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January 2000 • Vol. 17, No. 1 • Pages 1-12

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Special Report:
Human Genome Project and Genetic Testing

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Scientists discover body's 'fusebox' to diseases

Genetic recipe for human 'book of life'

They've done it! An international group of scientists from England, the United States, Canada, Sweden, and Japan gave the world a millennium present last month by announcing that the first human chromosome had been mapped.

Although the researchers were able to map only 97% of the chromosome's genetic material, the results are considered complete for now. There are 23 pairs of chromosomes — a molecular chain within a cell carrying hereditary characteristics — containing all the human deoxyribonucleic acid (DNA). The human genome, or genetic pattern, is a biological map consisting of the 3 billion pairs of chemicals within the DNA of each cell.

Special Report: Human Genome Project and Genetic Testing (part 2 of 2)

While the impact on hospital ethics committees may not be immediate in terms of providing diagnostic testing, the achievement means committees will need more education. Syndromes and diseases will be linked to one of 23 chromosomes, and ethics committees, along with genetic counselors, will have to be well-versed in each "chapter" of the human book of life, experts predict.

Chromosome 22 is the second smallest, but it was chosen because of its influence on the human body's functioning. The chromosome is one of the most densely packed, with 33.5 million pieces, or chemical components. More than 30 human disorders, however, are associated with changes in the genetic makeup of this chromosome.

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COMING IN FUTURE ISSUES

■ **Research centers cited again:** A follow-up look at the human research arena and the policing of institutional review boards

■ **When does 'therapy' go too far?** Do genetic advances and research justify the deaths of patients?

■ **Eagerly awaited:** An analysis of the Institute of Medicine's anticipated report on nonheart-beating organ donation policies

■ **Keeping a secret:** An update on the regulatory measures to comply with medical privacy legislation

■ **Granting the wish:** What happens when hospital staff fail to follow a patient's advance directive?

Previous research has revealed that chromosome 22 is instrumental in the workings of the immune system, congenital heart disease, schizophrenia, mental retardation, and several cancers, including leukemia. **(For a complete list, see chart, p. 4.)**

"For the first time we can see the entire landscape of a human chromosome, the basic unit of human inheritance, how the genes are organized, how they're laid out on the chromosome," says **Francis Collins**, MD, chair of the National Human Genome Research Institute (NHGRI) in Bethesda, MD. The achievement was published in the Dec. 2 issue of *Nature*.[1] NHGRI is a joint effort by the National Institutes of Health and the U.S. Department of Energy.

"I think this is probably the most important scientific effort that mankind has ever mounted. That includes splitting the atom and going to the moon," Collins says.

"This is the first time that we have been able to see the organization of a chromosome at the base-pair level. This immediately suggests new experiments and avenues of research which can be pursued," says **Ian Dunham**, MD, senior research fellow and principal scientist at the Sanger Centre in Hinxton, Cambridge, UK, and lead author of the *Nature* article. The Sanger Centre is the primary research facility in England involved in the international research effort.

One down, 22 to go

The achievement is not an indication for science to rest on its laurels, however. "One down, the others to go," notes Dunham. Researchers are testing gene therapies to correct misfirings and attempt to make cells work correctly. The hope, scientists say, is to create therapies reliable enough to treat diseases without the side effects of some medications.

"You will see buried in all sorts of papers that people have used the sequence already," says **Peter Little** of Imperial College in London. Little uses the existing map to study a protein on the surface of nerve cells.

The fact that the information is freely available is of major importance, scientists say. The sequence of chromosome 22, for example, includes 298 genes previously unknown in humans, and all are being released without the constraints of patents and fees. Their hope, say Collins and Dunham, is that the knowledge of genetic makeup will be used for the good of humankind.

There is, however, private competition to complete mapping of the entire human genome. **(See related story, below.)**

"What happens now is a whole host of fascinating experimental challenges to figure out. What do these genes do individually, and how do they work together to do all the things we humans are capable of? Until now, the ability to sequence an entire chromosome was just hypothetical. Having done this for chromosome 22 tells us we will be able to finish the human genome [completely] in another two or three years," explains Collins.

