

ANNUAL REPORT
2009 - 2010

Health  Law
I N S T I T U T E

FACULTY OF LAW, UNIVERSITY OF ALBERTA



SERVICE / MISSION / OBJECTIVES

WHO WE SERVE

The Health Law Institute serves the University of Alberta's Faculties of Law and the health professions, the University community at large, legal and health professionals, the public, and law and policy makers.

MISSION

The mission of the Institute is to initiate and promote interdisciplinary activities to raise awareness, enhance knowledge and understanding, and promote positive reform of Alberta, Canadian and international health law and associated health policy.

OBJECTIVES

The principal objectives in furtherance of our mission are:

To inform and educate students and practitioners of law and the health care professions, law and policy makers, and the public.

To contribute to, promote and publish innovative legal and interdisciplinary research.

To respond to the needs of the public, academic communities, professional communities, and health law and policy makers.

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MESSAGE FROM THE EXECUTIVE DIRECTOR

Tracey M. Bailey

The health and well-being of individuals and populations are issues important to all of us, and ones which occupy the imaginations and preoccupations of many. This is evidenced by the percentage of government and private funding spent on health, the volume of discourse heard in the media and other public forums, and the intensity of effort expended by health care providers and researchers around the globe. Law and policy is but one piece of this collective aim to improve the health of people. However, it is a key aspect of any well-coordinated effort to effect change. Indeed, well drafted policy or law can be a very effective tool to implement changes in the health care system. Poorly thought-out policy can lead to unintended and negative consequences for patients, providers and other stakeholders.

With our mission and objectives of interdisciplinary work to educate and promote positive reform of health law and policy locally, nationally and internationally, our team is excited to carry on our tradition of independent research aimed



at improvements in health care systems and services. Thanks to the continued support of many funders, and in particular, the Alberta Law Foundation who has supported our core operation for many years, we are excited to carry on with our work in serving the public, academic and professional communities, and health law and policy makers.

This year has been another period of incredible growth and change. Health Law Institute team members have worked with organizations and individuals on an enormous range of timely issues, including new discoveries related to health care technologies, genetics and other scientific advances, health care system reform, patient safety, public health, liability, health information, consent, end of life issues and challenges related to research. They have worked hard with our objective of service in mind. Thanks to the dedication of our staff, research fellows and colleagues far and wide, we are pleased to provide this report of our activities for this fiscal year.

BOARD MEMBERS

Wendy Austin, Professor, Faculty of Nursing and the Dossetor Health Ethics Centre at the University of Alberta

Tracey M. Bailey, Executive Director, HLI

Russ Brown, Associate Professor, Faculty of Law at the University of Alberta

Timothy Caulfield, FRSC, Professor, Faculty of Law and School of Public Health at the University of Alberta; Canada Research Chair in Health Law & Policy, Health Senior Scholar, AHFMR; Research Director, HLI

Renee Elio, Associate Vice President (Research) and Professor of Computing Science at the University of Alberta

Moe M. Litman, Chair, HLI and Professor in the Faculty of Law at the University of Alberta

John G. Martland, Q.C. (Honourary Member) is special counsel to the HLI

Erin Nelson, Acting Chair, HLI and Associate Professor in the Faculty of Law at the University of Alberta

Hon. Madam Justice Ellen Picard (Honorary Member) Justice of the Court of Appeal of Alberta and the Court of Appeal of the Northwest Territories, and founder of the HLI

Valerie Prather, Partner, Bennett Jones LLP

Gerald Robertson, Q.C., Professor in the Faculty of Law at the University of Alberta

David Shragge, Physician



STAFF



Tracey M. Bailey

Tracey Bailey is the Executive Director of the Health Law Institute, an adjunct professor with the John Dossetor Health Ethics Centre and the Faculty of Medicine and Dentistry, and a sessional lecturer in the Faculty of Law at the University of Alberta. Tracey graduated from that Faculty of Law in 1991 and went on to practice for a number of years with the firm now known as Fraser Milgrain Casgrain LLP in the area of health law. Tracey is actively involved in the education component of the HLI, including the coordinating of workshops and conferences, presenting at conferences, and providing outreach education to health care professionals and members of the public. Other activities include research, both contract and grant funded, to assist agencies in policy making. She is an editor of and contributor to *Public Health Law & Policy in Canada*, the first Canadian text on public health and the law, and has authored numerous other articles and reports. She is co-editor of the *Health Law Journal* and the *Health Law Review*. Tracey is currently a member of numerous ethics and policy related committees. She is a current Executive Member and former Chair of the Canadian Bar Association's (CBA) National Health Law section, and a former Co-Chair of the Northern Alberta CBA Health Law section.



Timothy Caulfield

Timothy Caulfield has been Research Director of the Health Law Institute at the University of Alberta since 1993, and was awarded a Canada Research Chair in Health Law and Policy in 2001. He is a Professor in the Faculty of Law and the School of Public Health and teaches biotechnology. Timothy Caulfield has been involved in numerous interdisciplinary research endeavours that have allowed him to publish over 150 articles and book chapters. He is a Health Senior Scholar with the Alberta Heritage Foundation for Medical Research, the Principal Investigator for a Genome Canada project on the regulation of genomic technologies, an AllerGen Network project on ethics, evidence and health policy research, and the theme leader for the Stem Cell Network. He has several other projects funded by the Canadian Institutes of Health Research. Professor Caulfield is, and has been, involved with a number of national policy and research ethics committees, including the Canadian Biotechnology Advisory Committee, Genome Canada's Science Advisory Committee, the Federal Panel on Research Ethics, and the Canadian Academy of Health Sciences Expert Panel on Pesticides. He is a Fellow of the Royal Society of Canada and a member of the Canadian Academy of Sciences. Timothy Caulfield is an Editor of the *Health Law Journal* and the *Health Law Review*.

Mark Ammann

Mark joined the HLI in September 2008. After earning his B.A. and LL.B. at the University of Alberta, he served as a Judicial Clerk at the Alberta Court of Queen's Bench before completing his articles at the Edmonton firm of Parlee McLaws LLP. As a Research Associate/Project Manager, he assists the Executive Director by conducting research, editing the Health Law Journal and Health Law Review, updating the HLI website, and delivering lectures on various health law topics.



Nina Hawkins

As its Administrator, Nina manages the HLI's grants and finances, and coordinates its conferences, public lectures, and student and staff activities. In addition, she is an Assistant Editor of the Health Law Journal and the Health Law Review, responsible for their production and promotion. She holds a diploma in business studies and has completed the Canadian Society of Association Executives Management Program.



Robyn Hyde-Lay

Its Project Manager since 2005, Robyn manages the administrative and financial aspects of the Genome Canada-funded project "Translating Science: Genomics and Health Systems." Previously she acted as Project Manager in the Faculty of Agriculture at the University of Alberta. She holds an M.A. in Medical Anthropology from the University of Victoria and an MBA from the University of Alberta.



Karin L. Kellogg

A Research Associate/Project Manager with the HLI, Karin conducts research on and recommends reform of various health law issues. She also edits the Health Law Journal and Health Law Review and performs public outreach education, delivering presentations on topics such as personal directives and health information confidentiality. She earned her B.A. (Hons.), LL.B. and M.A. at the University of Alberta, and joined the HLI in September of 2007.



Christen Rachul

Christen joined the HLI team in July 2009. She holds a BA in Applied Linguistics and completed her MA in Applied Language Studies in 2008 at Carleton University in Ottawa. Previously she worked as a Research Assistant at Norquest College in Edmonton. As a Research Associate, she is involved in a number of HLI projects and has a particular interest in media analysis.





Nola M. Ries

A Research Associate with the HLI, Nola is also an Assistant Professor in the Faculty of Law at the University of Victoria. She joined the HLI in 2003. Her work focuses on: public health law; health system reform, resource allocation and access to health care; consent, privacy and confidentiality; and legal issues in genetics and biotechnology. She is an editor, together with Tracey Bailey and Timothy Caulfield, of Public Health Law and Policy in Canada. She is a member of both the Canadian Public Health Association and the Canadian HIV/AIDS Legal Network.



Jacob Shelley

Jacob works as a researcher for the HLI. He is currently pursuing doctoral studies at the University of Toronto. Jacob's current research interests include the use of public health as a means of addressing the obesity epidemic. He has presented at numerous conferences in both Canada and the United States.



Lorraine Sheremeta

Lori is a Research Associate at the HLI. She is currently seconded as both a Research Officer at the National Research Council's National Institute for Nanotechnology and as a Special Advisor to Alberta Ingenuity Fund's Strategic Programs. Her research interests focus on the legal and regulatory implications of new technologies, such as genetics, genomics, regenerative medicine and nanotechnology.



Julie Van Hill

Julie joined the Health Law Institute as Administrative Assistant in April 2009. She has worked at the University of Alberta since August 2005, where she was the Program Administrator in the Division of Orthopedic Surgery and Otolaryngology Surgery, and then moved to the Division of Cardiology as a Medical Secretary. Julie provides administrative assistance to the Executive Director and the Alberta Law Foundation-funded Research Associates/Project Managers.



Amy Zarzeczny

Having recently completed her LL.M. at the London School of Economics and Political Science, Amy joined the HLI in August 2008 as Research Associate/Project Manager of the Stem Cell Network-funded project "The Stem Cell Research Environment: Drawing the Evidence and Experience Together" and of the CIHR-funded project "Neuroscience and Norms: Ethical and Legal Aspects of Norms in Neuroimaging." After graduating from the University of Alberta's Faculty of Law in 2005, she clerked for the Alberta Court of Queen's Bench and Court of Appeal before completing her articles at the law firm of Reynolds Mirth Richards & Farmer LLP, where she subsequently practised.

