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Profit from public research: How should study subjects' privacy be protected?

Boston initiative could be just the tip of the iceberg

The recent move by Boston University to form a private company to sell data derived from clinical information originally collected during its publicly funded Framingham Heart Study is drawing raised eyebrows from bioethicists across the country.

Many say the project represents the "tip of the iceberg" in what will quickly become an onslaught of research institutions taking a second, profit-focused look at the wealth of clinical, demographic, and genetic information collected over years of performing large-scale research.

Following the completion of a "map" of the human genome this year, tissue samples and clinical information collected from large groups of study participants could have value way beyond the limits of the original research protocol.

"Universities all over the country have all kinds of tissue and blood samples sitting on shelves," advises **Maxwell J. Mehlman**, JD, professor of law and director of the Law-Medicine Center at Case Western Reserve University School of Law in Cleveland. "This is going to be a very compelling means by which they could generate revenue for their institution."

Boston University administers the 52-year-old Framingham Heart Study, an ongoing study of 10,000 residents of Framingham, MA. Participants in the study volunteered to be followed by researchers and submit a large amount of personal information, including medical histories, medical records, and

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End-of-Life Care News

Patients help determine appropriate palliative care program

✔ *Patients help define quality of life*

The consensus of AIDS providers attending the XIII International AIDS Conference in Durban, South Africa, is that the dying patient can help define the concept of quality of life, and caregivers must respect the dying person's preferences to promote dignity and self-worth. Palliative care should be based on the belief that every patient has the right to participate in informed discussions about health care resources available and choosing the best possible option, says one caregiver who spoke at the international conference 91

In Brief

COMING IN FUTURE ISSUES

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DNA samples, in order to help determine causes and risk factors for heart disease and strokes. Raw data collected by the study are freely available to scientists and researchers worldwide, who have published more than 1,000 research papers based on this information.[1]

However, the university announced in June that, with the help of $21 million in venture capital from private investors, it would form Framingham Genomic Medicine, a company that will compile the raw data and develop computer tools to analyze and expand them. The company will then market the data to biotechnology and pharmaceutical companies for use in developing new genetically based diagnostic tests and drugs.

Raw data from the study will remain accessible to the public, but the company wants to establish ownership of the enhanced data, particularly the process of genotyping or documenting the variations among the participants' DNA. Requirements for protection of participants' confidentiality and rights to privacy as well as the company's proprietary rights will be negotiated between the university and the National Heart, Blood and Lung Institute (NHBLI), the division of the National Institutes of Health that provided almost $40 million in funding for the heart study.

Consent from participants

A key question for the university — and for other institutions seeking to use new genetic information derived from study material — is whether they must obtain consent from the study participants for the new use of the old information.

According to an article detailing the announcement of the company's formation, the university is still sorting this out with the NHBLI but believes the original consent forms covered future commercial uses of the participants' information.[1]

However, adequate informed consent in this instance would require that the participants have been informed of the vast potential uses of their genetic information and the risks involved in disclosure of this information, even anonymously, says Mehlman.

"I am not familiar with the consent used, but considering the length of time that the study has been going on, it is hard to believe that the participants would have been adequately informed of the possible future uses of their information, considering the researchers couldn't have been aware of the potential at the time [the study began]," he explains.

For example, the DNA from the blood and tissue samples can be replicated infinitely, meaning that the information obtained is not only used once but potentially thousands or millions of times over. Even if the DNA is delinked from individually identifiable information, or "anonymized," it still poses privacy risks to the participants, he adds.

"The information will still be linked to the city of Framingham," he says. "What if they discover a genetic mutation related to a certain disease, or even intelligence. If there were a genetic indication that the residents had lower intelligence, that information is potentially damaging to the city and its residents."

Mehlman cites the example of studies of Ashkenazic Jewish women used to isolate the BRAC1 and BRAC2 genetic mutations linked to the development of breast cancer. "Because this information was discovered initially in a Jewish population, breast cancer came to be seen as a 'Jewish' disease by some people," he states.

In addition, even if the participants gave consent for future commercial use of their tissue samples, it is not certain that they understood they were providing samples of their DNA, speculates **James W. Keller**, MD, chair of the human subjects committee in the office for sponsored research at Emory University in Atlanta.