He says the first benefit from mapping human chromosomes will be in diagnosing diseases or syndromes. "In other words, the identification, particularly the early identification, of disease."

The other chromosome mapping projects likely will evolve more quickly, researchers say. The next most likely candidate will be chromosome seven. Researchers expect to have the remaining chromosomes mapped by next spring.

Reference

1. Dunham I, Hunt AR, Collins JE, et al. The DNA sequence of chromosome 22. *Nature* 1999; 402:489-495. ■

Should gene discoveries be free or patented?

Controversy is over more than splitting genes

There might be collaboration rather than competition between privately funded efforts and the public consortium over mapping the human genome.

That's because discussions among Rockville, MD-based Celera Genomics, a privately funded biotechnology firm; the National Human Genome Research Institute (NHGRI), a joint effort funded by the National Institutes of Health in Bethesda, MD; and the U.S. Department of Energy are taking place, according to a report in *The New York Times*. At issue are billions of dollars in potential profit from genetic maps of the human genome. The ethical question is this: Should gene discoveries be free or patented?

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CME questions

1. The announcement that scientists have mapped virtually all of a human chromosome for the first time, according to Ian Dunham, MD, of the Sanger Centre in England, means:
- **A.** Unborn children will be born disease-free
- **B.** New avenues of research can be pursued
- **C.** Cures for diseases will be discovered rapidly
- **D.** All of the above

2. According to Judith Berkendorf, MS, senior genetic counselor and professor of obstetrics and gynecology, a genetics counselor is best suited to work with physicians to:
- **A.** Gain a better understanding of genetics
- **B.** Appropriately screen patients for testing
- **C.** Assist with genetic knowledge exceeding their expertise
- **D.** All of the above

3. A series of retreats held in Vermont last summer was part of the federally funded:
- **A.** Neighborhood Life Enhancement Project
- **B.** Community Ethics and Genetics Project
- **C.** Medicare Millennium Project
- **D.** Balanced Budget Act

4. The goal of the Vermont project, according to David Yandell, MD, is to:
- **A.** Inform and involve all of society in how genetic technology should be used
- **B.** Inform the public about the ramifications of genetic testing
- **C.** Teach clergy how to approach the subject of genetics with patients
- **D.** All of the above

Chromosome 22 disease and syndrome list

- Pheochromocytoma
- Meningioma
- Cat eye syndrome
- Hyperprolinemia type 1
- DiGeorge syndrome
- Bernard-Soulier syndrome, type B
- Thrombophilia due to heparin cofactor
- Breakpoint cluster region (CML)
- Malignant rhabdoid tumor
- Glutathionuria
- Breast cancer
- Cataract, cerulean, type 2
- Opitz G/BBB syndrome, autosomal dominant
- Schizophrenia
- Ewing sarcoma breakpoint
- Amyotrophic lateral sclerosis (susceptibility to)
- Neurofibromatosis, type 2
- Transcobalamin 2 deficiency
- Glucose-galactose malabsorption
- Sorsby's fundus dystrophy
- Heme oxygenase
- Schwannomatosis
- Pulmonary alveolar proteinosis (rare cases)
- Deafness, autosomal dominant
- Colon cancer
- Hirschsprung disease (dominant megacolon)
- Spinocrebellar ataxia
- Mental retardation, chromosome 22 associated
- Ovarian cancer
- Dermatofibrosarcoma protuberans
- Succinylpurinemic autism
- Lysosomal alpha-N-acetylgalactosaminidase deficiency
- Myoneurogastrointestinal encephalomyopathy
- Metachromatic leukodystrophy
- Glioma of brain

Source: The Sanger Centre, Hinxton, Cambridge, UK.

The public consortium, which includes the NHGRI and England's Wellcome Trust of London, has a policy of immediately releasing data. That policy would be difficult to change, says **Francis Collins**, MD, chair of the NHGRI. Celera, however, has applied for 6,500 patents for genes the company claims it has identified. Critics argue that the patents, if approved, would prevent scientists from conducting research and would allow Celera to profit at the public's expense.

Biotechnology is big business

Celera entered the biotechnology industry with a bang. Celera got backing amounting to roughly $410 million to start up, not counting the estimated $200 million spent on its human genome sequencing efforts. NHGRI, on the other hand, receives roughly $3 billion in funds from the United States and several other countries.

