Symposium Explores Baby Doe Rules 25 Years Later

When should medical treatment be provided for a seriously ill infant? What if aggressive treatment causes enduring pain? And what happens if doctors and parents disagree about whether treatment should be given? These are just a few questions that have been debated since the Reagan administration issued the “Baby Doe Rules” in 1984 in response to the case of an infant with Down syndrome and a reparable birth defect who was allowed to die without surgery. More than a dozen lawyers, doctors, and bioethicists from across the United States led discussions on the

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Paul Lombardo Is Georgia Author of the Year

Professor Paul A. Lombardo has been named a 2009 Georgia Author of the Year for his book, *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell* (Johns Hopkins University Press).

The legal historian was honored by the Georgia Writers Association in the history category. Lombardo was also featured in a June 24, 2009 USA Today article titled “U.S. eugenics legacy: Ruling on Buck sterilization still stands.” The article tracks Lombardo’s 30 years of research of eugenics programs in the United States, including the infamous case of a poor girl named Carrie Buck, who was the first victim of the 1924 sterilization law in Virginia.

His book is the only fully documented

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Baby Doe Rules and decision-making involving premature and other medically at-risk infants at the 2009 Georgia State University Law Review Symposium. Emory University Center for Ethics and the Center partnered with the Law Review in co-sponsoring the Symposium, which was supported in part by generous grants from the Greenwall Foundation and the Health Law Section of the State Bar of Georgia.

The Baby Doe Rules condition the grant of federal funds for any state’s child protective services program on the assurance that it can respond to reports of medical neglect. Medical neglect may include the withholding of medical treatment from disabled infants with life-threatening conditions.

“The hard cases today often involve extremely premature infants – at the cusp of viability, at 22 or 23 weeks gestational age when born – who have multiple medical needs,” said Georgia State Law Professor Charity Scott, director of the Center for Law, Health & Society. “Other hard cases today involve infants who have severe genetic abnormalities that can cause significant permanent physical and mental impairments. Doctors and parents struggle with whether or how a child’s uncertain prognosis for the future should impact their decisions about treatment.”

Advances in medical technology over the past 25 years have played a significant role in improving the health outcomes of infants who may have died because effective treatment was not available a generation ago.

More than 230 participants registered for the Symposium, titled “The 25th Anniversary of the Baby Doe Rules: Perspectives from the Fields of Law, Health Care, Ethics, and Disability Policy.” The interdisciplinary audience was highly engaged in the discussions and consisted of diverse professionals in law, government, medicine, nursing, social work, and public health. As one attendee said, “Wonderful! I wish all symposiums were as pertinent and filled with interesting, engaging speakers!”

Director’s Message

We enthusiastically celebrated the 5th Anniversary of the Center this year. Our many wonderful colleagues, graduates, friends, and supporters have all contributed to the Center’s success as we launched numerous new initiatives.

Highlights of our first five years are featured on this page, and recent events appear throughout this newsletter. We look forward to continued success in the next five years, and we hope that you will be a part of our on-going development.

Best wishes,

Charity Scott
Director, Center for Law, Health & Society
It began with one survey course in health law. Charity Scott, newly hired in 1987 as an assistant professor, now jokes about the first health law course at Georgia State Law. “I tried to cover the entire law school curriculum in 10 weeks, since that is what health law is – all laws affecting health,” she laughs. “I went from A to Z – Antitrust, Administrative law, Bioethics, Corporate law, Discrimination and so on down the alphabet to explore how these laws impacted our health care system. Admittedly, it was a bit much.”

Over 20 years later, the breadth of the health law field has been captured in the Center for Law, Health & Society, which recently celebrated its 5th Anniversary. Founded in April 2004, the Center was established to promote the development of the health law program at Georgia State Law that began with that single health law course. The anniversary celebration concluded with an event to express gratitude to the Center’s many supporters and friends and to launch plans for the next successful five years.

