



ONE ORIGIN ONE RACE ONE EARTH

TABLE OF CONTENTS

Welcome Letters.....	3 - 5
Conference at a Glance.....	6
Agenda - Thursday, November 15th.....	7
Agenda - Friday, November 16th.....	8 - 11
Agenda - Saturday, November 17th.....	12 - 14
Biographies - Keynotes.....	15 - 16
Biographies - Presenters.....	17 - 20
Abstracts.....	21 - 59
Index.....	60 - 61

CONFERENCE COMMITTEE

Deanna Cameron Dubuque
Rose Geransar, B.Sc.
Greg Hagen, LL.B., LL.M., Ph.D.
Linda McKay-Panos, B.Ed., LL.B., LL.M.
Rhonda McNeil
Brian Seaman, LL.B.
Oksana Suchowersky, M.D., F.R.C.P.C.
Stephanie Williscroft, B.A.



THANK YOU TO THE FOLLOWING FOR THEIR SUPPORT:

Volunteers

Abeer Anwar Al-Saegh
Niklas Bobrovritz
Deanna Cerny
Helene Childs
Kerry Cundal, Exhibit Coordinator
Cassandra Fera
Julia Gaunce
Jordan Hannah

Mary Hemmings
Gina Loitz
Tehmeena Malik
Brie McKenzie
Scott McLeod
Ndidi Metuh
Farah Mohamed
Carolina Niewola-Staszkowski

Noelle Orton
Melissa Pownall
Julie Quinn
Brandon Reid
Allison Russell
Aarti Shankar
Natalie Simpson, Volunteer Coordinator
Kenny Thompson

Concurrent Session Chairs

Gwen Blue
Stan Godlovitch
Mary Hemmings
Jennifer Koshan
Chris Levy
Noelle Orton
Linda McKay-Panos
Oksana Suchowersky
Michael Wylie

The Rosalind Franklin Exhibition

Linda Carreiro (Faculty of Fine Arts, University of Calgary)
Mireille Perron (Fine Arts, Alberta College of Art and Design)
Stephanie Willisicroft

And Special Thanks To

Margo Clendening (Faculty of Fine Arts, University of Calgary)
Arthur Nishimura (Faculty of Fine Arts, University of Calgary)
Richard Smolinski
Michelle Wong (Director, NUTV)

Conference Bursary Recipients

Ayesha Ahmad
Yvonne Bombard
Matthew Herder
Leia Minaker

Kenna Miskelly
Rhiannon Noble
Adit Pujari
Janna Rosales

Veronica Pinero
Victoria Seavilleklein
Jacob Shelley
Vasudha Singh

Heather Walmsley
Wei Wang
Brandace Windquist

Recipients of the Brian Seaman Bursary

Gina Freeman
Amina Osuoha
Dave Pelton
Chris Powell
Thushaanthini Thavaratnam



Welcome from the Conference Co-Chairs
Rose Geransar, B.Sc. and Brian Seaman, LL.B.



“Let’s have coffee.” When unlikely colleagues meet over a cup of joe and a dose of imagination, there’s always good conversation and sometimes the birth of a new idea. That’s how the *One Origin, One Race, One Earth* conference originated over two years ago.

The two of us had been having regular conversations about genetics, evolution, the origin of life, empiricism and its woes, the philosophy of science and its intellectual wars, ethics in the lab, the dissemination of knowledge and a host of other topics. We often found common ground but we sometimes disagreed – passionately. One matter on which we found both common ground and passion was our desire to assemble some of the best and the brightest to a weekend in Calgary to address current ethical, legal and social issues arising in the context of human genetic research.

Scientists agree on the common origin of all life on earth. The Alberta Civil Liberties Research Centre upholds the value that academics have the responsibility to pursue knowledge in such a way that the resulting benefits are made available to all members of the human family, and that these benefits must be available without wrongful distinctions based on ethnicity, gender, economic class, or such other distinctions. Human rights law and the ethical guidelines of our research ethics boards, hospitals, and universities should ensure that the greatest good flows from the work of laboratory scientists. Thus was born the title of the conference, to evoke the scientific notion of the common origin of life on earth and relate that back to equity in terms of how scientific knowledge is disseminated.

One of our areas of enquiry is to explore the role of art as a way to engage people in questions about science policy. Our delegates are encouraged to visit *The Rosalind Franklin Exhibition*, a display of original artwork by students from the University of Calgary, University of Alberta, and the Alberta College of Art and Design. Without a doubt, the imaginations of artists and writers have always inspired the public fascination with science, through images and stories that reflect the hopes and fears of their time. However, there are also timeless classics such as *Frankenstein* or *Brave New World* that not only question what it means to be human but also suggest the ethical metes and bounds beyond which an ethical science ought not to venture. The removal of these metes and bounds in a mid-21st century world where genetic science has gone awry was addressed by Margaret Atwood in her 2003 novel, *Oryx and Crake*. We are delighted that she will share her thoughts on science and ethics with us at our closing banquet, and that she will be available to engage in dialogue with us.

