

*Genetics, Immigration and Society:
International Perspectives
Workshop*

Open Seminar: 30 April 2015

08:30-16:30

Location: Best Western Ville-Marie, 3407 Rue Peel, Montreal, Quebec H3A 1W7

The aim of this seminar is to:

- *Provide Canadian experts and local stakeholders and participants with an update on the legal, ethical and social challenges and opportunities associated with DNA testing in the context of immigration for family reunification*

The Open Seminar will be chaired by *Co-Chair: Professor Yann Joly (Centre of Genomics and Policy, McGill University)*

08:00-8:30 Breakfast & Registration

08:30-8:45 **Introduction and welcome words**
*Professor Yann Joly (Centre of Genomics and Policy, McGill University) and
Dr. Michèle Stanton-Jean (Centre de Recherche en Droit Public, Université de Montréal)*

CANADIAN PERSPECTIVES

08:45-10:30 **Family sponsorship (procedures, appeal and DNA policies)**
*Me Jacqueline Lacey (Cabinet Bertrand, Deslauriers), and
Me Hugues Langlais (Cabinet Me Hugues Langlais, avocats)*

10:30-10:45 Coffee/tea break

10:45-11:30 **Unwarranted invitations to undergo DNA testing: recent cases**
Ida Ngueng Feze (Academic Associate, Centre of Genomics and Policy, McGill University)

11:30-12:00 **Issues concerning refugees and asylum seekers**
Janet Dench (Executive Director, Canadian Council for Refugees)

12:00-12:30 **Applicants' Perspectives**
Guests speakers: former applicants

12:30-13:30 Lunch Break

INTERNATIONAL PERSPECTIVES

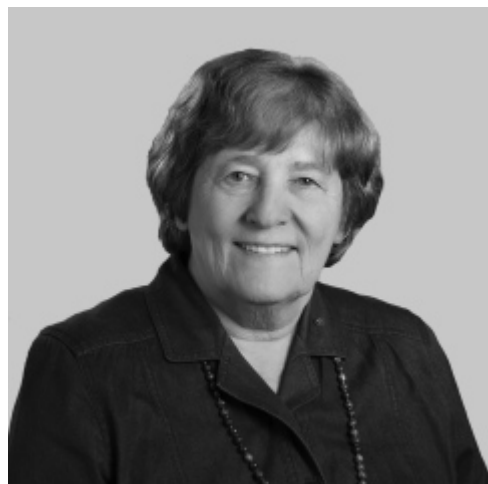
- 13:30-14:30 **Family reunification and DNA testing in the EUROPEAN UNION and GERMANY**
Torsten Heinemann (Professor, Institute of Sociology at Universität Hamburg)
- 14:30-15:15 **Family reunification and DNA testing in FRANCE**
Dr. Nadia Belrhomari, (Professor, Université Paris-Est Créteil)
- 15:15-15:30 Coffee/tea break
- 15:30-16:15 **Compulsory DNA testing of refugees in the USA**
Edward Dove (PhD Candidate, University of Edinburgh)
- 16:15-16:30 **Closing words**
Professor Yann Joly (Centre of Genomics and Policy, McGill University) and
Dr. Michèle Stanton-Jean (Centre de Recherche en Droit Public, Université de Montréal)
-

BIOGRAPHIES



**Yann Joly, Ph.D. (DCL), Ad.E.
Workshop Co-Chair**

Yann Joly, Ph.D. (DCL), Ad.E. is a Lawyer Emeritus from the Quebec Bar and holds the position of Research Director at the Centre of Genomics and Policies (CGP). He is an Associate Professor at the Faculty of Medicine, Department of Human Genetics and at the Bioethics Unit, at McGill University. He is a research fellow from the Fonds de recherche du Québec- Santé (FRQS) and an associate researcher at the Centre de recherche en droit public (Université de Montréal). He also works as an ethics and legal consultant in the private sector. Prof. Joly is the Data Access Officer of the International Cancer Genome Consortium (ICGC). His research activities lie at the interface of the fields of intellectual property, health law (biotechnology and other emerging health technologies) and bioethics. He has served as a legal advisor on several ethics committees in the public and private sectors. Prof. Joly is a member of the Scientific Committee of the legal journal *Lex Electronica* and an Advisory Board member of the *Current Pharmacogenomics and Personalized Medicine Journal*. He recently received the Quebec Bar Award of Merit (Innovation) for his work on the right to privacy in the biomedical field.