Gifts

Thank you for your support during our 5th Anniversary year. Your generosity supports the Center’s educational and community initiatives and the HeLP Legal Services Clinic.

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Students Learn From Social Security Disability Cases

In Spring 2009, students in the HeLP Legal Services Clinic prepared two children’s supplemental security income (SSI) cases for hearings before the Social Security Administration. The entire class worked on different aspects of the cases. For example, one student prepared lengthy indexes to medical records, another student performed legal research, and another student prepared a chart analyzing the child’s growth over a period of time, which was an issue in the case.

In preparation, Associate Dean Roy Sobelson joined the class to play the role of administrative law judge. Two clinic students represented clinic clients before administrative law judges of the Social Security Administration during the actual hearings.

“SSI cases present wonderful learning opportunities for the clinic class,” says Professor Bliss, co-Associate Director of the HeLP Clinic. Such cases allow students to learn how to be effective advocates at every step of the case. Clinic students gather all relevant medical and school evidence, and then create timelines and other analyses to present a complete picture of how the disability or impairment affects the child in his or her daily life.

“One of the advantages of our medical-legal partnership is that we are able to work cooperatively with the health care team to obtain information that helps students become better advocates for clinic clients,” says Bliss.

At the hearing stage, students learn to conduct an effective direct and cross examination and to make effective opening and closing statements.

Law Student Rounds with Medical Residents

By Jennifer Ivey, 3L Student

As a law student enrolled in the HeLP Legal Services Clinic, I interact with doctors almost more than lawyers when I am helping clients with chronic health issues. The HeLP Clinic is an in-house, live-client clinic located at Georgia State Law for law students to develop practical lawyering skills in substantive legal fields related to the health and well-being of low-income children and their families.

During Spring semester 2009, medical residents from Children’s Healthcare of Atlanta, Inc., at Hughes Spalding hospital joined us in our case rounds discussions. We asked the residents questions about medication dosages and the meaning of different medical terms. We discussed the uniqueness and special considerations involved in serving clients who are impoverished. Because I have a few clients with cystic fibrosis (CF), I asked the residents to explain and discuss the different percussive therapies available to CF patients. I also had the opportunity to accompany Dr. Joy Smith and her medical residents on rounds at Hughes Spalding hospital one morning. We discussed patient symptom changes, medication modifications, and discharge plans.

Comparing our professions, we realized that there are similarities and differences. The culture of law school is to question everything, to understand multiple, inconsistent positions in a single breath, and to challenge assumptions. In contrast, medical residents are trained to follow the recommendations of their attending physician. However, other aspects of our training are similar. Our clients often present a set of complex facts to us lawyers-in-training, through which we sift to determine what is relevant, what is true, what is half true, and whether there is a legal solution to assist the patient. Similarly, the medical residents listen to the patient’s and parent’s account of symptoms, which is frequently done via a foreign language interpreter. After assessing the situation, the residents determine whether there is anything they can do medically to assist the patient.

Through each of these multi-disciplinary interactions, I form a more complete picture of how my clients’ illnesses affect their daily lives. I learn more about where my clients and their physicians are coming from. Most importantly, I am connected with resources that provide evidence to help legally establish medical conditions. Each of these things makes me better able to serve my clients. Medical educators and law professors should seek to promote multi-disciplinary interactions among their students as much as possible – patients, clients, students, and even the professors will benefit from such collaborations.

Visit HeLP’s Web site at www.healthlawpartnership.org
The Georgia Department of Community Health has awarded the Center a grant of nearly $100,000 aimed at reducing inequalities in health and health care access among racial and ethnic minorities. The Georgia Health Equity grant focuses on the role of law and lawyers in addressing and reducing the socio-economic barriers that contribute to health disparities. It supports the opening of a third hospital-based HeLP office at Children’s Healthcare at Hughes Spalding hospital. The project helps to expand HeLP’s “best practice” model of promoting the health of low-income and minority children by combining public health legal services with focused interdisciplinary educational programs.

