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Genetic Counseling: Helping People Cope With Inherited Ills

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GENETIC COUNSELING

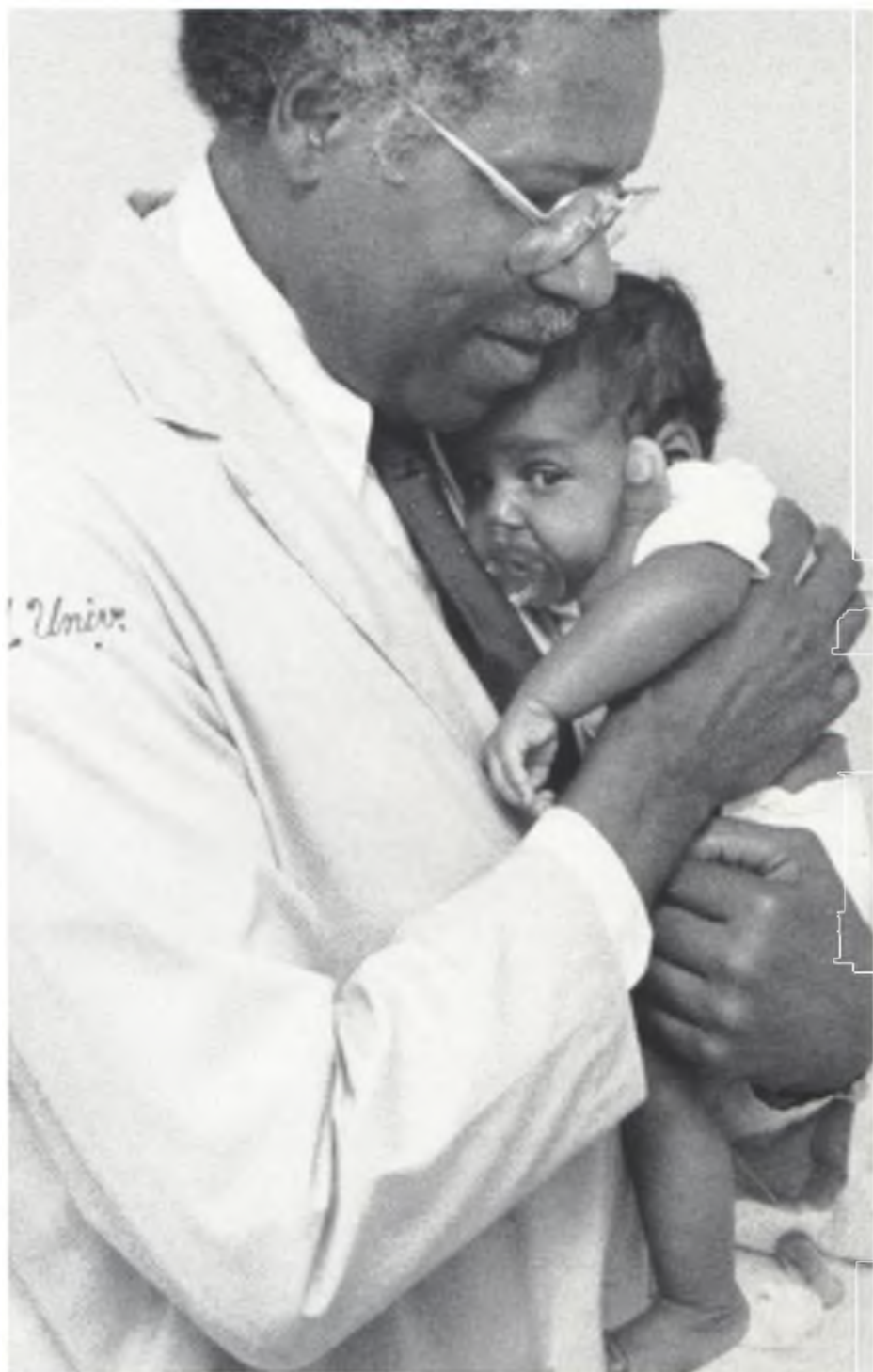
By Harriet Jackson Scarupa

Gloria is 40 and has been married two years. She and her husband would like to have a child. But she's heard that the chances of having a child with Down's syndrome increase dramatically when the mother is over 35. She's always been saddened when she's encountered children with this condition, viewing their retardation and the clumsy friendliness with which they have approached her as almost grotesque. Right now, she's torn between the desire she and her husband have for a family and her fear of giving birth to a child with severe mental and physical handicaps.

