Bioethics *in brief*

February 2001

UNIVERSITY HOSPITAL OF SUNY UPSTATE MEDICAL UNIVERSITY ETHICS COMMITTEE

CASE OF THE MONTH

THE CAREGIVER'S JUDGMENT VS. REGULATIONS TO PROTECT THE PATIENT:

Should a child be forced to take meds against her will?

CASE

Mrs. Thoreck is a woman with HIV, well controlled with the use of anti-viral medications. Her 9-year-old daughter, Jenny, was born HIV positive despite all standard protocol treatments for prevention of HIV transmission.*

Jenny has had unusually severe adverse reactions to all antiviral medications throughout her life. Dr. Tice, her attending physician, has tried many different combinations in efforts to minimize side effects, but to no avail. Jenny has weakness, nausea, vomiting, severe joint stiffness, and unbearable headaches; she can no longer attend school. She begs her mother to let her stop taking the medicine.

Mrs. Thoreck tells Dr. Tice that she is going to allow Jenny to stop the medicines because she is so sick from them that "she has no life anyway." Dr. Tice does not agree with this, but feels Mrs. Thoreck has her daughter's best interests at heart. She has always been a very caring and concerned parent. Mrs. Thoreck promises to bring Jenny in for bi-weekly blood tests to check her viral levels and reconsider putting her on medication if the levels rise. Dr. Tice acquiesces, afraid that she may stop coming altogether if he does not.

Later that month, Jenny falls while jumping rope and requires several stitches for a laceration. While stitching Jenny's forehead, the ED doctor, Dr. Larson, discovers she is no longer on anti-viral meds. He tells Dr. Tice he will report this to hospital administration if anti-viral treatments are not re-started immediately. (The hospital policy is that

continued, next page

**names and other identifying details have been changed.*

Bioethics *in brief*

ETHICS COMMITTEE

Bioethics in Brief is a newsletter of University Hospital's Ethics Committee, produced in cooperation with the Center for Bioethics and Humanities. Opinions expressed in *Bioethics in Brief* are those of the authors and should not be taken to represent the position of University Hospital or the Center for Bioethics and Humanities.

Questions, suggestions, or comments? Would you like to be added to our mailing list? E-mail us at ethics@upstate.edu.

Have a question about an ethical issue you're dealing with? We are always happy to talk in confidence about ethical concerns; you may reach us through the Center for Bioethics and Humanities at 464-5404. Ethics consultations are available by calling the hospital operator (464-5540) and asking for the ethics consultant on call, or by contacting any of the senior ethics consultants directly (Robert Daly, MD, 464-3104; Wendy Edwards, MD, 464-5404; Kathy Faber-Langendoen, MD, 464-5404; and Joel Potash, MD, 634-1100).

SUNY Upstate Medical University
University Hospital
MEDICINE AT ITS BEST®

Should a child be forced to take meds? *continued from page 1*

all children presenting to the hospital with HIV receive proper medications). Dr. Tice refuses to order the mother to restart medications for Jenny. Dr. Larson reports the case to administration. Mrs. Thoreck is informed by hospital personnel that she will be reported to Child Protective Services if she does not bring Jenny in for medications.

QUESTIONS:

- Is hospital administration the appropriate venue for Dr. Larson's concerns?
- Should Jenny be forced to take the anti-viral medications?

DISCUSSION:

This highlights a case in which an ethics consult would be of great value. Before this issue was reported to administration, a discussion among Dr. Tice, Dr. Larson, Mrs. Thoreck, and an ethicist could have helped prevent an adversarial situation and a breakdown in trust among colleagues, the patient and her mother, and the patient's mother and the physician.

WE SHOULD NOT AUTOMATICALLY "PLUG HER INTO A POLICY RECOMMENDATION" AND ASSUME THAT SHE HAS NO AUTONOMY OR VOICE IN THIS DECISION.

