

SICKLE CELL



Continued from last week.....

Sickle cell anemia legislation should provide funds to support the programs, in public education, testing, counseling and comprehensive health services.

Legislation is needed to establish actual services by outlining necessary procedures for allocating funds to support services from year to year. The extent of state funding will vary according to local needs, costs the likelihood of outside funding from federal contracts, foundation grants, private contributions, and community sponsored services.

Community groups should be eligible, through legislation, to receive funds to conduct sickle cell programs.

The long-range goal of supporters and advocates of the sickle cell movement is to fuse the services into a unified health care system, but in the immediate future, in addition to having sickle programming a part of other health care programs, there is a need for free standing sickle cell programs developed to predominately black community organizations.

For many years, black community groups have been attempting to develop programs to deal with social aspects of the sickle cell program (i.e., education, testing and counseling). These efforts have been hampered by inadequate funds and societal disinterest. The assignment of all funds to governmental agencies would discourage the black community from initiating self-help projects, would deny the black community an opportunity to demonstrate its competence and would not make use of all potential resources.

Sickle cell legislation should require that all testing be done on a voluntary basis.

Compulsory sickle cell testing would remove or restrict the individual's right to consent to, or to refuse, medical procedure. There is no justification for this infringement on human rights from either a public health or medical point of view. Sickle cell trait is not a personal or public health hazard, and the success of treatment of sickle cell anemia does not depend upon early diagnosis. Even if a cure were available, singling out sickle cell anemia for such compulsory screening is inappropriate because many more prevalent, curable diseases are not selected for such legislation.

Most compulsory sickle cell testing legislation was proposed by black physicians, black legislators or black community advocates who felt that the black community would benefit from a guarantee of the identification of persons with sickle cell anemia and sickle cell trait. Because of their role, it is reasonable to assume that compulsory testing laws have not been intended as tools for eugenicists or racial abuse. Regardless of the intent behind their creation, any coercive measures aimed at black Americans are likely to be misused, whether deliberately or accidentally, to feed racial tensions and polarization.

Other reasons for objecting to mandated testing are the methods employed to enforce it. One vehicle has been to establish testing as a requisite for entering public school. A Kentucky law imposed a fine of \$300 to anyone refusing testing when applying for a marriage license. Such practices render compulsory laws discriminatory and punitive.

In a New York statute, religious belief was the only acceptable grounds for refusing the test. Yet, for several valid reasons, persons might not wish to be tested or to have their children tested. One of the most compelling reasons is that sickle tests may reveal previously undisclosed extramarital relationships.

Sickle cell anemia legislation should indicate that the purpose of testing and counseling is not to prevent or control the disease, but to permit persons with sickle cell trait to make informed decisions.

The prevention approach is based on the unproven assumption that sickle cell anemia is so undesirable that trait-bearing potential parents would be better off not having any children than taking a 25% chance of having a child with sickle cell anemia; that those who have the trait and wish to have children should not marry a person with the trait, irrespective of all other desirable factors in the prospective marriage; and that those with sickle cell anemia cannot live satisfying lives.

The prevention approach also has unfortunate racial connotations. Some elements of the black community view this goal as an effort to limit the size of the black population (genocide). The net effect of raising the genocide issue is potentially destructive, for within the black community it would create dividiveness over the desirability of conducting sickle cell testing. We recognize that a few cases of sickle cell anemia which will not have been diagnosed during medical care will be identified by screening programs. But, the primary purpose of screening programs should be to identify individuals who carry the trait, and enable them to make their own decisions about childbearing.

Simply determining and informing a person of the possession of the sickling gene serves no useful purpose. It is potentially worse than not testing, since it can provoke anxiety and apprehension where there is unawareness that sickle cell trait is different from sickle cell anemia.

The purpose of genetic counseling is to enable individuals with sickle cell trait to make informed personal decisions in their own best interests with respect to childbearing; to convince them that sickle cell trait is not a disease; and to relieve any anxieties or apprehensions they may have as a result of learning that they have the trait.

