Flexner Is Bypassed:
Alternativists Invade U.S. Medicine

"Alternative medicine," which aims to fracture and then capture America's highly successful scientifically-based medical practice has not got its nose under the tent, as some scientists and physicians fear. Rather, the whole camel already is inside — snaffling the lunch.

The American Medical Association (AMA) and other professional groups that historically have fought quacks are largely quiescent, even acquiescent. The way thus is open to the most profound directional change since Abraham Flexner, M.D., in 1910, directed America's doctors away from faith-based empiricism — and fraud. The Flexner Report directed medical education toward the scientifically-grounded clinical practice that has made American doctors world leaders in health care.

The current, carefully directed drive for alternativism, sometimes called complementary care, is undermining Flexnerian medicine. It does so in the name of mind/body medicine, holistic medicine, and other vague, unproven, and hence unsafe folkloric practices. Quackery, in a word.

The rigor and rationality of science-based medicine already have been seriously damaged.

- At New York City's pre-eminent, high-tech heart transplant center, at Columbia University, an "energy healer," using an amalgam of ancient Chinese and Indian methods, claims to direct ambient energy into patients' bodies and adjust their energy balances (See story below).
- In Boston, Harvard Medical School and the Beth Israel hospital have just completed a 3-day postgraduate course called Alternative Medicine: Implications for Clinical Practice. It was directed by internist David M. Eisenberg, M.D., a student of Eastern medicine, and was supported by the John E. Fetzer Foundation of Kalamazoo, Mich., a $200 million organization. Fetzer wants to realign American medical practice away from its scientific base, toward a new spiritualism derived from ancient oriental religions. The AMA is granting continuing medical education credit to doctors who attended the $450-a-head conference, Harvard says.
- In Bethesda, Md., the National Institutes of Health's Office of Alternative Medicine (OAM) has just issued an inch-thick, 372-page federal report, Alternative Medicine/Expanding Medical Horizons, that seeks active consideration or reconsideration of virtually every quack remedy and method that has been used and discarded in the last 5,000 years. These include shark cartilage, Hoxsey treatments, and herbs for cancer, rolfing,

Heart Transplants Get 'Energy Healing'

The most cutting edge facility for cardiac transplant and artificial heart research in New York City is the department of cardiothoracic surgery at Columbia-Presbyterian Medical Center, on Manhattan's Upper West Side.

Among the many doctors, scientists, and bioengineers who work in the transplant operating room is Julie A. Motz, M.F.A. (Master of Fine Arts). Motz performs "energy healing" and needle-less acupuncture on patients before, during, and after operations to remove their diseased natural hearts and install artificial ones, and follow-up surgery to replace the artificial organs with human cadaver organs.

"I've done eight operations," Motz said last month by phone, a few weeks after she presented her work at a New York Academy of Sciences symposium on Alternative Medicine in Cardiac Care.

Motz said in the interview that she "keeps [her] hand on the patient's head throughout most of the operation. This allows me to send energy into the patient."

Bridge Is Built

"The touch creates a bridge that allows [the energy] to enter the body." Also, she said, she uses a combination of Chinese acupuncture, with its 12 energy chakras in the body, and Indian Ayurvedic medicine, with its 7 chakras (energy centers), to correct energy imbalances in the anesthetized heart bypass patients.

Motz has a private practice in energy healing and acupunc-
follow-up

Times Finally Finds: Pro-lifeers Get AB's

Almost a decade late, the New York Times, in its Sunday Magazine (March 19), has confirmed an important story of ours that it refused to publish under our byline. The story, the delay, and the way in which the Times finally came round warrant comment. They throw light on the established press's self-censorship of key, but disturbing, stories that if published might significantly advance America's stalled social agenda.

The story:

Ten years ago, we were tipped that Pro-life women often seek abortions, sometimes in the very clinics they have picketed and harassed. We conducted a wide investigation in the Midwest, centered in St. Louis. We interviewed abortion providers and patients, including some women who had switched, abruptly, from Pro-life to Pro-choice when they found themselves pregnant — but wished they were not — and then sought abortions. We documented the existence of this politically explosive behavior. We said it was hypocritical.

