NETWORK NEWS

The newsletter of the Florida Bioethics Network

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ETHICAL IMPLICATIONS OF INCREASED GENETIC INFORMATION

The Human Genome Initiative (HGI), a coordinated research endeavor with the goals of mapping the 50,000 to 100,000 human genes and sequencing the 3 billion DNA base pairs that comprise the entire human genome, is projected to take approximately another dozen years. Even after mapping and sequencing are complete, it will take decades more to unravel the human genome's elaborate functions. Long before the HGI is complete, however, it has already begun to yield dramatic benefits for diagnosis and treatment of human disorders and disease. One result will be that molecular genetic techniques will no longer be restricted primarily to searching for relatively rare, single gene disorders in the genetics clinics of academic medical centers. In addition to disorders caused by a single gene, genetic factors are likely to be a significant influence in common diseases, such as cardiovascular disease, cancer, and neurodegenerative disorders, among others, that affect respectively 40%, 30%, and 20% of adult Americans. As the genetic factors in such common health problems are implicated, other physicians besides geneticists will begin to utilize this information to predict health risks and, if possible, to intervene.

As HGI research identifies the genes or markers that predispose individuals to health problems, tests will be developed to provide probabilistic information to physicians and their patients that will bear on the potential for therapeutic interventions. One such test, for genetic predisposition to colon cancer, has recently been announced, and clinical trials will begin soon. At the very least, such a test should allow a cost-effective rationale for more frequent examinations, as well as earlier detection and intervention. In other cases, however, genetic tests will appear before genetic or other therapies are developed. In such cases, candidates for testing may legitimately wish not to be burdened with the knowledge of a significant risk of a debilitating fate they cannot ward off, such as Alzheimer disease. Thus, informed consent for submission to a genetic test may entail considerations not frequently encountered in routine informed consent.

Genetically influenced common diseases have multifactorial origins, requiring the occurrence of multiple genetic abnormalities or environmental events for the disorder to be expressed. Thus, the predictive value of a positive test result may be of limited utility in ascertaining the age of onset, the severity, or the absolute probability of disease. The genetic test for cystic fibrosis currently can only identify the genotype responsible for 80% of cystic fibrosis, meaning that a significant number of parents who test negative will have an affected child after all. It remains to be seen what effects such uncertainty will have on reproductive choices.

A recent event illustrates some of the tensions between reproductive rights and eugenic impulses that may result from increased genetic information. Brie Walker, a popular Los Angeles local television news anchor, has ectrodactyly, a genetically caused disorder that results in the absence of some digits (fingers and toes). The disorder is autosomal dominant, which means there is a 50% chance her offspring will have the condition. Already the parent of one child born with ectrodactyly, Ms. Walker was seven months pregnant when a local talk radio show found out and invited listeners to call in and comment on whether Ms. Walker should bear a child with such a high risk of a genetic deformity. Scores of callers ardently agreed with the show's host that the Walkers should not have the child. If this can happen in a case in which no genetic test was available to confirm or eliminate the risk of a disorder, imagine the possibilities when tests are available that can pinpoint with certainty some genetic disorders long before birth and anticipate the probability of others that may occur, if at all, well into adulthood, such as adult-onset diabetes. Traditionally, most persons have had virtually unfettered discretion to decide whether or not to procreate, with little information available about the relatively rare risk of genetic disorders that occur in the entire population. As a result of knowledge from the HGI, more informed reproductive decisions can be made by those who want to know such information. Unfortunately, some social and economic pressures may be imposed on individuals' reproductive choices both to avail themselves of such information and to make decisions influenced by utilitarian rationales, with the potential of financial incentives or disincentives to make the "right" decision.