In such a discussion, each person's concerns would be addressed. The hospital policy would be reviewed for intent. Was the intent to make antiviral medications available to all children? Or was it to force any child with HIV to take the medications, regardless of the medical side effects? If so, how would that be enforced? How is the policy reflective of NY state law? A hospital designated as a New York HIV/AIDS Center must provide treatment regardless of ability to pay. By itself, however, this policy does not necessarily mean that all patients are required to accept treatment.

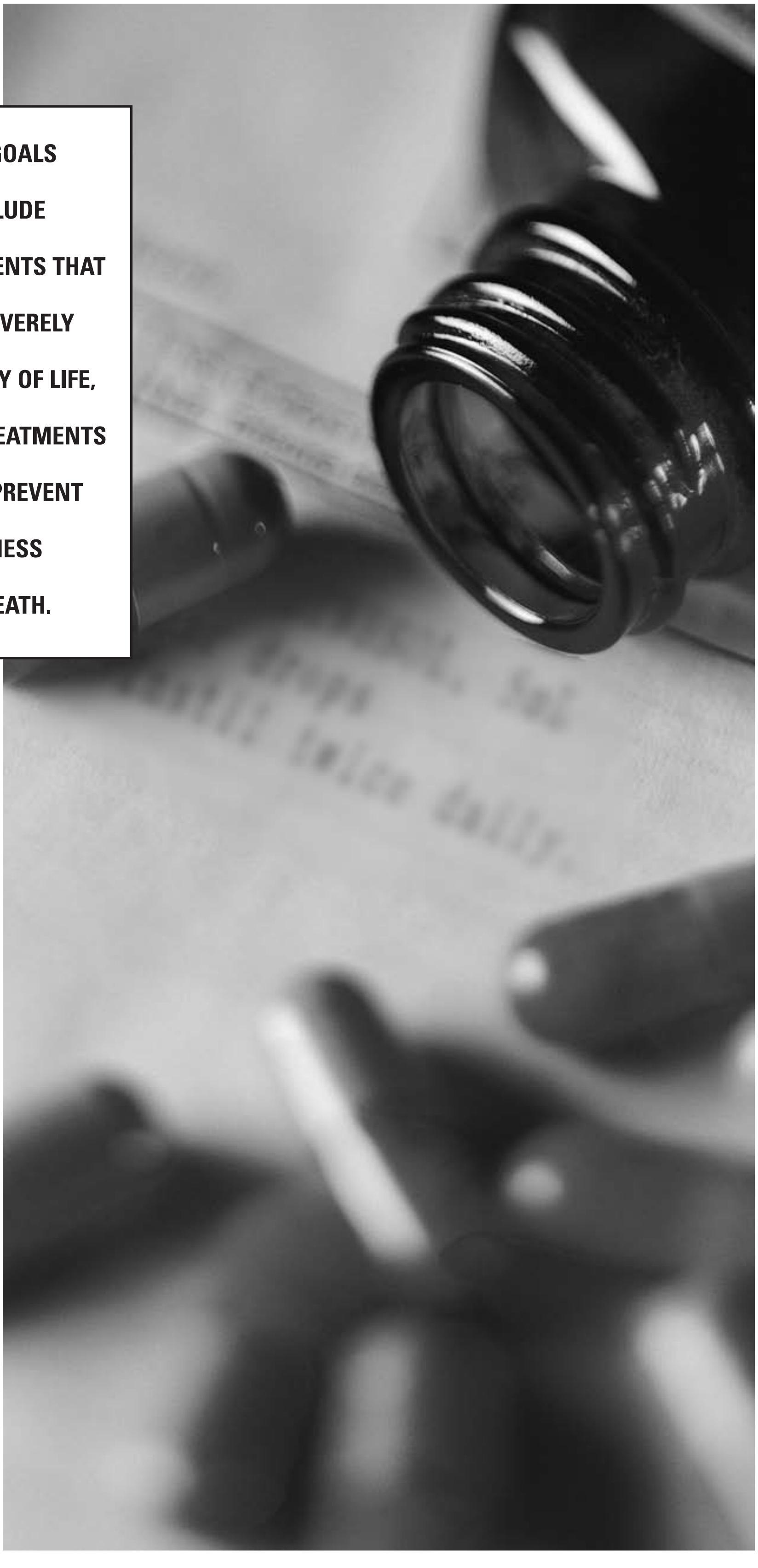
Without antiviral medications, Jenny will eventually become sick and die from her disease. However, if the medications make her so ill as to severely alter her quality of life, is it a reasonable suggestion to stop them, even if that could shorten her life? Dr. Tice has known Jenny and her mother for nine years. He had a sense of Mrs. Thoreck as a caring mother, interested in helping her daughter live as "normal a life as possible."