RESEARCH FELLOWS

Tania Bubela

Tania is an Assistant Professor in the School of Public Health at the University of Alberta and a Member of the Intellectual Property Modeling Group at McGill University. She holds a PhD in the biological sciences in addition to her LL.B. Her areas of research interest include not only intellectual property, but biotechnology, technology transfer, innovation and knowledge management, health law, science communication and media studies.

Peter Carver

Peter is an Associate Professor, jointly appointed to the Faculties of Rehabilitation Medicine and Law at the University of Alberta. In the latter he teaches Canadian Constitutional, Administrative and Immigration Law, as well as Disability Studies and Mental Health Law. Previously he served as a member of the federal Immigration and Refugee Board and practiced law in British Columbia.

Richard Gold

The BCE Chair in e-Governance at McGill Faculty of Law, Richard teaches in the areas of intellectual property and technology. He has in addition been a Senior Advisor in Intellectual Property to the Canadian Biotechnology Advisory Committee, a Legal Policy Advisor to Ontario's Ministry of Health and Long Term Care, and a Senior Fellow of the Einstein Institute for Science, Health and the Courts. His research explores the nexus between biotechnology, commerce and ethics.

Lori P. Knowles

Currently a member of the Scientific Advisory Board of Genome Canada and the Ethics Oversight Committee of the US Department of Veteran Affairs DNA Tissue Bank, Lori was for five years the Associate for Law at the Hastings Center. She has in addition acted as consultant to President Bush's Council on Bioethics, President Clinton's national Bioethics Advisory Commission, the US National Academy of Science, and the US Food and Drug Administration. Her research interests

include international law and biotechnology policy, intellectual property and reproductive technology.

Erin Nelson

An Associate Professor in the Faculty of Law at the University of Alberta, Erin teaches Tort Law and Health Care Ethics and the Law. Among her research interests are the interface of health care law and ethics, women's health, issues in reproductive health, and feminist legal theory. She has published articles and chapters on such topics as consent, intervention in pregnancy, pediatric genetics, the tort laws duties of pregnant women, and the regulation of health care practitioners. Prior to graduate studies at Columbia University, she acted as Project Manager at the HLI for two years.

Barbara von Tigerstrom

Barbara von Tigerstrom is an Associate Professor at the University of Saskatchewan College of Law and a joint member of the School of Public Health. After completing her PhD in Law at Cambridge University, she taught at the University of Canterbury in New Zealand before returning to Canada. Her main areas of teaching and research are health law and international law. She has published extensively in the areas of international law, trade law, population health and biotechnology..

CONSULTANT

Brent Windwick

Brent is a Practitioner Consultant with the HLI. He is a partner with the Edmonton law firm of Field Law LLP, where he practises almost exclusively in the area of health law. A founding member of the Canadian Bar Association Health Law Section for Northern Alberta, he currently sits on the Privacy Advisory Committee of the Canadian Institutes for Health Research.

AWARDS

Timothy Caulfield has been principal investigator and theme leader of numerous substantial research grants during his tenure as the HLI's Research Director. He has built a national and international reputation in health law scholarship, with particular expertise in the areas of genetics, stem cell research and biotechnology.



We are very pleased to report continuation of the following appointments held by Professor Caulfield:

Canada Research Chair in Health Law and Policy – 2007-2011

Health Senior Scholar

Alberta Heritage Foundation for Medical Research – 2007-2014

RESEARCH GRANTS

Alberta Innovates Health Solutions: Improving the Efficient and Equitable Care of Patients with Chronic Medical Conditions—Interdisciplinary Chronic Disease Collaboration (ICDC) – 2009-2014 (\$5,000,000)

The ELS team led by Timothy Caulfield will review legislative provisions regarding research access to administrative data, conduct surveys of health ministries and other information custodians to document specific policies and procedures related to such access, systematically study existing ethics and professional norms and relevant case law and conduct focus groups on the attitudes and views of the general public regarding the secondary use of personal information.

Genome Canada: Translating Science: Genomics and Health Systems – 2005-2010 (\$2,213,510)

Principal Investigator: Timothy Caulfield (HLI, University of Alberta)

This project investigates two broad questions: How is genomics knowledge translated in health systems? What are the consequent policy implications? Translation involves production, protection, interpretation, application and commercialization, while “health systems” refers to health research networks that take on a variety of forms.

Regenerative Medicine: CIHR Training Program in Regenerative Medicine – 2009-2015 (\$1,950,000)

Co-Investigator: Timothy Caulfield (HLI, University of Alberta)

Research Director Timothy Caulfield is acting as a co-investigator on a team developing the only comprehensive regenerative medicine training program in Canada. In partnership with industry, this program will identify and train scientists who will lead this important new field in health research. Organ failure is a pervasive medical problem that results in immense personal and economic costs, morbidity and death. At present, the only truly effective treatment for organ failure is transplantation, though the deficiencies of this option are increasingly apparent, and include a chronic shortage of donor organs, side effects from harsh immunosuppressive medications and chronic rejection leading to the eventual loss of most transplanted organs. Regenerative medicine, defined as the practice of repair, regeneration or replacement of tissues and organs that have failed, has enormous potential to revolutionize diagnostic and therapeutic alternatives to transplantation via the development of radical new therapies. However, at present, there are few scientists and practitioners of regenerative medicine in Canada.





Canadian Institutes of Health Research (CIHR) - Emerging Team in Genomics in Screening – 2008-2013 (\$1,500,000)

Co- Investigator: Timothy Caulfield (University of Alberta)

Professor Timothy Caulfield is part of a team which has received funding to investigate genetics in primary care and public engagement and education. The overall goal of this investigation is to facilitate the practical translation of genomics discoveries into population health gains, specifically focusing on areas where genomics meets general populations and primary care.

Alberta Health Services: Alberta Policy Coalition for Cancer Prevention (2008-2011 \$1,000,000)

Principal Investigator: Kim Raine (University of Alberta)

Co-Investigator: Timothy Caulfield (University of Alberta)

The ELS (ethics, law, society) team on this grant, led by Timothy Caulfield, will review legislative provisions regarding research access to administrative data, conduct surveys of health ministries and other information custodians to document specific policies and procedures related to such access, systematically study existing ethics and professional norms and relevant case law and conduct focus groups on the attitudes and views of the general public regarding the secondary use of personal information.

Stem Cell Network: The Stem Cell Research Environment: Drawing the Evidence and Experience Together – 2008-2011 (\$930,387)

Co-Investigators: Timothy Caulfield (HLI, University of Alberta), Bartha-Maria Knoppers (University of Montreal), Edna Einsidel, (University of Calgary) and Michael McDonald (University of British Columbia)

This three year project commenced in October 2008 and will draw an international team of collaborators together to examine the nature of the stem cell research environment and its impact on research strategies, movement of trained researchers, capacity to conduct research, intellectual property in and ownership of research outputs, funding opportunities, research productivity, reception of emerging technologies, public perceptions of the research and future investment mechanisms. This work seeks to inform public policy and to contribute to the broader knowledge base surrounding the ethical, legal and social issues engaged by stem cell research and other novel technologies.

AllerGen Network: Evidence, Ethics and Health Policy Research – 2009-2010 (\$300,000)

Principal Investigator: Timothy Caulfield (HLI, University of Alberta)

Co-Investigators: Susan Elliott (McMaster University) and Lisa Cicutto (University of Toronto)

This project – which will engage policy makers, health care professionals, research ethics boards, patient advocacy groups and the general public—will produce a variety of outcomes relevant to allergy and asthma

policy and research, including: consensus statements and recommendations (flowing from interdisciplinary workshops), academic articles, practical guidelines and articles in the popular press. We will also hold public seminars. It is hoped that our findings will be of value to all Canadians. By gaining a greater understanding of both the relevant research ethics environment and the ways in which evidence is used to inform policy making, we aim to make the process of creating evidence-based health policy more efficient and effective, thus heightening the value of research and contributing to the well-being and health of all Canadians.

CIHR: NeuroScience and Norms: Ethical and Legal Aspects of Norms in Neuroimaging (SCAN) – 2008-2011 (\$90,000)

Project Leader: Timothy Caulfield (HLI, University of Alberta)

This project commenced in 2008 and will run until 2011. The Neuroethics Initiative aims to bring together relevant and competitive researchers and research teams from Canada, Finland and Germany to design and carry out jointly organized research projects in the field of neuroethics. Funding within this Initiative is available for multilateral collaborative research projects consisting of researchers from at least two of the partners. The HLI research team will partner with researchers from the University of Bonn in Germany, University of Helsinki in Finland, and the Institute for Science and Ethics in Bonn, Germany. The other research teams are independently funded by their respective national funding agencies.

