

# Sara Huston Katsanis

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**Date / Place of Birth:** 17 July 1972, Winter Park, Florida, USA

**Current Position:** Instructor, Duke Science and Society, Duke University

## EDUCATION

Sep 2005 – June 2006 **Graduate Certificate** in Leadership and Management in the Life Sciences in the School of Professional Studies in Business and Education at Johns Hopkins University, Baltimore, MD.

Sep 1995 – Jul 1997 **Master of Science** in Medical Genetics with Immunology from Brunel University, University of West London, UK. Dissertation and thesis completed with Dr. Clare Huxley at Imperial College School of Medicine at St. Mary's, London, UK: Analysis of the interferon gamma receptor 1 gene as a mycobacterial susceptibility gene.

Aug 1990 – May 1995 **Bachelor of Science** in Biological Sciences from Clemson University, Clemson, SC. Minor in philosophy.

## WORK EXPERIENCE

<b>Instructor</b> Duke Science and Society at Duke University, Durham, NC	<b>Mar 2014 – present</b>
<b>Associate in Research</b> Institute for Genome Sciences and Policy at Duke University, Durham, NC	<b>Sep 2009 – Mar 2014</b>
<b>Genetics Policy Analyst</b> Genetics and Public Policy Center at Johns Hopkins University, Washington, DC	<b>Oct 2007 – May 2009</b>
<b>Business and Laboratory Manager</b> DNA Diagnostic Laboratory at Johns Hopkins University, Baltimore, Maryland	<b>Mar 2002 – Oct 2007</b>
<b>Associate Scientist</b> Lexicon Genetics, Incorporated, The Woodlands, Texas	<b>Apr 2000 – Feb 2002</b>
<b>DNA Analyst II</b> Harris County Medical Examiner's Office, Houston, Texas	<b>Jun 1998 – Apr 2000</b>
<b>Research Assistant</b> for Clare Huxley, Ph.D. Imperial College School of Medicine at St. Mary's, London, UK	<b>Sep 1995 – Jul 1997</b>
<b>Research Assistant</b> for Dr. Luciana Baldoni <i>Istituto di Ricerche sulla Olivicoltura</i> , Perugia, Italy	<b>May 1995 – Sep 1995</b>
<b>Research Assistant</b> for Charles Schwartz, Ph.D. Greenwood Genetics Center, Greenwood, South Carolina	<b>May 1994 – May 1995</b>
<b>Research Assistant</b> for Albert Abbott, Ph.D. Clemson University, Clemson, South Carolina	<b>Sep 1993 – May 1995</b>

**UNIVERSITY SERVICE AND ACADEMIC COMMITTEES**

Jul 2011- Sep 2011- 2014-2015	Member, Duke University Medical Center Institutional Review Board Member, Duke Applied Genomics and Precision Medicine Leadership Team Organizer, Distinguished Speaker Series in Bioethics & Science Policy, Duke Science & Society, Duke University, Durham, NC
2013-2015	Organizer, Annual Duke Genomes Family Forum, Task Force for Neonatal Genomics, Duke University, Durham, NC
Jan-Jun 2014	Contributor, Duke Science & Society blog
Oct 2014	Organizer and Speaker, 3 <sup>rd</sup> Workshop on DNA, Human Rights and Human Trafficking, Duke University, Durham, NC
Sep 2013 - Jun 2014	Workshop Organizing Committee, Duke Science & Society
Oct 2013	Delegate, International Commission on Missing Persons “The Missing: An Agenda for the Future,” The Hague, The Netherlands
Sep 2013	Organizer and Speaker, 2 <sup>nd</sup> Workshop on DNA, Human Rights and Human Trafficking, Duke University, Durham, NC
Mar 2013	Organizer and Speaker, Workshop on DNA, Human Rights and Human Trafficking, Duke University, Durham, NC
Jan 2010 - Aug 2013	Founder, Duke University Policy in Genome Sciences Working Group
Aug 2010 - Mar 2013	Consultant, Program Evaluation for Rapid DNA Project. Research Triangle Park, Institute Grant from Department of Homeland Security
Jan 2009	Direct-to-Consumer Genetic Tests: Confronting Issues for Canada, Toronto, ON. Invited by Canadian Institute of Health Research, Institute of Genetics
Jun 2008	Forensic DNA Databanks and Race: Issues, Abuses and Actions, New York, NY. Invited by Council for Responsible Genetics
Sep 2006	National Genetic Policy Summit, Washington, DC. Invited by Genetics and Public Policy Center