In this case, Jenny was left out of the discussion. It would have been helpful to speak with her and explain as gently as possible the likely consequences of stopping her medications. She has been struggling with her HIV+ status and its treatment for years; she may be able to offer important insight into the situation. Perhaps she understood more about what makes life unacceptable than we would expect from most 9-year-olds. A child psychologist may be helpful in understanding Jenny's view of her illness and its treatment. We should not automatically "plug her into a policy recommendation" and assume that she has no autonomy or voice in this decision.

MEDICINE'S GOALS DO NOT INCLUDE FORCING TREATMENTS THAT RESULT IN A SEVERELY REDUCED QUALITY OF LIFE, EVEN IF THOSE TREATMENTS WOULD LIKELY PREVENT FUTURE ILLNESS AND EVEN DEATH.

Child Protective Services should be used when we suspect parents are abusing or harming their children. Use of this agency was not optimal here at this stage of the case. It is difficult to imagine a court forcing a child to take medications that result in her being bed-ridden. However, just the process of reporting this case could result in Jenny's temporary removal from the home, adding to the trauma in her life.

Medicine's goals do not include forcing treatments that result in severely reduced quality of life, even if those treatments would likely prevent future illness and even death. On an ethical basis, absent newer medications with fewer adverse side affects, Jenny, her mother, and her physician should be allowed to make the choice about medications. Forced treatment should occur only by a court order, overruling parental authority. *(K. Kurtz/K. Faber-Langendoen)* ■



No Penalty for Pot

U.S. District Court Judge William Alsup in San Francisco, California banned the government from revoking physicians' licenses when "doctors recommend medical use of marijuana to a patient based on sound medical judgement." His injunction also blocked the government from initiating an investigation of a doctor solely because he or she prescribes marijuana. This will allow doctors who wish to discuss marijuana use with patients who may be helped by it—such as those suffering from the nausea and weight loss accompanying AIDS and cancer. It is unclear whether the government will appeal the ruling; several physician and civil liberties groups welcomed the news as expanding the appropriate care of patients. *(Based in part on* CNN *reports of September/December 2000)* ■

Baby Banking

Should women who do not want their newborn babies be allowed to drop them at "baby banks" with no questions asked? We are hearing more often about babies being abandoned in dumpsters or garbage bags. Mothers who are discovered doing this face criminal prosecution for murder or attempted murder. A concerned group of citizens believes that in most of these cases, the mothers are not intending to kill their babies, but are simply overwhelmed (substance abuse, domestic violence, poverty, and age). They have proposed a national program entitled "Operation Foundling" that would allow women to leave their unwanted children at places such as designated churches, fire, and police departments. Some in the U.S. think this is a good solution because of the many infertile couples who would be overjoyed to become the parents of these infants. Others say it just points out how derailed our social values are regarding life, adoption, and abortion. Would having safe places to leave unwanted babies encourage or increase sexual practice among women who can't care for their babies?

Unlikely. It may however, prevent some cases of infanticide. (*Based in part on* MSNBC News *report 12/4/00*) ■

Who Knows About You?