CIHR: Use of Legal Interventions to Address Environmental Factors Implicated in the Obesity Epidemic: The Role of Law as a Public Health Tool – 2006-2010 (\$81,250)

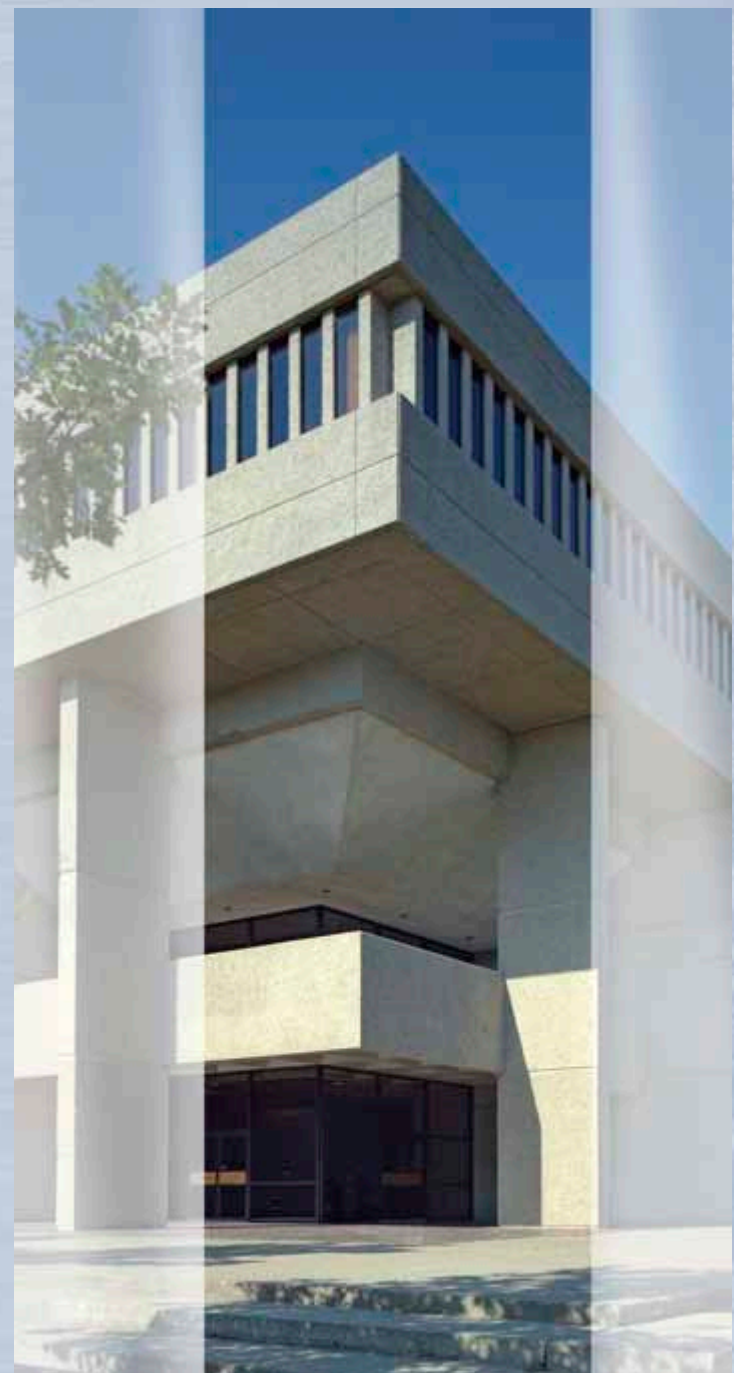
Principal Investigators: Barbara von Tigerstrom (University of Saskatchewan) and Timothy Caulfield (HLI, University of Alberta)

Analysis is focused on environmental factors related to obesity, such as availability, regulation and marketing of food. A comprehensive analysis and evaluation of the use of legal and regulatory mechanisms to change such environmental factors will be provided.

CIHR: Health Law and Policy Training Program – 2009-2015 (\$1,900,000)

Principal Investigators: Timothy Caulfield (University of Alberta), Colleen Flood (University of Toronto), Trudo Lemmens (University of Toronto) William Lahey (Dalhousie University), and Robert Kouri (University of Sherbrooke)

This grant is administered by the University of Toronto and provides funding for graduate students specializing in health law at Dalhousie University, the University of Toronto, the University of Alberta, and the University of Sherbrooke. The purpose of the grant is to build a comprehensive Canadian training program in the area of health law and policy.





Office of the Privacy Commissioner of Canada: Analysis of Privacy Policies and Practices of Direct-to-Consumer Genetic Testing Companies: Private Sector Biobanking and Private Protection Norms – 2009-2010 (\$49,450)

Co-Investigators: Timothy Caulfield (HLI, University of Alberta) and Nola Ries (HLI, University of Alberta)

Genetic privacy and biobanking are priority areas for the 2009-10 Contributions Program. The goal of this project is to identify and analyse privacy issues that arise in the context of private sector genetic testing services. A growing number of commercial firms are selling genetic tests directly to consumers, with the result that these firms become biobankers. The companies obtain biological samples from individuals for DNA testing and collect personal information, including details about lifestyle and individual and family medical history. The growth of direct-to-consumer (DTC) genetic testing companies means a proliferation of private sector biobanks. Moreover, some companies are establishing consortia with research institutions and health care organizations to pool resources that will facilitate even larger biobanks. Our project aims to conduct research that examines the privacy policies and practices of a comprehensive sample of DTC genetic testing companies to assess their compliance with fair information principles developed by the Canadian Standards Association in the Model Code for the Protection of Personal Information and incorporated into the Personal Information Protection and Electronic Documents Act. In addition to evaluating the extent to which these firms meet fair information practices, our analysis will consider whether clear privacy protection norms are emerging to govern how these companies handle genetic samples and personal information.

SSHRC Dental Grant: Rationing Publicly Financed Dental Care in Canada: Moving Beyond Individual and Social Responsibility – 2009-2011 (\$58,000)

Tracey Bailey is part of a team which has received funding to conduct a study aimed at detailing the exact principles and rules used to ration publicly funded dental care in Canada and continuing research into the political economy of dentistry. Publicly financed dental care is gaining prominence as a health policy issue in Canada and challenges continue to exist for low-income groups in need of dental care. The Canadian Medical Association has even called for the inclusion of dental care within Medicare, and the Canadian Dental Association is now recommending that governments establish a dental safety net for all disadvantaged Canadians. This represents renewal in the context of 25 years of decreasing expenditures for publicly financed dental care in Canada. This project is aimed at detailing the exact principles and rules used to ration publicly financed dental care in Canada. The study will consider the following question: What are the current standards for rationing publicly financed dental care in Canada, and what could they look like as Canada moves forward in this time of public dental care renewal?

Alberta Law Foundation: Giving Voice: Advocacy and Mental Health Forum – 2009 (\$14,210)

Tracey Bailey co-chaired this one-day forum which introduced participants to changes in Alberta mental health legislation, including the broadening of criteria for involuntary admission to psychiatric facilities and the introduction of community treatment orders. The forum also provided a unique opportunity to hear from leaders in mental health and law regarding advocacy on behalf of those living with mental illness or involved in the mental health and justice systems. Legal, ethical and professional challenges and responsibilities for health care providers, lawyers, caseworkers, therapists, justice workers, ethicists, community agencies and patient representatives in working with the mentally ill were explored.

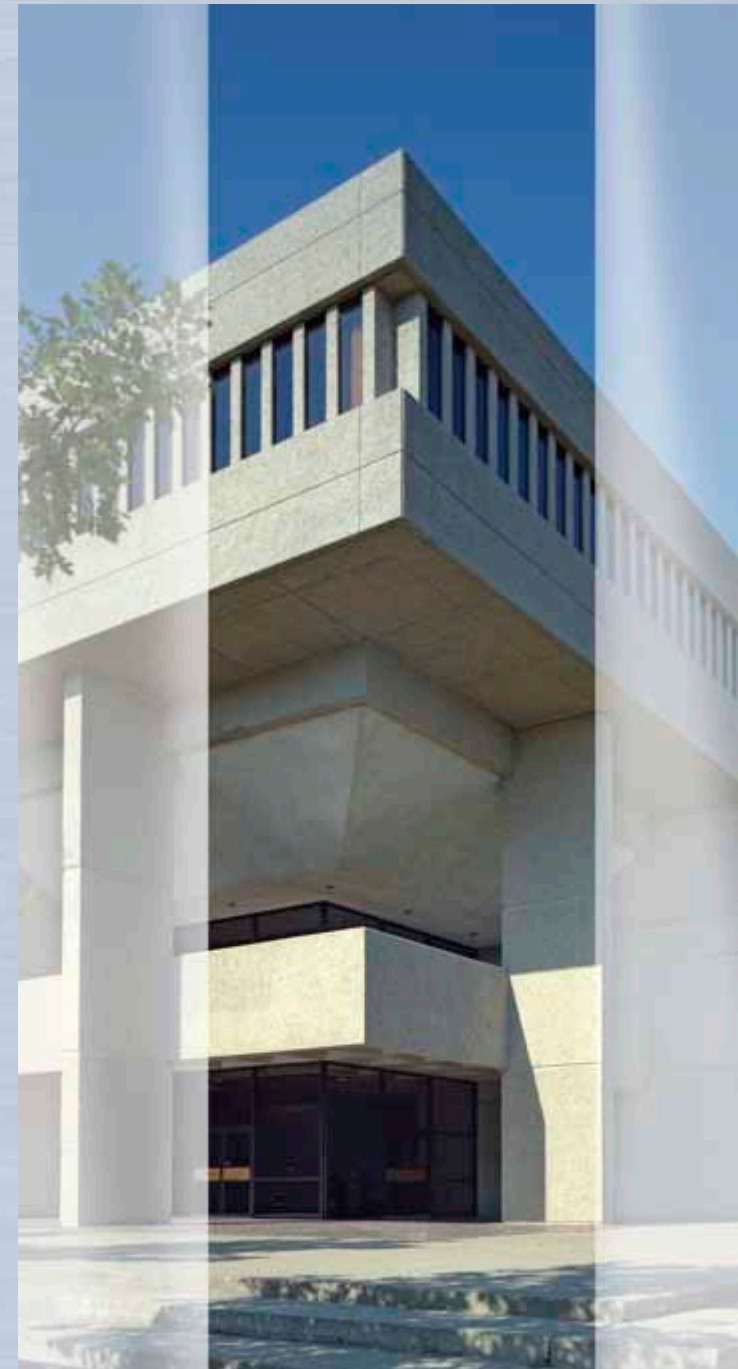
ALBERTA LAW FOUNDATION FUNDED RESEARCH

(2009-2010) – \$583,500

Tracey Bailey conducts and oversees research on a wide variety of issues aimed at the reform of law and/or policy making. Funding from the Alberta Law Foundation supports this work. Research is also conducted to publish in a variety of media (in publications both academic and those aimed at lay audiences), to organize and/or deliver talks at conferences, workshops and other educational sessions, and to respond to requests for information from numerous organizations and individuals that we serve.

