee for approval and, after that, copies would be mailed to the board of each of the four epilepsy groups.

The proposal, which dealt with structure, the purposes of the new organization, and other basics, was approved and sent to board members on May 15,1963.

Dr. Sterner, chairman of the epilepsy committee, also wrote to the four presidents, urging favorable action from their boards of directors on the plan, and notifying them that such action would be construed by the committee as acceptance of the merger outline.

Now there was little to do but wait and hope.

Chapter VIII Action is Accelerated (1964-1967)

Hopes for a united epilepsy movement rose as steadily as the thermometer in the summer of 1963.

A merger proposal form was mailed to the four major organizations in mid-May, and the first approval from the Chicago-based National Epilepsy League (NEL) was returned in June. In August, the American Epilepsy Federation (AEF) said it agreed in principle.

With two approvals in hand, Dr. James Sterner, who was chairman of the National Health Council's epilepsy committee, met with

the president of United Epilepsy Association (UEA) in the fall. He thought UEA's executive committee, after it had been informed of the plan, reacted favorably enough to warrant calling the presidents of the League, the Federation and the Association together.

Initial Agreement

A November meeting found the presidents in agreement on several points, namely:

- A unified organization should begin with equal board representation from each group, or 14 persons from each association;
- Headquarters should be in New York City;
- The Epilepsy Association of America should be the new organization's name;
- There would be opportunity for staff members of the three merging organizations to remain on the staff of the new Epilepsy Association of America (staff nervousness about disappearing employment was an underlying, but significant factor in organizational resistance to merger);
- A professional advisory board would include all the members of the medical advisory committees of the other groups;
- There would be continuing efforts to bring the Washington-based The Epilepsy Foundation (TEF) into the organization.

The merger plan called for a membership and affiliation committee of six members who would recommend, within 18 months of merger, a definition and criteria for membership in the new group.

Basic Conflicts Again

Merger plans were sent to The Epilepsy Foundation in the spring of 1964, and a meeting was arranged for June. The gathering disclosed two basic conflicts between TEF and the three other agencies.

First, TEF had long been more successful than the others in raising funds, and it operated on a larger budget. It wanted representation on the new organization's board of directors to be determined by the assets of (or the revenues contributed by) each group, thus retaining an influence its officers believed to be more appropriate to its comparative size and level of operation. But the merger terms to which the others had agreed provided for equal representation.

And secondly, while the merger agreement stipulated election of board members by the general membership, TEF sought what the National Health Council called a "predominantly self-perpetuating board."

The meeting was adjourned and another scheduled in 60 days. By then, it was hoped, TEF could come up with suggestions acceptable to all.

Actually, TEF strongly favored merger, but believed it would be more realistic after the three smaller organizations were consolidated into an entity more nearly equal in size to TEF. Again, it seemed a question of relative influence and relative size.

Not knowing that TEF, despite an apparent skittishness, was truly on the side of the angels, the Council commented sharply, ". . . the merg-" ing organizations were losing their separate identities and thinking as a group. The Foundation, on the other hand, could see only its own structure, its own program, its own way of raising funds."

The first meeting of the new entity, the Epilepsy Association of America (EAA) was scheduled for December, 1964, the same month that Harold Babbitt of TEF called (unsuccessfully, as it turned out) on President Lyndon B. Johnson to appoint a Presidential Commission on Epilepsy.

But that first EAA gathering was delayed when the National Epilepsy League learned it would be the beneficiary of a large legacy and asked for a postponement. NEL felt the money would be enough to liquidate the debt which had long troubled the Health Council's epilepsy committee.

Epilepsy Association of America

Finally, a month behind schedule, the new agency's board met for the first time in New York City. It was January 7, 1965. The new Epilepsy Association of America had representatives in 21 states, and was headquartered at 11 W. 57th St.

John L. Gibbons, chairman of the trust committee of Chemical Bank New York Trust Co., was elected president; Mrs. Fred Markham was first vice president; and Howard Koven, second vice president. Mrs. Ellen Grass was named 'treasurer, and Mrs. Edward McSweeney, secretary. Henry Blanchard became executive director of the Association.