NHGRI researchers have announced that the project will be complete by mid-2000, while officials with Celera contend they will finish before the public project is complete. ■

Genetics counselors will have expanded role

Unprecedented number of tests, therapies expected

With the completion of the Human Genome Project next year, new genetic therapies and diagnostic tests will become available on an unprecedented scale. Experts predict that genetic information will completely revolutionize health care in the next century.

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Hospitals that want to keep up will have to do more than stay abreast of scientific advances. They must have a staff prepared to explain genetic information, testing, and therapies to patients, helping them make choices and be aware of the far-reaching consequences.

"As we have a better understanding of the genetic bases of common disorders — heart disease, diabetes — as well as what we now think of as genetically linked conditions, there will be an increased need for institutions to have genetics

counseling programs and risk assessment," says **Stephanie Kieffer,** MS, CGC**,** co-chair of the ethics subcommittee for the National Society of Genetic Counselors. "Centers are going to have to have resources available to interpret the results accurately. Genetic counselors are the most qualified to address those issues," she says.

Although physicians have the capability to order genetic tests, many do not have sufficient knowledge to adequately screen which patients need testing or, for those who are tested, to correctly interpret the test results.

"There are people who get referred to me inappropriately," says **Judith Berkendorf**, MS, senior genetic counselor and professor of obstetrics and gynecology at Georgetown Medical Center in Washington, DC. "For example, a woman who is very anxious about breast cancer because both of her grandmothers had breast cancer, and they both had it in their 70s. She doesn't come from a hereditary breast cancer family. So, to be tested for the BRAC1 gene or BRAC2 gene is not going to be a good test for her."

Physicians need to work with genetic counselors to develop a better understanding of genetic risk assessment and testing, and counselors should be available to work with the physician and the patient when the situation exceeds the physician's expertise, Kieffer and Berkendorf say.

"Testing really needs to be a team effort. There really need to be genetics counselors involved in the team, even if the genetics professionals aren't even seeing the patient," adds Berkendorf.

"They should be involved in designing a good pre-test education and counseling program, and there need to be counselors involved in deciding what is going to be done with the results post-test," she says.

Providers need more genetics sensitivity

Working in tandem with genetics counselors can help physicians and other providers begin to screen for possible genetic involvement in disease processes and appropriately recommend patients for possible diagnostic tests.

"Health professionals need to become much more genetic-sensitive when they take family histories, to watch for clustering in the same lineage of families," says Berkendorf. "They should look for things that appear unusually early — that is kind of a hallmark for genetic diseases. We are seeing things striking much earlier. We are seeing cancers with an onset in the 20s, 30s, and 40s, as opposed to [age] 72. Look for clustering of things in the same lineage and, especially, any of these adult onset conditions very early."

For many genetic tests now available, there are clinical guidelines for ordering tests in patients meeting specific criteria, Berkendorf says, illustrating an area of expertise for genetic counselors.

> "There is a very real fear of the potential for discrimination, the loss of health insurance, loss of a job."
>
> Judith Berkendorf, MS
> Georgetown Medical Center

"Many providers need a better understanding of when testing is applicable," she says. "There are some risk assessment programs that are modeled probabilities that are available for breast cancer. There is one that is known as the GAIL model, which takes into account the woman's reproductive history, whether or not she has first-degree relatives with breast cancer, any breast biopsies she has had. It develops a new baseline of risk adjusted to the general population due to those factors."

In the future, there will be more modeled probabilities for which patients will be most helped by diagnostic genetic testing. "So, people can come in for a risk assessment, and many times a well-thought-out or well-done pedigree can allay a lot of fears," she explains. "For some patients, testing is not even appropriate."

Genetics professionals also are acutely aware of the unique effect that knowledge of genetic information can have on the patient's life. "There is no other testing in medicine that gives you information that isn't only about your own health, but is about your future health and the health of your close relatives," Berkendorf advises.

Patients also must consider the possibility that information will be released to employers and third-party insurers. "There is a very real fear of the potential for discrimination, the loss of health insurance, loss of a job," she says. "Once the lid is taken off the box, you can't put it back on. You can't go back to when you didn't know. Genetic counselors help patients decide, 'What are you going to do with this information? How are you going to feel about it?'"