The proceedings of *One Origin* will address ethical and legal issues in biobanking, ethical issues in genetic research in developing nations, and issues of control and access to genetic information. India and other countries with large Indigenous populations and traditional knowledge about the therapeutic value of plants, continue to face challenges in ensuring that such knowledge is not misappropriated without ensuring adequate compensation for the Indigenous group at issue. Large, population-based genetic research projects have great potential as sources of information about the gene-environment relationship behind most, if not all, of the debilitating diseases and conditions that adversely affect the quality of life. Finally, to proceed with ethnic-based pharmacological research for common conditions such as heart disease, or to research less common genetic conditions that are unique to small sub-populations is not only a question of fairness to the groups at issue but also a contribution to our wider understanding of the genetic and environmental factors behind disease.



Message of Welcome

Oksana Suchowersky, M.D., FRCP
Head, Dept. of Medical Genetics, University of Calgary

When Brian Seaman first approached me over one year ago to participate on a public panel discussion at the One Origin conference, I was intrigued by the prospect of contributing to a multi-disciplinary conference about the ethical, legal and policy issues surrounding medical genetic science. As I learned more about the scope and mandate of this conference, I saw an opportunity to become involved in an event that is part of a wider dialogue that will contribute to the public understanding of relevant issues in the interplay of health science and policy. The issues that the One Origin conference will address – equality of access to health care among them– are issues that are fundamental to the human condition generally, and to the allocation of health care resources in particular. I can remember at a very young age being fascinated with the how and why of life at its most basic level, and it doesn't get any more basic than the life of a cell. Science has been my life and calling for over three decades. Through conversations and email correspondence with Brian and other members of the organizing committee over these past several months, I have come to more fully appreciate the sense of wonder with which many lay people regard a science that has been my life's work. I am grateful for the generous support of our sponsors and I look forward to exchanging ideas and meeting new people over the course of the next two days.



Message of Welcome

Ed Webking, M.A., Ph.D.

Chair, Board of Directors, *Alberta Civil Liberties Research Centre*

Ask most Canadians what comes to mind when you say the word Alberta, and they'll say cowboys, The Calgary Stampede, and oil. You can't spend any time in Alberta without seeing evidence of these, true enough, but Alberta is so much more diverse than that. Currently in the midst of a period of unprecedented growth, as tens of thousands of Canadians migrate to Alberta each year thus joining the thousands of immigrants from around the world who continue to enrich our social and cultural landscape, the face of Alberta is changing, and for the better. As one of the agents of change, The *Alberta Civil Liberties Research Centre* has established itself as a research and educational centre that has made a significant and lasting contribution to an awareness of the importance of civil liberties and human rights for human freedom and social order – two values that many people around the world have come to see as two of the defining characteristics of Canadian society. It seems fitting that our research centre has taken the initiative to assemble such an impressive group of scholars and health care professionals in this 25th anniversary year of *The Alberta Civil Liberties Research Centre*. It also seems fitting that an organization devoted to equality and human rights should be working with the university's Department of Medical Genetics to address issues of profound importance to human health and well-being. I earnestly hope that participants will take the opportunity to expand their knowledge and meet people from different academic backgrounds. I also sincerely hope that you all enjoy your stay in Calgary. Finally, on behalf of our research centre board of directors and staff, I want to say a hearty thank you to our funders who made this event possible.

