# Some Negative Aspects of State Health Departments' Policies Related to Screening for Sickle Cell Anemia

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*A survey is presented of the attitudes of state departments of health in all 50 states and the District of Columbia with regard to sickle cell anemia screening programs.*

## *Introduction*

This paper presents the results of a mail survey of the state departments of health in all 50 states and the District of Columbia with regard to attitudes toward screening programs for sickle cell anemia and future priorities for the handling of "genetic diseases" in their state. Opinions of the state officials were sought with regard to the growing controversy over the efficacy of screening programs for diseases for which no treatment modalities exist.

Within the past 3 years the attitude of a significant portion of the American public regarding sickle cell anemia has evolved from one of relative indifference to that of social, political, and moral concern. In 1970, the campaign to initiate sickle cell screening and education programs emerged and reached its climax with President Nixon's health message to the 92nd Congress.[1,2] It called for a vast increase in federal expenditure to deal with sickle cell research, education, and screening programs and led to passage of the National Sickle Cell Anemia Control Act (Public Law 92-294; 86 Statute 136) on May 16, 1972. With this bill's enactment, plans to conduct extensive mass screenings of blacks were implemented.

As the political implications of sickle cell anemia grew, the call for federal- and state-supported sickle cell screening programs escalated to a point where currently 10 states have mandatory screening procedures and four more have laws for voluntary testing procedures.[3-5] Legislation dealing with sickle cell anemia screening is undergoing extensive examination by additional state governments and some presently have bills before their legislatures or have established commissions to investigate the issues.

It was not long before disappointment mixed with criticism was being expressed about the new federal legislation. In late 1972 an article appearing in the New York Times quoted Dr. Robert Nalbandian, a prominent sickle cell anemia researcher, in denouncing the Control Act as "reverse racism," saying it was the product of a "spasm of compensatory guilt-ridden excess."[6] The same article also cited the case of Fairfax County, Virginia, where the only black member of the school board, in reaction to the mandatory screening law recently passed by the Virginia legislature, feared the information gained from sickle cell anemia screening might be used to discriminate against the children.

Alleged abuses of screening programs are now begin-

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ning to be documented. For instance, persons found to have sickle cell trait, which many experts believe to be an essentially benign condition (except under extremely unusual circumstances),[7] can have trouble receiving life insurance and health insurance, and some have been discriminated against on the job.[8]

A recent editorial in the New England Journal of Medicine which enumerated the many abuses of sickle cell screening programs singles out mandatory testing laws as being "introduced before evidence that a compulsory program is needed, desired or in the best interest of the affected community."[9] However, the opinions expressed in this editorial were not widely accepted and, in fact, the laws of the 10 states with mandatory screening programs have not been repealed.

A brief questionnaire was mailed to the directors of the state departments of health in 50 states and the District of Columbia in January, 1973, to obtain current information on their attitudes and opinions concerning sickle cell anemia screening programs, governmental appropriations, and state and federal legislation dealing with sickle cell programs. During February and March, 1973, two follow-up mailings were made. The return was 100 per cent. To supplement the information gathered in the survey, the legal codes and statutes of all 50 states and the District of Columbia were reviewed to see whether further legislation dealing with sickle cell anemia had been passed.

## *Results*

The first two questions asked the state health officials whether they had a law requiring sickle cell anemia testing prior to a child's entering public school and, if not, whether they would favor the passage of one. It should be noted that the departments of health answered the first question with regard to any mandatory sickle cell anemia screening law and not necessarily only those directed toward children prior to their entrance into public school.

The returned questionnaires showed that there are 10 states with laws requiring mandatory sickle cell anemia testing. Review of these states' legal codes and statutes confirmed the existence of such laws and revealed additional states having statutes relating to various aspects of sickle cell anemia testing other than mandatory screening. The majority of these nonmandatory laws guarantee the availability of screening programs and confidentiality of records for those who request it (Table 1). Of the 10 states with mandatory screening laws, four respondents of their departments of health indicated opposition to their law and, of the 41 remaining departments, only one respondent specified that he would support the passage of a mandatory law.

The third question concerned whether routine sickle cell anemia screening should be conducted in conjunction with a blood test taken prior to marriage. Respondents from 22 departments of health indicated they were in favor of such screening in conjunction with the premarital blood test. However, 14 of them explicitly noted that this should be voluntary.

Question number four asked, "since there is no cure, at present, for sickle cell anemia, do you feel government appropriations should be directed toward finding the cure or in increasing the number of mass screening programs?" The majority (28) of the state health departments stated that government funds should be directed toward programs for finding the cure or treatment for sickle cell anemia. A minority (six) of the departments specified that there should be greater appropriations for screening programs whereas 10 states said funds should be equally spent in both of these areas. Seven of the health departments did not respond to this question.