The delay:

Medical World News, a doctors' magazine, published a brief, sanitized account of our findings in 1987. But the women's magazines and other consumer mags for which we regularly wrote refused it. We think they did not wish to stir up their readers' anger.

We tried elsewhere: At the Village Voice, an editor said we had failed to express proper compassion for women trapped by their circumstances. She told us to go back and reinterview them (an impossibility), and tell their stories more sympathetically. Then she would reconsider the piece.

We'll Call You

At Ms., our phone calls weren't returned; the editors were busy in meetings. The publisher of a small, progressive magazine in the Midwest said our exposé was gutter journalism of the worst sort. He suggested we be read out of the profession — for reasons we still can't fathom.

The Times Magazine passed on the story, too.

Frustrated, we set to work to start PROBE to evade this censorship. Meanwhile, a key abortion rights case, Webster v. RHS (Reproductive Health Service) blew up in St. Louis, and moved rapidly to the U.S. Supreme Court. Since some of our key research had been conducted at RHS, we sent the manuscript to our favorite Times editor. He said: "Dynamite story!"

His bosses may have agreed. But they were not interested in the market for explosive abortion stories.

We published the story ourselves, as our pilot issue, on June 15, 1989.

Talking to journalistic colleagues through the years, we found many had heard the same stories we had about Pro-life women getting abortions. They said their editors told them not to pursue these leads.

The confirmation:


What Higgins appears not to have done is to post our critique of Scifraud's science bashing, and its proposals to "burn" bad science for other scifrauders to see. We wonder why.

Index Sent with Issue

Subscribers will receive the Index for PROBE's Volume III with this issue. It includes information on how to order back copies.

Our excellent indexer — and colleague — Lynne Lamberg has prepared a second index, of names, for Vol. III. We'll send you a copy if you will send a SASE, marked "index" to the post office box listed in the Masthead.

We're also sending subscribers here the program for the forthcoming New York Academy of Sciences conference "The Flight from Science and Reason." It will be co-chaired by biologist Paul Gross, Ph.D., and mathematician Norman Levitt, Ph.D. Their brash counterattack on science bashers, Higher Superstition (Johns Hopkins), which we reviewed here last year, should be advanced by this conference. The dates are May 31 - June 2. PROBE readers will enjoy it.

Also enclosed is a letter asking for your help in carrying PROBE's pro-science, pro-reason — and, we fear, unpopular, anti-populist — message to young readers in high schools, colleges and universities. Institutional libraries are broke and cutting back new acquisitions. They need patrons and friends to put PROBE on their reading room shelves.

You can help. We hope you will!

-D.R.Z.
Pro-lifers . . .
continued from preceding page

Beth Karlin, M.D., director of the Women's Medical Center, in Madison, Wis., explained that women seek abortions because "we don't [at the time] have the resources to be the mother we expect to be" — and thus, why she provides them. In her brief essay, she precisely confirmed our earlier findings, including the fact that many of her patients are Catholics, and more than 1 in 20 come from actively Pro-life families, and previously have said, "I would never have an abortion" (see box below).

Special Reasons Cited

We of course are delighted to have our findings confirmed. But we are irritated, because it appears to us that the *Times* published Karlin's piece because she is a woman, a doctor, and an abortionist. And, because she is angry and frightened by the increasing anti-abortion violence that threatens her life, her patients, and her staff. For the *Times*, Karlin's special, personal credentials kosher the story. In publishing her opinions the paper of record doesn't have to take reportorial responsibility for her views or her facts, as it would if we or a staff writer were to have told the same story.

This cop-out is offensive and harmful to journalists and to readers. It bolsters the divisive and anti-professional myth that "multiculturalist" journalist (and reader) is trapped in his or her enclave; democracy is demeaned.