Informed consent brochure available

Alliance for Genetics Support Groups has a brochure called "Participating in Genetics Research Studies: Informed Consent," which lists questions that potential participants should ask. Contact the Alliance at 4301 Connecticut Ave., N.W., #404, Washington, DC 20008-2304. Telephone: (202) 966-5557. Fax: (202) 966-8553. Toll-free helpline number: (800) 336-GENE. E-mail: info@geneticalliance.org. ■

As more and more genetic markers for common chronic diseases become available, counselors involved in prenatal testing may get requests for prenatal diagnosis for those markers, says **Virginia Corson**, MS, genetics counselor in the prenatal diagnostic center at Johns Hopkins Hospital in Baltimore and former president of the American Board of Genetic Counseling.

"Down the road, you may have the occasional patient who requests prenatal diagnosis for a late-onset disorder [as opposed to testing for potential birth defects]," she says. "As a group, people need to decide if they are comfortable or willing or uneasy about providing that."

For example, a patient may have seen her mother die of breast cancer and request a prenatal diagnosis to determine whether a female fetus would carry the mutation on BRAC1/BRAC2 genes that are linked to breast cancer.

"We have provided it for something like Huntington's disease, which is a late-onset disorder," notes Corson. "Obviously, breast cancer is already here. You could, conceivably, do prenatal diagnosis for that as well. I don't know if anyone has done that."

Another key role for genetics counselors will be in aiding institutional review boards (IRBs) in developing appropriate informed consent procedures for participants in genetic research, says Berkendorf. "There are myriad issues when it comes to patients participating in research studies. Just in terms of what is on the consent form. What is the study looking for? Is the sample going to be used once? More than once? How is it going to be shared? Is it ever going to be shared in the future? Are the samples anonymous or will there be identifiers? How is the information going to be published? Under what conditions will the participant get information from the study?" Participants should ask all of those questions before agreeing to a research protocol.

Some IRBs have designed informed consent forms specifically for genetics research, adds Berkendorf. "I think there is a real place for a genetics counselor on an IRB."

Finding genetics counselors

Some experts worry there will not be enough trained genetics counselors to meet the future need, but Kieffer disagrees. "I think that the advances are coming about gradually, and the programs will expand to meet the need."

Currently, there is national certification for genetics counselors through the Wallingford, PA-based National Society of Genetic Counselors, which offers a certification exam every three years. There are 22 master's-level educational programs also certified through the NSGC. "This accreditation is phased in; some programs have new program status, interim program status, or full accreditation," Corson says.

At this time, there is no state licensure for genetics counselors.

Suggested reading

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✔ Gellar G, Botkin JR, Green MJ, et al. Genetic testing for susceptibility to adult-onset cancer. The process and content of informed consent. *JAMA* 1997; 277:1,467-1,474.

✔ Berkendorf JL, Reutenauer JE, Hughes CA, et al. Patients' attitudes about autonomy and confidentiality in genetic testing for breast-ovarian cancer susceptibility. *Am J Med Genet* 1997; 73:296-303. ■

SOURCES

- **Virginia Corson**, Johns Hopkins Hospital, Prenatal Diagnostic Center, 600 N. Wolfe St., Baltimore, MD 21287.
- **Stephanie Kieffer**, Medical Sciences Building, Room 853, Gather Clinic, University of Alberta, Edmonton, AB, Canada T6G2H7.
- **Judith Berkendorf**, MS, Georgetown Medical Center, Department of Obstetrics and Gynecology, 3800 Reservoir Road N.W., Washington, DC 20007-2197.

Retreat provides forum for genetic debate

Goal: Educate everyone on impact of technology

Two deaf parents want to conceive, and they have come to your hospital's prenatal diagnosis clinic asking that their pre-implantation embryos be screened to maximize the chance they will have a deaf child.

The physician and genetic counselor have come to the ethics committee seeking guidance. How should the committee respond? What process should it go through in making policy regarding the availability of genetic testing?

The above scenario and resulting questions were just one of many case studies posed to a group of hospital ethics committee members and institutional review boards in a unique retreat held in Vermont in June 1999.