Use is for public good

Proponents of the use of the information may argue that the genetic data could provide lifesaving treatments and tests not currently available and that the benefits to society outweigh the individual risks to the study population, says Keller.

"I tend to hold the opinion that the rights of the individual take precedence, but there are those, particularly in public health, who disagree with me," he says.

Due to the number of years the study has been in existence, it may be difficult — if not impossible — to contact the participants for additional consent. Also, the participants' physicians or the physicians who enrolled them in the study should be the ones to contact the individual participants and inform them of the additional use and the fact that someone from the Framingham Genomic company may seek more information from them, says Keller. That also may not be feasible.

Should the additional use of the genetic information be prohibited if those stipulations cannot be met?

CME questions

1. Boston University and a newly created company called Framingham Genomic Medicine will analyze and offer data to biotechnology and pharmaceutical companies based on original data from:
   A. Harvard School of Public Health
   B. National Institutes of Health
   C. Framingham Heart Study
   D. All of the above

2. According to **James Keller**, MD, chair of the human subjects committee in the office for sponsored research at Emory University in Atlanta, precedence in situations where old data are sold and reused should go to:
   A. The university or hospital
   B. The individual
   C. The company buying the data
   D. The public domain

3. According to **Daniel Visgard,** PhD, formerly the chair of the institutional review board for the New York City Board of Health, scientists studying the prevalence of certain diseases or conditions could request autopsy tissue samples from:
   A. The hospital morgue
   B. The coroner
   C. The medical examiner
   D. All of the above

4. The San Francisco-based PathServe Autopsy and Human Tissue Bank supplies a large number of organs and tissue samples to biotech and neuropathological researchers and accepts tissue donated via:
   A. Patient's expressed consent before death
   B. Patient's next-of-kin consent
   C. All of the above
   D. None of the above

"In my opinion, the university needs to make sure that it has the appropriate consent for the additional use of the participants' information," says Keller, "and they should be absolutely clear about how the confidentiality of that information will be protected. What demographic information will be provided to the company's consumers? How will the privacy of individual participants be maintained? Who will have access to the linkage file?"

Organizational concerns

With the rapidly advancing technology available to research the genetic causes of disease, research institutions must grapple with the larger ethical concerns of allowing the influence of the private sector, says **John Banja**, PhD, clinical ethicist at the Center for Ethics in Public Policy and the Professions at Emory University.

The situation creates a symbiotic relationship. Pharmaceutical and biotechnology companies need the expertise available at large research institutions to develop new drugs and tests, and the institutions need the money those companies have to fund the research, he says.

"But when you start looking at the issue of an 'entrepreneurial university,' as it is known, you have to consider the possible ethical implications," he says.

For instance, if an institution is doing research on the development of a new drug, it may ask its graduate lab or research assistants to sign confidentiality agreements, he says. That would prevent the graduate students from publishing research papers about their work — a requirement to advance their careers.

With the added influence of the profit-driven private sector, institutions may lean toward funding research that has more profit potential but is not as groundbreaking or interesting, he says. There will also be a lot of pressure to make research results look "better" than they actually may be, he speculates.

"Investors in companies want to see results, and, if the research studies don't justify the investment, the funding may be withdrawn," he explains.

Institutions will have to acknowledge the need for the input from the private sector while determining their ethical responsibilities to conduct research for the public good and how those interests will intersect with the profit motives of the private sector and be protected.

"What are the institutional or organizational mores that govern how the institutions relate to their various constituencies?" he says.

Another ethical complexity involves the use of public funds for a study in which some data derived from the information collected is eventually restricted or licensed by a particular company. In this case, genotypes derived from the DNA provided by study participants may be deemed proprietary information owned by Framingham Genomic Medicine.

The Framingham Heart Study is funded primarily through a government agency using public funds. Should a private company be able to restrict the public from information that would not be available without public funding? Is it fair for a university or private company to profit from genetic technologies, without also enriching the individual whose genes provided the base for the technologies' development?

"That is a difficult issue," says Banja. "Some would argue that this information should remain in the public domain. However, others would argue that the company provided the expertise and funding that made the information useful."