The *Times*' stance, and that of the rest of the establishment press, is dangerous from a public policy viewpoint. Abortion, second only to race, is our most divisive, damaging issue. Other policy questions have been side-tracked for decades now by the abortion impasse and the energy it consumes. Breaking this impasse is, or should be, journalists' goal. Proving that those who protest loudest against legalized abortion meanwhile avail themselves of it could be just the small, explosive bit of data needed to blow this blockade away. If *everyone* is doing it, how can we spend another moment arguing about it — let's move on!

We think newspapers and TV stations in every community should research this story and report it. We are hopeful that when Americans understand that "everyone's doin' it," the abortion debate will fade away.

Hypocrisy is said to be the only remaining civil sin. The press's job is to find and report it.

A Reader Reacts

A *Times* reader, Sara Watson, said it succinctly in a letter commenting on Karlin's piece (April 9):

"I am immensely frustrated that it took this long for the news media to reveal even offhandedly that many anti-choice protesters picket clinics one day, have an abortion the next, and immediately return to the front lines to prevent others from using this service. This practice has been common knowledge among ob-gyns for years. We need some enterprising investigative reporter to 'out' these hypocrites in a front-page expose."

Abortion Story Is Confirmed

The left column is from our investigations of abortion in the mid-1980s, published in the pilot PROBE, in June, 1989. The right column is from Elizabeth Karlin's Abortionist's Credo in the March 19, *New York Times Magazine*.

Many 'Pro-life' Women Get Abortions.

One clinic patient [whom we interviewed in the recovery room], a parochial high school student, told her counselor before her abortion, 'I'm against abortion, I don't feel it's right. But in my circumstances . . . .'

[A] scheduling administrator . . . recalled one woman blurring out in the recovery room: 'It should be illegal!'

'I know it's wrong, but in my case [a patient will say];' and then will explain why her case is special or different from those of other women in the waiting room.

Eight percent of women who had abortions disagree with the statement 'Any woman who wants an abortion should be able to obtain it legally.' [according to a Yankelovich poll].

Q.E.D.
Angry Alternativists Plan to Investigate and Discredit Foes

Alternative health leaders are building a coalition to defend their interests against quackbusters and the medical establishment — which they say thwart their efforts. It is called COACH, for Coalition for Options to Achieve Comprehensive Health.

At a planning meeting, convened in January by the American College of Advancement in Medicine (ACAM), a California professional group, a wide agenda was proposed. According to a report by a participant in the meeting, held at a Dallas resort, one “top” COACH priority is “to identify our opponents as specifically as possible. It was decided that we must utilize investigative reporters/attorneys in order to investigate the structure of our adversaries.”

These include, the report said, the AMA, dieticians, the National Council Against Health Fraud (NCAHF), American Council on Science and Health, and the National Organization of Medical Boards, which accredit medical specialists — but may debar quacks.

Strategy Planned

One COACH goal, the report says, is to “plan a strategy to discredit the individual quackbust­ers.”

The report was written by John Hammell, the political coor­dinator of the Life Extension Foundation, of Hollywood, Fla. PROBE obtained a copy of the report. Hammell confirmed that he wrote it in a recent telephone interview.

The convening group, ACAM, of Laguna Hills, Cal., has a mission statement, according to Gale’s Encyclopedia of Asso­ciations (’92) that identifies it as a physicians’ organization “for the promotion of preventive medicine”; it conducts research programs on chelation therapy, nutritional therapy and other preventive modalities.

Chelation Is Issue

One of ACAM’s immediate concerns, the report states, are state medical boards’ efforts, particularly in California, to drive chelation doctors out of business.

Quackbusters say that chelation is worthless and risky — a fraud. Advocates say it purges poisons.

“Quackbusters” named in the report include Viktor Herbert, M.D., Stephen Barrett, M.D., and William Jarvis, Ph.D., all of whom are NCAHF leaders. “The meeting be­gan,” the report says, “with ACAM president-elect Dr. Terry Chappell playing a tape of [these] quack­bust­ers . . . denouncing alternative medicine as the ultimate fraud, in order to get us fired up.”

(Herbert’s surname, Victor, is twice spelled incorrectly with a k instead of a c, in the report. This substitution, as in Amerika, is commonly found in neo-nazi and other far-right publications.) (See follow-up report, p. 6.)

