

citizens, is hereby recognized on the occasion of its 100th anniversary.

NATIONAL BONE MARROW REGISTRY REAUTHORIZATION ACT OF 1998

HON. C.W. BILL YOUNG

OF FLORIDA

IN THE HOUSE OF REPRESENTATIVES

Wednesday, May 20, 1998

Mr. YOUNG. of Florida. Mr. Speaker, I submit for the RECORD, this statement which should have followed my remarks in the House yesterday during Consideration of H.R. 2202, to Reauthorize the National Bone Marrow Donor Registry. Mr. Speaker, I rise in support of this measure and thank the Chairman of the Commerce Committee, Mr. BLILEY, and the Health Subcommittee Chairman, Mr. BILIRAKIS, for their efforts to help bring this legislation reauthorizing the lifesaving work of the National Marrow Donor Program to the floor for consideration.

H.R. 2202 will guide the National Marrow Donor Program into the next century by reauthorizing the program's core function of maintaining a bone marrow donor registry, strengthening efforts to increase minority recruitment, and improving patient and donor advocacy.

Mr. Speaker, with 218 cosponsors this bill enjoys the broad bipartisan support of our colleagues, as well as the support of the National Marrow Donor Program, the American Red Cross, the American Association of Blood Banks, the National Heart Lung and Blood Institute, and the Department of Health and Human Services.

The National Bone Marrow Donor Registry is an outstanding program that was created by the Congress to give hope to families where none would have otherwise existed. Since its establishment a little more than 10 years ago, this program has given life to thousands of people here and around the world.

It was on April 2, 1987 that I first testified before the House Commerce Committee on this issue. That was very early in my search for a home for a national bone marrow registry. In fact, that was very early in my education on the many issues that surrounded bone marrow transplantation. What I knew at the time, though, was that without a national registry, men, women, and children with leukemia and other fatal blood disorders would continue to die because there was no way to find unrelated marrow donors for them.

What I remember from that hearing 11 years ago was that there was nowhere within the Department of Health and Human Services to call home for a national registry. In fact, the Director of the National Institutes of Health testified after me that day saying there was no way that a national registry of unrelated volunteer donors would ever succeed. He told the Committee we would never find more than 50,000 people willing to take the simple blood test required to enter such a registry.

Mr. Speaker, while I already felt personally challenged to do something about creating a national registry, those remarks that day gave me the final incentive I needed to do all within my power to make this program a success.

A little over six months after that hearing, with a small appropriation I requested for the

United States Navy, we activated National Marrow Donor Program. And on my birthday, December 16, 1987, an airplane took off from a snowy airfield in Milwaukee to deliver the first bone marrow to a dying child from North Carolina.

Today, Mr. Speaker, I proudly report to you that we proved those skeptics wrong. We now have a national registry of 3,134,601 people willing to donate their bone marrow to save a life. In addition, our national registry is linked with 14 other similar registries around the world to allow us to ship bone marrow across the oceans to save lives.

There are so many heroes that have made this program such a success that my time today does not allow me to name them all. There are my colleagues in the House and Senate who were willing to take a chance and support this program when the so-called experts said it couldn't be done. A number of our colleagues have been personally touched by the success of this program when they were called to donate bone marrow or when one or family members received the tragic news that they would die without a bone marrow transplantation.

There are many other heroes, some such as Admiral Bud Zumwalt. It was Admiral Zumwalt that I bumped into in the early months of 1987 when he was working the halls of Congress searching for the same thing as I was, a home for this national registry. Together we joined as a team with Dr. Bob Graves, a cattle rancher from Colorado, Dr. John Hansen, a rising young physician and researcher from Seattle, and Captain Bob Hartzman, a Navy doctor from Bethesda. Together we found a willing partner in the United States Navy whose Surgeon General said he would give us a federal home for this great national program.

Then Mr. Speaker, there are the countless heroes around our nation who are the volunteers willing to be a part of the national registry and the patients who have undergone bone marrow transplants and have helped us learn and improve the process with each and every procedure. There are the families who have given us the support and the energy to push ahead. And there are those who have sponsored the thousands upon thousands of recruiting drives all around our nation to help us build such a large and diverse registry.

The result of our work is a program that saves lives every day by matching patients and donors. Few federal programs have been as successful in such a short period of time and it is the involvement of the federal government that has been the key to this success. Prior to our establishment of a national registry, there was only a piecemeal network of independent local registries of all sizes, with very little intercommunication. With the support of Congress, we activated a national registry in September 1987 that now links together more than 98 donor centers, through which donors are recruited and entered into the registry, and 112 transplant centers, which work with the patients to complete the transplants. From a small, fragmented system of individual donor centers was born a true national and international treasure that is the National Marrow Donor Program and links the United States with eight foreign donor centers, 23 foreign transplant centers, and 14 national registries in foreign nations.

With the support of Congress, the United States Navy, and the Department of Health

and Human Services, we have come a long way these past 11 years, but there is still a ways to go. With the number of bone marrow transplants using unrelated donors still increasing dramatically from year to year, it is obvious that we must continue to grow the size of the registry to save lives and give the largest number of children and adults the best possible opportunity to find a matched donor. While the likelihood of a patient identifying a fully matched unrelated donor has increased dramatically from 30 percent in 1989, to nearly 80 percent today, our continued commitment can help bring that figure closer and closer to 100 percent.

