

# Consortium on Law and Values in Health, Environment & the Life Sciences

## Student Proposal Cover Page

### Applicant Information

Applicant Name: Crystal Liu Date: 3/18/09  
Project Title: Donor Conceived Children and Their Fight for Knowledge: Using the Victorian Legislative Experience to Shed Light on Anonymity, Open Disclosure, and Access to Identifying Information  
Department: N/A College: Univ. of Minnesota Law School & School of Public Health  
Home address: 3233 Emerson Ave. S. #2 City & State: Minneapolis, MN Zip: 55408  
Faculty advisor name: N/A Email: N/A  Not applicable  
Dept. Head's name: N/A Dept. Head's email: N/A  
Dean's name: David Wippman Dean's email: dwippman@umn.edu

How did you hear about this funding opportunity? Email from the Joint Degree Program

### Funding

Amount of funding requested: \$ 6282.08

Funding justification: [a clear statement of what you will use the funds for without going into budget details]

A grant from the Consortium on Law and Values in Health, Environment & the Life Sciences would enable me to travel to Australia and conduct a legislative history and policy analysis of the Victorian legislation that has addressed issues surrounding anonymity, open disclosure, and access to identifying information in the context of donor conceived children. By identifying and understanding the rationale that led Victoria to change its policy on anonymous sperm donation and access to identifying information, as well as assessing the consequences of the legislation, it is my hope that I can identify recommendations as to a model policy.

### Approvals

*Check all appropriate approvals required for your proposal. Approvals must be obtained prior to receipt of funding. If you have applied for approval but have not yet received it, indicate that below.*

IRB Date submitted: \_\_\_\_\_ Number: \_\_\_\_\_  
 IACUC Date submitted: \_\_\_\_\_ Number: \_\_\_\_\_  
 Other Explain: \_\_\_\_\_

### For Use by the Consortium Office

The proposal is 1000 words or less excluding budget, biographies, references and citations.  
The proposal includes a work plan with a specific timeline using months or quarters to identify work to be done and completion dates.  
 The proposal includes a 1-2 paragraph biography of the applicant and all co-investigators.  
The budget form is complete including the funds sought for this project, other pending applications for this project, and the amount/source of matching or other funds.  
 The applicant's faculty advisor is copied on the application email. Professional students w/o advisors check NA.  
 All necessary approvals are pending or received.

Name: Crystal Liu  
Host Institution: The Infertility Treatment Authority  
Country: Australia

**PROJECT TITLE:** Donor Conceived Children and Their Fight for Knowledge: Using the Victorian Legislative Experience to Shed Light on Anonymity, Open Disclosure, and Access to Identifying Information

### STATEMENT OF PROBLEM/SIGNIFICANCE OF RESEARCH

The development of a variety of assisted reproductive technologies (ART) such as artificial insemination and IVF has provided ways for infertile couples to try to conceive. The coming of age of many donor conceived children<sup>1</sup> born using these technologies has brought to light many issues surrounding anonymity, open disclosure<sup>2</sup>, and access to identifying information.

Some of the concerns being raised revolve around preventive and mental health. From a preventive health perspective, it is important for donor conceived children to be aware of their genetic origins. Most diseases result from the interaction of multiple genes and environmental factors and cannot be detected using available DNA technology.<sup>3</sup> Thus, family history is an important tool in disease prevention and early detection. Family history can help predict risk for many chronic diseases such as heart disease and breast cancer.<sup>4</sup> From a mental health perspective, it is important to know about one's genetic background in order to discover one's own identity. Research shows that many offspring want to know more about their donors as a way of exploring their own identity.<sup>5</sup> Given the significant preventive and mental health impacts, it is important to address the concepts of anonymity, open disclosure, and access to identifying information.

The U.S. has relied on several patchwork methods to oversee ART. Government advisory committees and professional organizations both offer guidelines to infertility clinics. The FDA and CDC are also peripherally involved in regulating this realm.<sup>6</sup> However, there is no national legislation directly overseeing ART in the U.S.<sup>7</sup> The U.S. has not addressed concerns of anonymity, open disclosure, and access to identifying information in the context of donor conception.