**TEACHING / INVITED LECTURES**

2014-2015	Duke University: Course Instructor, BIOETHIC605, Contemporary Issues in Bioethics & Science Policy
2012-2015	Duke University: Course Co-Director and Co-Instructor, N562, Applied Genomics and Personalized Medicine in Clinical Care
2013-2014	Duke University: Course Co-Director and Co-Instructor, N563, Trends in Genetics and Genomics in Health Care and Society
Nov 2009-2014	Duke University: Guest Lecturer, GENOME 158S-03, Genetics, Race & Society “DNA in Criminal Justice and Race”
Nov 2013-2014	Duke University: Guest Lecturer, GENOME 612, Ethics & Policy in Genomics “Human Genetic Identification for Mass Fatality Management and Human Trafficking”
Sep 2014	Duke University School of Nursing Teaching Conversations, “Strengthening students' voices for justice and advocacy through the use of op-ed and elevator pitch assignments”
May 2014	Orange High School: Lecturer, DNA Day Forensics
Mar 2013-2014	Duke University: Guest Lecturer, GENOME 508, Responsible Genomics, “Human Genetic Identification Applications”
Feb 2011-2014	Duke University: Guest Lecturer, GENOME 148, Genome Sciences and Society, “DNA Applications in Law Enforcement”
Nov 2011-2013	North Carolina State University: Guest Lecturer, Toxicology, TOX 701, “Forensic DNA Analysis”

Nov 2013	Duke University: Guest Lecturer, GENOME 256, Genome Sciences & Society “Maryland v King”
Sep 2010-2013	Duke University: Computational Biology and Bioinformatics Annual Retreat: Faculty Instructor, Responsible Conduct of Research
Fall 2012	Duke University: Organizer and featured speaker, Introductory Sessions on Genomics & Personalized Medicine: How can we personalize medicine?
Oct 2011	American Association of Blood Banks Annual Meeting, “Policy Landscape of Nonmedical Genetic Testing”
Feb 2011	Duke University: Guest Lecturer, GENOME 44, The Past and Future of the Human Genome, “DNA in Law Enforcement”
Spring 2011	Duke University: Faculty Course Instructor, GENOME 198S, Capstone for Genome Certificate
Nov 2010	Guilford County Sheriff’s Office: Guest Instructor, “DNA in Law Enforcement”
Oct 2010	North Carolina Human Trafficking Task Force: Guest Speaker, “Genetic Identification for Human Trafficking”
Oct 2010	Duke University: Guest Lecturer, GENOME 108FCS, Genome Revolution Focus Cluster: “Nonmedical Application of Genetic Testing”
Jul 2010	North Carolina State University: Guest Lecturer, Molecular Biology for High School, “Genetics and Society”
Oct 2005	Johns Hopkins University: Clinical Genetics Training Program: Guest Lecturer, “Clinical Molecular Testing for Inherited Disorders”
Nov 2004	Johns Hopkins University: Clinical Genetics Training Program: Guest Lecturer, “Pitfalls of Molecular Testing”

### **TRAINING/MENTORING**

2014-2015	Alexa Barrett (undergraduate) – Duke University, International Comparative Studies
2014-2015	Jessica Ordax (MA graduate) – Duke University, Bioethics and Science Policy
Spring 2014	Gwen Caudle – Duke School, 8 <sup>th</sup> Grade culminating project
Sep 2012-Dec 2012	Katrina Greely (MSN graduate) – Duke University, School of Nursing
May 2012-Aug 2012	Amanda Seagroves (undergraduate Duke IGSP summer fellow) – Queens University of Charlotte
May 2011-Aug 2011	Joyce Kim (undergraduate) – Duke University, IGSP
May 2010-Jul 2011	Sarah Grantham (undergraduate) – North Carolina State University (Department of Sociology)
Sep 2002-Aug 2008	Johns Hopkins University: Trained multiple Postdoctoral Clinical Genetics Residents and Genetic Counseling students during 2-4 week rotations
Sep 2002-Aug 2008	Johns Hopkins University: Trained multiple Postdoctoral Molecular Genetic Laboratory Fellows during 1-2 year rotations

### **PROFESSIONAL SERVICES**

#### Membership

American Society of Human Genetics 2007-current

#### Manuscript Reviewer

*European Journal of Human Genetics, American Journal of Medical Genetics, Genome Research, Pharmacogenomics and Personalized Medicine, Human Molecular Genetics, Human Mutation, Journal of Public Policy & Marketing, Molecular and Cellular Probes*

#### Associate Editor

*ASCLD News* Official newsletter of the American Society of Crime Laboratory Directors, 1999-2000

