Since 1996, HAART (highly active antiretroviral therapy) has been the standard of care for patients with HIV disease in the United States. HAART has been an extraordinary life-saving tool. Just a few years after HAART became widely available, studies reported 60% to 80% reductions in new AIDS illnesses, hospitalizations and deaths. Because of HAART, many people with HIV/AIDS are living longer, more productive, and more normal lives. Although HAART does not cure HIV infection and may produce some debilitating side effects, HAART has changed HIV disease from a death sentence into a chronic, but usually manageable, condition. HAART also has contributed to an improvement in the overall quality of life for most HIV patients. Some people who were on disability are returning to work and changing their plans for the future. More HIV-positive women are considering pregnancy because the rates of mother-to-child transmission have come down to less than one percent for women on successful HAART regimens with undetectable viral loads.

This wonderful medical development has been observed with interest by Law & Health Care Program faculty member Deborah Weimer. Professor Weimer has been a member of the law school’s clinical faculty since 1988. She helped create the law school’s innovative AIDS Legal Clinic, a clinic she taught through the darkest period of the AIDS epidemic in Baltimore and one that she is still teaching. The advent of HAART has changed the nature of the Clinic’s caseload over time from primarily discrimination and standby guardianship cases to cases dealing with medication adherence and helping HIV/AIDS patients re-enter the workforce with appropriate accommodations and support. The evolution of the Clinic’s work over the last 22 years is a case study in the interaction between law and medicine and how one field shapes the other. In addition, a successful long-term partnership with the outpatient pediatric AIDS clinic at the University of Maryland Medical System has demonstrated the value of joining both fields in an interdisciplinary approach to addressing the challenges of a medically-needy population.

The University of Maryland AIDS Legal Clinic
The School of Law’s AIDS Legal Clinic was among the first HIV/AIDS legal clinics in the United States, serving the legal needs of individuals and...
The Law & Health Care Newsletter is published twice a year by the Law & Health Care Program at the University of Maryland School of Law 500 West Baltimore Street Baltimore, MD 21201

L&HCP Faculty
Diane E. Hoffmann, JD, MS Director, L&HCP and Associate Dean

There are a number of law school faculty who contribute to the diversity of the Law & Health Care Program through their teaching and scholarship. They include:

- Richard Boldt, JD
- Kathleen Hoke Dachille, JD
- I. Michael Greenberger, JD
- Deborah S. Hellman, JD, MA
- Leslie Meltzer Henry, JD, MSc
- Amanda Pustilnik, JD
- Karen Rothenberg, JD, MPA
- I. Michael Greenberger, JD
- W. Lawrence Fitch, JD
- Deborah J. Weimer, JD, LLM
- Deborah S. Hellman, JD, MA
- Kathleen Hoke Dachille, JD
- Amanda Pustilnik, JD
- Karen Rothenberg, JD, MPA
- Lawrence Sung, JD, PhD
- Ellen M. Weber, JD
- Deborah J. Weimer, JD, LLM

Adjunct Faculty
Ellen Callegary, JD
Callegary and Steedman

- Marc Charmatz, JD
- National Assn. of the Deaf
- James Doherty, Jr., JD
- Pecore & Doherty, LLC
- W. Lawrence Fitch, JD
- Maryland Dept. of Health and Mental Hygiene
- Janet Lord, LLB, LLM
- Blue Law, LLC
- Kevin McAnaney, JD
- Law Office of Kevin G. McAnaney
- Lisa Ohrin, JD
- Sonnenschein Nath & Rosenthal LLP
- Robert T.M. Phillips, MD, PhD
- Forensic Consultation Association, Inc.
- Frank Palumbo, PhD, JD
- University of Maryland School of Pharmacy
- Sanford Teplitzky, JD
- Ober/Kaler

L&HCP Managing Director
Virginia Rowthorn, JD

HIV/AIDS Community
Cont. from p. 1

families impacted by HIV illness since 1987. When the Clinic first opened its doors, the general public still considered AIDS a disease that primarily affected gay men but the law school’s clinical faculty realized that there was also a great need for AIDS-related legal services among inner-city Baltimore’s low-income population, particularly African-American women of childbearing age. The Clinic was prescient in targeting this population for assistance.

Through the Clinic, student attorneys provide legal services to individuals with HIV who usually have nowhere else to turn for advice, advocacy and legal representation. The Clinic also focuses on “impact work” with the legislature and through litigation, and has an excellent track record with the Maryland General Assembly. As an example, students were instrumental in the passage of a child welfare bill that allowed caregivers of children to sign affidavits to enroll children in school if they move into a new county. Prior to the passage of this bill, when a parent died of AIDS, and the children moved to live with their grandparent or another relative, the children would often be forced to sit out of school for months while the grandparent sought an order of legal custody from the Circuit Court. Prior to the passage of this bill, when a parent died of AIDS, and the children moved to live with their grandparent or another relative, the children would often be forced to sit out of school for months while the grandparent sought an order of legal custody from the Circuit Court. Students were also involved in helping to draft legislation authorizing a needle exchange program in Baltimore City to help prevent the spread of HIV through the sharing of needles.

As part of their clinical experience, students participate in a weekly seminar that focuses on professional responsibility and ethical issues in interdisciplinary practice as well as interviewing, counseling, negotiation, and litigation skills. The class also addresses the special needs of clients with HIV illness. Medical providers and social workers are invited to address the class to educate students about HIV illness and the challenges faced by children and families. Each student has two to four cases at any one time, and is expected to work at least 20 hours per week on their cases.