Vive La Différence!

Our fellow newsletterist, Jack Raso, editor of Nutrition Forum, has the fortitude required to examine each new (or old) alternative health care method as it emerges into view. In his Jan./Feb. issue, Raso, a dietician (R.D.), reviews a plethora of these methods and movements in a report headlined “Wholy, Holy, Holey.” He comes up with this useful distinction:

“Alternative healthcare” is one of a “motley bunch” of movements “whose central thesis seems to be: Faith, based on common sense, subjective experience, and/or reve­lation preempts rational understanding.” Collectively, Raso says, he calls these healthcare movements alternativism — which we think is cogent coinage.

Alternativists — to add just a twist — reject logic, reason, and science as guides to existence, being, and action.

PROBE readers who wish to learn more about alternativism should consult Nutrition Forum. Raso will send a sample copy if you mail him a 55-cent, 9 x 12 SASE at Prometheus Books, 59 John Glenn Drive, Amherst, N.Y. 14228.

Invade . . .

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reflexology, herbs, flowers, ad infinitum. Since most of these nostrums are not patentable, the report says, the federal govern­ment should pay for the research to test their worth.

* In Washington, meanwhile, psychiatrist James S. Gordon, M.D., a member of OAM’s board and a clinical professor at Georgetown University School of Medicine, is teaching medical­ students to use alternative methods to handle the stresses in their own lives. Learning to take care of themselves, he said in an interview, they can take better care of their patients. Acu­upuncture, self-hypnosis, meditation, osteopathy and homeopa­thy are among the methods he introduces to these busy students in an effort to “develop a more humanistic approach to healthcare, and find out which of these alternative therapies work and which don’t.”

* Across the U.S., about 27 of the 129 medical schools have already introduced courses, like Gordon’s, on alternative health. A directory from the Rosenthal Center for Alternative Medicine, at Columbia University, lists courses taught by nonphysicians, as well as by physicians like Gordon. In Los Altos, Cal., oncologist Wallace Sampson, M.D., of Stanford University, is developing a parallel list of alternative medicine courses. “I can count only four thus far that present anything like a balanced presentation,” he said by phone last month. “I’ve not been surprised,” that they are not balanced, he added: These courses are for the most part pro-alternative treatment.

Sampson, who describes himself as an “old-fashioned quackbuster,” is chairman of one of the very few organizations that is fighting the alternativists’ tidal wave, the National Coun­cil Against Health Fraud (POB #1276, Loma Linda, Cal. 92354). He said: “This is one of the most dangerous corners ever turned

continued on next page
Alternativism: It’s Time to Get Tough

No graduate program in astrophysics that we know of offers astrology instruction. Neither do we know of any graduate biology program that allows electives in creationism.

By hosting comparable irrationalist courses — and postgraduate medical education, as Harvard has just done — American medicine betrays the scientific foundation that has made it great. It does so at extraordinary peril to itself, its patients, and everyone’s hope for continuing progress against illness.

The issue is not, as some have suggested, whether this or that “alternative” procedure will be admitted, provisionally, to the corpus of care while its advocates scientifically demonstrate its worth. The issue, rather, is the establishment of an entirely different, anti-scientific amalgam of unproven practices, many of whose advocates have been accused, and some of whom have been convicted, of medical fraud.

What the alternativists aim to do, simply, is to take over America’s health care. How else to interpret this item in Action Plan 4, of the new Coalition for Options to Achieve Comprehensive Health, as reported on P. 6:

“A large marketing plan cooperative will be formed . . . . Marketing will include selling the product of the ‘New Doctor,’ which will be a paradigm shift redefining health care.” [emphasis added].

How should American medicine respond?

First, the medical schools should toss out the alternative medicine courses and departments, unless it can be clearly demonstrated that they are not alternativist stalking horses. No more continuing medical education credits for this type of program, either.

Second, the AMA is flabby and frightened (having lost a costly lawsuit when they tried to debar the chiropractors some years ago), and needs encouragement — and help.

