SPEECH OF HONORABLE JOHN E. FOGARTY, 2nd CONGRESSIONAL DISTRICT OF RHODE ISLAND, AT LUNCHEON HONORING DR. SIDNEY FARBER ~~THE~~ BY THE GOTHAM CHAPTER OF THE NATIONAL FOUNDATION FOR MUSCULAR DYSTROPHY, INC., ON MAY 4, 1957, IN THE EMPIRE ROOM OF THE WALDORF ASTORIA HOTEL, NEW YORK CITY.

Mr. Toastmaster, Mayor DeMuro, Dr. Farber, members and friends of the National Foundation for Muscular Dystrophy. It gives me a feeling of both pleasure and pride to be here today. I am pleased at the opportunity to address a group which is concerned with public health and medical research problems and is doing something about them. And, I am proud of my acquaintanceship with the man who is being honored here today.

You may wonder how it is that I have come to know Dr. Sidney Farber. The fact is that--on numerous occasions--Dr. Farber has come before committees of Congress to report on the problems, the needs, and the progress in medical science. He has found the time to do this despite his busy career in research, teaching and medical service. Advice such as his, freely given in the public interest, has been of tremendous value to the Congress which must have the best possible counsel if it is to legislate with wisdom.

I do not believe that the National Foundation for Muscular Dystrophy could have selected a more deserving individual for the award being bestowed today. His contribution to the furtherance of medical research has been a magnificent one. His status in the field of cancer research is that of a leader as well as of an innovator. And what he has done for the well-being of children is not susceptible to statistical measurement.

But perhaps most important of all, Dr. Farber is that precious intermingling of scientist devoted to precision research and humanitarian devoted to the well-being of his fellow man. It seems to me that the truly great scientific achievements of our era have been the product of precisely-trained minds which were dedicated to humanity and the general welfare.

I should like, in the next few minutes, to talk with you about some of these achievements in the medical research field. And I should like, if possible, to put those achievements in perspective. In short, I think it is as important to know how far we have yet to go as it is to know how far we have come.

And the distance in both directions is considerable!

As you may know, I have spent some 17 years in Congress. For more than half of that time, I have been directly concerned with health and welfare matters. For most of the past nine years, I have served as chairman of the House subcommittee dealing with appropriations for the Department of Health, Education, and Welfare and its predecessor, the Federal Security Agency.

So you might say that I have been able to observe the medical progress of the postwar decade from an excellent vantage point. We have, indeed, taken some giant strides in that decade.

Let me cite just a few examples.

A whole new field of chemistry--better known as chemotherapy--has opened up for the treatment of that terrible killer, cancer. Chemicals are now making it possible to control and alleviate some forms of cancer which formerly did not respond or did not respond as readily to the surgeon's knife or to radiation.

The infectious diseases are lending themselves more and more to control in the laboratory and in the clinic. Polio is but one case in point.

The progress in the heart field has been little short of phenomenal. In a few short years, it has become possible to operate on heart conditions involving the arteries leading to the vital organ as well as the heart itself--conditions which previously would have doomed the individual to death, or, at best, to that tragic twilight of existence in which the least expenditure of energy was considered too great.

Why, only the other day, I read that some scientists had even gone to work to perfect a "substitute"heart which would replace the original when it faltered. I am sure this is speculative and very experimental work--but it does demonstrate how rapidly the frontiers in science are being pushed back.

I could go on and cite dozens of other examples of progress against the cripplers and killers of our time. Yet, it is well for us to bear in mind that the terms "progress" and "conquest" are not synonymous.

We have made advances against cancer. True enough. Yet, about 250,000 Americans died of cancer last year.

The Salk vaccine appears to have opened the way to the ultimate defeat of polio. But, last year, there were still more than 15,000 polio cases reported in this country.

Wonders have been done with heart therapy. But in 1956, no fewer than 800,000 Americans died of heart disease.

Why do I offer you these elements of stark contrast? Am I any the less pleased with the progress we have made? Should any of us be any the less pleased?

Of course not!

I am merely suggesting that--hard though it may be for some of us--we must temper our desires and expectations with the soothing balm of patience and understanding. We must, perhaps, pause a bit and take stock of our national medical research effort. We must distinguish between medical miracles--which seldom occur--and solid advances, which often do. We must, in short, look at medical research in perspective.

I am pleased to report that our most recent action in the House, relative to appropriations for the National Institutes of Health, reflected that attitude in full. I might add, parenthetically, that I think these Public Health Service, tax-supported research programs have certainly fulfilled the expectations which brought them into being. The research at Bethesda and the research and training supported in hundreds of institutions throughout the country through grants-in-aid have accomplished a great deal and certainly paved the way for many conquests to come.