CONTRACTS & SERVICE AGREEMENTS

HLI staff have been retained by governmental organizations, health care institutions, professional regulatory colleges and other bodies to conduct research and/or to contribute to the creation of policy, law and ethics documents.



HEALTH LAW JOURNAL HEALTH LAW REVIEW



The Health Law Institute publishes two scholarly publications, the Health Law Journal and the Health Law Review. The Health Law Review was first published in 1991 as a continuation of a newsletter previously published by the Institute. Shortly thereafter, the first issue of the Health Law Journal was published in 1993. Our two publications have different scopes, but share the aim of publishing high-quality interdisciplinary papers that stimulate and advance discussion of health law. It is the intent that the content of both publications will be representative of the various disciplines involved in the health law arena.

The Health Law Journal is committed to publishing outstanding papers that explore innovative and original issues in the interdisciplinary area of health law. The Journal is published once a year and all submissions to the Journal are peer-reviewed.

The Health Law Review is published three times per year and features shorter articles. Special editions are often created, focusing on specific topics. The Health Law Review has a diverse audience of legal professionals, policy makers and health care professionals.



STAFF PUBLICATIONS

Mark Ammann

Tracey M. Bailey & **Mark Ammann**, “Defining ‘Best Interests:’ The Case of Baby Isaiah” The Edmonton Journal (23 January 2010) A19

Mark Ammann, “Would Presuming Consent to Organ Donation Gain Us Anything But Trouble?” (2010) 18:2 Health Law Review 15

Tracey M. Bailey & **Mark Ammann**, Submission on Draft Code of Conduct (Edmonton: Alberta Health Services, 2009)

Mark Ammann, “Alberta’s Bill 48 Threatens Universal Medical Coverage” (2009) 29 Lawyers Weekly 5

Tracey M. Bailey

Tracey M. Bailey, Nola Ries, et al, Halsbury’s Laws of Canada, 1st edition, Public Health vol. (Markham: LexisNexis 2010)

Tracey M. Bailey & Mark Ammann, “Defining ‘Best Interests:’ The Case of Baby Isaiah” The Edmonton Journal (23 January 2010) A19

Tracey M. Bailey et al., “Comfort, Hopes and Wishes: Making Difficult Health Care Decisions “ (Edmonton: Provincial Health Ethics Network, 2010) (contributing author)

Tracey M. Bailey & Brendan Leier, “The Case of Samuel Golubchuk and the Right to be Spared an Excruciating Death” (2010) 10 American Journal of Bioethics 67

Olive Yonge, Rhonda J. Rosychuk, **Tracey M. Bailey**, Rob Lake & Thomas J. Marrie, “Willingness of University Nursing Students to Volunteer During a Pandemic” (2010) 27 Public Health Nursing 174

Tracey M. Bailey, “New Frontiers for Electronic Health Records and Research Databases—Alberta’s Bill 52: Submission of the Health Law Institute on Bill 52” (2009) 18:1 Health Law Review 38

Tracey M. Bailey & Mark Ammann, Submission on Draft Code of Conduct (Edmonton: Alberta Health Services, 2009)

Tracey M. Bailey, Karin L. Kellogg & Nola M. Ries, National Unique Identifier and the Canadian Privacy and Health Professions Legislative Environment (Ottawa: Canadian Institute for Health Information, 2009)

Tracey M. Bailey et al., “Ethical Framework for Pandemic Planning” (Edmonton: Alberta Health Services, 2009) (contributing author)

Tracey M. Bailey, Karin L. Kellogg & Gergely Hegedus, Submission to Standing Committee on Health: Bill 52, Health Information Amendment Act, 2009 (Edmonton: Standing Committee on Health, 2009)

Tania M. Bubela

Tania Bubela et al., “Science Communication Reconsidered: Challenges, Prospects and Recommendations” (2009) 27 Nature Biotechnology 514



Timothy Caulfield, Amy Zarzeczny, Jennifer McCormick, **Tania Bubela** et al., “International Stem Cell Environments: A World of Difference,” online: (2009) *Nature Reports Stem Cells*

Timothy Caulfield, Amy Zarzeczny, Jennifer McCormick, **Tania Bubela** et al., “The Stem Cell Research Environment: A Patchwork of Patchworks” (2009) 5:2 *Stem Cell Reviews and Reports* 82

Timothy Caulfield

Nola M. Ries, Jane LeGrandeur & **Timothy Caulfield**, “Handling Ethical, Legal and Social Issues in Birth Cohort Studies Involving Genetic Research: Responses from Studies in Six Countries,” online: (2010) 11:4 *BMC Medical Ethics*

Timothy Caulfield, “Human Gene Patents: Proof of Problems?” (2010) 84 *Chicago-Kent Law Review* 133

Timothy Caulfield et al., “Stem Cell Research Policy and iPS Cells” (2010) 7 *Nature Methods* 28

Timothy Caulfield & Yann Joly, “Human Gene Patents and Genetic Testing” in George P. Patrinos & Wilhelm Ansorge, eds., *Molecular Diagnostics*, 2^d ed. (London: Elsevier, 2010)

Timothy Caulfield et al., “Direct-to-Consumer Genetic Testing: Good, Bad or Benign?” (2010) 77 *Clinical Genetics* 101

Timothy Caulfield, “Human Gene Patents: Proof of Problems?” (2009) 84 *Chicago-Kent Law Review* 133

Timothy Caulfield & Jane Kaye, “Broad Consent in Biobanking: Reflections on Seemingly Insurmountable Dilemmas” (2009) 10 *Medical Law International* 85

Amy Zarzeczny, Christopher Scott, Insoo Hyun, Jami Bennett, Jennifer Chandler, Sophie Charge, Heather Heine, Rosario Isasi, Kazuto Kato, Robin Lovell-Badge, Kelly McNagny, Duanqing Pei, Janet Rossant, Azim Surani, Patrick L. Taylor, Ubaka Ogbogu & **Timothy Caulfield**, “iPS Cells: Mapping the Policy Issues” (2009) 139:6 *Cell* 1032

Timothy Caulfield, Victor Alfonso & Jacob Shelley, “Deterministic? Newspaper Representations of Obesity and Genetics” (2009) *Open Obesity Journal* 1

Timothy Caulfield, “Direct-to-Consumer Genetics and Health Policy: A Worst Case Scenario?” (2009) 9 *American Journal of Bioethics* 48

Timothy Caulfield et al., “The Stem Cell Research Environment: A Patchwork of Patchworks” (2009) 5:2 *Stem Cell Reviews and Reports* 82

Amy Zarzeczny & **Timothy Caulfield**, “Emerging Ethical, Legal and Social Issues Associated with Stem Cell Research and the Current Role of the Moral Status of the Embryo” (2009) *Stem Cell Reviews and Reports* 96

Timothy Caulfield et al., “International Stem Cell Environments: A World of Difference,” online: (2009) *Nature Reports Stem Cells*

Alethea Adair, Robyn Hyde-Lay, Edna Einsiedel & **Timothy Caulfield**, “Technology Assessment and Resource Allocation for Predictive Genetic Testing: A Study of the Perspectives of Canadian Health Care Providers” (2009) 10 *BMC Medical Ethics* 6

Tania Bubela, Matthew Nisbet, Rick Borchelt, Fern Brunger, Christine Critchley, Edna Einsiedel, Gail Geller, Anil Gupta, Jurgen

Hampel, Robyn Hyde-Lay, Eric W. Jandciul, S. Ashly Jones, Pam Kolopack, Summer Lane, Tim Lougheed, Brigitte Nerlich, Ubaka Ogbogu, Kathleen O’Riordan, Colin Ouellette, Mike Spear, Stephen Strauss, Thushaanthini Thavaratnam, Lisa Willemse & **Timothy Caulfield**, “Science Communication Reconsidered” (2009) 27 *Nature Biotechnology* 514

Timothy Caulfield & Charles Weijer, “Minimal Risk and Large-Scale Biobank and Cohort Research” (2009) 17:2,3 *Health Law Review* 53

Peter Rugg-Gunn, Ubaka Ogbogu, Janet Rossant & **Timothy Caulfield**, “The Challenge of Regulating Rapidly Changing Science: Stem Cell Legislation in Canada” (2009) 4 *Cell Stem Cell* 285

Timothy Caulfield, “Profits and Research: A Good Mix?” *The Edmonton Journal* (18 June 2009) A14

Timothy Caulfield, “Discussing Our (Genetic) Differences” *University Affairs* (May 2009)

Richard E. Gold

Richard E. Gold, et al., “Are Patents Impeding Medical Care and Innovation?” (2010) 7 *PLoS Medicine* 1

