not to conceive of it as essentially a defensive mechanism. Our OTA bill is intended neither to enshrine the negative, fearful view of technology, nor to study good ideas to death, in order to postpone action. We intend it to be a positive, creative, effective instrument for seeking and identifying greater opportunities in technology development, as well as giving advance warning of dangers, and for proposing alternatives.

That now completes my list of 13 items. I could list many more. But I hope these are sufficient for my purposes here today which are (i) to remind you of the nature and variety of congressional decisions which affect science and technology, and to indicate some of the current trends—not necessarily coherent—in those decisions; (ii) to reveal some of the intrinsic difficulties and weaknesses, such as jurisdictional fragmentation, which exist—and probably to some degree always will—in our decision-making process, and also to indicate our current efforts to improve the process; (iii) to impress upon you the crucial impact of government policy-making decisions in all the ventures you are met here to discuss (to a very large degree, decisions in the Congress and the federal bureaucracy will define and control the levels and directions of your research and development activities); and (iv) to invite all of you, to urge all of you to become better informed and more active participants in the political decision-making process.

Obviously, there is no such thing today as a fully organized, coherent, articulated national policy for science and technology. Personally, I doubt that there can be or should be, if much greater concentration of authority is required to formulate and administer such a policy.

We are making progress, but we can and should do a lot better. There is abundant room and a very real need in the political policy-making system for more participation by you business, academic, scientific, and engineering people who are here today. We politicians need your help. I do invite you—urge you—to become much more politically "concerned," "relevant," "activist"—in all the more positive, affirmative meanings of those somewhat hackneyed phrases.

I suggest that in the past, too often you have been much too shy, timid, or diffident, sometimes too disdainful.

NEWS AND COMMENT

Sickle Cell Anemia: The Route from Obscurity to Prominence

Have you ever heard of a disease known as sickle cell anemia? Most people have not. Yet sickle cell anemia is one of the more common and one of the most serious of all childhood diseases. . . . The lack of attention that has been given to this disease is truly a national disgrace. At least now, we hope more people know about this terrible disease. And we promise you this is definitely not the last you will hear of sickle cell anemia on this station.—LEONARD J. PATRICELLI, President, WTIC Television and Radio, Broadcast-Plaza, Inc., Hartford, Connecticut.

On 12 November 1970, Hartford television viewers who were tuned in to channel 3 heard about sickle cell anemia from station president Leonard J. Patricelli, who pronounced the name of the disease slowly and emphatically each time he used it so that no one would forget it. That night Patricelli delivered what would be the first of four prime-time editorials he would give as part of a major campaign by WTIC to do something about sickle cell anemia. He went on the air just before the "CBS Evening News" with Walter Cronkite. During the next few months, the station ran four documentaries on sickle cell disease as well—each in prime time. Before raising the sickle cell issue on the air, Patricelli talked to about a dozen black leaders in Hartford. "Three," he recalls, "were against our going ahead with this. They feared the stigma it might place on blacks. But the others felt it was time to get this disease out in the open."

"The response we got to that first editorial was overwhelming and convinced us to go ahead with a full-scale effort," says Patricelli, who assigned a couple of staff members to stay with the story. He had heard from viewers who wanted more information and from community leaders, who formed an advisory committee to guide the station with its shows and help develop proposals for action. Staff members Rufus Coes and Richard Ahles recall that Patricelli told them to do "whatever has to be done" to bring the issues before the public effectively. They worked from a virtually unlimited budget, produced the four shows, and, ultimately, spent "many, many thousands of dollars" to pay for the programs, convene a meeting of health professionals, and publish a variety of educational booklets, which explained the nature of sickle cell anemia and sickle cell trait.

Sickle cell anemia is a grim disease that affects an estimated 1 in every 500 black children born in the United States. Between 25,000 and 50,000 individuals in this country have the disease now. Another 2 million blacks carry the trait, or gene, for sickle cell anemia and could pass the disease on to their children if their mate also has the trait. Based on Mendelian laws, there is a one-in-four chance in every such pregnancy of producing a child with the disease.