## PUBLICATIONS

1. **Katsanis SH** and Kim J (2014) DNA in immigration and human trafficking. In *Forensic DNA Applications: An Interdisciplinary Perspective*, CRC Taylor and Francis, Chapter 22 [Jan 31, 2014, commissioned].
2. Dal-Ré R, Katsanis N, **Katsanis S**, Parker LS, Ayuso C (2014) Managing incidental genomic findings in clinical trials: Fulfillment of the principle of justice, *PLOS Medicine*, 11(1):e1001584.
3. **Katsanis SH**, Dungan J, Gilliss C, Ginsburg GS (2013) Educating future providers of personalized medicine, *North Carolina Medical Journal*, 74(6):491-492.
4. **Katsanis SH** and Katsanis N (2013) Molecular genetic testing and the future of clinical genomics. *Nature Reviews Genetics*, 14(6):415-426.
5. Kim J and **Katsanis SH** (2013) Brave new world of human rights DNA collection. *Trends in Genetics*, 29(6):329-332.
6. Daley LA, Wagner JK, Himmel TL, McPartland KA, **Katsanis SH**, Shriver MD, Royal CD (2013) Personal DNA testing in college classrooms: Perspectives of students and professors. *Genetic Testing and Molecular Biomarkers*, 17(6):1-7.
7. **Katsanis SH** and Wagner JK (2013) Characterization of the standard and recommended CODIS markers. *Journal of Forensic Sciences*, 58 Suppl 1:S169-72. Epub 2012 Aug 24.
8. **Katsanis SH**, Jabs EW: Treacher Collins Syndrome (2012) in: GeneReviews at GeneTests: Medical Genetics Information Resource [database online]. Copyright, University of Washington, Seattle, 1997-2012. Available at <http://www.genetests.org>
9. Kim J, Mammo D, Siegel MB, **Katsanis SH** (2011) Policy implications for familial searching. *Investigative Genetics*, 2:22.
10. Macaya D, **Katsanis SH**, Hefferon TW, Audlin S, Mendelsohn NJ, Roggenbuck J, Cutting GR. (2009): A synonymous mutation in *TCOF1* causes Treacher Collins syndrome due to mis-splicing of a constitutive exon. *American Journal of Medical Genetics*, 149A(8):1624-7.
11. Javitt G, **Katsanis S**, Scott J, Hudson K. (2009): Developing the blueprint for a genetic testing registry. *Public Health Genomics*, epub ahead June 29.
12. **Katsanis S**, Javitt G, Hudson K. (2008): Response to Bombard AT and Brown T, Correcting the record on DNA Direct [letter and reply]. *Science*, 321(5890):769-771.
13. Kaufman DJ, **Katsanis SH**, Javitt, G, Murphy JA, Scott JA. (2008): Carrier screening for cystic fibrosis in U.S. genetic testing laboratories: a survey of laboratory directors. *Clinical Genetics*, 74:367-73.
14. **Katsanis SH**, Javitt G, Hudson K. (2008): Public health: A case study of personalized medicine. *Science* 320: 53-54.
15. Hudson KL, Murphy, JA, Kaufman DJ, Javitt GH, **Katsanis SH**, Scott J. (2006): Oversight of US genetic testing laboratories. *Nature Biotechnology*, 24: 1083-1090.
16. Steinberg S, **Katsanis S**, Moser A, Watkins P, Cutting G. (2005): Biochemical analysis of CVS for the prenatal diagnosis of peroxisomal disorders: Biochemical thresholds and molecular sensitivity for maternal cell contamination detection. *Journal of Medical Genetics*, 42:38-44.
17. **Katsanis SH**, Cutting GR. (July 2004): Treacher Collins Syndrome. In: GeneReviews at GeneTests: Medical Genetics Information Resource [database online]. Copyright, University of Washington, Seattle, 1997-2004. Available at <http://www.genetests.org>.
18. Huxley C, Passage E, Robertson AM, Youl B, **Huston S**, Manson A, Saberan-Djoniedi D, Figarella-Branger D, Pellissier JF, Thomas PK, Fontes M. (1998): Correlation between varying levels of PMP22 expression and the degree of demyelination and reduction in nerve conduction velocity in transgenic mice. *Human Molecular Genetics* 7:449-458.
19. May M, **Huston S**, Wilroy RS, Schwartz C. (1997): Linkage analysis in a family with the Opitz GBBB syndrome refines the location of the gene in Xp22 to a 4 cM region. *American Journal of Medical Genetics* 68:244-248.

