Curriculum Vitae

Aaron J. B. Goldenberg, PhD MPH

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PERSONAL INFORMATION

Contact Information

Office Address: Department of Bioethics, School of Medicine, Case Western Reserve University TA212
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Education

School: Michigan State University, East Lansing, MI
Degree: BS (History and Philosophy of Science-Lyman Briggs School)
Dates: 1994-1997

School: Case Western Reserve University, Cleveland, OH
Degree: MA (Bioethics)
Dates: 1999-2000

School: University of Michigan, Ann Arbor, MI
Degree: MPH (Health Behavior/Health Education and Public Health Genetics)
Dates: 2000-2002

School: Case Western Reserve University, Cleveland, OH
Degree: PhD (Bioethics)
Dates: 2004-2009

Ph.D. Thesis

Title: Ethics at the Crossroads of Public Health and Biobanking: The Use of Michigan's Residual Newborn Screening Bloodspots for Research.

Ph.D. Thesis Committee: Eric Juengst, PhD (Co-Chair), Patricia Marshall, PhD (Co-Chair), Leona Cutler, MD, Jennifer Fishman, PhD, Nicholas King, PhD, Benjamin Wilfond, MD (University of Washington)

ACADEMIC APPOINTMENTS

Position/Rank: Associate Professor (with Tenure)
Institution/Department Case Western Reserve University-School of Medicine, Department of Bioethics
Dates: 2015-present

Position/Rank: Assistant Professor
Institution/Department: Case Western Reserve University-School of Medicine, Department of Bioethics
Dates: 2009-2015

PROFESSIONAL APPOINTMENTS

Position/Rank: Associate Director
Institution/Department: Center foe Genetic Research Ethics and Law, Department of Bioethics, Case Western Reserve University
Dates: 2013-present

Position/Rank: Director of Research
Institution/Department: Department of Bioethics, Case Western Reserve University
Dates: 2015-present

Position/Rank: Masters Degree Program Director
Institution/Department: Department of Bioethics, Case Western Reserve University
Dates: 2013-present

Position/Rank: Assistant Director
Institution/Department: Center foe Genetic Research Ethics and Law, Department of Bioethics, Case Western Reserve University
Dates: 2009-2013

HONORS AND AWARDS

Glennan Fellow Award for Teacher/Scholars, UCITE Case Western Reserve University	Spring 2013
John S. Diekhoff Graduate Teaching Award Nominee, Case Western Reserve University	Spring 2013

MEMBERSHIP IN PROFESSIONAL SOCIETIES

American Society for Bioethics and Humanities, Member	2005-present
American Public Health Association, Member/Board Member-APHA Genomics Forum (2008)	2007-present

PROFESSIONAL SERVICES

Associate Editor
Journal: American Journal of Bioethics Empirical
Dates of Service: 2015-present

Editorial Boards
Journal: Frontiers in Genetics, ELSI in Science and Genetics Section
Dates of Service: 2013-2014

Study Sections/Grant Review Committees
Section/Committee: NIH, National Human Genome Research Institute, H3Africa Grant Review Panel
Dates of Service: July 2014

Section/Committee: NIH, National Human Genome Research Institute, Special Study Section H3Africa
Dates of Service: December 2013

Section/Committee: Lung Cancer Research Program (LCRP), Congressionally Directed Medical Research Programs (CDMRP), Department of Defense (DOD)- Lung Cancer Biospecimen Resource Network (LCBRN) Award Panel
Dates of Service: February 2010

Ad Hoc Journal Reviews

1. Pediatrics
2. Journal of Pediatrics
3. American Journal of Public Health
4. Community Genetics
5. Public Health Genetics
6. Personalized Medicine

7. Journal of Community Genetics
8. American Journal of Bioethics
9. American Journal of Men's Health
10. BioMed Central: Medical Ethics
11. Genetics in Medicine
12. Trends in Microbiology
13. Internal Medicine Journal
14. Tropical Medicine and International Health
15. IRB: Ethics and Human Research

NATIONAL COMMITTEE SERVICE

Organization:	Association of Public Health Laboratories
Committee Name/Role:	Legal and Legislative Workgroup Member
Dates of Service:	2015-present
Organization:	Global Alliance for Genomics and Health
Committee Name/Role:	Pediatric Task Team Member
Dates of Service:	2015-present
Organization:	Genetic Counseling Training Program, Department of Genetics and Genome Sciences, CWRU School of Medicine
Committee Name/Role:	Program Advisory Board Member
Dates of Service:	2014-present
Organization:	Secretary's Advisory Committee on Heritable Diseases in Newborns and Children (Health and Human Services)
Committee Name/Role:	Condition Review Workgroup/Ethics Representative
Dates of Service:	2012-2014
Organization:	Newborn Screening Translational Research Network, American College of Medical Genetics
Committee Name/Role:	Ethics and Legal Workgroup Co-chair
Dates of Service:	2011-present
Organization:	Secretary's Advisory Committee on Heritable Diseases in Newborns and Children (Health and Human Services)
Committee Name/Role:	Carrier Screening Workgroup
Dates of Service:	2011-2012
Organization:	American Public Health Association, Genomics Forum
Committee Name/Role:	Executive/Leadership Committee Member
Dates of Service:	2009-2011
Organization:	The Genetics Equity Network
Committee Name/Role:	Founding Steering Committee Member
Dates of Service:	2006-2009