The goal of the meeting, part of Vermont's three-year, federally funded Community Ethics and Genetics Project, was to impart a better understanding of the advances in genetic information and technology available to medical science and to highlight the ethical issues such advances are raising.

The retreat offered no easy answers.

"It was more of a collaborative effort," explains **Edward Mahoney**, PhD, co-director of the project and the associate dean of academic integrity, faith/spiritual journey, and the intellectual life at St. Michael's College in Colchester, VT. "What we really want people to do is to work together on fashioning and describing clearly what the ethical issues are and what the various perspectives and approaches might be, then to come to a resolution on some of those thorny questions. That is what we tried to do with the case studies."

Funded through federal program

Although the hard data from the national Human Genome Project may not have many practical applications for some time, the ethical, legal, and social issues (ELSI) of new genetic technologies have long been a priority with the government scientists organizing the study.

Since its inception in 1990, 3% to 5% of all funds dedicated to the project from both of its governing bodies, the U.S. Department of Energy and the National Institutes of Health, have been dedicated to supporting studies of the myriad ELSI implications this information will have for society.

One of the key goals of the ELSI program is to foster involvement of all segments of society in making decisions about how genetic technology should — and should not — be used.

"We received a grant under the project's ELSI program to develop a community-based educational program," says **David Yandell**, MD, the project's principal investigator and head of the Vermont Cancer Center at the University of Vermont in Burlington. "We wanted to both educate the community as a whole about genetic technology and the issues involved and get broad-based input on how these issues should be dealt with."

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So far, the project has sponsored about 10 retreats with different professional groups to discuss genetic technology and information. For example, one retreat was for members of the clergy, while another comprised elected representatives and policy-makers, and a third consisted of physicians and other health care professionals. Each group had about 40 participants and met for a 1½ to 2 days.

"When you consider the population of the state of Vermont is only about 600,000, that amounts to a significant number of people attending one of the sessions," Yandell says.

In addition to the retreats, the project also is sponsoring an ongoing discussion group and 10 more community forums. Over the course of three years, the project also will establish an informational Web site, publish a monthly newsletter, circulate a resource directory of individuals and institutions, and design methods to continue to share information.

Each retreat has the same basic format, he says. The selected group views several presentations about genetics: "What it is, where it has been, and where we are now." Then, representatives of families who have been affected by genetic testing in some way or who have a child or family member with a genetically linked condition are invited to speak to the group about their concerns. Finally, case studies targeted to each group of people are presented and discussed.

After the retreat, participants complete follow-up questionnaires and the results are compiled for further study. The goal of the grant is for Vermont to develop a nationally replicable

model for education and discussion of genetic issues in a community setting, and to encourage community input into societal decisions about access to and use of genetic information, Yandell adds.

At the close of the three-year study, the project will publish a report on its findings as well as a manual describing and evaluating each of the project's components for use by others considering similar programs in their communities.

> What happens when, in the process of doing a genetic study for one condition, additional information is gleaned? Who has access to that information?

The retreats themselves are designed to encourage people in professions directly affected by biogenetics to learn how the Human Genome Project will affect them and work together in developing strategies across the state and country.

Although all of the groups have listed the same main concerns with managing genetic information, each group lists different issues as main priorities, says Mahoney. "The physicians were most concerned about education: educating physicians and primary care health providers and then helping them educate their patients.

"For mental health professionals and social workers, their primary concern was confidentiality of the medical record. Each group was concerned with similar issues, but it was interesting to see how they stressed one area over another," he explains.

Asking the difficult questions

For ethics committees and institutional review boards, the questions were more specific: What happens when, in the process of doing a genetic study for one condition, additional information is gleaned? Who has access to that information? If you find something in a study that you were not looking for, do you notify the patient? What kinds of information do you give to the patient in the first place? What constitutes adequate informed consent?

"For hospital ethics committees, there are a variety of clinical issues that may occur," Mahoney says.

"For example, a daughter realizes she has inherited a genetic marker [for breast cancer risk] and she wants to know where it came from — her mother or her father. Her mother does not want to be tested, but the father does. What should you do? Do you test the father? It may be that testing the father could reveal that the mother is a carrier, but it could be a question of nonpaternity. The mother could have many different reasons for not being tested."

