

Noril'sk and Magadan, as well as a central one, Krasnoyarsk, all of which had been previously closed to foreigners.

But despite these "successes" of U.S. policy, some American experts are objecting to the way it is being enforced in this country. "We're not interested in selling national security down the river," says Lawrence C. Mitchell of the Commission on International Relations of the NAS. "But we are interested in honest answers. If there is a good reason

why a theoretical physicist from the Soviet Union should not spend 3 months in San Diego, fine. But it looks as though the military in particular is acting in a categorical manner."

Several American scientists, although they disagreed on whether the government Cold War era rules serve a useful purpose, did agree that the rules have been responsible for the restrained, arm's length character of the exchanges with the Soviet Union of the last 2

years. Several of them contrasted this situation with the Soviets with current scientific exchanges between the British and Americans. The latter are so free-wheeling and spontaneous that no official at the NAS could be found to even estimate how many scientists from each side are involved. Commented one American: "We don't really have scientific exchange yet with the Russians in the sense that we do with the British."

—DEBORAH SHAPLEY

Patients' Rights: Harvard Is Site of Battle over X and Y Chromosomes

Boston, Massachusetts. Patients have rights. It is a startlingly simple concept, one of those things that ought to go without saying. But today, rather suddenly it seems, people are putting into words ideas that sound strangely new, and patients are acquiring rights they have never had before: the right to be fully informed before consenting to an experiment, the right to refuse consent.

As patients gain rights, researchers lose prerogatives they used to take for granted; they are increasingly under fire for experimentation they are doing in the name of medicine and science. It is a difficult time, fostering controversies that probably never would have come up as few as 6 or 8 years ago.

Harvard Medical School is the site of one such controversy where a disagreement over a study of chromosomal abnormalities in newborns has become an acrimonious battle. One group of faculty members is trying to force another to abandon a chromosome screening study that has been going on for several years. The battle is cast in terms of the persecutors and the persecuted. There are those who say that the spirit of McCarthyism is alive at Harvard Med.

X and Y chromosomes are a significant part of the trouble. Since 1968, Stanley Walzer, a psychiatrist, and Park Gerald, a geneticist, have been looking at the chromosomes of every baby born at the Boston Hospital for Women, one of the Harvard teaching hospitals. (Some 15,000 newborns

have been screened.) Not surprisingly, they have identified some baby boys who have the XYY chromosome pattern; that is, they have one extra Y—male chromosome. The XYY pattern has been dramatically, if somewhat simplistically, associated with criminality.

A few years ago, XYY was used as a defense in two widely publicized murder trials, one in France (it was not accepted) and one in Australia (where the defendant was judged insane, but not by virtue of being XYY). The problem of understanding what XYY means was further compounded by the erroneous rumor that mass murderer Richard Speck, who killed eight Chicago nurses, was XYY. As late in the game as 1972, one of this country's leading geneticists stood up at a small meeting and pushed the XYY stigma to its limits. "We can't be sure XYY actually makes someone a criminal," he said, "but I wouldn't invite an XYY home to dinner." The audience was incredulous at his bias.

Today, no scientist with any experience in the matter actually believes there is such a thing as a "criminal

chromosome," but there is preliminary evidence that XYY boys are at risk for developing some rather ill-defined behavioral problems. Gerald says XYY boys seem to have "impulsivity and difficulty controlling themselves, but they are certainly not criminals." Walzer says that some XYY children are "hard to handle," that others are "perfectly fine." Both he and Gerald are of the opinion that XYY is a "disease," however, and that children who have it are entitled to medical treatment just as they would be for any other disease. (Not all XYY researchers are willing yet to commit themselves so flatly to a definition of the aberration as a "disease." Said one, "The reason we all need to continue our studies is to find that out." One thing that has emerged from work so far is the fact that XYY is not all that rare. It occurs in one out of every 1000 births, making it as common as Down's syndrome—mongolism.

The chromosome screening study has also identified a number of boys with a less publicly familiar aberration, XXY, which is also related to behavioral problems, although criminality has not even been implied. XXY boys, Walzer reports, have normal, even high, IQ's but are likely to suffer "speech and language difficulties" and may be handicapped by a "significant reading deficit." With early identification and intervention, he believes, these boys can be helped. The incidence of XXY is as high as that of XYY. Both Walzer and Gerald believe that screening for these, and other, chromosomal patterns is more than justified. And they believe that, in XYY and XXY cases, it is possible to offer useful help in the form of psychological counseling.

Not everyone agrees. Chief, or at least most vocal, among the opposition is Harvard microbiologist Jonathan

Recent advances in biomedical science are raising important problems of ethics and public policy. This is one of a series of occasional articles planned for News and Comment on the conflicts involved.