The debate continues

According to the proposal for the Framingham data at this point, the raw data are publicly available, and it is up to the NHBLI and the university to determine what the company can license and claim ownership of.

As for the participants, courts have held that they cannot claim ownership of their DNA, essentially their property, once they have surrendered a sample for study, say Banja and Keller.

However, ethicists are divided over whether the participants or the public at large should receive some sort of compensation for providing this benefit to the company to symbolically "compensate"

SOURCES

- **Maxwell J. Mehlman**, Case Western Reserve University, School of Law, 11075 E. Boulevard, Cleveland, OH 44106-7148.
- **James Keller**, Office of Sponsored Programs, 1784 N. Decatur Road, Suite 510, Atlanta, GA 30322.
- **John D. Banja**, PhD, Center for Ethics in Public Policy and the Professions, Suite 302, The Dental Building, 1452 Clifton Road, Atlanta, GA 30322.

the participants for the use of their property.

Plans have been discussed that call for Framingham Genomics to donate stock to a charitable trust for the town of Framingham and pay for an ethics oversight committee and science education in the town's schools.

Reference

1. Kowalczyk L. Ethicists debate plan to sell heart data. *Boston Globe*. June 17, 2000:C1. ■

Can autopsy tissue be used for study without consent?

Samples often taken during post-mortem exams

Use of donated human tissue from living participants for research is a thorny ethical question faced by many research institutions now that the map of the human genome makes human collection tissue valuable. **(See cover story.)**

But what about the use of tissue samples taken during autopsies? Organs or representative sample tissues often are taken during post-mortem examinations. Can small samples of that tissue be collected for research? If so, should researchers obtain consent from the person's next-of-kin for use of the tissue?

The problem arises in hospitals more often than you may think. Tissue samples removed during autopsies are requested for a number of research projects, says **Daniel Visgard,** PhD, research compliance officer for the Research Foundation of the City University of New York. Visgard was formerly the chair of the institutional review board (IRB) for the New York City Board of Health.

The board must approve research through the city medical examiner's office. Scientists studying the prevalence of certain diseases or conditions in a general population may request samples from the medical examiner. Researchers in behavioral health may seek brain tissue for behavioral research.

State law in New York prohibits the release of such samples without full disclosure to the person's next-of-kin when possible, says Visgard. "There are also a relatively small number of autopsies performed at hospitals, and those facilities usually have some sort of fine-print language on hospital forms that allow use of tissue samples for research," he adds.

State laws governing use of human tissue taken from dead persons vary, with some allowing use without consent and some prohibiting it. Federal regulations governing protection of human subjects define such subjects as "living beings." When the tissue is from a person who is no longer alive, the decision, along with the authority to make such decisions, becomes murkier.

There also are regulations governing the use of "archival" or "waste" tissue — tissue that may have been taken from a deceased individual — stored separately for a certain length of time and then designated as waste that will be disposed of, he notes. Some states permit use of such tissue, provided that no identifying information is linked to it, without obtaining consent from relatives.

In the New York City medical examiner's office, consent is obtained from the families of deceased persons if the tissue is taken at the time the autopsy is performed. Researchers are not permitted to see any identifying information about the person and are only given basic demographic information such as age, gender, race, or ethnicity by a medical examiner's office staff member.

If the tissue is archival or waste tissue, consent is not sought from the family and no identifying information, other than basic demographic data, is given to the researcher.

"The bottom line is, researchers are never allowed to walk out of that office with any identifying information," Visgard says.

Ethical considerations should govern use

If hospitals or other institutions receive requests for that kind of tissue, legally they should check the requirements in their states. California, for example, specifically permits the use of tissue taken at autopsy, as long as the study protocol is reviewed by an appropriate IRB. There is no mention of the requirement of consent. Even if the law may permit use without explicit consent, there are certain ethical considerations that should govern the use of the tissue, cautions Visgard.

"Even if the federal regulations only specifically cover tissue taken from a living person, I think that you have to look at it as any research that could affect a living person," he says. "And if

a person had a disease, HIV for example, or cancer, that information can have consequences for the living relatives. So, you don't just have carte blanche because the person is deceased."

