

**CONSORTIUM ON LAW AND VALUES
CONSORTIUM SCHOLAR FINAL REPORT**

**“Genomic Healthcare and Incidental Findings of Reproductive Significance: Neonatal
Litigation as a Source of Liability”**

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Project Summary

This project uses an analysis of tort litigation to provide a historical narrative of critical importance to clinical actors as healthcare turns to genomics and expands access to reproductive information. After hand-sorting several thousand search results, cases were plotted on STATA-generated graphs that are used to illustrate a narrative tracing the emergence in courts of a conceptual class of people—future people. The story involves the unfolding of a cluster of legal doctrines, with origins at least as old as Blackstone and Coke, that would allow tort recovery for pre-viability and pre-conception harms. The narrative emphasizes the critical importance of the concept of “prospective conditional liability” that would be imported from criminal and property law into the tort context in late nineteenth-century America, laying the groundwork for modern variants of neonatal litigation that would proliferate as reproductive technologies became more accessible in the twentieth century. Future people would “materialize” most noticeably from the late 1960s onwards as courts began to hold clinical actors liable for failing to disclose material information to a patient’s reproductive decisionmaking. Most states have been hostile to certain neonatal actions I discuss, barring them as contrary to the sanctity of life. In contrast, I use this narrative to argue these actions are of critical importance for protecting the interests of both present and future people in an age in which reproductive information is becoming more and more readily available.

Financial summary

- *Work hours for research.* The bulk of the project’s expenses were to facilitate the hours put into sifting through cases to determine the underlying facts and causes of action, which took much more time than initially expected. For most causes of action, this involved coding results an initial time, revising the methodology after reading the cases, and then re-coding them. This involved working with 692 Westlaw results for the search “wrongful life,” 631 for “prenatal injur*”, 231 for “wrongful conception,” 625 for “wrongful birth,” 115 for “salpingectomy,” 1,118 for “vasectomy,” and 1,167 for “tubal ligation.” (\$5,000)
- *Work hours for writing.* I have completed two work products, and have revised them in light of comments from professors. (\$575)
- *Work hours for shadowing genetic counselor.* I shadowed Mary Ahrens for a handful of genetic counseling sessions in an oncology specialty clinic. I have contacted another genetic counselor, Meg Eilers, who works in the prenatal context and will continue to pursue further shadowing experience with her and/or others. (\$375)
- *smSTATA version 14.2.* This was the software that seemed most reasonable to purchase, given the size of the data set I was working with, and the analysis I was hoping to do. Receipt attached. (\$100)
- *23andme - health and ancestry.* When I submitted the initial proposal, FDA had prohibited 23andme from including results for diseases or conditions. This ban was lifted in April 2017, enabling me to pursue this prong of the project by purchasing a direct-to-consumer test alone, rather than needing to seek clinical options. Receipt attached. (\$200)
- *Conference travel.* I had thought I would present at American Society for Bioethics and Humanities, but to facilitate discussions with dissertation committee members at a different, relevant conference, I instead presented it at the annual conference of the Association for the

Study of Law, Culture, and the Humanities at Stanford Law School. I plan to submit one of these products to present at next year's ASBH meeting. Receipts attached. (\$750)

Results

- “How Future People ‘Materialized’ in Courts: Neonatal Litigation from 1884 to the Present”
 - I plan to submit as an article to law journals when fall submissions open
 - Have submitted it as the third chapter of my dissertation, *Future People in America: An Intellectual History of Regulation over Reproduction*

- “Taking Birth Defects Seriously: Incommensurability, Self-Governance, and the Categorization of Congenital Impairment”
 - Presented in April 2017 at the annual ASLCH conference
 - Have submitted it as the fifth chapter of my dissertation

Future project plans

The project/publications are chapters in my dissertation. I submitted my dissertation in early July 2017. It is currently under review, and I proposed a graduation date of December 2017 to my committee. I have attached both chapters with this report, as well as the dissertation's introduction, which contextualizes these chapters in the project as a whole.

Nearly all of the work completed during the time funded by the Consortium focused on the third chapter (“How Future People Materialized in Courts”), but I also completed a draft of a subsequent chapter during that time period as well (“Taking Birth Defects Seriously”), which I presented at the 2017 ASLCH conference discussed above. I plan to develop several publications based on the research for the two work products I completed during this time. Regarding the first work product, I wrote it to be a full law journal article (~23,000 words). Using the graphs I created for this lengthier piece, I also plan to draft a much shorter version to submit to peer-reviewed outlets. Regarding the second product, I plan to write one or more articles that continue to develop my interest in categorizing congenital conditions. I plan to write a review of the literature on decision aids for information of relevance to reproductive decisionmaking, whether prenatal tests or cancer screening. I believe that this exploration into decision aids is an important project that would contribute to literatures related to genetic counseling and translational medicine.