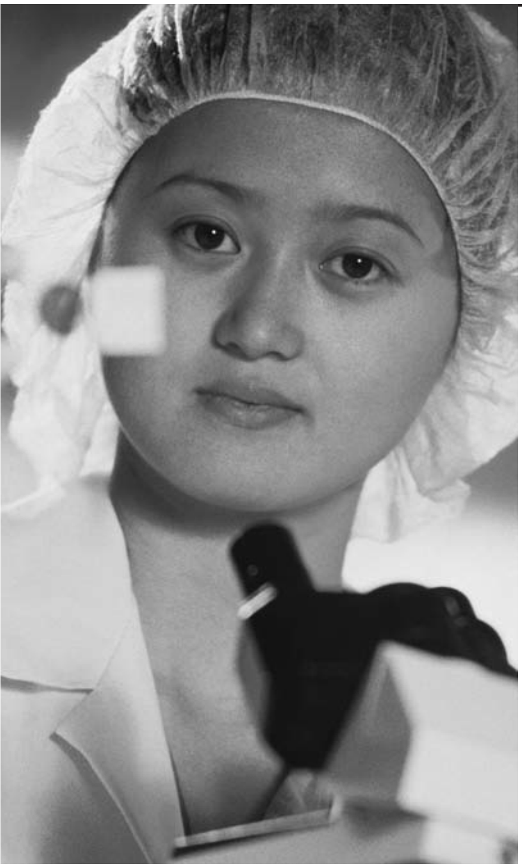
Rapid advances in genetics, combined with computerized databases, means that increasing amounts of health data are being collected and made available to a wider group of people. What used to be a private exchange of information between patients and their family physicians is now quite likely not so private. If genetic information about people is available electronically, questions must be asked: Who "owns" a person's medical history and genetic information? Who is entitled to have access to it? Is one's employer or insurance company able to find out genetic information that may affect one's employability/insurability?

As a parting act of his administration, President Clinton issued the first federal law protecting medical privacy. The law provides for a range of punishments to violators including fines and prison terms.

Senior aides said such provisions "will greatly protect the privacy of individual health records against improper use by insurers and employers." The administration stated that "persons' privacy violations must be kept to a minimum...; people must not be harmed by participation in genetic testing." Leaders in the health care industry stated they would ask President-elect Bush to revise the new rules, saying they are too stringent. However, broad public support for the safeguards in the law may affect how much revision the Bush administration will seek. *(Based in part on a* New York Times *article 12/21/00)* ■

Euthanasia Legalized

In November, the Netherlands became the first country to legalize euthanasia. For years, the Dutch have officially prohibited euthanasia but agreed not to prosecute physicians if guidelines were followed. Once the law goes into effect in early 2001, physicians will be legally protected if the physician is convinced the patient's request is sincere and voluntary and the patient is fully informed of the diagnosis, treatment options, and other alternatives. The patient must have "unbearable suffering" but need not be terminally ill. Currently, about 3 percent of all deaths in the Netherlands occur by euthanasia or assisted suicide. A Vatican spokesperson condemned the law saying "It is a very sad record for the Netherlands to become first to...approve a law that goes against human dignity". (*Based in part on* New York Times *article, 11/29/00)(M. Thompson/ K. Kurtz)* ■



Research Ethics Training to be Required in the Future

In the 20th century, medical research resulted in unprecedented medical advances. At the same time, some patients were coerced into participating, deceived about alternative treatments, or given inadequate information about the risks of being involved. This sad legacy is seen in the Tuskegee syphilis trial (where African American men were not treated for syphilis), Willowbrook (where institutionalized children were deliberately infected with hepatitis), and radiation experiments (where several patients were unknowingly injected with radioactive substances). The Federal government has tried to protect research subjects by mandating special committees, called "institutional review boards," that review all research done in an institution.

The university will soon be required to show that all staff involved in research activities understand their responsibilities to ensure that the rights of research subjects are protected. The office of Dr. John Lucas, vice provost for research, is developing an upstate-wide program to meet this requirement. In the meantime, if you are interested in learning more about research ethics, a well designed and easy-to-use website from the National Institutes for Health provides a useful tutorial. It can be accessed at http://ohsr.od.nih.gov/ *(K. Faber-Langendoen)* ■

Joined at Birth, Separated by Law

On August 8, 2000, twin girls Jodie and Mary (pseudonyms to protect privacy) were born in Manchester, England. During pregnancy, it was discovered that the twins were conjoined and would need a medical facility able to provide special care. The parents traveled to England from their remote homeland in Malta for the birth of their babies. The sisters shared one heart and one pair of lungs and were joined at their lower abdomens.