TEACHING ACTIVITIES

Curriculum/Course Development

1. Aided in the development for Block 1curriculum, School of Medicine, Block 1 Design Team (2010-Present)
2. Developed new Genomics and Ethics Course-BETH 412, Department of Bioethics/Genetic Counseling Program (Glennan Fellowship)
3. Developed new course in Public Health Ethics, BETH

Ongoing Teaching/Courses

1. Course Number/Name: BETH 412-Ethical Issues in Genetics and Genomics (3 credits)
   Description: This course is designed to familiarize graduate students with the major controversies regarding the generation and use of new human genetic information in clinical and research settings.
   Contact Hours: 37.5
   Number of Students: 18
   Years Taught: Spring 2014-16

2. Course Number/Name: BETH 402-Foundations in Bioethics 2 (6 credits)
   Description: I directed this team-taught bioethics overview course. I am the Unit Director for the Public Health and Genetics Units within the course. I teach between 8-12 sessions around topics of genetics and public health ethics. .
   Contact Hours: average 40 contact hours
   Number of Students: 17-33
   Years Taught: Spring 2010-Spring 2012, and Spring 2014-16

3. Course Number/Name: BETH 315/415- Public Health Ethics in the Netherlands (3 credits)
   Description: This is an international course comparing public health practice in the US and the Netherlands. This course covers a number of public health ethics issues such as STD prevention, sex education, and drug abuse.
   Contact Hours: 45 hours
   Number of Students: 12-29
   Years Taught: Spring 2009-Spring 2013

4. Course Number/Name: BETH 602- Independent Study in Bioethics (1-3 credits)
   Description: This is a student project-based independent study within the curriculum of the Masters in Bioethics Program
   Contact Hours: 10-25 hours/student
   Number of Students: 4 from 2010-2014 (Topics included 1) Islamic Bioethics 2) Ethics in Newborn Screening 3) Direct to Consumer Genetic Tests and Research 4) Grant Writing in Bioethics
   Years Taught: Spring 2010-Fall 2013

5. Course Number/Name: BETH 417-Introduction to Public Health Ethics (3 credits)
   Description: The goal of this course is to introduce students to theoretical and practical aspects of ethics in public health practice and research.
   Contact Hours: 37.5 hours
   Number of Students: 18
   Years Taught: Spring 2010

6. Course Number/Name: BETH 507-Introduction to Public Health Ethics (3 credits)
   Description: This course is designed to provide a detailed overview of quantitative research design methods
   Contact Hours: 39 hours
   Number of Students: 6
   Years Taught: Spring 2010

Other Selected Guest Lectures

2016 “Genomics and Precision Medicine”, SOCI 365, Health Care Delivery, Department of Sociology
2016 “Ethical Implications of Genome Sequencing”, GENE 500/504: Fundamentals and Current Topics in Genetics/Genomics Research
2016 “Ethics in Qualitative Research”, GENE 651: Research Thesis Seminar &Applied Biostatistics in Clinical Research Seminar Series
2016 “Survey Design”, GENE 651: Research Thesis Seminar &Applied Biostatistics in Clinical Research Seminar Series
2015 “Ethical Implications of Genome Sequencing”, GENE 500/504: Fundamentals and Current Topics in Genetics/Genomics Research
2015 “Ethics in Qualitative Research”, GENE 651: Research Thesis Seminar &Applied Biostatistics in Clinical Research Seminar Series
2015 “Survey Design”, GENE 651: Research Thesis Seminar &Applied Biostatistics in Clinical Research Seminar Series