20. Newport MJ, Huxley CM, **Huston S**, Hawrylowicz CM, Oostra BA, Williamson R, Levin M. (1996) A mutation in the interferon-gamma-receptor gene and susceptibility to mycobacterial infection. *New England Journal of Medicine* 335:1941-1949.
21. Hiatt EE, Georgi L, **Huston S**, Harshman DC, Lewis SA, and Abbott A. (1995): Intra- and interpopulation genome variation in *Meloidogyne arenaria*. *Journal of Nematology* 27:143-152.

#### MANUSCRIPTS IN PROGRESS

1. **Katsanis SH** and Kim J. Privacy challenges with genetic information. In *Handbook of Missing Persons*. Eds. Morewitz SJ, Colls DS. Invited, in preparation.
2. Kim J, Scully J, **Katsanis SH**. Ethical challenges in missing persons investigations. In *Handbook of Missing Persons*. Eds. Morewitz SJ, Colls DS. Invited, in preparation.
3. **Katsanis SH** and Katsanis N (2015) Molecular genetic testing and the future of clinical genomics. In *Essentials of Genomics and Personalized Medicine*, 3<sup>rd</sup> edition. Eds. Ginsburg GS and Willard H. Academic Press. Invited, in preparation.
4. Jordan D, Frangakis S, Golzio C, Kurtzberg J, **Task Force for Neonatal Genomics**, Davis EE, Sunyaev S, Katsanis N (2015) Identification of *cis*-suppression of human disease mutations by comparative genomics, submitted.
5. **Katsanis SH**, Kim J, M Minear, S Chandrasekharan, JK Wagner (2015) Exploratory survey of perspectives on DNA collection for investigating human trafficking. *Recent Advances in DNA and Gene Sequences*. Invited, submitted, in review.
6. Felini L, Costa J, Felini M, Eisenberg A, **Katsanis S** (2015) The Dallas High Risk Potential Victim's DNA Database as a novel intelligence tool for investigations of transient populations. *FBI Law Enforcement Bulletin*. In review.
7. Minear M, Yang N, Reeves J, Cook-Deegan R, Ginsburg, GS, Vorderstrasse A, Simons LA, **Katsanis SH** (2015) Provider perspectives on genetic and genomic technologies at Duke University. Submitted, in review.
8. Vorderstrasse A, **Katsanis SH**, Minear MA, Yang N, Rakhra-Burris T, Reeves JW, Cook-Deegan R, Ginsburg GS, Simmons LA (2015) Perceptions of personalized medicine in research and clinical care in an academic health System: Educational Findings and Implications. Submitted, in preparation.

#### ABSTRACTS

1. **Katsanis SH** and Wagner JK. (2014) Perspectives on DNA collection for human trafficking. Abstract at the 25<sup>th</sup> International Symposium on Human Identification, October 1, 2014, poster.
2. **Katsanis SH**, Angrist M, Sadeghpour A, Cope H, Robertson H, Cotten CM, Davis EE, Katsanis N. (2014): Return of research results for exome sequenced trios in Duke Task Force for Neonatal Genomics. Abstract at the American College of Medical Genetics, Nashville, TN, March 26, 2014, poster.
3. Davis EE, Sabo A, Øien C, **Katsanis SH**, Cope H, Sheets K, Sadeghpour A, McDonald K, Kousi M, Willer JR, Kim J, Dugan-Rocha S, Muzny DM, Ashley-Koch A, Hauser E, Hauser M, Sun J, Kurtzberg J, Murtha A, Boyd B, Gallentine WB, Goldberg R, McDonald MT, Gibbs RA, Angrist M, Cotton CM, Katsanis N (2012): Multidisciplinary and Translational Task Force for Neonatal Genomics. Abstract at American Society of Human Genetics, November 7, 2012, plenary presentation.
4. **Katsanis SH**. (2012): DNA identification for human trafficking prevention. Abstract at Economic and Social Research Council (ESRC) Genomics Network: Genomics in Society: Facts, Fictions and Cultures, April 23, 2012, platform.
5. Lorente JA, Kim J, Alvarez JC, Alvarez-Cubero MJ, Saiz M, **Katsanis SH**, Budowle B, and Eisenberg A. (2012): Efforts to infuse international collaboration to combat human trafficking. Abstract at Economic and Social Research Council (ESRC) Genomics Network: Genomics in Society: Facts, Fictions and Cultures, April 24, 2012, poster.