Much of the federal support we provide each year is for donor recruitment and education activities. With this federal support, we are maintaining the registry's remarkable rate of growth. Last year the donor rolls increased 17 percent by a total of more than 450,000.

Still, despite all of our good work, we have a ways to go to ensure that all ethnic groups have the best possible chance of finding a matched donor. The federal resources we began earmarking for minority recruitment beginning in 1991 have made a tremendous difference in the rate at which we have been able to increase minority participation in the program. In fact, the number of minority donors in the national registry have increased by 140 percent in the past four years, a rate far greater than the growth of the overall registry. As a result, there has been a corresponding 140 percent increase in the number of minority patients receiving life-saving transplants over the past four years. More minority patients received transplants last year than in the program's first seven years combined.

Mr. Speaker, as I have said time and time again, the key to the success of the National Marrow Donor Program is people—people who are willing to save a life by donating a small amount of their bone marrow. Unfortunately, people alone have not made this program the success that it is today. Without the federal support Congress has provided the National Marrow Donor Program over the past 11 years, we would still have a fragmented network of donor centers each sponsoring bake sales and other fund raising drives to pay for the testing of donors. Without federal support, it would be virtually impossible to maintain, let alone continue to increase the donor rolls of the national registry. With an attrition rate of just 5 percent, the national program will have to recruit more than 150,000 donors per year just to maintain the current size of the national registry.

Suffering the greatest from any reduction in our federal support for this program, would be the minority groups that we are working so hard to recruit and continue to be underrepresented in the national registry.

Our efforts here and now must build on our success, taking what we have learned since the program's establishment and applying this to improve our future. Likewise, we must recognize that we have learned of ways in which the program could do a better job. This is the goal of H.R. 2202.

The program's success is grounded in the more than 3 million donors who have volunteered to donate their bone marrow, in the coordinated system of donor, transplant and recruiting centers that has grown around the registry, and in the increased awareness of bone marrow transplantation. My legislation

will continue this by supporting further recruitment, coordination and educational activities.

However, if there is one thing we can agree on above all else, it is the fact that without continuing to increase the numbers of minority donors on the Registry, patients of these groups will continue to face a greater difficulty in finding a matched unrelated donor. For this reason, H.R. 2202 places a special emphasis on the need to increase potential donors of racial and ethnic minority heritage and makes this the priority of the program's recruitment efforts.

We have also learned a lot about the needs of patients and their families as they face the challenge of finding an unrelated donor match for their loved one. H.R. 2202 formally establishes an Office of Patient Advocacy and Case Management within the program to provide individualized services for patients requesting assistance. The office will provide information and coordinate all aspects of the search and transplantation process to ensure the needs of the patient are being met. While much of this work is already being done by an office within the program, H.R. 2202 builds on these efforts by codifying the office and granting it additional authority recommended by the Senate in legislation approved by that body in 1996.

My wife Beverly and I have met with and befriended hundreds of donors, patients, and their families from all over our nation. To each of these patients, I promise that I will continue to do all that I can to ensure that they have the best possible chance to find a donor. Unfortunately, some of these families never found a donor before it was too late. Many others, however, found their miracle match and they are alive and doing well today because of the living medical miracle that is this national registry.

There is nothing I have done in public service that I am more proud of than establishing the National Marrow Donor Program. Every member of Congress should share that pride as they are a part of a great federal program that works. The measure of this program's value is the lives it saves throughout our nation and throughout our world. As we continue to increase the number of life-saving transplants that take place each year, we know that our work is not yet finished and that there are more lives to save. In making tough budgetary decisions, Congress must measure the value of each and every program to the American taxpayer. With that as our test, their can be no disputing the success of the National Marrow Donor Program because there is no higher priority than giving someone back their life.

Mr. Speaker, I appreciate the Congress' strong support for this program and for my legislation that will enable us to continue on with our life-saving work for the next five years. That commitment to this program is evident from the special joint House-Senate hearing recently held and by the willingness to work together, House and Senate, to expedite the passage and enactment of H.R. 2202. On behalf of all those donors and patients still awaiting their opportunity to unite in the most special of ways, I say thank you to all my colleagues. And on behalf of those families who will experience the second chance to enjoy their life with a child, with a husband or wife, or with a brother or sister, I say thank you for being one of the countless heroes throughout the short history of this program. Together, day after day, we will continue to give the

most precious gift of all, here and abroad, the living gift of life.

THE SENIOR CITIZENS' FREEDOM TO WORK BILL

HON. SAM JOHNSON

OF TEXAS

IN THE HOUSE OF REPRESENTATIVES

Wednesday, May 20, 1998

Mr. SAM JOHNSON of Texas. Mr. Speaker, I rise today to introduce legislation that will eliminate the so-called "Social Security Earnings Test." Under current law, our senior citizens aged 65–69 can earn only \$14,500 before they lose \$1 in Social Security benefits for each additional \$3 of earnings. This test is unfair, discriminatory, and adversely affects our country's economy. The Social Security Earnings Test must be eliminated.