MINORITY VETS AT DEADEND

THE ARMED FORCES issues five types of discharges--honorable, general, undesirable, bad conduct and dishonorable. The last three are less-than-honorable, and the last two are conferred by sentences of Special and General Court-martial.

The general and undesirable are given by administrative action, usually by a commanding officer, and represent the vast majority of administrative discharges. Many individuals guilty of minor infractions have chosen quick release for the "good of the service" rather than a brief prison confinement. They fail to realize that a less-than-honorable discharge can carry with it a stigma for life.

Veterans with other-than-honorable discharges are looked upon askance by the civilian sector which rarely makes a distinction between "general," "undesirable," "bad conduct" and "dishonorable" discharges. Whether it is an employer, an apprenticeship program, an insurance company, a bank or a school, the other-than-honorable discharge is a signal to stay away. Even the "general discharge," which is considered an honorable one by the military services, carries a shame so that many veterans don't even apply for the veterans benefits for which they are eligible. The question is raised by employers: "Why didn't he get a straight honorable?"

In many cases the vet with a less-than-honorable discharge will find as he re-enters civilian life that he is ineligible for the benefits of the G.I. Bill such as educational assistance, medical care, VA loans, employment assistance and unemployment benefits and civil service point references.

And upgrading of discharges is no easy matter. The Discharge Review Board is in Washington, D. C. and the veteran must travel at his own expense for a hearing before the Board. He must assume his own legal fees in a procedure that is lengthy and cumbersome. Even then only about one out of every seven discharge cases is acted upon favorably by the Board. Since, at the most, only one out of every five veterans who receives a bad discharge ever appeals, only about three per cent have had their discharges upgraded.

THE REMEDIES to this deplorable situation would appear obvious. The creation of review boards at the VA regional level would reduce the waiting time, which is now eight months to two years. Enlisted personnel and civilians appointed to the board might provide for more equitable reviews. The payment of the appellant's legal expenses would be helpful since many of these individuals are the minority poor.

Consequently, more veterans with less-than-honorable discharges would be encouraged to upgrade their discharges and simultaneously their chances for employment, education and the better life.

But this is not enough. Much more can and must be done with regard to expanding the opportunities for the Vietnam veteran, particularly the black and other minorities.

There are federal and other agencies working on the problem of finding jobs for today's veterans, but the bureaucracy frequently gets bogged down in its efforts. The National Alliance of Businessmen has pledged to find jobs for 200,000 Vietnam-era veterans in 1975 and President Ford has ordered all federal departments and agencies to find jobs for 70,000 veterans. And nearly 60,000 of them are black and other minorities.

NEITHER THE Veterans Administration nor any other federal agency supports a program aimed specifically at the black or minority veteran. As a result of their location in the inner city, the United States Veterans Assistance Centers reach a large number of minority veterans. The Veterans Education and Training Service (VETS) of the National League of Cities and the U. S. Conference of Mayors has helped some 50,000 veterans, primarily minorities, through its projects in 19 cities. Recently the sponsorship of these projects passed from VETS to the local Community Action Agencies (CAAs). It is hoped that the local CAAs will use a portion of their funds to help the jobless Vietnam veteran.

There is money available through the recently enacted Comprehensive Employment and Training Act (CETA). Under the Act's broadly defined purpose, funds could be allocated to aid the vet.

BUT PERHAPS the best solution to the problems of black veterans rests with the individuals themselves, as evidenced by the experience of six black Vietnam-era veterans in New York City. Following their military service and during their quest for work, they kept running into one another on the unemployment lines. They had each been shunted from one prospective employer to another with no success. Finally William H. Tull told his five partners in search for employment, "If we can't find jobs, we'll make them."

Three years ago they went into business for themselves. Today the multi-service enterprise that Bill Tull heads up Viet Vets Corporation expects to gross approximately 3.5 million dollars.

"In the past few years government and business have been talking about how they have to do something for the Vietnam-era vets," says Bill Tull. "But they didn't do a damn thing. Except talk, talk, talk."

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