Physicians who treat sickle cell families emphasize the difference between sickle cell anemia, the disease that kills many of its victims by the time they are 20 years old, the rest by age 40, and sickle cell trait. The latter is a benign, symptomless state; the former, a painful disease that arises from abnormal blood cells. Sickle hemoglobin cells, which differ from normal hemoglobin cells by the substitution of only two amino acids, have a shortened life span and are unable to transport oxygen as normal hemoglobin cells do. Distorted, sickle-shaped cells that cannot pass easily through small blood vessels create jam-ups that block vessels and prevent oxygen from reaching body tissues. When this happens, a painful sickle cell crisis ensues. Other symptoms of sickle cell anemia

include impaired growth and development, jaundice, kidney problems, and a dangerous, increased susceptibility to infection in general and pneumonia in particular. There is no cure. Available treatment is less than ideal.

WTIC appears to have been the first station to take up the sickle cell cause in a serious way and did it months before the disease was thrust into the national limelight by the President in his health message on 18 February 1971. Patricelli, who was aware that sickle cell anemia was being considered for special mention by the President, is credited by some officials with helping things along.

"Before you knew it, all of Hartford was talking about sickle cell anemia," Patricelli remembers with pride. The talk eventually turned into action. On 15 January 1971, WTIC broadcast the second of its shows on the subject of sickle cell anemia, "the forgotten disease." This show included an interview with Roland B. Scott, chairman of pediatrics at Howard University in Washington, D.C. Scott, who has been studying and treating sickle cell for more than 25 years, talked of his dream of establishing a sickle cell center at Howard.

Spontaneously, citizens of Hartford began to send in contributions for that center and, even though it is unusual for a local station to try to raise funds for a nonlocal venture, WTIC decided to launch a drive on Howard's behalf. The response was enthusiastic —at times, too enthusiastic. "One problem we faced," Coes recounts, "was that of people—eager housewives, school girls, and kids—out collecting on street corners and in shopping centers. Most of them meant well, but we couldn't allow the public to think they were out there with our authorization. So, while they were collecting money, we were broadcasting warnings against giving on street corners and urging people to mail their contributions directly to us." In the end, WTIC surpassed its goal of $25,000 and sent Scott more than $40,000 to get his sickle cell center going.

Another tangible result of WTIC's saturation campaign is the sickle cell legislation that was passed in Connecticut in the spring of 1971. Patricelli is widely credited with getting the bill, which provides for screening of school children for sickle cell trait, through at a time when the governor, Thomas J. Meskill, was vetoing bills calling for new appropriations. Connecticut was the first state to pass sickle cell legislation.

Patricelli, a short, genial gentleman of modest stature and appearance, clearly has a bent for getting things done. An entrepreneur and civic leader as well as television station owner, he runs a large, modern plaza complex of office buildings, a hotel, and stores, and he devotes time to such cultural facets of life as the opera company. He hopes to arrange a performance of *Aïda* for the new civic auditorium and sports center in Hartford so people don't think it is just a "sweat box" for wrestlers.

Patricelli's interest in sickle cell anemia came about by chance. Early in the fall of 1970, he went to Washington, D.C., to visit his son Robert, who was then a deputy undersecretary at the Department of Health, Education, and Welfare (HEW). At the time, HEW officials were preparing options for the President's health message. In this connection, the younger Patricelli had just received a report from an HEW fellow who had been assigned to complete a statement on sickle cell anemia that a summer intern had begun. The fellow, a black man named Colby King, says he thinks the whole thing got started at HEW when a woman whose child is afflicted with sickle cell anemia, wrote to ask for help. In any case, King

Geologists Rebuild after Flood

Among the disastrous results of the floods unleashed by hurricane Agnes last spring was the more or less wholesale destruction of the headquarters of the Pennsylvania Geological Survey in Harrisburg.

The raging Susquehanna broke into the downtown first-floor headquarters in the early morning of 26 June and left behind well over $1 million worth of damaged books, records, maps, and equipment. The research library of over 40,000 volumes was totally destroyed; the collection of some 200,000 topographic and geologic maps was ruined, the photograph collection decimated, research laboratories destroyed, and offices left in shambles.

"We will be rebuilding from scratch," with the aid of disaster money from the federal and state governments, says Donald Hoskins, assistant director.

