

REMARKS OF HONORABLE JOHN E FOGARTY, U S REPRESENTATIVE SECOND CON-
GRESSIONAL DISTRICT OF RHODE ISLAND AT NATIONAL HEMOPHILIA FOUNDATION
LUNCHEON ON SATURDAY, JANUARY 13, 1962 AT ^{12 NOON} THE STATLER-HILTON HOTEL,
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Statler Hilton
Rep. John E. Fogarty
National Hemophilia Foundation
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It is a great pleasure for me to be invited to address a group whose interests in improving the nation's health run parallel to my own. Not only are we all interested in assuring a healthy and prosperous nation, but the efforts of such voluntary health agencies as the National Hemophilia Foundation illustrate the kind of hand-in-hand cooperation with the Federal government which is particularly gratifying to those of us who are privileged to play a role in the development of Federal health programs.

In this period when some are wondering if the increasing role of the Federal government in research may perhaps be a threat to other sources of research support, I would like to give you some impression of the ways in which Federal activities are cooperative and supplemental without being dominating. I can select no better instance of partnership in health -- Governmental and voluntary -- than the National Hemophilia Foundation.

Let me say that my own interests in the fields of medicine and health have grown with the years. I have been in Congress, representing the 2nd District of Rhode Island, for ^{over} 20 years, now, and for a major part of that time I have had the rare opportunity and responsibility of being chairman of the Subcommittee on Appropriations for the Department of Health, Education, and Welfare. In this period I have become increasingly aware of the ever-greater impact that the Federal research expenditures are having on research programs in the life sciences.

For those who fear a suppression of private expenditures as Federal activity increases in support of biomedical research, I can only say that there are so many problems of disease remaining before us that there are problems enough for all.

For those who say that the percentage of non-Federal funds has greatly decreased in relation to Federal funds, over the past 20 years, I have a ready answer. While the percentage of non-Federal funds has decreased, there has at the same time been a remarkable increase in the actual amount of non-Federal assistance to medical research. In 1940, some \$42 million was spent by non-Federal sources for medical research; today the amount is estimated to be around \$335 million. It seems to me that this is clear proof that Federal funds have stimulated, rather than suppressed, private expenditures for medical research.

For those whose doubts linger, let me come back to this Foundation, whose Board of Trustees and those present ~~tonight~~ ^{today} represent several thousand dedicated workers doing their part to combat one well-known but rare disease.

By its nature, hemophilia is a rare disease. Yet every literate man knows that its influence may well have changed the course of European history because Queen Victoria happened to carry the gene of this disease, and through her daughters carried it into the reigning houses of Spain and Russia. The "bleeder's disease" may appear in any family; when it appears in a family in high position -- such as the last Czar of Russia -- it may promote the interests of a Rasputin and influence vast events. But wherever it appears it visits tragic difficulties which those of us more fortunate hardly realize. Perhaps it is well for us to try to imagine what it would be like to be afraid that the common, every-day task of brushing one's teeth might expose us to the possibility of a dangerous loss of blood. This frightening prospect is just one of the daily burdens of the sufferer from hemophilia.

It is one of the purposes of your Foundation to disseminate just this kind of information. The greater the public understanding of the disease, the greater the support of research in hemophilia.

The work done by your Foundation since its inception in 1948 is impressive indeed. As members of this group you have been responsible for the raising of thousands of dollars to be used in the treatment and care of the afflicted, through your several state and local groups.

Although you are a relative newcomer in the field of public health, I am sure that the families with afflicted children never questioned the newness of your help but were grateful that someone was interested enough to give them assistance as well as helping to supply the large quantities of blood so often needed.

Although you are a relatively small organization in the field of public health, I am sure that the husbands with hemophilia never questioned the size of the organization that helped them get and hold a job so that they could be useful and productive members of society. It is not the size of an organization that is important; it is the quality and effectiveness of the organization. These qualities are needed in the alleviation of human suffering. And this Foundation has been able to fill a human need which others have left unanswered.

It would be difficult to say which of your many activities is the more important. The grants and funds given for research and fellowships are important, but not more so than the financial assistance you give to hemophilia victims. Your registration of all hemophiliacs, your educational efforts with them, and your help in the maintenance of blood and plasma banks are equally important and beyond mere praise a worthy effort of which you may be justly proud.

But all of our efforts in medical research are completely overshadowed by the problems of disease and disability still confronting us. I would like to restate my views, briefly, here, ^{today} ~~tonight~~.

The conquest of communicable diseases in the first half of this century has shifted the emphasis in medical research to the chronic, metabolic and degenerative disorders. Apart from the tragedy and unhappiness they cause, disease and disability are estimated to cost this Nation \$35 billion a year. Only through medical research and its application can these losses be reduced.

In the 1930's it became apparent that a major trend in the country was toward an aging population, with more and more people subject to chronic diseases whose control would be more and more essential. Accordingly, Congress in 1937 established a National Cancer Institute, and by 1949 six additional research Institutes had been authorized for the investigation of other specific disease categories. I am, of course, referring to the National Institutes of Health, the chief research arm of the Public Health Service. The chronic diseases are reflected in the names of some of these Institutes -- Arthritis and Metabolic Diseases, Cancer, Heart, Mental Health, Neurological Diseases and Blindness. And this is proper, in my view, when you realize that there are more than 70 million people in this country with one or more chronic disease.

The role that the National Institutes of Health plays in biomedical research today is a significant one. While it is carrying on scientific work in its Institute laboratories -- there are ^{8,700}12,000 workers at the NIH -- it is supporting individual investigators throughout the Nation. To realize the pervasiveness of this influence one has only to scan the medical literature.