In Victoria, Australia, there is a prohibition on all anonymous donations. Central registers are maintained that record information about donor conceived children and their donors. Information in the 1984 Central Register may be released with the consent of the person whose

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<sup>1</sup> The term donor conceived children refers to children born using donor sperm, donor embryo, or donor egg.

<sup>2</sup> Open disclosure is when parents of donor conceived children inform their children that they are donor conceived.

<sup>3</sup> Centers for Disease Control (National Office of Public Health Genomics). Family History Public Health Initiative. <http://www.cdc.gov/genomics/famhistory/famhist.htm> (accessed 2009).

<sup>4</sup> Guttacher, A.E., Collins, F.S., Carmona, R.H. (2004). The Family History – More Important Than Ever. *The New England Journal of Medicine*, 351(22), 2333-6.

<sup>5</sup> Scheib, J.E., Riordan, M., Rubin, S. (2005). Adolescents with open-identity sperm donors: reports from 12-17 year olds. *Human Reproduction*. 20 (1), 239-52.

<sup>6</sup> Kindregan, C.P. McBrien, M. (2006). Assisted Reproductive Technology: A Lawyers' Guide to Emerging Law and Science. *American Bar Association*: 196 & 204-05.

<sup>7</sup> Kindregan, C.P. McBrien, M. (2006). Assisted Reproductive Technology: A Lawyers' Guide to Emerging Law and Science. *American Bar Association*: 196 & 204-05.

information is being sought.<sup>8</sup> Information in the 1995 Central Register may be released to donor conceived children once they turn 18.<sup>9</sup> Unlike the U.S., Victoria has tackled the difficult questions surrounding anonymity, open disclosure, and access to identifying information. In light of this, I propose to conduct a legislative history and policy analysis of the Victorian legislation that addresses these three issues. By identifying and understanding the rationale that led Victoria to change its policy on anonymous sperm donation and access to identifying information, as well as assessing the consequences of the legislation, it is my hope that I can identify recommendations as to a model policy. I am optimistic that these lessons and recommendations will initiate a much needed dialogue in the U.S. surrounding the rights of donor conceived children.

### **INNOVATIVE CONTRIBUTIONS**

There is a lack of comprehensive ART oversight in the U.S.<sup>10</sup> and there has been an inability to promote community discussion about the ethical, social, and legal implications surrounding ART. To the extent that these concerns are addressed, the U.S. has traditionally taken a patient-centered, rights based approach. Given the nature of infertility treatments, which resemble traditional medical procedures, the focus is on the Doctor-Patient relationship. This relationship has been preoccupied with obtaining a successful pregnancy, rather than the welfare of the child to be born. Any discussion of oversight is often perceived as a challenge to the individual autonomy of the infertile person seeking treatment. As a result, the U.S. has been unable to engage in public dialogue surrounding the concepts of open disclosure, anonymity, and access to identifying information as it relates to donor conception.

In contrast, one of the guiding principles of ART legislation in Victoria is “the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount.”<sup>11</sup> It is this recognition that has enabled Victoria to engage in a robust discussion about the interests of donor conceived children as well as the interests of infertile persons seeking infertility services. By conducting a legislative and policy analysis on the Victorian legislation that surrounds issues of donor conception, it becomes possible to understand how to incorporate the rights and interests of both parties. This knowledge will be crucial in initiating a much needed dialogue in the U.S. surrounding the rights of donor conceived children.

### **METHOD OF STUDY/GOALS**

I propose to address this research project by identifying the key reasons behind the decision to prohibit anonymous donation, as well as the rationale behind the change in policy that led to the existence of two separate Central Registers. My observations here will be based on analyzing legislative debates and internal documents that are kept with the Infertility Treatment Authority. I hope to understand what factors were considered in passing the legislation, as well

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<sup>8</sup> Infertility Treatment Authority. Central Registers.