One of the most helpful segments of the retreat for the ethics professionals featured presentations by family members, Mahoney says.

"I think the perspectives of the family members of those patients varies, both their experiences as well as how they feel about what happened to them," he says, "what has happened to their children and the kinds of support they have received or not received, and the issues they face day-to-day, and the pressure it puts on them," he says. "That is one of the most powerful parts of the retreat."

Follow-up is important

At the end of each seminar, the participants were asked a series of questions designed to gauge how their personal knowledge of genetics and the ELSI issues involved has changed, says Mahoney.

"We have a couple of sessions early on, where we ask the participants what they see as the primary issues and concerns," he says. "At the end, we talk about that: What are the issues that have emerged through the discussions and presentations? As professionals, what impact will this have on their profession and how will they apply what they have learned at the retreat?"

The leaders of the project say they hope this information, gleaned from retreat participants, will not only benefit Vermont, but the rest of the country as well. ■

SOURCES

- **David Yandell**, MD, Director, Vermont Cancer Center, University of Vermont, Burlington, VT 05405.
- **Edward Mahoney**, PhD, Associate Dean Academic Integrity, Faith/Spiritual Journey and the Intellectual Life, St. Michael's College, Winooski Park, Colchester, VT 05439.

NEWS BRIEFS

Medical marijuana

Maine voters approve medical marijuana

An overwhelming majority of Maine voters approved a measure in the November elections supporting the medical use of marijuana.

The question, "Do you want to allow patients with specific illnesses to grow and use small amounts of marijuana for treatment, as long as such use is approved by a doctor?" was approved by 61% of voters. The law takes effect Jan. 1, 2000.

Exempt from prosecution under state laws would be patients in the following classifications:

- receiving a diagnosis from a physician as suffering from persistent nausea;
- experiencing vomiting;
- suffering from wasting syndrome or loss of appetite as a result of AIDS;
- undergoing chemotherapy;
- experiencing seizures associated with chronic, debilitating disease such as multiple sclerosis.

"We think it's clear Maine people have taken a stronger stand for a compassionate drug policy than has the federal government," says **Craig Brown**, coordinator of the Portland-based Mainers for Medical Rights, the leading proponent of the proposal.

Patients will be allowed to cultivate their marijuana or purchase it. Patients are limited to 1¼ ounces of harvested marijuana, or six plants. If they choose to grow the crop, no more than three can be mature, flowering plants.

Maine is the sixth state to legalize the medical use of marijuana by voter initiative — the first state east of the Mississippi River to do so. States with existing laws are Alaska, Arizona, California, Oregon, and Washington. Bills are pending in Hawaii and Minnesota, and one will be submitted to Maryland's legislature soon. Colorado voters will decide on the issue in November 2000.

The U.S. Justice Department, however, is challenging voter-aproved laws.

It will take decades — if ever — for medical marijuana to be approved by the U.S. Food and Drug Administration in Rockville, MD. That's what critics at the Washington, DC-based Marijuana Policy Project say about new guidelines from the U.S. Department of Health and Human Services, which went into effect Dec. 1, 1999. The guidelines are for procedures to provide marijuana for medical research.

The guidelines are too cumbersome and will restrict research projects because there are too many government agencies in the chain of approving a request, says **Chuck Thomas**, director of the lobbying group. The group's ultimate goal is the federal legalization of medical marijuana.

"It's much more difficult to get permission to do medical marijuana research than it is to get permission to study any other pharmaceutical substance," adds Thomas. The group also accuses the Clinton administration of not being truthful when it says the doors are "wide open" for research on medical marijuana.

