national goal." With an explicit national goal in place it might then be possible to coordinate the currently disparate federal, state and private activities. However, without adequate resources and powers, an act of this sort, no matter how nobly worded, "would simply provide a false reassurance that something was being done."

"Too much emphasis on the success of technology—in a very limited area—may be kidding the world that this problem is easy to solve."

Although the report recognizes the great importance of changing people's attitudes toward conservation biology through education, which is why it explicitly suggests the establishment of a National Conservation Act, it also sees potential problems "because of the trend to reduce the Federal Government's role in education and to rely more on State and private sector initiatives."

Biologists who are aware of the magnitude of the threat to biological diversity and who are concerned by its implications are nevertheless frustrated by the degree of scientific ignorance that still prevails about the scale and complexity of the biological world. As Edward Wilson of Harvard University frequently points out, annual spending on ecology in the United States is about $50 million, which is two orders of magnitude less than the amount spent on molecular biology and biomedicine. And only a tiny fraction—perhaps as little as $1 million—goes specifically to conservation biology. For this reason the OTA report suggests that the National Science Foundation (NSF) should be directed to set up a program for conservation biology.

"Current funding for research and technology development in conservation biology is negligible," notes the report, "in part because the NSF considers it to be too applied, while other government agencies consider it to be too theoretical." According to Ehrenfeld, most researchers who do work in conservation biology piggyback it on other projects. "All conservation genetics, for instance, is in effect supported by grants that were not specifically given with that goal," he says. "Conservation genetics is intellectually high-powered work but it is forced to be a parasitic endeavor on more conventional research."

Soule says that "there is a prejudice against anything that smacks of applied research, so there is always a high probability that conservation biology proposals will get a poor review when they go through the biology panels at NSF." Because of this barrier, Soule and several conservation-minded biologists are due to meet informally with NSF officials at the end of this month to discuss the OTA report's suggestion of a separate conservation biology panel within the Directorate for Biological, Behavioral, and Social Sciences.

Although conservation biologists are generally pleased with the attention that the OTA report brings to the issue of biological diversity, there is some concern about the implied philosophy of the overall approach. As the name of the report implies, there is considerable—but by no means exclusive—emphasis on technological intervention for protecting diversity, including artificial insemination in small captive populations and cryostorage of embryos, sperm, and ova.

As William Conway of the New York Zoological Society has pointed out, "These kinds of techniques can be effective, but only in crisis situations and for a tiny fraction of the world's endangered species." Thomas Lovejoy of the World Wildlife Fund says "If you know only 1 in 10 or 1 in 20 of the species that exist, technological intervention isn't going to make a big impact on the overall problem." The 1.7 million species so far recorded by biologists is estimated to be only one-twentieth of the total number that now exist. At current rates of destruction, most species seem destined to become extinct without ever being recorded by science. As a result, says Lovejoy, "Too much emphasis on the success of technology—in a very limited area—may be kidding the world that this problem is easy to solve." The only effective path to a solution, stresses Lovejoy, is a major commitment by governments to provide land and financial resources in order to maintain species and ecosystems in their natural contexts. ■ **ROGER LEWIN**

Panel Urges Newborn Sickle Cell Screening

If babies with sickle cell disease are identified at birth, they can be treated early to prevent what are otherwise deadly infections

A National Institutes of Health panel recommended on 8 April that newborn screening for sickle cell disease be made available for all babies. Only ten states offer screening now, but the panel concluded that the benefits of screening are "compelling." The early identification of babies with sickle cell disease could reduce their mortality rate by 15%.

The materials for a sickle cell screening test cost $0.22 and the panel expects that the test could be included among other routine procedures, such as blood counts and blood typing.

It is especially important that babies who are found to have sickle cell disease receive follow-up care, the panel stressed. During a consensus meeting, which took place on 6 to 8 April at the National Institutes of Health in Bethesda, Maryland, two mothers of children with sickle cell disease told of the difficulties they had when appropriate care was lacking.

Because sickle cell disease is inherited and incurable, health policy planners thought until recently that there was no advantage to identifying babies with the disease early. The disease causes abnormal, sickle-shaped red blood cells that can become stuck in small blood vessels, causing strokes or, more often, painful and swollen joints. It also results in anemia.

Sickle cell disease is a recessive genetic disorder that is particularly prevalent among blacks and among persons from Central and South America, India, Asia, and the Mediterranean. One in 400 blacks has sickle cell disease and about 1500 black babies are born with it each year.

All 50 states routinely screen newborns for the genetic diseases phenylketonuria and hypothyroidism, which are much less com-

mon than sickle cell disease. Only 1 in 12,000 children has phenylketonuria and 1 in 4,000 has hypothyroidism. Some states screen for other rare inherited disorders as well.

The genetic diseases that are already part of screening programs have specific treatments—children with phenylketonuria, for example, can follow a special diet and thereby avoid the mental retardation that otherwise is a consequence of the disease. Researchers initially thought that the only treatment for sickle cell disease was palliative and that it made no difference if a child was identified at birth or at the time of the first symptoms of the disease. "The greatest rationale for not doing screening [for sickle cell disease] to this point was that there was no magic cure and no other rationale for finding children in the neonatal period," said panel chair Doris Wethers, who is director of the Comprehensive Sickle Cell Center at St. Luke's–Roosevelt Hospital Center in New York.