Particularly pertinent to the progress that has been made in the fight against disease is the very fine cooperation that has developed between public and private organizations--a cooperation which has grown particularly close in the post-World War II period. Public and private research efforts have complemented each other in nourishing the research effort. And the role played by voluntary organizations such as the National Foundation for Muscular Dystrophy both in fostering research and in educating the public as to its importance has been of immeasurable benefit to the nation.

In carrying out their broad educational efforts, I think the voluntary groups have been particularly careful to distinguish between conquest of disease on one hand and progress on the other. And in no disease area is this distinction more important than that into which muscular dystrophy falls. I speak, of course, of the neurological and sensory disorders and--with your indulgence--I should like to concentrate on the problems presented by these diseases and on what is being done about them at the National Institute of Neurological Diseases and Blindness in Bethesda.

The National Institute of Neurological Diseases and Blindness, as many of you know, is the "baby" of the seven Institutes which make up the National Institutes of Health. However, it is a lusty baby.

And, though the U. S. Public Health Service has been doing medical research since 1887, the National Institutes of Health as such are just out of their swaddling clothes. If I remember correctly, only one of the seven Institutes--the Cancer Institute--was organized prior to 1948.

So, in effect, the progress in medical research made possible through the programs of the National Institutes has been achieved within less than a decade.

But, I have digressed. For it is with the National Institute of Neurological Diseases and Blindness, and with its research attack against the neurological and sensory disorders, that this group is most directly concerned.

In the five years since its establishment as an operative organization, the Institute has been concerned with the crippling disorders which attack the nervous system and which afflict an estimated 20,000,000 Americans today. Muscular dystrophy, cerebral palsy, mental retardation, epilepsy, multiple sclerosis, blinding diseases like glaucoma and uveitis--these are among the many disorders which the Institute and its many cooperating research organizations are attacking.

When you stop to think that the diseases I have just named are among the "unknowns" of medicine--that up to a few years ago we had almost no information as to the specific factors which bring them on--you can get some idea of the scope of the problem they pose. What I am saying is that anything which science has been able to discover about the nature and causes of these neurological and sensory disorders represents very substantial progress.

And--in those cases where effective treatment has actually been developed--progress has bordered on the miraculous.

I can perhaps illustrate my point best by directing your attention to one disorder which today afflicts an estimated 500,000 American men, women and children. It is a disease which I am sure Dr. Farber here has more than a passing acquaintance with inasmuch as it makes its presence felt very early in life. I refer to cerebral palsy-or--as some doctors put it--the cerebral palsies.

A friend of mine has referred to cerebral palsy as "a blank spot on the map of disease." He is, I think, very close to correct. For I understand that there is still disagreement among the doctors as to exactly what constitutes the disease.

On these facts, however, there is pretty general agreement: Cerebral palsy is brought on by factors active during the so-called perinatal period--the time span from about one month after conception to about one month after birth. It may, however, not manifest itself for several years and--in the past--it has not always been correctly diagnosed when it has manifested itself. The disease, which results from damage done to the brain in its developmental stages, is generally characterized by loss or impairment of control over voluntary muscles.

I don't think that I have to tell this group anything about the economic, social and psychological consequences of the disorder either for the individual afflicted or for his immediate family. The cost in these tragic terms is immeasurable.

What then, is the Institute at Bethesda doing about cerebral palsy?

For one thing, the Institute has launched a nation-wide collaborative investigation directed to determining exactly what goes on during the perinatal period to bring on cerebral palsy. The investigation is also designed to develop crucial information pertinent to the research attack against such related diseases as mental retardation and epilepsy and various forms of blindness and deafness.

When this broad investigation is in full swing, it is expected that 15 research organizations throughout the country will have joined the Institute in carrying it out. The study may go on for as long as a decade before all the sought-for data are collected. Eventually, as many as 15,000 cases may be under investigation each year.

It is the hopeof the Institute that, once the data have been collected and analyzed, medicine will have a relatively precise idea as to exactly how cerebral palsy and related disorders are caused. And, given such information, it is felt that effective preventives and therapy would not be too far away.

I have been told that there is one type of cerebral palsy for which research has already developed a treatment effective in many cases. I refer to kernicterus, which is better known as the "yellow jaundice" of infancy and which generally attacks within the first 48 hours after birth. Kernicterus is traceable to the so-called Rh factor--blood incompatibility between mother and child.

An Institute grantee discovered that a substance known as bilirubin was excessive in the blood of those exposed to the disease. He developed a specific test for the bilirubin level in the blood as well as a multiple transfusion technique for reducing that level.

When the blood transfusions are made immediately after birth, kernicterus is often prevented.

I should like, very briefly, to review some of the other very promising developments in the neurological and sensory disease field over the past several years.