Conference at a Glance

	Thursday November 15, 2007	Friday November 16, 2007	Saturday November 17, 2007
7:00am		Breakfast	
8:00am		MacEwan Ballroom (3rd Floor)	Breakfast
9:00am		Plenary Panel I <i>Biobanking, Population Genetic Research and Informed Consent</i>	MacEwan Ballroom (3rd Floor)
10:00am		MacEwan Hall A/B (Lower Level)	Concurrent Sessions
11:00am		Refreshment Break MacEwan Hall Foyer	Refreshment Break Bianca, Cassio, Escalus (2nd Floor)
12:00pm		Concurrent Sessions Bianca, Cassio, Escalus (2nd Floor)	Concurrent Sessions Bianca, Cassio, Escalus (2nd Floor)
12:00pm	Conference Registration (12:00pm - 5:00pm) MacEwan Hall Foyer (Lower Level)	Lunch Lunch Speaker: Tom Keenan <i>Bio-Information on the Internet</i>	Lunch Lunch Speaker: Christian Bok <i>The Xenotext Experiment</i>
1:00pm		MacEwan Ballroom (3rd Floor)	MacEwan Ballroom (3rd Floor)
2:00pm		Plenary Panel II <i>Genetic Research, Indigenous Peoples and the Developing World</i>	Plenary Panel III <i>Genetic Research and Issues of Ownership and Control</i>
3:00pm		MacEwan Hall A/B (Lower Level)	MacEwan Hall A/B
4:00pm	Gallery Opening Rosalind Franklin Art Exhibition The Space, CHD 100		
5:00pm		Poster Session & Reception MacEwan Ballroom (3rd Floor)	
6:00pm	Opening Reception Keynote Discussion: Gregory Stock Grant Gillett		
7:00pm	MacEwan Hall A/B (Lower Level)	Public Sessions	Closing Banquet Keynote Speaker: Margaret Atwood
8:00pm		Rozsa Centre Eckhardt Grammate	MacEwan Hall A/B
9:00pm		Panel Discussion <i>Bloodlines: The DNA Dilemma</i>	
		Panel Discussion <i>Prenatal Genetic Screening, Women's Voices and Women's Choices</i>	

Thursday, November 15, 2007

12:00 pm – 5:00 pm

Registration

Location: MacEwan Hall Main Lobby

4:00 pm – 5:30 pm

Opening, Rosalind Franklin Exhibition

In Memory of Rosalind Elsie Franklin (1920-1958)

Location: The Space, Room 100, Craigie Hall D

The Artists:

Lisa Borin
Adina Edwards
Eveline Kolijn and Christian Bok
Sarah Kundelius
Isabel Landry
Jamie McDonald Gray
Amie Rangel
Margo Van Lindenberg

The Rosalind Franklin Exhibition Committee would like to thank the following for their support:

Faculty of Fine Arts and Department of Art, University of Calgary
Alberta College of Art and Design
The Nickel Art Gallery, University of Calgary

6:00 pm - 9:00pm

Opening Plenary and Reception

Location: MacEwan Hall A & B

Chair's Welcome

Rose Geransar, B.Sc., PhD Student

(University of Calgary)

and

Brian Seaman, LL.B.

(Alberta Civil Liberties Research Centre)

Keynote Discussion

Human Evolution and the Changing Boundaries of Death

Gregory Stock, M.B.A., PhD.

Director of the Program on Medicine, Technology and Society, UCLA, and CEO of *Signum Biosciences*

The Evolutionary Foothills of the Mind

Grant Gillett, MBChB, PhD.

Professor of Medical Ethics and Professor of Neurosurgery at the Dunedin School of Medicine, University of Otago

Friday, November 16, 2007

7:30 am – 8:30 am

Hot Breakfast

Location: Conference Centre Ballroom

8:30 am – 10:30 am

Plenary Panel I

Biobanking, Populational Genetic Research and Informed Consent

Location: MacEwan Hall

Chair:

Glenys Godlovitch, LL.B., PhD.

(Chair, Conjoint Research Ethics Board for the Calgary Health Region and University of Calgary)

Panelists:

Bartha Knoppers, LL.B., PhD.

(CartaGene Project)

Kristian Hveem, MD, PhD.

(C.E.O. HUNT Biobank, Norway)

Hilary Rose, B.A., PhD.

(University of Bradford, U.K.)

Cathy Anne Pachnowski, LL.B., LL.M.

(Alberta Cancer Board)

10:30 am – 11:00 am

Refreshment Break

Location: MacEwan Hall Foyer

11:00 am – 12:30 pm

Concurrent Sessions

Location: Break-out Rooms, MacEwan Conference & Event Centre 2nd Floor

I **Discrimination, Law and Human Rights**

Location: Cassio Room

One Origin, One Race but is there Equal Treatment? Experiences of Genetic Discrimination Among Individuals at Risk for Huntington Disease

Yvonne Bombard, B.Sc., PhD. candidate

(University of British Columbia, Dept. of Medical Genetics)

The Rise of the Genetic Family and the Implications for Generation Reprotect

Cindy Baldassi, LL.M., PhD. candidate

(University of British Columbia, Faculty of Law)

Genetic Determinism and Discrimination: A Call to Re-Orient Prevailing Human Rights Discourse to Better Comport with the Public Implications of Individual Genetic Testing

Karen Eltis, LL.B./B.C.L., LL.M.

(University of Ottawa Faculty of Law)

II Consent Issues

Location: Bianca Room

Can Children Consent to Medical Treatment? An International Legal Exploration from a Children's Rights Perspective

Veronica Pinero, LL.M., LL.D. candidate

(University of Ottawa Faculty of Law)

Challenging the Corollaries of Commercialization: No Direct Financial Returns for Publics, Providers & Participants in Biomedical Research

Matthew Herder, LL.M., J.S.M.