<http://www.ita.org.au/www/257/1001127/displayarticle/1001410.html> (accessed 2008).

<sup>9</sup> Infertility Treatment Authority. Central Registers.

<http://www.ita.org.au/www/257/1001127/displayarticle/1001410.html> (accessed 2008).

<sup>10</sup> Parens, E., & Knowles, L.P. (2003). Reprogenetics and Public Policy: Reflections and Recommendations. A *Special Supplement to the Hastings Center Report*.

<sup>11</sup> Section 5, Infertility Treatment Act 1995 Act. No. 63/1995.

<http://www.ita.org.au/secure/downloadfile.asp?fileid=1001399> (accessed 2009).

as the perceived pros and cons of anonymity. In addition, because over a decade has passed since the legislative amendment that created the 1995 Central Register, it becomes possible to assess any unintended consequences of the Victorian legislation. This assessment will be based on evaluating archived media stories and public statements. By carrying out a detailed case study of the Victoria experience surrounding anonymity, open disclosure, and access to identifying information, I hope to assess whether the Victorian approach is effective, and if not, what changes could be made to better represent the interests involved.

I have established affiliations with the Infertility Treatment Authority in Victoria, Australia and will be working closely with Louise Johnson, the Chief Executive Officer of that institution. She is willing to guide me as I pursue this research and has also offered to help with any other Australian contacts I may need.

### **TIMELINE**

**Mid-July 2009:** Collaborate with the Infertility Treatment Authority and access legislative debates, internal documents, archived media stories, and public statements.

**August 2009 – November 2009:** Find relevant documents and analyze materials.

**Spring 2010:** Write research paper. The culmination of this research project will be the thesis for my masters in public health, and will also be submitted for publication.

## **BUDGET**

### Research-Related Expenses:

Travel costs: \$4200.23

Round trip airfare – DCA to Melbourne, Australia (Qantas.com): \$1885

Housing for 17 weeks – Melbourne (Melbourne Univ. Student Services):

\$475/month x 4.25 months = \$2018.75

Public Transportation for 17 weeks – Melbourne (Melbourne Yarra Trams): \$296.48

109.60 AUD (Monthly) x 4 months = \$438.40 AUD

29.40 AUD (Weekly) x 1 week = \$29.40 AUD

\$467.80 AUD\* = \$296.48 USD

\* Using exchange rate of 1 AUD = 0.633872 USD from xe.com on 3.01.2009

Equipment costs: \$240

NVivo8 Student qualitative research software

TOTAL: \$4440.23

**Research-Related Reimbursable Expenses: \$2000**

### Non-Recurring Salary:

\$16.22/hr x 8 hrs/week x 17 weeks = \$2205.92 (Fall 2009)

\$16.22/hr x 8 hrs/week x 16 weeks = \$2076.16 (Spring 2010)

TOTAL: \$4282.08

**Non-Recurring Salary Funding sought: \$4282.08**

Please see attached budget form for more details

Other funding sought: None

## CRYSTAL LIU BIOGRAPHY

Crystal Liu is a third year joint degree student pursuing a JD/MPH with a Concentration in Health Law & Bioethics. Prior to starting graduate school, she spent a year in Australia studying the regulation of assisted reproductive technologies as a Fulbright Postgraduate Scholar. She also received a Postgraduate Certificate in Professional Ethics from the Centre for Applied Philosophy & Public Ethics at the University of Melbourne during that year. Her article on HLA tissue typing and PGD was published by the *Journal of Bioethical Inquiry*. For the summer of 2007, she received an OIP International Internship Award to work with the WHO's Ethics and Health Department. This past summer, she worked as a Summer Associate at Hogan & Hartson in Washington, DC, working primarily in health law and FDA drugs. She is currently working as a Research Assistant for Professor Susan Wolf. Her article on limiting access to infertility services was recently published by the *Minnesota Journal of Law, Science & Technology*. She received a BA in Molecular and Cell Biology as well as a BA in Political Science with high honors from the University of California, Berkeley.