**Michèle Stanton-Jean, PhD
Workshop Co-Chair**

A visiting researcher at the Centre de Recherche en Droit Public of the University of Montreal, Michèle Stanton-Jean was also a representative of Quebec within the Canadian permanent delegation to UNESCO (Paris) from July 2011 until May 2014. She was Assistant Deputy Minister of Health of Canada (1993-1998), Special adviser to the Minister of Foreign Affairs in matters concerning health and social affairs in Brussels within the permanent Canadian delegation to the European Union (1998-2000), president of the International Committee on bioethics at UNESCO (2002-2005) during the elaboration and adoption of the *Universal Declaration on Bioethics and Human Rights*. Recently, in January 2015, Madame Stanton-Jean has appointed president of the joint committee on responsible conduct in research for the Fonds de recherche du Québec.

Author of many books and articles, Michèle Stanton-Jean received a PhD in applied social sciences (bioethics option), a Master degree in History and a Master degree in Education of Adults and an honorific Doctorate from Concordia University. She has received many awards and is the Officière de l'Ordre national du Québec and Chevalier in the l'Ordre national de la Légion d'Honneur de France.

Her publications include: En collaboration : *l'Histoire des femmes au Québec*, éditions du Jour (1982 et édition révisée 1992); Henk A.M.J. ten Have et Michèle S. Jean (dir.), *The UNESCO Universal Declaration on Bioethics and Human Rights*, Paris, UNESCO, 2009; Pierre Trudel et Michèle Stanton-Jean (dir.), *La malréglementation, Une éthique de la recherche est-elle possible et à quelles conditions?*, PUM, 2010; « Les systèmes informatisés complexes en santé sous le regard de la bioéthique et des droits de l'Homme », in Christian Hervé, Michèle S. Jean et Éric Martinent (dirs). *Les systèmes informatisés complexes en santé*, Paris Dalloz, 2013; « Les défis internationaux de la recherche en bioéthique », dans Edwige Rude-Antoine et Marc Piévic, *Un état des lieux de la recherche et de l'enseignement en*

| | |
|---|---|
| | <p><i>éthique</i>, Paris, L'Harmattan, 2014.</p> |
|  <p>Me Hugues Langlais</p> | <p>Me Hugues Langlais presides over his firm with offices in Montreal (Canada) and Shanghai (China).</p> <p>Since 2005, he acts as Foreign Legal Consultant to Jin Mao P.R.C. Lawyers, in Shanghai. The firm is also present in Beirut (Lebanon), in Paris (France), Quebec City (Canada) and Dakar (Senegal). Since October 2008, Mr. Langlais acts as Practice reviewer for the Quebec Bar Association to oversee the professional work of colleagues.</p> <p>He practices business immigration law for applicants to Canada (investors, entrepreneurs and self-employed persons) and is involved in international business transactions and investments for Canadian or foreign businesses setting up operations in Canada, in Asia or in other countries.</p> <p>Mr. Langlais is called regularly as an immigration legal expert by the Canadian Broadcasting Corporation (television and radio). He is the actual Chairman of the Immigration and Citizenship Committee of the Quebec Bar Association and Chairman of the International Relation Committee of the Montreal Bar Association.</p> <p>Mr. Langlais is an approved trainer of the Quebec Bar Association and has authored many training courses for lawyers, including Business Immigration Programs, Skilled Worker Immigration Programs, Residency Issues under Immigration Laws versus Citizenship Laws, Temporary Resident Permits, Immigration and Criminality, and Introduction to Immigration Laws in Canada.</p> <p>Mr. Langlais was called to the Quebec Bar Association in 1990 after earning his law degree from Université de Montréal, Quebec (Canada) in 1989.</p> |
|  <p>Me Jacqueline Lacey</p> | <p>Me Jacqueline Lacey is an attorney with more than 25 years of expertise in immigration law, including in family sponsorship and refugees.</p> <p>Since 1998 she has been an Independent Immigration Attorney specializing in family sponsorships, refugee claims, NAFTA TN permits; cross border working permits for U.S. citizens in Canada and Canadian Citizens in the U.S.; and waiver permits for Americans and Canadians who are inadmissible to the U.S. or Canada based on Criminal antecedents or breach of Immigration regulations.</p> <p>Between 1989 and 1998 she was a Refugee Hearing Officer and Legal Analyst at the Immigration and Refugee Board of Canada, and prior to that she articulated with Byers Casgrain, Montreal and The Department of Justice, Ottawa.</p> <p>B.C.L. L.L.B. McGill University 1983-1987 Member of the Barreau du Québec since 1989 Member of AQAADI</p> |
| | <p>Ida Ngueng Feze is an Academic Associate at the Centre of Genomics and Policy (CGP) at McGill University. Her main research projects at the CGP include the legal, ethical and social issues related to the access and use of genetic data by third parties and genetic</p> |