Informed Consent in Biobanking Research: Fresh Evidence for the Debate

David Secko, M.J., PhD.

(Concordia University Dept. of Journalism)

III Issues in Patent Law

Location: Escalus Room

Biotechnology Patents and the New Zealand Health and Research Sectors

Aphra Green, LL.B.

(University of Otago Faculty of Law)

Exploitation of Human Genetic Material: Towards Human Rights-Proof Patent Laws

Jerzy Koopman, LL.M., PhD.

(Utrecht University - Centre for Intellectual Property Law)

Potency, Preformation and Patenting

Greg Hagen, LL.M., PhD.

(University of Calgary Faculty of Law)

12:30 pm – 2:00 pm

Buffet Lunch

Location: MacEwan Ballroom (3rd Floor)

Lunch Speaker

On the Internet, Things Never Really Go Away: The Looming Challenge of Data Persistence of Bio-Information

Tom Keenan, Ed.D., FCIPS, I.S.P.

(University of Calgary, Faculty of Environmental Design)

2:00 pm – 4:00 pm

Plenary Panel II

Genetic Research, Indigenous Peoples and the Developing World

Location: MacEwan Hall

Chair:

Edna Einsiedel, PhD.

(University of Calgary)

Panelists:

Laura Arbour, M.Sc., MD

(Geneticist, University of British Columbia)

Doris Cook

(Aboriginal Health Researcher, Canadian Institute of Health Research)

Ikechi Mgbеoji, LL.M., J.S.D.

(author, *Biopiracy: Patents, Plants, and Indigenous Peoples' Knowledge Patents*, Osgoode Hall Law School)

4:30 pm – 6:00 pm

Poster Session and Reception

Location: MacEwan Ballroom (3rd Floor)

Ambiguity in the Name of the Embryo

Ayesha Ahmad, PhD. Candidate

(Peninsula Medical School, University of Exeter)

Nutrigenomics and Behavioral Change: A Public Health Perspective

Victor Alfonso, B.A.; Tim Caulfield, LL.M.; and Jacob Shelley, LL.M. candidate

(Health Law Institute, University of Alberta)

Human Genomic Variation Best Practices in Mapping Differential Disease Susceptibility in Sub-Population Groups: an African-American MS Study

Sarah Ali-Khan, PhD.

(McLaughlin-Rotman Centre for Global Health, University of Toronto)

Title Not Provided at Time of Printing

Julie Lauzon, M.D., FRCPC

(Department of Medical Genetics, University of Calgary)

Human Gene Patent in India: Possibility and Consequences

Vasudha Singh, B.A./B.L. (h) candidate

(National Academy of Legal Studies and Research (NALSAR), University of Law, Hyderabad)

Public Perceptions on Stem Cell Sources and Policies: A Comparison Between the Viewpoints of Young Adults and Seniors

Thushi Thavaratnam, B.Sc. (h) candidate

(University of Toronto)

Recasting an Understanding of Personhood: A Cross-Cultural Perspective on the Moral Status of the Human Embryo

Wei Wang, LL.B., M.A.

(Department of Philosophy, University of Alberta)

7:00pm – 9:00 pm

Evening Event #1

Location: The Eckhardt Gramatté Concert Hall, Rozsa Centre

Bloodlines: The DNA Dilemma

Screening of a 2003 Canadian National Film Board documentary called [Bloodlines: The DNA Dilemma](#), which examines populational genetic studies in Newfoundland and Iceland and the implications for human health. This critically acclaimed film implicitly raises the question: is there ever a time where ethics and human rights need to take a back seat to science?

A panel discussion and Q & A session will follow. Admission is free.

Chair:

Oksana Suchowersky, MD, FRCPC

(Head, Dept. of Medical Genetics, University of Calgary)

Panelists:

Karen Eltis, LL.B./B.C.L., LL.M.

(University of Ottawa Faculty of Law)

Tim Caulfield, LL.M.

(Research Director, Health Law Institute, University of Alberta)

Francois Bernier, MD, FRCPC

(Geneticist, Dept. of Medical Genetics, University of Calgary)

7:00pm – 9:00 pm

Evening Event #2

Location: Husky Oil Great Hall, Rozsa Centre

Who Decides, Anyway?: Prenatal Genetic Screening, Women's Voices and Women's Choices

Chair:

Linda McKay-Panos, LL.B., LL.M.

(Executive Director, Alberta Civil Liberties
Research Centre)

Panelists:

Ruth Kohut, M.Sc.

(Operation Manager, Department of Medical Genetics, Calgary Health Region)

Barbara Farlow, B.Eng., M.B.A.

(*Annie's Story*)

Krista Flint, B.A.