The Social Security Earnings Test is unfair and inappropriate because it imposes a form of a "means" test for a retirement benefit. As we all know, Social Security benefits have been earned by a lifetime of contributions to the program. American workers have been led to regard Social Security as a government-run savings plan. Indeed, their acceptance of the 12.4 percent Social Security payroll tax has been predicated on the belief that they will get their money back at retirement age. Thus, most Americans do not accept the rationale that the return of their money should be decreased just because they continue to work.

Additionally, the Social Security Earnings Test discriminates against senior citizens who must work in order to supplement their benefits. Currently, income from investments does not affect the amount of Social Security benefits that a senior citizen receives. It simply does not make any sense to treat less favorably income from work than income from investments. Clearly, the Social Security Earnings Test is inequitable to our nation's senior citizens who are in the greatest need of additional income.

The Social Security Earnings Test also negatively affects work incentives. The disincentive effect is magnified when viewed on an after-tax basis. Senior citizens who work lose a large percentage of their Social Security benefits due to the Social Security Earnings Test, but they must also continue to pay Social Security taxes, and probably federal and state income taxes as well. The Social Security Earnings Test forces senior citizens to avoid work, to seek lower paying or part-time work or to seek payment "under the table."

In addition to being complicated and difficult for the individual senior citizen to understand, the Social Security Earnings Test is complex and costly for the Government to administer. For example, the test is responsible for more than one-half of retirement and survivor program overpayments. Elimination of the Earnings Test would help minimize administration expenses, and recipients would be less confused and less tempted to cheat on reporting their earnings.

Finally, repealing the Social Security Earnings Test would greatly aid our country's economy. Our senior citizens would be likely to work more and the American economy would benefit from their experience and skills. The combined increase in the amounts that they would pay in Social Security and other taxes,

as well as the additional contribution to our Gross National Product, would largely offset the increase in benefit payments. For decades, our senior citizens worked and dutifully paid their Social Security taxes, it is only fair that they fully receive their Social Security benefits when they are at the retirement age.

H.R.—

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Senior Citizens' Freedom to Work Act of 1998".

SEC. 2. ELIMINATION OF EARNINGS TEST FOR INDIVIDUALS WHO HAVE ATTAINED RETIREMENT AGE.

Section 203 of the Social Security Act (42 U.S.C. 403) is amended—

(1) in subsection (c)(1), by striking "the age of seventy" and inserting "retirement age (as defined in section 216(l))";

(2) in paragraphs (1)(A) and (2) of subsection (d), by striking "the age of seventy" each place it appears and inserting "retirement age (as defined in section 216(l))";

(3) in subsection (f)(1)(B), by striking "was age seventy or over" and inserting "was at or above retirement age (as defined in section 216(l))";

(4) in subsection (f)(3)—

(A) by striking "33½ percent" and all that follows through "any other individual," and inserting "50 percent of such individual's earnings for such year in excess of the product of the exempt amount as determined under paragraph (8)."; and

(B) by striking "age 70" and inserting "retirement age (as defined in section 216(l))";

(5) in subsection (h)(1)(A), by striking "age 70" each place it appears and inserting "retirement age (as defined in section 216(l))"; and

(6) in subsection (j)—

(A) in the heading, by striking "Age Seventy" and inserting "Retirement Age"; and

(B) by striking "seventy years of age" and inserting "having attained retirement age (as defined in section 216(l))".

SEC. 3. CONFORMING AMENDMENTS ELIMINATING THE SPECIAL EXEMPT AMOUNT FOR INDIVIDUALS WHO HAVE ATTAINED RETIREMENT AGE.

(a) UNIFORM EXEMPT AMOUNT.—Section 203(f)(8)(A) of the Social Security Act (42 U.S.C. 403(f)(8)(A)) is amended by striking "the new exempt amounts (separately stated for individuals described in subparagraph (D) and for other individuals) which are to be applicable" and inserting "a new exempt amount which shall be applicable".

(b) CONFORMING AMENDMENTS.—Section 203(f)(8)(B) of the Social Security Act (42 U.S.C. 403(f)(8)(B)) is amended—

(1) in the matter preceding clause (i), by striking "Except" and all that follows through "whichever" and inserting "The exempt amount which is applicable for each month of a particular taxable year shall be whichever";

(2) in clauses (i) and (ii), by striking "corresponding" each place it appears; and

(3) in the last sentence, by striking "an exempt amount" and inserting "the exempt amount".

(c) REPEAL OF BASIS FOR COMPUTATION OF SPECIAL EXEMPT AMOUNT.—Section 203(f)(8)(D) of the Social Security Act (42 U.S.C. (f)(8)(D)) is repealed.

SEC. 4. ADDITIONAL CONFORMING AMENDMENTS.

(a) ELIMINATION OF REDUNDANT REFERENCES TO RETIREMENT AGE.—Section 203 of the Social Security Act (42 U.S.C. 403) is amended—

(1) in subsection (c), in the last sentence, by striking "nor shall any deduction" and