The best minds in medicine now are represented through specialty societies like the American College of Physicians. Ergo, what is needed is a coalition — a political and educational coalition — to alert the profession, governing bodies, and law-makers of the legitimate claims of scientific medicine, and the dubious claims — and power grab — of the alternativists.

For American doctors, anything less than all-out commitment to these goals is self betrayal.

— D.R.Z.

Invade . . .

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— more dangerous than anything that has to do with a national health plan. The quacks are gaining in stature and legitimacy.” Sampson said organized medicine is not fighting back. The AMA still is frightened because it lost a suit to the chiropractors a number of years ago, he said. But the suit involved restraint of trade not public education — which AMA is free to do.

Concerns Raised

Sampson said he raised his concerns with the American Association of Medical Colleges (AAMC), the medical schools’ national group, in Washington, D.C. He said he was told that he was the first person to complain, and was told AAMC doesn’t approve or disapprove of member schools’ curricula. Meanwhile, Sampson said, as in all schools many students come to resent their mentors. New MD’s are expressing this by embracing naturopathy and other anti-scientific quack practices.

Commenting on the doctors’ growing alienation from science, Sampson said, only half in jest: “Flexner! Who’s he?” The AMA’s position on alternatives is that “we can’t dismiss them out of hand, and say they have absolutely no merit,” said the group’s senior vice president for medical education and science, Roy M. Schwarz, M.D., in a phone interview last month. Some methods that once were considered alternative later were proven to be true, he explained.

“On the other hand,” Schwarz said, we know that the great, great majority have never been proven, and have been labeled ‘fraud’ by people outside the profession.”

The only criteria, Schwarz added, is scientific proof of safety and efficacy. Without that, he said, “none of it will be accepted by mainline medicine and mainline science. “In the mind of the scientific community that brought you the wonders of modern medicine, it will remain unproven.” But not unused.

Given his view that most alternative methods remain unproven, Schwarz was asked, why AMA would grant continuing medical education credits for the Harvard course? He referred the question to another AMA official, Charles Macenski, who said the AMA had not known about the conference, and didn’t endorse it.

“Our name certainly shouldn’t be used in that promotion. We’re not part of that,” he said, after examining the program. Macenski promised to check further. A week later he phoned back to say: “Our people think it’s okay.”

Referring to the NIH’s Alternative Medicine monograph (above), Macenski now suggests that the Harvard program appeared to be quite appropriate.

“It’s probably quite valuable!” he said.

Plea is Copped

After months of stoutly asserting his innocence, animal rights terrorist Rodney A. Coronado has now pleaded guilty to two felony charges, one of them for his role in torching a mink research facility at Michigan State University (PROBE, Dec. ’94).

In exchange for the plea, which has yet to be accepted by a judge, U.S. Attorneys in six states have agreed not to prosecute Coronado for his role in other terrorist acts in their jurisdictions.
Heart . . .
continued from page 1

ture in Putnam county, north of New York City; she makes house calls in Manhattan. But, she said, her work at Columbia's transplant program is voluntary and unpaid.

She said she has the permission and encouragement of the cardiothoracic surgery department and the patients whom she treats. Motz explained that she is working on her M.P.H. (Master of Public Health) degree at Columbia, where her thesis topic is the introduction of alternative health care to a main-
stream academic medical center, using Columbia as a model.

She said that she does not scrub for the operations. But she works close to the surgical field.

Efforts Described

After anesthesia has been induced, but before the patient is prepped, Motz explained, she stands at the foot of the operating table to "pull the energy field down, because under anesthesia the field tends to go to the top of the body... I send energy to the kidney meridian and the liver meridian in the foot," she continued, because "you want them to make urine and you want the blood to clot."

Motz then moves to the head of the table.

"I instruct the patient under anesthesia to relax, and allow the surgeon to enter the body." She said she tells patients that "the surgeon is entering [the chest] with loving intent." Although these patients are unconscious, Motz said, "I believe" they hear what she says.

She said she explains to them that they will be given an anti-
clotting drug before their circulation is switched to the heart-
lung machine, and said that she sometimes sings to the patients once they are on the bypass machine. One purpose of this communica-
tion, she said, is to prevent post-operative depression.