Ida Ngueng Feze Esq., LLM

discrimination. She co-authored the first systematic review on the evidence of genetic discrimination in the context of life insurance published in BMC ethics in 2013 and recently completed a study on Canadian life insurance proposition forms. She also provides legal expertise on the legal and regulatory framework for the environmental applications of novel biotechnologies in contexts such as water governance and food safety. Her other areas of research include human rights, pharmacogenomics, intellectual property, research ethics and the use of DNA testing in immigration processes.

Closely related to her work at the CGP, she currently teaches course sessions on the legal and ethical aspects of pharmacogenetics, pharmacogenomics and human genetics as a guest lecturer at the University of Montreal and the University of Laval. She is also interested in the application of cultural competency, traditional knowledge and the regulations of biotechnologies in Africa. She is a member of the African Society of Human Genetics and a member of the Montreal General Hospital's Research Ethics Board.

Ms. Ida Ngueng Feze Esq. is a lawyer admitted to practice in the State of New York and a member of the Quebec Bar Working Group "Forum pour une profession plus inclusive". She holds a Bachelor of Arts degree (B.A.) in Law and Society with a Minor in Psychology from Ramapo College, a Juris Doctorate degree (J.D.) from Howard University School of Law in Washington D.C., and an LL.M. in International Law from the University of Montreal.



Janet Dench, M.A.

Janet Dench is the Executive Director of the Canadian Council for Refugees, where she has worked since 1990 (as the Executive Director since 1997). The CCR is a national non-profit umbrella organization committed to the rights and protection of refugees and other vulnerable migrants in Canada and around the world and to the settlement of refugees and immigrants in Canada. The CCR works to keep its 170 member organizations informed, provides them with opportunities to meet and network, and undertakes advocacy on issues of concern to the membership. Ms. Dench has a BA (in Classics and Modern Languages) from the University of Oxford and an MA in Religious Studies from Concordia University. She was awarded the degree of Doctor of Sacred Letters, *honoris causa*, from Regis College, the Jesuit School of Theology at the University of Toronto on 23 November 2013.

Torsten Heinemann is Professor of Sociology with a focus on Social Problems and Social Control at the Faculty of Economics and Social Sciences at the Universität Hamburg, and a Marie Curie Fellow at the Institute for the Study of Societal Issues (ISSI) at the University of California, Berkeley. Prior to this he was a Principal Investigator in the Biotechnologies, Nature and Society Research Group at the Goethe University Frankfurt and a Lecturer in Science Studies at the Institute of Social Sciences at the Humboldt University of Berlin. His research interests are in social theory, science and technology studies, sociology of health and illness, qualitative research, cultural



Torsten Heinemann, Ph.D.

sociology, and public understanding of science. He is particularly interested in recent developments in neuroscience as well as forensic and medical uses of genetic testing.