2014 “Ethical Implications of Genome Sequencing”, GENE 500/504: Fundamentals and Current Topics in Genetics/Genomics Research
2014 “Ethics in Qualitative Research”, GENE 651: Research Thesis Seminar &Applied Biostatistics in Clinical Research Seminar Series
2014 “Survey Design”, GENE 651: Research Thesis Seminar &Applied Biostatistics in Clinical Research Seminar Series
2014 “Ethical Issues in Newborn Screening”, EPBI 460: Public Health Genomics Module
2014 “History and Ethics of Newborn Screening Programs”, BIOL 326/426 Genetics
2014 “Ethics of Biobanking and Tissue Research”, BETH 271: Introduction to Bioethics
2014 “Introduction to Communitarian Ethics”, BETH 401: Foundations in Bioethics I
2013 “Ethics in Qualitative Research”, GENE 651: Research Thesis Seminar &Applied Biostatistics in Clinical Research Seminar Series
2013 “Ethics of Biobanking and Tissue Research”, BETH 271: Introduction to Bioethics Dilemmas
2013 “Introduction to Ethics in Anesthesiology” (4 sessions), ANES 490: Ethics, Law & Diversity for Anesthesiologist Assistants
2013 “Ethics in Population Health”, Block 1, School of Medicine
2013 “Ethics of Engaging Communities”, Block 1, School of Medicine
2013 “Survey Design”, GENE 651: Research Thesis Seminar &Applied Biostatistics in Clinical Research Seminar Series
2013 “Ethical Implications of Genome Sequencing”, GENE 500/504: Fundamentals and Current Topics in Genetics/Genomics Research
2013 “Introduction to Communitarian Ethics”, BETH 401: Foundations in Bioethics I
2013 “Ethics and Tissue Banking”, BETH 401: Foundations in Bioethics I
2012 “Ethics of Biobanking and Tissue Research”, BETH 271: Introduction to Bioethics Dilemmas
2012 “Introduction to Ethics in Anesthesiology” (4 sessions), ANES 490: Ethics, Law & Diversity for Anesthesiologist Assistants
2012 “Ethics of Engaging Communities”, Block 1, School of Medicine
2012 “Introduction to Communitarian Ethics”, BETH 401: Foundations in Bioethics I
2012 “Ethics and Tissue Banking”, BETH 401: Foundations in Bioethics I
2011 “Genetics and Health Disparities”, EPBI 510: Health Disparities
2011 “Ethics in Population Health and Genetics”, EPBI 440: Introduction to Population Health
2011 “Ethical implications of Expanded Newborn Screening”. BETH 504: Critical Readings in Bioethics
2011 “Introduction to Ethics in Anesthesiology” (4 sessions), ANES 490: Ethics, Law & Diversity for Anesthesiologist Assistants
2011 “Ethical Issues in Pandemics”, Block 1, School of Medicine
2011 “Newborn Screening Programs-History and Ethics”, Block 1, School of Medicine
2011 “Introduction to Communitarian Ethics”, BETH 401: Foundations in Bioethics I
2011 “Ethics and Tissue Banking”, BETH 401: Foundations in Bioethics I

2010 “Genetics and Health Disparities”, EPBI 510: Health Disparities
2010 “Ethics of Biobanking and Tissue Research”, BETH 271: Introduction to Bioethics Dilemmas

2010 “Introduction to Ethics in Anesthesiology” (4 sessions), ANES 490: Ethics, Law & Diversity for Anesthesiologist Assistants
2009 “Genetics and Health Disparities”, EPBI 510: Health Disparities
2009 “Ethics of Biobanking and Tissue Research”, BETH 271: Introduction to Bioethics Dilemmas

Trainees/Mentees

Trainee Name	Type of Trainee	Training Period	Current Position of Past Trainees
Chaziom Ibegbu	Medical Student	2010-2011	Residency, Emory School of Medicine, Department of Neurology
Charley Willison	Masters Student	2011-2014	Starting PhD Program in Health Services Organization and Policy, University of Michigan
Jamie Ott	Masters Student	2010-2011	Medical Student, University of Buffalo
Apoorva Chandar	Masters Student	2012-2013	Working at Case Western Reserve University
Jack Brackney	Masters Student	2012-2013	Masters Student in Bioethics
Monica Nardini	Masters Student	2011-2013	Certified Genetic Counselor, The Cleveland Clinic
Charlisse Caga-Anan	Post-Doc, CGREAL	2011-2013	Program Director in the Epidemiology and Genomics Research Program's (EGRP) Host Susceptibility Factors Branch (HSFB)-National Cancer Institute
Mike Kapattos	Masters Student	2013-2014	Medical School, University of Virginia
Matthew Kucmanic	Masters Student	2013-2016	Masters student in Department of Bioethics and Public Health
Emily Schwessinger	Med/Masters Student	2015-2016	School of Medicine, CWRU

Thesis/Capstone Committees

Student Name	Program	Year Thesis/Capstone Completed	Thesis/Capstone Title
Matthew Kucmanic	Masters in Public Health/Bioethcis	August 2016 (Expected)	Assessing the Public Health Impact of Precision Medicien
Elana Wishnefsky	Masters in Genetic Counseling	May 2016 (Expected)	Perspectives and Needs of Siblings of Children with Prader-Willi Syndrome
Lauren Bokovitz	Masters in Genetic Counseling	May 2015	The impact of cystic fibrosis on women’s experience with reproductive decisions
Rebekah Moore	Masters in Genetic Counseling	June 2014	Providing Genetic Services Through Social Media
Charley Willison	Masters in Public Health	2013	State-By-State Variations in Coverage of Mental Health and Substance Use Disorder Benefits in the ACA Mandated Essential Health Benefits Benchmark Plans