It is also important that the IRB carefully weigh the goals of the research and why the tissue is requested.

"We would always do a very careful risk-benefit analysis of what the goals of the research were," he says. "There had to be a clear benefit that could be derived from gathering the information. There were very few studies that we turned down; there were some that we asked the researchers to go back and be more specific or do some more research, and I can think of one in which we felt that the request for human tissue was not justified by the goals that the researchers sought."

Tissue bank seeks informed consent

The San Francisco-based PathServe Autopsy and Human Tissue Bank, formed in 1990, supplies a large number of organs and tissue samples to biotech and neuropathological researchers, says **Roman Karp**, the bank's executive director. The bank will not accept tissue donated without either the patient's express consent (obtained before death) or the consent of the patient's next-of-kin.

"If someone calls us from the hospital and says that they have a patient who wants to donate tissue, we are not only required to get consent, but informed consent, to the extent that is possible," Karp says. "Informed consent should mean that we inform the family that we want to take a bone sample, that the sample will be given to a specific company, and for what type of research."

Because the bank often does not know how the sample will eventually be used in research at the time it is obtained, getting that level of consent is rare, he admits. Bank representatives, however, always get separate consent for the specific tissue donated, consent for testing of blood samples if obtained, and consent for the release of the patient's medical information, he adds.

"We only seek the basic demographic information: age, gender, brief medical history," he says.

Consent forms for an autopsy should be designed so consent for all procedures can be obtained at once, even though it must ensure that the patient or patient's family understands that they may consent to part, all, or none of the requested donation.

"For example, a family may feel OK that an autopsy is performed but want no organs retrieved," he says. "Other times, they will consent to a certain organ but not another, or they do not consent at all."

In the event that the bank obtains "waste" tissue, the bank ensures it does not link the samples with any known identifying information.

Government offers guidance

The National Bioethics Advisory Commission in Washington, DC, offers guidance on this issue in its report *Research Involving Human Biological Materials: Ethical Issues and Policy Guidance, Volume I, Report and Recommendations*.

"It might be thought that once the source is dead, no interests remain that require protection," the committee writes. "But, for a number of reasons, this is not the case. For example, the decedent's family or other loved ones may have an interest in how the material is used, or members of the source's ascriptive group may have an interest in what happens to it."

Furthermore, the report continues, individuals may have interests that survive their deaths. For example, some have religious or ethical concerns about the uses of the tissue.

"In addition, new information obtained about persons after they have died may affect the memories, perspectives, and relationships of family members and others," it states. "Even if, strictly speaking, the dead do not have interests that require protection, the living may want to establish policies to ensure that some of these outcomes do not occur."

Although recent court decisions have held that donated tissue is not the property of the source, and the source does not necessarily have to profit from any future uses, Karp speculates that the legal and regulatory climate could change.

SOURCES

- **Daniel Vasgird**, PhD, Office of Research Compliance, Research Foundation of CUNY, 30 W. Broadway, 11th Floor, New York, NY 10007.
- **Roman Kahn**, PathServe Autopsy and Tissue Bank, P.O. Box 22023, San Francisco, CA 94122-0023.
- **National Bioethics Advisory Commission.** *Research Involving Human Biological Materials: Ethical Issues and Policy Guidance* is available on the World Wide Web:

"At the very least, if you are collecting human tissue for research and it is discovered that you did not attempt to get permission from the person from which you obtained the sample, or their relatives, it could make you look very bad," he says.

PathServe has found it simple to construct an autopsy consent form that allows family members to choose whether they would like tissue donated at the time they are deciding whether they want a post-mortem examination performed.

"The family deals with this as part of the entire process of deciding what will happen to their loved one," he adds. ■

End-of-Life Care News

Patients help determine palliative care program

Patients help define quality of life

Ethics committees wanting to provide effective palliative care for terminally ill AIDS patients in the last stages of life should look no further than the patient for answers, experts suggest.

The consensus of AIDS providers attending the XIII International AIDS Conference in Durban, South Africa, is that the dying patient can help define the concept of quality of life, and caregivers must respect the dying person's preferences to promote dignity and self-worth.