Referrals to the Clinic come from all over Maryland, but the primary service area is Baltimore City and surrounding counties. In 1987, the Clinic began working with families and children impacted by HIV when Dr. John Johnson, an immunologist at the University of Maryland Medical System, invited the AIDS Legal Clinic into his Pediatric AIDS Care and Treatment Program (known as the PACE Clinic). Dr. Johnson was hoping to find support for his patients—children with HIV illness and their families. The mothers of the children were, for the most part, also HIV-positive, but received their health care elsewhere. Most of these families were in a crisis situation. At that time, when an individual received an AIDS diagnosis, life expectancy was about two years (usually about 10 years after infection with HIV for adults, but about one-fourth of children were fast progressors). These mothers were very concerned about caring for their HIV-positive children and making a plan for custody of them. The majority of the mothers were functioning as single parents although most had family support, including at least one older child who was not HIV-positive. The laws at the time did not allow a parent to share custody with a non-parent. One of the Clinic’s first collaborative projects was addressing this issue as a policy matter. Students found that New York had just enacted a standby guardianship statute to address this situation. The students drafted similar legislation and helped shepherd it through the Maryland General Assembly.

Although Dr. Johnson passed away, Professor Weimer’s clinic continued to work with the PACE Clinic and later with the Evelyn Jordan Center, an outpatient HIV/AIDS clinic at the Univer-
University of Maryland School of Medicine. This year, the Evelyn Jordan Center, working jointly with the AIDS Legal Clinic, received funding from the Ryan White Foundation to create a formal medical/legal partnership with the clinic and to enhance the services that this multidisciplinary partnership provides to HIV/AIDS patients in Baltimore.

Having this new funding available has enabled the AIDS Legal Clinic to initiate a Clinical Fellows Program this fall. Two recent law graduates have been hired as the first Clinical Fellows. The Fellows will work with faculty and students on clinical cases, and have the opportunity to learn firsthand about interdisciplinary practice and how to effectively provide legal services to support the needs of families and children. They will assist in supervision of student attorneys and learn about the goals and methods of clinical teaching and also enable the Clinic to expand the number of HIV-positive clients it can serve.

**HIV/AIDS Legal Assistance in the HAART Era**

As noted earlier, the advent of HAART has changed the nature of the cases handled by the law school’s AIDS Legal Clinic. When the clinic first began serving clients, it handled a wide variety of civil legal cases, including employment and health care discrimination, social security disability appeals, breach of confidentiality, standby guardianship, custody, and drafting wills and powers of attorneys. With the advent of HAART, the clinic’s case load has evolved, as one would expect when the source of clients’ legal problems is a chronic disease rather than a terminal illness.

**Drug Therapy Adherence Cases**

In some respects, the Clinic’s current caseload involves cases that are more complex and ethically nuanced than earlier cases. One difficult issue relates to drug adherence among children born of women with HIV/AIDS. These “second generation” cases often come to the Clinic as Child In Need of Assistance (CINA) cases in which the Clinic represents the parent of a child who has been prescribed HAART therapy. The question that presents itself to the Clinic is whether the parent of a child—especially a child age 12 or older—who refuses to take medication or takes it irregularly, can be held responsible for non-adherence and whether this should be considered child neglect. Clinic students have argued that, in some cases, just the fact of a child’s non-adherence is not sufficient grounds for a neglect finding because there are often multiple factors at play that interfere with drug adherence. Further, Clinic students have argued that removing the child from the parent may harm the child. For example, in one recent case, a mother and her 15 year-old daughter were seriously ill and did not wish to be separated. The Department of Social Services felt that its resources were inadequate to help this family. It became clear that the 15 year-old’s depression was a major factor in her refusal to take medication. When connected with a mental health provider, she did improve for a time. Unfortunately, this provider left the practice and her patient relapsed. Clinic faculty and student attorneys believe that counseling and family assistance is usually a better solution than removing the child from her home and placing her in foster care.

The Clinic has represented HIV-positive mothers in several cases where their newborns were removed because of a positive screen for marijuana in the mother and/or baby. Officials take this step because they are concerned that the mother will not adequately ensure her child’s adherence to HAART (which is administered to newborns of HIV-positive women for an extended period even if the newborn initially tests negative). But removing a child and placing him in foster care is an extreme reaction to this situation. Further screening of the mother is essential—in one of these cases, the mother had been employed full time for three years in the same workplace, owned her own home and was raising two older children with no apparent difficulty. In most situations, a less dramatic intervention can address the concern (e.g., employing a visiting nurse to help administer the medication). In a 2003 article entitled “Medical Treatment of Children with HIV Illness and the Need for Supportive Intervention: the Challenges for Medical Providers, Families and the State,” Weimer argued that these families need supportive intervention not punishment because, not only is such intervention much less expensive, it avoids the trauma of separating the mother and child at birth. (See 54 Juvenile and Family Court Journal, 1 (Winter 2003)).

**Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) Cases**

A common case handled by the AIDS Legal Clinic involves helping clients appeal denials of Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). Today, because of the availability of effective medication, people are less likely to get the opportunistic infections that lead to an AIDS diagnosis. Many are able to return to full time work. However, other patients have...
difficulty with the HAART medication regimen, or develop side effects, and are unable to work. Often the patient has a combination of impairments, including HIV illness, that is disabling. But these individuals often do not develop the opportunistic infections that would lead to a presumptive finding of disability. These cases are more complex because medical evidence of multiple illnesses, including evidence of mental impairment such as depression, must be presented. They almost always go to a full hearing before an administrative law judge.

