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HEMOPHILIA ACT OF 1973

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HEARING
BEFORE THE
SUBCOMMITTEE ON HEALTH
OF THE
COMMITTEE ON
LABOR AND PUBLIC WELFARE
UNITED STATES SENATE
NINETY-THIRD CONGRESS

FIRST SESSION

ON

S. 1326

TO AMEND THE PUBLIC HEALTH SERVICE ACT TO PROVIDE FOR PROGRAMS FOR THE DIAGNOSIS AND TREATMENT OF HEMOPHILIA

NOVEMBER 15, 1973



Printed for the use of the Committee on Labor and Public Welfare

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HEMOPHILIA ACT OF 1973

THURSDAY, NOVEMBER 15, 1973

U.S. SENATE,
SUBCOMMITTEE ON HEALTH OF THE
COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met at 10:15 a.m. in room 4232, Dirksen Office Building, Senator HARRISON A. WILLIAMS, presiding, pro tempore.

Present: Senators WILLIAMS, JAVITS, and DOMINICK.

Senator WILLIAMS. The Senate Subcommittee on Health will come to order.

We meet today to consider S. 1326, the Hemophilia Act of 1973.

We have been taken a little bit by surprise by the number of people that are here, and our room is not adequate for all of you. We apologize. We frankly did not know that we should have engaged the auditorium for this hearing. I hope that everybody is as comfortable as can be.

We would like to open our hearing with my brief statement on the disease and the need for this legislation.

Hemophilia is a genetically transmitted blood disorder which prevents normal blood coagulation and results in excessive and sometimes fatal bleeding for its victims. The typical hemophiliac is usually a male who is born with the disease and, in the absence of treatment, suffers its effect throughout his lifetime.

In the United States today, there are 100,000 individuals suffering from hemophilia. Of these, an estimated 25,000 have severe or moderately severe forms of this disease and almost 90 percent of these individuals are below the age of 25. Hemophiliacs are unique among chronic disease victims because they are not born crippled and they can be treated if financial conditions permit them to take advantage of newly developed forms of therapy.

Without this kind of ongoing care, severe and moderate hemophiliacs must suffer tragic consequences throughout their lifetime and become an unnecessary burden to themselves, their families, and indeed to our whole society. An individual is constantly threatened with great uncertainty, since a bleeding episode may strike without warning.

As a result, there is a tendency among family members and the hemophiliac himself, to curb many otherwise routine daily activities. This kind of toll is impossible to measure and in many cases it is devastating.

In recent years, medical research has made great advances in discovering new means to treat hemophiliacs. These techniques have made

it possible for most hemophiliacs to administer the appropriate clotting factor at home, much like a diabetic injects himself with insulin on a daily basis. Because of this, inpatient care is usually necessary only when surgery is indicated or when a serious trauma is inflicted. In addition, outpatient care by a physician or nurse may only be required for initial testing and training.

And so, it has become possible for most hemophiliacs to be able to lead normal, healthy lives.

Unfortunately, despite these remarkable breakthroughs, these new therapy techniques are simply out of reach for the average hemophiliac. They are unavailable for several reasons.

They are unavailable because the minimum cost for replacement therapy for severe and moderate hemophiliacs runs upward of \$4,000 per year.

They are unavailable because this Nation has simply been wasting its precious blood resources.

They are unavailable because, at the present time, they are only a scattering of medical centers in the United States which provide any major emphasis on the treatment and diagnosis of this disease, and they are unavailable because we face a short supply of professional and paraprofessional personnel, trained in hemophilia diagnosis, treatment, and research.

It is for these reasons that earlier this year I introduced S. 1326, the Hemophilia Act of 1973. The purpose of this bill is to provide the necessary Federal assistance so that hemophiliacs no longer have to face these uncertainties. Today we are commencing hearings on this legislation. I will not now take the time of the committee to summarize its specifics. However, I will order a copy of the bill, together with my introductory remarks, inserted in the hearing record at this point and also the statement of Senator Dole.

[A copy of S. 1326 along with Senator Williams' introductory remarks follow:]

93^D CONGRESS
1ST SESSION

S. 1326

IN THE SENATE OF THE UNITED STATES

MARCH 22, 1973

Mr. WILLIAMS introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

A BILL

To amend the Public Health Service Act to provide for programs for the diagnosis and treatment of hemophilia.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*
3 That this Act may be cited as the "Hemophilia Act of
4 1973".

5 STATEMENT OF FINDINGS AND PURPOSE

6 SEC. 2. (a) Congress finds and declares—

- 7 (1) that there are a significant number of indi-
8 viduals residing in the United States who suffer from
9 hemophilia;
- 10 (2) that there exists today the technology and the
11 skills to enable such individuals to lead productive lives;

1 (3) that the high cost of such technology and
2 skills are in most cases denying the benefits of such
3 advances to individuals suffering from hemophilia.

4 (b) It is therefore the purpose of this Act to guarantee
5 individuals suffering from hemophilia their entitlement to
6 care commensurate with the technology and skills that are
7 available.

8 SEC. 3. Title XI of the Public Health Service Act (42
9 U.S.C. 201) is amended by adding at the end thereof the
10 following new part:

11 “PART C—HEMOPHILIA PROGRAMS

12 “DEFINITIONS”

13 “SEC. 1121. As used in this part the term—

14 “(1) ‘hemophilia diagnostic and treatment center’
15 means an entity which provides the following:

16 “(A) access for all individuals suffering from
17 hemophilia who reside within the geographic area
18 served by the center;

19 “(B) programs for the training of professional
20 and paraprofessional personnel in hemophilia re-
21 search, diagnosis, and treatment;

22 “(C) a program for the diagnosis and treat-
23 ment of individuals suffering from hemophilia who
24 are being treated on an outpatient basis;

25 “(D) a program for association with providers

1 of health care who are treating individuals suffering
2 from hemophilia in areas not conveniently served
3 directly by such center but which is more conven-
4 ient (as determined by the Secretary) than the next
5 geographically closest center;

6 “(E) programs of social and vocational coun-
7 seling for individuals suffering from hemophilia;

8 “(F) individualized written programs for each
9 person treated by or in association with such center;

10 and

11 “(G) complies with guidelines for treatment
12 established by the National Hemophilia Advisory
13 Board, under this part.

14 “ENTITLEMENT TO TREATMENT

15 “SEC. 1122. (a) Any individual suffering from hemo-
16 philia may file a claim for benefits under this part with the
17 Secretary in such form and containing such information as
18 he may reasonably require.

19 “(b) Benefits under this part shall be paid to, or on be-
20 half of a claimant, in an amount equal to 100 per centum of
21 the actual cost of providing blood, blood products, and serv-
22 ices associated with the treatment of hemophilia, less—

23 “(1) amounts payable by third parties (including
24 governmental agencies), and

1 and private entities for projects for the establishment of
2 hemophilia diagnostic and treatment centers as defined in
3 section 1121.

4 “(2) No grant or contract may be made under this
5 part unless an application therefor has been submitted to and
6 approved by the Secretary. Such application shall be in such
7 form, submitted in such manner and contain such information,
8 as the Secretary shall by regulation prescribe.

9 “(3) An application for a grant or contract under this
10 part shall contain assurances satisfactory to the Secretary that
11 the applicant will serve the maximum number of individuals
12 that its available and potential resources will enable it to
13 effectively serve.

14 “(c) In establishing such centers the Secretary shall—

15 “(1) take into account the number of persons to be
16 served by the program supported by such center and the
17 extent to which rapid and effective use will be made of
18 funds by such center; and

19 “(2) give priority to programs operating in areas
20 which the Secretary determines have the greatest num-
21 ber of persons in need of the services provided under such
22 programs.

23 “(e) There are authorized to be appropriated to carry
24 out the purposes of this section \$5,000,000 for the fiscal

1 year ending June 30, 1974, \$10,000,000 for the fiscal year
2 ending June 30, 1975, and \$15,000,000 for the fiscal year
3 ending June 30, 1976.

4 "PUBLIC HEALTH SERVICE FACILITIES

5 "SEC. 1124. The Secretary shall establish a program
6 within the Public Health Service to provide for diagnosis,
7 treatment, and counseling of individuals suffering from hemo-
8 philia. Such program shall be made available through the
9 facilities of the Public Health Service to any individual re-
10 questing diagnosis, treatment, or counseling for hemophilia.

11 "BLOOD FRACTIONATION CENTERS

12 "SEC. 1125. (a) The Secretary may make grants to
13 public and nonprofit private entities, and may enter into
14 contracts with public and private entities and individuals to
15 establish blood fractionation centers, for the purpose of frac-
16 tionating and making available for distribution blood and
17 blood products, in accordance with regulations prescribed
18 by the Secretary to hemophilia treatment and diagnostic
19 centers.

20 "(b) For the purpose of making payments pursuant to
21 grants and contracts under this section, there are authorized
22 to be appropriated \$5,000,000 for the fiscal year ending
23 June 30, 1974, \$10,000,000 for the fiscal year ending
24 June 30, 1975, and \$15,000,000 for the fiscal year ending
25 June 30, 1976.

1 “(3) A vacancy in the Board shall not affect its activi-
2 ties, and eleven members thereof shall constitute a quorum.

3 “(4) The President shall designate one of the appointed
4 members to serve as Chairman for a term of two years. The
5 Board shall meet at the call of the Chairman, but not less
6 often than four times a year.

7 “(c) The Board may hold such hearings, take such
8 testimony, and sit and act at such times and places as the
9 Board deems advisable to investigate programs and activities
10 conducted under this part.

11 “(d) Members of the Board who are not officers or em-
12 ployees of the United States shall receive for each day they
13 are engaged in the performance of the duties of the Board
14 compensation at rates not to exceed the daily equivalent of
15 the annual rate in effect for GS-18 of the General Schedule,
16 including traveltime; and all members, while so serving away
17 from their homes or regular places of business, may be al-
18 lowed travel expenses, including per diem in lieu of sub-
19 sistence, in the same manner as such expenses are authorized
20 by section 5703, title 5, United States Code, for persons in
21 the Government service employed intermittently.

22 “(e) The Director of the National Institutes of Health
23 shall make available to the Board such staff, information, and
24 other assistance as it may require to carry out its activities.

1 "FUNCTIONS OF THE BOARD

2 "SEC. 1127. It shall be the function of the Board to (1)
3 establish guidelines for the diagnosis and treatment of persons
4 suffering from hemophilia; and (2) submit a report to the
5 President for transmittal to the Congress not later than
6 January 31 of each year on the scope of activities conducted
7 under this part.

8 "RECORDS AND AUDIT

9 "SEC. 1128. (a) Each recipient of a grant or contract
10 under this part shall keep such records as the Secretary may
11 prescribe, including records which fully disclose the amount
12 and disposition by such recipient of the proceeds of such
13 grant or contract, the total cost of the project or undertaking
14 in connection with which such grant or contract is made or
15 used, and the amount of that portion of the cost of the project
16 or undertaking supplied by other sources, and such records
17 as will facilitate an effective audit.

18 "(b) The Secretary of Health, Education, and Welfare
19 and the Comptroller General of the United States, or any of
20 their duly authorized representatives, shall have access for
21 the purpose of audit and examination to any books, docu-
22 ments, papers, and records of the recipient of any grant under
23 this title which are pertinent to any such grant."

[From the Congressional Record—Senate, Mar. 22, 1973]

HEMOPHILIA ACT OF 1973

Senator WILLIAMS. Mr. President, hemophilia is a genetically transmitted blood disorder which prevents normal blood coagulation and results in excessive and sometimes fatal bleeding, either internally or externally. The typical hemophiliac is usually a male who is born with the disease and, in the absence of treatment, suffers its effects throughout his lifetime.

Hemophiliacs fall into three major categories depending on the severity of the disease:

First. The severe hemophiliac is subject to spontaneous hemorrhaging into soft tissues, bones, joints, and muscles, and bleeds after any type of trauma or minor surgery. His system lacks virtually all ability to clot.

Second. The moderate hemophiliac rarely hemorrhages spontaneously but may experience significant bleeding after minor trauma. This individual may go undiagnosed for a long period of time.

Third. The mild hemophiliac is detected only after severe trauma or surgery during which bleeding cannot be easily controlled but in all other circumstances may be said to live a normal life.

Of the 100,000 hemophiliacs in the United States today, an estimated 25,000 were treated for severe and moderate hemophilia during 1970 and 1971, and almost 90 percent of these individuals are below the age of 25.

Mr. President, hemophiliacs are unique among chronic disease victims because they are not born crippled and they can be cured if financial conditions permit them to take advantage of newly developed forms of therapy. Without this ongoing treatment, severe and moderate hemophiliacs must suffer tragic consequences throughout their lifetime and become an unnecessary burden to themselves, their families, and to the whole society. Not only is there a severe physical crisis confronting the hemophiliac, but he is constantly threatened with great uncertainty since a bleeding episode may strike without warning. As a result, there is a tendency among family members and the hemophiliac himself to curb many otherwise routine day-to-day activities for the sake of the sufferer. This kind of psychological toll is impossible to measure, and in many cases it is devastating.

In the mid-1800's, it was found that bleeding in a hemophiliac could be controlled to some extent through the transfusion of whole blood into the patient. This was the beginning of what is known as replacement therapy. But, this was not a very satisfactory or efficient means of treatment. In the last two decades, medical research made great advances in discovering the missing factor which prevented blood coagulation and in 1964 it was demonstrated that this factor—primarily the element now known as factor VIII—could be removed from human plasma by a process called cryoprecipitation. At last there was new hope for effective treatment for hemophilia.

Unfortunately, replacement therapy for those afflicted with this disease has not been widely available principally because of money. The administration of the clotting factor by a physician or nurse is expensive. Costs are further increased because blood banks often fail to

fractionate, cryoprecipitate, or do not have it on hand thus necessitating purchase of more expensive commercial forms of factor VIII. And so, when clotting factors were first approved for therapy, it would easily cost \$25,000 for such ongoing treatment. This made replacement therapy virtually out of reach for the typical patient.

Some progress has been made in recent years. New techniques have made it possible for most hemophiliacs to self-administer the appropriate clotting factor at home. Inpatient care is usually necessary for surgery or when a serious trauma is inflicted. Outpatient care by a physician or nurse may only be required for initial testing and training with only periodic followup treatment. And the clotting factor itself is beginning to be a bit more available than at the outset. And so, the costs associated with replacement therapy have been brought down to the point where it is estimated that the hemophiliac requiring ongoing treatment may obtain it for an average cost of \$6,000 per year.

But, Mr. President, \$6,000 is a lot of money, especially for the average American family. We are all aware that the median family income in the United States is \$10,300 and it is clear to me, therefore, that most households with a hemophiliac simply cannot afford to take advantage of this lifesaving therapy. In my judgment, this Nation has a responsibility to provide the necessary assistance to assure that every individual afflicted with hemophilia will be able to afford replacement therapy for this dread disease. Because the resources are available to save these lives and to permit a normal future we must provide the funds necessary to achieve this goal. We can do no less even for this relatively small segment of our population.

It is for these reasons that I am today introducing the Hemophilia Act of 1973. This is a simple bill with a clear objective. It says that every hemophiliac shall be entitled to care of this disease consistent with available technology and with that person's ability to pay for such care. It establishes a claims program to be administered by the Secretary of Health, Education, and Welfare whereby any hemophiliac in need of replacement therapy shall be entitled to payment either directly or on his behalf in an amount equal to 100 percent of the actual cost of providing blood, blood products and services associated with such treatment.

The Secretary is authorized to make such payments minus the amounts payable for such treatment by third parties and minus amounts determined by him to be payable by such individual based on the income of the individual. Thus, with the enactment of this legislation, no hemophiliac need ever be concerned that he shall go untreated for lack of funds. This is an entitlement payment on behalf of such individuals and as such the necessary funds would be appropriated out of general revenues in order to meet the costs of these claims. My estimates are that this aspect of the bill would cost between \$125 and \$150 million annually.

In addition to this provision, the bill would address itself to several other important problems associated with hemophilia.

At the present time there are only a scattering of medical centers in the United States which provide any major emphasis on the treatment and diagnosis of this disease. Thus, there are only a few areas in the country where there are adequate treatment and diagnosis facili-

ties or where there is decent social and vocational counseling for hemophilia patients.

Also, we face short supply of professional and paraprofessional personnel trained in hemophilia diagnosis, treatment, and research. Nor do we have adequate mechanisms whereby physicians in outlying areas have adequate contacts with those centers which have hemophilia, diagnostic and treatment programs.

In order to meet these needs and to provide a better focal point for individuals participating in the hemophilia claims program, my bill authorizes funds for the establishment of no less than 15 hemophilia diagnostic and treatment centers. The Secretary is authorized to make grants to public and private nonprofit entities for such projects and it is contemplated that such centers will be established in areas where there is the greatest need for such services.

Another problem associated with hemophilia is the existing lack of blood fractionation centers which provide the clotting factor.

In large part this situation is due to the fact that this Nation has yet to develop a rational and efficient blood policy. It has been estimated that the demand for blood products for treatment of hemophilia could necessitate the use of 13 million units of blood annually. This represents more than the current annual supply of all whole blood units.

Thus, it is necessary that only those factors needed by hemophiliacs be fractionated out of whole blood for their use and the other components be fractionated for other uses. This is precisely why we need a more intelligent blood fractionation policy like that which has been developed in Australia and Scotland. That is why I have included a provision in my bill to authorize the Secretary to make grants and enter into contracts for the establishment of fractionation centers to extract necessary blood components and make them available for distribution to hemophilia and treatment centers.