A Health Disparities Fellow, Rebecca Propst (COL ’07), J.D., has been hired under the grant to provide public health legal services at Children’s at Hughes Spalding hospital. She is also coordinating educational sessions about the socio-economic and legal challenges faced by patients and families for the social workers, medical faculty, residents, students, and other health care professionals.

A Health Disparities Instructor, Marie Cameron, FACHE, is providing focused educational programs on cultural competency for health care providers to improve the delivery of health care and reduce health disparities.
New Poverty Law Course

Professor Lisa Bliss offered a course on “Public Interest Law and Social Welfare” for the first time in Fall 2008. This new course complements the lawyering skills education offered in the HeLP Legal Services Clinic by offering a more in-depth examination of the laws and social policies that affect people living in poverty in America. The course explores state and federal laws that impact social welfare, including welfare reform, benefit programs, Medicaid, Medicare, food stamps, consumer fraud, problems of the uninsured, and access to appropriate education, affordable housing, and safe environments.

“Students who took the course gained a better appreciation of the challenges faced by lawyers representing the poor and other vulnerable populations,” says Bliss.

The new class provides important background for students who enroll in the live-client HeLP Clinic because the clinic serves clients who face a broad spectrum of the legal issues addressed by the course. It also provides a stand-alone introduction to public interest law for students who do not enroll in the clinic, but who desire a survey of the laws and programs affecting social welfare.

Mentoring High School Students in Downtown Atlanta

The Center continued its community initiative this year, developed by associate director Jerri Nims Rooker, for Georgia State law students to mentor high school students from the New Schools at Carver in downtown Atlanta. Over twenty law students participated in the program as mentors and joined the Carver students for events organized by the Center.

The program kicked-off with a social outing to Midtown Bowl in Atlanta where mentors and mentees enjoyed getting to know each other over friendly bowling competitions. For some Carver students, this was their first time bowling, and prizes were given out in a variety of categories.

Law student mentors played a primary role in organizing a presidential election-related event for the Carver students in Fall 2008. The event involved teams of mentors and mentees presenting information to the rest of the group on issues discussed during the presidential race of John McCain and Barack Obama and then debating the issues.

The three issues discussed were health care reform, school voucher programs, and the war in Iraq. Law student mentors Heather Carter, Dana Jackson, Korinne Lassiter, and Jameel Manji researched the issues and compiled information packets that included diverse perspectives for the teams. There were six mentor/mentee teams, and each team chose an issue and a particular stance to advocate for in the debate without tying the stance to a particular candidate. At the end of the lively debate, the Carver students voted on the issues: a large majority favored market-driven over government sponsored health care as well as a phased withdrawal of U.S. troops from Iraq over no set withdrawal date. A small majority supported school vouchers over no voucher programs.

The Carver students then learned which candidate supported each stance, and they had a spirited conversation about how their votes did not always match the candidate they thought they supported. Law student mentor Lisa Bobb commented, “I thought the event was incredibly special because it gave our mentees an opportunity to realize where they may stand on some of the most important issues facing our nation and to voice their opinions about those issues.”
Professor Leslie E. Wolf conducts research in a variety of areas in health care law, public health law, and ethics. Her particular focus is on research ethics, including empirical research on conflicts of interest, Institutional Review Board (IRB) web guidance, and HIV-related laws and policies. Prior to joining Georgia State Law, Wolf taught medical ethics and research ethics at the University of California, San Francisco Medical Center. She also served on the UCSF IRB and the advisory committee on stem cell research.

Research on Conflicts of Interest in Clinical Research

When research sponsors pay finder’s fees to researchers and clinicians to identify potential study participants for a research study, it could compromise the recruitment process and harm human lives. Yet many medical schools fail to address this conflict of interest in their Institutional Review Board (IRB) policies.

Professor Wolf studied the IRB policies posted on the Web sites of 117 medical schools that received National Institutes of Health funding. Among the study’s findings, Wolf revealed that less than half of the IRB policies discuss finder’s fees or bonus payments as conflicts of interest. Finder’s fees raise concern because researchers and their colleagues may be tempted to enroll individuals in studies for which they are ineligible, Wolf said.