Many leading public figures praised the merger, including Dr. Howard A. Rusk and the late Sen. Robert F. Kennedy of New York, who urged TEF to join in the endeavor.

But it soon became obvious that organizing a unified attack on the stigma, prejudice and misunderstanding about epilepsy was as difficult with two major epilepsy agencies going separate ways as it had been with several.

There was no common research effort; it was difficult to develop meaningful educational, vocational, and social rehabilitation programs; and a single program to secure the needed funds was out of the question.

Something had to be done, and Paul E. Funk, (later to serve two terms as president of the unified organization, and now executive vice president and chief executive officer of EFA) knew it. He had been directing TEF strategies since 1964, as chairman of the organization's unity committee.

In June, 1965, at a National Information Month dinner in Washington, Mr. Funk told his audience bluntly that "the most immediately resultful action" to accelerate progress would be the organization of one strong lay voluntary national health agency for epilepsy.

With a combined attack, he said, "results would be greater, could be achieved faster, and would cost less."

His words had some effect, for in the winter of

1965-66 the boards of both EAA and TEF instructed their merger committees to speed up negotiations.

"Let's merge ... no matter what"

Chairman of EAA's merger committee was Henry Lewis III, later to be an EFA vice president. At their first meeting, he and Mr. Funk had agreed on basics. "Let's merge, no matter what—let the details come later. Let's take whatever action is necessary to convince our own organizations about the inevitability of the move," they said.

And there was progress on other fronts, too. Even as the new merger talks were getting under way, support was building in the U.S. House of Representatives for a bill (H.R. 2633) to change the blatantly discriminatory wording of the U.S. Immigration and Nationality Act.

This time it was U.S. Rep. James A. MacKay of Georgia who led the successful battle to eliminate what some newspapers were calling the last "stigma by statute." In the winter of 1966, President Johnson signed the amended Immigration and Nationality Act in a ceremony at the base of the Statue of Liberty.

The "Three Cities" Program Begins

Action accelerated elsewhere, too. The Epi-lepsy Foundation pushed ahead with an ambitious demonstration program to aid the hardcore jobless whose problems stemmed primarily from epilepsy.

The U.S. Department of Labor had contracted with TEF to administer three epilepsy rehabilitation centers in Atlanta, Chicago and San Antonio for two years. The program had the cooperation of the U.S. Employment Service, Vocational Re-

"Let's merge—no matter what. Let the details come later."

Henry Lewis III

Paul E. Funk

The measure was introduced by Rep. George P. Miller of California and co-sponsored in the Senate by Sen. Phillip A. Hart of Michigan. It received bipartisan backing, including support from Senators Jacob K. Javits and Kenneth R. Keating, both of New York, and Hubert H. Humphrey of Minnesota.

At that time, the immigration statutes barred from this nation "anyone who is found to be suffering from epilepsy." Federal doctors were supposed to examine all aliens at their point of entry, and "if the immigrant is found to be suffering from epilepsy, or has had epilepsy attacks prior to his entry into the U.S." he would be deported.

In June, 1966, Congress amended that act and the wording on epilepsy was thrown out—almost. Lawmakers had overlooked Section 255 of the law, which stipulated that persons with epilepsy who were aboard ships arriving in this country would be denied employment.

habilitation Administration and other federal agencies.

Sociologist Donald S. Frank headed the "Three Cities Project," which subsequently produced what at the time were considered astonishing results in rehabilitation of those with seizure problems and associated barriers to employment.

Merger: The Boards Move Closer

In the meantime, the maneuverings to bring EAA and TEF together continued. Inner-involvement between the two agencies heightened when determined matchmaker Paul E. Funk became a member of EAA's board in addition to serving with TEF. Thomas E. Jenks, a former TEF president, had already become a member of the EAA board. With the boards thus "integrated" the final steps became easier to achieve.

A final lobbying effort within both organizations brought about agreement in broad areas, leaving the more sticky details to be worked out

later. If the final merger was more of a hopeful handshake than a bear hug, it nonetheless achieved its purpose of officially tying most of the epilepsy movement into one national organization. The news that agreement had been reached came in January, 1967. Actual unification was announced in the summer of 1967. In January, 1968, the Epilepsy Foundation of America was incorporated.