While this will only make a dent in solving the blood supply problem, it will be an important first step in assuring that a larger supply of blood products is available for hemophiliacs and at the same time will assure that other blood products may be derived from the same blood units. I realize that this is a very difficult and complex problem, but it is time that we addressed ourselves to the whole issue in a well thought-out fashion. For without better management of our blood resources we will soon be faced with a major crisis in medical treatment which requires the use of blood and blood products.

Finally, the bill would establish a National Hemophilia Advisory Board which would establish guidelines for the diagnosis and treatment of hemophilia. The Board will be composed of 20 members including the Secretary, the Director of NIH, and 18 others from among the leading scientific and medical authorities in this and related fields. The guidelines which are developed would have to be followed by those treating hemophiliacs and who are reimbursed pursuant to the authority in the bill.

Mr. President, in the past 2 years, several States, including New Jersey, have enacted legislation to establish programs for the care and treatment of hemophiliacs. These assistance efforts were undertaken because of the enormous costs associated with the disease and

the inability of the private sector to provide adequate funding for on-going treatment. But these States which have taken action are unable to appropriate more than a small amount of money for this purpose. Nor is the National Hemophilia Foundation, with its 55 local chapters, in a position to raise enough funds from private resources to assure that hemophiliacs and their families will be able to bear the heavy financial burden of replacement therapy.

During the past several months, I have noted the beginning of a great national debate which poses the question: "What good is having the ability to control disease if we cannot get treatment to those who need it?" It does not seem possible that so rich a Nation as the United States can say to an individual suffering from kidney disease, cancer, or hemophilia that we are not going to provide you with the resources to live a normal life, or that we have made enormous progress in finding new therapies but they are of no use to you since you cannot afford them. And yet, some people are indeed taking this view.

As one Senator, I cannot and will not adhere to such a philosophy. If it will cost \$150 million to save the lives of 25,000 Americans who suffer from hemophilia, then I say let us act now to provide those funds. Man's humanity to his fellow man demands at least that much. And if we can at the same time find more effective and less expensive means of controlling hemophilia, let us vigorously pursue that course as well. But we must not delay any longer in either endeavor.

PREPARED STATEMENT OF HON. BOB DOLE, A U.S. SENATOR FROM
THE STATE OF KANSAS

Senator DOLE. Mr. Chairman, more than 100,000 Americans are afflicted with hemophilia, a disease characterized by the deficiency of necessary clotting factors in the blood. Many more Americans can bear personal witness to the burden borne by those suffering from hemophilia, who must face each day with the ever-present knowledge that even the slightest cut or bruise could prove a major crisis.

For thousands of years, the only treatment for hemophiliacs from birth to death was to live limited and guarded existences. Now, within the last decade, medical research has perfected a technique for isolating the specific blood plasma factors lacking in the blood of hemophiliacs. With regular transfusions of these clotting factors, hemophiliacs can be freed from the atmosphere of daily fear in which they have been forced, merely by an accident of birth, to live.

I think it is important that all Americans suffering from hemophilia be guaranteed the right to benefit from these medical advances. Therefore, I am glad to express my support of S. 1326, the Hemophilia Act of 1973, today to be considered by this committee. This bill provides for the creation of at least 15 centers for the diagnosis and treatment of individuals suffering from hemophilia, at a cost of \$30 million over the next 3 years. An additional \$30 million will be used to develop blood fractionation centers, for the purpose of creating an adequate supply of blood and blood products for hemophiliacs. Finally, financial assistance will be made available to those individuals who are unable to afford the necessary treatment—the latter aspect is fiscally prudent, while at the same time it guarantees equal accessibility, which is intrinsic to the American concept of equality.

Senator WILLIAMS. We have a great number of witnesses this morning who have come to discuss hemophilia: the nature of the problem; its impact on patients and their families; and its relationship to blood policy in the United States.

You have come from all parts of our country, I know. You arrived early and have made your time on Capitol Hill most productive. I do not think there is a Senator I have spoken to since noon yesterday that has not received a visitor and learned of interest in this bill, as a response to a disease that need not have all of the devastating effects that it does have today. It need not because the techniques are there, methods are there, knowledge is there to meet the disease, and that is in part what this bill is all about.

Let me first call on Roy Heavner, president of the National Hemophilia Association.

Roy, can I make you sort of chairman of this opening panel? Would you introduce them one by one?

STATEMENT OF ROY HEAVNER, CHAIRMAN, HEMOPHILIA ASSOCIATION; SAM HUFF, MANAGER OF MARKET DEVELOPMENT, MARRIOTT HOTELS; LOUIS N. FRIEDLAND, PRESIDENT, MCA-TV, NEW YORK CITY AND CHAIRMAN, NATIONAL HEMOPHILIA FOUNDATION; LOUIS M. ALEDORT, M.D., MOUNT SINAI MEDICAL CENTER, NEW YORK CITY; HENRY TAUB, PRESIDENT, AUTOMATIC DATA PROCESSING SERVICE, NEW YORK CITY, AND VICE CHAIRMAN, NATIONAL HEMOPHILIA FOUNDATION; KATHERINE EARNSHAW, EXECUTIVE DIRECTOR, THE NATIONAL HEMOPHILIA FOUNDATION, NEW YORK CITY; AND ELIZABETH WINCOTT, SOCIAL WORKER, THE MOUNT SINAI HOSPITAL, NEW YORK CITY, A PANEL

Mr. HEAVNER. Thank you. On my immediate left is Sam Huff, who was formerly with the New York Giants and now manager of market development of the Marriott Hotels. Mr. Huff will tell how and why he is involved with hemophilia.

On my immediate right is Mr. Louis N. Friedland, chairman of the board of the National Hemophilia Foundation and president of MCA-TV, who will speak as a father.

At the far end of the table on the far left is Mr. Henry Taub, president, Automatic Data Processing Service, New York City, and vice chairman, National Hemophilia Foundation, who will talk a little bit about why he as a successful businessman became involved in foundation affairs.

Next to Mr. Taub will be Katherine Earnshaw, executive director of the National Hemophilia Foundation, who will tell you of the role of the foundation.

Next to Mrs. Earnshaw is Dr. Louis M. Aledort, who is the medical director of the National Hemophilia Foundation, and he will tell of the medical aspects of the disease and also an associate professor of clinical medicine, Mount Sinai Hospital in New York.

Next to Dr. Aledort is Elizabeth Wincott, social worker in the comprehensive clinic at Mount Sinai Hospital in New York.

With that we will proceed with Mr. Huff.

Senator WILLIAMS. Mr. Huff, we are very pleased to have you here and are looking forward to your statement on this bill.

Mr. HUFF. Senator, it is very nice to be here and I appreciate your presence and the help you have given us in introducing Senate bill No. 1326, and we hope you will assist in getting it passed in the Senate. As you know, and many of you know, I am an ex-athlete. I played for a small high school in Farmington, W. Va., in the great State of West Virginia, and I see Senator Randolph is the senior Senator on this committee.

Also I attended West Virginia University and I played football for the New York Giants for a period of 8 years, and I might add they were successful years in New York. Also in 1964 I was traded to the Washington Redskins, and those were in the intermediate building of character years here in Washington.

I have also had a run at running for the U.S. Congress and I could not run fast enough, and I appreciate the efforts of so-called Senators and Congressmen.

A lot of people have asked why Sam Huff is interested in hemophiliacs. Of course I am interested in the health and welfare of all Americans across this country, but when I was a youngster I myself used to have quite a lot of nose bleeds. That was before I became an athlete, and the doctors had thought that I was a hemophiliac and that was the first time that I had heard of the disease, and in playing the great sport of football or any other contact sports, as many of you know, a hemophiliac does not have the opportunity for the simple reason if he receives a scratch or an internal injury which goes along with playing the sports like football, you cannot get the bleeding stopped. Therefore, these youngsters, such as Matthew, whom you are going to meet later on. He is a hemophiliac, and he is 6 years old. He will never have the opportunity that I had to the fun and games that we have played. This is the reason I am here this morning to see what I can do to lend my support and help to you, Senator Williams, in doing everything that I can to see that boys like Matthew and other hemophiliacs have an opportunity and maybe cure other youngsters so they will have the opportunity to play and participate and even take a simple thing like a vacation in this great country of ours, because now the problem in John and Ann taking Matthew away from Washington or away to another city, even to take a simple thing like a vacation, is that if something should happen to Matthew, where would they go to get the treatment? Where would they go to get the particles of blood that Matthew needs if an accident should happen? So these are the problems that confront hemophiliac parents and the hemophiliac youngsters. They have a hard time even taking a vacation.

As I said earlier, I am from West Virginia. In a lot of ways we are behind some other States in health, education, and in a lot of ways, but we are coming on. Our State is coming on. It is becoming known as a recreational State. But where would you go if you attended one of our State parks and an accident did happen to Matthew or any other hemophiliac? Where would you go to get treatment? Who would you go to that knows how to treat a hemophiliac, which is another big problem?

I am sure in a lot of medical centers, a lot of clinics and hospitals, a lot of people do not know how to treat a hemophiliac patient, and become very frightened just at the word "hemophiliac." They really do not understand. So we have a great path to follow in the world of education, letting people know what hemophiliacs are. You take a lot for granted.

Even in the world of athletics, there is a lot taken for granted. If you pull a muscle, injure yourself, you sprain an ankle, how many people do not know to put ice first, heat later after 24 hours? A lot of people do not know this. Even athletes do not know it. If you injure yourself and apply heat, you create internal bleeding.

So we have a great job ahead of us in educating people to the problem of hemophiliacs and what hemophilia really is.

These are some of the problems that we present here today. I am looking over some of the things that we need which your bill covers and that is financial assistance, so that no hemophiliac need ever be concerned that he shall go untreated for lack of funds. If you are a hemophiliac and there is medicine available, it is quite expensive. I understand it costs \$22,000 if you are a severe hemophiliac. There are great strides that have been made in being able to break the whole blood down into different parts, so that a hemophiliac like Matthew only needs one part of blood and the other parts of the blood can be used for other types of disease. These are some of the great strides that have been made in the medical field.

There are other things that really need to be accomplished also. That is to make these research centers and these treatment places available so that our people when they are traveling and taking vacations or going maybe back home know where these treatment centers are and these centers have the proper doctors and proper staffs to man them and take care of hemophiliacs.

To quote a great man that I used to have the pleasure of playing for and coaching with, Vince Lombardi. He said that in the world of football everything happens between the goal lines. Everything that happens in between the goal lines is for the fans. When you get to the goal line, that is for us. Get the ball into the end zone because that is for us.

I think that in this world of research, a lot has been accomplished, a lot has been accomplished between those goal lines, and now we are at the goal line, let's get it in and get the game over with and let's educate the people to what hemophiliacs really are.

Senator WILLIAMS. Thank you. Very excellent statement. I would say in your profession there are two other respected and most admired well-known football players, that are honorary cochairman of the national association, Roger Staubach and George Blanda, who were invited here, but they are getting ready for Sunday and could not be here today.

Mr. HUFF. Those are two quarterbacks, Senator, and there is not a whole lot of problem because they have 10 guys protecting them, you see. You are in real trouble when you have 10 guys after you, like I had, and that is the reason I got out of the game early. I would like to make a statement that I am still younger than Sonny Jurgenson, and he is still playing.

Senator WILLIAMS. Some of those fellows got to Staubach last time.

Mr. HUFF. You do not see him running any more like he used to.

Mr. HEAVNER. Senator, Louis N. Friedland will be next.

Mr. FRIEDLAND. The first thing I want to do is to thank you personally and your staff for a remarkable demonstration of what Government is at its best. I do not refer to this particular session. I refer to the great conviction and ability that you have all demonstrated and to you, sir, a really great humanitarian, we thank you one and all.

Senator WILLIAMS. Thank you very much.

Mr. FRIEDLAND. My name is Louis Friedland. I am chairman of the National Hemophilia Foundation. Sometimes when I get a chance to do it, I am also president of MCA-TV, which is associated with Universal Studios in California.

I am here today to speak for the fathers of hemophiliacs, and especially those fathers whose sons have not escaped from the chains of this disease as my son has done. Really we have participated in something that truly can be called a medical miracle, because for the first 17 years of his life, my son Eric, who is in the back, lived, and I mean literally lived in leather braces day and night, never took them off. The purpose of the braces was to offer him some support and protection for his joints which had been destroyed by hemophilia. Most people do not understand or do not know—they think that if you have hemophilia, you simply bleed if you cut yourself. One of the great consequences of hemophilia is that it bleeds massively into the joints, as Dr. Gilbert will show later, and it rusts and rots the bone tissues, so that you have really a tremendous amount of damage and injury. But more than anything in my experience is the pain that these young people undergo when the joints swell.

I might give you some kind of idea of what we are up against. You can barely lift these braces [indicating] when you put them all into a golf bag. Nothing moves. The joints do not move. Sometimes they do if you are lucky. The muscle and everything else deteriorates pretty badly. Eric wore these on his legs most of his young life. He wore these on his arms. He wore this on his hand very often. Eric is a hell of a pianist now and does not need any of this.

The amazing thing is that 4½ years ago when the concentrate, which is a blood derivative, became available—and Eric will show you later how he infuses this—Eric was one of the first kids to be put on a daily routine of self-infusion. Every day of his life he gives himself an infusion of a white substance about the size of a quarter cube of sugar and makes an injection into the vein. He protects himself for that day so he can live a very normal life during that day. I will tell you this for Eric, he has lived one heck of a normal life for the last 4½ years. The first year out, he drove 40,000 miles, and as I say, "straight up." He went to Europe, traveled all over Europe. He has a girl friend, and she is a remarkable gal. He also attends Harvard as a student. He is in his third year now.

Here is a boy who was really never surely able to get to the bathroom without assistance, and in these things [indicating] as I said, day and night—who now lives a perfectly normal existence, and then some. But it costs us \$60 a day. He takes two vials, \$30 a vial, and he really should take four or five, but that is another question. It costs us \$22,000 a year.

What about all the other kids? How many kids do we know—I pay for it, by the way—how many kids do you know in this world whose parents could give them \$22,000 a year, or even the \$5,000 or \$6,000 a year which on average we think it would take to take care of most of the hemophiliacs; those that are less severe would need it less frequently or in less massive doses. We figure that it would be about \$5,000 or \$6,000 a boy—for these other kids, the ones that really do not get this treatment at all, the ones we are pleading here for you to do something about. What Eric does is he gives himself this shot at home. He never shows up at a hospital; he just goes right by it. He does not bother to call his doctor from time to time as he should. Maybe once a year he shows up in California because he likes it there.

This is the degree of security and degree of safety that he has had.

I want to tell you this one thing that really made it absolutely essential for us to continue in this work. When I used to go to pick up the stuff that Eric uses, in those days they did not deliver the material to your home because of the newness of the project. You had to go to the hospital to get it. Eric and I and his mother used to spend 4 or 5 nights of each and every week in the emergency rooms of hospitals waiting from 11 o'clock at night until 2 a. m. for this thing to be done; we literally spent our lives there. When I went back to these hospitals to pick up material that was delivered there for us—there were four, five, six kids waiting there, joints swollen, in speechless pain, really—I walked through emergency rooms to bring this package of goodies home for Eric, while these kids sat there waiting for some intern to infuse them with some substance. You cannot have a situation where, based on ability to pay, for want of a dollar bill some kids do not have it.

By tremendous amount of work, magnificent people—many of the people are in this room and elsewhere—were able to give many kids pretty good care. Were able to give them enough material so that if they had been hurt or think they had been hurt, they infuse themselves and protect themselves from the consequences of the thing.

In some areas we have very few kids that are on what we call prophylaxis—preventive care like Eric is. But in a lot of cases, a tremendous number of kids despite all our efforts, the medical profession, doctors, community people, people with or without money, all sorts of people have come forward to render some kind of assistance.

What we need to do is make sure that all assistance is level. The material exists. The procedure is relatively simple. It can be taught to a young person or his parents, and it is truly unfair, incorrect, and immoral to hold it on the basis of ability to pay. There really is no way that I can think of—and I understand the problems that Government faces, or at least I have begun to understand them—but there really is not any way that you can say to a kid that the Government is not ready this year or next year, so in the meantime, you know, sleep in these braces [indicating]. It hurts a hell of a lot, I tell you, but in 2 or 3 years we will get to you. We just cannot do that.

Thank you.

Senator WILLIAMS. Thank you very much, Mr. Friedland.

Senator Dominick came in during your testimony. I was going to ask you to exhibit the braces. Your son wore them for how long?

Mr. FRIEDLAND. Eric wore various kinds of braces in his first 6 or 7 years. But from the 7th year of his life, until the 17th year of his life, he wore these at all times. By the way, these are not terribly inexpensive, either. I think they are close to \$900 or \$1,000 a piece. He wore these and at the same time he wore this one on his left arm and this one on his right arm. We got to the point where this small amount of motion on the right arm had to be eliminated and there is a little device in here that locks it. He opened it only on rare occasions.

Senator WILLIAMS. Eric was in braces until he was age 17?

Mr. FRIEDLAND. Seventeen.

Senator WILLIAMS. And he is now how old?

Mr. FRIEDLAND. Twenty-two.

Senator WILLIAMS. What happened at age 17?

Mr. FRIEDLAND. Now, at 17, Eric went to California to a general care center, such as is called for in one of your bills. They gave him a daily infusion of this new blood derivative; it is a concentrate which made it possible for them to exercise him. That is something that would have been unthinkable with his joints rusted as they were; all kinds of damage could have occurred. By exercising him for 5 or 6 hours a day with the concentrates, at the end of about 6 weeks he built up enough muscle and resilience around his bone and tissue that he could leave, and then he was put on a daily routine. He was put on it only because he can afford it. There was no way on earth that he could have been given this relief except that he could pay the \$60 a day to give himself a daily infusion.

He has done that now for 4½ years. And as I say, he has been absolutely free to do whatever it is that a young man realistically might be expected to do.