Beckwith who would like to see the study shut down and who, with others, has taken formal action to do just that. "I'm involved in a science for the people group that has been looking into the XYY study for about a year. It began when we heard that all newborns were being screened," he recalls.

Beckwith and his associates, including Jonathan King of the Massachusetts Institute of Technology, object to the study on several grounds. They have looked at the available literature on XYY from Harvard and elsewhere and concluded that the XYY syndrome is a "dangerous myth." Furthermore, it is their opinion that there is no meaningful medical or psychological treatment. As they see it, the stigma of being XYY or XYY is so great that behavioral problems arise as part of a self-fulfilling prophecy. If you tell parents that their son is going to have problems, they will treat him abnormally and he will, indeed, develop problems.

Another major ground for objection rests with the matter of informed consent. Beckwith contends that parents have been anything but fully informed of the consequences of agreeing to have their babies screened. He says that parents should be told not only that they are participating in a search for aberrant chromosomes but that, if their child turns out to be afflicted, they will then be asked to consent to further experimental studies of his development. Beckwith and his colleagues in the opposition believe parents should be given information about the statistical risks of finding an aberration and the possible courses of action then. In all, he thinks that parents should be given a course in genetics. Even he admits that this would be impractical, if not impossible, and therefore thinks the proper route is to stop the study altogether.

Feelings about the ethics of the study, particularly as it regards the question of consent, are strong, and a number of people are getting into the act with comments on the issue. One comes from Jay Katz, a psychiatrist on the Yale Law School faculty. Beckwith sent him several documents about the study, including the consent form about which Katz had this to say in a 30 September letter of reply: "In its present form, Dr. Waltzer's [sic] initial approach to the parents is neither straightforward enough nor does it comply with what I consider the re-



Y chromosomes, which show up as two bright spots above, are easily identified when stained with quinacrine mustard. The technique is one of a couple used for chromosome analysis. [Courtesy of Digamber S. Borgaonkar, Johns Hopkins University]

quirements of informed consent to imply. Elements of 'fraud, deceit,' and even 'duress and overreaching,' proscribed by the Nuremberg Code, are clearly present."

Those are fighting words, the sort of emotion-laden pitch that has left Walzer feeling persecuted and drained by this bitter affair. "This has been a very ugly time in my life. I've even had threatening phone calls," he says. "This is like the McCarthy era."

Walzer feels particularly offended by some of the charges made against him because his study has been conducted well within the bounds of requirements set by the hospital, the medical school, and the National Institutes of Health, which has just reviewed the project and agreed to fund it for another 3 years. "We've been reviewed and reviewed," Walzer laments. "We're not doing anything behind anyone's back. Nor have we been disrespectful of our patients. They are grateful for what we're doing."

Both Walzer and Gerald see the current controversy as being very much related to the "ethical" times in which we are living. They say they do not object to change but they resent being called unethical.

They began the screening program at a time when developments in genetics were making it possible to perform increasingly sophisticated chromosome analyses on a large scale at a reasonable cost. (At Harvard, the tab is about \$6.00 per baby and is paid out

of research funds.) "In the late 1960's," Walzer declares, "the issue of consent was not there. We took a little blood and got a lot of information. The attitude was, 'What harm can it do?'" But even then, when similar screening programs were being set up at other institutions,* there was disagreement about what to do if one found an aberration. Some groups, looking at the screening as purely a matter of research, did not tell parents what they discovered. But Walzer and Gerald have consistently rejected that idea. "We've always felt that, if we found a variation, we had to tell," Walzer comments. "Secrecy is no good. We believe the most destructive thing you can do to parents is to tell and then not follow up. We follow up closely, and I do not believe our families feel like guinea pigs. I agree with Beckwith that there is a risk to labeling kids, but I think we have to take it."

Acknowledging that what was considered acceptable in 1968 is no longer acceptable in 1974, Walzer says he has been continually revising his consent forms. The most recent changes incorporate those suggested by Beckwith and others. Now, parents are asked to give consent after the baby's birth. (Incredibly, women used to be asked for consent while they were in labor.) Information is provided about the risk that an aberration will be detected; parents are told that some aberrations are thought to be related to developmental problems, and they are informed that they may be asked to participate in a further study if any chromosomal variations are present. They are also explicitly told that they do not have to agree to participate in the screening, and they will not receive less good medical care if they decide they don't want anyone looking at their baby's chromosomes.

The question of whether to allow the study to continue is now before the medical school's standing committee on medical research, which is chaired by Dana Farnsworth. "We're the referee when there is a disagreement," he explains, adding that "there have not been many cases as emotional as this. The field seems to draw people with particularly strong opin-

* Among places in the United States where newborn screening is being done are hospitals in Denver and New Haven, in addition to Boston. Screening is also being carried out in Winnipeg and London in Canada; Edinburgh, Scotland; and Denmark. In all, about 50,000 babies have been screened. In many of the studies, parents are not told the outcome.

ions. We will have to decide what is right, not who is right."