"A growing coalition of health and medical groups, doctors, scientists, and members of Congress disagree with the Clinton administration's claim that the door is wide open for research," says Thomas. Further, the new guidelines reject the Institute of Medicine's (IOM) recommendation for immediate patient access to marijuana through federal "compassionate use" programs. The IOM panel concluded that marijuana can help fight pain and nausea and should be tested further in scientific trials. The report was not released without controversy, however. **(See *Medical Ethics Advisor*, April 1999, p. 40.)**

Thomas and fellow activists also say the new guidelines place a greater burden on medical marijuana researchers than on drug companies that develop and study synthesized pharmaceuticals. ▼

Less-intensive care not linked to deaths of elderly

Does lower treatment intensity explain shorter survival in elderly patients? That's what researchers suspected when analyzing data on more than 9,000 patients. Results were published in the Nov. 16, 1999, issue of *Annals of Internal Medicine.*

What the researchers found, however, was that hospital resources were less likely to be available to older patients, and the likelihood of deciding to withhold life-sustaining treatments

increased with patient age. For the purposes of predicting survival, however, researchers found that factors such as diagnosis and severity of illness were more important than age or intensity of treatment.

In an accompanying editorial, Steven Schroeder, MD, of the Princeton, NJ-based Robert Wood Johnson Foundation, which funded the study, congratulates the researchers for their findings. The study results, Schroeder says, will challenge the conventional wisdom of caring for the elderly ill. ▼

Nursing homes will need hospice services

Nursing homes are increasingly providing hospice services to their residents, and the trend is expected to continue in the competitive long-term care industry, according to a recent report in the journal *Gerontologist*.[1]

An estimated 13,369 Medicare hospice beneficiaries reside in Medicare / Medicaid-certified facilities on any given day. For the most part, the study says, hospice beneficiaries are being served in nursing homes that do not have specialized hospice units because only about 1.3% of nursing homes have such units. Nevertheless, residents of those nursing homes are more likely to receive hospice care.

Is the trend deliberate?

The authors conclude that U.S. nursing homes are increasingly providing hospice services. They suggest the trend represents a deliberate management strategy for ensuring organizational survival in a rapidly long-term care market. Their investigation further suggests that the economically motivated path and potential profit motive in health care may give rise to unequal service and access.

Nursing homes with higher percentages of residents receiving the hospice benefit are more likely to be for-profit, belong to a chain, and not provide full-time physician coverage, the authors say. The proportion of residents receiving the hospice benefit increased in counties with fewer certified nursing home beds and in areas with more certified hospices, for-profit hospices, or larger hospices, they note.

The report's authors assert, however, that those developments are occurring in the absence of much-needed outcomes data. While the significant variation in the distribution of hospice beneficiaries among states may be influenced by state Medicaid reimbursement rates and coverage policies, the findings of this study do not permit conclusions regarding the impact on individual residents.

Also, because research has shown that in many health care settings, "practice makes perfect," concentrating hospice patients in a relatively small number of facilities may be appropriate. The authors recommend further examination of the access and quality implications of providing hospice care to dying nursing home residents in order to inform future public policy.

Reference

1. Petrisek AC, Mor V. Hospice in nursing homes: A facility-level analysis of the distribution of hospice beneficiaries. *Gerontologist* 1999; 39:3. ▼

First genetics, now proteins

Effort may 'change the future of health care'

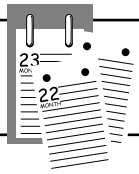
Armonk, NY-based IBM is launching a new endeavor similar to the supercomputer developed to play chess, but this time the human body's the focus of the computer's effort.

A computer will be built of "staggering power" according to a company statement to solve the mystery of the structure of proteins. Proteins are considered the building blocks of the body.

"With this project we have a chance not only to change the future of computing, but also the future of health care," says **Paul Horn**, senior vice president of research at IBM.

IBM estimates it will take four to five years to build the estimated $100 million Blue Gene computer, which will be a million times faster than the average desktop computer. It will perform an estimated 1 million billion mathematical operations per second. The computer will be built and operated at IBM's Watson Research Center in Yorktown Heights, NY. ■

CALENDAR



• **Eighth International Workshop on Chromosomes in Solid Tumors. Jan. 30-Feb. 1, 2000.** Tucson, AZ. The workshop is designed to assess the current state of progress in the field. The scientific program will include plenary lectures, proffered papers, and poster sessions related to molecular genetics and cytogenetics, chromosome banding of human tumors, and experimental cytogenetics. Sponsored by the Arizona Cancer Center and the National Human Genome Research Institute. For more information, contact: Conference Coordinator, Arizona Cancer Center, P.O. Box 245024, Tucson, AZ 85724-5024.