Senator WILLIAMS. When was this blood first isolated or discovered, whatever the word is?

Mr. FRIEDLAND. Senator Williams, I think Dr. Aledort will cover that. I will tell you it became commercially available to us in sufficient quantity about 4½ years ago.

Senator WILLIAMS. The number that I have been told who are now being treated is 25,000, but there are known to be at least 100,000 who probably should be in treatment?

Mr. FRIEDLAND. That is correct. The National Institutes of Health has published a survey which they conducted and which I think was a very authoritative piece of work indicating 100,000 hemophiliacs, 25,000 of whom required substantial treatment within the last 2 years.

Senator WILLIAMS. I am sure we will develop through the rest of the day all of this. Thank you very much.

Senator Dominick?

Senator DOMINICK. I must say, Mr. Chairman, that I have read over your opening statement and have read over the bill and there is nothing in the world that I would not like to see done in order to help solve this problem. It is a thing which is tough for anybody who has this particular disease. A number of my friends whom I have known well have had it in the past, one of whom subsequently died. It is a very, very tough problem. I would like to ask Mr. Friedland just a couple of questions on it just the same. First of all, Mr. Friedland, you are working with the National Hemophilia Foundation. Do you not get con-

tributions into that from foundations and a variety of other groups that will help you fund these expenses?

Mr. FRIEDLAND. We certainly do. But if you consider the cost of an average of \$5,000 and multiply that out by 20,000, you arrive at a figure about 30 times larger than we have been able to get our hands on, you see. Where the help has come from is the capacity of people in this room and many like them to organize medical centers where third-party payments were found, where blood campaigns are conducted and traded out for industrial products, where the community itself gets behind the service as in Rochester, for example, and furnishes substantial care. In one or two places, Pennsylvania is very noteworthy, the State has come forward recently to help us. But generally it was a tremendously tough schedule until about 31½ years ago when we reorganized the foundation, to be able to bring a modicum of respectable care to kids in emergency situations. We are getting to the point where we are reasonably past the dreadful emergencies and getting some kind of medical care, but we still lost two young men last month that I personally knew.

Senator DOMINICK. I do not want to get fiscally prudent on a situation like this nor in trouble, but practically every one of the States is in a surplus position, and the Federal Government is in a totally deficit position. Why do you not go to the States for help?

Mr. FRIEDLAND. Well, Senator, I am sure this will be covered by others. I will tell you very briefly. The degree of assistance that is received in one State as compared with another makes it impossible for us to get a reasonable degree of similar care for all of these kids. The fact that some States are in surplus really does not mean that we could protect these kids throughout the country. It would be too much of a crazy-quilt of treatment. We do look for State assistance and will continue to do so.

Senator DOMINICK. I wondered about that. You mentioned Pennsylvania. My own State passed a bill in 1973 and appropriated some funds for it, which I am very proud of. I wish it had been a little bit more than they appropriated, but that is a start. What effort is being made through other legislatures to try and get this done?

Mr. FRIEDLAND. Senator, in this year we are planning to make a very substantial effort, and the reason we have not, quite honestly, is we have dragged ourselves up from a fantastic debt 3 years ago, to the point where we are beginning to meet this capacity to pay.

Pennsylvania succeeded because of wonderful people at both ends, your end and ours.

Mr. HEAVNER. May I make a suggestion. We are going to deal with the role of the foundation and several aspects I think of all of these questions. Perhaps it might answer some of Senator Dominick's questions.

Senator WILLIAMS. I did want to accelerate that for Senator Dominick. I know he has many meetings this morning, in the event he has to go to one of the other meetings.

Mr. HEAVNER. The next witness will be Dr. Louis Aledort, who is medical director of the foundation.

Dr. ALEDORT. Mr. Chairman, I am Dr. Louis Aledort, associate professor of medicine at the Mount Sinai School of Medicine, director

of the coagulation laboratory, codirector of the International Hemophilia Training Center at the school and medical director of the National Hemophilia Foundation.

Hemophilia is a genetic disorder of the blood in which a clotting factor is either partially or completely missing. Hemophilia is widely known as "bleeder's disease." From a recent NIH survey there are approximately 26,000 severely and moderately severely involved patients in this country. This disease has no predilection for any race, color or creed.

The hemophiliac is subject to hemorrhaging, both internally and externally. Bleeding is usually spontaneous; that is, without apparent cause. Bleeding is extremely painful and the episodes are unpredictable.

With repeated bleeding into joints, the hemophiliac becomes crippled by his own blood. Even a simple tooth extraction, for example, presents a major problem for the patients, requiring many transfusions, and in some instances, hospitalization.

Major studies are being carried out in both the basic and clinical research areas of the disease. Few diseases have profited as much from scientific advances as has hemophilia. Until the 1960's the treatment of hemophilia was inadequate and many patients were both physically and psychologically crippled.

Since the discovery that a small portion of human blood plasma, rapidly frozen and slowly thawed, contains material rich in the missing clotting factor for 80 percent of hemophiliacs, treatment of this disease has been revolutionized. By replacement of this missing factor, derived totally from human blood, bleeding is rapidly checked with prompt cessation of pain. Extrapolating from experimental data, prophylactic care promises to eliminate all sequelae of hemophilia.

The clinicians, no longer having to focus on the acute crises produced by bleeding, have made major strides in this disease. They have developed the concept of home care, of self-infusion and the comprehensive care approach to hemophilia. It is now possible for patients to self-administer treatment immediately, following bleeding, thereby obviating (1) the crippling effects of delayed treatment and (2) the need to be brought to a treatment facility which is both time consuming and costly.

At present, as only 10 percent of hemophiliacs are on home therapy, 65 percent of patients under 16 years of age have poor school attendance. In addition, more than one-half of the 40 percent of hemophiliacs over the age of 16 who are unemployed, are not working because of the ravages of the disease. It is for lack of funds that many patients are unable to get care and this is false economy.

The amounts of money required for replacement materials is truly small when compared to the sums required to support these people when they are medically indigent. We have the knowledge and tools to make them productive.

There are many reasons why this disease has such high morbidity. Twenty-two percent of hemophiliacs are being treated today by physicians who have only seen one such patient. Thus despite the brilliant scientific and clinical advances such as the programs of self-infusion which emancipate the patient, a large number of sufferers are not

recipients of good care. Only a handful of comprehensive care clinics exist in this country, staffed by hematologists, orthopedists, dentists, social workers, psychiatrists, physical therapists and vocational and genetic guidance counselors.

These centers are capable of making accurate diagnosis, prescribing care, making the patient aware of the available resources in his community, to delivery or help pay for care.

It is imperative to guarantee all hemophiliacs such opportunities, if not in their immediate area, at least within a reasonable geographic distance from their home. Hemophiliacs are unique among chronic disease victims because they are not born crippled, and can be maintained as normal productive citizens if they are allowed to continually receive their missing clotting factor appropriately.

Replacement therapy requiring human blood, challenges our blood banking technology. In 1971, approximately 9.5 million units of blood were collected in this country by more than 5,000 facilities. Recently it has been recognized that by fractionation of blood, a single unit of blood can supply the needs of many. This means that a unit of blood is fragmented and its parts distributed according to specific needs.

One type of hemophiliac, for example, needs only a small plasma portion called cryoprecipitate. Another hemophiliac is able to utilize the remaining plasma, a leukemic is able to utilize the platelets derived from the same unit, while another patient perhaps hospitalized with a bleeding ulcer, might use the red cells.

Because of our poorly coordinated blood services, only about 30 percent of our blood is fractionated, in contrast to Australia where all collected blood is fractionated into 15 components. In addition, 28 percent of all blood is wasted, in part due to its uneven distribution and utilization.

For all hemophiliacs to receive prophylactic care, it is estimated that the material from more than 13 million units of blood is required. Thus, hemophiliacs face a critical shortage of this precious natural resource. Our country can only come to grips with this by providing the funds for centers charged with fractionation of whole blood into its component parts, so that optimal utilization of blood can be achieved. If all blood now collected was fractionated, we might find that our present volume could meet our national blood needs.

Hemophilia poses severe financial problems. Replacement material is extremely costly, running from \$5 to \$30 a unit, depending on the locality where it is administered. A single hemophiliac commonly uses between 100 and 150 units per year. The average family spends at least \$2,400 per year per involved child for replacement therapy, but may be as high as \$41,000 per year.

Families with more than one hemophiliac child are not common. These costs are solely for materials to treat spontaneous bleeding. In addition, there are hospital costs, doctors' fees, and the immeasurable losses in time away from school and work.

It is estimated that these total costs add up to \$6,400 per year per patient. At present, a large number of hemophiliacs are handicapped by deformed joints which impair their ability to achieve vocational and educational rehabilitation. Reconstructive surgery for the correction of crippled joints is extraordinarily expensive, and the costs

of replacing the missing clotting factor alone, without medical or hospital costs, can be as much as \$15,000. Programs of early therapy offer hope of diminished crippling, thus enabling the hemophiliacs to be productive citizens.

It is not unusual to find that the adequacy of treatment is directly related to the ability to pay for it. Even when patients are eligible for medical insurance, medicaid, crippled children's service, State hemophilia programs, et cetera, the coverage is variable from area to area and frequently inadequate.

Hemophilia is an excellent example of coordinated scientific and clinical advances which have changed the patient from an inhospital patient to an active productive member of society frequently receiving his lifesaving treatment by himself on the job, or at school, unfortunately in many cases to his financial disadvantage.

His insurance may well pay for inhospital and/or outpatient blood needs, but rarely at home or at work or school. It seems quite contradictory to spend large sums of money developing technology to alleviate suffering and promote productive lives for such patients, without creative programs for financing its delivery.

Hemophilia offers us the rare opportunity of being challenged by a solvable medical problem requiring three things: (1) A rational utilization of a natural resource, blood; (2) providing the adequate financial support to pay for it, and (3) the development of centers to deliver the care we have already mastered. If we cannot solve this medical problem, what other disease can be conquered? It is for these reasons that we support this bill, S. 1326, wholeheartedly. It is the first imaginative and creative attempt to solve all aspects of a disease. Thank you.

Senator WILLIAMS. Thank you, Doctor. For easier understanding, at least for me, what is a more convenient measure for a unit of blood, is it equal to a pint?

Dr. ALEDORT. We talk about a unit of blood and we are talking about a unit of plasma, talking about derived from a single unit of blood. A unit is equal to a unit of blood.

Senator WILLIAMS. What is a unit?

Dr. ALEDORT. It is a pint of blood.

Senator WILLIAMS. And right now, am I correct in understanding that 13 million units of blood are collected each year?

Dr. ALEDORT. What we are collecting presently is only about 9½ million units of blood, and we calculated from the National Institutes of Health survey that about 13 million units would be needed to meet the needs of prophylactic care for hemophiliacs in this country.

However, it is felt when fractionated blood is being collected appropriately, we might not need this deficit type of blood collecting which is a problem at the present time. This country has been importing plasma from other countries to make the concentrates for these patients because we did not have enough blood to meet demand. At the moment, there has been a major stoppage of this importation because the other countries no longer want their plasma being sent to this country.

Senator WILLIAMS. Will there be any other testimony on our present blood policy?

Mr. HEAVNER. It will be developed later.

Senator WILLIAMS. Thank you.

Mr. HEAVNER. Our next witness is Elizabeth Wincott, social worker at the Mount Sinai Hospital.

Ms. WINCOTT. Mr. Chairman, ladies, and gentlemen, I am Elizabeth Wincott, a social worker at the Mount Sinai Hospital in New York, and I am assigned to the Hemophilia Clinic.

Social workers are concerned with the achievement of optimal social functioning of patients as individuals, with their families and within the context of the community. I would like to address myself to two provisions of the bill—those concerning costs and with the establishment of comprehensive care clinics.

Currently, the enormous cost of medical care, particularly for blood products, presents an impossible burden for almost all economic levels. This creates an overwhelming anxiety, especially for families who are already coping with the extraordinary demands of rearing a hemophiliac.

The anxiety quickly transmits itself to the attitudes of the child himself. These families and medical facilities are currently caught up in a frantic search for means of financing the required care. I can attest to case after case illustrating the extreme hardships and frustrations for the people affected.

A comprehensive care clinic includes a hematologist, orthopedist, psychiatrist, physiatrist, dentist, social worker, physical therapist, and vocational counselor. This clinic provides help to patients and their families, not only in crisis, as they are usually seen in hospitals, but also in coping with day-to-day adjustments.

In our clinic at Mount Sinai all new patients and their families are screened by the full team and a plan is developed for the various specialists to follow through as the group determines the need.

Patients also understand that all members of the team continue to be available. Experience in our clinic shows a very favorable response to this approach. Many expressed the wish that this scope of help had been available to them earlier.

Early social work intervention helps—

1. By providing families assistance in minimizing their natural tendency to overprotect the hemophiliac and to maximize his independence within recommended medical limits. Among other benefits this increases the school attendance rate.

2. Preparing hemophiliacs and their families to meet the normal stages of social adaptation including schooling, vocational selection, development of personal relationships, and participation in community activities.

3. Helping to deal with the feelings in parents, of guilt, anger, apprehension, and rejection and in the hemophiliac himself with a sense of difference as well. These feelings can lead to distortions and misconceptions which require professional clarification.

4. Meeting the concerns about marriage and parenthood within the framework of genetic counseling.

5. Helping the hemophiliac who is having particular emotional problems in adjusting to his situation. For example, acting out in a way that is dangerous to him. We can, together with the psychiatrist, work

with the patient and his family in helping him to understand the causes of his behavior and hopefully to modify it.

6. Acting as an educational and informational resource for schools and other community agencies, often minimizing their reluctance to accept hemophiliacs.

I have just described one part of an interdisciplinary approach to working with hemophiliacs and their families. The overwhelming psychological, social, and environmental impact on these families calls for comprehensive care clinics which we believe will minimize the need to use facilities staffed by nonspecialist personnel unprepared to deal with the complications resulting from the disease, thereby reducing the overall costs in money, in time, and in emotional trauma.

It is for the above reasons that I should like to strongly support bill S. 1326.

Senator WILLIAMS. Thank you very much. How long have you been working with hemophiliacs as a social worker in Mount Sinai?

Ms. WINCOTT. I have been at Mount Sinai Hospital for 4 years, Senator.

Senator WILLIAMS. Well, your dedication to your work can be measured in many ways: One way today, I gathered from the inflection, a little bit British, and you are here and not at the wedding. [Laughter.]

Mr. HEAVNER. Mr. Chairman, in the interest of time, I would simply like to enter for the record the statement of Dr. John Hickman, a Dallas psychiatrist and leader in the foundation, on the psychological aspects of comprehensive treatment.

[The prepared statement of Dr. Hickman follows:]

PREPARED STATEMENT OF DR. JOHN HICKMAN, PSYCHIATRIST, DALLAS, TEX.

THE PSYCHOLOGICAL IMPACT OF A TOTAL TREATMENT CENTER ON THE HEMOPHILIAC

I am Dr. John F. Hickman, private practitioner of psychiatry, consultant psychiatrist to the Dallas County Sheriff's Department, National Hemophilia Foundation Executive Committee member, and Co-Chairman of the Medical and Scientific Advisory Board of the Dallas/East Texas Chapter of the National Hemophilia Foundation.

I have been asked to direct a few comments to the psychological impact that a total treatment center has upon the hemophiliac patient and his family. In order to understand why these remarks are being made one must first understand basically two aspects of the typical treatment available to the hemophiliac.

First, there is an appalling divergence in the basic treatment approach to hemophilia that exists from town to town and from one section of a city as compared to the other. Even more appalling is the lack of communication between specialty physicians located in the same area who are involved in treating the same patient. Many of our patients and their families are fully aware of the disparity and inconsistency of treatment modes and all of them sense the lack of communication that exists. The emotions of despair, confusion, and futility accompany any family who is in search of treatment for this illness. If the crisis of confused treatment modalities has not been solved when their search begins, serious erosion of the patient's identity by the aforementioned emotions begins.

Secondly, superimposed on this state of affairs is the psychological crisis that accompanies any hemophiliac and his family. Familial tension and dissension are invariably created by an overprotective (or infrequently underprotective) mother who harbors potent guilt feelings concerning her role in transmitting this genetic defect to her offspring. The father, who resents this overprotectiveness as well as the defect within his child, withdraws into ineffectiveness. Familial communication ceases, schizm occurs, and the patient's psyche is threatened.

Such psychic threats to the hemophilic and such familial and medical disunion and discord cannot be handled by a singular physician. Only the cohesive identity of a unitized total treatment program comprised of all the medical specialties required to adequately treat this illness (hematologists, orthopedists, dentists, psychiatrist, etc.) can overcome the aforementioned disparities and psychic assaults. In the total treatment center atmosphere I have found supposedly knowledgeable patients and their families begin to "open up" and ask questions which are utterly appalling in their simplicity and absolutely fundamental to any understanding of the illness. One wonders in utter amazement why or how those questions could not have been asked or answered beforehand.

The emotions that accompany any bleeding episode, any operative or dental procedure, or any physical therapy treatment, can only be observed and treated in this type of setting. Direct psychiatric intervention, interpretation, and cooperation with the allied specialties involved in treating the illness is the greatest educator of the patient and his family. From this the patient becomes aware of how to psychologically cope with all aspects of his illness. Hope is provided and an identity is begun. Family discord ceases, the frequency of bleeding episodes diminishes, and resultant center visits become infrequent.

It is our feeling and direct observation that only through the combined effort of all the specialties involved in treating this illness will the patient gain the medical and psychic experience not only to understand his illness but to gain an identity in the process.

As never before and with this foundation can he offer himself to his community and country as a viable, confident, and contending human being.

MR. HEAVNER. Our next witness, Senator, will be Mrs. Katherine Earnshaw, executive director of the National Hemophilia Foundation.