For example, one provider of employee health benefits learned of an elevated risk of genetic abnormality during the mother's pregnancy and agreed to pay for a genetic test, but refused to cover the child's health care costs if the test was positive and the parents chose not to abort. Anticipated health care financing reforms may prevent insurers from making such social decisions. Ironically, however, such reforms may increase the pressure from other quarters to limit the economic burdens society bears for genetic abnormalities associated with chronic, severe disorders that result in costs that individual families cannot bear. The sentiments of those who deem Brie Walker irresponsible for having a child, even though she could afford to bear the extra costs, are likely to be even less generous when it comes to sharing the costs of care for affected individuals they believe should never have been conceived or carried to term in the first place.

The impact of the HGI will by no means affect only reproductive decisions, however. Information about individual's genetic risk can have result in social stigma, as well as have adverse consequences for insurance coverage, employment, and access to public accommodations. The recently enacted Americans With Disabilities Act may provide significant protection against genetic discrimination in some of these contexts, but its potential protections have not yet been tested adequately. In the instance of social stigma of the sort that resulted in reduced marriage options for persons of known carrier status on one Mediterranean island, no legal protection imaginable in a free society would be sufficient. Ultimately, education and acceptance will be the keys to dispelling the myths that inevitably accompany genetic discrimination. Since genetic information is intimately tied to inherent and somewhat immutable characteristics, which have potential implications for family members as well, it is especially sensitive. Genetic information can leave affected persons particularly vulnerable to its misunderstanding and misuse. Health care providers must, therefore, be especially cautious in its utilization and disclosure to ensure that its burdens do not outweigh its benefits.

Article submitted by **Bill Allen, J.D.,** Medical Humanities, University of Florida, College of Medicine, Gainesville.

PRESIDENT'S MESSAGE . . . Esther Sangster, RN.

At our recent board meeting, plans were finalized for our annual conference. The conference will be held October 21-22, 1993, in Orlando. The title of this year's conference is "Bio-Ethics Committee Practices." This program is in response to members' requests and program evaluations.

This year's conference addresses issues of effective bioethics committee, how to start an ethics committee and concerns of established ethics committees. We also have planned mock case consultations for members to observe.

The board continues to address long range goals to increase membership, influence health policy in the state, and provide resources to the membership. The board also needs to hear from the membership. Write and let us know how we can better meet your needs. Our best method of communication is through the newsletter. Let us know what you think of the Network News, and give us your ideas.

Plan to attend the October Annual Conference. We have planned opportunities to network. See you then!

SPOTLIGHT ON ETHICS COMMITTEES -- BOCA RATON COMMUNITY HOSPITAL . . .

submitted by **Mary E. Boyd,** Patient Representative, Facilitator of the BRCH Ethics Committee, Boca Raton Community Hospital, Boca Raton.

A casual after-hour meeting brought six co-workers together and as usual the topic of discussion was Boca Raton Community Hospital (BRCH). Administration, Patient Services, Medical Intensive Care, Radiation Oncology and the Medical staff were represented by **Nat West; Jennie Guastella; Julie Benthal, RN; Dale Wickstrum, MD; Marjorie O'Sullivan, RN**; and **Dorothy Murray, MD.** They identified the need for:

- further education
- a forum for discussion among hospital, medical and community professionals on bioethical issues
- an advisory committee to act as a resource to persons involved in bioethical decision making
- a review process to evaluate institutional experiences and policies having biomedical ethical implications.

Although these health care professionals felt strongly that all of these areas needed to be addressed, the Boca Raton Community Hospital Ethics Committee got off to a slow start on October 29, 1986.

Membership consisted of representatives of the medical and nursing staff, clergy, ethicist/philosopher, legal profession, patient advocate and administration.

Temporary ad hoc members could be appointed by the chairperson when their expertise is necessary for a particular issue or under specific urgent circumstances. When an ad hoc committee meeting occurs on an emergency basis, a summary of the case will be included in the next regular monthly meeting.

Relevant players may be asked to be present at a monthly meeting or at an ad hoc meeting if their presence could shed light on an issue under consideration. One key point of the BRCH Ethics Committee that proved to be advantageous was a cap on the membership of fifteen persons. The importance did not surface until the committee became well heeled within the organization.