The Lambda Legal Defense and Education Fund, an organization that advocates on behalf of people with HIV/AIDS, submitted comments to the Social Security Administration (SSA) in response to a March 2008 Notice of Proposed Rulemaking inviting public comment on how it might update its HIV disability guidelines. In its comments, Lambda outlined ways to improve SSA’s criteria for evaluating HIV disability so that the criteria reflect the complications of new AIDS therapies, including increased attention to claims from individuals who are unresponsive to treatment or suffer the combined impact of HIV and other impairments, such as impaired mental functioning, metabolic abnormalities, and hepatitis.

Another SSI/SSDI-related situation the AIDS Legal Clinic handles involves counseling patients about maintaining social security benefits during a trial work period and avoiding overpayments of benefits if a client starts earning more money than permitted by SSI/SSDI. Counseling upfront can help to avoid this outcome later. Student attorneys are prepared to counsel clients about their rights and are also involved in helping clients who are charged with receiving overpayments.

**Employment Discrimination Cases**

The Clinic handles discrimination claims under the Americans with Disabilities Act (ADA) and the Family Medical Leave Act (FMLA). Employers are often unaware of the intermittent leave provisions of the FMLA. People with HIV illness have the right under the FMLA to take off time on a regular basis or as needed for medical appointments. Student attorneys educate clients about their rights under the FMLA and occasionally advocate directly with the employer, depending on the client’s situation. They have also represented clients who were fired in violation of their rights under the ADA and the FMLA.

**The AIDS Legal Clinic – New Opportunities**

In December 2008, an AIDS Service organization in Baltimore known as HERO (Health Education Resource Organization) closed its doors due to loss of funding, leaving a huge gap for low-income, HIV-positive individuals needing HIV/AIDS legal services. The Ryan White Foundation grant recently awarded to the University of Maryland will help fill this gap and enable the AIDS Legal Clinic to significantly increase the number of cases it presently handles.

Although medical advances allow people with HIV illness to live longer and have relegated some of the more blatant forms of HIV/AIDS discrimination to the shelves of history, Weimer warns AIDS advocates not to become complacent. The Clinic still gets cases in which individuals are discriminated against simply because of their HIV/AIDS status. Also, protecting the confidentiality of people with HIV is still an issue. Some of the privacy protections put in place in the early years of the AIDS epidemic have been eroded. For example, as a precondition for the receipt of Ryan White funds, Maryland (and other states) have recently had to implement name-based HIV/AIDS infection reporting and do away with unique identifier reporting.

In addition to these ongoing legal questions, HAART therapy and a generation of children infected by AIDS has created new legal issues. Weimer is very concerned at the speed at which the epidemic is spreading among adolescents and young adults, particularly in the African-American community. Medication compliance is a particular challenge with teenagers who are HIV positive. Issues of consent for testing and treatment are also a concern for this group. For example, can an adolescent consent or refuse testing or treatment for HIV without a parent or guardian’s consent? The Clinic has worked on implementing an appropriate consent process for the adolescent population.

The AIDS Legal Clinic is also beginning to study the role it can play on the international level. The Clinic’s counterparts at the medical school and hospital have traveled to Ghana and South Africa and other countries dealing with a large HIV population to share their experience in treating HIV illness and preventing the transmission of HIV from parent to child. One of the current projects of the law school’s Clinic is to explore ways to best apply its legal expertise to fight the HIV epidemic on the international level.

Weimer believes that one of the Clinic’s roles is to continue to fight discrimination when it occurs and raise the issue in front of judges, policy makers, and the community until it becomes a thing of the past.
Over the last two years, three University of Maryland law students—Mbili Mwaniki, Danielle Turnipseed, and Lola Burford—have had the opportunity to work at UNAIDS in the organization’s Human Rights Programme Office. Another student, Rebecca Spence, is interning there this fall. The Human Rights Programme Office works with national governments to help them meet their human rights obligations and to empower individuals and communities to claim their rights in the context of the HIV epidemic. The governing principle of the Office is the belief that protection of human rights, both of those vulnerable to infection and those already infected, is not only a moral imperative but also produces positive public health results against HIV.

Susan Timberlake, Senior Human Rights and Law Adviser, who supervises the law students is an attorney who is internationally known for her work on legal and human rights issues related to HIV/AIDS. Timberlake spent a number of years working as an attorney at the United Nations High Commissioner for Refugees before joining UNAIDS in 1996. All the students who have worked with Timberlake have found her to be very knowledgeable in global health issues and an incredible supervisor.

The law students, all of whom had a prior interest in HIV/AIDS advocacy and global health, have been able to work closely with the Human Rights Programme team in researching legal and policy issues that relate to the core human rights identified by UNAIDS as a critical in the fight against HIV. These core human rights spell out the protections that should be afforded to individuals with HIV illness and all individuals with regard to testing, prevention, and education about HIV illness. They include:

• Non-Discrimination: individuals should be protected against discrimination if they seek counseling or medical assistance and should not be discriminated against if they are HIV-positive;
• Right to Privacy: individuals should be protected against mandatory HIV testing and an individual’s HIV status must be kept confidential;
• Right to Liberty and Freedom of Movement: individuals with HIV must be protected against imprisonment, segregation, or isolation in a special hospital ward simply because of their HIV status;
• Right to Education/Information: all individuals should have access to HIV prevention education and information and sexual and reproductive health information and education;
• Right to Health: All individuals should have access to all health care prevention services, including those for sexually transmitted infections (including tuberculosis), as well as access to voluntary counseling and testing, and to male and female condoms.