MRS. EARNSHAW. Senator Williams, I am Katherine Earnshaw and I reside in New York City. I am the executive director of the National Hemophilia Foundation.

Ours is a national, nonprofit voluntary health organization dedicated to the needs of the hemophilic patients we represent. Incorporated in New York State in 1948, the avowed purposes of the foundation are:

1. To organize and develop a national program of research and clinical studies in the field of hemophilia;
2. To develop and expand the foundation, its benefits and facilities, to areas throughout the country not now served;
3. To publish information and knowledge relating to early diagnosis and correct treatment of hemophilia;
4. To organize a national fundraising program and to advise and assist chapters.

For these 25 years our primary activity has been to improve patient care and to find ways to provide treatment for those who could not otherwise obtain it. The 1972 Booz-Allen and Hamilton survey for the National Heart and Lung Institute has borne out the foundation's estimates of more than 25,000 severely to moderately affected hemophiliacs with a national total of probably 100,000.

Through the efforts of the foundation and its 48 affiliated chapters, we have sought out and utilized all existing community resources in order to meet the needs of patients.

Such resources include public welfare assistance, medicaid, crippled children's and maternal and child health services, third party payors, and local family agencies. Also, within the past year, some States have recognized the need and have appropriated special funds for this purpose. In some areas we have succeeded well, but in other parts of the country resources for care are spotty, poor or nonexistent. Our society has generally been willing to let the chronic blood user carry respon-

sibility for his own donor recruitment program. Many have been imaginative and successful while others have had to bribe neighbors, friends, even advertise for donors to meet their replacement requirements. The price of a given blood component varies markedly even when supplied by the same agency in different parts of the country.

Insurance coverage for chronic blood users is inadequate and uneven. Again, there are localities where we have worked out adequate assistance through the cooperation of third party payors and blood suppliers as well as community resources but they are few and far between.

It is clear that these makeshift attempts to provide treatment are only partially and locally successful. We cannot do the job alone. Help is needed from the Federal Government not only to meet the heavy costs of necessary blood products but also to develop regional diagnostic and treatment centers which can furnish model programs of comprehensive care within the reach of all hemophiliacs. We believe such centers would lead to higher standards of treatment generally and could also offer training for medical and other professionals in the optimum care of hemophilia.

In addition, we desperately need a national system of regional blood fractionation centers to bring cleaner, more efficient, and less costly blood products. One cannot speak of hemophilia without recognizing the complexity as well as the inefficiency and inequity of the present system of blood supply and distribution. It is time to apply our rudimentary knowledge of ecology to this vital national resource so that it is properly utilized and conserved to meet the needs of all. One pint of blood can take care of the needs of at least a dozen people, with fractionation.

We have heard from some Senators, in the last day or two, the concern that our foundation is fostering the disease-of-the-month syndrome when we ask that you give special attention to hemophilia. However, gentlemen, ours is a success story—almost.

Clinical research has made tremendous strides so that the entire treatment of this disease has been revolutionized within the past 10 to 15 years. With early diagnosis and prompt, informed treatment with the new blood products on a prophylactic basis, any young boy can avoid crippling and can lead a full and nearly normal life with average life expectancy. But—and this is the big but—the cost is still outside the reach of the average family without financial assistance.

In dollars and cents, would it not be worthwhile to spend the \$5,000 average per year to maintain a young man in healthy condition so that he can become a productive citizen, rather than to let him become crippled so that he becomes a burden to himself, to his family, and to society?

Sometimes people say that genetic counseling should be a major thrust of our efforts—so that children with hemophilia would not be brought into the world. Whatever the merits of this argument, it would not eradicate hemophilia. Approximately 35 percent of all new cases are thought to represent mutations. That is to say, they occur in families with no prior history of the disease. No, hemophilia will not go away.

We in the foundation were filled with elation when the National Heart, Lung, Blood Vessel and Blood Act was enacted in 1972. It provided additional funds for the essential basic research as well as the regional centers. Now we are deeply disappointed because these additional funds have not been released and the pace of research is slowing. Not only are we at the crossroads where the laboratory must give us some of the answers to keep pace with the improvements in treatment, but also the research on hemophilia can produce learnings in relation to thrombosis—one of the great killers of our time.

Perhaps this is an oversimplification, but if we can remember that hemophilia is underclotting of the blood, whereas thrombosis is overclotting, we can see the relationship. Basic research funds in this area will also benefit those who suffer from leukemia and other chronic blood disorders.

We welcome this opportunity to appear before you today. The National Hemophilia Foundation is committed to helping to provide the best possible care for hemophiliacs and this requires us to be an advocate for hemophilia on the national scene, for we know we cannot provide the necessary floor under care from our own resources. Nor can we singlehandedly bring about the solutions to the problems of hemophilia. We must bring the problems and the possibilities before the larger community and particularly before the Congress of the United States.

Based on knowledge which grows out of 25 years of living with the realities of this disease, the foundation believes that the Hemophilia Act of 1973 represents both a humane and a rational approach to the problems of hemophilia.

In the first place, by providing a floor under care for all hemophiliacs regardless of individual financial resources and by developing regional diagnostic and treatment centers to provide optimum care, thousands of hemophiliacs would be spared the needless suffering and crippling which is the fate today of those who cannot obtain such care. Thousands of young hemophiliacs could look forward to leading productive lives.

Second, establishment of regional blood fractionation centers is an essential step toward a more equitable and efficient blood system.

We thank you for hearing us today, and we urge your support of the Hemophilia Act of 1973.

Senator WILLIAMS. We thank you very much.

Mr. HEAVNER. Our next witness, Senator, will be Mr. Henry Taub, chairman of the board of the Automatic Data Processing Company, New York City, and also vice chairman of the National Hemophilia Foundation.

Mr. TAUB. Thank you, Senator. As you know, my company is involved in one of the most advanced stages of computer technology. I am here today to comment on the disease which has afflicted man since the earliest moment of recorded history.

I thank the Committee for the opportunity of briefly explaining my interest in the NHF. Neither I nor any member of my family have been directly involved in this dread crippling disease.

My original exposure to foundation activities was extremely casual and goes back some 5 years. I had been solicited to financially assist

this group and responded with little more than token support. Needs of the hemophiliac seemed not far different from the scores of appeals most businessmen are called upon to assist.

Modest as our support was, several caring members of the foundation took the time to make me aware of medical developments which suggested the potential for control of hemophilia. It intrigued me that the solution to this age-old affliction could be conceptualized in business terms—cost, supply, distribution were the problems—medical research had provided the answer through fractionization and development of concentrates.

The plight of the hemophiliacs and the anguish of their families was all the more appalling when one recognized that relief was available except for cost. The fact that tens of thousands could move from lives of crippling dependency to that of contributing, useful citizens made the opportunity unfulfilled seem to be immoral and cruel.

I have in these 5 years become further aware of our archaic approach to blood management. Since we are dealing in a commodity with limited shelf life—inventory must be carefully managed. Sad it is that 28 percent of donated blood becomes outdated and is literally flushed down the toilet because we can't relate supply to need.

Even more regretful is contamination of that supply when available—hepatitis. Doctors and patients both, intimidated by the risk of hepatitis, often transfuse only as a last resort instead of freely utilizing this lifesaving therapy.

Regional fractionization centers will make concentrates available to hemophiliacs. Control and solution of their dilemma will permit the community to enjoy enormous savings in costs and at the same time secure useful productive contributions from those personally afflicted.

Beyond this meritorious objective is the knowledge that in better understanding and managing the Nation's blood supply, we may touch the lives of nearly every American.

This hearing today, and the tangible results that must follow, further convince me that I have invested my resources wisely in supporting the National Hemophilia Foundation.

I thank you for the opportunity of giving this statement.

Mr. HEAVNER. Senator, Mr. Friedland had planned and does plan to show a short 3-minute summary of some TV spots. I wonder if he could do that now.

Senator WILLIAMS. That would be fine.

Mr. FRIEDLAND. These four spots, taking about $3\frac{1}{2}$ minutes to do, were made about $4\frac{1}{2}$ years ago. The first one was made by Eric, and he is prettier now. The last one was made by Peter. These are the two rich kids. Pardon me for saying that, Peter and Eric are here. These spots were played 150 times a month in the city of New York for 4 years as compared with the average of 6 for cancer. The second and third we have not played that much. We did not feed them into the stations. But the first and fourth are probably the most widely played television spots in television history for this type of thing. They brought our cause to thousands of cab drivers and college professors everywhere.

At this point four television spots were shown, audio-visual. The script for the spots follow.

[The information referred to and subsequently supplied follows:]

Jerry Della Femina & Partners Inc.

Hemophilia
:60 Seconds

You're looking at something that will let a hemophiliac live and bleed like a normal person. The substance in blood that makes it clot.

Twenty years of research and we've finally got it.

But getting it to the thousands of people who need it is another story. It's still so expensive we can only get it to a few people.

Every other hemophiliac is just waiting. And bleeding. Just waiting...and bleeding.

The only way they're going to get it is if you give it to them.

We need your money.

We're so close, yet so far.

Della Femina, Travisano & Partners Inc.

December 14, 1970
 As produced scripts
 "House of Horrors" :60 TV
 National Hemophilia

AUDIO

Camera travels down walk
 to front door of a house.

The House of Horrors.

Thru door & into a kitchen.
 Zoom in on cabinets, then a
 draw filled with knives,
 a cat crying.

To a hemophiliac, his own house is a house
 of horrors.

Travels upstairs to a
 bedroom. Door closes.

Where anything can make him bleed and send
 him to the hospital.

Bedroom door opens slowly
 showing boy sitting on
 bed.

But the most horrible thing of all is that
 we finally have a way to control his bleeding.

Zooms in on boy.

Only he's not getting it because he can't
 afford it.

Close-up of boy's face.

The only way he's going to get it is if you
 give it to him.

Cut to Titles:
 National Hemophilia Foundation
 We're so close, yet so far.

We need your money.
 We're so close, yet so far.

Della Femina, Travisano & Partners Inc.

December 21, 1970
 "Haves/Have. Nots"
 National Hemophilia Foundation
 :60 TV

VIDEO

(Peter speaking)
 Long shot of Peter
 sitting in room.

Gets up and moves
 around room.

He walks into kitchen,
 opens refrigerator and
 takes out serum.

Walks back into den
 sits down and injects
 himself.

(Charles speaking)
 Cut to c/u of
 Charles.
 He goes over to
 refrigerator and
 opens it.

Freeze frame on
 Charles.

AUDIO

Hello, my name is Peter. Come in. I want
 to tell you something about myself.

I'm a hemophiliac. You know, the people who
 can't stop bleeding.

Until last year all the money in the world
 couldn't stop my bleeding. But now there's
 something called a clotting factor that can.

Let me show you. All I have to do is give
 myself a shot of this everyday. And for the
 first time in my life I can bleed like a
 normal person.

But it's very expensive. In fact it costs
 \$22,000. a year.

But I'm lucky enough to be able to afford it.

My name is Charles.

I have hemophilia.

But now there's something that can control
 my bleeding.

Only my parents tell me we can't afford it yet.

- 2 -

Freeze frame on
Charles

V/O: 100 hemophiliacs can afford the clotting factor,
100,000 can't.

Fade to titles with v/o.

We need your money.

Titles:

We're so close, yet so far.

We're so close, yet so far.

National Hemophilia

Foundation

Senator WILLIAMS. I appreciate that very much.

Mr. HEAVNER. Senator, this concludes the first panel which has dealt with the problem of the disease. You heard the problem as told from some people who are not involved. You have heard some of the aspects about the medical part of the problem. You have heard some of the problems from those people who are involved.

I would like to thank you very much, your committee, and if you have any further questions, fine, we will be glad to answer them. If not, we will make way for the second panel which Marvin Gilbert will chair.

Senator WILLIAMS. All right.

STATEMENT OF MARVIN S. GILBERT, M.D., MOUNT SINAI SCHOOL OF MEDICINE, NEW YORK CITY; FRANK BACKER, SR. AND FRANK BACKER, JR., WATERVLIET, N.Y.; ERIC FRIEDLAND, KINGS POINT, N.Y.; JACK LAZERSON, M.D., CHILDREN'S HOSPITAL, LOS ANGELES; AND MR. AND MRS. JOHN BIRMINGHAM, AND PAT AND MIKE BIRMINGHAM, SUNNYVALE, CALIF.; MARTIN DEENEY AND MARK DEENEY, GLENOLDEN, PA., A PANEL

Dr. GILBERT. Mr. Chairman, members of the Senate committee, my name is Marvin Gilbert and I am associate professor of orthopedic surgery, School of Medicine, and codirector of Mount Sinai Hemophilia Center, and medical codirector of the National Hemophilia Foundation.

The aim of this panel is to demonstrate the spectrum of this disease over the past two decades. The Backers who are directly on my left and Eric Friedland on my right are examples of patients who have lived through the era when care was not available and will describe their rehabilitation in two comprehensive care clinics.

Eric Friedland will demonstrate self-infusion, the control now available. After this, Dr. Lazerson will introduce the Birmingham boys, who have had the benefit of this control from early childhood.

Mr. Deeney on the far left, and his young boy will touch on the hopes for the future.

Although hemophilia is primarily a disorder of the blood clotting mechanism, it is not exsanguination (loss of blood) that poses the real threat to the hemophiliac's normal and productive existence. Medical care, equipment, and supplies can most always be made available for such a dire emergency. It is less dramatic but recurrent bleeding into nonvital organ systems that insidiously renders the hemophiliac ill or crippled so that he is unable to function normally, making him a burden, rather than a contributor to society.

I do not want to totally dismiss the occurrence of a life-threatening hemorrhage as a real possibility. Though rare, it hangs as a sword of Damocles over the head of each and every patient afflicted by this disorder. No one should be asked to bear such a burden, where the technology for control is available.

It is apparent from these statements that the hematologist alone cannot care for these patients, but rather that a cadre of medical and

nonmedical specialists is required. Not only must they be able to care for the ravages of bleeding, but also they must be able to afford the psychologic, social, and economic support the patient requires.

The ideal comprehensive care clinic requires the backing of a major hospital with a superb blood bank. Doctors in attendance at all times, must include the hemotologist, pediatrician, orthopedic surgeon, a specialist in physiotherapy, dentist and oral surgeon, psychiatrist, psychologist, social worker, and a vocational rehabilitation counselor.

It would take too long to hear from each specialist, but I refer to the statement from Dr. John Hickman, a psychiatrist, on the psychological impact of a total treatment center on the hemophiliac, which has been entered in the record.

After infancy, most all severe untreated hemophiliacs begin to bleed into the joints and muscles of their arms and legs. The joints, especially the knees, elbows, and ankles, are the most common sites of hemorrhage. By age 7 or 8, arthritic changes resulting from hemorrhage into the joint are noted on X-ray and in a few more years pain, swelling, stiffness and deformity are manifest.

Blood is the irritant that causes the breakdown of the normal delicate joint tissues and recurrent bleeding episodes cause irreparable damage. I would like to demonstrate some of these changes.

I have here, Senator, a picture of a young boy who came to our clinic from upstate New York where treatment was not available to him. This young boy had bled recurrently into this limb. I think you can see how it is enlarged, how it is swollen, how it is painful, how it is kept bent. He has a smile on his face, as all hemophiliacs do, but he walked with a terrible limp and he had to have surgery.

The blood clotting factor, this alone cost him over \$10,000. Unfortunately there are many hemophiliacs who cannot have surgery to correct something like this.

Senator, a closeup of his limb, the destroyed joint, the painful joint that one of these young boys must suffer from. But even worse than that, and I hesitated to show you some of these photos, but I think it has to be shown, because they are daily occurrences in a hemophilia clinic. This is the calf of a young man who had recurrent bleeding. I think you can see the pressure was so great that it burst out through the skin, that it caused such pressure that it caused his bone to fracture. I think we can all appreciate the pain that must have been associated with this and what this boy who did not have treatment had to go through.

Or a boy who accidentally stuck a pin into his finger as Eric did on the commercial we saw, who did not come to the emergency room for 20 hours. We thought we might even lose his finger.

Or even, Senator, the simple occurrence of a father stepping on his son's toe and bringing him immediately for treatment, but this is what happened within 24 hours. I think we all have stepped on our child's toes at one time or other.

Senator, these are examples of what happens without treatment. Orthopedic surgery is that specialty concerned with disorders of the musculo-skeletal system. Orthopedics is derived from the Greek (ortho—straight and pedia—child), literally meaning "to straighten the child." It is in hemophilia that this challenge is most severely tested.

To straighten bent limbs, large, complicated, and costly casts must be applied. To strengthen weak muscles and overcome stiffness, long, intensive, and painful courses of physical therapy must be started. To correct damaged joints, risky surgical procedures must be undertaken, and to help support the limb damaged beyond repair, heavy, bulky braces must be applied.

In the long run, this becomes more expensive than prevention. The physical and emotional pain, the days missed from school for each bleeding episode, and the months missed from school for orthopedic treatment contributes further to the hemophiliac's difficulty. These complications should not occur and in the future the orthopedic surgeon should not be called upon to treat deformity, but only to set the wrist fracture or tape the sprained ankle of the "normal hemophiliac" who has biked to school, played ball in the playground, and achieved in the classroom on an equal footing with all his classmates.

To me as an orthopedic surgeon, the "Williams Hemophilia Bill" represents an opportunity to "straighten the child" before he is bent.

Senator WILLIAMS. Doctor and members of the panel, there is a vote in progress. Perhaps it would be well to break now, but first Senator Javits would like to say a word.

Senator JAVITS. I am engaged in a very critical problem of marking up the major education bill, as I am the ranking member of the Labor and Public Welfare Committee, and regret I cannot stay.