According to Arthur Socolow, the survey's director, one of the worst casualties was five sets of aerial photos covering the whole state which had been taken at intervals since 1950.

Many of the library's books are irreplaceable, including reconnaissance reports of the state's geology and mineral resources which date back to 1839.

The survey's reference collection of minerals is being gradually pulled back together and relabeled with the aid of local college students. But its collection of core samples—over 100 tons which were stored in the basement—has been either swept away, ruined by oil, or rendered useless because the markings and labels are gone. The cores were drilled by the Army Corps of Engineers during the 1930's, when a mine drainage tunnel was planned to run under the anthracite mines and down into the Delaware River. They supplied a systematic and complete record of the mineral formations in the area, says Socolow.

First priority in the salvage operation has been to find, dry out, and recopy, if necessary, notes and maps relating to current projects—since there were as yet no copies of these documents.

The survey intends to purchase new photographs wherever it can find them, and will obtain new maps from the U.S. Geological Survey in Washington, D.C. Libraries are helping by donating back collections of periodicals, but the survey is still lookng for donations of geological books and journals.

Socolow says that now, more than 3 months after the flood, they have just finished drying out some of the records. He estimates it will be 2 years before the survey, which must move into new headquarters, has fully recovered from the flood.—C.H.

interviewed a few persons at Howard and at the National Institutes of Health (NIH) and wrote a memo outlining the nature of the disease, the fact that it is confined primarily to the black population, and the fact that there is no cure and very little research. He turned his report in to Patricelli, who later gave a copy to his father, saying, "Pappy, why don't you editorialize about this some time?"

As is now well known, the issue of sickle cell disease made its way through the many channels at HEW, all the way to the White House, where it was finally chosen to be singled out for special attention in Nixon's health message. "It is a sad and shameful fact that the causes of this disease have been largely neglected throughout our history," the President said. "We cannot rewrite this record of neglect, but we can reverse it."

Suddenly everybody, not just the people of Hartford, was talking about sickle cell anemia. Black Congressmen, athletes, actors, and community leaders all began to push for action against sickle cell as interest in the disease accelerated. As Scott sees it, there are a couple of reasons why sickle cell anemia emerged from relative obscurity at this time. The President's statement is one. "To give credit where credit is due, the most prestigious person in the land said in 1971 that sickle cell anemia is an important disease and that something should be done about it. And so it is."

The tremendous upsurge of self-awareness among blacks is another explanation for the current enthusiasm for dealing with sickle cell phenomenon. "Nixon's message came at a time when black people are asserting their needs, indeed their demands. His statement piggybacks on that assertion." And so, sickle cell anemia is having its day. "Every disease has its day," says Scott philosophically. "These things come and go in cycles."

Before sickle cell anemia became a fashionable issue, the federal government was spending about $1 million a year on sickle cell research. The President proposed that the figure be increased by $5 million, but, by the time Congress completed hearings on the subject and passed the National Sickle Cell Anemia Control Act, the authorization was a lot higher.