Monica Nardini	Masters in Genetic Counseling	2013	Genetic counselors' opinions regarding genomic counseling in the newborn period
Karen Buser	Masters in Genetic Counseling	2012	Parental Attitudes Regarding Newborn Screening for Duchenne Muscular Dystrophy

Teaching Administration (e.g. residency directorship)
1. Co-Director, Masters in Bioethics Program, 2010-Present
2. Bioethics Representative, Block 1 Design Team, School of Medicine, 2010-Present

RESEARCH SUPPORT

1. Health Recourses and Services Administration (HRSA), Child and Maternal Health Bureau
   Title: The National Newborn Screening Clearinghouse (Baby's First Test)
   PI: Sharon F. Terry, Natasha F. Bonhomme, Genetic Alliance
   Role: Director for Policy, Ethics and Practice and Co-Investigator
   (I will provide ethics and policy expertise for the development and evaluation of new educational tools about Newborn Screening for the public and health professionals. I will also lead efforts to develop new activities to promote public and professional dialogue on the social and ethical implications of Newborn Screening.)
   Percent Effort: 1.8 calendar months
   Project Dates: Sept 2014-Sept 2018

2. NIH, National Human Genome Research Institute/National Institute for Child Health and Disease
   Title: Video Informed Consent Information (VICI) for Residual Bloodspot Biobanking *(Pending)*
   PI: Erin Rothwell, PhD (University of Utah)
   Role: Co-Investigator (If funded, I will provide methodological support for the analysis of qualitative data, and expertise for the translation of study results into normative policy and practice recommendations)
   Percent Effort: 1.2 calendar months
   Project Dates: October 2015-September 2018

3. Health Services and Resources Administration, Child and Maternal Health Bureau
   Title: Improving the Newborn Screening System in the Genomic Era
   PI: Aaron Goldenberg, PhD MPH
   Role: PI
   Percent Effort: 2.4 calendar months
   Project Dates: 4/1/14-3/31/16
   Total Direct Costs: 148,068 (FY 2013)

4. NIH, National Human Genome Research Institute
   Title: Biobanking at Birth: Parental Attitudes towards the Use of Perinatal Samples
   PI: Aaron Goldenberg, PhD MPH
   Role: PI
   Percent Effort: 3.0 calendar months
   Project Dates: 6/15/12-3/31/15
   Total Direct Costs: 150,000 (FY 2013)

5. NIH, National Human Genome Research Institute
   Title: Return of Research Results from Samples Obtained for Newborn Screening
   PI: Michelle Lewis, MD, PhD
   Role: Co-Investigator (Sub-contract from Johns Hopkins University) (I provide expertise and experience with how State Health Departments store and use their residual bloodspots from newborn screening for research. My role includes helping to analyze the policies and practices of health departments with regard to newborn screening research)
   Percent Effort: 1.2 Calendar Months
   Project Dates: 9/23/2011-8/31/2014
   Total Direct Costs: 75,000 (FY 3013)

6. NIH, National Human Genome Research Institute
   Title: Prenatal Education about Newborn Screening and Bloodspot Retention

PI: Jeff Botkin, PhD, University of Utah
Role Co-Investigator/Site PI (Sub-contract from the University of Utah) (My role on the project is to help lead Aim 3 of the project: the normative assessment of the ethical, legal, and social implications of our results for how education is provided and how newborn screening and sample retention is conducted. I also provide key methodological support for the design of study instruments, and analysis of study data.)
Percent Effort: .6 calendar months
Project Dates: 9/20/2011-6/30/2015
Total Direct Costs: $474,999 (FY 2013)

7. NIH, National Human Genome Research Institute
   Title: Advancing Collaborative Genetic Research: Ethical and Policy Challenges
   PI: Suzanne Rivera, PhD, Case Western Reserve University
   Role: Co-Investigator (I provide key expertise on biobanking and data sharing, lead one of the projects aims to analyze CTSA policies regarding genomic data sharing, and provide general methods support for other project aims)
   Percent Effort: 1.2 calendar months
   Project Dates: 5/26/11-2/28/15
   Total Direct Costs: $380,324 (FY 2013)

8. NIH, National Human Genome Research Institute
   Title: ELSI Issues: Colon Cancer and Cancer Genomics Research
   PI: . Marshall, Ph.D., Department of Bioethics, CWRU
   Role: Co-Investigator (I provided methodological support for the development of surveys and aided in data analysis)
   Percent Effort: 1.2 calendar months
   Project Dates: 9/27/2010-8/31/2011
   Total Last Grant Years Budget: $295,440