There are a great many people from New York, including the witnesses, who are here. I just wish to assure them—and submit for the hearing record the complete text of my statement—that I am very sympathetic to this measure and that I will do my utmost to help in this particular problem. That is the best I can do today. But as Senator Williams, I think, can assure you, when I say that it is not a light matter. I will really follow through.

[The prepared statement of Senator Javits follows:]

OPENING REMARKS BY HON. JACOB K. JAVITS, A U.S. SENATOR FROM
THE STATE OF NEW YORK

Senator JAVITS. Mr. Chairman, until recent years, hemophiliacs were doomed to lead an unnatural life, for they survived only because of whole-blood transfusions and, as research progressed, through transfusions of blood plasma.

Today, because of miracles of scientific technology, the clotting factors have been separated from the plasma of normal blood and made available in concentrated forms. When administered regularly as a preventive against hemorrhaging, the hemophiliac can live a relatively normal, self-sufficient life. The transfusions themselves, because they are in concentrated form, are markedly reduced in volume. Unfortunately, as is all too often the case in scientific breakthroughs, the cost of the product is still very high. Only a privileged few can afford the quantities of yearly transfusions necessary to prevent hemorrhaging. It is estimated that the hemophiliac requiring ongoing treatment will have to spend \$6,000 per year if he is to have this life-saving therapy.

I believe that personal finances should not dictate who shall live and who shall die. I want to assure the author of the bill—Senator Williams—and our witnesses of my commitment to bring to fruition the objectives of this legislation—that every hemophiliac shall be entitled to care of this disease consistent with available technology and with that person's ability to pay for such care. Thank you.

Senator WILLIAMS. Well, I know Senator Javits regrets that he has not had a chance to hear all the statements that have gone before; but we are, as you know, in this bind of competition of time and committee demands. I am sure the record will support this commitment.

Let us take just a moment here. Mr. Friedland demonstrated what Eric, who is in the center of the table, lived with until he was age 17. Could you give us another demonstration of that?

Mr. FRIEDLAND Senator, I imagine you have seen some of the television spots and two of the young fellows who made them are here, and my son is one, and the young fellow in the back is the other who made the spots.

Eric wore this on his right arm most of his life, from the age of 6 or 7 to the age of 17. It is totally rigid. It rendered his left arm useless. The only time he ever looked unhappy in his life was when he was told he would not be able to play the piano. This he wore on his right arm, and he has a locking device on it. He wore one of these on each leg [indicating].

The weight of this bag combined is such that a grown man would have difficulty in carrying it.

Senator WILLIAMS. Could I interrupt? You were going to give us a demonstration of administering the dosage. I wonder if that could be done now while Senator Javits is still with us, and within a matter of 3 minutes. This is getting the presentation out of order.

Mr. ERIC FRIEDLAND. This concentrate I have been administering to myself for about 5 years, since 1969.

In 1969 I received a thorough program of physical therapy in coordination with the administration of this concentrate. Right now I am just as strong and as healthy as anyone. I am a student at Harvard.

The administration is a very simple process that I can do in about 5 or 10 minutes, once a day.

[Demonstration was given.]

The only thing we want now, I guess, to be really satisfied is to see that other hemophiliacs, my friends, thousands of people, can begin to live the kind of life that I do, without any fear of having their plans for the future cut off, having their future cut short, to be able to live and work in complete confidence.

It is just this simple procedure of self-infusion of the antihemophilic factor which is just that fraction of the blood which a hemophiliac needs to enable his blood to clot, that provides the hemophiliac in coordination with physical therapy and other therapy programs to be able to live a life just as any other young man does, to be able to foster his career and raise a family and plan his future just as every young man wants to do. We hope that no hemophiliac will ever have to be deprived of the treatment I have received, so he can really begin to live. The shot has just taken about 2 or 3 minutes. It is all over now.

I have removed the needle and the shot is over in 2 or 3 minutes, and that is all I have to do every day to keep myself in full working condition.

Senator WILLIAMS. There will be a brief recess while I go to the Senate Chamber to vote.

[A short recess was taken.]

Senator WILLIAMS. We are ready to return to order.

Dr. Gilbert, we regret these interruptions, and we can return to our continuity now.

We want to thank you, Eric, for helping us with that demonstration out of turn. Maybe you can describe that again a little later.

Dr. GILBERT. What we will now do is go on to Frank Backer and Frank Backer, Jr., on my left, who will describe their experiences with hemophilia before the control was available and their experiences in a comprehensive care clinic for rehabilitation.

Mr. BACKER, Sr. Mr. Chairman, the problem of hemophilia presents severe emotional, physical, and financial strains. The emotional strain is particularly difficult when your son is very young, as there is constant anxiety and apprehension.

When my son, Frank, Jr., was 11½ months old, while creeping around on the floor, he struck his face on the leg of the couch causing him to bleed profusely from under the middle of his upper lip. His mother and I took him to the hospital in Troy, N.Y., where he continued to bleed for 17 days. On his first birthday, February 16, 1954, we took him to Children's Hospital in Boston and almost immediately we were sent to nearby Bath-Israel Hospital. Within an hour he received a blood transfusion, which literally brought him back to life. Dr. Alexander's team, including Dr. Hartman, made the diagnosis of severe classic hemophilia.

From that point on, during Frank's very early childhood, we took every precaution we could think of. We padded the legs of furniture with foam rubber, putting fishnetting over his crib and so forth. Many times we would take Frank to the hospital in the middle of the night because of hemorrhages from his tongue or nose.

The problem was particularly acute during the hayfever season from which he suffers, and a couple other occasions upon checking during the night we found him bleeding from the nose while asleep. We took him to the hospital where he was treated over a period of 4 to 5 hours.

Shortly after getting home, he vomited substantial quantities of blood, causing another nasal hemorrhage and an immediate return trip to the hospital.

From the time he began to walk until age 7, Frank was most active and sustained many injuries causing hospitalization. During 2 years, he was in the hospital more days than he was home. At age 7, his leg became frozen in a jackknife position due to repeated hemorrhages in his knee joints. He was in a wheelchair until age 17, when he was treated at Mount Sinai Hospital in New York City by Drs. Marvin Gilbert, Aledort, and others for a period of 94 consecutive days, with miraculous results. The greatest thrill of my life was when I saw him upright after about 9½ years in wheelchairs.

During these 9½ years in wheelchairs, Frank attended grade and high school. Everyone was tremendously cooperative. The teachers arranged to change classes so that Frank would have limited stairs

to cope with. We have five wheelchairs: Two at home, one in our car, one at school, and one at church where he attended mass from the side. Because of the eventual fine treatment which Frank received and because of the fact that everyone—school, friends, teachers, even relatives—were so great, I rejected many very substantial job offers which would have taken us to other cities.

On the financial side, one of the things that was particularly difficult was the fact that when Frank was very young and hospitalized often, he had insurance on inpatient coverage, which was good for 90 days. When the 90 days were used up, he would have to stay out of the hospital for 90 consecutive days for insurance to be reinstated.

Several times while in this situation, he would stay out 70 or 80 days or more, and then have to be hospitalized. It was most frustrating. Frank is tremendously interested in sports and is a close friend of the great George Blanda, honorary chairman of the National Hemophilia Foundation.

At age 9, Frank injured his ankle and foot while playing basketball from a wheelchair. His right foot and ankle were in a cast for about 16 months. One night while visiting him at the medical center, we found him to be in a tremendous state of depression. He was to be operated on the next morning. He was plain scared and inconsolable. When we arrived at the hospital the next morning, we found him smiling and bubbling with enthusiasm.

He had in his hand a telegram from good old George Blanda, and as they wheeled him out, he was showing it to everybody.

Frank has a brother Tom, 2 years older, and quite a basketball player. Frank was Tom's biggest fan while Tom was playing on championship teams, grade school and Union College where he is now a junior. While at the junior high school, Frank disagreed with a foul that was called against his brother and he pounded his hands on the arm of his wheelchair. While the friends exalted over the victory and celebrated, Frank, his mother, and I went to the medical center with his arm puffed up like a balloon.

I think Frank will want to tell you about the new life which started at age 17, thanks to Drs. Gilbert and Aledort and others, the other wonderful people. I feel honored and proud to be the father of Frank, Jr., a lad of determination and guts, and along with many prayers that enabled him to survive until medical help came to the fore.

Please help us control or miraculously end this miserable problem of hemophilia.

Thank you, Senator Williams, and may God bless you for your interest and support.

Senator WILLIAMS. Thank you very much, Mr. Backer. That is an amazing and magnificent story, but unique.

There are not many success stories, are there?

Mr. BACKER, Sr. That is right, Senator, not yet.

Senator WILLIAMS. There are many who have the disease and have the problem and do not have an equally happy result.

We have another problem now with a vote on the Senate floor, but I am sure because of the subject matter before us, the patience will be complete. I will be right back.

[Short recess.]

Senator WILLIAMS. Now we will return to the Backer family.

Dr. GILBERT. Frank, just make one sentence quickly so we can continue on because I know the Senator is pressed for time. We will submit your statement for the record at the conclusion of your testimony.

Mr. BACKER, Jr. Thank you. I am going to have to cut this short because of the time limit. My father did cover all the important parts of my life anyway.

I would like to say I am one of the fortunate few who can now receive a daily prophylactic treatment, and it does hurt me deeply to know there are thousands of other youngsters in the country who, for financial reasons only, are in the same position I was in just a few short years ago as my father explained, who could be living the good life I now enjoy.

Senator WILLIAMS. Thank you, Mr. Backer. Let me ask you, are you now a college student?

Mr. BACKER, Jr. Yes; I am a junior at the Union College in Schenectady, N.Y.

Senator WILLIAMS. What were your prospects of college education before the methods of treatment reached you? Did you have any prospect of going to college?

Mr. BACKER, Jr. Senator, I am sure I could have gone to a college, but I do not think I could have gone to such as fine a school as I am in now. I seriously doubt I would have been able to get through school in 4 years. It probably would have taken me twice as long because I missed annually over 100 days of class from the 5th through the 10th grade.

Senator WILLIAMS. Have you established in your mind your career goals?

Mr. BACKER, Jr. I am not sure yet. I am thinking of industrial psychology, but I am not sure.

[The prepared statement of Mr. Backer follows:]

PREPARED STATEMENT OF FRANK J. BACKER, JR., WATERVLIET, N.Y.

Mr. Chairman, members of the Senate committee, ladies and gentlemen, my name is Frank J. Backer, Jr. I live at 16 Idlewild Park, Watervliet, N.Y. My father has mentioned that I was confined to a wheelchair for over nine years and these certainly were very trying years for me. I had a lot of good friends who would spend some time with me but when they would run out to play ball I would have to stay in the house and read or watch television.

Eventually I learned to manipulate my wheelchair and could get around fairly well. My father bought me a pool table and I would spend a great deal of my time shooting pool and shooting baskets in the driveway. However, the tremendous strain caused by throwing a basketball from a sitting position caused many hemorrhages in my elbows and this would incapacitate me for several days.

I said a moment ago that I could get around fairly well and this is true but only until I came upon a flight of stairs. This caused a great deal of frustration because the pizza place all the kids went to after the games was on the second floor of a building, the only pool hall in town required one to climb four flights of stairs, and there was only one movie theater in the area that catered to the handicapped and this usually showed movies much too sophisticated for a young teenager.

There were other problems too. From the fifth through tenth grades I was absent annually more than 100 days of class because of bleeding; I rarely dated because where would I go and who would want to go out with me? I couldn't travel and I knew that I was the reason my mother never had a vacation.

Everything changed four years ago when I first visited Dr. Gilbert and Dr. Aledort and they said they thought they could get me on my feet.

I spent over three long, hot months in the hospital with many ups and downs but when I left I was walking for the first time since I was a very small boy. I wore cumbersome braces and used crutches and it was at this time that I started prophylactic treatment which is the only reason I am still walking.

Since I began walking again everything has kept on improving. I soon went from crutches to a cane, then shed the cane. In six months I wore but one brace and in two and a half years I was free of any artificial aid. My last two years in high school were terrific. My social life improved greatly. I did almost everything I stated previously I couldn't do. My class attendance and grades improved enough so I was accepted at a fine University: Union in Schenectady, New York.

I am very involved at school, I am on many committees, I have a job in the news bureau, I am chief statistician of all varsity sports on campus and I am the vice president of my fraternity: Alpha Pi of Chi Psi.

One of the things that makes me most happy is that my mother is now free to travel and in the last three years has seen most of the country. Since I began self-administering the Factor 8 to myself fourteen months ago, I too am free to travel and have done so, including a two week vacation in Florida last spring with some school buddies; something I never dreamed I would be able to do.

Fortunately my father has an insurance policy which covers all my medical expenses but most hemophiliacs aren't so lucky. It pains me deeply to know that there are thousands of other youngsters in the United States who, for financial reasons only, are in the same position I was in just a few short years ago, when they could be living the good life I enjoy.

Senator Williams, my family and I thank you for your kindly interest.

Dr. GILBERT. Can I introduce Andrew Thorne, our poster boy. Andrew, could you stand up one second? I think you see a shining example of what hemophiliacs of the future are going to be like. I did want to introduce Andrew before we continue on.

Senator WILLIAMS. Maybe our record ought to reflect Andrew's age and where he lives. We cannot put his picture in. He is certainly smiling, as they say all hemophiliacs do.

Dr. GILBERT. Tell us your age and where you live.

Andrew THORNE. Seven. I live in Upper Saddle River.

Dr. GILBERT. Where do you go to school?

Andrew THORNE. I forget.

Dr. GILBERT. Thank you.

Senator WILLIAMS. By the way, Upper Saddle River is in New Jersey.

Dr. GILBERT. Next we have Dr. Lazerson, who will relate some of his experiences with early age home treatment, and he will demonstrate to us two Birmingham children who will show us how the hemophiliac can be rendered normal.

Dr. LAZERSON. Senator Williams, members of the Senate subcommittee: My name is Jack Lazerson, and I am a pediatric hemotologist, presently director of the coagulation defects program at Children's Hospital of Los Angeles, and formerly director of the Hemophilia Program at the Children's Hospital at Stanford.

I would like to put forth before the subcommittee one or two ideas that may help reinforce the importance and need for passage of the Hemophilia Act of 1973.

Senator Williams, both you and the previous speakers have more than adequately stated the problems that patients with hemophilia and their families face. The solutions to these problems have been outlined and incorporated into the Hemophilia Act of 1973, and I will not attempt to reiterate them.

What I would like to point out, however, is from a pediatrician's point of view, the ultimate control of a disorder is either its preven-

tion or an effective form of therapy to control or prevent the complications of that disorder. Hemophilia and its treatment is an excellent example of the latter point.

An effective form of therapy that is currently available, and has been demonstrated today, if appropriately and adequately used, may not only control the known ravages of this disorder, but more importantly, provide this society with active young men who are fully functional, productive members of that society. If the purpose of medical control of a disorder is to allow individuals with that disorder to lead productive lives, then hemophilia is such an example.

Concrete data from a number of comprehensive care programs, have established that when young patients with hemophilia and their families are appropriately educated and trained as to the most effective therapeutic programs (home self i.v. treatment for suspected bleeding), the morbidity from bleeding is minimized. If one utilizes school attendance records as one of the criteria of morbidity, then it has been repeatedly demonstrated by both Dr. Rabiner and myself that home treatment programs decrease school absenteeism.

The figures, in fact, show a decrease from 70 days absenteeism a year to less than 20 days a year, normal schooldays a year being 176, with expected absenteeism of 7 days per year.

The quality of attendance and life is also normalized.

The cost of treatment within a home program results in a net decrease in expenditures as the family and/or child treats himself earlier, as a result of requiring less total dose of material per unit of body weight per bleeding episode. Necessity for the prophylaxis becomes minimized, and total doses of material used from year to year do not drastically increase.

A more important concept than this data provide is the fact that although what has been discussed refers to patients presently receiving adequate treatment, after much of the damage has been done, this act will allow the physician and his staff to have facilities available to them to provide earlier and better diagnostic and treatment programs for younger patients, thereby allowing these boys to grow up in an atmosphere that allows them to be physically and emotionally normal.

They would then be able to perceive their disorder as simply as, and I quote from one boy, "I think I am having a bleed in my ankle. Mom, help me with my I.V. so I can go back and finish my Little League ball game."

Senator WILLIAMS. Thank you very much.

Dr. LAZERSON. What I would like to do at this point is, I would like to introduce Mr. and Mrs. John Birmingham and their children, and let them relate some of their experiences with home care programs.

Mr. BIRMINGHAM. Thank you, Dr. Lazerson, and thank you, Senator. We are very proud to be here as examples of what good conditions boys can be in. We first found out about it when Mike was approximately 13 months old. We were on vacation about 900 miles from home when Mike was just starting to walk, he fell and knocked his two front teeth loose. We took him to a local hospital of a town of about 30,000. After 3 days, about 7 one evening, they suggested that we take Mike someplace else because they did not know what to do for him.

We went back to our own area where they did diagnose it as hemophilia. Mike was in and out of hospitals for the next 5 years. This was the time just at the start of the availability of cryoprecipitate. But we were part of what was referred to as the wait-and-see attitude. The doctors felt they should wait and see if the bleed would subside on its own before they would actually transfuse him.

As a result of this, in the first grade Mike missed approximately 3 months of school. At the end of that year, when Mike was 7 and Pat was 5, I was transferred to the San Francisco Bay area. I quite accidentally ran across the home care program that Dr. Lazerson had set up, and within 60 days we were transfusing the boys at home.

This program has completely changed our lives. An example of this is that this year Pat has only missed a total of 25 minutes of school because of hemophilia. He has not really accepted the fact yet that he has a problem. In playing soccer one day at the recess, somebody kicked him, so he went to the office, called his mother, and said you better set it up, I will be on my way home.