Wolf is also concerned that only 26 of the IRBs in the study mentioned potential conflicts when physicians recruit their own patients and that only four percent ask doctors to tell their patients that they are not obligated to participate.

“Recent media stories about such conflicts of interest could undermine our confidence in research and prevent important research from going forward,” Wolf said. “We need to have a trustworthy research enterprise so that we can get good research that hopefully improves the lives of the rest of us.”

Wolf’s research was sponsored by the Greenwall Foundation. It was published in the January / February 2009 issue of IRB: Ethics & Human Research.

Appointment to CDC Ethics Subcommittee

If a pandemic flu fills hospital beds and ventilators become scarce, who gets first priority? Should individuals with certain kinds of diseases be prevented from traveling, even if their condition is managed by medication and they pose no risk to others? When the Centers for Disease Control and Prevention (CDC) seeks answers to these and other ethical questions, it turns to its Advisory Committee to the Director and that committee’s subcommittee on ethics.

Professor Wolf is the subcommittee’s newest member, and says the CDC is trying to think through these scenarios ahead of time so it is prepared if the need arises. “The idea is to give helpful guidance to people who are going to have to make these decisions,” Wolf said.

The subcommittee’s members include well-known philosophers, public health professionals, doctors and medical ethicists. Wolf said she hopes to translate her experience with the CDC’s ethics subcommittee to her work in the classroom. “It’s a remarkable honor,” Wolf said. “I think it’s going to be a lot of fun to work on some really interesting and challenging issues.”
The Role of Conscience in the Practice of Medicine

The Center hosted a panel program with the Student Health Law Association on the role of conscience when health care professionals object on moral and religious grounds to certain practices and procedures. The conference, “The Role of Conscience in the Practice of Medicine,” featured speakers Dr. Farr Curlin, an assistant professor of medicine at the University of Chicago, and Martha Swartz, an attorney and adjunct professor of law at Rutgers School of Law-Camden.

While the debate often focuses on abortion, panel moderator Professor Leslie Wolf explained that conscientious objection can come up wherever there is tension between health professionals’ beliefs and patient access to medical services. Examples include decisions in an intensive care unit, at the pharmacy counter, and in the family physician’s office.

Martha Swartz began by telling of a medical malpractice case in which a physician due to his religious and moral beliefs refused to provide certain medical procedures to a pregnant woman facing health complications. The patient experienced life-threatening and irreversible damage. Swartz contended that, consistent with most health care codes of ethics, medical professionals should not be encouraged to prioritize their personal beliefs above the interest of patients. She asked, “If we encourage these kinds of behavior, won’t the public’s trust in health care professionals be undermined?”

Farr Curlin focused his presentation on the new relationship that has developed between doctor and patient and the logical and necessary conscientious refusals made by medical professionals. Curlin stated, “To say a refusal is conscientious is simply to say that it is based on a physician’s best judgment about what he or she ought to do in a given case.” He also discussed how patients have become more demanding consumers of new biomedical technologies. Curlin warned of the dangers to both medical professionals and patients if the doctor-patient relationship continues down the path of denying the physicians’ expertise and making the professional a passive agent.

Paul Lombardo Is Georgia Author of the Year

account ever written of Buck v. Bell, a notorious U.S. Supreme Court decision that endorsed involuntary sterilizations of people described as “feebleminded and socially inadequate.” The book documents how Buck was sent to an institution to hide the shame of her pregnancy after she had been raped.

Supreme Court Justice Oliver Wendell Holmes Jr., who wrote in the 1927 ruling in favor of the constitutionality of the Virginia statute, said: “Three generations of imbeciles are enough.”

“Carrie Buck was railroaded. And one of the giants of the Supreme Court was driving the train,” Lombardo said.