"Caregivers need to take direction from the dying person when considering issues related to quality of life," explains **Theo Weber**, board member of the Dutch HIV Association and a member of the Global Network of People Living with HIV / AIDS in Europe. Weber, who spoke at the conference, is a professional nurse working in a community care organization in Amsterdam.

Palliative care should be based on the belief that every patient has the right to participate in informed discussions about health care resources available and the best possible option, he says. "Decisions are made by the patient and family in collaboration with caregivers, respecting the level of participation desired by both the patient and family," he explains.

Weber defines palliative care as an attitude, not a clinical care program. Palliative care is the active, compassionate care of a person whose disease is no longer responsive to traditional treatment aimed at curing the patient, he says. "The goal of palliative care is to promote quality of life through the control of symptoms whether they be physical, psychological, social, or spiritual."

Caregivers often surprised

He says that caregivers often are surprised by how much help they can offer dying patients. There are many concrete things that can be done to help relieve a person's physical pain and suffering, he says. "Whether they be drugs or hands-on caregiving techniques such as back-rubs, these tools can be very effective in promoting and maintaining a person's level of comfort."

In addition to physical aspects, psychological and social concerns are important when planning palliative care. It is important to accept that palliative care is intimately connected with loss, dying, and death, says Weber.

Palliative care can be provided by almost anyone, he notes, as long as the caregiver believes in the dignity of others. The skills needed to care for the dying can be learned. Coordinated and continuous care should be maintained, he says.

Palliative care is not only about providing for the dying person, however. It should continue by offering support and care for the bereaved who are left behind. Weber says, "It is important to consider this when planning your caregiving to ensure that those who are bereaved have the support they need through the period of transition following the loss of someone they love."

Don't ignore spiritual considerations

Spiritual considerations also are vital in providing palliative care to dying persons, says Weber. "Many people who are dying will come to a deeper religious faith, while others will come to see life in a new way. Spiritual care involves supporting and being a companion to the dying person through these personal moments."

The spiritual aspect of palliative care is the most crucial, according to **Jim Thorne Jr.**, a South African bereavement counselor, practicing death educator, and ordained priest. Thorne is founder of the National Association of Loss and Grief and author of the book *A Guide on How to Cope with Dying, Death and Bereavement*.

He says palliative care should include the following:

- appropriate deathbed counseling;
- support to immediate love ones;
- bereavement counseling for 13 months after the date of death;
- training courses on dying, death, transition, and bereavement to persons working in the AIDS field;
- education for those who are terminally ill with AIDS.

Such care would better equip families to understand the dying process and enable those working with AIDS patients to function better under the emotional strain of continuously being exposed to death, dying, and bereavement.

"We need to be assisting survivors to actualize their loss," Thorne explains. "We all need to accept the reality and finality of the loss we have experienced."

Thorne emphasizes that it's the families who need to be taught how to cope with death, dying, and bereavement so the dying and the bereaved are not deprived of support. "When the person has died there are millions still to look after. You can't die with that person," he says.

The "care for the caregiver" aspect of palliative care is particularly important, he says, when one takes into account that in South Africa, 4 million people are infected with HIV. As many as 500 people die each day of AIDS-related deaths, and 1,750 new HIV diagnoses are made every day.

Teaching basic skills

Linda Knox of the Hillcrest AIDS Centre says palliative care in the poverty-stricken communities in the Hillcrest area, outside Durban, is about "making sure that a person is OK to die."

Caregivers are mostly volunteers from rural communities who are being taught basic home-based care skills, including turning patients, changing the bed linen or newspaper on which the patient is lying, and treating bedsores, as well as providing information about basic prevention and transmission.

Describing several people the Centre had assisted, Knox says that at times the only thing caregivers could do was to hold a person's hand while he or she was dying.

Discussing the situation in the Netherlands, Weber says that the Dutch Minister of Health concluded that palliative care is not as good as it should be. Research should be conducted to ensure that organizations providing care coordinate their efforts so it becomes more accessible, he suggests.