For the three students who have completed a semester at UNAIDS, each has commented that the experience of working on these issues at the global level was an experience that will shape their future legal careers.
HEALTH LAW & BROADWAY:
PROFESSOR ROTHENBERG STUDIES
THE USE OF THEATRE AS A TEACHING TOOL

Professor Karen H. Rothenberg, who is rejoining the L&HCP faculty after serving as Dean of the law school for 10 years, will spend academic year 2009-2010 on sabbatical. Her sabbatical project will focus on combining two of her great loves—theatre and health law. Rothenberg believes that theatre offers a structured and stimulating avenue to engage students and the public in identifying and discussing complex health and science policy issues. Her research will focus on cataloging the plays and musicals that relate to health and science themes and the use of theatre as a learning tool in the area of health and science policy. Rothenberg will spend this year conducting research on her theater project (in addition to working on other projects relating to stem cell research and prenatal genetic testing) as a Visiting Professor at the Berman Institute for Bioethics at Johns Hopkins University. She will also serve as a Scholar-in-Residence at Columbia Law School and Senior Sabbatical Fellow at Columbia University Law School’s Center for the Study of Law and Culture.

Numerous plays that have appeared on Broadway deal with health and science issues, including the following three plays that opened last year:

- **33 Variations**, a play by Moises Kaufman about a musicologist who is researching Beethoven’s manuscripts while suffering from Amyotrophic Lateral Sclerosis (ALS) and coping with medical decision-making at the end of life.
- **Distracted**, a play by Lisa Loomer about a mother trying to deal with her son’s attention deficit disorder and whether to treat him with drugs.
- **Next to Normal**, a musical by Brian Yorkey about a housewife suffering from mental illness and the implications of various treatments, including drugs and electroshock therapy, for her and her family.

Rothenberg plans to study the use of plays and musicals such as these to encourage dialog on complex health and science issues and to identify issues of concern that should be taken into consideration by health policy makers. She also hopes to use her sabbatical to develop an interdisciplinary professional course to teach students to recognize, discuss, and find policy solutions to complex, and often emotional, health and science policy issues. Rothenberg’s long-term goal is to fill a void in current scholarship and propose an innovative way to combine L&HCP INTERDISCIPLINARY COURSES

In addition to the interdisciplinary work of Professor Deb Weimer, other members of the Law & Health Care Program are approaching their teaching and scholarship from an interdisciplinary perspective.

**Critical Issues in Health Care**

This course, taught by Diane Hoffmann, gives students from the schools of medicine, law, nursing, dentistry, social work and pharmacy the opportunity to reflect on the legal, ethical and policy issues surrounding a number of health care issues.

**Conflict Resolution in Health Care**

This course, offered by Professors Hoffmann and Wolf, allows a multidisciplinary group of students to examine the theories of conflict resolution, sources of conflict in health care, their personal orientation to conflict and styles of conflict resolution, and various methods of resolving conflicts in health care settings.

**Health Law: Special Topic: Legal and Policy Issues in End-of-life Care**

This multidisciplinary seminar, taught by Professor Jack Schwartz, examines the last three decades’ legal developments in the law governing decision making about the use of life-sustaining medical treatments.
Law and Policy of Emergency Public Health Response

This course, taught by Professor Michael Greenberger, surveys federal, state, and local laws directed toward giving extraordinary powers to each level of government to respond to catastrophic public health events whether caused by natural disasters or terror attacks.

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In Professor Hoffmann’s Critical Issues in Health Care course, students are required to write journals as part of their experience. Excerpts from those journals reveal the important lessons that flow from learning in an interdisciplinary course:

“It was extremely rewarding to hear what other non-law students had to say about the laws and standards being discussed. Their questions and manner of thinking forced me to re-examine my approach in certain aspects.” (Law Student)

“Looking at the medical field on such a large scale and through the eyes of different fields gave me an incredible amount of perspective. Understanding how I will be both supported and limited by law, ethics, and policy will have a very important impact on my career as a physician . . . .” (Medical Student)

“I have realized that the structure of law is not far off from medicine—a lawyer is provided with a set of laws to interpret and apply in order to achieve the appropriate outcome, and a doctor is prepared with a set of scientific facts to also interpret and apply—every legal case is situational, as is every patient’s health.” (Nursing Student)

MEDICAL/LEGAL PARTNERSHIPS: A FOCUS FOR SCHOLARSHIP & TEACHING

Medical/Legal Partnerships integrate legal service and advocacy into health care settings to address the legal issues that are connected to poor health outcomes. Increasingly, law schools are offering opportunities for students to participate in interdisciplinary medical/legal partnerships and to learn the value of collaborative problem-solving. Professor Weimer’s successful partnership with the AIDS clinics at the University of Maryland Medical System has led her to develop a scholarly interest in interdisciplinary partnerships, which she views as a highly effective model to provide comprehensive assistance to clients in need. Her current scholarship focuses on interdisciplinary practice with grandparent families, a project that grew out of her work with families impacted by HIV illness. Her article “Providing Interdisciplinary Services to At-Risk Families to Prevent Placement of Children in Foster Care” will be published in a forthcoming issue of the Juvenile and Family Court Journal. Recently, Weimer has also had the opportunity to share her experiences working with medical organizations.