(Executive Director, Canadian Down Syndrome Society)

Julie Lauzon, MD, FRCPC

(Dept. of Medical Genetics, University of Calgary)

Saturday, November 17, 2007

8:00 am – 9:00 am

Hot Breakfast

Location: MacEwan Ballroom

9:00 am – 10:30 am

Concurrent Sessions

Location: Break-out Rooms, MacEwan Conference & Event Centre (2nd Floor)

I Clinical Challenges

Location: Cassio Room

Prenatal Screening in Saskatchewan: Input, Uptake, and Ethics

Brandace Winquist, M.Sc., PhD. candidate

(University of Saskatchewan College of Medicine)

Challenges to Clinical Medicine in the New Era of Genetics: The Elephant in the Living Room

Aneal Khan, M.D., F.R.C.P.C.

(Dept. of Medical Genetics, University of Calgary)

Nutrigenomics from a Population Health Perspective

Jacob Shelley, LL.B., LL.M. candidate

(Health Law Institute, University of Alberta)

and **Leia Minaker, M.Sc., PhD. candidate**

(School of Public Health, University of Alberta)

II Issues in the Developing World

Location: Bianca Room

Sustainable Development and Genetic Research - Reconciling the Interests of Developed and Developing Countries

Catherine Rhodes, PhD.

(University of Bradford, Dept. of Peace Studies)

Applying a Corporate Governance Framework to Promote the Bioethics of Genetics Company Activities in Developing Countries

Anita Huntley, LL.B., LL.M. candidate

(Patent Lawyer, Fasken, Martineau, DuMoulin, LLP)

Protecting Traditional Knowledge in India: Creating a Future Based on Past Projections

Adit Pujari, B.A., B.Sc.

(National University of Juridical Sciences, Kolkata, India)

III Pushing the Boundaries

Location: Escalus Room

Transhumanism, Eugenics, and the Principle of Procreative Beneficence

Janna Rosales, M.A., PhD. candidate

(University of Toronto, Centre for the Study of Religion)

New and Emerging Sciences and Technologies and the Social Construction of Boundaries

Gregor Wolbring, PhD.

(University of Calgary, Dept. of Molecular Biology)

Dealing with the Reality of Race and Ethnicity: A Bioethics-Centered Argument in Favour of Race-Based Genetics Research

Michael Malinowski, B.A., J.D.

(Louisiana State University, Paul M. Hebert Law Centre)

10:30 am – 11:00 am

Refreshment Break

Location: Break-out Rooms, MacEwan Conference & Event Centre (2nd Floor)

11:00 am – 12:30 pm

Concurrent Sessions

Location: Break-out Rooms, MacEwan Conference & Event Centre (2nd Floor)

I Issues in Biobanking

Location: Cassio Room

Biobanking: Preserving Patient Privacy and Autonomy

Marsha Hanen, M.A., PhD.

(University of Victoria, Dept. of Philosophy)

and

Kenna Miskelly, B.Sc., M.A.

(University of Victoria)

From Infertile Super-Humans to a United Nations for Biobanks: Public Hopes, Fears and Innovative Design Solutions for Biobank Governance in BC

Heather Walmsley, M.A., PhD.

(University of British Columbia)

Protecting Both Patient Privacy and Scientific Integrity: A Technical Perspective

Aaron Sheldon, B.Sc.

(Platform Architect, University of Calgary Faculty of Medicine)

II Prenatal Testing

Location: Bianca Room

Ethical Implications in Genetic Testing: Promise and Peril

Kerry Bowman, PhD.

(Bioethicist, Mount Sinai Hospital)

The Public Health Value of Prenatal Genetic Screening

Victoria Seavilleklein, M.A., PhD. candidate

(Dalhousie University)

Informed vs. Implied Consent: In Search of an Ethical-Legal Screening Threshold for Clinicians

Anna Zadunayski, B.Sc., M.Sc. candidate

(University of Calgary)

III Access to Knowledge and Regulatory Issues

Location: Escalus Room

Access to Data and Materials in Life Sciences: The C. Elegans Knock-out Project as a Case Study

Noelle Orton, M.Sc.

(University of Calgary, Faculty of Communication and Culture)

Values in Genomic Research Governance in the International Context

Shawn Harmon, LL.B., LL.M.

(Innogen Centre, University of Edinburgh)

Examining Patents of Basic Research Tools and their Downstream Effects

Rhiannon Noble, PhD. candidate

(University of Alberta)

12:30 pm – 2:00 pm

Buffet Lunch

Location: MacEwan Ballroom (3rd Floor)

Lunch Speaker

The Xenotext Experiment

Christian Bok, M.A., PhD.