6. Øien NC, **Katsanis SH**, Davis EE, Cope H, Sun J, Kurtzberg J, Ashley-Koch A, Goldberg R, Angrist M, Murtha A, Cotten CM, Katsanis N. (2012): Multidisciplinary and translational Task Force for Neonatal Genomics. Abstract at the American College of Medical Genetics, Charlotte, NC, March 25, 2012, platform.
7. Grantham S and **Katsanis SH**. (2011): Impact of pharmacogenetic labeling on testing for HLA-B\*1502 for carbamazepine. Abstract at International Congress on Human Genetics / American Society of Human Genetics, November 4, 2010, poster.
8. **Katsanis SH**. (2011): Gaps in oversight of nonmedical genetic testing. Abstract at ELSI Congress, April 13, 2011, University of North Carolina at Chapel Hill, Chapel Hill NC, platform.
9. **Katsanis SH**. (2010): Role of DTC Relationship testing laboratories in human trafficking Prevention. Abstract at American Society of Human Genetics, Washington DC, November 4, 2010, poster.
10. Javitt G, **Katsanis S**, Scott J, Hudson K. (2009): Developing the blueprint for a genetic Testing registry. Abstract at American College of Medical Genetics, Tampa FL, platform.
11. **Katsanis SH**, Javitt G, Scott J, Hudson K. (2008): Claims and evidence: CYP450 genotyping and SSRI prescribing. Abstract at American College of Medical Genetics, Phoenix AZ, platform.
12. Steinberg S, Delozier-Blanchet D, Crowe C, Raymond G, Kemp S, Waterham H, van Geel B, Schroer R, Watkins P, Nino M, Braverman N, Moser A, Moser H, Karczeski B, **Katsanis S**, Cutting G. (2005): *ABCD1* mutation analysis in patients with X-linked adrenoleukodystrophy (X-ALD), adrenomyeloneuropathy (AMN) and other clinical phenotypes. Abstract for SSIEM meeting (Society for the Study of Inborn Errors of Metabolism), Paris FR, poster.
13. Macaya D, **Katsanis SH**, Hefferon T, Audlin S, Cutting GR. (2004): A synonymous *TCOF1* change in a patient with Treacher Collins syndrome causes skipping of a constitutive exon due to disruption of a putative splicing enhancer. Abstract in *American Journal of Human Genetics*, Toronto ON, poster.
14. **Katsanis SH**, Karczeski B, McDonald-McGinn DM, Driscoll D, Krantz I, Kellogg A, Audlin S, Boehm C, Wang X, Jabs EW, Zackai E, Cutting, GR. (2003): Molecular diagnosis of Treacher Collins Syndrome by DNA sequencing reveals a spectrum of *TCOF1* mutations and non-penetrance. Abstract in *American Journal of Human Genetics*, 73:224, Los Angeles CA, platform.
15. Tyson H, Chong S, Benner A, Al Hasnan Z, **Katsanis S**, Thrift K, Lawler A, Stetten G, Zhao Y, Cutting GR. (2003): Validation of preimplantation genetic diagnosis for clinical applications. Abstract in *American Journal of Human Genetics*, 73:2521, Los Angeles CA, poster.
16. **Huston S**, Stillwell E, Georgi L, and Abbott A. (1994): Identification and characterization of genes differentially expressed in development of plant-parasitic nematodes, abstract. *Journal of Nematology* 26:552, San Antonio TX, poster.

#### NON-PEER-REVIEWED WORKS and MEDIA

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|----------|--|
| Mar 2014 | Video Brief: Browery M and <b>Katsanis S</b> . Genome Sequencing.  |
| Mar 2013 | Report: <b>Katsanis SH</b> . Human DNA Identity Testing Policy Report.   |
| Feb 2013 | Brief for genetic scientists Robert Nussbaum and <b>Sara H Katsanis</b> as <i>amici curiae</i> in support of respondent in the Supreme Court of the United States, <i>Maryland v. Alonzo Jay King, Jr.</i> , February 1, 2013. |
| Dec 2012 | Opinion editorial: <b>Katsanis SH</b> and Kaufman D. "Genetics won't explain Newtown," <i>Huffington Post</i> , December 21, 2012.   |
| Sep 2012 | Blog entry: Wagner J and <b>Katsanis SH</b> . ENCODE, CODIS, and the Urgent Need to Focus on what is Scientifically and Legally Relevant to the DNA Fingerprinting Debate. <i>Genomics Law Report</i> , September 21, 2012.    |
| Sep 2012 | Blog entry: Wagner J and <b>Katsanis S</b> . Reconciling ENCODE and CODIS. <i>Penn Medicine News</i> , September 19, 2012.   |
| Aug 2012 | Report: Kim J and <b>Katsanis SH</b> . Nonmedical DNA Applications Case Study Report: DNA-PROKIDS.   |

