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REMARKS BY SENATOR HUBERT H. HUMPHREY

STATEMENT ON SICKLE CELL ANEMIA  
AND THE HEALTH NEEDS OF AMERICA'S MINORITIES

PHILADELPHIA, PENNSYLVANIA

OCTOBER 20, 1971

201-2180

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ONE OF THE MOST IMPORTANT CHALLENGES CONFRONTING  
MEDICAL RESEARCH TODAY IS THE DISCOVERY OF A CURE FOR SICKLE  
CELL ANEMIA.

THIS BLOOD DISEASE WILL AFFLICT AT LEAST ONE OF EVERY  
500 BLACK BABIES BORN THIS YEAR, AND THE CHILDREN AFFLICTED  
WILL FACE A LIFE EXPECTANCY OF ONLY 20 TO 40 YEARS, WITH MUCH  
OF THAT TIME SPENT IN PAIN AND RECURRENT ILLNESS AND  
HOSPITALIZATION.

IT IS A NATIONAL DISGRACE THAT WE HAVE FAILED TO LAUNCH  
AN ALL-OUT EFFORT TO DETECT AND COMBAT THIS DISEASE CAUSED  
BY A GENE MUTATION OCCURRING ALMOST EXCLUSIVELY AMONG BLACK  
PEOPLE.

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ALMOST 2,000,000 AMERICANS TODAY CARRY THE SICKLE CELL TRAIT, OR DEFECTIVE GENE. WHEN INHERITED FROM BOTH PARENTS, IT IS TRANSFORMED IN A SIGNIFICANT PERCENTAGE OF CHILDREN INTO A MALADY AFFECTING THE RED BLOOD CELLS THAT ELONGATE UNDER STRESSFUL ACTIVITY TO BLOCK CAPILLARIES AND DEPRIVE TISSUES OF VITAL OXYGEN.

A COMPREHENSIVE NATIONAL PROGRAM OF RESEARCH, TESTING, AND PUBLIC EDUCATION ON SICKLE CELL ANEMIA WILL REQUIRE SUBSTANTIAL PUBLIC AND PRIVATE FINANCIAL ASSISTANCE JUST TO CONTROL THE SPREAD OF THIS INSIDIOUS DISEASE.

THE RECENT ESTABLISHMENT OF THE BLACK ATHLETES FOUNDATION FOR SICKLE CELL ANEMIA RESEARCH IS AN OUTSTANDING EXAMPLE OF THE KIND OF ACTION REQUIRED TO MEET THIS CHALLENGE. IT IS A RESEARCH-FINANCING EFFORT BORN OF DEEP COMMITMENT AND DIRECT PERSONAL EXPERIENCE, AND I PLEDGE MY FULL SUPPORT AND ASSISTANCE TO THE FOUNDERS OF THIS VITAL ORGANIZATION, WILLIE STARGELL AND DOCK ELLIS OF THE PITTSBURGH PIRATES.

ADEQUATE FINANCIAL SUPPORT CAN GREATLY ACCELERATE THE SIGNIFICANT PROGRESS THAT HAS ALREADY BEEN MADE IN THE DEVELOPMENT OF TWO ACCURATE TESTS FOR THE IDENTIFICATION OF THE SICKLE CELL ANEMIA TRAIT AND DISEASE, AND IN THE DISCOVERY OF VITAL DISEASE-CRISIS TREATMENT MEASURES.

WE MUST IMMEDIATELY PROVIDE FOR THE INTENSIVE EVALUATION  
OF THESE MEDICAL ADVANCES AND THE PROMOTION OF FURTHER  
DISCOVERIES. WE MUST WAGE AN ALL-OUT CAMPAIGN TO EDUCATE PEOPLE  
ABOUT THIS DISEASE AND TO ENCOURAGE THEIR VOLUNTARY PARTICIPATION  
IN TESTING PROGRAMS.