Richard E. Gold & Jean-Frederic Morin, “The Missing Ingredient in Medicine Patent Pools” (2009) 374 *Lancet* 1329

Robyn Hyde-Lay

Alethea Adair, **Robyn Hyde-Lay**, Edna Einsiedel & Timothy Caulfield, “Technology Assessment and Resource Allocation for Predictive Genetic

Testing: A Study of the Perspectives of Canadian Health Care Providers” (2009) 10 BMC Medical Ethics 6

Tania Bubela, Matthew Nisbet, Rick Borchelt, Fern Brunger, Christine Critchley, Edna Einsiedel, Gail Geller, Anil Gupta, Jurgen Hampel, **Robyn Hyde-Lay**, et al., “Science Communication Reconsidered” (2009) 27 Nature Biotechnology 514

Karin L. Kellogg

Karin L. Kellogg, “Specific Health Care Decisions Under Alberta’s Adult Guardianship and Trusteeship Act” (2010) 18:2 Health Law Review 45

Comfort, Hope and Wishes: Making Difficult Healthcare Decisions (Edmonton: Provincial health Ethics Network, 2010) (contributing author)

Karin L. Kellogg, “Field Notes” (2009) 18:1 Health Law Review 1

Tracey M. Bailey, **Karin L. Kellogg** & Nola M. Ries, National Unique Identifier and the Canadian Privacy and Health Professions Legislative Environment (Ottawa: Canadian Institute for Health Information, 2009)

Tracey M. Bailey, **Karin L. Kellogg** & Gergely Hegedus, Submission to the Standing Committee on Health: Bill 52, Health Information Amendment Act, 2009 (Edmonton: Standing Committee on Health, 2009)

Erin Nelson

Erin Nelson, “Alberta’s New Organ and Tissue Donation Law: The Human Tissue and Organ Donation Act” (2010) 18:2 Health Law Review 5

Ubaka Ogbogu

Amy Zarzeczny, Christopher Scott, Insoo Hyun, Jami Bennett, Jennifer Chandler, Sophie Charge, Heather Heine, Rosario Isasi, Kazuto Kato, Robin Lovell-Badge, Kelly McNagny, Duanqing Pei, Janet Rossant, Azim Surani, Patrick L. Taylor, **Ubaka Ogbogu** & Timothy Caulfield, “iPS Cells: Mapping the Policy Issues” (2009) 139:6 Cell 1032

Timothy Caulfield, Amy Zarzeczny, Jennifer McCormick, Tania Bubela, Christine Critchley, Edna Einsiedel, Jacques Galipeau, Shawn Harmon, Michael Huynh, Insoo Hyun, Judy Illes, Rosario Isasi, Yann Joly, Graeme Laurie, Geoff Lomax, Holly Longstaff, Michael McDonald, Charles Murdoch, **Ubaka Ogbogu** et al., “The Stem Cell Research Environment: A Patchwork of Patchworks” (2009) 5:2 Stem Cell Reviews and Reports 82

Tania Bubela, Matthew C. Nisbet, Rick Borchelt, Fern Brunger, Christine Critchley, Edna Einsiedel, Gail Geller, Anil Gupta, Jurgen Hampel, Robyn Hyde-Lay, Eric W. Jandciu, S. Ashly Jones, Pam Kolopack, Summer Lane, Tim Lougheed, Brigitte Nerlich, **Ubaka Ogbogu** et al., “Science Communication Reconsidered” (2009) Nature Biotechnology 514

Timothy Caulfield, Amy Zarzeczny, Jennifer McCormick, Tania Bubela, Christine Critchley, Edna Einsiedel, Jacques Galipeau, Shawn Harmon, Michael Huynh, Insoo Hyun, Judy Illes, Rosario Isasi, Yann Joly, Graeme Laurie, Geoff Lomax, Holly Longstaff, Michael McDonald, Charles Murdoch, **Ubaka Ogbogu** et al., “International Stem Cell Environments: A World of Difference,” online: (2009) Nature Reports Stem Cells

Peter Rugg-Gunn, **Ubaka Ogbogu**, Janet Rossant & Timothy Caulfield, “The Challenge of Regulation of Rapidly Changing Science: Stem Cell Legislation in Canada” (2009) 4 Cell Stem Cell 285

Christen Rachul

Timothy Caulfield, **Christen Rachul** & Amy Zarzeczny, “‘Neurohype’ and the Name Game: Who’s to Blame?” (2010) 1 AJOB Neuroscience 13

C. Toole & **Christen Rachul**, “The Age of Personal Genomics” (2009) Journal of International Biotechnology Law 262

Nola M. Ries

Nola M. Ries, Jane LeGrandeur & Timothy Caulfield, “Handling Ethical, Legal and Social issues in Birth Cohort Studies Involving Genetic Research: Responses from Studies in Six Countries,” online: (2010) 11:4 BMC Medical Ethics

Nola M. Ries & Barbara von Tigerstrom, “Roadblocks to Laws for Healthy Eating and Activity” (2010) 182 Canadian Medical Association Journal 687

Rebecca Rodal, **Nola M. Ries** & Kumanan Wilson, “Influenza Vaccination for Health Care Workers: Towards a Workable and Effective Standard” (2009) 17 Health Law Journal 297

Barbara von Tigerstrom & **Nola M. Ries**, “Cancer Surveillance in Canada: Analysis of Legal and Policy Frameworks and Tools for Reform” (2009) 17 Health Law Journal 1

Timothy Caulfield, **Nola M. Ries** et al., “Direct-to-Consumer Genetic Testing: Good, Bad or Benign?” (2010) 77 Clinical Genetics 101

Tracey M. Bailey, Karin L. Kellogg & **Nola M. Ries**, National Unique Identifier and the Canadian Privacy and Health Professions Legislative Environment (Ottawa: Canadian Institute for Health Information, 2009)

Jennifer Farrell, **Nola M. Ries**, Heather Boon & Natasha Kachan, "Foods and Natural Health Products: Gaps and Ambiguities in the Canadian Regulatory Regime" (2009) 34 Food Policy 388

Jacob Shelley

Timothy Caulfield, Victor Alfonso & **Jacob Shelley**, "Deterministic? Newspaper Representations of Obesity and Genetics" (2009) 1 Open Obesity Journal 38

Lorraine Sheremeta

Rose M. Geransar, Edna F. Einsiedel, Jacques Galipeau, Rosario Isasi, **Lorraine Sheremeta**, Bartha Maria Knoppers, "Catalyzing Umbilical Cord Blood Research in Canada: A Survey of Current Needs and Practices of Principal Investigators" (2009) 31 Journal of Obstetrics and Gynaecology Canada 63

Barbara von Tigerstrom

Nola M. Ries & **Barbara von Tigerstrom**, "Roadblocks to Laws for Healthy Eating and Activity" (2010) 182 Canadian Medical Association Journal 687

Barbara von Tigerstrom & Nola M. Ries, "Cancer Surveillance in Canada: Analysis of Legal and Policy Frameworks and Tools for Reform" (2009) 17 Health Law Journal 1

Barbara von Tigerstrom, "Mandatory Nutrition Disclosure for Restaurants: Is Menu Labelling Coming to Canada?" (2010) 28 Windsor Review of Legal and Social Issues 139

Timothy Caulfield, Amy Zarzeczny, Jennifer McCormick, Tania Bubela, Christine Critchley, Edna Einsiedel, Jacques Galipeau, Shawn Harmon, Michael Huynh, Insoo Hyun, Judy Illes, Rosario Isasi, Yann Joly, Graeme Laurie, Geoff Lomax, Holly Longstaff, Michael McDonald, Charles Murdoch, Ubaka Ogbogu, J. Owen-Smith, S. Pattinson, S. Premji, **Barbara von Tigerstrom** & D.E. Winickoff, "The Stem Cell Research Environment: A Patchwork of Patchworks" (2009) 5:2 Stem Cell Reviews and Reports 82

Timothy Caulfield, Amy Zarzeczny, Jennifer McCormick, Tania Bubela, Christine Critchley, Edna Einsiedel, Jacques Galipeau, Shawn Harmon, Michael Huynh, Insoo Hyun, Judy Illes, Rosario Isasi, Yann Joly, Graeme Laurie, Geoff Lomax, Holly Longstaff, Michael McDonald, Charles Murdoch, Ubaka Ogbogu, J. Owen-Smith, S. Pattinson, S. Premji, **Barbara von Tigerstrom** & D.E. Winickoff, "International Stem Cell Environments: A World of Difference," online: (2009) Nature Reports Stem Cells

Amy Zarzeczny

Timothy Caulfield, Christen Rachul & **Amy Zarzeczny**, "'Neurohype' and the Name Game: Who's to Blame?" (2010) 1 American Journal of Bioethics Neuroscience 13

Timothy Caulfield, Christopher Scott, Insoo Hyun, Robin Lovell-Badge, Kazuto Kato & **Amy Zarzeczny**, "Stem Cell Research Policy and iPS Cells" (2010) Nature Methods 28

Amy Zarzeczny et al., "iPS Cells: Mapping the Policy Issues" (2009) 139:6 Cell 1032

Timothy Caulfield, Amy Zarzeczny et al., "The Stem Cell Research Environment: A Patchwork of Patchworks" (2009) 5:2 Stem Cell Reviews and Reports 82

Amy Zarzeczny & Timothy Caulfield, "Emerging Ethical, Legal and Social Issues Associated with Stem Cell Research and the Current Role of the Moral Status of the Embryo" (2009) 5:2 Stem Cell Reviews and Reports 96