Louise watched her two older brothers die of Duchenne muscular dystrophy when they were entering the prime of their lives: their mid-twenties. Duchenne muscular dystrophy is a progressive, eventually fatal muscle-wasting disease that affects only the male children of women who carry the genetic trait for the disease. Louise has already had several blood tests to measure the enzyme level in her muscle cells [which can be a marker of the trait] and the test results indicate that she, like her mother before her, is a carrier of the disease. She's just learned she is pregnant. And all she can think about are her brothers' years of suffering and too-early deaths.

Jonathan and Cynthia, avid joggers and health food enthusiasts, are the picture of health. While ambling by exhibits at a local health fair, they decide to have their blood tested for sickle cell anemia. Much to their surprise, they learn each is a carrier for sickle cell trait. They're perplexed and troubled about what that means: for themselves and for the children they hope to have one day.

Betty had been ready for her baby for months. She'd set up a crib in a freshly painted room, hung frilly new curtains at the windows, assembled a menagerie of stuffed animals to await the new arrival.



Robert F. Murray, Jr., comforts a baby following genetic testing at the Howard University Genetics Clinic.

Helping People Cope With Inherited Ills

She'd done everything her doctor told her — eaten all the "right" things, exercised moderately, gotten plenty of rest, cut out her occasional after-dinner cigarette. But all her excited preparations seem a bitter memory as she lies on her hospital bed mulling over her doctor's words: "There's a problem with the baby."

The problem with her baby, a little girl, is spina bifida, a disabling birth defect caused when the spinal cord forms abnormally and the bones that surround it fail to develop. And with it, her new daughter also has hydrocephalus, a buildup of cerebrospinal fluid which puts damaging pressure on the brain. Dimly, Betty remembers giving a neurosurgeon permission to close the hole in her baby's back (in order to minimize the risk of infection) and to implant a drainage tube in her head (in order to help relieve the pressure.)

But mostly what she remembers are the questions that raced through her mind when she heard the horrifying news: "Why me? Why did it happen? How did it happen? Was it my fault? My husband's? Is God punishing me? Us? How can I ever learn to love this baby? To care for her? What kind of future can she possibly have? . . . If we should ever decide to have a second child, will the same thing happen again?"

Betty, Jonathan and Cynthia, Louise and Gloria are composites representing people who have sought genetic counseling through the Howard University Genetics Clinic.

Overview of the Field

In a comprehensive overview, a committee of the American Society of Human Genetics has defined genetic counseling as "a communication process which deals with the human problems associated with the occurrence of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to:

- Comprehend the medical facts, including the diagnosis, the probable course of the disorder, and the available management;
- Appreciate the way heredity contributes to the disorder and the risk of recurrence in specific relatives;
- Understand the alternatives for dealing with the risk of recurrence;
- Choose the course of action which seems appropriate to them in view of their risk, their family goals and their ethical and religious standards; and
- Make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder."

Genes, of course, are that part of the cell that determines the characteristics people inherit from their parents; they are contained in packages called chromosomes. A genetic disorder occurs when one or more genes are faulty or missing or there may be an error in the number, structure or arrangement of chromosomes.

In practice, genetic counseling deals not only with strictly genetic disorders, but also with those congenital disorders — or birth defects — which are caused when some environmental factor harms the baby as it is growing in the womb or emerging from it. These factors include malnutrition, infection, toxic chemicals, alcohol, drugs, radiation, insufficient oxygen. While an individual genetic or congenital disorder may strike a relatively small number of people, collectively these disorders have been estimated to affect up to 10 percent of the nation's population.

The Howard Context

The Howard University Genetics Clinic, which is headquartered in Howard University Hospital, delivers genetic services to some 600 residents of the Washington metropolitan area a year. These services include diagnosis of and counseling about in-

herited, congenital and developmental disorders as well as a limited amount of treatment and follow-up care to those affected by them.