But a recent randomized, controlled clinical trial sponsored by the NIH demonstrated conclusively that the sooner a baby with sickle cell disease is diagnosed, the better. It provided, said Wethers, the first "hard data" in favor of screening.

The study was designed to test whether prophylactic penicillin therapy can reduce the mortality and morbidity of the disease. For reasons that are unclear to researchers, children with sickle cell disease who are under 3 years of age frequently are unable to fight off bacterial infections, in particular infections caused by *Streptococcus pneumoniae*. An infection can occur so quickly that a child can seem well until 6 hours before death. Children with sickle cell disease have a 15% chance of dying from infection in the first few years of life. A child with sickle cell disease who develops sepsis—an overwhelming infection—has a 30% chance of dying from it. Sepsis can be the first clinical sign of sickle cell disease and it can occur as early as 4 months after birth.

The goal of the clinical trial was to see if sepsis could be prevented. The study involved 215 children with sickle cell disease, 105 of whom were given a placebo and 110 of whom were given oral penicillin. The children were followed for an average of 15 months. Those who received the placebo had 13 septic episodes and 3 deaths. The group that received penicillin had two septic episodes and no deaths. These results were so dramatic that although the study was scheduled to end in February of 1986, it was terminated 8 months early.

Based on the results of this study, the NIH panel recommended that there be no attempt to limit screening to ethnic groups most at risk. It is too easy, said Wethers, to miss babies with sickle cell disease if someone must first decide if they are black, white, Hispanic, or Indian. "There is always a big controversy over who makes ethnic decisions and there is always room for doubt," Wethers said.

Once children are determined to have sickle cell disease, they should receive penicillin from the time they are 4 months old until they are at least 5 years old. It is not yet clear at what age they should stop taking penicillin, but there will be a study beginning this summer to address that question.

An infection can occur so quickly that a child can appear well until 6 hours before death.

Researchers from comprehensive sickle cell centers told the panel that they go far beyond simply prescribing penicillin to affected children. In California, for example, where there is already mandatory newborn screening for sickle cell disease, parents are given extensive counseling and are asked to attend family education sessions every 2 to 4 weeks in the first few months after their child is born. The family members are taught to read thermometers and are told that a fever of 101° is a life-threatening emergency for their child, whether or not there are any other symptoms of illness. The children are inoculated with *Hemophilus influenza* vaccines, the hepatitis vaccine, and influenza vaccines.

The parents also are given a letter to carry with them when they travel that informs doctors that the child has sickle cell disease and gives the doctors certain basic medical information, including the advice to hospitalize the children when they develop fevers. Such letters are necessary, said Ann Earles, nurse coordinator for the Children's Hospital Sickle Cell Program at the University of California at San Francisco, because, "we've had children hospitalized at community hospitals where no one knew anything about sickle cell disease."

At the opposite extreme are the experiences of two New York women, Deborah Henry and Ruth Issac-Gumbs, both of whom are the mothers of children with sickle cell disease. Although there was a screening program in New York at the time her child was born, Henry said she was "missed by the system. I was unaware that such screening was done on newborns." When her daughter, who is now 11 years old, was 10 months old, she had her first sickle cell crisis. The child had a fever, swollen joints, and joint pain, so Henry brought her to a hospital emergency room. There, she said, "I was accused of child abuse." Henry was told that if she did not cooperate and tell the authorities who was battering her child, the hospital would inform the police.

Henry denied that her daughter was being abused and she was sent home with her child. The next month, Henry brought her daughter to the hospital again, this time with an enlarged spleen, which is a characteristic symptom of sickle cell disease. Once again, she was accused of abusing her daughter. Finally, she sought care for her daughter at St. Luke's Hospital, where sickle cell disease was diagnosed.

Issac-Gumbs' 10-year-old son was screened at birth as part of New York's routine program. But she was not told the result. When her baby was 3 months old, she took him to the clinic at Elmhurst Hospital and saw on the child's chart a notation that he had sickle cell trait (actually, he had sickle cell disease). When Issac-Gumbs asked what the notation meant, she was told "do not worry, your child is still young."

When Issac-Gumbs' son was 6 months old, she took him to the clinic because he was not moving his right arm or right leg. The doctor took x-rays and told Issac-Gumbs that he could find nothing wrong with her baby. When Issac-Gumbs' son was 10 months old, she took him to the clinic at Elmhurst Hospital again because he had a cold that had lasted more than 2 weeks. The doctor who saw her son said the child's spleen was enlarging but never mentioned sickle cell disease to Issac-Gumbs. Eventually, Issac-Gumbs took her child to a different hospital and learned what was wrong with him and how he should be treated. But it took persistence and determination to get appropriate medical treatment—it was far from easy.

The need for counseling, education, and comprehensive medical care for children with sickle cell disease means, of course, that the panel's recommendations are far more expensive and difficult to implement than a simple blood test. Nonetheless, the consensus panel said it is confident that its recommendation for sickle cell screening will soon be acted upon. Panel member Sara Reed DePersio, who is chief of Maternal and Child Health Medical Services of the Oklahoma State Department of Health remarked, "many states are already considering expansions of their newborn screening programs. It is my opinion that many states will look at our recommendations and move quickly to incorporate them." ■

GINA KOLATA