As the committee gained respect, there became a waiting list to be on the committee as a singular representative of the respective professions within the facility and the community.

All members serve for a two-year term from July through June. The terms are staggered to allow for continuity with half the membership rolling off every June. The chairperson serves also for a two-year term after first serving as a committee member for a minimum of one year.

Persons desiring to be on the committee may submit their requests to the chairperson or through the office of the patient advocate who acts as the facilitator for the committee.

The facilitator along with the chairperson establishes the monthly agenda, relying on the members of the committee to feed into the agenda. Referrals to the committee are 'open' coming from the staff, patient and their families or the medical profession.

The facilitator will initiate an investigation in his/her role as patient advocate, pulling from the individual membership to evaluate the viability of the referral.

Whether the concern is brought by the patient, patient's family, or the medical professionals, there is a need identified and often the need can be met within the facilitator's role without pulling together a quorum membership meeting.

The committee provides a structural framework that encourages communication that addresses, defuses and aids in solving problems that often have no simple or singular answer.

The BRCH Ethics Committee has developed over the past seven years to aid the facility and the community in serving a need that too often is overlooked while trying to heal the patient.

BIBLIOGRAPHY . . . submitted by **Mary Lou Jones, RN, MSN,** Director of Education & Research, Florida Hospital Medical Center, Orlando.

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INSTITUTIONAL POLICIES AND PROCEDURES COMMITTEE . . . submitted by **Judy Gygi, LCSW,** Social Work Department, West Florida Regional Medical Center, Pensacola.

Committee members have gathered policies and procedures from various hospitals throughout the state. The policies address withholding and withdrawing life prolonging procedures, organ and tissue donation, authorization and purpose of the bioethics committee, and obtaining ethics committee consultation. Contributors of policies and procedures range from a small rural hospital to a tertiary medical center affiliated with a major university. These policies and procedures of other hospitals may be particularly useful to hospital staffs that are developing or revising policies.

To request information or a copy of a specific policy and procedure, contact **Judy Gygi,** at 904/494-4874 -- Office hours: 8:00 a.m. - 4:30 p.m., central time.

To contribute policies and procedures from your institution, mail them to: **Judy Gygi, LCSW,** Social Work Department, West Florida Regional Medical Center, 8383 North Davis Highway, Pensacola, FL 32514.

EDITORIAL COMMENT . . . submitted by **Judy Gygi.**

Until recently, I have been away from direct patient care. When I began providing clinical services within the hospital again, I was surprised by the behavior of some professionals caring for patients whose families had decided not to withhold or withdraw life prolonging procedures. I observed a change in interactional patterns after the decision was made.

Professionals, who felt strongly that the family had made a decision that was not in the best interest of the patient, tended to become less accessible, less supportive, and were sometimes overheard making disparaging remarks among themselves. They did not remain objective and did not take into consideration some of the factors influencing the family in the decision making process, such as guilt, dependency needs, acute versus chronic condition, religious, cultural and social values, and previously expressed wishes of the patient.

We, as professionals, do not have to agree with, but do need to respect the family's right to self-determination and to avoid letting our own bias color our behavior and interaction with the family.

FORMS EXCHANGE AT ANNUAL MEETING . . . submitted by **Hana Osman, LCSW,** Social Work Department, Tampa General Hospital.

The Florida Bioethics Network annual meeting will be held October 21-22, 1993, in Orlando. A variety of topics will be presented including a discussion on the different types of Advance Directives.

This discussion will focus on an exchange of ideas and forms used by various hospitals. Please send a copy of your hospital's current Advance Directive form to me by October 1. FBN will duplicate and make them available to conference registrants. Since foreign language advance directives forms may not be readily available to many hospitals, participants are especially encouraged to make them available for duplication and distribution. Please send forms to **Hana Osman, LCSW,** Social Work Department, Tampa General Hospital, P.O. Box 1289, Tampa, FL 33601 -- Fax: 813/253-4057.