

Congressman John E. Fogarty
Kickoff Dinner
Cystic Fibrosis Rhode Island
Chapter
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I am grateful to have this opportunity to meet with my friends who have taken a keen interest in mobilizing the battle against a relatively little known disease that has been on the rise in recent years. You who are members and friends of the Cystic Fibrosis Rhode Island Chapter are to be commended for taking it upon yourselves to tell others about the disease, to promote service activities for those who have been stricken, and to raise funds for the support of research -- which is the only hope for prevention of this malady that affects almost one out of every 600 ^{babies born} ~~live births~~ in this country.

In pointing up the importance of research, I don't mean to belittle the necessity for providing the services necessary to sustain those already stricken with the disease. But because of the direct role I have been privileged to play in affecting the development of this Nation's research through Federally supported programs, I have become convinced that the ultimate victory over disease and disability comes first through research -- new knowledge about the disease -- then through the application of this knowledge within the community, the state, and the Nation.

For a moment, then, I should like to discuss some of the developments of mutual concern in the relationships of medical research and voluntary agencies. To provide a setting, let me recall briefly the recent history of medical research, with particular reference to its support and to the interplay of forces which have brought it to its present ~~condition.~~ ^{status,}

In the current fabric of medical research, I may say here, there is no thread brighter nor more essential to the design than that woven into the pattern by the partnership of voluntary agencies.

Medical Research Aids Progress

The years of the recent past are replete with convincing demonstrations of the progress resulting from medical research and its impact on the Nation's health.

These are some of the manifestations of that progress:

... Fewer and fewer mothers die in childbirth, and infant mortality has been reduced continuingly.

... Typhus, tetanus, diphtheria, malaria, pellagra--diseases that once struck fear in every heart--have been virtually eliminated from our shores.

... Life expectancy has increased to 67 years for male babies, and to 73 years for female babies.

... With the developments of the antibiotics, many infectious diseases can be effectively treated and damaging complications avoided.

... Diabetes can be controlled, tuberculosis reduced, and poliomyelitis potentially eliminated.

... Major advances permit better diagnosis and treatment of the still-pressing problems of heart disease, cancer, mental illness, and the other chronic and degenerative diseases.

As a result of such advances, the United States has achieved a health status that is second to none among the large nations of the world.

How Medical Research Developed

Medical research in this country began on a good foundation, developed in a tradition that has been typically American, expanded slowly in response to economic and other stimuli, and then entered a period of rapid and sustained growth during and immediately after World War II.

In the evolution of a comprehensive and truly national medical research effort in this country, the governing factor has been the expectations and aspirations of the American people. Such developments as the emergence of the voluntary health agencies and the growth in support of medical research (both largely post-World War II developments) are reflections of the public interest.

Between 1944 and the present, there has been more than a seven-fold growth in the support of medical research, as measured in dollar expenditures for research, from \$60 million in 1944 to an estimated \$890 million in 1961. Well over half, some \$526 million, will come from the Federal government; the remainder will come from a variety of sources such as the voluntary agencies, industry, and foundations.

This investment represents about 4 percent of the total national research and development effort -- a percentage ratio that has remained constant in recent years and continues to the present moment.

Although, in terms of sources of support, the proportionate growth has been greater in industry and government, two things are evident: (1) that with multiple sources of support, it has been possible to maintain in our research institutions conditions conducive to productive inquiry; and (2) that Federal funds have not "dried up" private support, but have perhaps even tended to stimulate giving from other sources.

It is, of course, not by accident nor chance that American voluntary agencies have been able to flourish. Just as in the instance of medical research, they have been responsive to real needs and have produced tangible human benefits.

I submit that the successful, healthy growth and development both of medical research and of the voluntary agencies has been possible only because the interests concerned with both, in government and out, have always looked upon their endeavors as enterprises in partnership and have sought to carry them out in spirit and in letter that way.

It is true that the research programs themselves have had fine professional leadership. But in the last analysis, it has been the combination of the lay and professional leadership of our large voluntary agencies which has channeled otherwise aimless strivings into strong social and political forces with well-defined and understandable objectives that captured the imagination of the American people. The consequences have been emphasized already: a significant expansion of medical research support from a combination of private and public agencies.

Perhaps this factor in medical science will be given the place it merits when the medical history of the past decade and a half is written.

With or without such deserved recognition, for myself I can express the firm conviction that, without such forces as your group represents, locally, on the State level, and nationally, we could never have achieved today's position in medical research -- with the United States a world leader.

NECESSITY OF CONTINUING VOLUNTARY ROLE

Moreover, I am equally sure that there will be a continuing necessity for the voluntary agencies to play an essential role in the support of medical research, as well as in the provision of community services and in aiding professional and public education in the health and welfare field.

I would make this prediction even stronger by saying that the necessity for such a role by the voluntary health and welfare agencies will be both continuing and increasing in scope. It will become, if it is not already, a major challenge to you in the years ahead.

As is apparent, I view the national voluntary health agencies as a vitally important and complementing force on the national health scene. They derive their strength from one of America's greatest assets--generosity and concern for the well-being of others. Through the efforts of these agencies, substantial funds are made available for programs that have tangible benefit to our society.