(University of Calgary, Dept. of English)

2:00 pm – 4:00 pm

Plenary Panel III

Genetic Research and Issues of Ownership and Control

Location: MacEwan Hall

Chair:

The Honourable Justice Marshall Rothstein,

B.Com., LL.B.,

(Supreme Court of Canada)

Panelists:

Cynthia Ho, B.A., J.D.

(Loyola University School of Law)

Bitá Amani, LL.B., S.J.D.

(Queen's University Faculty of Law)

Michael Malinowski, B.A., J.D.

(Louisiana State University, Paul M. Hebert Law Center)

7:00 pm

Closing Banquet

Location: MacEwan Hall

Banquet Speaker: Margaret Atwood

Join internationally-acclaimed Canadian author Margaret Atwood as she dares us to look inside of “Pandora’s Box” with her. Drawing on her best-selling 2003 novel *Oryx and Crake* for inspiration, Margaret asks where science could take us if we leave compassion, humility and ethics behind.

Following the keynote address and Q&A session, Ms. Atwood will have limited time available to sign books. If you have a specific message that you wish to have inscribed in the book, please write out the brief message prior to the signing and present it to Ms. Atwood when you reach the front of the line. Notepaper will be made available, should you need it. Anyone requesting three or more books to be signed will wait at the end of the queue, per the author’s request.

KEYNOTE SPEAKERS



Margaret Atwood

Margaret Atwood has been a dominant presence in the Canadian and international literary world for almost 40 years. Her prolific writing has been translated into over 20 languages. She has won many national and international writing awards, including the Governor-General's Award and the Booker Prize. Witty, urbane and provocative, join Margaret as she dares us to look inside of "Pandora's Box" with her. Drawing on her best-selling 2003 novel *Oryx and Crake* for inspiration, Margaret asks where genetic research could take us if we leave our compassion and ethics behind. After her speech, Margaret will be taking questions from our delegates.

This is the way the world ends
This is the way the world ends
This is the way the world ends
Not with a bang but a whimper.
(From *The Hollow Men* (1925), by T.S. Eliot)



Grant Gillett

Grant Gillett, MBChB, PhD, is Professor of Medical Ethics at the Bioethics Centre and Professor of Neurosurgery at the Dunedin School of Medicine, University of Otago. He also teaches philosophy – a discipline that he sees as one that helps answer the fundamental questions of mind and body that confronted him throughout his practice as a neurosurgeon. Grant obtained his doctorate in Philosophy at Oxford University and has authored *The Mind and its Discontents* (1999), and *Bioethics in the clinic: Hippocratic reflections* (2004) as well as over 200 articles in general philosophy, philosophy of mind, medical ethics, philosophy of psychiatry, and philosophical theology. He is a member of the New Zealand Medical Association Ethics Committee and of the Royal Australasian College of Surgeons Ethics committee. His views are often sought by media on issues such as stem cell research and the "right to die" debate (most recently during the Terry Schiavo case in the United States). His current research interest lies in topics to do with genetics and cultural reality, subjectivity in medicine, and moral issues surrounding human identity and action.



Dr. Gregory Stock

Dr. Gregory Stock has a Doctorate in Biophysics from Johns Hopkins University, and an MBA from Harvard University. He is a passionate advocate for a broad public debate on new bio-medical technologies and their implications, leading to wise public policies surrounding their realization. Of particular interest to him are the implications for society, medicine, and business of the human genome project and associated developments emerging from today's revolution in molecular genetics and bioinformatics. A prolific author and recognized authority on the impact of new technologies on human society, Gregory has edited *Engineering The Human Germline: An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children*. His best-known work is *Redesigning Humans: Our Inevitable Genetic Future*, which won the Kistler Book Award for Best Science Book for 2002.

BIOGRAPHIES



Bitu Amani, LL.B., S.J.D.

Intellectual Property Professor, Faculty of Law, *Queen's University*

Bitu Amani, LL.B., S.J.D., teaches intellectual property law at Queen's University in Kingston, Ontario. She has recently completed her S.J.D. from the University of Toronto; her doctoral thesis (with funding from the CILP and SSHRC of Canada) examines the nexus of international trade regulations and human rights issues within the biopatenting context. Prof. Amani has acted as a consultant on genetic patenting for the Ontario Advisory Committee on Predictive Genetic Technologies. Her main research interest lies in the area of regulating genetic research as it pertains to donor privacy, property rights, and risk assessment of genetically modified foods. An article she co-authored with Rosemary Coombe analyzing the politics of genetic patenting appears in William Gallagher, ed., *Intellectual Property* (part of the International Library of Essays in Law and Society series; Aldershot: Ashgate Publishing Company, 2006). She has been a guest commentator on biopatenting issues for CBC Radio's "Ideas" series. Called to the Ontario Bar in 2000, Prof. Amani currently sits on the executive of the Iranian-Canadian Lawyers Association.