Heart Heaven Seen

Motz said she tells patients to bring their consciousness to their blood, and tell their blood to let go of the old hearts, and that if there is a heaven for hearts, their natural hearts certainly will go there. She said that she sometimes communicates directly with the patient's blood.

"I discovered that it was actually the blood that missed the old heart!" she said.

If there is time, she added, she goes to the ice chest, where the cadaveric heart is kept in readiness, and performs "energy work" on it. She said she does not touch the organ, but can feel energy moving toward it through her hands.

These treatment ideas, which have been around for 3,000 years, all can be explained by the laws of physics, Motz as-
serted. She said some of the new hearts are extremely happy. Some are worried. "It varies," she said. Once implanted, she added, if the new heart does not start beating right away, she sends energy to it.

In Motz' view, consciousness and personality are not loc-
ed in the brain. They inhere in every cell in the body.

Alternativists
Set an Agenda

While the AMA waits for alternative providers to prove their methods scientifically, the alternativists aren't waiting at all to mainstream their opposing health care agenda.

After the January summit meeting convened by the Ameri-
can College of Advancement in Medicine (ACAM), its presi-
dent-elect, L. Terry Chappell, M.D., of Bluffton, Ohio, distri-
uted a set of "action plans" for a coalition called COACH — for Coalition for Options to Achieve Comprehensive Health.

These are some of the planned actions, according to Chappell's late March mailing:

• Change state laws to protect alternative medicine.
• Get health insurance to pay for it.
• Defend "environmental medicine" and chelation therapy before state medical boards.
• Expand links to medical schools for teaching. "Alternatives in Medicine" (his preferred title for these practices).
• Develop a marketing plan, based on one used by chiro-
practors. "Marketing will include selling the product of the "New Doctor," which will be a paradigm shift redefining health care."
• Educate patients on how to challenge insurance companies that refuse to pay for alternative care.
• Legislation to curb FDA powers.
• Prepare and circulate "white paper to expose the quackbusters."
• Serve as "preceptors" for medical students.
• Provide "expertise" to medical schools, while attempting to "avoid polarization within the field."

Asked to comment on the COACH agenda, quackbuster Victor Herbert, M.D., of Mt. Sinai Medical Center, in New York city, said by phone, that the "products" COACH is promoting are "products of scam artists, fraudulently repre-
sented as the 'New Doctor.'" The proposed laws, he said are to protect "fraudulent alternative medicine, as distinguished from responsible alternative medicine."

The COACH initiative in medical schools, Herbert added, is an attempt "to teach health fraud as if it is health science."

Life Extension Officials Indicted

The Life Extension Foundation, whose political coordinator reported on the ACAM meeting, has a few problems of its

continued on next page

own: As described by quackbusters Stephen Barrett, M.D., and Victor Herbert, M.D., in their new book The Vitamin Pushers (Amherst, N.Y.: Prometheus), FDA officials and U.S. marshals raided its Hollywood, Fla., premises in 1987. They seized unapproved drugs, including BHT, DMSO, Coenzyme Q10, and Cognitex — claimed to enhance mental function.

Later, a 28-count indictment was filed in the U.S. Southern District Court of Florida, in West Palm Beach, charging company officers with importing and selling unapproved new drugs and misbranded prescription drugs. The case is due to come to trial next January, according to a spokesman for the U.S. Attorney's office in Miami.
Bad HD Genes Are Purged From Families

Several most-valued babies will be born in the next few months. If all goes well they will bring dramatic, new, high-tech relief to parents who have faced an anguishing dilemma:

One partner in each couple is a member of a family that has been hit by Huntington’s disease (HD). Each couple wants their own baby: his sperm, her ovum. But they don’t want a child who must live in fear of suffering HD, or passing it on yet again to another generation.