Now, hemophilia is one of the chronic diseases I was talking about which NIH is combatting. Practically all of the leading research scientists working on hemophilia in the United States today acknowledge the support of the Public Health Service. This support is coming from a variety of Institutes and Divisions at NIH, and covers a wide spectrum of research in hemophilia.

Again, one of the leading centers for the care and study of hemophilia has grown up here in New York City under the auspices of a variety of organizations. This is at Mt. Sinai Hospital, and I am proud to note that the Public Health Service supports many of the investigations at this center.

I was also happy to learn that the National Hemophilia Foundation is supporting a project at Mt. Sinai to develop a more effective means of the production of blood plasma through a new "deep freeze" project. I understand that it is hoped that by freezing and storing the blood plasma at minus 93 degrees Centigrade -- instead of minus 20 or 40 degrees Centigrade -- a more efficient product will be produced which will retain a high degree of coagulation factor and will store for longer periods.

Meanwhile, I have learned, the Clinical Center at NIH is pursuing studies on the biochemistry of blood coagulation with particular reference to the development of better forms of therapy for various congenital and acquired blood diseases.

It was tremendously reassuring to me to learn that even so rare a disease as hemophilia is being attacked by joint Federal and private efforts. This working together to overcome a common scourge is the kind of cooperative effort that is moving us all forward in our advance against illness and disease. This is an excellent example of the very kind of Government and non-governmental cooperation which we in Congress hope to stimulate.

I am convinced that the remarkable progress that we have made in the past has been the result of this sort of sustained, cooperative effort among a variety of organizations at the local, state and national level. Many factors lie behind this remarkable growth. Among these factors is the public's interest in health, as manifest in increased tax-supported programs as well as in the rise of the national voluntary health organizations.

As I have observed this increased interest and confidence grow through the years I have come firmly to believe that every American shares with me the desire to do everything possible to assure the best medical care, treatment and rehabilitation for all our citizens who may be physically afflicted. By doing so we may avert some of the annual loss in human productivity, which contributes to the mainstream of our economy, but this is not our sole or even main obligation.

For, as our Nation has assumed new leadership in the medical sciences, we have demonstrated our adherence to the moral principle that human lives are inherently precious. We then have the obligation to uphold our American heritage of humanitarian concern for the handicapped -- as the National Hemophilia Foundation has been so successful in doing.

In this connection, I cannot say too much in favor of the importance of the personal services that the Foundation offers to hemophilia victims and their families. Local clinics and patient services mean much to a person who may need continuing care throughout life. Families have to be helped in their internal adjustments; employment and other social problems must be solved. Research and patient services are recognized by this Foundation to be two phases of one program.

I am pleased to learn that the executive committee of the Foundation has decided to broaden its program to include victims of a number of rare blood diseases related to hemophilia. As I understand it, all persons afflicted with inherited deficiencies of the coagulation factors will now be included in the Foundation's research program. This represents your desire to serve more people who have similar problems, and it also reflects your desire to keep in step with the expansion of the Nation's total medical research effort, as outlined by the President in his Message to Congress last year.

Medical science is making great strides, however small they may seem, at times, in its conquest of the dread diseases. We know much more than we knew ten years ago, or five years ago, or even a year ago. But to continue to know more we must have many new research facilities, and many, many more trained investigators.

As President Kennedy said last year, "The next ten years will require a vast expansion of this Nation's present total effort in medical research, if knowledge is to keep pace with human progress."

He concluded, in part, that "The health of the American people must ever be safeguarded; it must ever be improved. As long as people are stricken by disease which we have the ability to prevent, as long as people are chained by a disability which can be reversed, as long as needless death takes its toll, then American health will be unfinished business."

We cannot afford to slow down the research momentum that has been so carefully and painstakingly built up over the years. That is why I urge you to join me in telling the people in your organization, in the areas where you have a voice, how important it is that nothing interfere with the rising tide of medical research in this Nation.

It is, of course, gratifying to know of the President's deep personal interest in health and medical research, and I believe he is most serious in his desire to direct our best efforts toward the improvement of the Nation's health. I am fully confident that the Administration will move to forward research for the benefit of all of the American people.

For my part, I shall do what I can in Congress to support medical and health-related research in governmental agencies. We cannot do without some of these Federal activities. I might mention here the recent discovery by Federal

agents that unsafe blood was being processed and mislabeled in the New York area. This discovery was made because the government maintains standards for the production of blood products which can damage or kill if they are not properly handled. Every manufacturer and every product must be approved by the Public Health Service. Fortunately the blood was detected to be faulty, in time, so that there were no fatalities or illnesses. The significance of this action will be clear to you, who work with people who must have quantities of unadulterated blood to save their lives. I think all Americans are reassured to learn that a branch of the Federal government is safeguarding the interests of any one of us who, at any time, may have to use blood and blood products. I hope that this fact, and not the publicity over the discovery of defective blood, is the fact that remains with the American public.

I am convinced, that with research support continuing to expand, with all of us working together, there is good reason to believe that science will find the cure for hemophilia and other chronic diseases.

There are some areas of hope for a cure for hemophilia, I am told. Research may reveal a dietary supplement that may control the disorder. There is some progress in the attempt to isolate the antihemophilic factor in the blood. There are prospects for improved treatment of hemophilia, especially in the case of improved antihemophilic globulin.

But, and I repeat, to continue this progress and increase the prospects for improved treatment, we must not allow ourselves to slow down in our research efforts. Through the activities of the Federal government, through the voluntary agencies -- and, as with this Foundation, through the joint activities of both -- we share in the responsibilities and the rewards of the conquest of disease. Only by working harder than ever, and by working in harmony, can we succeed.