- Aug 2012 Report: Kim J and **Katsanis SH**. Nonmedical DNA Applications Case Study Report: Dallas Prostitute Diversion Initiative.
- Jul 2010 Opinion editorial: Heaney C and **Katsanis SH**. “Readers’ Forum: Rape evidence goes untested because of misguided policies,” *The Oakland Tribune*, July 1, 2010; *Contra Costa Times*, July 1, 2010; “Expanding DNA databases could set back justice,” *Detroit Free Press*, July 8, 2010; “DNA and crime: Where we should focus,” *News and Observer*, July 8, 2010; “Expanding DNA databases delays justice,” *Baltimore Sun*, July 9, 2010; “Addressing the DNA backlog” *Physorg.com*, July 13, 2010; “DNA, cold cases and more: Addressing DNA backlog in criminal investigations” *WRAL Techwire*, July 16, 2010.
- Jun 2010 Video Brief: **Katsanis S**. Expansion of CODIS to include arrestees.
- Jun 2010 Issue Brief: Grantham S and **Katsanis SH**. Expansion of CODIS to include arrestees.
- Feb 2010 Opinion editorial: **Katsanis SH**. “Use DNA to stop child trafficking,” *Toronto Globe and Mail* Feb 23, 2010, *News and Observer*; “The DNA way to valid adoptions,” Feb 28, 2010.
- Oct 2009 Declaration of **Sara Huston Katsanis** in support of motion for preliminary injunction, United States District Court for the Northern District of California, *Elizabeth A. Haskell v. Edmund G. Brown*, October 26, 2009.
- Oct 2009 Report: Devaney S, Javitt G, **Katsanis S** and Hudson K. Integrating pharmacogenetic information in drug labeling: Challenges and policy options.
- Feb 2009 Newsletter article: **Katsanis S**. Right to post-conviction DNA testing headed to Supreme Court.
- Feb 2009 Newsletter article: **Katsanis S**. DOJ begins collecting DNA from federal arrestees and detained immigrants.
- Jan 2009 Issue Brief: **Katsanis S** and Javitt G. Surreptitious DNA testing.
- Jan 2009 Report: **Katsanis S** and Javitt G. State laws pertaining to surreptitious DNA testing.
- Oct 2008 Newsletter article: **Katsanis S**. Government advisory committee recommends new genetic testing laboratory practices.
- Oct 2008 Newsletter article: **Katsanis S**. Congress reauthorizes DNA backlog grant program; removes amendments expanding DNA collection
- Sep 2008 Issue Brief: **Katsanis S** and Javitt G. Pharmacogenomics: Hope and hype.
- Aug 2008 Report: **Katsanis S**. Summary of New York and California correspondence with health-related direct-to-consumer genetic testing businesses.
- Aug 2008 Newsletter article: **Katsanis S**. Reauthorization of DNA backlog grant program could expand forensic DNA collection
- Feb 2008 Report: **Katsanis S**. Analysis of public comments on the SACGHS genetic testing oversight draft report.

## PRESS

- Jul 28, 2014 Wren, Kathy. Forensics, Internet freedom cited as key junctions for science and human rights. *AAAS News* [referenced research]
- Jan 8, 2014 Chi, Kelly Rai. Family match. *Biotechniques* [featured interview on DNA-PROKIDS]
- Nov 25, 2013 Responded to inquiry from Greg Miller of *Wired* on the FDA action against 23andMe.
- Aug 1, 2013 Clark, Maggie. How big is the DNA backlog? *Stateline*. [quoted on the GAO report on federal funding for DNA backlogs]
- Jun 10, 2013 Aldhous, Peter. Artworks highlight legal debate over ‘abandoned’ DNA. *New Scientist* [quoted on surreptitious collection of DNA]
- Jun 10, 2013 Atkins, Kimberly. DNA ruling leaves states to fill in the blanks. *Lawyers USA* [provided background on arrestee DNA collection]