Lombardo hopes the public attention to his book will help in his efforts to publicize an accurate history of eugenic legislation. He has been instrumental in the movement to solicit apologies and legislative denunciations of past state eugenic laws in seven states. He traveled to Rome to speak about the danger of eugenics at the Vatican in February 2009.

“We tend to forget most scandals in our past. We should probably remember more of them so that we can make public policy with our eyes open in the future,” Lombardo said.

Lombardo is also a nominee for the Library of Virginia Annual Literary Award in the area of nonfiction.

Professor Lombardo has given dozens of interviews on radio and TV related to Three Generations, No Imbeciles. Since its release, the book has been widely praised, including in the New England Journal of Medicine, the Harvard Law Review, and the American Journal of Bioethics.
There is a common thread in the fields of assisted reproduction and embryonic stem cell research: human eggs. Some eggs and embryos produced for fertility purposes may be transferred to research use. Stem cell research relies on the commercial and medical practices developed in the context of the fertility industry.

University of California-Davis law professor Lisa C. Ikemoto spoke at the College of Law in January on “Taking Women to Market: Eggs, Embryos and Informed Consent.” She discussed how the collection of eggs, whether for in-vitro fertilization or for research purposes, involves the same processes and poses the same risks to women’s health.

Ikemoto identified informed consent as a legal constant for both the fertility industry and research. The informed consent process not only protects patient interests, but also transfers commercial benefit to the fertility industry or research enterprise. Increasingly, eggs are being treated as a commodity with little oversight over their collection.

“There’s very little direct regulation of the fertility industry,” said Ikemoto. “In the research context, it’s mixed right now. Some states, like California, are regulating the procurement process and some states and countries are not.”

Ikemoto expressed concern that the market for human eggs may be unduly influencing women to sell or donate eggs without fully understanding the risks. She stated, “The disclosure tends to be on paper and it’s not necessarily reflected in conversation. People tend to gloss over what’s in print when they get a long document [to sign].”

Professor Lisa C. Ikemoto, J.D., LL.M., teaches bioethics and health law courses at the University of California – Davis School of Law. She has written extensively on genetic and reproductive technology use, the regulation of fertility and pregnancy, and race and gender disparities in health care. Her current work examines emerging issues in regenerative medicine, including stem cell research, and the human tissues market.
Center Highlights

Roberta Berry
Professor Berry spoke on “The Relationship between U.S. Law and Bioethics,” for the Collaborative Educational Program in Bioethics: A Cross Cultural Exchange with Russian Healthcare Leaders, at Emory University in October 2008. She continued to serve on the Research Ethics Consultation for an NIH-Funded Clinical and Translational Science Institute spanning Emory University, Georgia Tech, and Morehouse School of Medicine, contributing to research ethics opinions available at <http://www.actsi.org/areas/erks/ethics/index.html>. She was invited to a three-year term of service on the NSF advisory review panel for the Science, Technology & Society program.

Lisa Bliss

Sylvia Caley
Professor Caley presented at numerous conferences, including the Midwest Clinical Conference, Indiana University on “Building Bridges: Medical-Legal Collaboration within a Law School Clinical Program”; the Global Alliance for Justice Education Conference in Manila, Philippines on Medical-Legal Collaboratives in Clinical Legal Education; the Medical-Legal Partnership (MLP) National Summit on “The Lawyer-Driven MLP”; the AALS Clinical Legal Education Conference on “Students and Professionalism: Helping Our Students Bridge the Gaps”; and the Justice Federal de Primeiro Grau, Rio de Janeiro, Brazil on “Preventive Law: Improving Health and Social Well-being through MLPs.”

Paul Lombardo
Professor Lombardo spoke in Rome during the International Congress on The New Frontiers of Genetics and the Risk of Eugenics held at the Vatican, in Russia at the Sechenov Moscow Medical Academy on the ethics of reproduction, and at the Annual Meetings of the American Society of Bioethics and Humanities, the American Association for the History of Medicine, and the International Academy of Law and Mental Health. He gave numerous talks and interviews about his new book on the Carrie Buck case: Three Generations, No Imbeciles, which was also featured on Cspan BookTV.