TO HELP MOVE TOWARD THESE GOALS, I HAVE JOINED ~~AS AN~~ <sup>with Senator</sup> *John Tunney*  
~~ORIGINAL SPONSOR~~ <sup>to</sup> OF THE NATIONAL SICKLE CELL ANEMIA PREVENTION  
ACT, ~~INTRODUCED BY SENATOR TUNNEY OF CALIFORNIA.~~

*WE* HAVE CALLED FOR PROMPT CONGRESSIONAL ACTION ON THIS  
BILL.

IT WOULD PROVIDE FOR A COORDINATED FEDERAL GRANT PROGRAM  
OF \$25 MILLION PER YEAR FOR 3 YEARS FOR RESEARCH, VOLUNTARY  
SCREENING, AND COUNSELING AND PUBLIC EDUCATION, AS WELL AS, A  
SPECIAL \$15 MILLION GRANT PROGRAM OVER THREE YEARS FOR THE  
DEVELOPMENT OF CENTERS FOR RESEARCH AND RESEARCH TRAINING IN  
SICKLE CELL ANEMIA.

↳ EMPHASIS IS ALSO PLACED IN THIS BILL ON THE DEVELOPMENT  
OF SCREENING AND COUNSELING PROGRAMS BY THE DEPARTMENT OF  
DEFENSE FOR ALL MILITARY AND PERSONNEL AND CIVILIAN EMPLOYEES.  
AND A SIMILAR REQUIREMENT IS DIRECTED AT THE VETERANS'  
ADMINISTRATION AND THE PUBLIC HEALTH SERVICE ON BEHALF OF  
PERSONS ELIGIBLE FOR HEALTH CARE IN THESE AGENCIES.

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UNDER ALL THESE PROGRAMS, THE VOLUNTARY PARTICIPATION OF AN INDIVIDUAL AND THE PROTECTION OF HIS PRIVACY, THROUGH HOLDING TEST RESULTS CONFIDENTIAL, MUST BE ASSURED.

I AM APPALLED AT THE FAILURE OF THE FEDERAL GOVERNMENT TO HAVE TAKEN MORE COMPREHENSIVE MEASURES BY NOW TO PROMOTE RESEARCH, VOLUNTARY TESTING, <sup>and</sup> ~~THE~~ PUBLIC EDUCATION ON SICKLE CELL ANEMIA, IN THE FACE OF THE EXTENSIVE EVIDENCE OF THIS DISEASE AND DEVELOPMENTS IN RESEARCH THAT HAVE COME TO LIGHT IN RECENT YEARS.

<sup>recent appropriation</sup>  
THE ~~BUDGETARY ALLOCATION~~ OF \$6 MILLION FOR RESEARCH IN THE CURRENT FISCAL YEAR REPRESENTS AN IMPORTANT BEGINNING.

HOPEFULLY, IT WILL BE PRESSED FORWARD BY THE RECENTLY APPOINTED  
NATIONAL ADVISORY COMMITTEE ON SICKLE CELL DISEASE UNDER THE  
DEPARTMENT OF HEALTH , EDUCATION, AND WELFARE.

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IT IS TIME WE FACED THE CLEAR FACTS OF HIGHER RATES OF  
DISEASE AND DEATH AMONG THE DISADVANTAGED MINORITY GROUPS  
OF AMERICA THAN AMONG THE WHITE MAJORITY. IT IS TIME FOR US  
TO ACT TO ASSURE ALL AMERICANS AN EQUAL RIGHT TO GOOD HEALTH,  
L TODAY IN THE BICENTENNIAL CITY OF PHILADELPHIA, LET US  
ESTABLISH THE PRIORITY GOAL TO BE ACHIEVED BY 1976: THE  
CONQUEST OF SICKLE CELL ANEMIA.

TO A CHILD, SICKLE CELL ANEMIA REPRESENTS SUFFERING,  
CHRONIC FATIGUE, CONSISTENT ABSENCES FROM SCHOOL.

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IN A MAN, THE CONDITION MAKES THE HOLDING OF A JOB  
EXTREMELY DIFFICULT.