Within 25 minutes, he was back in school. That is the total amount of school that they have missed this year.

We could see some of the early effects of problems that Mike had in relating to other children, especially at school, that he did have a problem. We can see the comparison between Mike and his early first grade treatment versus Pat who has never really had the problem and how the relationship with their peers at school, and we can only say good things about the program.

We would very much like to see this available in all parts of the country. It has progressed quite a bit to the point where we are going back for a 2-week Christmas vacation to the place where Mike was first treated and we first found out about it.

We feel confident we can take care of the problem there. Our situation has changed. I am sure that that town has not changed.

Maybe some day we will be able to find the time when we can go and live in an area like that. Thank you very much.

Senator WILLIAMS. Thank you very much, Mr. Birmingham.

Mr. BIRMINGHAM. Both Mike and Pat would like to make a statement.

Mike BIRMINGHAM. What I would like to say is that it is not very easy being a hemophiliac, and it is hard and it is painful. But now that we have the home treatment, all I have to do is just tell my mother that I need this, and she will set it up, and within a few minutes we will be in and out.

Senator WILLIAMS. Let me ask you, Mike, do you only have the treatment when you feel you have been bumped or something, or is it a daily treatment for you?

MIKE BIRMINGHAM. Well, every time I get hurt.

Senator WILLIAMS. Is this not daily? It is just every other day, maybe, when you get a bump playing soccer?

MIKE BIRMINGHAM. When my arm gets stiff or something like that.

Mr. BIRMINGHAM. They have gone for a period of over a month without having to have anything, especially in the summertime when they are in good shape and go swimming, sometimes it is more often than that.

Senator WILLIAMS. Pat?

PAT BIRMINGHAM. It is expensive. When I get older, I want to do more athletic things.

Senator WILLIAMS. Well, I have a feeling you will be a good athlete. Which sport are you going to be good in or at?

PAT BIRMINGHAM. Basketball.

Senator WILLIAMS. Great. Let me ask you, Mr. Birmingham, do the boys have anything more to say?

Mr. BIRMINGHAM. I think that is it.

Senator WILLIAMS. After you discovered this problem with Mike, did you trace back in your family to see whether there had been any other members in the family tree that have had this hemophilia?

Mr. BIRMINGHAM. We traced back as far as we could. My wife's grandparents were alive at the time. They knew of no history in the family. As far as we could figure out, there was never any history in the family.

Senator WILLIAMS. You discovered this when Mike was about 13 months old?

Mr. BIRMINGHAM. About 13 months old. There were indications of it before that. We knew he was getting his bruises, but we did not know why, and it really came to a head when he was 13 months.

Senator WILLIAMS. Now when Pat was born, was he tested before there was an episode that would determine it?

Mr. BIRMINGHAM. He was tested at birth right in the delivery room, so we knew within 2 days that he also was a hemophiliac.

Senator WILLIAMS. By that time the factor was available, you were ready to deal with it?

Mr. BIRMINGHAM. Yes, as a result, he is in very excellent shape today.

Senator WILLIAMS. Mr. Backer described his immobility because of the need to stay in the Albany area because of the treatment available to Frank Jr. there. Have you had any similar experience?

Mr. BIRMINGHAM. Yes, I have. About a year and a half ago I made a decision to change jobs because I was subject to transfer, and decided that I would just as soon find a job where I could stay in that area, so I gave up 9 years with one company to be able to stay in the San Francisco Bay area. It is very interesting that I was only able to accept that job because of the home care program. At the time both boys were born they were covered under an insurance program.

When I went to change jobs, I was very concerned as to what would happen under the insurance. In checking into it, I found out that if they did not have any medical care for a 90-day period, then they would be covered. They defined the 90-day care as treatment by a doctor or medical expenses. Now home care did not count. So therefore we were able to lay in a supply of cryo and all our needs for 3 months, and we passed with no problem at all.

So I have been very fortunate with insurance.

Senator WILLIAMS. Are insurance policies today written that way?

Mr. BIRMINGHAM. To my knowledge most group policies are written that way. Under present existing conditions, you do have a waiting period of 90 days before they can be covered.

Senator WILLIAMS. Did you not run into the same thing, Mr. Backer, when you had hospitalization before 90 days had been reached?

Mr. BACKER, SR. That was a situation when Frank was very young, yes, Senator. I am from Albany, New York area, where they have very fine treatment today.

Senator WILLIAMS. Is your insurance policy the same, does it have the same provisions now?

Mr. BACKER, SR. The insurance picks up all the daily treatment, and I hesitate to ask any questions.

Dr. GILBERT. Could we just have the two Birmingham boys walk in front.

[Mike and Pat Birmingham walked across the front of the room.]

Senator WILLIAMS. I can say when I returned from voting they were trying the chairs up here and seemed to fit pretty well.

Dr. GILBERT. I think it is important to point out that they only need this treatment occasionally because they have been kept normal from birth on and that Eric needs it much more frequently because he has had to overcome the ravages of the disease, and I think we can point out the economic advantages of getting it early.

I would like to conclude, Senator, with Mr. Martin Deeney. He will not have time for his testimony. He is just going to say a sentence or two, and I would like to submit his written testimony.

Senator WILLIAMS. Well, I do appreciate your understanding of the time demands. It will certainly be included in the record.

Mr. DEENEY. Mr. Chairman and ladies and gentlemen, although there is not time I would just like to point out that unlike the Birmingham boys, my son Mark, who is sitting next to me here, has accumulated \$31,000 in bills in the last 2 years alone. Surely with the life he leads, which is much different than the boys sitting at the other end of the table, where he is transfused at least every other day, or over the past month he has been transfused twice daily for a period of 3 weeks, and once daily for a period of a week, because he had a slight fracture of the arm, and I just ask: is this any way for any young boy to live?

I would just like the Government to take a good hard look at our spending priorities, because we live in a country that can surely spend billions on war, but has not even put millions into hemophilia research. We live in a country that through research can put man on the moon in 10 short years, but cannot solve the age-old problem of hemophilia.

I just ask them, wake up, America, your children are bleeding. Your children are suffering and dying.

[The prepared statement of Mr. Deeney follows:]

TESTIMONY OF
MARTIN E. DEENEY
TREASURER
NATIONAL HEMOPHILIA FOUNDATION
BEFORE THE
HEALTH SUBCOMMITTEE
OF THE
SENATE LABOR AND PUBLIC WELFARE COMMITTEE
IN SUPPORT OF
S. 1326, THE HEMOPHILIA ACT OF 1973

November 15, 1973

Mr. Chairman, Honorable Members of the Senate, Ladies and Gentlemen:

My name is Martin E. Deeney and I am the Treasurer of the National Hemophilia Foundation. I live in Glenolden, Pennsylvania and am employed by the IBM Company in Philadelphia.

Gentlemen:

This morning I would like to talk about another need of the hemophiliac. That is -- research.

Just why is the need for research so great?

To better understand the need for research, let's take a quick look at the world of a young hemophiliac. I will use my own son only because his statistics are readily available to me and of all the hemophiliacs I know, I know him the best.

Mark is 6 years old and attends first grade at the local parochial school. He is described by his teachers as being typical of most boys his age. In many ways, he is. He likes riding his bike, playing ball, and watching T V. He dislikes taking a bath, going to bed, and eating vegetable. But in another way he is terribly grown up for he has probably already seen more of the inside of a hospital than most of us would see in ten lifetimes. During the past two years, he has had five special dental checkups, spent more than 25 days in the hospital, visited the outpatient department of the local hospital over 300 times, and flown 3,000 miles to Orthopaedic Hospital in Los Angeles for two weeks of orthopedic consultation and therapy while accumulating bills in excess of \$31,000. But most importantly during this time he has been transfused with blood and blood products over 500 times.

Surley with a life like this a young hemophiliac must wonder -- "Can I grow up without fear?" "Is anyone trying to solve my problem?" To answer the last question, let's look back at hemophilia treatment over the past five years. When my son was small he would receive one bottle of concentrate for a hemorrhage. Today, five years later, he would receive two bottles of concentrate for the same hemorrhage. No this isn't progress -- he simply requires more concentrate due to his increase in size.

Not since the late 1950's with the discovery of cryoprecipitate has there been any major advances in the treatment of hemophilia. We seem to be content with a control instead of a cure. Let me give you an example of the control we have -- a simple ankle hemorrhage could mean 3 days in the hospital, 4 outpatient transfusions, 6 home transfusions, a total of 20 bottles of concentrate and 4 units of plasma. And when that ankle hemorrhages again -- 9 days in the hospital, 7 outpatient transfusions, 8 home transfusions, total of 45 units of cryo, 18 bottles of concentrate, and 4 units of plasma. All this of course comes with no guarantee of success.

Gentlemen, don't get me wrong -- for indeed I am grateful -- I thank Almighty God that Mark has no crippling effects from the disease of hemophilia. But I ask you "Is this any way to live?" Why just a few weeks ago one of the country's leading hematologists apologized to me for not being able to do more for Mark. He told me "We are doing all we can." I am not ready to accept this as fact. I do not believe we are doing all we can. I am not content to see Mark suffer. Nor am I content to see Mark being transfused without any guarantee of success.

We live in a country that can spend billions on war but cannot put millions in hemophiliac research. We live in a country that through research put a man on the moon in 10 years but cannot solve the age-old problem of hemophilia.

Wake up America, your children are bleeding.

Wake up America, your children are suffering.

Wake up America, your children are dying.

Just what can be done? First, your prompt and positive action on this bill will put proper medical treatment within the financial reach of every hemophiliac. Second, positive action on this bill will provide for the establishment of blood fractionation centers. These centers would be beneficial not only to hemophiliacs but all children suffering from blood disorders. Third, we are looking to you to provide the funds to carry on the research to find that better way of life for the hemophiliac.

Gentlemen, only when we find a better control -- or better yet only when we find a cure -- can we tell our young hemophiliac - we have solved your problem - so go ahead and grow up and don't be afraid even though you are a hemophiliac.

Senator WILLIAMS. Mr. Deeney, I appreciate that. This afternoon this will be described to Mr. Ash, who is the Director of the Office of Management and Budget. This of course is a national concern that we have. It appears almost unlimited resources in certain areas, but in areas of health and delivery of services and research, it is very difficult to get what is needed.

All of you, what you have done here this morning, will be described to the budget man this afternoon.

Dr. GILBERT. Senator, I want to thank you—I really cannot thank you, I am doing my job—it is really the hemophiliacs to my left and right of me throughout the United States who thank you for this bill and your help.

Senator WILLIAMS. Thank you, doctor. Was there any family history, Mr. Backer—

Mr. BACKER SR. Negative, Senator.

Mr. DEENEY. Negative.

Senator WILLIAMS. Eric, we cut you off because of the need to go and vote. You will be the anchor man here. Did you have anything else to say?

Mr. FRIEDLAND. I just want to say we are also excited to be here, and I think it is a very important day to us. We are very happy.

Thank you very much.

Senator WILLIAMS. Well, you are the reasons we are here today, knowing of you, and knowing your father, certainly accelerated Congress and the country to action. We are confident that was a significant acceleration having learned so much from your father and those that he is associated with in the foundation. Thank you very much.

What is your career goal, by the way, Eric?

Mr. FRIEDLAND. It is undecided now. I have very broad-range interests.

Senator WILLIAMS. Again, if treatment had not reached you, you would never be at Harvard at the level you are now?

Mr. FRIEDLAND. I get A's at Harvard now. But it was very difficult when I first attended Harvard. It was impossible for me to attend classes. At that time I had to receive comprehensive treatment.

Senator WILLIAMS. Thank you very much. Now we will have our last panel.

Your prepared statements will appear following your testimony.

STATEMENT OF AARON KELLNER, M.D., GREATER NEW YORK BLOOD PROGRAM, NEW YORK CITY; WARREN R. JEWETT, WOODBRIDGE, CONN.; DONALD MEYERS, BLUE CROSS (ASSOCIATED HOSPITAL SERVICE) OF NEW YORK; MARY GOOLEY, EXECUTIVE DIRECTOR, HEMOPHILIA CENTER OF ROCHESTER AND MONROE COUNTY, ROCHESTER, N.Y.; AND RICHARD HALDAN, M.D., THE CARTER BLOOD CENTER, FORT WORTH, TEX., A PANEL

Dr. KELLNER. I have been requested to serve as chairman of this panel, which deals broadly with the question of hemophilia and its relationship to blood policy.

We recognize the constraints of time and we will do our best to curtail the presentation.

I should like first to present my colleagues on the panel. On my left is Mr. Donald Meyers, who is assistant vice president of Blue Cross in New York. On the far right is Mrs. Mary Gooley, executive director of the Hemophilia Center of Rochester and Monroe County, Rochester, New York; next to Mrs. Gooley is Dr. Richard Halden, Carter Blood Center in Fort Worth, Texas. To my immediate right is Dr. Warren Jewett, Woodbridge, Connecticut.

I am Dr. Aaron Kellner.

Senator WILLIAMS. Before you start, I want to hear you all fully, but I might have to break in for 5 minutes to go over to the Senate Chamber in the Capitol to vote. Why do we not start but at midway during the vote, I will have to leave and then return. I will just postpone luncheon a little, but maybe that will not hurt some of us very much.

Dr. KELLNER. I am executive vice president and director of the Community Blood Council of Greater New York, which operates the Greater New York program. I am clinical professor of Pathology at Cornell and attending pathologist of the New York Hospital.

I am a past president of the American Association of Blood Banks. During the current year I served as chairman of the Blood Resources Panel, which was appointed by the director of the National Heart and Lung Institute, in accordance with the requirements of Public Law 92-423, otherwise known as the National Heart, Lung, and Blood Act of 1972.

Senator WILLIAMS. You are the director of what?

Dr. KELLNER. I was the chairman of the Blood Resources Panel that wrote the 5-year plan submitted to Dr. Cooper as director of the National Heart and Lung Institute.

Senator WILLIAMS. When did you start working as a group?

Dr. KELLNER. We started working as a group in the late summer or early fall of 1972, when it was clear that the President would sign the bill, but before it had actually gone into effect.

Senator WILLIAMS. Just a year ago?

Dr. KELLNER. Yes, approximately a year ago.

Senator WILLIAMS. You have done remarkable work. I have reviewed some of it most recently, but let me not interrupt.

Dr. KELLNER. I come before you as a blood banker of more than 30 years' experience in blood transfusion and blood banking. I come as a proponent of the concept of community and regional blood centers.

The community and regional blood centers of this country are an essential link in the lifeline of the hemophiliac. In this regard we have a twofold responsibility. It is our responsibility to provide the basic raw material and it is also our responsibility to see to it that it is used wisely.

The basic raw material is blood, human blood. As you know, human blood can only come from another human being. It cannot be manufactured. It cannot be made in a factory. Providing adequate supplies of human blood to meet all the needs is not easy. There is a reluctance on the part of many people to give blood. The amount needed increases year by year. This is further complicated by the fact that we have in this country dedicated ourselves to a total national voluntary blood program.

We have said in effect that it is no longer acceptable in our society to rely on the underprivileged, on the poor, on prisoners, on the residents of our skidrow areas as a major source of our supply of blood and plasma. To get an adequate supply of blood voluntarily will require the education of the community and careful organization.

Giving blood must become a responsibility of citizenship.

Our experience in New York indicates that this is a realistic and attainable goal. In New York, the Greater New York Blood Program serves an area in which live 15 million people. We have progressively increased blood collections by 20 percent a year, all of it voluntary. Last year we collected 315,000 units of blood, voluntary blood. This year our goal is 400,000 units of blood. This is now by far the largest blood program in the country.

It is realistic to expect that if properly organized and informed, the American public will respond and provide the blood that we need.

However, it is not enough merely to collect huge amounts of blood. We must use it wisely and prudently. It is the responsibility of regional and community blood centers to see to it that all who have a legitimate claim on the community's blood resource have equal access to it, not just hemophiliacs. It means that we must have enough blood for the patient requiring surgery or coronary artery bypass, open-heart surgery, the victim of an accident or bleeding, post partum hemorrhage, a child with leukemia, or a child with Cooley's disease or the young man or boy with hemophilia.

Fortunately, modern science and technology has made it possible for us to do this in a rational and organized fashion. This is what Dr. Aledort and others have referred to as component therapy—divide blood into its components and to provide for each patient that specific portion of the blood which that patient lacks and needs, such as Factor VIII in the treatment of hemophilia.

Thus, it is now possible from a single blood donation to provide red cells for a patient with anemia, platelets for a child with leukemia, leucocytes for someone else who needs them, and still have many things left over for many other people, including Factor VIII for the hemophiliac.

And we have not yet used up all the priceless ingredients in blood. We still have left the plasma, which can be further fractionated chemically. We have the possibility of a totally integrated system to extract from a single unit of blood useful materials to meet the needs of many people.

New York produces not only the cellular components, we also have facilities for the production of fractions. We have facilities and licenses from the Food and Drug Administration for gamma globulin, plasma protein solution and so on. I should tell you that we are at present the only regional or community blood center in this country, the only one without exception that has these facilities, the only one with the appropriate licenses to serve as a fully integrated blood center.

Senator WILLIAMS. I will interrupt at this point. I have to go for a vote.

[Short recess.]

Senator WILLIAMS. Dr. Kellner, we will return to you.

Dr. KELLNER. I should like to conclude briefly the thought I was on when you were called to vote. I will then say a few words about the national blood policy.

As you were leaving, I pointed out that the only really integrated blood center in this country, that is the one with the capacity to collect blood, produce components, and that is licensed to manufacture fractions, is the blood center in New York. We need many more such centers. This is why I support strongly that section of the Hemophilia Act of 1973 which speaks to the creation of fractionation centers throughout the country.