Three physicians with specialized training in genetics are involved in the clinic's operations: Verle E. Headings, M.D., Ph.D., a professor of pediatrics and child health in the College of Medicine and a professor of genetics and human genetics in the Graduate School of Arts and Sciences, who directs the graduate curriculum and research in genetics; Robert F. Murray, Jr., M.D., whose titles include that of chief of the division of medical genetics within the College of Medicine's department of pediatrics and child health and chairman of the department of genetics and human genetics in the Graduate School; and Barbara A. Quinton, M.D., an associate professor of pediatrics and child health in the College of Medicine, who serves as director of the genetics clinic and its affiliated Tissue Culture Laboratory.

The three also provide genetic services at D.C. General Hospital and three public health centers in the District of Columbia (Hunt Place, Benning Heights and Congress Heights) and oversee genetic counseling at Howard's Center for Sickle Cell Disease.

The clinic's outreach efforts fit snugly into the tradition of community service to which the hospital and university are committed. But there is an educational rationale for such involvement as well. The clinic and its affiliated care-giving facilities serve as training sites for graduate and medical students pursuing studies in genetic counseling.

Whereas in the past such counseling was done almost exclusively by medical geneticists holding the M.D. or Ph.D. degrees, in recent years more and more of this task has been assumed by those trained at the master's degree level. This training qualifies graduates to assume the title of *genetic counselor* or *genetic associate* and it is esti-

10 mated that some 700 men and women in the nation currently hold these titles. [See, for instance, "Genetic Counselors Multiply" in a special High Technology supplement published by *The New York Times*, March 23, 1986.] Generally, those in this relatively new category of health professionals work at a teaching hospital or large medical center as part of a genetic counseling team headed by a medical geneticist.

Howard University is one of 11 educational institutions in the nation (and the only predominantly Black one) to offer specialized training in genetic counseling at the master's degree level. Sarah Lawrence College, in 1969, became the first.

These programs represent a response to the increased demand for genetic counseling services today. Why is this? After all, haven't genetic disorders and diseases always been around?

"It's true that there have been genetic diseases since the origins of human beings," observes Murray. "But in the past the degree to which they were an important factor in medical practice was not very great because people died of infection, trauma, malnutrition and a variety of other things. Now that people are surviving those things to a greater degree, genetic diseases play a greater role."

In the past, for instance, babies born with spina bifida died of hydrocephalus or infections of the nervous system soon after birth. Today, with sophisticated neurosurgical techniques and antibiotics, 80 to 95 percent of babies born with the condition survive and grow to maturity, as a recent National Institutes of Health report notes.

The boom in genetic counseling services also reflects the fact that today's genetic counselors can give their clients far more concrete information than would have been possible in the past because of advances in the technology to detect, diagnose and, in some cases, prevent genetic disorders.

"Part of what provides the impetus toward any new service in medicine is the development of technology which makes certain things possible," observes Headings. "When I was being trained in human genetics back in 1965-70 at the University of Michigan we couldn't really offer a broad spectrum of services with regard to genetic disorders. We could counsel people about recurrence risks and try to respond to their psychosocial needs, but the approaches to intervention by way of offering prenatal diagnosis in which people could choose termination of pregnancies wasn't very well developed. Today, we have the means to detect some 200 genetic disorders through prenatal diagnosis."

The most prevalent type of prenatal diagnosis is made through amniocentesis in which a needle is used to withdraw a small amount of the amniotic fluid which surrounds the developing fetus in the uterus. The fluid, which contains fetal cells, is then analyzed for chromosomal or chemical abnormalities.

Ultimately, though, genetic counseling is not about technology. It's about people — as the return to the four cases of our opening scenario makes clear.

Case Studies

When Gloria sought genetic counseling from one of Howard's medical geneticists at her neighborhood health center, she learned that, yes, she was at higher risk for having a child with Down's syndrome than a younger woman. Down's syndrome (formerly called mongolism) results from a chromosomal error (an extra chromosome #21) and the chances of that error occurring is approximately 1 in every 105 children for a woman Gloria's age (40) compared to 1 in 1500 for a woman of 20.

At the center, she learned that amniocentesis would enable her to find out if a baby she were carrying showed signs of Down's syndrome, but was cautioned that

there was no test on Earth that could guarantee her (or anyone else) a perfect child.

She and her husband did decide to try to have a child. When she became pregnant, she opted for amniocentesis, got the good news that no chromosomal abnormalities had been found and later delivered a healthy baby girl. Unwilling to press her luck, the couple decided to have no more children.