The committee has heard testimony on both the scientific and ethical points in the case and has even solicited the informal opinion of David Bazelon, chief justice of the U.S. Court of Appeals. Bazelon, who has long had an interest in questions of medical ethics and law, discussed in an interview with *Science* some of the issues raised by the Harvard controversy.

The judge is concerned that a cult may be growing up around the ethics

of human experimentation that may neither be good for patients nor for the progress of medicine. "Experimentation," he observes, "is becoming a dirty word." He finds that his own feelings about patients' rights are changing a little as "the pendulum swings against experimentation."

Bazelon has always been a defender of patients and believed they had rights before it became fashionable. But now he wonders whether concern may not be getting mixed up with paternalism on the part of some "elitist"

scientists who underestimate patients' abilities to cope with complex information and tough decisions.

On 20 November, the Farnsworth committee will meet to prepare its final recommendations, which will be delivered to the full medical school faculty at a meeting on 13 December. Ultimately, the full faculty will have to decide whether to permit research in an area that is not without risk or whether to permit only that which is guaranteed to be safe.

—BARBARA J. CULLITON

Congress: A Seismic Shift toward the Young and Liberal

The Democratic tsunami that swept through the House on mid-term election day was the third such deluge to strike the Republican Party since the end of World War II. It was comparable in magnitude to the debacles of 1958 and 1964, and it dramatically reversed the small gains toward a more balanced Congress which the GOP had made with the Nixon landslide of 1972.

Although half a dozen congressional races were still subject to alteration by recount as of mid-November, it appeared that the Democrats had gained 44 seats in the House for a veto-resistant margin of 291 to the GOP's 144. A net gain in the Senate of 3 seats widened the Democratic margin there to 61 to 38 (with 1 Conservative). By and large, the members of Congress who will be departing at the end of this session are conservative. The freshmen who will replace them in the 94th Congress are predominately young and liberal.

Whether one reads this reversal of Republican fortunes as a post-Watergate deluge or merely, as some analysts would have it, as a cyclic inclemency in the electorate, the fact is that an unusually large freshman class of congressmen was made possible, in large part, by an unusually large number of retirements. This term, 30 representatives and 7 senators are retiring; 13 other representatives and 2 senators were defeated in the

primaries; and another 9 House members ran for other offices. Thus in 61 congressional races neither candidate enjoyed the incumbent's edge.

Voluntary departures and primary losses, in fact, had a more dramatic effect on the structure of committee power in most instances than did the November election. Certainly this was the case with the committees dealing with science and the environment.

Most sharply depleted were the House Science and Astronautics committee and the Joint Committee on Atomic Energy. Seven of the JCAE's most senior members are leaving at the end of this term. Senate dean George Aiken (R-Vt.) retires this year, and so do Senators Wallace Bennett, a deeply conservative Utah Republican, and Alan Bible, a Nevada Democrat and an influential member of the Senate Interior Committee. Senator Peter Dominick (R-Colo.), a Goldwater conservative on the joint committee and the ranking minority member of Senator Edward Kennedy's science subcommittee, lost his bid for reelection to Gary Hart, the young and liberal manager of George McGovern's presidential campaign in 1972.

On the House side, the joint committee will lose its two most doctrinaire advocates of nuclear technology, Chet Holifield (D-Calif.) and Craig Hosmer (R-Calif.). Both are retiring.

A member of Congress since 1943

and a former chairman of the committee, Holifield has dominated congressional thinking on the mysteries of nuclear technology for the better part of 20 years. Hosmer arrived in Congress in 1953, having begun his career as a lawyer for the Atomic Energy Commission at Los Alamos in the late 1940's. Few if any congressmen in recent years could match their knowledge of nuclear energy's intricacies, but their departure is likely to facilitate a mellowing trend in the committee's attitude toward nuclear critics and environmental groups.

The House Committee on Science and Astronautics faces the next session with 24 members and 6 vacancies. Among those not returning are John W. Davis (D-Ga.), the chairman of the science research and development subcommittee, whose territory includes general science policy and the National Science Foundation budget. Davis lost out in the primaries.

His departure, and the retirement of Representative Charles S. Gubser (R-Calif.), leave two vacancies on the governing board of the congressional Office of Technology Assessment. (Gubser also was the ranking Republican member of the Armed Services Research and Development subcommittee.)

Other members of the Science and Astronautics committee not returning are Representatives Paul W. Cronin (R-Mass.), John N. Happy Camp (R-Okla.), and Stanford E. Parrish (R-Va.), who were unseated in this month's election, and Representative Bill Gunter (D-Fla.), who lost a primary bid for the Senate.

Ordinarily, Representative James W. Symington (D-Mo.) would be expected to succeed Davis as chairman of the