9. NIH, National Human Genome Research Institute
   Title: From Specimen to Biobank: Using an Organizational Perspective to Study ELSI Issue
   Principal Investigator: Gail Henderson, PhD, University of North Carolina
   Role: Co-Investigator (I provided key expertise on the banking of newborn bloodspots, and led the data collection and analysis related to the project’s neonatal case study)
   Percent Effort: 1.56 calendar months
   Project Dates: 9/27/2010-8/31/2011
   Total Last Grant Year: $20,872 (Carry over-no cost extension)

10. NIH, National Human Genome Research Institute
    Title: Center for Genetic Research Ethics and Law
    (renewed-original award from 2004 PI: Eric Juengst, PhD)
    Principal Investigator: P. Marshall, Ph.D., Department of Bioethics, CWRU
    Role: Co-Investigator, Associate Director
    Percent Effort: 3.0 calendar months
    Project Dates: 8/5/10-7/31/14
    Total Direct Costs: $518,526 (FY 2013)

11. NIH, National Human Genome Research Institute
    Title: Community Voices on Health Disparities and Translational Genomics
    PI: P. Marshall, Ph.D., Department of Bioethics, CWRU
    Role: Co-Investigator (I oversaw data collection and analysis of results, conducted focus groups, and supervised project staff)
    Percent Effort: 3.0 calendar months
    Project Dates: 9/29/09-8/31/11
    Total Last Grant Years Budget: $486,427

BIBLIOGRAPHY

Peer Reviewed Articles

1. **Goldenberg, Aaron J**., Anne Marie Comeau, Scott D. Grosse, Susan Tanksley, Lisa A. Prosser, Jelili Ojodu, Jeffrey R. Botkin, Alex R. Kemper, and Nancy S. Green. "Evaluating Harms in the Assessment of Net Benefit: A Framework for Newborn Screening Condition Review." *Maternal and child health journal* 20, no. 3 (2016): 693-700.

2. Botkin, Jeffrey R., Erin Rothwell, Rebecca A. Anderson, Nancy C. Rose, Siobhan M. Dolan, Miriam Kuppermann, Louisa A. Stark, **Aaron Goldenberg**, and Bob Wong. "Prenatal Education of Parents About Newborn Screening and Residual Dried Blood Spots: A Randomized Clinical Trial." *JAMA pediatrics* (2016).

3. **Goldenberg, Aaron J**., Karen J. Maschke, Steven Joffe, Jeffrey R. Botkin, Erin Rothwell, Thomas H. Murray, Rebecca Anderson, Nicole Deming, Beth F. Rosenthal, and Suzanne M. Rivera. "IRB practices and policies regarding the secondary research use of biospecimens." *BMC medical ethics* 16, no. 1 (2015): 1

4. Lewis, Michelle Huckaby, and **Aaron J. Goldenberg**. "Return of results from research using newborn screening dried blood samples." *The Journal of Law, Medicine & Ethics* 43, no. 3 (2015): 559-568.

5. Dodson, Daniel S., **Aaron J. Goldenberg,** Matthew M. Davis, Dianne C. Singer, and Beth A. Tarini. "Parent and public interest in whole-genome sequencing." *Public health genomics* 18, no. 3 (2015): 151-159.

6. Hartmann, Christopher D., Patricia A. Marshall, and **Aaron J. Goldenberg**. "Is there a space for place in family history assessment? Underserved community views on the impact of neighborhood factors on health and prevention." *The journal of primary prevention* 36, no. 2 (2015): 119-130.
   **Senior author on this manuscript*

7. Botkin, Jeffrey R., Erin Rothwell, Rebecca A. Anderson, **Aaron Goldenberg**, Miriam Kuppermann, Siobhan M. Dolan, Nancy C. Rose, and Louisa Stark. "What parents want to know about the storage and use of residual newborn bloodspots." *American Journal of Medical Genetics Part A* 164, no. 11 (2014): 2739-2744.

8. Rivera, Suzanne M., **Aaron Goldenberg**, Beth Rosenthal, Heide Aungst, Karen J. Maschke, Erin Rothwell, Rebecca A. Anderson, Jeffrey Botkin, and Steven Joffe. "Investigator Experiences and Attitudes About Research With Biospecimens." *Journal of Empirical Research on Human Research Ethics*10, no. 5 (2015): 449-456.

9. Rothwell, Erin, Karen J. Maschke, Jeffrey R. Botkin, Aaron Goldenberg, Thomas H. Murray, and Suzanne M. Rivera. "Biobanking research and human subjects protections." *IRB Ethics and Human Research* 37, no. 2 (2015): 8-13.