- Jun 4, 2013 DNA swabbing: A genetic panopticon? *Huffington Post Live* [guest panelist on arrestee DNA collection]
- Jun 3, 2013 Clark, Maggie . Police can take DNA samples from arrestees, US Supreme Court rules, *Stateline*. [provided background on arrestee DNA collection]
- Jun 3, 2013 Kirchner, Lauren. DNA Collection Is the New Fingerprinting. *Pacific Standard*. [quoted on arrestee DNA collection]
- May 30, 2013 Huang, Yongming. DNA database worries. *Southern Weekend*. [quoted on the use of DNA for human rights and human trafficking, genetic discrimination, and autonomy]
- May 16, 2013 Johnson, Mark. Could DNA databases curb human trafficking? *Milwaukee Journal Sentinel*, [quoted on the use of DNA for human rights and human trafficking]
- May 15, 2013 Vargughese, Ansa. DNA databases could help find victims of human rights and human trafficking, *Medical Daily*, [cited on the use of DNA for human rights and human trafficking]
- May 15, 2013 Hughes, Virginia. Could DNA databases curb human trafficking? *National Geographic*, [quoted on the use of DNA for human rights and human trafficking]
- May 10, 2013 Responded to inquiry from Sergio Ferrer Pérez of Spanish scientific agency SINC on the use of DNA for human rights.
- May 10, 2013 Responded to inquiry from Erika Check Hayden of *Nature* on the use of DNA for human rights.
- Mar 2, 2013 Resnick, Brian. What is a gene and how does it apply to the law? The Supreme Court still doesn't know, *National Journal*. [quoted on arrestee DNA collection]
- Feb 23, 2013 *Bloomberg News*. DNA privacy gets first Supreme Court test, *Chicago Daily Herald*, [cites Feb 1 2013 *amici brief*]
- Feb 22, 2013 Stohr, Greg. DNA privacy gets first Supreme Court test in rape case, *Bloomberg News* [cites Feb 1, 2013 *amici brief*]
- Oct 11, 2012 Aldhous, Peter. Cheap genome sequences demand new rules of privacy, *New Scientist*, [quoted on surreptitious DNA collection]
- Oct 3, 2012 Krakauer, Hannah. Appeal against DNA fingerprinting cites ENCODE project, *New Scientist*, [provided background on non-coding DNA and CODIS]
- Sep 24, 2012 Spoke with Amy Maxmen of *Nature*, on non-coding DNA and CODIS.
- Aug 7, 2012 Clark, Maggie. Courts, states differ on police use of DNA, *The Statehouse File*, [quoted on Supreme Court consideration of arrestee DNA sampling].
- Jul 13, 2012 Pollack, Andrew. Conflict potential seen in genetic counselors, *The New York Times*, [provided background on corporate-based genetic counselors].
- Jun 19, 2012 Pollack, Andrew. Before birth, dad's ID, *The New York Times*, [quoted on prenatal paternity testing].
- Mar 18, 2012 Maynard, Melissa. Crime labs struggle with DNA test demands, *Sacramento Bee*, [quoted on DNA databank expansion].
- Mar 18, 2012 Maynard, Melissa. Federal funds help crime labs struggling with DNA evidence backlogs, *The Washington Post*, [quoted on DNA databank expansion].
- Aug 1, 2011 Gardner, Eriq. Gene swipe: Few DNA labs know whether chromosomes are yours or if you stole them, *ABA Journal*, [quoted on surreptitious DNA collection].
- Feb 2, 2011 Schirtzinger, Alexa. New Mexico faces coming fight over DNA collection. *Santa Fe Reporter*, [quoted on DNA databank expansion].
- Oct 2010 Le, Thai Phi. Guilt by association, *Washington Lawyer*. [Duke IGSP cited, and provided background DNA databank expansion and familial searching of CODIS].
- Jul 30, 2010 Asher, Colin. New Jersey considering new, stricter DNA collection law, but concerns remain. *The Jersey City Independent* [quoted on DNA database expansion].
- Jul 27, 2010 Shrestha, Bibeka. DNA testing for crime suspects sparks ethics debate. *Smoky Mountain News* [referenced opinion editorial].