Even in situations as varied as those in the Netherlands or South Africa, palliative care is a necessity, not an option, says community activist **Janet Frohlich**. Frohlich helps carry out clinical trials with South Africa's Medical Research Council. She conducts her work primarily in Hlabisa, north of Durban, where there are seven to 10 deaths each week. ▼

First winners announced for end-of-life innovations

Emmy Award-winning broadcast journalist Bill Moyers presented the first checks and awards to three programs that improve the care people receive in the last days of their lives.

The first Circle of Life Awards: Celebrating Innovation in End-of-Life Care were presented at the American Hospital Association's (AHA) Health Forum Summit in Orlando, FL, in early May. The award, along with a $25,000 check, will be presented annually to up to three programs and is funded by the Robert Wood Johnson Foundation in Princeton, NJ.

The awards are initiated by AHA and co-sponsored by the American Medical Association, the National Hospice and Palliative Care Organization, and the American Association of Homes and Services for the Aging.

The winners were Franciscan Health System in Tacoma, WA; The Hospice of the Florida Suncoast in Largo; and Louisiana State Penitentiary Hospice in Angola. "We know the [end-of-life] experience can be much better, and these extraordinary institutions have created models of compassionate care that others can look to for inspiration," says AHA president **Dick Davidson**.

"This diverse group of awardees demonstrates that good end-of-life care is doable everywhere for everyone," says **Meg Campbell**, chair of the Circle of Life Awards committee.

Honorary mentions went to six organizations: Beth Israel Medical Center in New York City; Butterfly Program in Galveston, TX; Calvary Hospital in Bronx, NY; Fairview Health Services in Minneapolis; Harry Horvitz Center of the Cleveland Clinic; and San Diego Hospice. ▼

Hospital patients near death still report pain

Oregon study shows sharp increase in pain levels

A new study shows that dying patients in Oregon hospitals are experiencing an increased incidence of pain before death.

The study, printed in this month's issue of *The Western Journal of Medicine*, shows 54% of family members reported their loved one had moderate or severe pain in the last week of life. Previous data show a sharp increase in pain levels for dying hospitalized patients.

Researchers from Oregon Health Sciences University (OHSU) in Portland revealed that complaints of high pain levels increased from 33% to 57% in late 1997. **Susan Tolle**, MD, director of OHSU's Center for Ethics in Health Care; **Virginia Tilden**, PhD, RN, dean of research in OHSU's school of nursing; **Susan Hickman**, PhD, project director at the Center for Ethics; and **Anne Rosenfeld**, PhD, assistant professor in the school of nursing, conducted both studies.

Causes of increase unknown

When combined, the studies identify a continued sharp increase in family reports of pain at the end of life for hospitalized patients. However, researchers point out that neither study draws conclusions about cause and effect.

"We will never know why family members of hospitalized dying patients reported higher rates of pain in late 1997, or why they continued to report higher rates of pain in late 1998," says Tilden, a co-author of the study. "Late 1997 was a volatile time in Oregon's political and regulatory climate. Events such as the legalization of physician-assisted suicide and an extensive pre-ballot media campaign about end-of-life care were just a couple of the things that were happening at the time."

Team members suggest that possible explanations for increased reports of pain include more family awareness about pain treatment options and a possible change in physician prescribing practices due to fear of regulatory sanctions.

"On the one hand, families may have higher expectations about pain management than they have in the past and may be reporting pain more frequently," says Tolle, lead author of the study. "On the other hand, if families are right that their loved ones did experience more pain, this raises grave concerns. Were doctors writing less pain medication for these patients, and if so, why?"

Both studies used similar methods to reach participating family members through a random sampling of Oregon death certificates. Respondents were contacted two to four months after the death of their loved one. A total of 475 family members responded to the initial study, and 103 people participated in the follow-up study.

"One challenge we faced in gathering this data was that Oregon death certificates do not list contact information," says Hickman. "In order to find family members, we had to search publicly available records, such as obituaries. We were able to locate 51% of potential respondents, and just over half of these family members agreed to participate."

"Our study raises concerns about why more families are reporting moderate and severe pain in dying hospitalized patients."

The telephone interview included questions about advance planning, pain management, and communication issues. Only the question about pain yielded changes over time, and those changes were in hospitalized dying patients only. The three main causes of death in hospitalized patients were cancer, heart disease, and cerebrovascular disease.