Dr. Laura Arbour, M.Sc., MD

Clinical Geneticist & Assistant Professor, *Department of Medical Genetics, University of British Columbia*

Dr. Laura Arbour, M.Sc., MD, is a clinical geneticist in the Department of Medical Genetics at the University of British Columbia. She obtained her M.Sc. (with a concentration in genetic counseling) and another M.Sc. (genetics and biology) at McGill University in 1988. She received her medical degree at McMaster University in 1991, and then did postdoctoral fellowship training in pediatrics and genetics at McGill University. Dr. Arbour's broad interests lie in clinical medicine, genetics and ethics, with a particular focus on northern and Aboriginal health issues as they pertain to genetics and child health. Her current research includes the study of the nutrient and genetic basis of congenital heart defects in the Inuit of Nunavut and the genetics of Primary Biliary Cirrhosis in Pacific Northwest Native Peoples. Dr. Arbour has participated in several Canadian workshops which have explored participatory methods of conducting biomedical research in Aboriginal populations. She is a member of the Canadian Institutes of Health Research (CIHR) Aboriginal Ethics Working Group; serves on the CIHR Science Advisory Council for Rural and Northern Health Research, and is on the executive councils of the Canadian Society of Circumpolar Health and the International Union of Circumpolar Health.

BIOGRAPHIES

Picture Not Available

Doris Cook

Aboriginal Health Researcher, *Canadian Institutes of Health Research*

Doris Cook has done extensive work in developing research ethics protocols for health research projects involving Canada's First Nations peoples. Between 2003 and 2007, she was the Manager, Aboriginal Ethics Policy Development in the Ethics Office, CIHR where she coordinated the development of the new Aboriginal research guidelines. Prior to the assignment with the CIHR, she spent 10 years in the Policy Division at Health Canada where she was the lead analyst on files such as ethics, genetics and assisted human reproduction. She was part of the Canadian delegation that negotiated UNESCO's Declaration on the Human Genome and Human Rights and represented Canada at the Council of Europe's Standing Committee on Ethics. She is also involved in ethics review at the community level in her First Nation community. Doris is an Elder in the Akwesasne Mohawk Nation, a territory that comprises parts of the state of New York and the two Canadian provinces of Ontario and Quebec.



Cynthia Ho, B.A., J.D.

Director, Intellectual Property and Technology Program, *Loyola University School of Law, Chicago*

Cynthia Ho, B.A., J.D., is Director of the Intellectual Property Program, at the Loyola University School of Law in Chicago. She teaches courses in Intellectual Property, Patent Law, Comparative Patent Law, Policy and Health Care. Prof. Ho's articles have been published in several different major law reviews. Though she has written about various aspects of IP law, she has made particular contributions in the area of international intellectual property and patent issues involving biotechnology and ethical issues. Prof. Ho's expertise has been drawn on at the highest levels internationally and in the United States, as she has acted as a consultant to both the United Nations Convention on Biological Diversity and to the U.S. National Institutes of Health.



Kristian Hveem, M.D., PhD.

CEO of HUNT Biobank and Associate Professor of Medicine, *Norwegian University of Science and Technology, Trondheim*

Kristian Hveem, M.D., PhD., is CEO of [HUNT Biobank](#) and associate professor of Medicine at the HUNT Research Centre, which is located in Verdal, Nord-Trøndelag County, Norway. He has been Principal Investigator on behalf of the Medical Faculty of the Norwegian University of Science and Technology for two major studies commissioned by the European Union: a 2004 design study entitled "Structuring Biobanks" and a 2005 study entitled "European Genetic Epidemiological Research Infrastructure (EUGENERA)". He is currently Vice-Director of the executive board for Norway's FUGE (Functional Genomics) platform, "Biohealth Norway." He is also currently the Principal Investigator in a handful of national research projects, including screening-detected hereditary hemochromatosis (1994-2010) and diabetes in an unselected general population (2004-08) where his research team is looking at risk factors, genetics and clinical symptoms with a special focus on gastrointestinal disorders. Kristian has published dozens of papers as principal or contributing author in various medical journals including *Scandinavian Journal of Gastroenterology*, *International Journal of Cancer*, *Advanced Series in Biomechanics*, and *JAMA*.

BIOGRAPHIES



Bartha Knoppers, LL.B., PhD.