Jerri Nims Rooker
Jerri Nims Rooker spoke on “The Role of Law in Decision-Making of Ethics Committees” at the Healthcare Ethics Consortium of Georgia’s annual workshop for ethics committee members. She was invited by the Association of Pediatric Oncology Nurses to present on Georgia’s Advance Directive for Health Care to nurses at Children’s Healthcare of Atlanta. She provided commentary in an Augusta Chronicle story on in vitro fertilization regulations and Georgia’s proposed “Option of Adoption Act” regarding embryo adoption (“Embryo bills look at legal limitations,” Walter C. Jones, March 4, 2009).
Rebecca Propst
As the Health Disparities Fellow with the Health Law Partnership (HeLP), Rebecca Propst has handled more than 70 civil law cases for low-income patients and families receiving care at Hughes Spalding Children’s Hospital. Rebecca attended the 4th annual Medical-Legal Partnership National Summit in Cleveland, Ohio and has given several presentations to the physicians, nurses, social workers and medical staff at Hughes Spalding Hospital about Medical-Legal Partnerships and HeLP’s legal services. She also co-presented a 1.5 hour CLE at Georgia Legal Services University about effective advocacy in mediation.

Aisha Saeed
As an Equal Justice Works Fellow with the Health Law Partnership (HeLP), Aisha Saeed continues to handle numerous education cases in various areas of education law. In addition to direct representation, Aisha has conducted several education law trainings across the state. She also presented “An Examination of the Health Law Partnership: A Community-based Collaborative of Lawyers, Health Care Providers and Law Students” at the Working in the Public Interest Law Conference and “An Overview of Special Education” at the Children’s Healthcare of Atlanta Social Worker’s Conference.

Charity Scott
Professor Scott spoke at various conferences sponsored by the International Academy of Law and Mental Health (on interdisciplinary collaboration); American Society of Law, Medicine & Ethics (on health law teaching); Morehouse School of Medicine (on public health law and ethics); Emory School of Medicine (on landmark cases in law and bioethics, and the history of reproductive rights); Healthcare Consortium of Georgia (on medical futility); Perinatal Care Annual Conference (on neonatal decision-making); and Children’s Healthcare of Atlanta (on communication skills in health care, and parental decision-making for minors).

Jonathan Todres
Professor Todres authored the lead article, “Law, Otherness, and Human Trafficking,” in the Santa Clara Law Review (Vol. 49, No. 3, 2009) and an article, “Lawyers and the Universal Declaration of Human Rights” in the ABA’s International Law News (Winter 2009). He also published an op-ed on human rights in the Atlanta Journal-Constitution (Dec. 24, 2008). Todres spoke on child exploitation issues at conferences at the University of Hull (UK) and the University of Liverpool (UK), and on children’s rights in the new Administration at a Columbia Law School program.

Leslie Wolf
Professor Wolf was named as a member of the CDC’s Ethics Subcommittee to the Advisory Committee to the Director which provides counsel to CDC on a broad range of public health ethics questions. In October, she coordinated the Center program on “The Role of Conscience in the Practice of Medicine.” Wolf and colleagues at UCSF and Oregon State published three papers from their national survey of IRB administrators and Chairs in the December 2008 issue of the Journal of Empirical Research on Human Research Ethics.
Upcoming Event

Join us September 24-25, 2009 in Atlanta, Georgia

Interdisciplinary Collaborative Education: Partnerships Between Law Schools and the Health Professions

Law schools are increasingly partnering with other professional schools and other professionals in their community who work in health-related disciplines, such as medicine, social work, public health, nursing, mental health, and education. This conference explores the opportunities and challenges in these interdisciplinary collaborations in various educational settings, with an emphasis on experiential learning. Such educational settings include in-house clinics, externship programs, and interdisciplinary classrooms.

Visit www.lawhealthconference.org for all event details and to register.