Her interest in the intersection of ethics, law and biotechnology relates to her desire to help preserve the integrity of biotechnology – to use an interdisciplinary approach as a means to ensure that biotechnology continues to be used in a responsible and beneficial manner. While she has a range of interests in the realm of ethics and health, her research background is in ethics and the regulation of assisted reproductive technologies. During her Fulbright research year, she worked with the Infertility Treatment Authority in Victoria, Australia assessing whether the approach taken by the Victorian government to regulate assisted reproductive technologies is one which the United States should consider adopting. Prior to that experience, she pursued an independent research project that discussed whether the United States should regulate assisted reproductive technologies and possible public policy options that could address the ethical implications raised by these technologies. She has also interned with the Stanford Center for Biomedical Ethics and the American Association for the Advancement of Science. Through each of these experiences, and her pursuit of future opportunities, she aims to gain the tools that will enable her to help make the difficult decisions society will have to make when applying biotechnology to human life.

**Project Title: Donor Conceived Children and Their Fight for Knowledge: Using the Victorian Legislative Experience to Shed Light on Anonymity, Open Disclosure, and Access to Identifying Information**

**Instructions:** add rows for multiple personnel.

Category	Description & justification	Requested funding	Matching/other funding	
		Amount	Amount	Source
<b>Personnel</b> <i>Explain what hourly wage &amp; fringe are based on--departmental, community or other rate? Hourly wage is based on standard university graduate/RA rate</i>	Salary = <u>  </u> 136_hrs x <u>  </u> 16.22_ hrly wage	2205.92		
	Fringe rate			
	What work will this person do? The Infertility Treatment Authority is responsible for administering the regulation of infertility services in Victoria, Australia. I will be working with this government agency and conducting a legislative history and policy analysis as to whether the Victorian approach to anonymity, open disclosure, and access to identifying information is effective.			
	<b>Subtotal</b>	2205.92		
Speaker Honoraria	<u>  </u> speakers x \$ <u>      </u> honorarium			
Supplies & Services	List items and explain use.			
<b>Equipment</b> <i>Equipment costs are allowable only if the justification clearly shows that the equipment is necessary for the project. Include explanation of what will happen to equipment at completion of project.</i>	Identify and explain use. NVivo8 Student is software that would enable me to code legislative documents. This is necessary for the project because of the extensive qualitative research I will be conducting. NVivo would help me manage and assess the information I acquire. The software license is only for 12 months, so after completion of this project it will no longer be valid.	240		
<b>Travel</b> <i>Travel costs must include a description of the purpose of the travel, start and stop dates of travel, transportation costs, housing costs, and allowable per diem (use University rates found at http://travel/umn.edu).</i>	Round trip airfare from DCA - Melbourne, Australia (7/19/09 - 11/25/09): <i>Estimate from qantas.com.au</i>	1885		
<b>Travel</b> <i>Travel costs must include a description of the purpose of the travel, start and stop dates of travel, transportation costs, housing costs, and allowable per diem (use University rates found at http://travel/umn.edu).</i>	Housing Costs in Melbourne for 17 weeks: \$475/month x 4.25 months = \$ 2018.75 <i>Estimate from Melbourne Univ. Student Services</i>	2018.75		
<b>Travel</b> <i>Travel costs must include a description of the purpose of the travel, start and stop dates of travel, transportation costs, housing costs, and allowable per diem (use University rates found at http://travel/umn.edu).</i>	Transportation Costs in Melbourne for 4.25 months: (109.60 AUD/month x 4 months) + (\$29.40 AUD/week x 1 week) = \$467.80 AUD = 296.53 USD <i>Estimate from Melbourne Yarra Trams</i>	296.48		
	<b>Subtotal research supplies, equipment, travel, other</b>	4440.23		
<b>TOTAL BUDGET</b>		6646.15		