10. Simpson, Claire L., **Aaron J. Goldenberg**, Rob Culverhouse, Denise Daley, Robert P. Igo, Gail P. Jarvik, Diptasri M. Mandal et al. "Practical Barriers and Ethical Challenges in Genetic Data Sharing." *International journal of environmental research and public health* 11, no. 8 (2014): 8383-8398.

11. Nardini, Monica D., Anne L. Matthews, Shawn E. McCandless, Larisa Baumanis, and **Aaron J. Goldenberg*.** "Genomic Counseling in the Newborn Period: Experiences and Views of Genetic Counselors." *Journal of genetic counseling* (2014): 1-10.
    **Senior author on this manuscript and primacy mentor to the first author for this project.*

12. Botkin, Jeffrey R., Michelle Huckaby Lewis, Michael S. Watson, Kathryn J. Swoboda, Rebecca Anderson, Susan A. Berry, Natasha Bonhomme et al. "Parental Permission for Pilot Newborn Screening Research: Guidelines From the NBSTRN." *Pediatrics* 133, no. 2 (2014): e410-e417.

13. Haldeman, K. M., R. J. Cadigan, A. Davis, **A. Goldenberg**, G. E. Henderson, D. Lassiter, and E. Reavely. "Community Engagement in US Biobanking: Multiplicity of Meaning and Method." *Public health genomics* 17, no. 2 (2014): 84-94.

14. Kemper, Alex R., Nancy S. Green, Ned Calonge, Wendy KK Lam, Anne M. Comeau, **Aaron J. Goldenberg**, Jelili Ojodu, Lisa A. Prosser, Susan Tanksley, and Joseph A. Bocchini Jr. "Decision-making process for conditions nominated to the Recommended Uniform Screening Panel: statement of the US Department of Health and Human Services Secretary/'s Advisory Committee on Heritable Disorders in Newborns and Children." *Genetics in Medicine* (2013)

15. **Goldenberg, Aaron J**., Daniel S. Dodson, Matthew M. Davis, and Beth A. Tarini. "Parents 'interest in whole-genome sequencing of newborns." *Genetics in Medicine* (2013).

16. **Goldenberg, Aaron J**., Christopher D. Hartmann, Laura Morello, Sanjur Brooks, Kari Colón-Zimmermann, and Patricia A. Marshall. "Gene–environment interactions and health inequalities: views of underserved communities." *Journal of community genetics* (2013): 1-10.

17. Botkin, Jeffrey R., **Aaron J. Goldenberg*,** Erin Rothwell, Rebecca A. Anderson, and Michelle Huckaby Lewis. "Storage and research use of residual newborn screening bloodspots." *Pediatrics* 131, no. 1 (2013): 120-127.

18. Tarini, Beth A., Laura L. Konczal, **Aaron J. Goldenberg**, Edward B. Goldman, and Shawn E. McCandless. "The Perils of SNP Microarray Testing: Uncovering Unexpected Consanguinity." *Pediatric neurology* 49, no. 1 (2013): 50-53.

19. **Goldenberg, Aaron J**., and Richard R. Sharp. "The ethical hazards and programmatic challenges of genomic newborn screening." *JAMA: The Journal of the American Medical Association* 307, no. 5 (2012): 461-462.

20. Tarini, Beth A., and **Aaron J. Goldenberg**. "Ethical issues with newborn screening in the genomics era." *Annual review of genomics and human genetics* 13 (2012): 381.

21. Broder, Sherri M., Roselle S. Ponsaran, and **Aaron J. Goldenberg***. "US public cord blood banking practices: recruitment, donation, and the timing of consent." *Transfusion* 53, no. 3 (2013): 679-687.
    **Senior author on this manuscript and PI for the study.*

22. Botkin, Jeffrey R., Erin Rothwell, Rebecca Anderson, Louisa Stark, **Aaron Goldenberg***, Michelle Lewis, Matthew Burbank, and Bob Wong. "Public attitudes regarding the use of residual newborn screening specimens for research." *Pediatrics* 129, no. 2 (2012): 231-238.

23. Rothwell, Erin, Rebecca Anderson, **Aaron Goldenberg***, Michelle H. Lewis, Louisa Stark, Matthew Burbank, Bob Wong, and Jeffrey R. Botkin. "Assessing public attitudes on the retention and use of residual newborn screening blood samples: a focus group study." *Social science & medicine* 74, no. 8 (2012): 1305-1309.

24. Lewis, Michelle H., **Aaron Goldenberg***, Rebecca Anderson, Erin Rothwell, and Jeffrey Botkin. "State laws regarding the retention and use of residual newborn screening blood samples." *Pediatrics* 127, no. 4 (2011): 703-712.