At the AALS Annual Meeting in January 2009, Weimer spoke about her work on a joint Pro-Bono and Public Service Opportunities Section and Law, Medicine and Health Care Section panel entitled, “Opportunities for Collaboration and Interdisciplinary Learning: Medical-Legal Partnerships.” This month, Professor Weimer will be speaking at a conference on Interdisciplinary Collaborative Education at Georgia State Law School. The conference is designed to address partnerships between law schools and the health professions. Weimer will speak on a panel entitled “Advocacy and Policy Change.” Director of the Law & Health Care Program and Associate Dean Diane Hoffmann, will speak at the same conference on a panel entitled, “The Challenges of Crafting an Educational Curriculum in Interdisciplinary Settings.”
Amanda Pustilnik

Professor Amanda Pustilnik joined the Maryland faculty this fall as an Assistant Professor of Law. Prior to coming to Maryland, Pustilnik was a Climenko fellow at Harvard Law School. Pustilnik graduated from Harvard College magna cum laude and Phi Beta Kappa, with a concentration in History of Science. She also served as the John Harvard Visiting Scholar at the University of Cambridge, Emmanuel College, where she was affiliated with the History and Philosophy of Science department. Prior to law school, Pustilnik worked for McKinsey & Company as a management consultant. In 2001, Pustilnik graduated from Yale Law School, where she was an editor of the Yale Journal of International Law and published notes on law and science. After law school, she clerked for the Hon. José A. Cabranes on the United States Court of Appeals for the Second Circuit. Pustilnik then joined the law firm of Covington & Burling in Washington D.C. where she focused on pharmaceutical and securities litigation and regulation. She is the legal advisor to the Board of Network 20/20, a for-profit organization.

Professor Pustilnik’s scholarship focuses on the intersection of law & science. Her current research includes the role of neuroscience in criminal law and the application of tort law to semi-autonomous machines. Pustilnik is teaching Criminal Law this Fall and will teach Evidence and Neuroscience and the Law in the Spring.

Leslie Meltzer Henry

Professor Henry is joining the faculty this fall as an Assistant Professor of Law after serving as a Visiting Professor and Health Law & Policy Fellow last year. Prior to joining the law school faculty, she was a Greenwall Fellow in Bioethics and Health Policy at the Johns Hopkins Berman Institute of Bioethics. Henry earned her JD at Yale Law School, her MSc in the History of Medicine at University of Oxford, and her BA, summa cum laude, in both History and Medical Ethics at the University of Virginia. She is currently a doctoral candidate in the Department of Religious Studies (bioethics specialization) at the University of Virginia.

Henry’s undergraduate and Masters theses focused on research ethics, an area of interest that she has pursued in her service on the Yale Institutional Review Board, at the NIH Office of Human Subjects Research, and as Chair of the American Society for Bioethics’ research ethics subcommittee. In her doctoral research, Henry is exploring the concept of “dignity,” its various interpretations in bioethics and throughout history, and the degree to which it has any moral force as a normative concept. Drawing on her philosophical, legal and theological training, she will examine how dignity is used at the edges of life, how it differs from notions of personhood, autonomy and identity, and whether rationality and/or sentence are prerequisites to possessing dignity.

Henry is teaching Public Health and the Law in the Fall and the Bioethics Seminar in the Spring.
Imagine you are counsel for a hospital in which the following situation arises. A patient is in the intensive care unit (ICU) and close to death. The patient’s wife informs the attending physician that she has contacted a urologist to perform a sperm retrieval procedure on her husband so that she can attempt to conceive a child with her husband’s sperm. The physician is troubled by this request and contacts you. You call your hospital’s ethics committee for help. Will you and the stakeholders involved in this case be helped by the ethics committee’s involvement? Maybe yes. Maybe no. That depends on the qualifications of those responding to this ethics consultation request.

On June 8th, the Maryland Health Care Ethics Committee Network (MHECN) partnered with the Veterans Health Administration (VHA) to host a training conference to help ethics committee members perform ethical consultations such as that described above. While many ethics committee members are taught about bioethical theories, they often have little training in the actual process of clinical ethics consultations (CECs). Given this lack of practical training, there have been some questions raised about the quality of ethics consultations. The workshop was designed to address this issue through the use of state-of-the-art materials to hone clinical consultation skills. These materials were developed by the National Center for Ethics in Health Care, a center within the VHA that examines questions about ethical health care practices for VHA ethics programs, staff, and others involved in health care ethics.

The conference, “Fine Tuning Clinical Ethics Consultation – A Workshop for Health Care Ethics Committee Members,” focused on skills necessary for clinical ethics consultations (CEC). In Maryland, this service is typically provided by one or more members of a health care institution’s ethics committee. Maryland law requires hospitals to have, and nursing homes to have access to, an ethics committee (specifically, a “patient care advisory committee”) to address certain disputes or uncertainties involving end-of-life decision-making. This provides an alternative to resolving such disputes or uncertainties through the courts. However, Maryland law does not mandate that ethics committee members—including those who perform CEC—have specific qualifications.

Attendees first learned about common misconceptions that individuals have about the role of a clinical ethics consultant and how to correct these misconceptions and still respond to the requestor’s concerns. Dr. Anita Tarzian provided examples of common misperceptions on behalf of hospital staff as to what ethics consultants can do. These misperceptions include the belief that an ethics consultant can investigate physician wrongdoing, or tell a health care practitioner what should be done or what is legally allowed (i.e., giving legal advice). It would be inappropriate, for example, for an ethics consultant in the case described above to call the urologist and tell him he cannot perform the sperm retrieval. Instead, the ethics consultant should clarify the ethics consultation request and proceed through a defined process, such as the VHA’s “CASES” approach (Fox, Berkowitz, Chanko, & Powell, 2006).