Amy Zarzeczny "Legal Policies Steer Direction of Stem Cell Research" (2009) 28 Lawyers Weekly 15

Timothy Caulfield, **Amy Zarzeczny** et al., "International Stem Cell Environments: A World of Difference," online: (2009) Nature Reports Stem Cells

HOSTED CONFERENCES

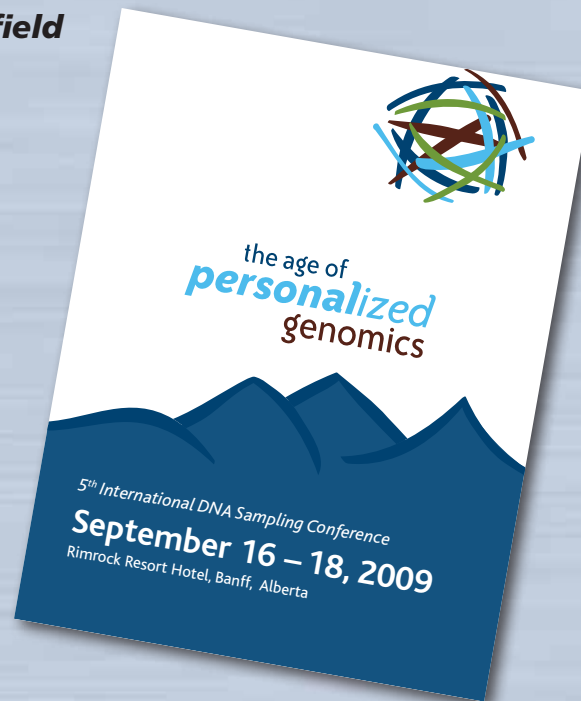
The Health Law Institute hosted two conferences

THE AGE OF PERSONALIZED GENOMICS 5th International DNA Sampling Conference

Co-Chair Timothy Caulfield

September 16-18, 2009

**Rimrock Resort Hotel
Banff, Alberta**

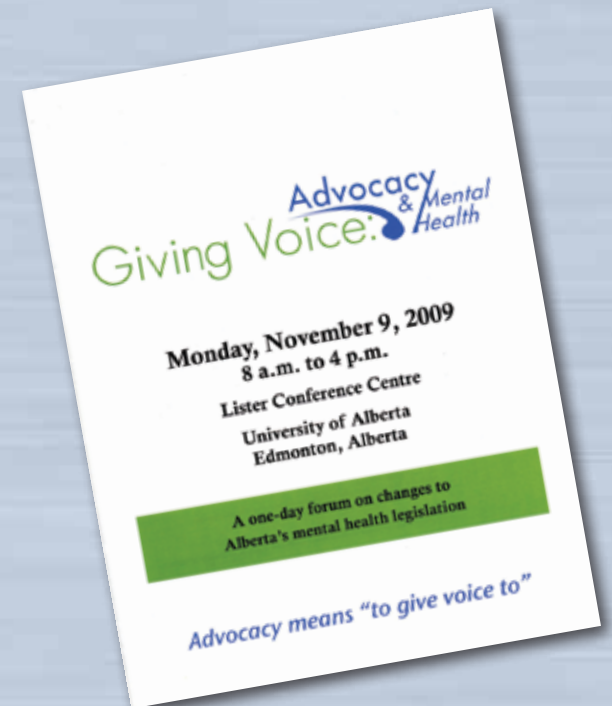


GIVING VOICE Advocacy & Mental Health

Co-Chair Tracey Bailey

November 9, 2009

**Lister Conference Centre
University of Alberta
Edmonton, Alberta**





CIHR TRAINING PROGRAM

The Canadian Institutes of Health Research (CIHR), in partnership with the Alberta Heritage Foundation for Medical Research and the Nova Scotia Health Research Foundation, has been providing graduate fellowships of up to \$17,850 per year per student to selected LL.M. students at the University of Alberta who are pursuing graduate research and writing in the area of health law and policy. The CIHR training grant provides support for an innovative interdisciplinary program that facilitates interactions between students and faculty in a number of different disciplines in three different institutions (University of Alberta, Dalhousie University and the University of Toronto). In addition to providing fellowship funding, the CIHR program supports interdisciplinary seminars at all three institutions and an annual colloquium for graduate students and health law teachers. CIHR-funded graduate students may also have opportunities to apply for placements or internships with organizations such as Health Canada, provincial ministries of health and health care organizations

MEDIA & INQUIRIES FROM THE PUBLIC

HLI staff addresses a variety of health law inquiries from academics, health care and legal professionals and the general public. We also respond to requests for interviews from national and local press, radio and television media.

EDUCATION

PRESENTATIONS

In 2009-10, HLI staff were pleased to present on a wide array of health law topics to audiences at and well beyond the University of Alberta.

Some highlights are as follows.

At the invitation of governmental and non-governmental organizations, academia, health professional associations and community groups, HLI staff spoke on a wide range of topics, including: stem cells, neuroscience, genomics, health care reform, consent, capacity, nanotechnology, apology legislation, medical malpractice, health information confidentiality, substitute decision making, end-of-life decision making, withholding or withdrawal of treatment, disclosure of medical error, organ donation after cardiac death, mental health, and physician-assisted suicide and euthanasia.

International:

Timothy Caulfield, "Selling Hope: The Face of the Stem Cell Tourism Industry," Life Sciences Governance Research Platform, University of Vienna, Vienna, Austria

Timothy Caulfield, "Looking Back, Looking Forward: Canada's Stem Cell Research Policy," Life Sciences Governance Research Platform, University of Vienna, Vienna, Austria

Timothy Caulfield, "Neuroscanning Research: Return of Results and Incidental Findings,"

Bonner Symposium: Modern Neurosciences, Bonn University, Bonn, Germany

Timothy Caulfield, "Personal Genomics, Direct-to-Consumer Testing and Health Care Systems," Biotechnologia Habana '09, Havana, Cuba

Timothy Caulfield, "Are Gene Patents the Problem? A Look at Emerging Evidence," HUGO Symposium on Genomics and Ethics, Law and Society, Geneva, Switzerland

Timothy Caulfield, "What Data Do We Owe Back to Participants in Genetics and Genomics Research?" American Society of Bioethics and Humanities 11th Annual Meeting, Washington, D.C., U.S.

Timothy Caulfield, "Stem Cell Patents and Stem Cell Tourism," World Stem Cell Summit, Baltimore, U.S.

Peter Carver, "Health Care Reform in Canada and the U.S.: Private and Public Health Insurance Through the Looking Glass," American Law and Society Association Conference, Denver, U.S.

Erin Nelson, "Universal Access to Health Care in Canada," American Law and Society Association Conference, Denver, U.S.



Ubaka Ogbogu, "Stem Cell Research Policy and Speculative Economic Benefits: Evidence and Commentary," 7th Annual Meeting of the International Society for Stem Cell Research, Barcelona, Spain (poster presentation)

Ubaka Ogbogu, "Balancing Public and Private Interests: Genetic Research and Access to Information Law," GeneBanC International Conference, Leuven, Belgium

Christen Rachul, "Tracing the Use and Source of Racial Terminology in Representations of Genetic Research," HUGO Symposium on Genomics and Ethics, Law and Society, Geneva, Switzerland (poster presentation)

Amy Zarzeczny, "Stem Cell Tourism and Doctors' Duties to Minors," 7th Annual Meeting of the International Society for Stem Cell Research, Barcelona, Spain (poster presentation)

National:

Tracey Bailey, "Giving Voice: Mental Health and Advocacy," Into the Light Conference: Transforming Mental Health in Canada, Vancouver, BC

Tracey Bailey, "Consent Barriers to Organ Donation," Donation Symposium, Toronto, ON

Tracey Bailey & Cheryl Mack, "Lost in Translation: Challenges of a Religious, Cultural and Language Mosaic," CHAC Convention, Vancouver, BC

Tania Bubela, "Grand Challenges for Evidence and Health Policy: Metrics and Indicators in Complex Systems," National Health Law Conference, Montreal, QC

Timothy Caulfield, "Stem Cell Research: The

Ethics and Policy Landscape," StemCellTalks Symposium, University of Toronto, Toronto, ON

Timothy Caulfield, "Promises, Promises: Stem Cell Research and Economic Expectations," National Health Law Conference, Montreal, QC

Timothy Caulfield, "The Culture of Concealment," The (Screwy) Role of the Law," Annual Canadian Association for Health Services and Policy Research Conference, Calgary, AB

Timothy Caulfield, "Popular Representations of Obesity and Genetics: Cause for Concern?" 1st National Obesity Summit, Kananaskis, AB

Nola M. Ries, "Legal Issues in the Development of National Cancer Control Standards," Canadian Partnership Against Cancer National Forum on Cancer Control Standards, Toronto, ON

Lorraine Sheremeta, "Privacy Challenges Raised by Nanotechnology," 2010 Privacy Conference, Toronto, ON

Barbara von Tigerstrom, "Food, Chronic Disease and International Law: Barriers and Opportunities," Canadian Council on International Law Annual Conference, Ottawa, ON.

Barbara von Tigerstrom, "Grand Challenges in Chronic Disease Prevention," National Health Law Conference, Montreal, QC

Barbara von Tigerstrom, "Nutrition Disclosure for Restaurant Foods: Legal and Policy Issues," 1st National Obesity Summit, Kananaskis, AB

Amy Zarzeczny, "Regulation of Neuroimaging in Canada and Implications for Non-Traditional Uses," Brain Matters Conference, Halifax, NS

University of Alberta:

Courses taught in the Faculty of Law at the University of Alberta included "Health Law and Policy," "Contemporary Issues in Health Law," "Health Care Ethics and the Law," "Biotechnology and the Law" and "Commercializing Medical Research".