More research needed

OHSU's Center for Ethics in Health Care has been tracking end-of-life care markers for more than a decade. Until this study, the research suggested that end-of-life care was improving in all areas. Markers of improvement include increased attention to advance planning, increased rates of hospice referrals, increased physician and public education about end-of-life care issues, decreased rates of in-hospital deaths, and decreased barriers to prescribing narcotics.

The results of this study raise many questions, and the research team stresses the need for more information. "Our study raises concerns about why more families are reporting moderate and severe pain in dying hospitalized patients," says Tolle. "Clearly, there is a pressing need for more research into this troubling finding." ▼

Donor gives $3 million for end-of-life initiative

Hospice to create research institute

Hospice of Michigan will develop a research institute to study end-of-life care issues, funded by a $3 million gift from an anonymous southeast Michigan donor.

The Institute for Care at the End of Life will support research and education aimed at improving care for terminally ill people and their caregivers. It also will research quality-of-life issues faced by older people, identify ways they can live fully through the end of life, and educate them on how to plan for their own end-of-life care.

"This new research facility will be a welcome addition to Michigan. End-of-life issues will continue to be a major focus in health care, and the institute will add immeasurably to their study," said Gov. **John Engler**.

"Already a leader in hospice care, Hospice of Michigan's new research institute will keep Michigan at the forefront of offering compassionate care to the dying," he said.

Bringing experts together

Hospice of Michigan's new headquarters will be located in Southfield near a number of health care institutions, including the Detroit Medical Center, Wayne State University, and Henry Ford Hospital.

"We hope the institute will be a place where end-of-life researchers from other institutions will come together to exchange ideas, to move the care of the dying to the forefront, and increase our ability to collaborate with educational institutions," said **Dorothy E. Deremo**, Hospice of Michigan president and chief executive officer.

Hospice of Michigan has other end-of-life research projects, including the Robert Wood Johnson Foundation Palliative Care Project with the University of Michigan, which focuses on the benefits of providing comfort care along with traditional treatments for patients with cancer and heart disease, and the Telehospice Project with Michigan State University, which uses video-telecommunication to connect patients and their hospice care team. ■

NEWS BRIEFS

Would you want to know how you're going to die?

That's the question the consumer health Web site drkoop.com asked in June for its more than 1.3 million registered members. More than two-thirds of the respondents answered yes to the question, "If it were possible to find out how you were going to die through genetic screening, would you want to know?" The other third said they would not want to know.

The response, according to a statement from **C. Everett Koop**, MD, former U.S. Surgeon General and chairman of drkoop.com, demonstrates that Americans are aware of the implications of the recent genome mapping announcement. "Americans are aware largely because they have been told about possible scientific advances that are actually decades away," said Koop.

"What has not been studied are the ethical implications that will ensue if we do not find a way to keep the genetic makeup of each individual in total privacy," he added. "This issue poses substantial questions not just for the health profession, but for each and every person." ▼

Cord blood is most viable for stem-cell research

The American Heart Association's (AHA) decision in early July to support the use of federal funds for stem-cell research was met with an endorsement from the Cord Blood Registry.

The San Bruno, CA-based Cord Blood Registry is the nation's largest cord blood stem-cell bank, with more than 20,000 individuals with stored stem cells.

"Umbilical cord blood represents an easily accessible and high quality source of stem cells that does not involve fetuses, but rather a unique and invaluable byproduct of a new life," says **Paul R. Billings**, MD, PhD, medical consultant to the Cord Blood Registry.

AHA officials say stem cells could help people suffering from heart disease, strokes, and other ailments. The primary sources of stem cells, however, — aborted fetuses or discarded human embryos — have created controversy among some medical ethicists and anti-abortion groups.

The AHA estimates that 128 million Americans have ailments that could be treated or cured with discoveries from stem-cell research, such as cardiovascular disease and stroke, which the AHA reports are the No. 1 and No. 3 killers in the United States. ▼

Genetic health data need privacy protection

The Chicago-based American Health Information Management Association (AHIMA) recently issued a statement urging caution in protecting the confidentiality of individual health information.