Louise also opted to have amniocentesis, not to detect abnormalities, but in order to determine the sex of the baby she was carrying. When she learned she was carrying a boy, her genetic counselor reviewed with her a fact Louise sometimes tried to block from her mind: because she had been identified as a carrier of Duchenne muscular dystrophy, there was a 1 in 2 chance her baby would be born with the disease. The counselor also made sure she understood the corollary stemming from that fact: if she decided to abort the pregnancy, there was a 1 in 2 chance the baby would have been free of the disease.

That knowledge filled Louise with anguish. But she also felt she was incapable of risking bringing a child into the world with the foreknowledge he was doomed. Emotionally, she felt incapable of knowingly duplicating her mother's experience of having to watch her two sons wither away. She opted to terminate the pregnancy and made the painful decision she would do so again if she found she were carrying a male fetus. Her counselor supported her in her decision.

Jonathan and Cynthia met with a genetic counselor at Howard's Sickle Cell Center. In talking with the counselor, they learned that their good health was no mirage. It's not unusual at all for carriers of sickle cell *trait* to feel — and be — healthy. But they also learned that if they have children, the chance is 1 in 4 that any child conceived will have sickle cell *disease* (sickle cell anemia), a condition in which the red blood cells are abnormal in shape (sickled) and contain an



Verle E. Headings (right) examines a child with a possible genetic disorder at the Howard University Genetics Clinic. Looking on are two visiting physicians from Chongqing Medical College in Chongqing, China.

At the Howard University Genetics Clinic, **Barbara A. Quinton** advises a parent about the educational needs of a daughter with a genetic problem.

12



abnormal type of hemoglobin. This life-threatening blood disorder causes episodes of intense pain, especially in muscles and joints, which are called *crises*. (See *New Directions*, Fall, 1973.)

From the counselor, Jonathan and Cynthia learned more about the course and prognosis of the disease, how it is treated today and the kind of support services available to those diagnosed with it. They left the center far less anxious than when they arrived. Not that what they found out wasn't disturbing. It was. But at least now they were armed with *facts*, facts which could help them make rational decisions about having children somewhere along the line.

Exposure to facts also played an important part of the first session Betty had with a medical geneticist at Howard's genetics clinic. One fact: that although she had never even heard of spina bifida before, it is one of the most prevalent birth defects, occurring in 1 to 2 out of every 1,000 babies born in the U.S. Another fact: that thanks to advances in treatment and management, many of those with spina bifida are able to lead productive lives.

Somehow learning these facts helped Betty feel less alone in her misfortune. Her feelings of isolation and helplessness were reduced even more when her counselor arranged for a referral so Betty's daughter could receive long-term evaluation and treatment at a hospital outreach clinic specializing in spina bifida and other crippling diseases.

But the most important thing Betty got from that initial counseling session was neither the facts nor the referral, as important as they were, but emotional support. In her counselor she found someone who would listen to her outpourings of pain, guilt, anger and disappointment about what had happened to her, who would empathize with her as she mourned for the loss of the perfect child of her dreams and would help her

work through her grief so that she could face the prospect of caring for the child she *did* have.

At a later counseling session, Betty even got up the courage to ask what her risk of having a second child with spina bifida would be. The request enabled the medical geneticist she was seeing to take on the role of medical detective as he tried to determine whether Betty's daughter's condition had been caused by genetic or environmental factors, or a combination of both.

Among steps in that investigative process: taking a complete medical history of Betty and her husband; mapping out a family pedigree (a family health history going back a few generations); doing another complete medical examination of the baby as well as the couple; ordering various laboratory tests on all three; checking the latest research findings on the disorder; consulting with colleagues about the case.

Once the counselor would be able to make some estimate of Betty's risk of having a second child with spina bifida (and sometimes such estimates are impossible to make), she and her husband would then have to work out a whole new range of feelings as they weighed that risk and responded to it.

Thus does Betty's experience with genetic counseling at the Howard clinic reveal the human face behind this specialized profession. From her experience and the experiences depicted in the three other examples, three basic tenets of genetic counseling — especially as practiced and taught at Howard — stand out.