25. Rothwell, Erin W., Rebecca A. Anderson, Matthew J. Burbank, **Aaron J. Goldenberg***, Michelle Huckaby Lewis, Louisa A. Stark, Bob Wong, and Jeffrey R. Botkin. "Concerns of newborn blood screening advisory committee members regarding storage and use of residual newborn screening blood spots." *American Journal of Public Health* 101, no. 11 (2011).

26. **Goldenberg, A. J.,** S. C. Hull, B. S. Wilfond, and R. R. Sharp. "Patient perspectives on group benefits and harm research." *Public Health Genomics* 14, no. 3 (2010): 135-142.

27. **Goldenberg, Aaron J**., Sara Chandros Hull, Jeffrey R. Botkin, and Benjamin S. Wilfond. "Pediatric biobanks: approaching informed consent for continuing research after children grow up." *The Journal of pediatrics* 155, no. 4 (2009): 578-583.

28. Tarini, B. A., **A. Goldenberg***, D. Singer, S. J. Clark, A. Butchart, and M. M. Davis. "Not without my permission: parents' willingness to permit use of newborn screening samples for research." *Public Health Genomics* 13, no. 3 (2009): 125-130.

29. Kardia, Sharon LR, Jennifer Bodzin, **Aaron Goldenberg**, Toby Citrin, Sarah F. Raup, and Janice V. Bach. "Genomics and public health: development of Web-based training tools for increasing genomic awareness." *Preventing Chronic Disease [Electronic Resource]* 2, no. 2 (2005).

Invited, Non-Peer Reviewed

1. **Goldenberg, Aaron J.**, Patricia A. Marshall, and Richard R. Sharp. "Next-generation disadvantages: identifying potential barriers to integrating genomics into underserved medical settings." *Personalized Medicine* 10.7 (2013): 623-625.

2. Wilfond, B and **Goldenberg, A**. "Genetic Testing & Screening II: Newborn Genetic Screening" (revision of pervious edition's entry by Ellen Wright Clayton). *Bioethics (Encyclopedia), 4th Edition.* Edited by Bruce Jennings. Farmington Hills, MI: Macmillan Reference USA, 2014.

Book Chapters

1. Juengst, Eric T., and **Aaron Goldenberg**. "Genetic diagnostic, pedigree, and screening research." *The Oxford Textbook of Clinical Research Ethics* (2008): 298.

Invited National/International Presentations

April 2016	"What we know about the psychological impact of uncertain results from newborn screening", Columbia University-Center for Excellence in ELSI Research, New York, NY
April 2016	"Genomics and State Newborn Screening Programs: Ethical and Programmatic Challenges", New England Genomics Collaborative, Portsmouth, NH
March 2016	"Ethical issues in Genetic Testing for Rare Diseases", Alpha-1 Foundation Seminar on Research in Rare Disease, Washington DC
November 2015	"Parental Attitudes Regarding Genomic Sequencing in Newborn Screening", The Hastings Center Symposium on Newborn Screening, Garrison, NY
October 2015	"Newborn Screening and Informed Consent for Sample Use, Newborn Screening Translational Research Network Meeting" Washington DC
June 2015	"Parental Attitudes Regarding Consent for the Future Use of Newborn Screening Bloodspots", Association of Public Health Laboratories-Meeting on Informed Consent, Washington, DC
January 2015	"Integrating Genomics into State Newborn Screening Programs: Ethical and Programmatic Challenges", UC Davis Human Genomics Seminar Series, Sacramento, CA
October 2014	"New Ethical Challenges for Genomic Sequencing in Newborns" Individualized Medicine Conference, Mayo Clinic, Rochester, MN
October 2014	"Sequencing and return of results in newborn screening" Special American Society for Bioethics and Humanities/American Society of Human Genetics symposium: "From Clinical to Community Sequencing: Emerging Ethical, Legal and Social Issues in Genomics, San Diego, CA
October 2013	"Genomic Newborn Screening: Ethical Hazards, Programmatic Challenges, and Parental Interest" American Society of Human Genetics Annual Meeting. Boston, MA
August 2013	"Parental Interest in Whole Genome Sequencing in Newborn Screening"

