The 25th Anniversary of the Baby Doe Rules:

Perspectives from the Fields of Law, Health Care, Ethics, and Disability Policy

Friday, February 13, 2009 • Atlanta, Georgia

www.BabyDoeSymposium.org

GEORGIA STATE UNIVERSITY LAW

CENTER FOR Law, Health & Society

EMORY CENTER FOR ETHICS

OVERVIEW

2009 Georgia State University Law Review Symposium

The 25th Anniversary of the Baby Doe Rules:

Perspectives from the Fields of Law, Health Care, Ethics, and Disability Policy

Presented by

Georgia State University College of Law
Georgia State University Law Review
Center for Law, Health & Society

In Partnership with

Emory University Center for Ethics

Platinum Sponsor

Health Law Section of the State Bar of Georgia

Supporter

Supported in part by a grant from the Greenwall Foundation.

Target Audience

Bioethicists, attorneys, physicians, hospital administrators, hospital ethics committee members, nurses, social workers, other health professionals involved in pediatric and neonatal care, disability policy organizations and individuals, and academics involved in these disciplines

Symposium Objectives

At the conclusion of the symposium, participants will:

- Understand the impact of the Baby Doe Rules over the past 25 years in decision-making for medically at-risk infants
- Recognize the key provisions of the Baby Doe Rules and how they apply to treatment decisions for infants
- Appreciate the roles of parents, health care providers, and government in treatment decisions for extremely premature or other sick newborns
- Understand how principles from different perspectives - ethics, disability rights, law and health care - influence and interact in decision-making regarding treatment of seriously-ill newborns
- Identify key legal and ethical issues in the provision of care that some providers may deem futile
- Learn ways of resolving conflicts over the care of very sick newborns, including mediation and communication skills

25th

SYMPOSIUM

A highly publicized and controversial case involving the withholding of medical treatment from a "Baby Doe" with Down syndrome gave rise in 1984 to the federal law known as the Baby Doe Rules, which went into effect the following year. The law conditions the grant of federal funds for any state's child protective services program on the state's assurance that it can respond to reports of medical neglect, which may include the withholding of medical treatment from disabled infants with life-threatening conditions. Leading scholars and practitioners from the fields of health care, law, ethics, and disability policy who are experts in the field of neonatal medicine and decision-making involving very premature and other medically at-risk infants will gather to provide thoughtful commentary and debate on the occasion of the 25th Anniversary of the Baby Doe Rules. The *Georgia State University Law Review* will publish a symposium volume on the topic in Spring 2009.

SCHEDULE OF EVENTS

7:30 am	Registration and continental breakfast
8:30 am	Welcome
8:40 – 9:00 am	Introduction of moderators and overview of program • Kathy Kinlaw, M.Div., Emory University • Charity Scott, J.D., Georgia State University • Leslie E. Wolf, J.D., M.P.H., Georgia State University • Paul Root Wolpe, Ph.D., Emory University
9:00 – 9:45 am	The aftermath of Baby Doe and the evolution of newborn intensive care • Mark R. Mercurio, M.D., M.A., Yale School of Medicine
9:45 – 10:45 am	Legal Perspectives on the Baby Doe Rules • Burke J. Balch, J.D., Robert Powell Center for Medical Ethics • Sadath A. Sayeed, M.D., J.D., Harvard Medical School
10:45 – 11:00 am	BREAK
11:00 – 12:30 pm	Ethical Perspectives on the Baby Doe Rules • Jatinder J. Bhatia, M.D., Medical College of Georgia • Loretta M. Kopelman, Ph.D., Brody School of Medicine • William J. Winslade, Ph.D., J.D., Ph.D., University of Texas Medical Branch
12:30 – 1:30 pm	LUNCH
1:30 – 2:30 pm	Disability Perspectives on the Baby Doe Rules • Mary Crossley, J.D., University of Pittsburgh School of Law • Anita Silvers, Ph.D., San Francisco State University
2:30 – 2:45 pm	BREAK
2:45 – 4:15 pm	Futile Care Debate and Baby Doe: Resolving difficult cases when further treatment may be considered futile • Thomas W. Mayo, J.D., Southern Methodist University Dedman School of Law • Robert D. Truog, M.D., Harvard Medical School • Ellen Waldman, J.D., Thomas Jefferson School of Law
4:15 – 5:00 pm	Roundtable discussion with all the speakers
5:00 pm	Adjourn

FACULTY

Burke J. Balch, J.D., serves as Director of the Robert Powell Center for Medical Ethics which specializes in euthanasia-related issues and is associated with the National Right to Life Committee. He has worked as Attorney-Advisor for the U.S. Commission on Civil Rights, helping to write a report on denial of life-saving medical treatment to children with disabilities ("Baby Doe" cases). He was Chief Staff Counsel for the National Legal Center for the Medically Dependent and Disabled, and worked as a lawyer for Americans United for Life Legal Defense Fund.