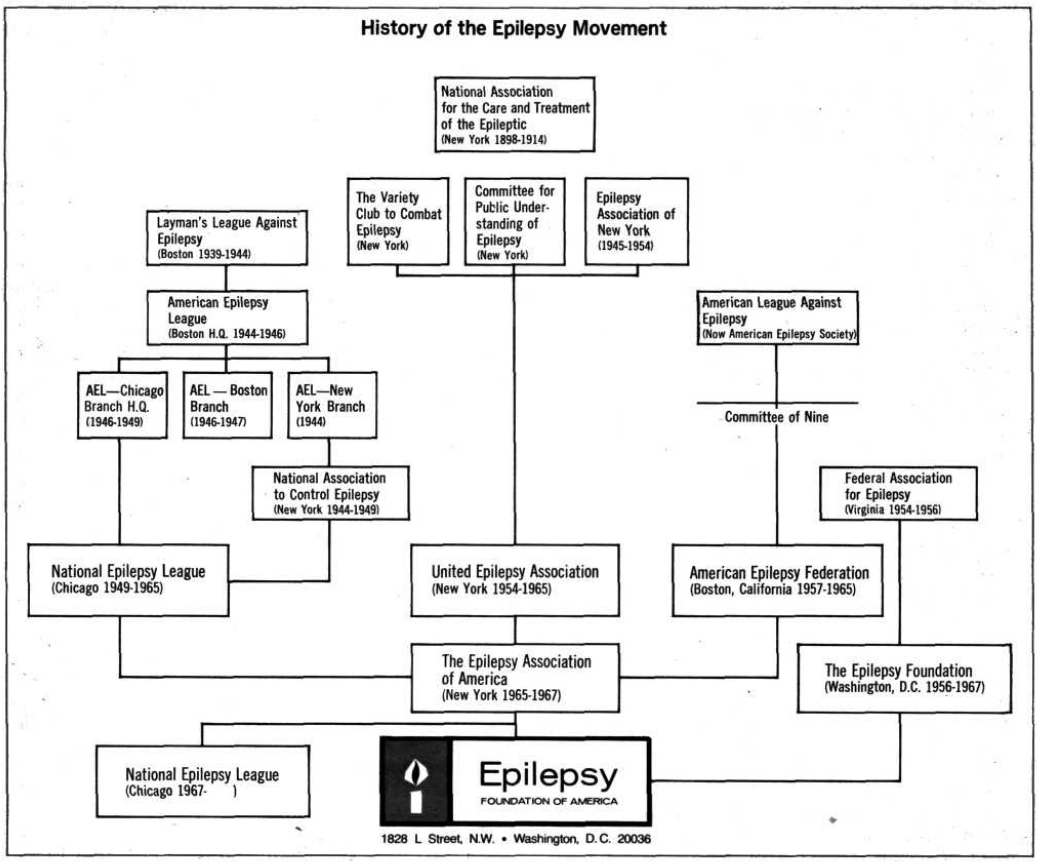
It was a new beginning in an ancient struggle.

The late President Lyndon B. Johnson was the first to praise the merger creating the Epilepsy Foundation of America as a "milestone in a major health field" and he pledged his "sustained interest and cooperation."

Sen. Robert A. Taft Jr. of Ohio was also quick to see the value of consolidation. Speaking to the U. S. House on Oct. 23, 1967, then-Rep. Taft said, in part, "The merger represents a previously unrealized opportunity to provide important and necessary services to . . . Americans who are afflicted with epilepsy. It is a welcome step."

U. S. Surgeon Gen. William H. Stewart said EFA was "engaged in a magnificent humanitarian effort," and scores of other officials, leading citizens, senators and representatives also hailed the new organization.

But as praise continued to pour in, the National Epilepsy League sent word from Chicago that it had decided to withdraw. NEL still operates independently in Chicago.