In that connection I should like to make a plea that these centers be more than supermarkets for blood. I should like to suggest that there be built in an intellectual dimension, the capability for doing research, because as my colleague Dr. Jewett will point out, one of the major shortcomings in our abilities at the present time is the enormous loss that is entailed in the production from human blood of an effective amount of factor 8 concentrate.

At this point, I should like to comment on the relationship between the bill that you have introduced and the national blood policy.

While the thrust of the bill is clearly aimed at hemophilia, it goes considerably beyond hemophilia. In my view it is consistent with and supportive of the intent of the national blood policy. The national blood policy briefly says that the goals of the blood program in this country are to have an ample supply of blood and all the things that come from blood, that this should be of high quality, that this should be low in cost, and that our blood resources should be efficiently managed.

What it says is that we have in this country a common pool of blood and everyone who has need of something from this pool should have ready access to it. Access should depend on medical need, not on ability to pay.

Your bill is also consistent with the important concept of regionalism, regionalism in the organization of our national blood system. As Dr. Aledort pointed out earlier, the blood collected in this country comes from more than 5,000 separate and independent agencies. Our blood resources are not only fragmented, they are unplanned, uncoordinated, poorly regulated and inefficiently managed.

We must now move toward consolidation and regionalization of our blood resources at the operating level and better coordination and planning at the national level, if we are to extract the maximum benefit from each gift of blood. This is true not only for the hemophiliacs, but for all of us.

Thank you, sir.

Senator WILLIAMS. Have you decided who will be next?

Dr. KELLNER. The next speaker will be Mr. Donald Meyers from Blue Cross in New York.

Mr. MEYERS. Thank you.

I am Donald Meyers, assistant vice president, program development, Blue Cross of Greater New York.

I have a longer statement which I hope will be entered into the record in the interest of time.

Before my current association with Blue Cross, I was involved in the administration of hospitals.

Blue Cross of Greater New York insures 8.8 million subscribers in the southern 17-county area of New York State (we are the largest Blue Cross plan in the country). We also serve as the medicare intermediary in the payment of institutional claims to approximately 120 institutions in our service area. Our total payments to health care providers for both Blue Cross and medicare is about \$1.3 billion.

The Blue Cross standard benefits exclude the payment for blood and all blood products. This principle is an outgrowth of a national policy taken by the Blue Cross Association intended to encourage voluntary blood donations.

In 1974 we entered into an agreement with the Community Blood Council of Greater New York, Inc. (CBC) to provide blood replacement benefits for our subscribers. The intent was both to increase the blood supply and to improve the quality of the product by stimulating voluntary donations, centralizing blood processing in a high quality, scientifically managed program and influencing cost containment through the better management of blood. In addition, we developed agreements to include other blood banks in the community, coordinated through CBC.

At the time we initiated this program we excluded coverage for hemophiliac patients because of the unknown potential demand that this might place on the system. Subsequently, in 1968, we entered into an agreement with the New York Metropolitan Chapter of the National Foundation which provided for blood and blood product replacement for hemophiliac patients who are members of the Metropolitan Chapter and also for Blue Cross subscribers. This coverage provides for the replacement of all blood and blood products provided hemophiliacs covered under this agreement, when such blood products are provided within an institutional setting.

Although the existing program is successful, it is limited in the number of people it covers and the extent and scope of such coverage. Our ability to expand this coverage in the face of rising costs for other care has been limited. We believe, however, that our support of CBC has encouraged the regionalization of blood resources with resultant efficiency, and with a significant improvement in the quality of the product available.

Now I would like to turn to specific aspects of the proposed legislation. These comments derive as much from my experience in managing hospitals as from my current experience with a not-for-profit prepayment health insurer.

1. Section 1121, in referring to hemophilia diagnostic and treatment centers, correctly, I think, emphasizes the desirability of treatment programs on an outpatient basis but it must, of course, include the available inpatient resource as well.

2. Section 1122 provides for financial support exclusively for hemophiliacs. It is regrettable that many hemophiliacs, because of disability and other reasons, have been unable to obtain conventional health insurance and this legislation attempts to remedy that.

However, as a health professional I am opposed to categorical assistance and entitlement. Rather, I would hope that all persons in need of health care could receive such care without financial barriers.

3. Section 1122, paragraph C provides for a means test. I am opposed to the establishment of a means test, which is intended to limit payment where the patient or family can sustain such costs. I can tell you from my own experience that there will be people who are in need of care, and cannot afford such care, but will not subject themselves to the indignities of a means test.

4. Section 1123, paragraph (a) provides for the establishment of only 15 specialized treatment centers. I would hope that this will be seen as a first step in the establishment of a larger network of centers to meet the needs of all hemophiliacs in our country.

5. Section 1123, paragraph b.3 sets some requirements for size of treatment center programs. I believe that any facility established under this legislation should be a large scale treatment center, so as to attract the best qualified professionals and to operate cost-effectively.

From my experience in the metropolitan area of New York I think a minimum of 100 patients under care in one center is not an unreasonable requirement to make. In less densely populated areas perhaps 50 would be a more reasonable number.

6. Section 1124 establishes this program with still another new payment mechanism. It would seem preferable for payment to be handled through the Social Security Administration or other existing health care funding programs.

7. Section 1125 calls for establishment of fractionation centers. I would expect that the fractionation centers established under this legislation would be required to become integral parts of the larger regionalized blood system that is now taking shape under the guidance of the Assistant Secretary for Health.

I thank you for the opportunity to offer these comments.

It has been a pleasure to be here.

Senator WILLIAMS. Thank you very much, Mr. Meyers. I am not making comments because of the necessities of time. I am sure we will find a great deal of merit in many of your suggestions.

Mr. JEWETT. Senator Williams, my name is Warren Jewett. I am a biomedical engineer, vice president of Bio-Gant Corp., Woodbridge, Conn., and a past president of the National Hemophilia Foundation. My company and I have conducted extensive research into the problems of blood plasma fractionation as a part of the NHLI contract No. 1-HL-3-2969.

While it is the considered opinion of those currently fractionating plasma in the United States that there can be an adequate supply of the II, VII, IX, X concentrate for treatment of Christmas disease (Factor IX Hemophilia), there is no immediate way of meeting the need for an adequate supply of Factor VIII concentrate.

At the present time the commercial yield of Factor VIII is between 12 and 15 percent of the available starting material. Approximately 85 to 88 percent has been lost or has become inactivated during the manufacturing process. Of the 13 commercial producers in the United States, only one claims to have a yield nearer 25 percent. Others using specialized laboratory techniques have achieved yields as high as 60 percent.

The Cohn method of plasma fractionation, using the batch process, has been in existence virtually unchanged since 1947. Through the

application of modern engineering techniques applied to the Cohn process, considerably greater yields are anticipated. The Scottish National Transfusion Service using an automated, semicontinuous flow process has achieved yields of 50-55 percent. Similarly, advances will also be made in the quality of albumin, gamma globulin, and Factor IX complex.

If we stop to consider that one unit of antihemophilic factor (AHF) is that derived from 1 cc. of normal fresh human plasma, then a 500 cc. blood donation should contain on the average about 200 to 250 AHF units. Because of timelag between the drawing of blood and its preparation for removal of the Factor VIII cryoprecipitate, the amount available for concentrate manufacture is down to an average of 100 to 120 AHF units.

If you then consider that only 12 percent of that amount will be recovered, as a final product, it is easy to understand why such large quantities of blood plasma are required. In order to raise the Factor VIII level to 30 percent in the severe 170 pound classical hemophiliac he must be transfused with 800 units of AHF.

If we consider the worst case situation of low starting input, plus poor yield in manufacture, this could require sixty-six 500 cc. donations to provide an adequate amount of the necessary Factor VIII. There is no question but through automation and proper handling of fresh plasma, it will be possible to greatly improve this picture.

Even so, an increased supply of fresh frozen plasma, greater than anything now available to us, will be the key to future prophylactic treatment of those afflicted with severe classical hemophilia.

The National Blood Resource Committee at the National Institute of Health has long had a program to encourage the development of automated techniques, but until very recently there were no researchers interested in such a project. Work is presently being done by two independent contractors to perfect an automated, continuous flow process.

In addition, research is currently being undertaken to harvest blood fractionations by new chemical means. Any new methods of fractionation will require years of testing before FDA approval can be granted; therefore, the automation of the Cohn method of fractionation holds the most promise for increased yields and purity for the immediate future.

There is one comment I would like to add about something that was said in the last panel. There may have been a bit of misunderstanding. Today 30 to 35 percent of all the hemophiliacs are the result of a spontaneous mutation, that is, there appears to be absolutely no history going back for many generations though we know that hemophilia can skip many generations.

The number of spontaneous mutants would indicate that the increase is going to accelerate greatly over the coming years, and I think that we will find the need for care will grow ever more important as time goes by.

Senator WILLIAMS. The last thing you said is opinion?

Mr. JEWETT. The 35 percent?

Senator WILLIAMS. No, the increase.

Mr. JEWETT. There appears to be an increase in numbers. That is the rate at which we are seeing these mutations appears to be increas-

ing. It is only very recently that scientists have learned of methods of detecting the mutants. Since this is not yet being done on a large nationwide program and is only being done in a few areas, the State of Connecticut is doing this, and we are seeing it within our own small areas, increasing rapidly, we believe that this is probably extended through the whole Nation.

We will know more about this as data is collected in the next 2 or 3 years.

Senator WILLIAMS. Is it considered by all a purely genetic problem?

Mr. JEWETT. The spontaneous mutation is not a genetic problem. It is simply appearing.

Senator WILLIAMS. You said you know that the generations skip. That suggests that it is in the family genes.

Mr. JEWETT. Yes, but we believe in 35 or 30 percent there is no previous history and no demonstrated skip. There are probably 20 percent of the hemophiliacs who are not spontaneous mutants, but who may not have observable future as far as—may have skipped, in other words, for seven generations.

Senator WILLIAMS. This is a good time for another break because I have to go vote. Thank you very much. I will be back as soon as I can.

[Short recess.]

Senator WILLIAMS. We will come back to order.

Mr. JEWETT. Senator Williams, I had been asked to make those statements regarding the 30 some odd percent of hemophiliacs who are spontaneous mutations, but I am afraid in doing so I have also made some misconceptions. I would like to ask Dr. Lazerson if he would be kind enough to give the straight scoop on that.

Dr. LAZERSON. It turns out that the figure of 30 percent fresh mutations is factually based on the large population surveys of hemophilia families. As a matter of fact, there may not have been any previous disorder, in that the mother that gave rise to a child with hemophilia will not produce another member with hemophilia, and as a result, one considers that boy a fresh mutation. It turns out the business of skipping generation is not really skipping generations.

What you are talking about is clinical expression that the disease or disorder may not be manifest throughout numbers of generations but is genetically passed on. The fact that you have multiple females placing the trait on and then just by pure chance you give rise to a male who has the defect. It appears that the defect is skipped, but it really is not. It is just passed on.

Senator WILLIAMS. I see. There have been manifestations of this in females?

Dr. LAZERSON. That is correct. There are true hemophilia females, and through one of three ways, either a male with hemophilia, marrying a female carrier. As a result, that female offspring may get a double dose, get a dose of the defect from the male and the female carrier.

There are also the other two ways which are chromosomal defects, which the expression of the defect—I should say the lack of expression of the normal gene in a female carrier allows her then to assume the status of the hemophilic female.

Senator WILLIAMS. Thank you.

Dr. KELLNER. Mrs. Gooley will be the next witness.

Mrs. GOOLEY. I am the executive director of the Hemophilia Center of Rochester and Monroe County, Inc., and have been since its inception.

For the past 18 years the leadership of the hemophilia chapter and the community of greater Rochester have combined their resources to bring comprehensive health care to hemophilic families residing in the 13-county Genesee region.

In June 1959, these united efforts culminated in the opening of the Hemophilia Center, an independent health agency, now located in the Research Building of Rochester General Hospital. The treatment center, as well as the coagulation laboratory, is fully licensed by the New York State Department of Health, and serves approximately 170 patients. Its working team includes physician directors of laboratory, orthopedics, behavioral sciences, and medicine; medical technologists, registered nurses, social worker, and physiotherapist; executive director and office staff.

This outpatient clinic provides transfusion and medical treatments, including a supervised home transfusion program, a full range of orthopedic and physical therapy services, coordinated dental care, diagnostic laboratory which also performs extensive quality controls on all blood products used by hemophiliacs in the 13-county area.

Social services ranging from individual, family, and genetic counseling, school conference to financial consultation are a crucial part of the service system. In addition, the center provides a setting for a busy schedule of professional education, reaching medical, nursing and laboratory students and all others professionally concerned with the total care of patients suffering from clotting disorders.

From the beginning our chapter and professional leadership assumed that the legendary community spirit which pervades every aspect of life in the Rochester area would stretch to include another community problem—hemophilia. We were right. Although each contact or commitment was cemented only after much hard work and planning, these community resources have remained firmly pledged to our program.

Through a working agreement with the Rochester General Hospital, many reciprocal services, including medical and dental house staff coverage, are provided. Our affiliation with the University of Rochester brings further program review and staff educational benefits. Graduate students at the Eastman Dental Center rotate through our center for training, and much of the dental care of our patients is performed at the Eastman Dental Center.

Our project nurse or social worker works closely with the Office of Vocational Rehabilitation and some 23 other agencies which help to establish more effective patterns of living for our families. The American Red Cross through the Rochester regional blood program is our oldest and one of our most vital resources.

Through an aggressive commitment to component therapy, they are able to provide all of the cryoprecipitate we can use, and in so doing, place no responsibility on patient families to recruit donors for replacement. We also utilize large amounts of commercial concentrates for specific purposes.

The Hemophilia Center is a participating agency of the United Community Chest of Greater Rochester which has contributed over \$400,000 to our program since we were admitted to the fund. However, our primary sources of income are third party payers, such as Blue Cross, Medicaid, hospitals, and private insurances.

The Medicaid program, through the Division of Health Economics, New York State Department of Health, and Blue Cross/Blue Shield of the Rochester area routinely audit our records and annually establish clinic rates for our services which includes our supervised home transfusion program and the cost of blood products. This coverage was a pioneering effort in the Rochester area, and has not been established in our sister city of Buffalo where the Hemophilia Center of Western New York derived its genesis and patterned its program very similarly.

During our 1972-73 fiscal year ended March 31, 1973, 4,900 patient visits were recorded in the center; 2,838 of them for transfusion therapy for which 23,000 bags, vials, or bottles of blood products were used. The cost to patients of these blood products was \$391,127. Since 80 of our severely affected, most regularly transfused patients used the bulk of this total, it averages about \$4,890 per patient for blood products annually.

To illustrate the wide range of need and usage, however, two adult patients who are part of our Rochester delegation in Washington today, used transfusion services totaling \$19,462 last year. One a doctor of philosophy and professor of mathematics at a Rochester college, who has a relatively milder form of hemophilia, required \$3,454 of this total, and the other, a young banker with severe classical hemophilia, used \$16,008 worth of transfusion services. These figures are exclusive of any laboratory, orthopedic, dental or social services provided through the center to these patients.

It cost the Hemophilia Center \$535,670 last fiscal year to provide this degree of continuity of care and caring to our patients in the Rochester region, and we anticipate our total expenditures in our current year to exceed \$620,000.

Despite our best efforts, we are providing "stopgap" measures for patients who could be joining the mainstream of society as full-fledged productive members. We cannot look to our community and State resources for the moneys needed to provide truly preventive or prophylactic treatment of this disease.

We become very angry and frustrated when we see our 3- and 4-year-old toddlers plagued with the same crippling joint deformities as our young adults for lack of early and vigorous care. We would like very much to set up satellites in the outer reaches of our 13-county area, and find it impossible to do so because of lack the funds or insurance coverage in these areas.

We need to be more effective in our outreach and casefinding work. We become angry and frustrated knowing that patients in other areas of New York State, and indeed, all over the country are waiting for this help.

In essence, we are proud of the excellent return on the investment made by concerned people in the greater Rochester area, but we are still angry and frustrated because we are trained, equipped, and geared

to give back to the hemophiliac his total life and we must settle for something less.

The passage of the Hemophilia Act of 1973, S. 1326, would insure this country one of the most fruitful and most satisfying returns on any investment it has ever made.

Thank you.

Senator WILLIAMS. Do you fractionate blood at your center?

Mrs. GOOLEY. No, through Red Cross regional blood program, Senator.

Senator WILLIAMS. Where is it done, do you know?

Mrs. GOOLEY. On their premises they have a fractionation program.

Senator WILLIAMS. Where?

Mrs. GOOLEY. In their Rochester chapter building.

Senator WILLIAMS. This is done both ways, commercially, am I right on that?

Mrs. GOOLEY. We purchase commercial blood products, yes, Senator, but we also receive from the Rochester Red Cross blood program 20,000 to 25,000 bags of cryoprecipitate a year. That is about 50 percent of their total collection of blood.

Senator WILLIAMS. Is that entirely a voluntary program on the part of the Red Cross?

Mrs. GOOLEY. Yes; it is.

Senator WILLIAMS. To supplement that, you do purchase commercial—

Mrs. GOOLEY. Some 8,000 or 9,000 more bottles of concentrate.

Senator WILLIAMS. Now, who is next, Dr. Kellner?

Dr. KELLNER. At long last our patient colleague, Dr. Halden.

Dr. HALDEN. Mr. Chairman, I am Richard Halden, medical director for the Carter Blood Center, Fort Worth, Tex., some 14 years of activity.

Initially let me applaud you, Senator Williams, and Senate bill 1326. It is the first major step to emancipate the hemophiliac from the totalitarian economic yoke. It recognizes that the 15,000 hemophiliac victims are a politically impotent miniscule minority whose problem has had virtually no impact on affluent America today.