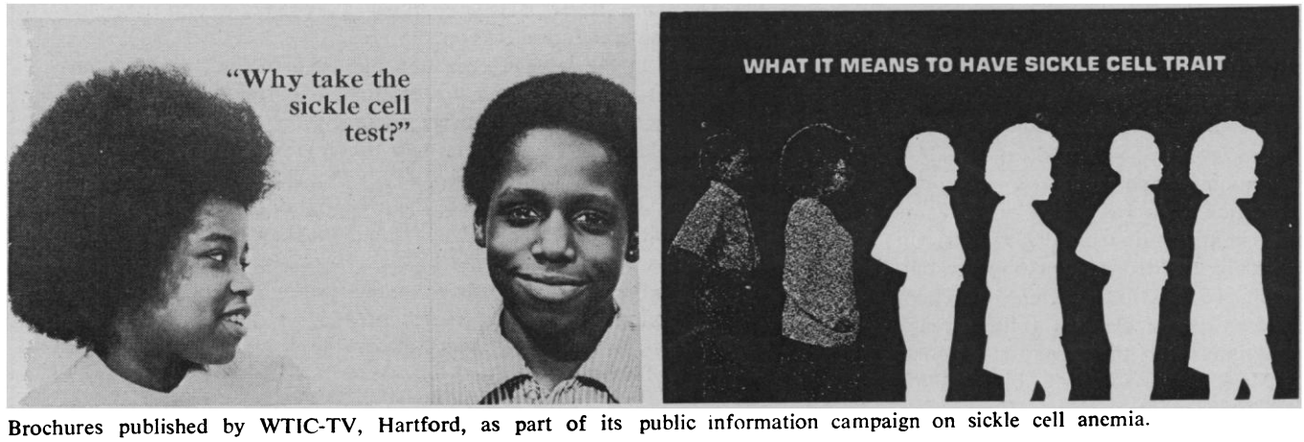
Even though the President had taken the lead in introducing sickle cell anemia to the public consciousness, the Administration did not favor the congressional move to create a separate national sickle cell program with its own legislative authority. The first thought in Congress was to create a national institute for sickle cell anemia, which could join the other categorical institutes at the NIH. Various Administration officials protested that proposal, and, because the idea apparently lacked firm backing elsewhere, the idea of a separate institute was dropped. But Administration attempts to kill legislation altogether failed. Nevertheless, it is worth noting, for the record, that spokesmen for the military, the Veterans Administration, HEW, and NIH all testified against the National Sickle Cell Anemia Control Act on the grounds that it would merely duplicate authority they already had and was, therefore, unnecessary. John S. Zapp, speaking as deputy assistant secretary for legislation at HEW, further defended opposition to the legislation by pointing out that, at the President's direction, HEW had already begun a new program to combat sickle cell anemia.

Centered within the National Heart and Lung Institute (NHLI) and headed by the institute's Deputy Director, Robert Ringler, the program had been allotted $5 million by NHLI to be equally divided between research and community service. That division of funds was determined by a special advisory committee, which, Zapp said, had been appointed in August and had met twice since then. Of the $5 million, $2.5 would go for comprehensive research and service centers, "no more than five in number"; $1 million was slated for screening clinics—10 to 20 of them; and $1.5 million would support research for better treatment of sickle cell anemia. In short, things were moving along fine.

Congress was not satisfied. Both the Senate, where John Tunney (D–Calif.) was the first to introduce a sickle cell bill, and the House, where Paul Rogers (D–Fla.) was one of the prime movers in this field, wanted more. During the November hearings, Rogers, for example, argued for immediate, mass screening of the black population for sickle cell trait, suggested that all states be urged to require screening before issuing marriage licenses, and pushed the doctors testifying before his subcommittee for answers about why things could not be accomplished more rapidly.

Representatives of the Black Athletes' Foundation for Research in Sickle Cell Disease, in Pittsburgh, went to Washington to lobby on behalf of an intensive national effort. Congress heard from former pro football player John Henry Johnson and Hank Aaron of the Atlanta Braves, among others. The foundation was incorporated in May of 1971. Members of Congress, both black and white, city mayors, and others turned out by the score on behalf of the sickle cell campaign.

In the end, the bill that the President signed into law last May, 15 months



Brochures published by WTIC-TV, Hartford, as part of its public information campaign on sickle cell anemia.

after he had first raised the sickle cell issue, provided funds far above the level anyone in the Administration had requested. Congress authorized $25 million for fiscal year (FY) 1973, $40 million for FY 1974 and $50 million for FY 1975. Whether those sums will actually be spent in toto is uncertain.

In July, HEW announced that it had awarded $9 million worth of grants and contracts for sickle cell studies. With the preexisting $1 million added in, the current federal total comes to $10 million for FY 1972. Instead of five comprehensive centers, there are ten, with Howard receiving the largest single grant, $829,505. Thirty-four research contracts were let, 27 of them new and 7 extended from the previous year. Screening and education clinics are being set up in 19 communities, where the clinics will be administered by the Health Services and Mental Health Administration.

Rudolph Jackson is now the full-time coordinator of the program, supplanting Ringler, who, with other responsibilities at the NHLI, was devoting only part of his time to it. Jackson, a black hematologist and oncologist, was recruited from St. Jude's Hospital in Memphis. (After a racial encounter between blacks and whites at the NHLI last year, institute Director Theodore Cooper promised to name a black to the top spot in the sickle cell program.)