Chapter IX
EFA Becomes a Reality (1967-1973)

Gilliat Is First President

In September, 1967, Neal Gilliatt, a prominent New York advertising executive, was named the first EFA president. It was an appropriate choice, for the first few months of its life the infant organization needed all the diplomacy, the wisdom, and the vision which Neal Gilliatt brought to it.

Harold Babbitt, president of the old TEF, and Howard Koven, who had been president of EAA and a national chairman of NEL, were chosen co-chairmen of the board. A. B. Baker, M. D., Mrs. Fred Markham and Mrs. Ellen Grass were elected senior vice presidents. Paul E. Funk, first vice president of TEF, was named a vice president of EFA and chairman of its program committee.

The new organization, with 78 affiliates in 34 states, set up its headquarters at the former TEF offices on H Street in Washington, D. C.

By winter of 1968, quarters had been moved to 15th Street, where they would remain for three years. In addition, announcement had been made of the first annual awards to be given to outstanding volunteers for achievement and service, and to chapters for program and development.

In the spring of 1969, Paul E. Funk became the second president of EFA. Harold Babbitt and Neal Gilliatt were elected co-chairmen of the board. They were re-elected in 1970.

An annual search for a poster child to dramatize the epilepsy cause was begun in 1969, and Dawn Martin was chosen the first of EFA's poster children.

Three Cities Project

As EFA grew steadily, so did the demonstration program which had originally been undertaken by The Epilepsy Foundation in cooperation with the U. S. Department of Labor.

When the Three Cities Project marked its first anniversary in January, 1968, the project director, sociologist Donald Frank, reported a 62 per cent success rate in placing the unemployed job-seeker with epilepsy. The program ended with an astonishing 70 per cent placement rate.

Encouraged by this dramatic demonstration that people with epilepsy can work when there are special programs to help them, EFA President Funk and the commissioner of the federal Rehabilitation Services Administration, Dr. Edward Newman, signed a pledge of cooperation. Each agency promised greater efforts to seek work and assistance for epilepsy's victims.

It was hoped the two agencies would actively cooperate in four key areas: case finding and referral, service projects, research and development, and information services.

It seemed to auger a promise of far better assistance for adults who could not get help from vocational-rehabilitational programs because of epilepsy. Despite encouraging advances in some areas, however, the promise has not yet really been fulfilled. Baker Heads EFA

In 1971, Dr. A. B. Baker, the energetic former chairman of EFA's distinguished professional advisory board, was elected EFA president. At the same time, Paul E. Funk accepted the board's request that he devote his full energies to the administrative post of executive vice president.

Dr. Baker, now Regents professor of neurology at the University of Minnesota, has been dubbed the founder of neurology in this country. He is founder and former president of the American Academy of Neurology, a past president of the American Neurological Association, and former chairman of the National Advisory Council on Neurology to the National Institute of Neurological Diseases and Stroke (NINDS).

He served for 15 years as chairman of the National Committee for Research in Neurological Disorders, and is author of the standard reference, work, Clinical Neurology, revised and reissued in 1972.

During his term of office, the young Epilepsy Foundation of America grew dramatically in numbers, in influence, and in its capacity to promote positive change.

First National Law

That same winter which saw Dr. Baker become EFA's president also saw epilepsy specifically mentioned in a piece of landmark legislation: the Developmental Disabilities Services and Facilities Construction Act (Public Law 91-517), better known as DDSA or the DD act.

The legislation was mainly sponsored by Sen. Edward M. Kennedy (D-Mass.) in the Senate and by Rep. Paul Rogers (D-Fla.) in the House. It provides funds to serve those who have "neurological handicaps originating in childhood", specifically including epilepsy, cerebral palsy and mental retardation.

Under DDSA, the federal government grants funds to states on the basis of population, need for services and financial needs of the state.

The act also authorizes the Secretary of Health, Education and Welfare to set aside up to 10 per cent of appropriated funds for project grants of national significance. Such projects are 90 per cent federally funded, with the remaining 10 per cent paid by the public or nonprofit agencies administering them.

The Developmental Disabilities Services Act went into effect in 1971—a full 73 years after the beginning of America's epilepsy movement.