Jatinder J. Bhatia, M.D., is Professor and Chief, Section of Neonatology, Department of Pediatrics, at the Medical College of Georgia. Dr. Bhatia's areas of research interest include a wide variety of neonatal issues such as neonatal nutrition, total parenteral nutrition, reaction oxygen species, hepatic dysfunction and outcomes research. His research has been supported by the National Institutes of Health, industry, and foundations. He is the author of more than 100 articles, abstracts, and book chapters and has made presentations of his work nationally and internationally.

Mary Crossley, J.D., is Dean and Professor of Law at the University of Pittsburgh School of Law. Widely recognized for her scholarship in disability and health law, Dean Crossley has written broadly on issues of inequality in the financing and delivery of health care, including potential legal remedies for physician bias in medical treatment, how recent trends in health insurance coverage discriminate against unhealthy people, and how assisted reproductive technologies implicate equality concerns. She has published articles in numerous law journals.

Loretta M. Kopelman, Ph.D., is Professor of Medical Humanities in the Brody School of Medicine at East Carolina University, where she founded and chaired the Department of Medical Humanities from 1978 to 2005. She was the founding president of the American Society for Bioethics and Humanities and received the 2007 William G. Bartholome Award for Ethical Excellence from the American Academy of Pediatrics. She has published widely on issues in bioethics, children's rights and welfare, the rights of retarded individuals, research ethics, philosophy and medicine, and the fair allocation of health care resources.

Thomas W. Mayo, J.D., is the Director of the Cary M. Maguire Center for Ethics and Public Responsibility at Southern Methodist University; Associate Professor at SMU's Dedman School of Law; Adjunct Associate Professor of Internal Medicine at the University of Texas Southwestern Medical School; and Of Counsel, Haynes and Boone, all in Dallas. Professor Mayo specializes in law involving health care, bioethics, and nonprofit organizations. He was involved in the drafting of the Texas Advance Directives Act, also sometimes called the Texas Futile Care Law.

Mark R. Mercurio, M.D., M.A., is Director of the Yale Pediatric Ethics Program, Associate Professor of Pediatrics at Yale University School of Medicine, and an attending neonatologist at Yale-New Haven Children's Hospital. He currently serves as Chair of the Pediatric Ethics Committee at Yale-New Haven Children's Hospital as well as Co-Chair of the Adult Ethics Committee at Yale-New Haven Hospital. Dr. Mercurio is the National Program Director for the American Academy of Pediatrics Section on Bioethics. He has written and spoken widely on ethical issues in pediatrics, particularly the newborn period.

Sadath A. Sayeed, M.D., J.D., is an Instructor in the Division of Medical Ethics, Department of Global Health and Social Medicine, at Harvard Medical School, and an Assistant in Medicine in the Division of Newborn Medicine at Children's Hospital Boston. His research interests focus on medical ethics, population health, and resource prioritization issues with specific attention on newborns. He is on the Steering Committee for the Program in Ethics and Health at Harvard and is a staff member of the Ethics Committee at Children's Hospital Boston.

Anita Silvers, Ph.D., is Professor and Chair of the Philosophy Department at San Francisco State University. She has written numerous books on disability and discrimination, and has published more than 100 articles and book chapters, mainly in law reviews, philosophy journals, medical journals, and volumes on philosophy and on medical ethics. Dr. Silvers is a former board member of the National Endowment for the Humanities and the American Philosophical Association. She also is the recipient of the California Faculty Association's Human Rights Award for her advocacy work for the rights of people with disabilities.

MODERATORS

Robert D. Truog, M.D., is Professor of Medical Ethics, Anaesthesiology and Pediatrics at Harvard Medical School and a Senior Associate in Critical Care Medicine at Children's Hospital Boston. Dr. Truog has published more than 200 articles in bioethics and related disciplines, including recent national guidelines for providing end-of-life care in the Intensive Care Unit. Dr. Truog is an active member of numerous committees and advisory boards and has received several awards over the years, including the Christopher Grenvik Memorial Award from the Society of Critical Care Medicine for his contributions and leadership in the area of ethics.

Ellen Waldman J.D., LL.M., is Professor of Law at Thomas Jefferson School of Law and Director of the law school's Mediation Program, which she founded. Professor Waldman speaks, trains, and publishes in the areas of mediation and medical ethics. She has mediated numerous disputes in a wide variety of contexts and sits on the ethics committees of both for-profit and non-profit health care institutions. Professor Waldman is currently working on a book entitled "Practical Ethics for Mediators" and exploring the application of therapeutic justice approaches to both bioethics and dispute resolution dilemmas.