Jackson considers educating the public the priority item of the program, and lists screening of the black population, genetic counseling, and referral of patients for treatment as its other important features. One of his primary concerns, which is shared by virtually every physician who had been involved in any controlled screening program, is the problem raised by identifying someone as a carrier of sickle cell trait. "We've heard of all sorts of things happening to trait carriers," he says, noting that at least one airline stewardess was grounded after her company found she carried sickle cell trait, that persons have allegedly been denied jobs because they are carriers, and that school children reputedly have been told they cannot participate in sports

The New Federalism in Science: More Fingers in the Pie

President Nixon's concept of a "new federalism" in science won a measure of grassroots support last week from an unusual colloquy of representatives of local, state, and federal government, as well as industry and academia. A leading feature of the new federalism—and one warmly endorsed in a report by the group—would be to give states and cities a voice as to how the federal government spends its largesse on research and development for domestic problems. At the same time, however, the report underscored a caveat seemingly already understood by the White House: Local and state governments are going to need a great deal of help from the federal government in learning how to work with industries, universities, and Washington's own science policy machinery before legislatures and city councils can effectively apply new technology to traffic jams, solid waste disposal, and the myriad other nightmares of modern urban life.

The 33-page report is the product of a 3-day conference at Harrisburg, Pennsylvania, last June that was funded partly by the National Science Foundation (NSF) and partly by the Pennsylvania state government. More precisely, the report is the handiwork of a preselected resolutions committee populated by a bipartisan sprinkling of congressmen, state legislators, one governor (Russell W. Peterson of Delaware), and such scientific luminaries as Detlev Bronk, the former president of Rockefeller University and the National Academy of Sciences.

The assemblage billed itself as an "action conference," and the action it proposed fell into seven broad categories. Briefly summarized, the committee recommended inclusion of scientists familiar with state and local problems on such science policy councils as the President's Science Advisory Committee and the National Science Board; additional funding for an NSF program that helps states and cities set up their own science advisory apparatus; joint state and federal funding for demonstration projects in applied R & D for local problems in five states; a similarly funded trial run for "technology utilization programs" in ten states; government encouragement for universities to provide technical consultation to cities and states; use of federal laboratories for applied R & D projects designed by state and local authorities; and vigorous backing for the above-mentioned measures by such pan-governmental agencies as the National League of Cities and the United States Conference of Mayors.

The sincerity of the Harrisburg manifesto is hardly to be questioned, although its spontaneity might be. It turns out that all these recommendations go hand-in-glove with the views and advice expressed last May in a report by a special committee of the Federal Council for Science and Technology. The FCST committee was headed by M. Frank Hersman, who directs an NSF program for helping states and cities set up science advisory machinery. Hersman's committee provided the rationale behind President Nixon's call for a "new partnership" with states and cities in the President's technology message last March. And it was Hersman's office that helped pave the way, and pay for, the Harrisburg meeting, which kindly ratified the FCST report.

It's common practice, of course, for a federal agency to plant the seeds of new science policy and then to cultivate them as best it can. And in this case, the problems at hand would seem no less genuine for all the bureaucratic horticulture surrounding them. The FCST report is only one of several in the past 2 years bearing similar conclusions: That state and local governments are, for the most part, simply not yet equipped to manage new technologies, and that the federal government has done far too little to solicit advice from these levels of government in planning new R & D for domestic problems.

It is true that nearly every state and a handful of cities have science advisers of one form or another. But the FCST report questions their ability to influence policy, and bluntly concludes that "state and local governments stand, with respect to the utilization of science and technology, roughly where the federal government did in 1940."—ROBERT GILLETTE

because of the trait. "Some teachers equate sickle cell trait with central nervous system disease and learning and behavior disorders," says Jackson. "We know of no reason why this should be so and we must educate the public about this." Another serious burden that allegedly falls on trait carriers is either an inability to get health or life insurance or an ability to get it only at grossly inflated premiums.