From the beginning of 1971 through late 1972, a total of $43.4 million had been allocated to the states for alleviating epilepsy, cerebral palsy or mental retardation.

Of this amount, less than $1 million had been used specifically for epilepsy by the end of 1972. But as chapters, with the aid of regional staff, became more expert in applying for service

grants, the totals went up, and another $1 million for epilepsy was granted in the first six months of 1973.

A second bill, the National Multiple Sclerosis and Epilepsy Act of 1972 (S-3664), whose principal sponsor was Sen. Frank Moss of Utah, died in committee. The ambitious proposal, introduced June 2, 1972, would have mandated the director of the National Institute of Neurological Diseases and Stroke to develop a far-reaching neurological disorder and disease study, research and rehabilitation program. It authorized national clinical centers and up to $375 million in federal funds. It was re-introduced in 1973.

The concept of treating epilepsy at multi-disciplinary centers received a further boost in 1973 when the National Institute of Neurological Diseases and Stroke adopted guidelines for its new centers program. In addition, states have blazed their own trails in drawing up some much needed epilepsy related legislation.

State Laws, Too

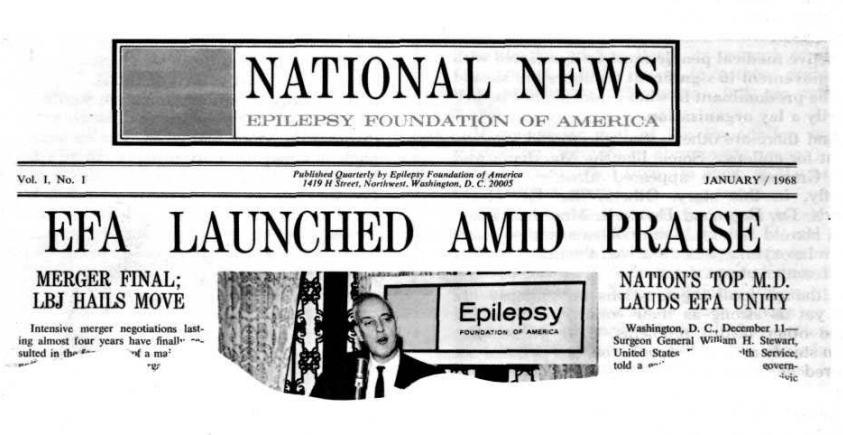
For instance, in August, 1972, New Jersey became the first state to prohibit discrimination of any type against those with physical handicaps. The New Jersey law specifically includes epilepsy.

Similar bills are pending in other states and there is a movement to prohibit questions about certain medical handicaps on routine job applications where such questions are irrelevant.

In Maryland, Georgia and Pennsylvania, law enforcement officers now are required to routinely search for medical identification before arresting as disorderly someone who may actually be undergoing a seizure. Many other states are sponsoring similar legislation:

Legislation approved in Indiana requires school districts to pay up to $2,000 for tuition of a severely handicapped child who attends public education classes. Other Indiana laws provide funds to retrain teachers of the handicapped in poverty areas.

So far, the record of state or federal legislation to help those with epilepsy, compared to the amount of legislation shoring up other rights, and aiding those with other handicaps, has been small. But a strong advocate organization, speaking to the conscience of the whole nation, can create an awareness of need, a determination to change what needs to be changed in our society. And that raising of public consciousness is one task which lies before the unified organization known as the Epilepsy Foundation of America.



NATIONAL NEWS

EPILEPSY FOUNDATION OF AMERICA

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EFA LAUNCHED AMID PRAISE

MERGER FINAL; LBJ HAILS MOVE

Intensive merger negotiations lasting almost four years have finally [illegible] resulted in the [illegible] of a ma[illegible]

Epilepsy FOUNDATION OF AMERICA

NATION'S TOP M.D. LAUDS EFA UNITY

Washington, D. C., December 11— Surgeon General William H. Stewart, United States [illegible]lth Service, told a [illegible] govern[illegible]vic

Front page news in the Foundation's quarterly newspaper was the final achievement of merger, and the satisfaction with which it was greeted by national leaders.

