

The development of the programs of the National Institute of Neurological Diseases and Blindness has been a matter of special interest to me. This Institute was created during the 81st Congress, at which time I was Chairman of the Subcommittee which considered its appropriation. The Institute had been authorized under Public Law 690 in 1950 but was not allocated operating funds until Fiscal Year 1951.

Prior to that time, through the interest and efforts of the voluntary health agencies in the field, some progress had been made against the neurological and sensory disorders. We learned that they affected some 20 million people in the United States, half of whom are gravely disabled. We heard that many of these victims are rejected by society, for those crippled by such disorders as multiple sclerosis, cerebral palsy and epilepsy, or blinded by glaucoma and cataract, either are stigmatized by their ailments or make others retreat from them because of our inability to be of assistance.

These disabilities with but very few exceptions are incurable. It is perhaps just as disturbing to know that such treatment and care as might ameliorate their suffering is rarely available. We have learned that there are only about 250 qualified neurologists in the United States. Some states have none at all.

The voluntary health agencies have done much to bring both aid and welfare to the unfortunate victims of these diseases, but the excessive financial burden has made it impossible to aid all of them. It was and is,



therefore, a major difficulty for such agencies also to support adequately such research and training as might eventually lead to the prevention or cure of many of the neurological and sensory disorders.

In past testimony on behalf of the Neurology Institute, it has been said that patients with these disorders are the "forgotten men." Rejected by society, spoken of only within the family circle, virtually neglected by medicine and science, bereft of compassion during their slow, disabled progress towards death, we can only agree that this phrase is truly appropriate.

In 1950 I was convinced that the plight of these "forgotten men" warranted action--and further, that it warranted such immediate and extensive action as only the Congress could stimulate. It was apparent, too, that a broad program to attack these problems should be centered at the National Institutes of Health. I then proposed, with the hearty concurrence of the Subcommittee, that a significant program be established immediately, stressing training, research in non-Federal institutions, and direct research at Bethesda. The Congress approved appropriations for the National Institute of Neurological Diseases and Blindness totaling \$1,250,000 in 1952, \$1,972,000 in 1953, \$4,500,000 in 1954, and \$7,600,500 in 1955.

Within a year after the first funds were made available to this program, it was already evident that a national force had been established. Sound programs were already under way in research grants, research fellowships, clinical traineeships, and at Bethesda, the nucleus of an outstanding group of scientists had been formed.



Now, a little more than three years later, this early promise has come to fruition, and the Institute has begun to stand firmly on a record of research and training productivity of which Congress may well be proud.

At Bethesda, the basic chemical abnormalities responsible for epileptic seizures has finally been brought to light by Institute scientists. Based on this discovery, a treatment with two substances, glutamine and asparagine, promises to bring greater control over this dread disease. Again, drugs for the medical control of a major eye disorder, granulomatous uveitis, have been developed, thereby saving some 2500 persons each year from probable loss of vision.

Through grant support of research at non-Federal institutions, the leading cause of blindness in children, retrolental fibroplasia, has now become largely preventable; a major cause of cerebral palsy, kernicterus, has been virtually eliminated, and I have learned from a recent report that incidental to the study of nerve muscle disorders, a potential antidote for war nerve gases is in the process of development, so that we may now hope for neutralization of that horrible weapon of war.

The training programs of the Neurology Institute have also been effective in helping meet the needs of the victims of the neurological and sensory disorders. Some 92 physicians and paramedical personnel have received specialized training in neurology, ophthalmology and rehabilitation, as a result of the clinical traineeship program. Last year and this year, the Congress made available a total of \$1½ million for aid to medical schools to initiate



or expand their training in neurology and ophthalmology. As a result, there are now another 7½ residents in neurology and 16 in ophthalmology who are already or will be treating patients and who are or will be conducting research. Twenty-eight teachers in the clinical or basic neurological sciences have emerged from this program, as have 1½ in the ophthalmological sciences.

I am glad to say that the Institute's relations with the voluntary health associations in its fields are very effective. The study of retrolental fibroplasia was conducted in cooperation with two such agencies; two other agencies are cooperating in the national cerebral palsy study which is being spearheaded by the Institute; and many other projects have been conducted through mutual assistance and cooperation. The Institute in truth has become a focal point for the attack on the neurological and sensory disorders.

This history of success would suggest that all the Institute's needs and thereby the nation's are being fully met. This is not so, and as our Subcommittee found, as might be expected in a new program, there were still several serious deficiencies in support of the Neurological Institute program. One of these deficiencies was that there were not enough clinical facilities available to the Institute. It had been originally planned that the Institute should have 52 beds in the Clinical Center. In the past year, they have had to "borrow" 13 beds from the other Institutes. And their absolute need is for 78 beds. This means that if we are to encourage the Institute to achieve maximum effectiveness, we should provide additional funds in the amount of



\$280,000 to permit activation of an additional Institute nursing unit in the Clinical Center.

One reason for the increased need for research beds lies in the fact that the many diseases under investigation demand specialized bed facilities. Another reason is the need for beds in connection with research on blindness-- a program which is just getting into high gear. Dr. Ludwig von Sallmann, one of the three leading eye researchers in the country, will be joining the Institute, and activation of the eye research program as originally planned and supported by Congress will then become possible. Dr. van Sallmann's work in glaucoma is of particular promise; and he hopes as well to activate studies on cataract and corneal opacity on a larger scale than has hitherto been possible. These disorders of the eye are responsible for more than 50 percent of blindness in the United States but at present receive little clinical research attention.

The fifty-two beds now available to the Institute cannot possibly absorb new research without terminating present research of promise. Moreover, eye research, as other research, demands certain specialized procedures in medical care requiring separation of its research patients from neurological patients; and the eye research program, therefore, requires a specialized nursing unit of twenty-six beds.

It should be noted that the two standard nursing units of 26 beds each now available to the Institute are also specialized; one unit receives medical patients, chiefly those with muscular dystrophy, myasthenia gravis and epilepsy;



the other receives surgical patients, chiefly those with cerebral palsy, brain tumors, and those epileptics for whom surgical intervention has proved necessary. This division is not arbitrary; it is essential for proper medical care and research determinations; it facilitates research control; it guarantees that each area as a whole will be geared to the special needs and welfare of the patient. Similarly, therefore, eye research and eye research patients will require a distinct separate research-nursing unit for the optimum benefit of the patient and for maximum research productivity.

I do not want to conclude this discussion of the program of the National Institute of Neurological Diseases and Blindness without referring to its role in the study of mental retardation. The National Institute of Mental Health is also interested in this problem. There is of course necessarily a very close correlation between these two Institutes. I will discuss on another occasion the problem of mental retardation and some of the things I hope can be done about it.

It is for all of these reasons, which add up to the need for rounding out a research program of great merit, that I propose modest increases for the National Institute of Neurological Diseases and Blindness.