Careful, controlled studies of carriers of sickle cell trait are few and far between, so the matter is clouded by a slew of impressions and, many physicians believe, erroneous notions. Persons with the trait, who have some sickle hemoglobin, or hemoglobin S, in their blood, can get into trouble in circumstances where the oxygen supply is diminished. Thus, trait carriers are cautioned against such activities as sky diving, deep-sea diving, and the like, and the military generally bans carriers from flight and diving duty, as well as duty in the Special Forces. At present, the military screens for sickle cell trait only those blacks who are applying for such potentially dangerous duty. A committee of the National Academy of Sciences (NAS) is currently looking into the advisability of routine screening of all black military personnel and will report its opinion to the Department of Defense by the end of the year. Other than these few precautions, according to Jackson, Robert Murray of Howard, head of the NAS study, and others, there is no reason to treat trait carriers in any special fashion. Warnings that they spurn strenuous exercise or avoid anesthesia, for example, are, in their opinion, silly.

At the Indiana University School of Medicine in Indianapolis, Joseph Christian and his colleagues are concentrating their efforts on research on trait carriers. (Indianapolis is one of the ten comprehensive sickle cell centers.) "We have no evidence that trait carriers have a higher risk of disease or a shorter than normal life-span," Christian asserts. Among his main interest at the moment is the matter of trait carrier being discriminated against by insurance companies. For the last year or so, Christian has been working with an actuarial firm. "We know of several firms that have a special rating for trait carriers on the books," he says. "Some of them charge as much as 150 percent of the usual premium, some added 30 percent. For a company to rate you at an increased risk of 30 percent for obesity, you'd have to weigh 300 pounds and be 5 feet tall. We'd like to know the medical basis of their rating system for sickle cell trait." Christian would like to conduct a survey of insurance companies and is hoping to gain their cooperation in sorting fact from fancy. Admitting that it may be a bit naive, he says he would like to try to get the companies to voluntarily drop their ratings for trait carriers rather than instigate an adversary situation, and he adds that he'd welcome any information or help he can get. (Persons with sickle cell anemia itself are not at issue here—with their acknowledgedly short life span, they are uninsurable.)

Screening for sickle cell trait raises other thorny questions as well. Experience thus far, with screening and with the national effort to combat sickle cell anemia on the whole, makes it apparent that things are not as simple as one might like and, that by plunging into such an expansive program, one can stir up new issues by the score.

Sickle cell anemia has risen from relative obscurity to national prominence in just 2 years. Today the sickle cell program has a life of its own. How it is working, with respect to the law, community relations, medical science, and the private lives of the individuals it touches will be discussed in a second article.

—BARBARA J. CULLITON

Nader's Congress Project: Political Scientists Intrigued but Fretful

Who Runs Congress?, the finger-pointing title of a $1.95 paperback published last week, is the opening salvo of a grandly conceived campaign, the purpose of which is to refashion the U.S. Congress. The campaign, announced by Ralph Nader not quite a year ago at a National Press Club luncheon, has begun on schedule and will culminate some 3 months hence after the publication of an encyclopedic volume of material about Capitol Hill, its denizens, and their way of doing business.

Congress, Nader says in his introduction to the paperback, is "the great American default." It has fallen under the domination of the White House and "relentless special interests" because citizens have failed to involve themselves in its activities. It has "shackled itself with inadequate political campaign laws, archaic rules, the seniority system, secrecy, understaffing, and grossly deficient ways to obtain crucial information."

The findings of the Nader project, while they cannot be anticipated in detail, will presumably point to reforms along these lines. Their persuasiveness is harder to gauge, but among academic political scientists, who will be one of the many determinants of the project's impact, enthusiasm for the project's general aims and the wealth of data it will produce is tempered with certain misgivings about the way the study has been conducted.

The "Ralph Nader Congress Project/ Citizens Look At Congress," to give the project its official title, is by far the most ambitious task that Nader has undertaken. At its height, the project commanded the services of more than 1000 volunteer researchers working in the home districts of all 535 representatives and senators, as well as an editorial and research staff, about 200 strong, which worked in Washington, D.C., during the summer. According to a *National Journal* article, the project is expected to cost $200,000, all of it put up by Nader from his own earnings, and to produce some 21,000 pages of printed material. The director of the project, Robert C. Fellmeth, is a 27-year-old graduate of Stanford University (where he helped organize for Barry Goldwater's 1964 presidential campaign) and the author of three previous Nader studies. The principal