Chapter X
A Look to the Future
(1974 And Beyond)

Conclusion

For the past year this has been the "history" page of *Spokesman,* upon which we have tracked the progress of a movement which has not yet reached its final goals, but which is more united and stronger than ever before.

It has been, first of all, a story of personal drive and dedication on the part of a relatively small number of people. There was Dr. Lennox, for example, a towering figure on the medical scene who was equally absorbed with the social toll of epilepsy and who, throughout a long and distinguished career, worked to establish and sustain lay organizations.

Dr. Lennox is immediately remembered for his many writings on epilepsy, among which is his classic work "Epilepsy and Related Disorders." Not so well known, perhaps, is the fact that he donated the royalties from this volume to the epilepsy organization he founded in Boston.

Dr. Lennox's involvement with the movement, and his emphasis on building an organization of informed citizens illustrates what is perhaps the first lesson which our story imparts:

Active medical people must be associated with the movement in significant numbers but should not be predominant in what is and should be primarily a lay organization.

And there are others, too, who forged a movement for epilepsy. Some, like the Markhams and the Grasses, have appeared already, however briefly, in this story. Others, like Dr. Harry Sands, Dr. Raymond Dennerll, Mrs. Joel Broyhill, Harold Babbitt, John Gibbons, and so many more have perhaps not received the attention that their contributions deserved.

Although local organizations for epilepsy are not yet as strong as their counterparts serving some other health problems, their growth has been steady and that growth, too, has perhaps not figured as prominently in this story as it might have.

Indeed, the whole story could well have been told in terms of local growth, had it not seemed that the slow movement toward unity in a national sense and the meeting of overall national needs provided a more cohesive point of view. Which brings us to the second lesson:

The significance of local organizations is central to our movement. The problems of people with epilepsy will ultimately be solved by individual actions and activities in local communities when the people living in those communities recognize the need and the obligation to solve the problem.

Implicit in this local movement, too, is the need for effective relations and dialogue with government at all levels, and particularly the reflection of local views at national levels. We must, moreover, become as expert in *obtaining* services as we are in *providing* them ourselves.

And it is important for the movement to work toward continuity as well as strength in local organizations. Unless we do so, the enterprise is always threatened.

The EFA family tree shows how fleeting were some of the quasi-national epilepsy groups. A similar chart of local organizations would show many more rising, waxing, and waning as their principal spirits passed from the scene. Lesson:

No one person, no matter how brilliant, no matter how inspired, can do it all.

So many times the frailty of human life and the ephemeral nature of a one-man or one-woman organization is borne out when a dynamic leader moves, or for any reason becomes unable to continue, and leaves no organization behind to carry on the work. And the moral of that is:

The proper grasp of business management is as important when your motives are philanthropic as when they are bent on profit.

And there's surely another lesson, too, in the short lives of some epilepsy organizations and that is:

Nothing can be done without money.

The quality of program services is directly related to the money available to run them. And it is no accident that organizations with the longest history are also those which have found a reliable, established source of funds.

No history of any organization would be complete without some mention of disagreements and disputes on policy and goals. The epilepsy movement has had its share of these, there's no question about it, and the lack of a single organization for epilepsy over so many years has kept our

Paul D. Holland, the west coast attorney volunteer who was elected president of the Foundation in May of 1973.

cause from the public attention it would have gained. The lesson?

We are stronger together than we are individually.

Yet even today there are organizations which have not yet been able to see their way clear to join the national organization.

What do they lose? First and foremost, an opportunity to influence the make up and direction of the national movement. Secondly, ready access to scores of organizational service elements, exhibits, chapter service aids, counsel, and materials of all kinds.

What does EFA lose? The talent and experience of good people, the new ideas they would contribute, the strength that would accrue if one organization could finally say that it represented all voluntary organizations for epilepsy in the land.

We've looked across some 75 years since the series began.

We've seen the fragmentation of the movement again and again, and the effort it took to get suspicious and often hostile groups to bury their differences for the common good. We've seen how government money such as that available through the Developmental Disabilities grants can galvanize program activity and build many peripheral benefits for people with epilepsy.