	Genetic Alliance Symposium: Beyond the Bloodspot: How will emerging technologies shape detection and clinical care. Washington, DC
June 2012	“Residual Dried Bloodspot Use: Parental Attitudes Towards Privacy” National Webinar Providing Newborn Screening Specimens for Research Legal Issues Faced by State Health Departments-Network for Public Health Law and Association for Public Health Laboratory’s
November 2011	“Research Ethics, Blood Samples, and Stored Tissue” European Association of Tissue Banks World Congress” Barcelona, Spain
August 2011	“New Ethical Issues in Biobanking and Tissue Donation”, The Musculoskeletal Transplant Foundation, Donation Board of Trustees, Portland, OR
January 2011	"A Review of Newborn Screening Educational Materials: Storage and Research Use of Bloodspots" Newborn Screening Residual Bloodspots Expert Workshop", Salt Lake City, UT
March 2010	"Parental Attitudes on the Use of Dried Blood Spots and Newborn Screening Patient Data. The ETHOX Bioethics Center, Oxford UK
August 2007	“Use of Newborn Screening Bloodspots for Genetic Research” European Conference on Philosophy of Medicine and Health Care Cardiff, United Kingdom
November 2006	“Ethical Issues in Genetics and Public Health” National Society of Genetic Counselors Annual Education Conference Nashville, TN
April 2006	“Use of Dried Bloodspots for Research: Ethical and Legal Considerations” Newborn Screening Dried Blood Spots BioBank: Implications for Research and Public Health, Michigan Department of Community Health, Lansing MI
June 2005	“Medical Ethics vs. Public Health Ethics in Cancer Genomics” Cancer Genetics for Public Health, Michigan Department of Community Health, Lansing MI
September 2005	“Genetics and Sudden Cardiac Death: Lessons for Public Health Practice and Research”, Sudden Cardiac Death in the Young Symposium Michigan Department of Community Health, Lansing MI

Other Selected National/International Presentations

April 2016	“Navigating An Evolving Newborn Screening System and Its Impact o Education and Policy” Association of Maternal and Child Health Programs Annual Meeting, Washington DC
October 2015	“Sequencing Healthy Newborns: Critical Reflections on the Intersection of Genomics, Pediatrics and Public Health”, American Society for Bioethics and Humanities Annual Meeting, Houston, TX
October 2014	“New Ethical Challenges for Genomic Sequencing in Newborns” Individualized Medicine Conference, Mayo Clinic, Rochester, MN
October 2014	“Sequencing and return of results in newborn screening” Special American Society for Bioethics and Humanities/American Society of Human Genetics symposium: “From

	Clinical to Community Sequencing: Emerging Ethical, Legal and Social Issues in Genomics, San Diego, CA
October 2014	“Polices and Practices of Public Cord Blood Banks” American Society for Bioethics and Humanities San Diego, CA
November 2013	“Ethical and Programmatic Challenges of Genomic Newborn Screening" American Public Health Association Meeting. Boston, MA
October 2012	"The Benefits and Limitation of Empirical Research on Biobanking" American Society for Bioethics and Humanities Annual Meeting, Washington, DC
November 2011	“Cleveland Community Voices Project on Health Disparities and Translational Genomic Research” American Public Health Association Annual Meeting, Washington DC
April 2011	“Challenges of Community Based Research for Institutional Review Boards”, Ethical, Legal, and Social Implications of Genetics Congress, Chapel Hill NC
April 2011	“Community Voices on Genetics and Health Disparities (Poster)”, Ethical, Legal, and Social Implications of Genetics Congress, Chapel Hill NC
April 2011	“Who’s Cutting the Cord? Ethical Issues related to using umbilical cord blood for genetic research”, Ethical, Legal, and Social Implications of Genetics Congress, Chapel Hill NC
October 2011	“Opting-out is Hard to Do: Ethical Challenges to Mandatory Public Health Screening Programs for Children” America Society Of Bioethics and Humanities Annual Meeting, Minneapolis, Minnesota
November 2010	“Opting-out is Hard to Do: Ethical Challenges to Mandatory Public Health Screening Programs for Children” American Public Health Association Annual Meeting, Denver CO
October 2010	“Community Voices on Genetics and Health Disparities ” American Society for Bioethics and Humanities Annual Meeting, San Diego, CA
October 2010	“Patient Perspectives on Group Harm from Genetic Research” American Society for Bioethics and Humanities Annual Meeting, San Diego, CA
July 2010	“Patient Perspectives on Group Harm from Biobanking” Genetics and Ethics in the 21st Century Meeting, Denver CO
October 2009	“Ethics and Biobanking in Public Health” American Society for Bioethics and Humanities Annual Meeting Washington, DC
Sept 2009	“Genetic Research, Race, and Health Disparities” Health Disparities Course School of Medicine, Case Western Reserve University
October 2008	“Research Use of Michigan’s Residual Newborn Screening Bloodspots” American Public Health Association Humanities Annual Meeting San Diego, CA
October 2008	“Parental Advocacy and the Use of Residual Newborn Screening Bloodspots for Research ” American Society for Bioethics and Humanities Annual Meeting Cleveland, OH

Other Training Activities

September 2008	Academic Stay, The Brocher Foundation, Hermance Switzerland Project Title: "Conceptions of Group Harm in Large Scale Biobanks: A comparative analysis of Europe and the United States"
July 2006	Visiting Scholar (CEER Exchange Program), Center on Genomics and Social Identity in the African Diaspora, Howard University, Washington, DC
August 2005	Visiting Scholar, Geneforum, Portland, OR