To place sickle cell anemia in context with all "genetic diseases," the final question asked how important a role

**TABLE 1—State Laws Relating to Sickle Cell Anemia**

| State | Code or Statute Number | Date Effective |
|---|---|---|
| Mandatory screening laws | | |
| District of Columbia | Information not available | 1972 |
| California | H. & S.C.A. Art. 3.5 Sec. 310 | March 4, 1972 |
| Georgia | Ga. Code Ann., §88-1202.2 and Ga. Code Ann., §53-216 | 1972 |
| Illinois | S.H.A. ch. 122 §27-8 | October 1, 1972 |
| Indiana | Information not available | 1972 |
| Kentucky | K.R.S. 402.310 | January 1, 1973 |
| Louisiana | L.S.A.-R.S. 40:1299.1 | July 26, 1972 |
| Massachusetts | Education ch. 76 §15A | September 29, 1971 |
| New York | Domestic Relations Law §13-aa | September 1, 1972 |
| Virginia | Education ch. 5.2 §32-112.10 | 1972 |
| Nonmandatory screening laws | | |
| Arizona | Public Health Art. 13 §36-797.41 | August 31, 1972 |
| Connecticut | Information not available | 1971 |
| Maryland | Health Art. 43 §33A and Health Art. 62 §6A | July 1, 1972 |
| Ohio | Health §3701.131 | October 18, 1972 |

**TABLE 2—Population Affected in States with Mandatory Testing Laws**

| State | Population | | | |
|---|---|---|---|---|
| | Newborns | Preschool | Premarital | Inmates of state institutions |
| District of Columbia | | Mandatory | | |
| California | | Judgment of the physician* | Judgment of the physician* | |
| Georgia | Mandatory | | Voluntary | |
| Illinois | | Judgment of the physician* | | |
| Indiana | | Judgment of the physician* | Judgment of the physician* | |
| Kentucky | Mandatory | | Mandatory | |
| Louisiana | Judgment of the physician* | | | |
| Massachusetts | | Mandatory | | |
| New York | | | Mandatory | |
| Virginia | | Judgment of the physician* | Judgment of the physician* | Judgment of the physician* |

* In certain states "judgment of the physician" is interpreted as a mandatory law by the department of health.

mass screening programs for genetic diseases will play in the future preventive medicine programs in their states. Twenty states responded that these programs will play an important to very important role in the future, 24 said they would be moderately important, while five answered this as being not important. Two departments failed to respond.

## *Discussion and Conclusions*

An analysis of the 10 states with mandatory screening laws revealed no consistent policy relating to the age of the population being tested (Table 2). As indicated, the population can include newborns, preschool children, couples applying for marriage licenses, and even inmates of state institutions or some combination of these. Further, certain of these laws evidence weakness by failure to appropriate funds and provide education and counseling in conjunction with the legislated screening programs.

Data from the 10 states were analyzed in an attempt to find a reason for some states having mandatory laws and others not. When the states were arranged by geographical regions, no discernible pattern emerged. Further analysis, however, showed that the distribution of states with mandatory laws is related to size of the total black population in each state. This is borne out by the fact that states with total black populations greater than 200,000 include nine of the 10 states with mandatory screening laws, and of the states with less than 200,000 black population, only one has a mandatory law. The overall impact of this distribution is that it affects more than 40 per cent of the total black population of the United States.

In view of the possible discriminatory aspects of sickle cell screening programs, it was felt by many state health officials that these laws should be repealed or at least put on a voluntary basis. In fact, one health department official stated that "laws requiring mandatory screening will be declared unconstitutional."

There is a definite need to consider the potentially negative aspects of sickle cell anemia screening programs before more of these abuses are perpetrated as part of mandatory screening laws. This is especially true in light of the fact that sickle cell anemia, as opposed to PKU or Tay-Sachs, the only other genetic diseases currently tested for on a mass basis, is uniquely unsuitable for such testing. This lack of suitability is seen in that PKU testing allows for the detection of affected newborns with therapy available if needed, and Tay-Sachs screening provides means for couples detected as carriers to have unaffected children by monitoring of the pregnancy with termination if so desired, while sickle cell anemia is untreatable and, at this time, cannot be monitored for in utero. A recent correspondence with the editor of the New England Journal of Medicine has called for the repeal of the existing mandatory laws in the District of Columbia, Massachusetts, and Virginia.[10]

Concerning premarital screening programs, respondents from 22 state health departments reported approval for screening procedures as a prerequisite to obtaining a marriage license. Analysis by geographic region showed no relationship present nor was there a strong population bias as demonstrated in the case of mandatory screening laws (Figure 1). The attitude of the many state health department respondents opposed to premarital screening was summed up by one health official who stated that screening as a prerequisite to obtaining a marriage license, even on a voluntary basis, "is too late for any effective program."