Underlying Principles

Tenet #1. *Decisions on actions to take as a result of genetic counseling — such as whether to undergo prenatal diagnosis, have an abortion, opt for sterilization or place a handicapped child in a special in-*

stitution — must be made by the person or persons affected, not by the counselor.

Counseling embodying this tenet is called *nondirective*.

"We believe we ought to respect the autonomy of the client," explains Headings. "In counseling, we're prepared to describe the options that exist to enable clients to think through their situation, all the while encouraging them to take the lead in their decision. We don't attempt to specify for a person what constitutes too much risk, for example. For one person, a five percent risk is too much because for that person the first experience of having a child with a particular problem was so horrendous. Whereas another person might say, 'Well, this problem [e.g. cleft palate] hasn't been all that big a deal. Surgeons were reasonably able to correct it.' So how someone regards the risks depends on the severity of the problem, the person's coping abilities and also how much exposure to similar cases the person has had."

What happens, though, if a woman he is counseling who has been identified as a carrier for a particular disorder persists in asking "What should I do?" about having a child or aborting a pregnancy?

"Most of the time people don't put the question like that," answers Headings, whose concern with medical ethics is reflected in the additional graduate credits he's earned in the area as well as his chairmanship of Howard University Hospital's Perinatal Ethics Committee. "But for the few who do, I preface my answer by saying, 'I don't really think I could give you an answer that would necessarily fit your situation. I can give you what I think I might do, given what I know about my situation.' On that basis, I would state what I think I would do, trying to make clear that decisions about genetic disorders are decisions that must be one's own. It is a decision that person must live with — not me — for the rest of her life."

Continued on page 16

The Howard Program

14 "G enetic counseling is a hybrid field combining aspects of medicine, biology and psychology," observes Professor Verle E. Headings, who oversees the training of future genetic counselors at Howard as part of his responsibilities with the university's Graduate School of Arts and Sciences. And the curriculum reflects this mixture.

Organizationally, genetic counseling is one of several subspecialties students can elect as part of the master of science and doctoral programs in genetics and human genetics offered through the department of that name within the Graduate School. The other subspecialties are cytogenetics, immunogenetics, biochemical genetics, molecular genetics and endocrine genetics.

Graduate programs in genetics and human genetics were authorized by the Board of Trustees in 1973, with the genetic counseling subspecialty introduced in 1976. This semester, 10 students have elected this subspecialty, most of them holding bachelor's degrees in a science.

All students in the department must take an initial core set of courses in human genetics, biochemical genetics and biostatistics as well as an introductory course on genetics research, explains Headings, whose own research in genetics earned him a 1984 Distinguished Faculty Award from Howard. Those opting for the genetic counseling concentration take three additional courses: Principals and Practice of Genetic Counseling, which provides an over view of the field; Cytogenetics, the study of chromosome structure and abnormalities; and Introduction to Medical Genetics, which is part of the curriculum of the College of Medicine as well.

This formal coursework is buttressed by a practicum in genetic counseling in which students are assigned to the Howard University Genetics Clinic and its three satellite centers on a rotating basis. The practicum is one year for master's students, who are seeking to become *genetic counselors* or *genetic associates*, and two years for doctoral students, who are seeking to become *Ph.D. medical geneticists*, or for medical students or physicians, who are seeking to become *clinical geneticists*.

Students working towards the master's degree start out by observing the physician/geneticist to whom they are assigned (Headings, Robert F. Murray, Jr. or Barbara A. Quinton) as each diagnoses, counsels and, in some cases, treats clients. The students then gradually take on such tasks as taking medical and family histories, evaluat-

ing laboratory data, explaining genetic disorders to clients and writing case summaries.

M.D. and Ph.D. students must master more complex tasks, such as demonstrating their ability "to document natural history variability, genetic heterogeneity and environmental variables which pertain to a given genetic or congenital disorder," as a program description puts it.

Students must keep a detailed log of the cases they see — 50 cases for master's students, 150 for Ph.D. and M.D. students. They also must participate in regular medical genetics case conferences at Howard University Hospital (45 for master's students, 100 for Ph.D. and M.D. students) and make in-depth presentations at some of them.