Dr. Ellen Fox, Chief Officer for the National Center for Ethics in Health Care at the VHA, spoke to conference attendees about clarifying the values, uncertainties, and conflicts that give rise to an ethics consultation request. For example, in the case above, two values are in conflict: accountability (i.e., an obligation on the part of the health care staff and wife to accept responsibility for the actions involved in retrieving and using the husband’s sperm without his expressed permission) and compassion toward the grieving wife. Attendees then practiced writing values statements that frame an ethics consultation. An example using the case above would be: “Given that respect for this patient would involve not treating him merely as a means to an end, and that compassion for the wife involves supporting her in her grief over her husband’s impending death, the attending physician is uncertain whether allowing the patient’s sperm to be retrieved would be ethically justifiable.” The ethics consultant(s) would then proceed with a process for addressing this values conflict and provide ethically acceptable recommendations to the involved stakeholders.

Maryland Professor Diane Hoffmann led a session on ways to proactively defuse conflict in a formal CEC meeting. For example, an ethics consultant should first decide if a formal meeting is the best way to proceed with the ethics consultation. In the case above, a formal meeting with the patient’s wife should only be scheduled after first talking with the attending ICU physician and urologist to determine if such a meeting would be helpful. If so, goals of the meeting...
Fine Tuning
Cont. from p. 9

should be defined and relevant information should be accessed in advance. At the beginning of the meeting, the ethics consultant should review ground rules for the meeting, explain his or her role in the consultation process, have participants introduce themselves, and establish the goal(s) of the meeting. Workshop attendees reviewed, practiced, and discussed other components of an effective formal meeting.

Edmund Howe, JD, MD, University Professor of Psychiatry and Director of the Programs in Ethics at the Uniformed Services University of the Health Sciences, presented the last session of the conference on strategies for avoiding “group think,” a menacing threat to ethics committee deliberations. Mutual friendship, power imbalances, and subconscious emotions provide potential catalysts for ethics committee members to fall prey to group think. For example, in the case featured above, members of the ethics committee might be led to agree with one strongly opinionated, influential physician member who is convinced that the sperm retrieval is illegal and unethical. In fact, neither the ICU attending nor the ethics consultant(s) have ultimate authority in this case to determine whether sperm retrieval can be done. Any recommendations provided by an ethics committee or consultation team should take into account various perspectives and be consistent with known norms (see Strong, Gingrich & Kutteh, 2000 and Strong, 2006). Furthermore, ethics committee members involved in ethics consultations should develop the emotional insight to know when they may be vulnerable to group think decisions, and the moral courage to speak up to make their voices heard.

Anita J. Tarzian, PhD, RN
Program Coordinator
Maryland Health Care Ethics Committee Network

REFERENCES

EMERGING ISSUES IN FOOD & DRUG LAW
A National Conference for Lawyers, Policy-Makers, and Corporate Leaders
MONDAY, NOVEMBER 16, 2009
Keynote Speakers
Dr. Andrew C. von Eschenbach
Former Commissioner, U.S. Food and Drug Administration
Jeffrey Senger
Deputy Commissioner, U.S. Food and Drug Administration
Hosted by
University of Maryland School of Law
Whiteford, Taylor & Preston, LLC
Greenleaf Health LLP
University of Maryland School of Pharmacy’s
Center on Drugs & Public Policy
For more information and a list of speakers, please visit www.law.umaryland.edu/foodanddrug


MHECN is a membership organization, established by the Law & Health Care Program, to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. MHECN publishes a newsletter and has held numerous conferences on timely issues such as the one addressed in the June conference.
On April 17, the University of Maryland School of Law hosted a conference and training session entitled, “Veterans Legal Assistance Conference: An Opportunity to Serve Those Who Served Our Country.” The conference brought together experts on legal issues relating to veterans and provided participants with an overview of benefits available to veterans. The keynote speaker was Brigadier General James A. Adkins, Secretary of Veterans Affairs for Maryland. He gave attendees an update on current challenges facing veterans and described recent state initiatives to address these challenges. Michael Taub from the Homeless Advocacy Project in Baltimore held a benefits training session for attendees (which included a number of law students). The training provided basic instruction on how to assist veterans access the numerous benefits for which they are entitled or eligible.

The conference was the brainchild of rising third year student Noah Isserman. Isserman, who is pursuing a concentration in health law, is dedicated to using his legal training to help the nation’s veterans. Before law school, Isserman worked for two and a half years as a Research Assistant at the Veterans Affairs Medical Center in Baltimore administering comprehensive neuropsychological assessments and social functioning evaluations to patients with substance abuse problems and mental illness. This experience sparked Isserman’s interest in helping veterans with the legal issues that confront them. Since coming to the law school, Isserman interned at the VA’s Office of the General Counsel in Washington, D.C. and, in the fall, is externing at the Senate Veterans Affairs Committee. Isserman was also granted an Albert Schweitzer Fellowship to assess the mental health needs of homeless veterans through the Homeless Persons Representation Project in Baltimore. This project is ongoing.

Isserman was recently profiled in Maryland’s Daily Record newspaper. In that article, he summed up why he has become such a tireless advocate for the veteran community — “Veterans served our country; they were willing to put their necks on the line to make sure we’re safe. Whether you agree with the government’s policy or not, the soldiers are doing something that is rather dangerous so we don’t have to do it.”
WHO’S REGULATING WHAT GOES IN YOUR YOGURT?

A team of University of Maryland faculty members led by L&HCP Director Diane Hoffmann was recently awarded a $535,000 NIH grant to make recommendations about federal regulation of probiotics. This three-year grant is an interdisciplinary collaboration between Hoffmann, Drs. Claire Fraser-Liggett and Jacque Ravel of the School of Medicine and Dr. Frank Palumbo of the School of Pharmacy. The grant was awarded under the Human Microbiome Project, a $140 million, five-year effort by the National Institutes of Health (NIH).