And we've seen how splendid, federally funded programs like the Three Cities employment project can glow brightly on the scene and then, if they are not actively pursued and maintained, flicker out.

We have learned that we need a plan. We need a plan, not just for this organization, but for the way the nation is to tackle a national health problem involving the varied needs of four million citizens.

What is needed is a national plan for the social and medical management of the epilepsies.

Just as the epilepsy movement was fragmented a few short years ago into many agencies, each with its own pet programs (many of which were very good) and its own priorities, so the many national, governmental, voluntary, social and medical agencies approach epilepsy today.

A head count around the Department of Health, Education and Welfare reveals dozens of major and minor agencies with some influence on epilepsy, including the Bureau for the Education of the Handicapped, Crippled Children Services, Developmental Disabilities, and the National Institute of Neurological Diseases and Stroke (NINDS).

There is clearly a need for a focal point for epilepsy within government. And it is scarcely a new need; the voluntaries and the professional neurological societies petitioned President Nixon for one early in his first term.

A look at the voluntary health agency list produces a good many more organizations which involve people with epilepsy. And a glance at the number of professional associations in medicine and social work reveals scores of them which, to varying extents, affect the lives of the man, woman, or child with epilepsy.

What is needed, then, is a careful meshing of these diverse elements into a national plan. Such a plan would interrelate in an orderly way the contributions to be made from different sources much as a national organization interrelates the strengths and services of its chapter system.

Without a national plan, the scattered approach that for so long weakened the organizing of a national epilepsy movement will prevail in the area of epilepsy services as well. And while no plan should be so rigid as to rule out uncharted discoveries, a system based solely upon the hope that something will turn up will move ahead erratically if at all.

It is no accident that there are Departments of Mental Health and Departments of Mental Retardation in virtually every state. They are there because they were natural and inevitable outcomes of a national plan for those health problems.

The ideal plan would involve the many sections of our society already engaged in activities related to epilepsy, including at least 250 specialists of all kinds, some 30 organizations involving medicine, psychology, children's services, education, social and support services, and vocational rehabilitation.

Also needed is the contribution to be made from the Foundation itself, its network of chapters, and, it is to be hoped, from those organizations which are still outside but are needed inside.

If one major goal of the Foundation is the production (through an appropriate agency) of a national plan, what then are some of the other, more internal goals?

Public education remains an urgent priority for those people who, because of reliable seizure control, are capable of total integration into the society, yet still face the stigma imposed by public attitudes. More publicity, through the more active cooperation of such groups as the Advertising Council, National Association of Broadcasters, Magazine Publishers Association and the American Newspaper Publishers Association, will be sought.

The concept of an EFA Service Center for chapters has also been suggested, in which a separate unit within the organization would function solely to meet chapter needs, and be financed in whole or in part by fees for services and materials.

Another goal is to increase the strength of the Foundation as the nation's representative of four million people through a membership campaign, which aims to add a million members during the next few years. And more than members on paper are needed.

The movement needs an army of volunteers to support its activities and spread the word.

And within this army of volunteers the Foun-

dation must mobilize and motivate a key group — those individuals who themselves have epilepsy and know the needs as nobody else can. The Foundation must enlist the person with epilepsy in his own fight—his voice for his cause has the greatest public impact.

It may be that in the future, there will be opportunities for more combined activity and perhaps even the concept of a Brain Society should get some study.

There are some who would say that in 75 years the movement has made but minimal progress. And in comparison with the cancer movement or the mental retardation movement they would be right. The price of disunity runs high.

But today the epilepsy movement is more united than ever before, has a sense of its future, and a sense of its past. If the past is prologue, then the 75 years and our review of them here is just the beginning of more positive, rapid progress for the movement and the people it exists to serve—four million people of all ages who have epilepsy.

Photo courtesy of National Library of Medicine

Patients paring vegetables at the Craig Colony, near Sonyea, New York, in Livingston County. Founded in 1892, Craig Colony was one of the earliest institutions for people with epilepsy.

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