In addition to Headings, Murray and Quinton, the practicum faculty includes psychologist Shirley Wilson and social worker Eva Molnar, both on the faculty of the College of Medicine. The two help students develop some of the practical skills necessary in genetic counseling, among them: being able to gain a client's trust so he or she will reveal the information needed for a family health history and being able to identify community agencies and programs that can help someone with a particular disorder. Wilson and Molnar are also concerned with making sure counseling students are attuned to the psychosocial needs of their clients.

In the case of a child with a genetic disorder, for instance, "It's important that genetic counselors be aware of the comprehensive situation of the child" Molnar says. "Just as there is a medical diagnosis and a genetic diagnosis, there is also a psychosocial diagnosis and that involves all the non-medical aspects of the personal situation such as the cultural background, the socioeconomic background, the immediate family constellation, the family's informal support network — friends, co-workers, church members.

"The counselor must be able to put together the child, on one column, and all the facets of the child's environment, on the other, to see how all these facets can work together to ensure the child's optimum development. Because the genetic counselor's concern should be the optimum total development of the child and not just the genetic problem or the risks stemming from that genetic problem."

Upon completion of the practicum, students receive a certificate from the College of Medicine.

For graduate students, a thesis (at the master's level) or dissertation (at the doctoral level) is also required. These can be either in a laboratory area or in an area

more directly related to counseling. Consider two research projects with a counseling orientation.

Valerie Jackson, a master's student with a bachelor's degree in life science from Indiana State University, is examining "the psychosocial effects that certain genetic disorders have not only on the affected person, but on the entire family," she explains. Her methodology is to do videotaped interviews with two "primary caregivers" of families affected by six types of disorders: Duchenne muscular dystrophy, Down's syndrome, Huntington's disease, sickle cell disease, albinism and congenital malformations (specifically cleft lip and cleft palate.)

"I'm trying to see if there is a difference in how a family is affected by having a child with Duchenne muscular dystrophy, say, compared to having a child with sickle cell disease," she explains. "My hope is that such comparisons can provide information that can help counselors know what kinds of specific issues should be discussed with a family coping with a particular disorder."

One of her interview subjects, who was a client at the Howard genetics clinic, certainly seems a model of successful coping — by anyone's standards. Lucy (a pseudonym) saw each of her four sons die of Duchenne muscular dystrophy as each entered his mid-twenties. Somehow she was able to instill in her sons an affirmative outlook about life, however short, and to not bow to despair herself. How did she do it?

"People would say, 'I don't see how you can stand it. I would go crazy,'" she recalled in an interview. "But I didn't think like that. I just saw it as God's will and I accepted that it was just one of those things that happened to me. I thank God for letting me be able to accept things like that and for allowing me to do what I could for my boys. And then when it got to the point where I couldn't do any more to help them, maybe it was a blessing that they went . . . but it was *God*. I kept God on my mind. That's what kept me going."

Don Quedelle Philip, a genetic associate with the Howard University Sickle Cell Center, received his Ph.D. in genetics and human genetics from Howard last year. His dissertation centered on the coping skills of women who *have* given in to life's problems, providing a sharp contrast to the Lucys of this world. These were mothers who gave birth to babies with fetal alcohol syndrome, a congenital disorder that is a direct result of the alcoholism of the mother. Babies so affected show varying degrees of mental impairment and have characteristic

facial features which cause them to look more like other babies with the syndrome than they do their own brothers and sisters, explains Philip.

He studied 17 women who delivered such babies at Howard University Hospital in order to assess how they felt about their babies condition and then followed the development of the babies over a period of time. Not surprisingly, he found many of these mothers had severe problems stemming from their alcoholism. Those who continued their excessive drinking after giving birth had no real comprehension of the problems their drinking had caused their babies. Those who stopped drinking were often beset with remorse and guilt. The rationale for his project was that learning more about the attitudes of alcoholic mothers can better help genetic counselors to serve these troubled women.

Paula Berry, a Ph.D. student, and Bracie Watson, a master's student who plans to go on to earn a Ph.D. at Howard, have both opted for the genetic counseling subspecialty, but have chosen to do thesis and dissertation projects with a laboratory focus. Berry holds a bachelor's in biology and chemistry from Spelman College and a master's in environmental toxicology from American University. Watson has a bachelor's in biology and chemistry from the University of Alabama at Birmingham.