William J. Winslade, Ph.D., J.D., Ph.D., is James Wade Rockwell Professor of Philosophy of Medicine, Professor of

Preventive Medicine and Community Health, and Professor of Psychiatry and Behavioral Sciences, and is a member of the Institute for the Medical Humanities at the University of Texas Medical Branch, Galveston, Texas. Philosophic, legal, and psychoanalytic ideas are applied in his work to the study of human values in science, medicine, technology, and law. He has written numerous articles and essays on topics such as privacy and confidentiality, human rights, death and dying, and legal and ethical aspects of mental health practice.

Kathy Kinlaw, M.Div., is Associate Director of the Emory University Center for Ethics and Director of the Center's Program in Health Sciences and Ethics. She is the Executive Director of the Health Care Ethics Consortium of Georgia, a network of 100 health care organizations which she supports through ethics education, research and consultation state-wide. Her publications and scholarly interests are primarily in the areas of perinatal and neonatal ethics, ethics and medical education, the work of ethics committees, and futility and quality of life concerns. She is a member of the Ethics Subcommittee of the Advisory Committee of the CDC.

Charity Scott, J.D., is Professor of Law with a joint appointment in Georgia State University's College of Law and J. Mack Robinson College of Business, Institute of Health Administration, and she is the Director of the Center for Law, Health & Society at the College of Law. The Center oversees the law school's health law program, which is ranked among the top ten health law programs nationally by *U.S. News & World Report*. Professor Scott is a member of the American Law Institute, and has served in leadership positions with national and state bar associations. She has published numerous articles on health law, policy, and ethics.

Leslie E. Wolf, J.D., M.P.H., is Associate Professor of Law at Georgia State University's College of Law. She was selected as a Greenwall Fellow in Bioethics and Public Policy and as a Greenwall Faculty Scholar. She conducts research in a variety of areas in health and public health law and ethics, with a particular focus on research ethics. She has conducted empirical research on conflicts of interest, research with stored biological materials, Certificates of Confidentiality, IRB Web guidance, and HIV-related laws and policies. Previously she taught medical ethics and research ethics at the University of California, San Francisco.

Paul Root Wolpe, Ph.D., is the Asa Griggs Candler Professor of Bioethics and Director of the Center for Ethics at Emory University. Previously he was Professor of Sociology at the University of Pennsylvania. Dr. Wolpe is immediate past president of the American Society for Bioethics and Humanities, and is co-editor of the American Journal of Bioethics. He is the author of more than 100 articles and book chapters. His writings range across multiple fields of sociology and bioethics, including mental health and illness, death and dying, genetics and eugenics, gender, alternative medicine, and bioethics in extreme environments such as space.

INFORMATION

SYMPOSIUM LOCATION

Georgia State University
Student University Center
Speakers Auditorium
44 Courtland Street, Atlanta, Georgia 30303
Parking available in Deck M on Auditorium Place for $6
Directions and parking at www.BabyDoeSymposium.org

SPECIAL NEEDS

If you require any special accommodations, please call Anna Agrow at 678.612.8818.

EVENT CONTACT

Anna Agrow, Angelfish Meetings & Events
(P) 678.612.8818
(F) 888.253.1271
(E) anna@angelfishmeetings.com
616 Linwood Avenue, N.E., Suite A
Atlanta, GA 30306

HOTEL

The Ritz-Carlton, Atlanta
181 Peachtree Street, N.E., Atlanta, GA 30303
Phone: 404.659.0400 • www.ritzcarlton.com

A block of rooms has been reserved for symposium attendees at The Ritz-Carlton, Atlanta at the reduced rate of $129.00 per night plus applicable sales tax.

Reservations
1.800.542.8680 or www.ritzcarlton.com
Use group code SULX when booking a room to receive the reduced symposium room rate. Hotel accommodations are not included in the symposium registration fee.

TRAVEL

Air
Hartsfield-Jackson International Atlanta Airport (airport code ATL) is located less than 30 minutes from the symposium hotel and venue. http://www.atlanta-airport.com

Public Transit
The MARTA rail transit system serves the Atlanta area. Symposium attendees can travel to and from the symposium location on MARTA. http://www.itsmarta.com

Stations include:

Airport Station
(North-South Rail Line): Located in the Atlanta Airport next to baggage claim

Peachtree Center Station
(North-South Rail Line): Less than a block from The Ritz-Carlton, Atlanta

Georgia State Station
(East-West Rail Line): From Peachtree Center Station adjacent to The Ritz-Carlton, ride the North-South train one stop South to the Five Points Station. Change to the East-West train and ride one stop East to the Georgia State Station. Walk North on Piedmont Avenue two blocks to the Georgia State University Student Center located on your left at the intersection of Piedmont Avenue and Gilmer Street.