The members of this team of researchers will bring their professions’ unique expertise and perspective to the project. Dr. Fraser-Liggett is Director of the Institute for Genome Sciences and a Professor of Medicine at the University of Maryland School of Medicine. She was previously the President and Director of the Institute for Genomic Research. She is known for her work in sequencing and analysis of human, animal, plant and microbial genomes to better understand the role that genes play in development, evolution, physiology and disease. Dr. Ravel is an Associate Professor in Microbiology and Immunology at the Institute for Genome Sciences and the School of Medicine. Both Ravel and Fraser-Liggett are currently working on NIH-funded human microbiome research studies. Dr. Palumbo, an adjunct professor at the School of Law and Executive Director of the University of Maryland School of Pharmacy’s Center on Drugs and Public Policy, is both a licensed pharmacist and a lawyer. He and his colleagues at the School of Pharmacy conducted much of the early work on drug use review, a subject on which he has published widely.

The Human Microbiome Project (HMP) supports research relating to the human microbiome—the trillions of microorganisms that live on and in the human body. Projects funded under the HMP include studies of the genetic composition of these microorganisms and how they affect human health. Probiotics, or microbiotic compositions developed from microbiome research, form one strand of HMP research. Probiotic compositions are added to foods, drinks and topical creams for the purpose of altering an individual’s existing microbial communities to promote such health benefits as weight loss, better digestion, and ameliorate skin conditions such as eczema and psoriasis.

The use of these probiotic formulas in commercial products has skyrocketed in recent years, Dannon’s Activia Yogurt serving as a prime example. According to Dr. Fraser-Liggett, “as we learn more about the microbiome, which differs greatly from person to person, there is the potential for personalized probiotics that could be tailored to suit the microbial communities of each individual,” says Dr. Fraser-Liggett.

Hoffmann, who has written about regulation of biotechnology, became interested in the subject of probiotic regulation after learning about human microbiome research and its potential probiotic applications. Hoffmann notes that “because this is a new area of study, new claims are being made about the role and value of probiotics in promoting human health and there is a great deal of uncertainty about how these products should be regulated.”

The project will entail regular meetings with a group of scientists, bioethicists, legal academics, physicians, pharmaceutical industry representatives and federal regulatory experts. The experts will debate the legal issues surrounding probiotics and try to come to a consensus on how they should be regulated. “With any new technology comes regulatory issues,” explains Hoffmann. “We want to create a healthy debate among the experts we bring together about the risks and benefits of probiotics and whether and how they should be regulated.”

SHARING AND SPEAKING THE SAME LANGUAGE IN AN EMERGENCY

The Center for Health and Homeland Security (CHHS), which works closely with the Law & Health Care Program, recently received $2.68 million from FEMA’s Regional Catastrophic Preparedness Grant Program (RCPGP) for two emergency preparedness projects in the Mid-Atlantic region. CHHS uses scientific research and legal expertise to develop and coordinate public policy, training programs, government consulting and
scholarly programs relating to counter-terrorism crises, public health emergency preparedness, and consequence management issues within the seven professional schools of the University of Maryland, Baltimore. CHHS is directed by Michael Greenberger, a L&HCP faculty member.

The two RCPGP projects focus on resource management across the region. In the first project, CHHS will bring together public, private, and non-profit sector partners to resolve state and regional resource needs during an emergency. CHHS will survey existing resources for agencies in each jurisdiction in the areas of health/medical, transportation, and emergency management/response; identify resource gaps that agencies note as mission-critical; and develop solutions to fill those gaps through partnerships with private and non-profit sectors in each of the jurisdictions.

The second project involves developing a specific plan to enhance the resource management systems of the region into a consistent and interoperable network (the region is comprised of Washington, D.C., Virginia, West Virginia, Pennsylvania, Delaware, and Maryland). The Maryland Emergency Management Agency (MEMA) is taking the lead within the region on the projects covered by this grant and CHHS will work in tandem with MEMA on this project, as it has on a number of other projects. According to Professor Greenberger, “The relationship between MEMA and the Center is longstanding and we are delighted to be closely affiliated with that agency on such an important endeavor.”

The Center for Health & Homeland Security and The Maryland Healthcare Ethics Network invite you to attend

“The Ethics of Pandemic-Driven Health Care Resource Rationing”

Tuesday, October 27, 2009
1 p.m. to 3 p.m.
University of Maryland School of Law
500 West Baltimore Street
Baltimore, MD

For more information email
MHECN@law.umaryland.edu
At a breakfast reception held on May 13, 2009, at the School of Law, Professor Diane Hoffmann, Director of the Law & Health Care Program (L&HCP), and Virginia Rowthorn, Managing Director of the L&HCP, awarded the Health Law Certificate to 31 graduating students. This ceremony marked the 12th year that the School of Law has been awarding the Health Law Certificate to those students who have concentrated their legal studies in the area of health law. In order to earn the certificate, students must take a certain number of health law courses and seminars, produce a scholarly health law paper, and participate in a health law clinic and/or externship. Many of the student awardees this year went beyond the minimum requirements necessary to receive the certificate and immersed themselves in the full breadth of health law-related curricular and non-curricular opportunities open to students. Many completed more than one externship, served as research assistants to L&HCP faculty, participated in service activities, and took part in health law activities such as the Student Health Law Organization (SHLO), Health Law Moot Court, and the Journal of Health Care Law & Policy.