Both are working in collaboration with researchers at the Howard University Cancer Center. Berry is trying to determine if there is a correlation between chromosome abnormalities and the high incidence of cancer in certain families. Watson is investigating whether exposure to low level radiation may increase a woman's risk of giving birth to a child with neuroblastoma (a tumor of the nervous system).

Before enrolling at Howard, Watson worked in vocational rehabilitation, assisting children with a variety of genetic and congenital disabilities. Berry did laboratory research in cytogenetics and cancer genetics. Both were attracted to Howard's program in genetics and human genetics because they saw it as an ideal way to combine their interest in scientific research with their interest in people.

"In many genetics programs you may learn why a genetic problem happens, over here, and maybe how to treat it, over there, but you never learn anything about the individual who has to accept it and deal with it," says Berry. "So having counseling [in the curriculum] just rounds out the program. It gives it that extra dimension."

GENETIC COUNSELING

Continued from page 13

16 Admittedly, it isn't always easy for a genetic counselor to be nondirective. Consider a case recalled by Paula Sheppard, a Howard-trained genetic associate who coordinates genetics services between Howard's genetics clinic and the three neighborhood health centers it serves.

The case involved a child born with a disfiguring congenital condition, an ear that had only a tiny appendage in place of a lobe. Sheppard explained to the child's mother that cosmetic surgery could make this anomaly look less pronounced. But the mother said she wanted to wait until her daughter was old enough to decide for herself if she wanted to have surgery.

"Ideally," Sheppard observes, "you'd like for your child to make decisions about her own body. But you also have to recognize how other kids are, how society is. When that child goes to kindergarten, she'll be bombarded with 'Where's your other ear?' 'Where's your other ear?' By the time she gets old enough to decide for herself about cosmetic surgery, psychological damage already could have been done." Sheppard explained to the mother the type of reaction her daughter was likely to get when she entered school, but the mother was adamant. Sheppard didn't press her.

Tenet #2. *In many cases, merely imparting facts about genetic or congenital conditions and the risks of their recurrence isn't enough. The emotional stress caused by these conditions must be addressed.*

This is especially true in counseling the parent of a child who is mentally retarded or has other serious developmental problems, points out Quinton.

"Mothers might need help living with these children and accepting that their child's developmental potential is less than they thought it was going to be," she observes. "Many of these mothers are very depressed and many of them are very angry. Sometimes things have reached the point where a woman is so depressed she can't

take care of the child and she can't take care of herself. Every now and then you have a situation that has led to child abuse.

"And often you have a situation where the mother and father are separating because the strain of taking care of the child becomes too much. Sometimes the father finds having a handicapped child just too unacceptable, although the production of that child was just as much his doing as the mother's. So he goes away, leaving it all to the mother to handle. And what mothers do in that situation varies. Some may then doubly reject the child, saying, 'I don't want you. You wrecked my home.' On the other hand, some families, faced with these tragedies, pull together and function in a way that is just commendable."

What all this means for the genetic counselor, she says, is "you help people where their needs are. If they're simply seeking information [as Jonathan and Cynthia were], then it's clear-cut. If they come to you for psychosocial help [as Betty was], and you sit there and just give them facts, you really haven't done your job. Often people do need facts in order to plan the rest of their lives. But they're not going to be receptive to the facts until you help them deal with the 'I feel,' 'I was hurt,' 'I was cheated.'"

Tenet #3. *Genetic counseling raises weighty ethical issues — for the individual, the family, the society — and sensitivity to these issues is essential.*

One of these issues has already been addressed: the *autonomy* of individuals to choose for themselves what course of action they will take in response to a genetic or congenital disorder.

Consider, further, this issue in relation to a recent mind-boggling medical development: fetal surgery. In one well-publicized case, when a sonogram revealed that the baby a San Francisco woman was carrying had an enlarged bladder and kidney, pediatric surgeons opened the mother's abdomen and uterus, pulled the 23-week-old

fetus halfway out, performed corrective surgery on it, returned it, and then stitched the woman's uterus and abdomen back up. Nine weeks later, the baby was born, a month premature.

While the case represented an undoubted surgical breakthrough, it also raised alarm in many circles about potential threats to maternal autonomy. It prompted *The Baltimore Sun*, for instance, to observe in a November 16 editorial:

"... the implications of such procedures make the moral muck of maternal autonomy even more complex. What of a woman, for instance, who discovers the fetus in her uterus will not develop to term without medical intervention, but doesn't want to go through surgery? Could she be prosecuted and forced under the surgeon's knife?"