Taxi Cabs
Atlanta Checker Cab, 404.351.1111, http://www.atlantacheckercab.com

Atlanta Lenox Taxi, 404.872.2600, http://atlantalenoxtaxi.com

CONTINUING EDUCATION

Symposium organizers are applying for continuing education credits in Georgia for a variety of disciplines including medicine, nursing, and social work. Check the symposium Web site at www.BabyDoeSymposium.org periodically for updated continuing education information. Please call Barry Hester with the Georgia State University Law Review at 404.694.0548 with questions.

Continuing Legal Education
6 CLE hours have been applied for from the Georgia Commission on Continuing Lawyer Competency. To receive credit, bring your Georgia Bar number and $50 CLE payment to the symposium by check or cash.

Certificates of Attendance for Out-of-State Attendees and Other Professionals
Certificates of Attendance indicating number of symposium hours can be provided for attendees at the symposium.

CANCELLATION POLICY

Registrants may cancel their symposium registration and receive a refund of the registration fee, less a $25 administrative fee, if the cancellation is received in writing (by email, fax, or mail) by January 15, 2009. Registration cancellations received after January 15, 2009 will not be refunded, but the registration may be transferred to another attendee if notice of the transfer is received in writing by February 12, 2009. Please send all symposium registration cancellations or transfer notifications by EMAIL to anna@angelfishmeetings.com or by FAX to 888.253.1271 or by MAIL to Baby Doe Symposium, c/o Angelfish Meetings & Events, 616 Linwood Avenue, N.E., Suite A, Atlanta, GA 30306.

REGISTRATION FORM

The 25th Anniversary of the Baby Doe Rules:

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Please contact Anna Agrow at Angelfish Meetings & Events at 678.612.8818 with questions about conference registration.

TO REGISTER

Online: www.BabyDoeSymposium.org · **Fax:** 888.253.1271, ATTN: Anna Agrow

Mail: Send payment and completed registration form by mail to:

Baby Doe Symposium, c/o Angelfish Meetings & Events,
616 Linwood Avenue, N.E., Suite A, Atlanta, GA 30306

REGISTRATION FORM

First Name _____ Last Name _____
Title _____
Institution / Organization _____
Address _____
City _____ State _____ Zip _____
Daytime Phone _____ Mobile Phone _____
E-Mail Address _____

Profession or Affiliation:

- ☐ Academic
- ☐ Attorney
- ☐ Community Organization
- ☐ Ethics Committee Member
- ☐ Government
- ☐ Hospital Administrator
- ☐ Nurse
- ☐ Physician
- ☐ Policy Organization
- ☐ Social Worker
- ☐ Student
- ☐ Other _____

REGISTRATION FEES

Registration includes breakfast, lunch, and breaks at symposium (payment received by Thursday, January 15, 2009) **$75.00**

Late Registration includes breakfast, lunch, and breaks at symposium (payment received between Friday, January 16 - Thursday, February 12, 2009) **$125.00**

On-site Registration includes breakfast, lunch, and breaks based on availability (at symposium on Friday, February 13, 2009) **$150.00**

REGISTRATION FEE WAIVER

All students and Georgia State University faculty and staff members receive complimentary admission to the conference. Advance registration is required for all students and Georgia State faculty and staff.

☐ I am a student at _____

☐ I am a Georgia State University faculty or staff member.

ADVANCED PARKING RESERVATION

Add $6 to your registration fee if you would like to reserve a parking space in Deck M across the street from the symposium location on Friday, February 13, 2009.

☐ I would like to reserve a parking space in Deck M for $6.

PAYMENT METHOD

☐ Check or money order in the amount of $_____(U.S. funds only) made payable to 'Georgia State University College of Law' with memo line for 'Baby Doe Symposium'

☐ Credit card: ☐ Visa ☐ MasterCard ☐ American Express ☐ Discover

Card number _____
CCV code _____ Exp. Date _____ Amount $ _____
Name on card _____ Signature _____

Symposium registration fee will appear as a charge from Angelfish Meetings on your credit card statement.

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REGISTER

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— Register by January 15, 2009 and save! —

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Nationally-prominent experts in the fields of neonatal medicine, law, ethics, and disability policy explore controversial issues involved in treatment decisions for premature and other medically at-risk infants.

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