In analogizing, one might consider it as a very thin rapierlike iceberg whose effect rarely surfaces for middle-class America to view. The torment and the agony of suffering and hopelessness are down deep, submerged, hidden, and occult but quite real to those at bedside.

Thus, what happens to the individual afflicted with hemophilia is a measure of the philosophy of the health services dispensing unit in the community in which he lives.

Unfortunately there exist too many prestigious medical complexes with giant institutional egos and too few organizations with simple human compassion which have attempted a solution of this pernicious medical and social dilemma.

The reason? Simple. The prodigious cost of care when it is available.

I have sent to you, Senator Williams, and to your staff, a cost analysis for 15,000 hemophiliac victims based on the experience of the Carter Blood Center which treats 185 severely afflicted individuals. Data provide commutations of very serious import. One, a verification of a suspected incredible potential cost for Factor VIII. And, two, a detri-

mental impact on our national blood resources already taxed beyond its capacity, if one believes the comment of Mrs. Bernice Hemphill at a recent meeting concerning the national blood program—the worst shortage this summer in 30 years of blood banking.

I might say that in the analysis in our manner of handling costs Factor VIII units for the entire Nation would be \$24 million. If commercial concentrate were used at 14 cents a unit, it would be \$100 million.

To digress for a moment, I come before you wearing four hats. No. 1 is medical director of a metropolitan blood center which by means of volunteers serves 60 hospitals. As a consequence of this experience, some knowledge and understanding of the problem of donor motivation in education has developed. We too this summer had difficulty in supplying the hospital commitment in whole blood components.

During the last 5 years the Carter Blood Center has had a deficit of \$50,000 a year because of its program to normalize the hemophiliacs.

No. 2, as the hemotologist and personal physician for 185 victims, we have ceased to hospitalize, except for elective surgery, usually orthopedic, or massive bleeding. Now beginning in 1960, the inception of home infusion, we now have a majority of the 185 individuals on home infusion, either by his parents or by himself.

Our youngest home infusion individual is 11 years of age, hopefully cutting the 60-yard invisible umbilical cord.

The effects on the social and medical environment are dramatic. The patients consider themselves as normal. Under most circumstances they are eager to participate in all events of community life. This reduces the costs which are obvious.

No. 3, as administrator of a blood center, the cost factor had to be analyzed critically. By means of components, the cost of each factor VIII unit was maintained at less than 4 cents.

No. 4, just as an ordinary citizen who thought that the problem was worthy of solution because such action would be consistent with the attitudes for which America stands. The normalized hemophiliac is a source of untapped intellectual wealth, not a chronically ill non-productive individual.

Thus, wearing all four hats at once, one must come to the conclusion that invariably the success of any widescale hemophiliac program will be directly related to the volume of the national blood resources. Now this I consider very important because the unlocking of the biochemical and immunologic secrets of blood by means of research increases its potential therapeutic and inevitably results in increasing demands.

I think this will continue.

Fractionation centers will depend on an active donor force, to minimize costly reduplication of services which is so evident at our present hospitalization policy. Money payment does not necessarily insure response in the seller of blood or safety in the recipient. The average citizen, free, white or black, and 18, of their volition must contribute and know why. Our entire society must be made to be blood conscious with special emphasis on the education of youth before the blood shortage will come to an end. This responsibility belongs to all.

In closing I would like to suggest one specific method for donor motivation. The reason I wish to suggest it is that it involves the hemo-

philiacs themselves; namely, the campus blood drives in which the tragic story of hemophilia is unfolded. The students respond like gangbusters. I have personally seen it. They give their blood away to help solve the financial problems of hemophiliacs.

Simultaneously, the blood relieves the shortages. Educationally they learn that donation is not painful or perilous. I guess it is up to individuals like Dr. Kellner and myself to insure them that such is true.

Finally, they leave the campuses convinced of the validity of the story of hemophilia and the needs for voluntary blood donors. As future leaders, they will put away the problems of blood donations. At the University of Texas at Austin, 10,000 plus since 1971. A small Baptist college in central Texas, 40 percent of the 1,400 members of the student body donated blood free.

It all began at TCU 5 years ago.

With the correct approach using the hemophiliac families as volunteers, a personal touch with the student, the phenomenon can be reduplicated throughout the country, but we need more money to continue. I understand Dr. Kellner has undertaken this educational facet in hospitals. I would like to applaud that idea also.

We had a youth program involving seniors of the high school in which we introduced the concept of voluntary blood donation. Their gregarious nature makes it highly successful when you offer them a humanitarian goal.

I thank you for my chance to speak.

Senator WILLIAMS. Excellent. Do you want to comment on that high school program, Dr. Kellner?

Dr. KELLNER. Yes. I agree with Dr. Halden that it is necessary to begin the education process early in life. I would suggest starting in the grade schools and let the children educate their parents.

Senator WILLIAMS. What is the outlook on the donation of blood in terms of age?

Dr. KELLNER. It is 18 years in New York, and New Jersey, Senator Williams. In some States, in the State of Washington, for example, at the King County blood bank in Seattle, high school youngsters donate blood at age 16 with the parents' consent.

Senator WILLIAMS. What are the outer limits?

Dr. KELLNER. The age limits are 18 to the 66th birthday. As to the usefulness of blood with respect to age you have to decide what portion of the blood one is talking about. For red cells it is the conventional 21 days unless frozen. For platelets, it is a few hours to a few days. For cryo, if frozen, or dried VIII, 6 months to a year. Blood is a very complex mixture, and one cannot generalize about all its constituents.

Senator WILLIAMS. When does blood get so tired that you cannot get any good from it?

Dr. KELLNER. That it is extremely psychological—

Mr. FRIEDLAND. At 3 in the afternoon. [Laughter.]

Dr. KELLNER. In closing, Senator Williams, I for one and on behalf of my associates here want to thank you for the opportunity to come before you and for your patience. It is perfectly clear that we have vast resources in this country that have not been fully utilized and that there are important changes in the offing in our national blood complex. We wish to support your bill because we regard it is a very

important step forward in the mobilization of our human resources and our blood resources.

Thank you.

Senator WILLIAMS. Well, we are grateful to all of you that contributed so much today and come from distant places. We appreciate all who came here and your patience was appreciated because it was one of these days where the schedule had so many interruptions. I appreciate your patience and this most constructive, one of the most telling statements or combination of statements in support of legislation that I have been part of.

I am very, very grateful. We will of course have to continue these hearings. The executive side has not been heard from. If there are any informal ways of bringing your message to those who will be spokesmen for the administration between now and the time they will be able to appear in response to our invitation, it might be helpful.

I do not think we will require many further days of hearings. I would think another day of hearings should make this telling story clear to Members of Congress sufficient for them to say yes or no. My reaction so far and the reaction I have felt and heard from my colleagues so far has been most favorable and very positive and most affirmative.

You have made again, to use the word three times, a compelling case for the need.

Thank you. [Applause.]

[The prepared statements referred to earlier follow:]

Mr. Chairman, Members of the Senate Committee,
Ladies and Gentlemen:

My name is Warren Jewett. I am a bio-medical engineer, Vice-President of Bio-Gant Corporation, Woodbridge, Connecticut and a past president of the National Hemophilia Foundation. My company and I have conducted extensive research into the problems of blood plasma fractionation as a part of NHLI contract No. 1-HL-3-2969.

While it is the considered opinion of those currently fractionating plasma in the United States that there can be an adequate supply of the II, VII, IX, X concentrate for treatment of Christmas disease (Factor IX Hemophilia), there is no immediate way of meeting the need for an adequate supply of Factor VIII concentrate. At the present time the commercial yield of Factor VIII is between 12 and 15 percent of the available starting material. Approximately 85 to 88 percent has been lost or has become inactivated during the manufacturing process. Of the thirteen commercial producers in the United States, only one claims to have a yield nearer 25 percent. Others using specialized laboratory techniques have achieved yields as high as 60 percent.

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Respectfully submitted,

Warren R. Jewett, Sc.D.
Executive Vice-President
Bio-Gant Corporation

11/12/73

TESTIMONY OF
DONALD MEYERS
ASSISTANT VICE PRESIDENT
BLUE CROSS OF GREATER NEW YORK
BEFORE THE
HEALTH SUBCOMMITTEE
OF THE
SENATE LABOR AND PUBLIC WELFARE COMMITTEE
ON S.1326, THE HEMOPHILIA ACT OF 1973

November 15, 1973

I am Donald Meyers, Assistant Vice President, Program Development, Blue Cross of Greater New York. Before my current association with Blue Cross, I was involved in the administration of hospitals.

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containment through the better management of blood. In addition, we developed agreements to include other blood banks in the community, coordinated through CBC.

At the time we initiated this program we excluded coverage for hemophiliac patients because of the unknown potential demand that this might place on the system. Subsequently, in 1968, we entered into an agreement with the New York Metropolitan Chapter of the National Hemophilia Foundation which provided for blood and blood product replacement for hemophiliac patients who are members of the Metropolitan Chapter and also for Blue Cross subscribers. This coverage provides for the replacement of all blood and blood products provided hemophiliacs covered under this agreement, when such blood products are provided within a hospital setting.

Each of these agreements, i.e. contract with CBC, other community blood banks and the Metropolitan Chapter of NHF have shown a steady growth in the amount of coverage provided over the last several years. Fundamental to these agreements is the encouragement of voluntary blood donations, since coverage is contingent upon such voluntary blood donations.

Although the existing program is successful, it is limited in the number of people it covers and the extent and scope of such coverage. Our ability to expand this

coverage in the face of rising costs for other care has been limited. We believe, however, that our support of CBC has encouraged the regionalization of blood resources with resultant efficiency, and with a significant improvement in the quality of the product available.

I would like to cite one important detail of our relationship with CBC. The contract provides for Blue Cross to perform an annual audit of their books of account. Our reimbursement to CBC has been based on actual costs, as determined by this audit. It is notable that the price we pay to CBC has increased less than 6% in the past four years, while during the same period we have seen hospital costs soaring.

We are well aware of the difficulty in determining charges, prices, fees and costs within many segments of the blood banking industry. When whole blood was the only product available the task was relatively simple. Where a combined cost embraces multiple products, the costs of individual products cannot be separately determined. Our audit of CBC's costs covers all their products, and results in derivation of a simple arithmetic average. However, with the improvement in the standardization of accounts and our continued experience in this area we believe that we, in conjunction with CBC, will have a very significant body of knowledge concerning the true cost of running blood banks.

Now I would like to turn to specific aspects of the proposed legislation. These comments derive as much from my experience in managing hospitals as from my current experience with a not-for-profit prepayment health insurer.

1. Section 1121, in referring to hemophilia diagnostic and treatment centers, correctly, I think, emphasizes the desirability of treatment programs on an out-patient basis but it must, of course, include the available in-patient resource as well.
2. Section 1122 provides for financial support exclusively for hemophiliacs. It is regrettable that many hemophiliacs, because of disability and other reasons, have been unable to obtain conventional health insurance and this legislation attempts to remedy that. However, as a health professional I am opposed to categoric assistance and entitlement. Rather, I would hope that all persons in need of health care could receive such care without financial barriers.
3. Section 1122, paragraph C provides for a means test. I am opposed to the establishment of a means test, which is intended to limit payment where the patient or family can sustain such costs. I can tell you from my own experience that there will be people who are in need of care, and cannot afford such care, but will not subject themselves to the indignities of a means test.

4. Section 1123, paragraph(a) provides for the establishment of only 15 specialized treatment centers. I would hope that this will be seen as a first step in the establishment of a larger network of centers to meet the needs of all hemophiliacs in our country.

5. Section 1123, paragraph b.3 sets some requirements for size of treatment center programs. I believe that any facility established under this legislation should be a large scale treatment center, so as to attract the best qualified professionals and to operate cost-effectively. From my experience in the metropolitan area of New York I think a minimum of 100 patients under care in one center is not an unreasonable requirement to make. In less densely populated areas perhaps 50 would be a more reasonable number.

6. Section 1124 establishes this program with still another new payment mechanism. It would seem preferable for payment to be handled through the Social Security Administration or other existing health care funding programs.

7. Section 1125 calls for establishment of fractionation centers. I would expect that the fractionation centers established under this legislation would be required to become integral parts of the larger regionalized blood system that is now taking shape under the guidance of the Assistant Secretary for Health Dr. Charles Edwards.

I thank you for the opportunity to offer these comments.

STATEMENT OF

MRS. MARY M. GOOLEY
EXECUTIVE DIRECTOR
HEMOPHILIA CENTER OF ROCHESTER
MONROE COUNTY, N.Y., INC.

before the

SUBCOMMITTEE ON HEALTH
U. S. SENATE
WASHINGTON, D.C.

NOVEMBER 15, 1973

STATEMENT OF HEMOPHILIA CENTER OF ROCHESTER AND MONROE COUNTY, INC.

Mrs. Mary M. Gooley, Executive Director

For the past eighteen years, the leadership of the hemophilia chapter and the community of greater Rochester have combined their resources to bring comprehensive health care to hemophilic families residing in the thirteen-county Genesee region.

In June, 1959, these united efforts culminated in the opening of the Hemophilia Center, an independent health agency, now located in the Research Building of Rochester General Hospital. The treatment center, as well as the coagulation laboratory, is fully licensed by the New York State Department of Health, and serves approximately 170 patients. Its working team includes physician directors of laboratory, orthopedics, behavioral sciences, and medicine; medical technologists, registered nurses, social worker, and physiotherapist; executive director and office staff.

This outpatient clinic provides transfusion and medical treatments, including a supervised home transfusion program, a full range of orthopedic and physical therapy services, coordinated dental care, diagnostic laboratory which also performs extensive quality controls on all blood products used by hemophiliacs in the thirteen-county area. Social services ranging from individual, family, and genetic counseling, school conferences to financial consultation are a crucial part of the service system. In addition, the Center provides a setting for a busy schedule of professional education, reaching medical, nursing, and laboratory students and all others professionally concerned with the total care of patients suffering from clotting disorders.

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Mrs. Mary M. Gooley
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From the beginning our chapter and professional leadership assumed that the legendary community spirit which pervades every aspect of life in the Rochester area would stretch to include another community problem - hemophilia. We were right. Although each contact or commitment was cemented only after much hard work and planning, these community resources have remained firmly pledged to our program.

Through a working agreement with the Rochester General Hospital, many reciprocal services, including medical and dental house staff coverage, are provided. Our affiliation with the University of Rochester brings further program review and staff educational benefits. Graduate students at the Eastman Dental Center rotate through our Center for training, and much of the dental care of our patients is performed at the Eastman Dental Center. Our project nurse or social worker works closely with the Office of Vocational Rehabilitation and some twenty-three other agencies which help to establish more effective patterns of living for our families. The American Red Cross through the Rochester Regional Blood Program is our oldest and one of our most vital resources. Through an aggressive commitment to component therapy, they are able to provide all of the cryoprecipitate we can use, and in so doing, place no responsibility on patient families to recruit donors for replacement. We also utilize large amounts of commercial concentrates for specific purposes.

The Hemophilia Center is a participating agency of the United Community Chest of Greater Rochester which has contributed over \$400,000 to our programs since we were admitted to the fund. However, our

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primary sources of income are third party payors, such as, Blue Cross, Medicaid, hospitals, and private insurances. The Medicaid program, through the Division of Health Economics, New York State Department of Health, and Blue Cross/Blue Shield of the Rochester area routinely audit our records and annually establish clinic rates for our services which includes our supervised home transfusion program and the cost of blood products. This coverage was a pioneering effort in the Rochester area, and has now been established in our sister city of Buffalo where the Hemophilia Center of Western New York derived its genesis and patterned its program very similarly.

During our 1972-73 fiscal year ended March 31, 1973, 4,900 patient visits were recorded in the Center; 2,838 of them for transfusion therapy for which 23,000 bags, vials, or bottles of blood products were used. The cost to patients of these blood products was \$391,127. Since eighty of our severely affected, most regularly transfused patients used the bulk of this total, it averages about \$4,890 per patient for blood products annually. To illustrate the wide range of need and usage, however, two adult patients who are part of our Rochester delegation in Washington today, used transfusion services totaling \$19,462 last year. One a Doctor of Philosophy and professor of mathematics at a Rochester college, who has a relatively milder form of hemophilia, required \$3,454 of this total, and the other, a young banker with severe classical hemophilia, used \$16,008 worth of transfusion services. These figures are exclusive of any laboratory, orthopedic, dental, or social services provided through the Center to these patients.

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It cost the Hemophilia Center \$535,670 last fiscal year to provide this degree of continuity of care and caring to our patients in the Rochester region, and we anticipate our total expenditures in our current year to exceed \$620,000.

Despite our best efforts, we are providing "stop-gap" measures for patients who could be joining the mainstream of society as full-fledged productive members. We cannot look to our community and state resources for the monies needed to provide truly preventive or prophylactic treatment of this disease.

We become very angry and frustrated when we see our three and four year old toddlers plagued with the same crippling joint deformities as our young adults for lack of early and vigorous care. We would like very much to set up satellites in the outer reaches of our thirteen-county **area**, and find it impossible to do so because of lack of funds or insurance coverage in these areas. We need to be more effective in our outreach and case finding work. We become angry and frustrated knowing that patients in other areas of New York State, and indeed, all over the country are waiting for this help.

In essence, we are proud of the excellent return on the investment made by concerned people in the greater Rochester area, but we are still angry and frustrated because we are trained, equipped, and geared to give back to the hemophiliac his total life and we must settle for something less. The passage of the Hemophilia Act of 1973, S. 1326, would insure this country one of the most fruitful and most satisfying returns on any investment it has ever made.

Senator WILLIAMS. This hearing of the Subcommittee on Health now stands adjourned.

[Whereupon at 2 p.m. the hearing was adjourned.]



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