The editorial concluded that the San Francisco case and that of another California woman who was charged with fetal abuse when her son was born brain-dead with amphetamines in his system "cast a new and foreboding light on the dimensions of a woman's right to privacy, and on whether the state has a right, a responsibility — indeed a justification — to reach into a woman's uterus at any time for virtually any reason."

Another key ethical issue revolves around *confidentiality*. Murray, who has written extensively on ethical considerations in genetic counseling, has been active in numerous bioethics advisory committees and been a Fellow of the Hastings Center's Institute of Society, Ethics and the Life Sciences, broaches a discussion of this issue with a question: "Is information that demonstrates a genetic causation of some disorder or disease to be shared with other members of the family who might be interested because they, too, are at risk? Or is that information to be kept confidential as in any doctor-patient relationship?"

"Most people in the field feel that our clients are like our patients and that they deserve to have their privacy protected unless there is an overriding reason not to do so," he says. "This means that genetic information should be treated as any other medical information is: that it should be up to the client whether or not to tell relatives. And that's our orientation here. But there are some who feel genetic information is different: that other family members have a right to information that might affect them."

Still another ethical question revolves around *truth telling*. In a chapter on genetic diseases and counseling which Murray contributed to the "Encyclopedia of Bioethics" (The Free Press, 1978), he poignantly dramatized this issue by using the example of Huntington's disease, a degenerative, always-fatal neurological condition:

"When diagnosis is made very early, i.e., at a time when the patient has no idea he or she is affected, the counselor is faced with a critical decision. Should the patient be told about an incurable condition like this one, with such a devastating prognosis that a significant proportion of those who know about the outcome or have seen its end stages commit suicide? Or should the information be withheld until the time when the symptoms become obvious to the patient, thereby postponing at least for a while the long period of anxiety and depression such patients so frequently experience when first told of the diagnosis?"

"The second course of action may avoid severe emotional upset and perhaps postpone suicide, but in the interval between the diagnosis and the appearance of definite symptoms the patient and spouse may have one or more children, each of whom has a fifty percent risk of being affected with the disorder."

As more and more advances are made in genetic knowledge and medical technology, individuals and society will be forced to deal

with more and more such ethical dilemmas. On one hand, these advances and the attendant increase in genetic counseling services can better help people plan their reproductive futures. Improved techniques to detect carriers of genetic disorders, diagnose prenatal abnormalities and abort "damaged" fetuses can go a long way toward preventing the recurrence of many inherited ills. What's more, the ongoing revolution in genetic engineering holds out the dazzling possibility of eventually making some disorders obsolete by enabling genetic engineers to identify genes, excise them and replace them with healthy substitutes.

On the other hand, advances in genetic knowledge and medical technology and the attendant increase in genetic counseling services can lead to abuses, culminating, perhaps, in a kind of Orwellian future where only "perfect" parents can have children and only "perfect" babies can be born — with perfection defined by an oppressive, omnipotent, omnipresent state. In a paper entitled "Genetic Counseling: Boon or Bane," which was published in "The Tricentennial People: Human Applications of the New Genetics" (Iowa State University Press, 1978), Murray painted a harrowing vision of such future:

"Abortion of fetuses which don't meet certain health standards might then become mandatory. There would have to be a 'new' kind of genetic counselor paid by the state to see that persons with 'defects' were not born so they wouldn't be a drain on its resources. There would be no concern for the needs of parents only for the cost/benefit ratio or boon/bane ratio projected for the individual."

And then he resoundingly rejected that vision:

"I personally want no part of such a program for it cannot help but end in promoting genetic conformity in the same way that there are and have always been pressures to promote cultural conformity. As a physician-geneticist, I feel compelled and believe it wiser to continue to steer the course we have steered in the past, namely, to meet the needs of the [individual] family and the individual fetus or child.

"I would prefer to see man become extinct in the process of following principles based on love and humane concern for the needs of our brother and sister human beings than to ensure our survival under regimented, inhuman programs in which we are programmed like so many computer punch cards."

Murray seemed to be speaking not only for himself, but also for his colleagues in Howard's department of genetics and human genetics and the new generation of genetic counselors they are training. □