- Jul 13, 2010 Nimocks, Amber and Laura Leslie. DNA Collection, *The State of Things* (WUNC-91.5) [interviewee].
- Jul 13, 2010 Hewlett, Michael and John Hinton. Will DNA law clear up more crime?, *Winston-Salem Journal*, [quoted on expansion of DNA databases in law enforcement].
- Jun 2, 2010 Graham, Judith. Government moves to oversee at-home genetic tests, June 14, 2010, *Chicago Tribune*, [provided background on DTC genetic testing and oversight].
- Jan 12, 2010 Spoke with Holly Ramer of Associated Press about retention of DNA samples collected for CODIS. NH House give initial nod to DNA tests of felons, January 13, 2010, [quoted on retention policies].
- Dec 2008 Jaret, Peter. Special Reports: How to Eat for Your DNA. *Eating Well*, [http://www.eatingwell.com/news\\_views/special\\_report/eat\\_for\\_your\\_dna.html](http://www.eatingwell.com/news_views/special_report/eat_for_your_dna.html) [quoted on nutrigenomic testing oversight and state actions on DTC genetic testing companies].
- Nov 11, 2008 Spoke with Katie Drummond of *Men's Fitness* about potential uses of risk assessment genetic testing and what men can/should do with the results of such testing.
- Nov 10, 2008 Spoke with Howard Wolinsky of *Ancestry* magazine about DTC regulatory actions in California and New York and their likely impact on genetic genealogy testing.
- Oct 3, 2008 Domínguez, Nuño. 2008. Las rebajas llegan a los genes. *Publico*, October 3. [provided background on personal genomics and Knome].
- Aug 29, 2008 Alltucker, Ken. 2008. TGen find promises big leap in forensics. *The Arizona Republic*, [quoted on a new forensic DNA analysis technique].
- Aug 25, 2008 Responded to an inquiry from Anja Gruenenfelder of the German press agency DPA about direct-to-consumer genetic testing companies in the US.
- Aug 25, 2008 Spoke with Peter Jaret of *Eat Well* magazine about nutrigenomic testing oversight and state actions on DTC genetic testing companies.
- Jul 22, 2008 Spoke with Joe Palca of National Public Radio about use of DNA for forensic identification.
- Jun 30, 2008 Jenks, Susan. 2008. Genetic testing likely to become more common. *News-Leader* (Missouri), [quoted on how many companies offer DTC tests; re-print of *South Florida Sun-Sentinel* article].
- Jul 1, 2008 Jenks, Susan. Out of the gene pool: Tests can identify risks before they take shape. *Norwich Bulletin*, sec Lifestyles, [quoted on how many companies offer DTC tests; re-print of *South Florida Sun-Sentinel* article].
- Jun 16, 2008 Jenks, Susan. Gene tests drive Brevard family to eliminate risks. *Florida Today*, [quoted on rapid advance of genetic testing field].
- Jun 17, 2008 Kohler, Jeremy. Crime scene DNA can lead to knock on relative's door. *St. Louis Post-Dispatch*. [quoted on familial searching of forensic DNA databases].
- Jun 4, 2008 Spoke to Peter Aldhous of *New Scientist* magazine about surreptitious DNA testing.
- Apr 28, 2008 Spoke with Bruce Goldman, writing for the *Journal of Life Sciences*, about the *Science* article.
- Apr 23, 2008 Spoke with Gabrielle Worman of CBS News about state laws surrounding direct-to-consumer genetic testing.

## ONGOING RESEARCH SUPPORT

NIH/NIDDK 1R01HG007074-01 (PI: S. Chandrasekharan) 07/01/13 - 06/30/16  
*Intellectual Property and Access to Noninvasive Prenatal Genetic Testing*  
 This project will evaluate the effects of intellectual property and commercialization of non-invasive prenatal genetic tests (NIPT) on patient access and barriers to clinical adoption of NIPT.  
 Role: Investigator

Josiah Charles Trent Memorial Foundation Endowment Fund (PI: S. Katsanis) 01/01/13 - 12/31/14  
*DNA and Human Rights and Wrongs: Social and Political Uses of DNA for Human Protections*

This goal of this award is to form a coalition at Duke to explore the ethics and practicalities of DNA collection in immigration for protection of human rights, with a focus on human trafficking.

Role: Principal Investigator

NIH/NIDDK 1P50DK096415-01 (PI: N. Katsanis)

07/01/12 - 06/30/17

*Whole-Exome Sequencing of Neonates with Renal and/or Urogenital Malformations in conjunction with the Duke Task Force for Exome Sequencing and Return of Results*

The major goal of this project is to perform whole-exome sequencing on undiagnosed neonates likely to suffer from genetic illness, to identify causative mutations, and to develop ways to return both primary and secondary findings to family members with renal and urogenital disorders.

Role: Research Associate, Enrichment Program

### **COMPLETED RESEARCH SUPPORT**

Eli Lilly Foundation (PI: Javitt)

09/01/08 - 05/31/09

*Pharmacogenetics in Drug Labeling*

The major goal of this project was to evaluate how labeling of pharmaceuticals with pharmacogenetic information impacted medical practices.

Role: Genetics Policy Analyst

Pew Charitable Trust (PI: Hudson)

10/20/07 - 05/31/09

*Quality in Genetic Testing*

This project examined the oversight adequacy and factors influencing quality of genetic testing.

Role: Genetics Policy Analyst

### **TECHNICAL EXPERTISE**

Manual and automated DNA Sanger sequencing; DNA and RNA isolation; Southern and RFLP; PCR, STR, SSCP, and AFLP; Quantitative RT-PCR; Recombinant DNA cloning; Northern; Linkage analysis; FISH; Tissue/cell culture; Taqman QPCR; Third Wave Technologies' Invader Assay