A special point should be made, however, of the intangible benefits associated with the presence of a strong voluntary health movement in this country. One of these is the benefit of diversity, which I have mentioned previously. Your foundation and others like it represent an effective partner for both public and private groups, lay and professional, which comprise the resources for the health in the United States.

A second intangible benefit is the opportunity the voluntary health agencies provide for individual participation in a very direct and personal sense. Both those who work on behalf of the agencies and those who contribute to their programs and activities do so of their own free will and so help perpetuate a characteristically American tradition which is one of our primary sources of national strength.

Because of both the substantive and the intangible contributions of the voluntary health agencies, I have always felt that government at all levels should be affirmative in dealing with such groups. Furthermore, the net impact of the voluntary health agency movement is beneficial rather than detrimental to the raising of necessary funds from all sources, both private and public, and at all levels -- national and state and local -- for health purposes.

It is heartening that there has been steady increase in the amount of money raised for health programs from private, voluntary agencies. I believe it is fair to assume that this trend will continue, particularly if the fund-raising processes provide maximum opportunity for the individual to give freely to the areas of his own choice.

Progress Against Cystic Fibrosis

This brings me to the choice each of you has made -- a choice to give of your time, your talents, and your money -- in the fight against Cystic Fibrosis.

Many of you have based your choice on first-hand knowledge of some youngster whose recurring pneumonias, undernutrition despite a lusty appetite, and difficulty in withstanding the stressing effects of heat were ultimately diagnosed as cystic fibrosis.

Many of you have based your choice on the knowledge that the cost of providing medicine for these youngsters averages about \$2.00 per day.

Many of you have also been encouraged by research that has pointed to the high levels of salt in the perspiration of cystic fibrosis patients.

These were some of the considerations that the Committee on Appropriations for the Public Health Service and other agencies, which I have been privileged to serve as Chairman for more than 10 years, took into account over 3 years ago. At that time, we asked the National Institutes of Health to make a special effort to fill the research void in this important area.

The National Institutes of Health sponsored a research conference in January of 1959, collected the scientific papers and discussions of the Nation's top investigators in the field upon which plans for future research could be based.

Since that time, over 30 teams of investigators in non-Federal institutions have been enlisted in the fight against cystic fibrosis and more than 50 cases have been studied at the National Institute of Allergy and Infectious Diseases.

In studies elsewhere, investigators are making new and interesting observations. ^u This ^{K,} in addition to the various projects underway at Bethesda, 30 research project grants have been authorized this year for studies on cystic fibrosis at research centers elsewhere. They range in subject from the microchemistry of the sweat glands to investigators ^{ions} of the eye changes that are now being seen in certain CF patients.

At the Babies Hospital of the Presbyterian Hospital, New York, impaired vision and abnormal ocular findings were detected several years ago. Since then all cystic fibrosis patients admitted to the hospital are being carefully checked for eye changes.

At the University of Pennsylvania School of Medicine, physicians are experimenting with new methods to promote drainage of mucus from the lungs and increase the present use of antibiotic-containing aerosols to combat lung infections.

In another investigation, the U. S. Children's Bureau, working in cooperation with the National Office of Vital Statistics, compiled new data on how widespread cystic fibrosis is. This is the second phase of a three-part study designed to assess the magnitude of the cystic fibrosis problem in the United States.

The pilot survey was conducted in three nearby states. Its main purpose was to develop and test procedures which will form the basis for a future national survey. The states serving as the test areas-- Massachusetts, New Hampshire, and Vermont--were chosen because they offer a large urban and rural population as well as a well-defined medical care areas.

While the main purpose was to test the sampling techniques for nationwide use later, the study has given us interesting statistics. Data collected on 671 patients in the three-state area confirm the belief that cystic fibrosis can no longer be considered an invariably fatal disease of early infancy. Almost 50 percent of the 169 deaths in the

study population were patients aged 5 years and over. About 18 percent of the fatalities involved patients ten years and older. Only 24 percent of the deaths occurred in infants.

These efforts have indicated on the one hand, that cystic fibrosis is not a uniformly fatal disease but has a more optimistic outlook for many cases. On the other, we must still realize that the disease may involve not merely the pancreas and lungs but many tissues and organs throughout the body.

These facts, to me, are signposts of hope that help us to carry on in providing medical services and public education. ^{as} ~~As~~ research investigators search for the new knowledge that will eventually enable us to control this disease.

Now, in closing, I would like to generalize once again and leave you with one single thought with respect to the relationships between agencies such as the Cystic Fibrosis Rhode Island Chapter and medical research. I shall introduce this thought by saying that you who are a part of the voluntary health movement are in an enviable position.

By this I mean that I think you are, on the whole, freer and more flexible in your capacities for action than are the other major supporters of medical research programs: the university world, industry, government. You are, perhaps, more able to adapt more quickly to the changing needs and dimensions of research; you can be rapidly responsive, for example, to needs, because your whole history is one of meeting just such challenges in such areas as community health services.

In one sense, you are not apart from the other major influences and supporters of research; in another, you are.

On the one hand, you are an integral part of them because your leadership is made up of individuals who are also leaders in industry, universities, communities, and government.

On the other hand, when you as individuals band together for voluntary health enterprises, you become a separate force.

In either sense, you represent the hope, the will, and the capacity to rid this country of diseases that cripple and incapacitate and cut off life before it has even reached maturity. Best of luck to each of you in the campaign ahead.