The experiences and interests of the 2009 certificate recipients reflect the full breadth of the field of health law. Several of the students focused their studies on the intersection of public health and the law, particularly in the areas of environmental health and emergency preparedness. Others spent time in Annapolis and Washington D.C., working on health policy issues in the Maryland General Assembly and the U.S. Congress. Several of the students are pursuing the corporate practice of health law in the nation’s most prestigious health law firms. Still others externed or will develop a career in the alphabet soup of the federal government—in the FDA, CMS, NSA, and IOM (Institute of Medicine). With their varied interests and backgrounds, these students brought a wonderful depth to the law school’s health law community and, as alums, will undoubtedly enrich the community of health law practitioners. In their three years at the law school, we got to know all of the certificate awardees and will deeply miss the individual perspectives they brought to the Program. Each student pursued his or her interest in health law in a unique way and each student’s story is worth recounting but, given the limits of space, in this article we focus on five certificate students whose various backgrounds and career aspirations highlight the breadth of health law and its future practitioners.

Elizabeth (Liz) Cappiello
Liz graduated from McGill University in Montreal, Quebec in 2004 with a BA in Economics and, prior to coming to the law school, worked as an advocate for individuals with disabilities. Liz threw herself into the Law & Health Care Program the minute she stepped into the law school, and managed to participate in a wide variety of health law-related activities and experiences. Liz pursued her interest in disability law by interning at the Maryland Disability Law Center in Spring 2008. She later externed at the University of Maryland Center for Health and Homeland Security and the Center for Medicare and Medicaid Services (CMS). Liz also found time to serve as a Research Assistant for Professor Hoffmann on the issue of pain management and the criminal justice system.

Liz was also the Treasurer of the SHLO during her second year and did a wonderful job organizing various educational and networking opportunities for students interested in health law. In her third year, she served as Senior Articles Editor for the Journal of Health Care Law & Policy. After her second year, Liz was a Summer Associate at Ober | Kaler, a Baltimore law firm with a thriving national health law practice. Liz began at Ober as a first year associate this Fall.

Paul Gadiock
Like other students with science backgrounds, Paul found that health law is a perfect way to study and work at the intersection of science and policy. He graduated from the University of Maryland, College Park with a BS in Neurobiology & Physiology. Prior to coming to law school, Paul worked for Cell Technology, Inc., the American Red Cross Biomedical Sciences Laboratory, and as a Research assistant for the Washington Hospital Center in the area of kidney disease research.

While Paul was still a law student, he began working as a Program Analyst for the FDA in the Center for Devices and Radiological Health on the Regulations Staff. In this position, he reviewed Guidance Documents, Notices and Rules that are issued by the FDA in the area of devices and radiology. He will continue in the same office as a staff attorney in the Fall.
Julia Loyd

Julia didn’t come to the law school with an advanced degree or years of experience in the health field like some of the Law & Health Care Program’s students, but she’s an example that those things aren’t necessarily a prerequisite to success as a health law student. Julia graduated magna cum laude from George Washington University with a BA in History and French Language and Literature.

However, once she arrived at the law school, she devoted herself to the study of health law. She was the Notes and Comments Editor for the Journal of Health Care Law & Policy, a member of SHLO, and a student attorney in the Legal Issues in Health Care Delivery and Child Welfare Clinic. Her clinic professor, Deb Weimer, noted that Julia was an incredibly valuable member of the clinic and singled out a particular case in which Julia was able to develop a trusting relationship with a client in a child welfare case that involved a contested hearing. The client was the mother of an HIV infected child. As a result of Julia’s advocacy, the Department of Social Services and the child’s attorney agreed to give the client more time to work towards reunification with her child, despite strict timelines under new federal law.

Julia was a Summer Associate at the well-know health law firm of Epstein, Becker and Green in Washington, D.C. after her second year and has recently started there as an associate.

Deborah Scop

Deborah graduated with both the Health Law and the Environmental Law Certificates which demonstrates her long-standing interest in the intersection of health and the environment. In addition to meeting the requirements for both Certificates, Deborah found time to serve as Co-Executive Director of the Maryland Environmental Law Society, Secretary and Maryland State Representative to the National Association of Environmental Law Students, and as a member of the Maryland Public Interest Law Project.

Deborah also managed to work for the Environmental Protection Agency, the Maryland Department of the Environment, and as a research and legal assistant to Professor Rena Steinzor.

In addition to supervising an independent written work for Deborah, Professor Kathleen Dachille had her as a student in the Tobacco and the Law Seminar and the Tobacco Control Clinic. Professor Dachille commented that Deborah promises to be a tireless public health advocate.

Danielle Turnipseed

Danielle came to the law school via Duke University, where she graduated with a BA in Policy Studies, and University of Michigan, where she earned a Masters in Public Policy and a Masters of Health Services Administration. Danielle had a career in health policy before coming to the law school. She was a Policy Advisor & Health Legislative Assistant for United States Senator Jon Kyl and a Health Legislative Assistant for Senator Elizabeth Dole. Prior to working on the Hill,
Danielle was a Healthcare Consultant for Arthur Andersen as well as KPMG/BearingPoint. In the Fall 2008, Danielle externed at UNAIDS in Geneva where she worked for the Senior Law and Human Rights Advisor, Susan Timberlake who found Danielle to be a true team player able to produce high quality work in an often highly pressured and complex international environment (For more details on this externship, see p. 5). In the summer after her second year, Danielle was a summer associate at Epstein, Becker and Green in Washington, D.C. Danielle is now clerking for the U.S. Court of Federal Claims in the Office of Special Master, which hears cases under the National Childhood Vaccine Injury Program and determines compensation arising from injuries attributed to vaccines.