The 40,000-member organization applauded the Human Genome Project on completing the working map of the human genome but emphasized the need for confidentiality legislation.

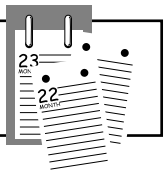
"The Human Genome Project offers the promise of better health and will profoundly affect how medicine is practiced in the next century," said AHIMA president-elect **Barbara P. Fuller**, JD. Fuller also is a senior policy analyst at the National Human Genome Research Institute at the National Institutes of Health.

AHIMA calls for legislation

AHIMA has called for confidentiality legislation that would protect health information for several years. The group says the misuse of any individually identifiable medical information could be destructive to the health and well-being of patients. The organization also says a breach of confidentiality could lead to a person being discriminated against in employment, insurance, and health care.

"Fear of participating in genetics research can be expected to increase if the research information can be used against the participant," stated Fuller. AHIMA pledges to continue working with Congress and the Clinton administration to pass meaningful legislation that would protect the confidentiality of all health information. ■

CALENDAR



• **Summer Seminar in Health Care Ethics, July 31-Aug. 4, 2000.** Sponsored by the Department of Medical History & Ethics, University of Washington School of Medicine. This annual one-week seminar provides an intensive introduction to the concepts, methods, and literature of health care ethics. It is directed to, and registration is limited to, physicians, nurses, social workers, chaplains, teachers, and others who are involved in the care of patients or the education of providers.

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• **The Third Annual International Bioethics Retreat. Sept. 12-16, 2000**. Pembroke College in Cambridge, England. Sponsored by Loyola University of Chicago, The Joint Medical Program and Human Rights Center at the University of California Berkeley, and Cambridge University Press.

For more information, contact: Doris Thomasma, Retreat Coordinator, Loyola University of Chicago, Medical Humanities Program, 2160 S. First Ave., Maywood, IL 60l53. Phone: (708) 327-9200. Fax: (708) 327-9202. E-mail: dthoma2@luc.edu.

• **Fifth World Congress of Bioethics, Sept. 21-24, 2000.** Imperial College, London. Sponsored by the International Association of Bioethics, the Centre for Ethics in Medicine, University of Bristol, and the Millennium Festival of Medicine. Major topics include bioethics, law, and public policy; the ethics of genetic advance; feminism and gender equality; end-of-life issues; ethical challenges in surgery; humanities in medicine; transplantation and organ sales; and psychiatric ethics. The Congress' language will be English.

For more information, visit the Web site: http://uclan.ac.uk/facs/ethics/fifthcon.htm. E-mail: Anne.Lavender@bristol.ac.uk.

• **International Collaboration in Nursing: The Influence of Ethics and Policy on Health and the Quality of Life, Oct. 1-4, 2000.** Tysons Corner, VA. The Fourth Nursing Academic International Congress. Sponsored by the College of Nursing and Health Science at George Mason University.

For more information, contact Beverly T. Boyd, congress co-chair. E-mail: BBOYD@wpgate.gmu.edu. Web site: http://www.gmu.edu/departments/nursing/congress.

• **Ethics in Research: An Intensive Training Workshop Focusing on Behavioral Health Services, Oct. 16-19, 2000.** Sponsored by the University of South Florida and the National Institutes of Health. This intensive course is designed to better equip researchers to conduct ethically responsible behavioral health research. Issues to be addressed include informed consent, decisional capacity and competency, diversity and multicultural perspective, emotional health of research participants, confidentiality and privacy, data ownership, and coercion.

For more information, contact: Kelly M. Lyon, Coordinator, Education and Training Programs, Department of Mental Health Law and Policy, University of South Florida, Building MHC-2628, 13301 Bruce B. Downs Blvd., Tampa, FL 33612. Phone: (813) 974-7623. Fax: (813) 974-9327. Web site: http://www.fmhi.usf.edu/mhlp/ethics/ethics.html. E-mail: Lyon@fmhi.usf.edu.

• **Third Annual Meeting of the American Society for Bioethics and Humanities. Oct. 26-29, 2000.** Salt Lake City. More information on the conference will be posted as it becomes available on the American Society for Bioethics and Humanities Web site: http://www.asbh.org. E-mail: info@asbh.org. ■