Toxoplasmosis infection is a virulent form of the blinding disease, uveitis. The infection is brought on by a parasite. Last year, a new diagnostic technique was developed which permits the early detection of this infection and--in so doing--will make possible the prevention of many cases of blindness.

Or take brain tumors.

One of the major problems confronting the surgeon who suspects a brain tumor is to locate it in specific terms without having to resort to exploratory surgery. Another, perhaps even more basic problem is to locate the tumor in time since many tumors do not readily lend themselves to early detection by existing methods.

During the past year, investigators at the National Institute of Neurological Diseases and Blindness told me that they have developed a brain tumor detection technique which is more than 80 percent effective. The device precisely defines the size and location of growths, many of them deeply-seated in the brain. Efforts are already underway to increase the technique's effectiveness.

Still another development of interest has to do with a blinding disease known as retrolental fibroplasia. Over the past decade, this disease has blinded thousands of premature infants. Today, as the result of a coordinated nation-wide research attack involving 18 medical institutions, retrolental fibroplasia is rapidly disappearing.

How did it happen? The explanation is almost too simple. A researcher working with animals found a clue indicating that retrolental fibroplasia might be due to excess oxygen. The nation-wide investigation I have just mentinned was launched to check the finding. The finding was confirmed and now--through the judicious use and control of oxygen in prematurity cases--the disease is on the verge of extinction.

A report which came to me only a few weeks ago shows that--here in New York City--the incidence of retrolental fibroplasia has dropped seventy-eight percent in one year.

Now, the developments I have just described are most encouraging. And there are others of equal importance that I could point to in the neurological field.

But--and I feel I must be absolutely frank about this--there are many diseases for which the outlook is not nearly as encouraging. I regret to report that the neuromuscular diseases and muscular dystrophy are among these diseases. ✓

That is not to say that a cure or effective treatment for muscular dystrophy will not be achieved. Nor is it to say that such cure or treatment is <u>necessarily</u> still many years away.

It is only to say that the current status of our knowledge of this disease is such as to indicate that cure and prevention are not just around the corner.

As you know, scientists are not even sure of the specific causes of muscular dystrophy. They do know that it is a progressive, non-contagious wasting disease of the muscles. And they suspect that faulty metabolism may have something to do with bringing it on. Some scientists think that the inability of the body to utilize Vitamin E properly may play a role.

But it is not really known for certain.

As for effective treatment, a wide variety of substances and diets have been used in an effort to control or halt the disease. But, to date, there is no substantiated evidence that any of the methods used are truly effective over the long run.

Now, does this mean that we are making little or no progress against muscular dystrophy. . . . that little is being done about this and related disease?

The naswer is a clear-cut "no."

At the National Institutes of Health in Bethesda, hundreds of thousands of dollars are being spent on basic research into the nature and function of the nervous system. Additional hundreds of thousands are being expended through cooperating research projects directed toward the same ends. This, in addition to the funds made available from private sources.

For if there is to be a cure or effective treatment for muscular dystrophy and related neuromuscular diseases such as myasthenia gravis, our most direct approach is to learn the specific causes. And we cannot normally expect to know those until we know exactly how nerve impulses are transmitted from nerve to nerve and from nerve to muscle.

We are handicapped in our search for cures and preventives if we are unable to explain exactly what happens when nerve impulses are blocked, as is the case in neuromuscular diseases. The muscles just do not get the "message" from the nervous system.

Today--at Bethesda and elsewhere--scientists are hard at work trying to find out what blocks that message and the specifics of why and how the nervous system operates in its relationships with other parts of the body.

Experiments are underway to determine the impact of temperature, pressure and usage upon nerve fiber.

A new electronic device has been developed which detects and accurately measures even small amounts of a chemical called acetylcholine in the nerve fibers. This chemical plays an essential role in the nerve impulse transmission.

An ingenious micro-electrode recording device has been devised which makes it possible to measure electrical impulses of millionths of a volt lasting for only millionths of a second in the so-called synapse--the space between nerve endings.

Now, these developments are in what is generally called the basic research field. They are perhaps not as dramatic as some which have been widely publicized. But they are every bit as important. They are the stepping stones we must have if we are to span the sea of knowledge that lies between us and the effective treatment and cure of muscular dystrophy.

I think, my friends, that you can see that there is hope--much hope. There is also much work to do. Much has been achieved. Much remains to be achieved. Much more will be achieved.

There is no question in my mind but that the National Foundation for Muscular Dystrophy--like the other voluntary groups concerned with the conquest of disease--will have much to do with writing the record of this achievement.

As those of us concerned with medical research look ahead, we can see the broad outlines of the work which has been cut out for us. But we can also take heart from the perceptive words written by Samuel Taylor Coleridge: "Work without hope draws nectar in a sieve, and hope without an object cannot live."

Poet Coleridge's little verse is, I think, a most appropriate theme on which to finish. I thank you very much.