• **Conference on Ethical Issues in Clinical Trials. Feb. 25-26, 2000.** Birmingham, AL. Sponsored by the University of Alabama at Birmingham. Topics include informed consent, placebo controls, decisions to terminate or repeat trials, and multinational clinical trials. For registration material, contact: Harold Kincaid, Center for Ethics and Values in the Sciences, 900 13th St. S., Birmingham, AL 35294. E-mail: kincaid@uab.edu.

• **Developing Healthcare Ethics Programs, April 24-29, 2000.** Sponsored by the Center for Biomedical Ethics at the University of Virginia in Charlottesville in cooperation with the office of continuing medical education. Participants can choose to concentrate on clinical ethics, health care organizational ethics, or research ethics. For more about the course, contact: Ann Mills. Phone: (800) 982-3978. E-mail: amh2r@virginia.edu.

• **Seventh Annual Teaching Research Ethics Workshop, May 17-20, 2000.** Bloomington, IN. Sponsored by Indiana University. For additional information, contact: Kenneth D. Pimple, Poynter Center, Indiana University, 618 E. Third St., Bloomington, IN 47405-3602. Phone: (812) 855-0261. Fax: (812) 855-3315. E-mail: pimple@indiana.edu. World Wide Web: www.indiana.edu/~poynter/index.html.

• **Ethics of Research With Humans: Past, Present, and Future. June 12-16, 2000.** Seattle. Sponsored by the University of Washington Department of Medical History and Ethics. A detailed brochure with registration form will be available in mid-February 2000. For additional information or to receive a course brochure, contact: Marilyn Barnard, Manager, Continuing Education Program, University of Washington, Department of Medical History and Ethics, Box 357120, Seattle, WA 98195-7120. Phone: (206) 616-1864. Fax: (206) 685-7515. E-mail: mbarnard@u.washington.edu.

• **Summer Seminar in Health Care Ethics. July 31-Aug. 4, 2000.** Seattle. Sponsored by the University of Washington Department of Medical History and Ethics. The cost of the seminar is $795 for health care professionals with degrees in law or medicine and $770 for other health care professionals if payment is received by June 30, 2000. A detailed brochure with registration form will be available in March 2000. For additional information or to receive a course brochure, contact: Marilyn Barnard, Manager, Continuing Education Program, University of Washington,

Medical Ethics Advisor™ (ISSN 0886-0653) is published monthly by American Health Consultants®, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Periodical postage paid at Atlanta, GA 30304. POSTMASTER: Send address changes to **Medical Ethics Advisor**™, P.O. Box 740059, Atlanta, GA 30374.

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Customer Service: (800) 688-2421 or fax (800) 284-3291, (customerservice@ahcpub.com). Hours of operation: 8:30 a.m. -6 p.m. Monday-Thursday; 8:30 a.m.-4:30 p.m. Friday.

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Editorial Questions

Questions or comments? Call **Kevin New** at (404) 262-5467.

Group Publisher: **Brenda Mooney**, (404) 262-5403, (brenda.mooney@medec.com).
Managing Editor: **Kevin New**, (404) 262-5467, (kevin.new@medec.com)
Contributing Writer: **Cathi Harris**.
Production Editor: **Terri McIntosh**.

Department of Medical History and Ethics, Box 357120, Seattle, WA 98195-7120. Telephone: (206) 616-1864. Fax: (206) 685-7515. E-mail: mbarnard@u.washington.edu.

13th Congress on Medical Law. Aug. 6-10, 2000. Marina Congress Center, Helsinki, Finland. A call for papers is being issued for the following topics: (1) Quality of and priorities in health care ethics, law, and policy. (2) Status and rights of patients. (3) Health care personnel. (4) Liability and enforcement; forensic medicine. (5) Forensic medicine and psychiatry. (6) Biomedicine and human rights. (7) Human dignity and the beginning and end of life. For information, contact: Eva Lindberg, Stakes, P.O. Box 220, FIN-00531, Helsinki, Finland. Telephone: (358) 9 3967 2173. Fax: (358) 9 3967 2030. E-mail: eva.lindberg@stakes.fi. World Wide Web: www.stakes.fi/medlaw. ■

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