The experimental method to prevent these tragedies — by providing an HD-free baby — is called preimplantation genetic diagnosis (PGD) and embryo selection. The method is revolutionary because it will permanently remove the deleterious HD gene from the baby’s lineage. The technique was described last month at a conference at the Harvard-affiliated Faulkner (Hospital) Institute for Reproductive Medicine here, one of the first U.S. facilities to offer PGD.

Method Described

In the procedure, a couple at high risk of conceiving a baby that carries the bad gene for HD, or for some other severe, single-gene inherited illness, is put through the standard in vitro fertilization (IVF) procedures. This usually yields several or more fertilized embryos, conceived in a petri dish, from his sperm and her ovum.

Then, in a carefully timed maneuver, when the embryos are at the 4- to 8-cell stage of development, one cell is removed from each embryo. The DNA is extracted, and the HD or other gene that is at issue is extracted from the genomic gниш. It then is rapidly amplified in quantity by the technique called polymerase chain reaction (PCR). Using this DNA, the HD defect and others can be identified, if present.

Embryos that carry a defective gene are discarded. One or more embryos that carry the normal gene are implanted into the mother’s uterus by standard IVF methods, and the pregnancy proceeds — normally — to term.

If more HD-free embryos are obtained than the mother and her doctors wish to implant, some can be frozen for later use in case the first pregnancy fails, or to produce a second HD-free infant.

Research Sites Undisclosed

This clinical experiment is being coordinated by reproductive geneticist Mark R. Hughes, M.D., of the National Center for Human Genome Research, in Bethesda, Md. In a brief interview, Hughes declined to identify the research sites where the HD experiments are unfolding. However, only six centers in the U.S., including Baylor University, in Houston, and Faulkner hospital, here, are currently funded by the National...continued on next page

Anguish, Hopes Told

“My primary goal is to have children who do not have Huntington’s Disease (HD).”

Tearfully, Keith Kidd explained to researchers and clinicians why he is contemplating the procedure unveiled at a meeting here. Kidd, who is a former official of the Huntington’s Disease Society of America, said his father and other family members had suffered at length, and died from the devastating neurologic illness.

Current family members’ lives have been strongly shaped by fear. One sister, Kidd said, decided to have her children at a very young age — so she could be sure to be with them as they grow up, before HD dementia may overtake her. (HD symptoms usually first appear between ages 40 and 50.)

Kidd said his second reason for weighing, with his wife, the use of the experimental new procedure was to relieve the “incredible stress” the anticipation of illness placed on his immediate family. He said he did not know if, in fact, he carries the deleterious form of the gene: He has no symptoms at present, and has declined to be tested. Besides the personal anguish that the knowledge could bring, he said that if he were found to carry the HD mutation he might no longer be able to buy insurance for himself and his family.

The new method, he said, between painful pauses, could give him and his wife the “ability to have children who do not have HD, without finding out what my own status is.”
Institutes of Health (NIH) for these clinical studies.

Faulkner has had inquiries, but has not yet attempted the procedure, its reproductive institute director, Machelle Seibel, M.D., said. Two kinds of families may benefit from the procedure, he added:

- Families in which HD has occurred, and in which the husband or the wife has taken the genetic test for HD, and so knows that he or she in fact carries the deleterious gene. The new method obviates the need for later fetal diagnosis, by amniocentesis, and the abortion of fetuses found to carry it — the usual outcome.
- Families in which HD is present in one or the other partner’s lineage, but that partner has not taken the HD genetic test, perhaps because he (or she) does not want to know if he is carrying the bad gene. The new method, as described by geneticist Hughes, spares the individual this dire knowledge, since the parents are not told if examination of the embryos' DNA has identified one, or more, that carry the gene. This information is withheld.

The couple, rather, only is told that HD-free embryos have been identified, and implanted in the mother. If three, four, or more embryos have been obtained, the odds are that at least one will be HD free, and so can be used in this way.

If it works, the method thus will provide an HD-free infant in the present generation. It also will purge the mutant HD gene from that offspring’s lineage, thereby achieving the goal of germ cell, or genomic, therapy.

A major purpose of the Faulkner conference was to explore the ethical dimensions of PGD — a subject that we covered extensively last year (PROBE, June ’94).