A WOMAN MAY HAVE SEVERE DIFFICULTY WITH ALL PHASES  
OF HER PREGNANCY AND DELIVERY; SHE TOO, FACES INTERMITTENT  
ILLNESSES.

WITH NO KNOWN MEDICAL CURE, PHYSICIANS CAN ONLY HELP  
RELIEVE SYMPTOMS, REDUCE PAIN AND PREVENT COMPLICATIONS.

TO EFFECTIVELY COMBAT SICKLE CELL ANEMIA, WE NEED MORE  
MONEY AND MANPOWER ALL ALONG THE LINE -- FOR RESEARCH,  
EDUCATION, THERAPY AND COUNSELING.

AND WE NEED RESOURCES WHERE THEY COUNT -- IN THE  
NEIGHBORHOODS OF BLACK AMERICANS AND IN RURAL AMERICA, WITH  
BLACKS INVOLVED IN THE PLANNING AND DELIVERY OF THESE SERVICES.

I URGE THAT WE GIVE PRIORITY TO SCREENING EVERY SINGLE PRE-SCHOOL AND SCHOOL CHILD IN AMERICA.

WE CAN SET UP SCREENING CENTERS AT FIXED SITES AS WELL AS IN MOBILE VANS THAT WOULD TRAVEL TO SCHOOLS, PLAYGROUNDS, PARKS AND RESIDENCES.

UNDER THE MEDICAID LAW, EVERY CHILD OF WELFARE FAMILIES WAS LONG SINCE TO HAVE BEEN SCREENED FOR ALL MAJOR AILMENTS; THIS LAW MUST BE IMPLEMENTED NOW FOR SICKLE CELL AND FOR ALL OTHER MAJOR HEALTH PROBLEMS.

BUT IN ALL SUCH EFFORTS, WE MUST BECOME FULLY AWARE OF THE LARGER SIGNIFICANCE OF THE DISEASE OF SICKLE CELL ANEMIA.

AND THAT IS THAT THE OVERALL HEALTH STATISTICS FOR BLACK,

SPANISH-SURNAME, AND INDIAN AMERICANS ARE MUCH <sup>WORSE</sup>~~HIGHER~~ THAN FOR WHITE AMERICANS.

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LOOK AT THE TOLL TAKEN BY SPECIFIC KILLERS AND CRIPPLERS  
-- HEART DISEASE, CANCER, STROKE, KIDNEY DISEASE, TUBERCULOSIS,  
ACCIDENTS. IN INSTANCE AFTER INSTANCE THE COLOR OF ONE'S  
SKIN INCREASES THE LIKELIHOOD OF BEING A VICTIM OF DISEASE,  
DISABILITY AND PREMATURE DEATH. NEARLY 200 YEARS AFTER OUR NATIONAL  
INDEPENDENCE, BLACK, SPANISH-SPEAKING, AND INDIAN AMERICANS  
ARE STILL IN BONDAGE -- TO EXCESSIVE PHYSICAL AND MENTAL  
AFFLICTIONS AS WELL AS TO SLUMS, INFERIOR EDUCATION, AND POOR  
JOBS.

WE KNOW SICKNESS MAKES PEOPLE POOR AND POVERTY MAKES  
PEOPLE SICK. WE KNOW HOW POVERTY AND MALNUTRITION SKYROCKET  
INFANT MORTALITY.

BUT THERE IS MUCH WE DO NOT KNOW.

THIS IS NOT A TASK FOR THE U.S. GOVERNMENT ALONE; IT IS  
A TASK FOR STATE AND LOCAL GOVERNMENTS; FOR FOUNDATIONS, MEDICAL  
AND PARAMEDICAL SOCIETIES; PRIVATE CITIZENS, YES, FOR ALL OF US,

LET THIS BE A DECISIVE ACTION BY WHICH WE ENDEAVOR TO ASSURE  
ALL AMERICANS EQUAL HEALTH OPPORTUNITY.

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