Guest lectures were delivered in the University's faculties of Science, Extension, and Medicine and Dentistry; its Schools of Public Health, and Library and Information Studies; and for the John Dossetor Health Ethics Centre.

For a complete list of all presentations delivered by the HLI in 2009-10, please visit the staff and research fellows profiles portion of our website ("People at the HLI") at www.law.ualberta.ca/centres/hli.

HEALTH LAW INSTITUTE SEMINAR SERIES

**“The Council of Europe’s Convention on Human Rights and Biomedicine:
Why is it of International Interest?”**

Caroline Rodiger, Research Assistant, Health Law Institute

**“Performance-Based Regulation: Enterprise Responsibility for Reducing Death,
Injury and Disease Caused by Consumer Products”**

Stephen Sugarman, Robert J. Traynor Professor of Law, University of California

“Real Impediments to Academic Biomedical Research”

John Walsh, Professor, School of Public Policy, Georgia Institute of Technology

“Reforming U.S. Health Care: Why So Difficult? Why So Nutty?”

Dayna Matthews, Associate Dean, University of Colorado Law School

**“Physicians in Law Suits: How the Bench and Bar View Doctors in Medical
Malpractice Cases”**

John Martland, Q.C., Special Counsel, Health Law Institute

“The Persistence of Race in Biotech Patenting and Drug Development”

Dr. Jonathan Kahn, Professor, Hamline University School of Law

**“Baby Isaiah May: Decision-Making When Parents and Health Care Providers
Disagree About a Child’s Treatment”**

Joan Gilmour, Associate Professor, Osgoode Hall Law School

**“Science Communication at a Crossroads: Promising Directions,
Lingering Distractions”**

Matthew Nisbet, Associate Professor, School of Communication, American University

Each academic year, the HLI invites speakers to present as part of its Seminar Series in Health Law. Our audience is diverse and includes legal and health care academics, practitioners and students, representatives of government and NGOs, representatives of community organizations and members of the general public. We were pleased to present the following seminars in 2009-10.



STUDENTS

In 2009-10, eight University of Alberta Faculty of Law students gained invaluable experience researching a wide variety of health law topics at the HLI. Some of this work resulted in the following publications and presentations:

STUDENT PUBLICATIONS AND PRESENTATIONS

Lindsey Jo Ehrman, “Comparing the Use of Ethnic and Racial Terms in Genetics Research: An Analysis of Academic Journals, Press Releases and News Media,” 5th International Conference on DNA Sampling, Banff, AB (poster presentation)

Lindsey Jo Ehrman, “Fatalism and Genetic Testing: Fact or Fiction?” 5th International Conference on DNA Sampling, Banff, AB (poster presentation)

Laura Geddes, “Going Down the Same Road? Economic Imperatives in Gene Therapy and Stem Cell Research,” 5th International Conference on DNA Sampling, Banff, AB (poster presentation)

Laura Geddes, “Willingness to Pay for Genetic Testing: A Study of Attitudes in a Canadian Population,” 5th International Conference on DNA Sampling, Banff, AB (poster presentation)

Laura Geddes, “Stem Cells and Jurisdiction: Variance in Ethical, Legal and Social Issues,” Stem Cell Network Annual General Meeting, Montreal, QC (poster presentation)

CJ Murdoch, “Personalized by Proxy,” 5th International Conference on DNA Sampling, Banff, AB (poster presentation)

CJ Murdoch, “Fresh Disorder? Social, Legal and Ethical Implications of Disease Concepts,” Palo Alto, CA (poster presentation)

Colin Ouellette, “Comparing the Use of Ethnic and Racial Terms in Genetics Research: An Analysis of Academic Journals, Press Releases and News Media,” 5th International DNA Sampling Conference, Banff, AB (poster presentation)

Caroline Rodiger, “A Legal Framework for Neuroscientific Research? European Law as a Blueprint for a Future International Instrument,” 5th International DNA Sampling Conference, Banff, AB (poster presentation)

Ciara Toole, “Stem Cell Tourism: The Patient’s Online Perspective,” Stem Cell Network Annual General Meeting, Montreal, QC (poster presentation)

Ciara Toole, “A Review of the Comparison Between Genetic and Neuroimaging Research Ethics,” 5th International Conference on DNA Sampling, Banff, AB (poster presentation)

SERVICE

Health Law Institute staff serves on a number of local, national and international committees and working groups with the objective of public service in mind.

STAFF SERVICE COMMITTEES

Tracey M. Bailey

Co-Chair, Organizing Committee, Giving Voice: Advocacy and Mental Health Conference
Alberta Health Services Pandemic Influenza A/ H1N1 Ethics Working Group
Organizing Committee, 2nd National Health Law Conference, Canadian Bar Association
Alberta College of Pharmacists Code of Ethics Review Committee
Glenrose Rehabilitation Hospital Ethics Committee Working Group, Safe Disposal of Methadone/ Opioids
Clinical Ethics Committee, University of Alberta, Stollery Children's Hospital and Mazankowski Heart Institute
Executive, National Health Law Section, Canadian Bar Association
Ethics Advisory Group, Capital Health Pandemic Influenza Planning
Capital Region Health Ethics Coordinating Council Standing Committee re Emergency Preparedness and Business Continuity and Public Health, University of Alberta
Alberta Medical Association RHA-Sponsored EMR Task Force

Arts and Humanities in Medicine Program Advisory Committee
Data Haven Committee for Laboratory Alberta
Provincial Health Ethics Network (PHEN) End of Life Decision-Making Initiative Committee
Health Research Ethics Board—Panel B, University of Alberta, Capital Health Authority and Caritas Health
Capital Care Group Ethics Committee

Tania Bubela

Research Advisory Committee, School of Public Health, University of Alberta
Space Planning Committee for Edmonton Clinic, School of Public Health, University of Alberta
Health Policy and Management Re-Design Committee, School of Public Health, University of Alberta
Umbilical Core Blood and Tissue Collection and Banking Steering Committee
Training and Education Committee, Stem Cell Network
Co-Chair, Canadian Coalition for Global Health Research (CCGHR) Policy Influence Program (PIP)

Timothy Caulfield

Co-Chair, 5th International DNA Sampling Conference: The Age of Personalized Genomics
Chair, "Direct-to-Consumer Genetic Tests: Confronting Issues for Canada," Institute of Genetics and Ethics Office, Canadian Institutes of Health Research and Health Law Institute
Chair, "Lay of the Land: An International Planning Workshop," Stem Cell Network Planning Committee, "Examining Governance for Biobanks"
Expert Panel on Integrated Testing of Pesticide, Council of Canadian Academies
Pediatric Biobanking Advisory Committee, University of Pennsylvania
Planning Committee, "Neuroscience in the Courtroom: What Judges Need to Know," National Judicial Institute
Chair, Policy, Ethics, Law and Society Committee, AllerGen, National Centres for Excellence
Research Advisory Panel, Science Media Centre of Canada
Government Affairs Committee, International Society for Stem Cell Research
Institutional Advisory Board, Institute of Genetics, Canadian Institutes of Health Research

Scientific Advisory Board, Genome-Environment Interactions in Type 1 Diabetes
Interagency Advisory Panel on Research Ethics (PRE), Government of Canada
Scientific Advisory Board, Pathogenomics of Innate Immunity, Genome British Columbia
Social Issues and Policy Advisory Board, Archon X Prize in Genomics Foundation
Research Awards Advisory Committee, University of Alberta
TSEs and Society Committee
Ethics Committee, Canadian Stroke Network
Program Advisory Committee, Alberta Heritage Foundation for Medical Research
Science and Industry Advisory Committee, Genome Canada
Assessments Committee, Canadian Academy of Health Sciences
Forum Recommendations Group, Canadian Council for Donation and Transplantation
Theme Leader, Research Management Committee, Stem Cell Network NCE
European Public Health Ethics Network
National Research Advisory Board, Center for Excellence in Health Marketing/Health Communication, University of Georgia
Advisory Panel for “Governing Genetic Databases,” Oxford Genetics Knowledge Park, Oxford University
Research Management Committee, AllerGen NCE (Allergy, Genetics and Environment)
Co-Chair, Canadian Lifelong Health Initiative Ethical Legal Social Issues (CLHI-ELSI) Advisory Committee, Canadian Institutes of Health Research
Co-Chair, Institute of Genetics, Ethical, Legal and Social Issues Committee (IGELS)

Co-Chair, GELS Priorities and Planning Committee, Genetics Institute, Canadian Institutes of Health Research
Chair, University of Alberta Stem Cell Task Force Stem Cell Advisory Panel, Juvenile Diabetes Research Foundation International
Social Issues Committee, American Society of Human Genetics
Canadian Biotechnology Advisory Committee, Government of Canada
Advisory Board, International Institute for Qualitative Methodology
Advisor, “The DNA Files,” Genome Radio Project, PBS
Edmonton Genetics Group Working Committee, Alberta Cancer Board
Institute Representative, Canadian Bioethics Society
Alternate, Research Ethics Review Committee, College of Physicians and Surgeons of Alberta

Karin L. Kellogg

Organizing Committee, Giving Voice: Advocacy and Mental Health Forum
Specific Decision-Making Focus Group, Office of the Public Guardian, Seniors and Community Supports, Government of Alberta
Capacity Assessment Advisory Group, Office of the Public Guardian, Seniors and Community Supports, Government of Alberta
Alternate, Glenrose Rehabilitation Hospital Ethics Committee
Alternate, Health Research Ethics Board—Panel B, University of Alberta
Alternate, Capital Care Group Ethics Committee