No conclusions can be offered for the large number of health departments desiring premarital screening other than

they have apparently neither taken into consideration the attitudes of the black community about genetic counseling nor the limitations inherent in counseling for sickle cell trait. In the black community "voices have already been heard charging that this (genetic counseling) is simply another white plot aimed at carrying out genocide against the blacks,"[6] whereas genetic counselors claim they are not advising couples heterozygous for the trait not to have children,[11] the belief that such advice creates a lack of options which is often accompanied by some emotional difficulty.[12] Considering these two points, the case for premarital screening programs is both unfounded and unwise until effective preventive and therapeutic measures are available.

Sickle cell anemia is the first genetic disease for which mass screening has been applied for the detection of carrier states. Recently, screening programs to detect carriers of Tay-Sachs disease have begun. In the future, as increasing capabilities for the detection of carrier states in other genetic diseases are developed, more screening programs will undoubtedly be considered. This is reflected in the attitudes of the 44 state health departments which indicated that mass screening programs for genetic diseases will have some importance in future preventive medicine programs in their states.

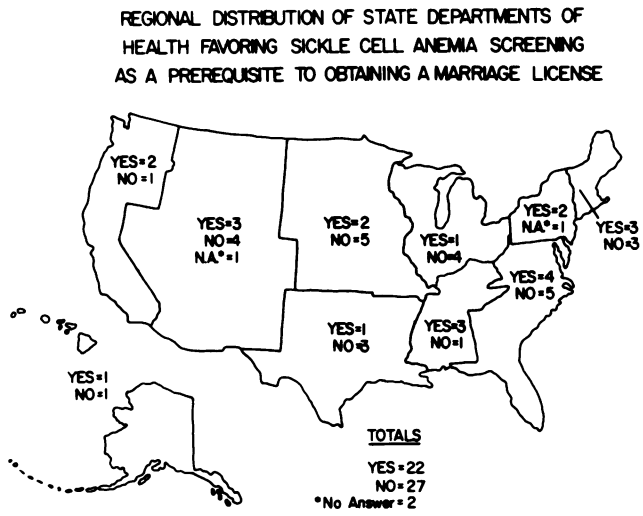


**figure 1** Regional distribution of state departments of health favoring sickle cell anemia screening as a prerequisite to obtaining a marriage license.

As was noted above, there is a great deal of disagreement of opinion about screening programs (including the laws and the priorities for appropriation) among state and federal legislators, state health officials, and the black community. Following a recent screening program held in 1972 in a St. Louis County (Missouri) school district, a survey was conducted with junior high school and high school students who were screened for sickle cell and the parents of all school age students tested.[13] The attitudes of those questioned, with regard to spending priorities for sickle cell anemia, closely parallel those of the state departments of health (Table 3). These views are contrary to the intention of the sickle cell legislation of the 92nd Congress and of 10 state legislatures which called for increased mass screening programs.

These differences should be resolved before any continuing sickle cell screening programs or laws are enacted. In view of the increasing likelihood of future screening programs for other genetic diseases, our hope is that the lessons learned from sickle cell screening will aid not only those affected by sickle cell anemia or trait but also those who may be carriers or victims of newly detectable genetic diseases.

## *Summary*

A mail survey was conducted of the state departments of health of all 50 states and the District of Columbia to obtain their attitudes and opinions concerning sickle cell anemia screening programs, governmental appropriations,

**TABLE 3—Attitude of a Previously Screened Community Concerning Spending Priorities for Sickle Cell Anemia Programs Contrasted with Those of the State Departments of Health**

| Response | State Departments of Health (n = 51) | High School Students (n = 116) | Junior High School Students (n = 129) | Parents (n = 177) | All Persons (n = 422) |
|---|---|---|---|---|---|
| | | | Per Cent | | |
| Cure | 54.9 | 63.7 | 70.6 | 65.0 | 67.3 |
| Screen | 11.8 | 13.8 | 14.7 | 16.0 | 14.5 |
| Both | 19.6 | 14.0 | 3.9 | 9.6 | 9.7 |
| Neither | 7.8 | 8.5* | 10.8* | 9.4* | 8.5* |
| No answer | 5.9 | | | | |

* Failure to respond to this question could not be interpreted as a "neither" or a "no answer" response.

and state and federal legislation dealing with sickle cell programs.

The responses showed 10 states having laws requiring mandatory screening for sickle cell anemia, with the black population of these states totaling greater than 40 per cent of the black population of the United States.

Twenty-two state health departments favored some type of screening procedure being conducted in conjunction with the blood test taken as a prerequisite to obtaining a marriage license. Of these 22, 14 of them wanted this only on a voluntary basis.

A majority of the health officials felt government appropriations should be directed toward finding a cure as opposed to increasing the number of mass screening programs.

The conclusion calls for further investigation into the harmful aspects of routine screening programs prior to the institution of more mass screenings for a disease which, at the present time, is not amenable to therapy.

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