Project Director of HumGen International, *University of Montreal*

Bartha Knoppers, LL.B., PhD., is a law professor and senior researcher at the Centre for Public Law Research, University of Montreal. Her research interests lie in the following areas: human rights, biotechnology, comparative law, and ethical issues arising in the context of genetic research. She is past Chair of the International Ethics Committee of the Human Genome Organization and was a member of the UNESCO committee that wrote the Universal Declaration on the Human Genome and Human Rights. Dr. Knoppers is co-founder of the International Institute of Research in Ethics and Biomedicine and is co-Director of the Quebec Network of Applied Genetic Medicine. She is currently the Canada Research Chair in Law and Medicine, project director of HumGen International, and is a researcher for a populational genetic research project in Quebec called CARTaGENE.



Michael Malinowski, B.A., J.D.

Biotechnology and Bioethics Professor, *Paul M. Hebert Law Center, Louisiana State University, Baton Rouge*

Michael Malinowski, B.A., J.D., teaches biotechnology law and bioethics at the Louisiana State University in Baton Rouge. He received his J.D. from Yale Law School, where he was Articles Editor for the Yale Law Journal. Prof. Malinowski is a member of Oxford University's 21st Century Trust, has served on the American Bar Association President's Special Committee on Bioethics and is past Chair of the ABA's Health and Human Services Committee, Administrative Law Section. Prior to joining academia, he practiced law in the areas of biotechnology and health care, including technology development and transfer agreements. Prof. Malinowski has also worked for the Massachusetts Biotechnology Council, Inc., is a former member of the Biotechnology Industry Organization's Bioethics Committee and Working Group on Biomedical Information and is past member of the Special Committee on Genetic Information Policy for the Commonwealth of Massachusetts. Prof. Malinowski has written extensively on the commercialization of biotechnology and related health care issues and has lectured on these topics throughout the United States, Europe and Canada.



Ikechi Mgbeoji, LL.M., J.S.D.

Patent Law Professor, Osgoode Hall Law School, *York University*

Ikechi Mgbeoji, LL.M., J.S.D., teaches Canadian patent law at York University's Osgoode Hall Law School where he has been a faculty member since 2003. Prior to then, Dr. Mgbeoji was an assistant professor in the Faculty of Law, University of British Columbia, Vancouver. His teaching and research interests are in the areas of Intellectual Property, especially patenting, international environmental law, and Indigenous Peoples and intellectual property regimes. Dr. Mgbeoji is also a member of the IUCN Commission on Environmental Law. He is the author of *Global Biopiracy: Patents, Plants, and Indigenous Knowledge* (UBC/Cornell University Press: 2006).

BIOGRAPHIES



Cathy Anne Pachnowski, LL.M.

Information and Security Privacy Officer, *Alberta Cancer Board*

Cathy Anne Pachnowski is the Information Security and Privacy Officer for the Alberta Cancer Board. She has worked on Privacy Impact Assessments for initiatives including the Alberta Research Tumor Bank, the Cancer Surgery Alberta Web Surgical Medical Record (Web SMR), and provincial Screening Programs for breast, cervical and colorectal cancer. Cathy Anne graduated from the University of Alberta with her Masters of Law in 2006. Her thesis topic was “Independence, Impartiality and Accreditation of Research Ethics Boards.” She has acted as a Consultant for the Alberta Heritage Foundation for Medical Research, coordinating the initial phases of the Alberta Research Ethics Community Consensus Initiative (ARECCI). Prior to undertaking graduate studies, Cathy Anne received her Bachelor of Arts in history and religious studies from the University of Winnipeg and her Bachelor of Laws from the University of Manitoba. Following admission to the Manitoba Bar, she pursued a career in human rights, first investigating complaints of discrimination and harassment for the Canadian Human Rights Commission, and then being appointed as the Senior Advisor, Employment Equity in the Office of Human Rights at the University of Alberta.



Hilary Rose, B.A., PhD.

Sociologist, *City University, London, U.K.*

Professor Emerita of Social Policy, *University of Bradford, Bradford, U.K.*

Hilary Rose, B.A., PhD., is a prominent U.K. sociologist whose career writing and teaching the sociology of science from a feminist perspective spans four decades and includes teaching or visiting scholarship positions on three continents. She is widely published, having authored, co-authored or co-edited 11 books and over 130 articles. In 2001, her highly acclaimed *Love, Power and Knowledge: Towards a Feminist Transformation of the Sciences*, was listed as one of the “101 Best Books of the 20th Century” (Mulheres Seculo XX 101 Livros) as published by Portugal’s Ministry of Culture. Her current research interest is biobanking, where genomics and social policy meet, sometimes with agendas that conflict. Two critical biobanking studies have been completed: of the *deCode* project in Iceland and of the *Umanogenomics* project in Northern Sweden. Dr. Rose currently has a book in progress about the U.K.’s biobank initiative. Finally, she continues to work with the European Community’s research division to promote policies and programs that better ensure equity in how research grants are allocated to female scientists.



ABSTRACTS