Erin Nelson

Research Ethics Review Committee, College of Physicians and Surgeons of Alberta
Ethics Committee, Society of Obstetricians and Gynecologists of Canada

Nola M. Ries

Joint University of Victoria/Vancouver Island Health Authority Minimal Risk Research Ethics Review Panel
Advisory Board, School of Public Health and Social Policy, University of Victoria
Ethical, Social and Legal Issues Advisory Committee for the Canadian Longitudinal Study on Aging, Canadian Institutes of Health Research

Lori Sheremeta

Scientific Advisory Committee, OneMatch Stem Cell and Marrow Network, Canadian Blood Services
Scientific Advisory Board, Hereditary Breast and Ovarian Cancer Society
Research Ethics Review Committee, College of Physicians and Surgeons of Alberta

Barbara von Tigerstrom

Peer Review Committee, India-Canada Collaborative Teams in Childhood Obesity Research, Canadian Institutes of Health Research
Academic Integrity Committee, School of Public Health, University of Saskatchewan
Governance Committee, School of Public Health, University of Saskatchewan
Biomedical Research Ethics Board (REB 1), University of Saskatchewan

HEALTH LAW INSTITUTE FINANCIAL STATEMENTS

*Health Law Institute
Operating Fund
(Alberta Law Foundation Grant)*

*Financial Statements
For the Year Ended March 31, 2010*





STUART COWEN PROFESSIONAL CORPORATION

Chartered Accountants • Management Consultants • Business Advisors

AUDITOR'S REPORT

To the Directors of Health Law Institute

I have audited the balance sheet of **Health Law Institute Operating Fund** (the Institute) as at March 31, 2010 and the statements of revenue and expenses, and changes in fund balances for the year then ended. These financial statements are the responsibility of management. My responsibility is to express an opinion on these financial statements based on my audit.

I conducted my audit in accordance with Canadian generally accepted auditing standards. Those standards require that I plan and perform an audit to obtain reasonable assurance whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation.

As outlined in Note 4 to the financial statements, the Institute has elected to charge capital assets to expenses and not record depreciation. In this respect, the financial statements are not in accordance with Canadian generally accepted accounting principles. If Canadian generally accepted accounting principles had been followed the excess of revenues over expenses would be decreased by \$14,864 in the current year and increased by \$3,170 in the prior year.

In my opinion, except for the effects of the policy to not record capital assets and depreciation as described in the preceding paragraph, these financial statements present fairly, in all material respects, the financial position of the Institute as at March 31, 2010 and the results of its operations for the year then ended in accordance with Canadian generally accepted accounting principles for not-for-profit entities.

Phone (780) 431-0151
Fax (780) 431-0165

11148 - 81 Avenue
Edmonton, Alberta
Canada
T6G 0S5



Stuart Cowen

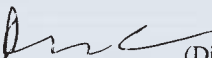
CHARTERED ACCOUNTANT


Edmonton, Alberta
June 08, 2010

**HEALTH LAW INSTITUTE
OPERATING FUND
BALANCE SHEET
March 31, 2010**

	<u>2010</u>	<u>2009</u>
ASSETS		
Current		
Cash	\$ 86,647	\$ 109,934
Receivables	--	2,697
Prepaid expenses	--	<u>1,363</u>
	<u>\$ 86,647</u>	<u>\$ 113,994</u>
LIABILITIES		
Current		
Payables and accruals	\$ 80,447	\$ 81,794
NET ASSETS		
Fund balances		
Externally restricted fund (Note 5)	<u>6,200</u>	<u>32,200</u>
	<u>\$ 86,647</u>	<u>\$ 113,994</u>

Approved by the Board

 (Director)

 (Director)

See notes to financial statements





**HEALTH LAW INSTITUTE
OPERATING FUND
STATEMENT OF REVENUES AND EXPENSES
Year Ended March 31, 2010**

	<u>2010</u>	<u>2009</u>
REVENUES		
Operating grant	\$ 583,500	\$ 569,276
Website grant	<u>12,075</u>	<u>--</u>
	<u>\$ 595,575</u>	<u>\$ 569,276</u>
EXPENSES		
Salaries	388,471	369,004
Benefits	81,135	74,583
Contracts	20,477	7,671
Data entry/student assistance	17,144	16,393
Equipment/furniture	533	8,705
Supplies/services	12,484	10,101
Print/copy	1,730	14,344
Phone/fax	3,552	3,777
Post/courier	3,414	3,747
Advertising	692	787
Travel/accommodation	9,323	7,782
Board expenses	1,368	690
Staff development	763	505
Professional fees	2,955	1,070
Books/subscriptions	5,100	5,053
Renovations	<u>20,034</u>	<u>--</u>
	<u>569,175</u>	<u>524,212</u>
EXCESS OF REVENUES OVER EXPENSES	\$ <u>26,400</u>	\$ <u>45,064</u>

See notes to financial statements

**HEALTH LAW INSTITUTE
OPERATING FUND
STATEMENT OF CHANGES IN FUND BALANCES
Year Ended March 31, 2010**

	<u>2010</u>	<u>2009</u>
	<u>Fund Total</u>	<u>Fund Total</u>
Balance, beginning of year	\$ 32,200	\$ 34,200
Excess of revenues over expenses	26,400	45,064
Transfer to Funder	(52,400)	(47,064)
	<u>\$ 6,200</u>	<u>\$ 32,200</u>

See notes to financial statements





**HEALTH LAW INSTITUTE
OPERATING FUND
NOTES TO FINANCIAL STATEMENTS
Year Ended March 31, 2010**

1. NATURE OF OPERATIONS

The Health Law Institute was founded in 1977. The Health Law Institute Operating Fund's primary objectives are to initiate and promote interdisciplinary activities to raise awareness, enhance knowledge and understanding and promote positive reform of Alberta, Canada and international health law and associated health policy. As an initiative of the University of Alberta, the Institute is not subject to tax.

2. SIGNIFICANT ACCOUNTING POLICIES

These financial statements have been prepared in accordance with Canadian generally accepted accounting principles, are expressed in Canadian dollars, using the restricted fund method of accounting and include the following significant policies:

Cash

Cash consists of cash on deposit and cash on disbursements from the Operating Fund.

Revenue recognition

All restricted and unrestricted contributions are recognized as revenue of the Operating Fund when received or receivable.

Use of estimates

The preparation of financial statements, in conformity with Canadian generally accepted accounting principles, requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosures of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from these estimates.

Capital Assets

The Health Law Institute's policy is to expense Capital assets when purchased.

Contributed Services

The University of Alberta provides office space and administrative support at no cost to the Health Law Institute. Contributed services are not recognized in the financial statements.

**HEALTH LAW INSTITUTE
OPERATING FUND
NOTES TO FINANCIAL STATEMENTS
Year Ended March 31, 2010**

2. SIGNIFICANT ACCOUNTING POLICIES (continued)

Statement of Cash Flows

A statement of cash flows has not been presented as the required cash flow information is readily apparent from these financial statements.

Capital Disclosures

The Health Law Institute's objective in managing capital is to allocate funds in the operating budget as approved by the Board of Directors and the Alberta Law Foundation. As well, the management of capital is critical to safeguarding the sustainability of gathering grant funding in health law research activities.

3. FINANCIAL INSTRUMENTS

The Institute's financial instruments consist of Receivables which will result in future cash receipts, as well as Payables and accruals that will result in future cash outlays.

Loans and receivables

This category consists of receivables. They are initially recognized at fair value and are subsequently carried at amortized cost, using the effective interest rate method, less any provision for impairment. Transaction costs related to loans and receivables are included in the amount initially recognized.

Other financial liabilities

Other financial liabilities include accounts payable and accrued liabilities. The fair value is considered the same as the carrying value due to the short-term nature of the liability.





**HEALTH LAW INSTITUTE
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NOTES TO FINANCIAL STATEMENTS
Year Ended March 31, 2010**

4. CAPITAL ASSETS

Capital assets are charged to expenses on purchase. The revenue threshold that allows exemption from generally accepted accounting principles, CICA 4430, which requires not-for-profit organizations to capitalize and depreciate capital assets was exceeded. The Institute is not in compliance with this accounting principle.

Estimated net realizable value of capital assets is as follows:

	<u>2010</u>	<u>2009</u>
	<u>Net</u>	<u>Net</u>
Furniture	\$ 5,758	\$ 7,522
Computer equipment	6,412	8,816
Renovations	<u>19,032</u>	<u>--</u>
	<u>\$ 31,202</u>	<u>\$ 16,338</u>

Current year expenditures totalled \$20,034 (2009 - \$7,339)

5. EXTERNALLY RESTRICTED NET ASSETS

Externally restricted funds consists of \$6,200 of the Picard Lecture carry forward for the Health Law Moot.

6. RELATED PARTIES

Health Law Institute

The Health Law Institute Operating Fund is part of the Health Law Institute. All expenses and revenues are associated with the Institute.

Alberta Law Foundation

The Institute has a beneficial relationship with the Alberta Law Foundation, which provides grant funding for research and education. For the grant year April 2009 to March 2010, the Alberta Law Foundation contributed \$583,500.

University of Alberta

The University of Alberta provides office space and administrative support to the Health Law Institute at no cost. The value of these contributed services are not recognized by the Health Law Institute Operating Fund.