OUR PRESENT MEDICAL VALUES GENERALLY FAVOR INTERVENTION IN AN EFFORT TO MAXIMIZE A CHANCE AT LIFE.

Jodie, the stronger and alert baby, supported her much weaker sister, Mary, who could not sustain effective heart and lung function independent of Jodie. But Jodie could not remain Mary's life support indefinitely; without surgical intervention to separate the girls, doctors predicted that both would die in a few months. Doctors expected that if the girls were separated, Mary would surely die but Jodie might live.

Jodie and Mary's parents, devoutly religious, refused the surgery. They stated, "Why should we kill one of our daughters to enable the other one to survive?"[1] The parents believed that to intervene in such a dramatic way would violate the will of God. In addition, the parents argued that Jodie's disabilities would be overwhelming and she would be socially stigmatized when they returned to Malta. Despite the parents' objections, surgeons in the Manchester hospital went to court seeking permission to perform the surgery. The court ruled in favor of the surgeons on the basis that if the surgery did not proceed, both children would die. It is worth noting that in the U.S., even in situations in which parents agree to the separation of conjoined twins, surgeons may still turn to the courts for permission to conduct the surgery, and for assurances that there will be prosecutorial immunity from homicide charges when it is expected that one twin will die.[2]

SHOULD OUR MORAL, ETHICAL AND LEGAL FRAMEWORK PERMIT US TO ACT IN A MANNER THAT HASTENS THE DEATH OF ONE IN ORDER TO SAVE THE LIFE OF ANOTHER?

Surgeons separated the girls in early November and, as expected, Mary died shortly afterwards. Jodie survived and although she was in critical condition following the operation, it has been reported that her prognosis, for the most part, is good. She is expected to require multiple reconstructive surgeries over the next few years and may not be able to return home for several months.

Responses regarding law and medicine's authority to intervene against the parents' wishes varied. Should our moral, ethical and legal framework permit us to act in a manner that hastens the death of one in order to save the life of another? Some believe that no institution should make any decision that effectively selects one life over another. Others argue that the state ought not override the parents' agonizing decision, particularly given that a good outcome from the surgeries is by no means certain.

It is unclear how the courts in New York would treat this situation, as there is very little legal precedent on point. In New York, as in most states, medical decision-making for minors is ultimately based upon the best interests of the child. In the search for analogies to better understand

Jodie and Mary's situation, some commentators have drawn a tenuous comparison to a court-ordered blood transfusion for a minor against the religious beliefs of the child's parents. But this analogy soon fails. When we order a treatment for a child over the objections of the parents, the decision is made in the best interests of the child. Here, there were two children and while the decision to separate the twins may have been in the best interests of Jodie, it seems problematic to argue that it was in Mary's best interests when it was certain she would not survive.

Our present medical values generally favor intervention in an effort to maximize a chance at life. Legal scholar George Annas writes, "[I]t is better to intervene to try to save one life than to passively observe two lives end. Both law and ethics support reasonable medical attempts to separate Siamese twins with conjoined hearts. Nonetheless, defining a rationale better than human instinct is perplexing, as is developing a fair and useful procedure to apply it."[2] Whether this sentiment should trump parental authority in this case is less clear. *(L. Baum)* ■

---

[1] *BBC News On Line*, 8/25/00.

[2] Annas, G. J., "Siamese Twins: Killing One To Save The Other" Hastings Center Report 17, 2, (1987): 27-29.

Nursing Education in Ethics: Off to a Great Start!

Last April, Wendy Edwards, Lester Friedman, and Kathy Kurtz (faculty in the Center for Bioethics and Humanities) began a new nursing education initiative funded by the hospital. They developed three units of ethics education regarding ethical issues in end-of-life care, and completed all three units on the neuroscience, critical care, and hematology/oncology floors in August. The next sessions began in January with medicine and cardiology. Specific topics include patient/physician relationships, patient autonomy and physician integrity, medical futility, advance directives, and end-of-life care plans.

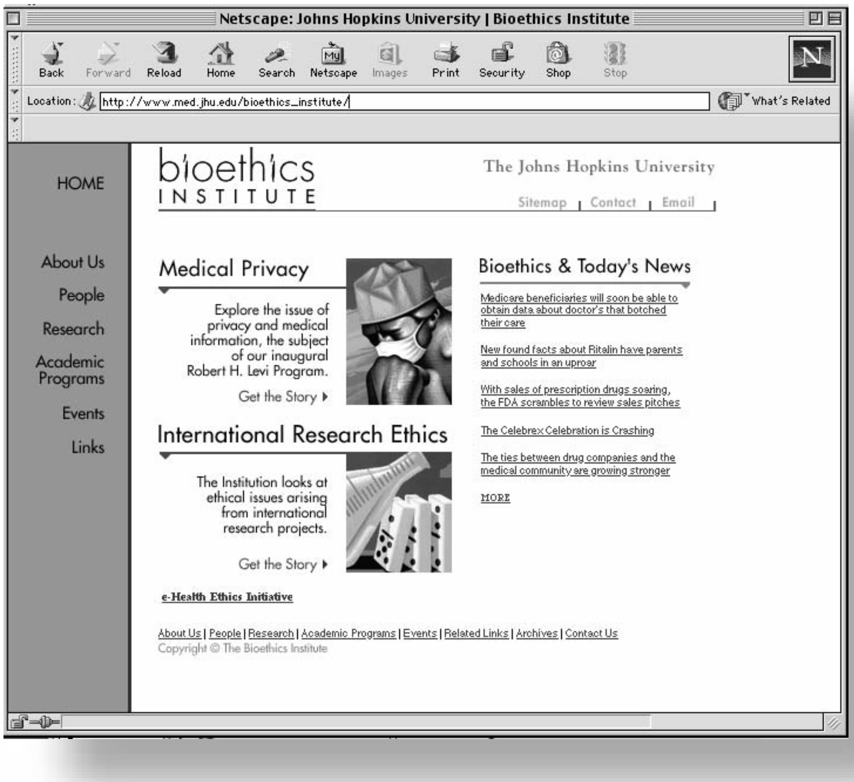
The data from the first session reveals that 102 nurses, nurses' aides, and supervisors attended the sessions. 92 percent of the evaluations were favorable regarding content and presentation. The nurses stated they have learned new ways to be "moral players" in ethical situations that arise on their floors. We want to thank all the attendees for their excellent participation and for alerting us to particular institutional issues that affect ethical practice.

This effort was aided by foundational education on advance directives, developed by an interdisciplinary task force led by Maxine Thompson, CSW.

If you have ideas for ethics education that you would like to see implemented, please speak up now, as we are formulating ideas for 2001. Please e-mail Kathy Kurtz at kurtzk@upstate.edu with your thoughts—we would appreciate hearing your views on what would be useful! *(K. Kurtz)* ■

Web Site of the Month

www.med.jhu.edu/bioethics_institute/



Netscape: Johns Hopkins University | Bioethics Institute

Location: http://www.med.jhu.edu/bioethics_institute/

bioethics INSTITUTE

The Johns Hopkins University

Medical Privacy

Explore the issue of privacy and medical information, the subject of our inaugural Robert H. Levi Program.

Get the Story

International Research Ethics

The Institution looks at ethical issues arising from international research projects.

Get the Story

Bioethics & Today's News

Medicare beneficiaries will soon be able to obtain data about doctor's that botched their care

New found facts about Ritalin have parents and schools in an uproar

With sales of prescription drugs soaring, the FDA scrambles to review sales pitches

The Celebrex Celebration is Crashing

The ties between drug companies and the medical community are growing stronger

MORE

e-Health Ethics Initiative

About Us | People | Research | Academic Programs | Events | Related Links | Archives | Contact Us

Copyright © The Bioethics Institute

Johns Hopkins' Bioethics Institute is a great source for many bioethical issues in the news, providing useful links to articles in newspapers across the world. ■

SUNY Upstate Medical University
University Hospital

Ethics Committee
750 East Adams Street
Syracuse, New York 13210