Recent publications include Heinemann, T. et al. 2012. Risky Profiles: Societal Dimensions of Forensic Uses of DNA Profiling. Special Issue of New Genetics and Society 31(3); Heinemann, T. and T. Lemke. 2013. Suspect Families: DNA Kinship Testing in German Immigration Policy. In: Sociology. 47(4): 810-827; Heinemann, T. and T. Lemke. 2014. Biological Citizenship Reconsidered: The use of DNA analysis by immigration authorities in Germany. In: Science, Technology and Human Values. 39 (4): 488-510; Heinemann, T. et al. eds. 2015: Suspect Families: DNA Analysis, Family Reunification and Immigration Policies. Farnham: Ashgate.



Nadia Belrhomari, Ph.D.

Having completed a PhD in international public law and the subsequent qualification allowing her to supervise doctoral students (HDR), Nadia Belrhomari is a specialist in bioethical law and health law. She has specific interests in the law in relation to genetics. She teaches particularly the law of biomedical research and clinical medicine as well as the patent law at the University of East Paris – Creteil. She speaks annually at the doctoral symposium of the Institute of Political Studies of Paris. As a collaborator with the League of Human Rights on international matters, she speaks at various institutions, such as the Observatory for Synthetic Biology at the National Arts and Crafts Centre (Conservatoire national des arts et métiers CNAM) in her capacity as an expert in synthetic biology law, and the reflexion committee and consultation of the national network for health mediation, ReMeDiE. Nadia also co-organises and leads high-level international inter-disciplinary colloquia. The most recent of these are Big Data in Public Health (13th Feb 2015), End of life issues in Public Health (11th June 2014) and Issues in Personalised Medicine in Public Health (7th Feb 2014). In her other capacity as a political journalist, Nadia specialises in parliamentary work.

Recent publications include N. Belrhomari, *Génome humain, espèce humaine et droit*, (Paris: L'Harmattan, 2013); N. Belrhomari, "Analyse et commentaire des articles 15 et 21 de la Convention d'Oviedo" in H. Gros Espiell, J. Michaud, and G. Teboul, *Convention sur les Droits de l'Homme et la Biomédecine, Analyses et commentaires*, (Paris: Economica, 2010), pages 285-295 & 373-388. N. Belrhomari, "Epigénétique et Médecine personnalisée : la liberté de choix du patient" in C. Herve & M. Stanton-Jean, *Les nouveaux paradigmes de la médecine personnalisée ou médecine de précision*, (Paris: Dalloz, 2014); N. Belrhomari & B. Boyer Beviere "La loi n° 2012-300 du 5 mars 2012 relative aux recherches impliquant la personne humaine," (2014) Journal de médecine légale et de droit médical. N. Belrhomari, "Avis de la Conférence citoyenne sur la fin de vie : considérations et réflexions juridiques", (2014) 50 Revue générale de

| | |
|---|---|
| | <p>droit médical 296-306; N. Belrhomari, “<i>L’affaire Vincent Lambert: un cas de conscience pour le juge</i>”, (2014) 53 <i>Revue générale de droit médical</i>, 131-151; N. Belrhomari, “<i>Le tourisme procréatif lié à la gestation pour autrui: un casse-tête pour l’ordre juridique français</i>”, <i>Revue générale de droit médical</i> [forthcoming in 2015].</p> |
|  <p>Edward S. Dove, LL.M.</p> | <p>Edward (Ted) S. Dove is a PhD student in the School of Law at the University of Edinburgh. From 2011 until 2014, he was an Academic Associate at the Centre of Genomics and Policy (CGP) at McGill University in Montreal. He holds a Bachelor of Arts degree (BA) in Political Science, a Civil Law and Common Law degree (BCL, LLB) from McGill, and a Master of Laws degree (LLM) from Columbia Law School in New York City. A dual U.S. and Canadian citizen, Ted has past work experience in corporate law firms in Montreal and Toronto, as well as editorial writing and research expertise in public policy think tanks in Washington, D.C. His primary research interests are in the areas of privacy/data protection, data access and sharing, governance of international research collaboration, and genomics public policy. Ted is also a Section Editor at <i>BMC Medical Ethics</i> and a member of the International Cancer Genome Consortium’s (ICGC) Working Group on Identifiability and Privacy.</p> <p>He recently completed and published a socio-legal study on the use of DNA in US immigration: Dove E.S., <i>Back to Blood: The Sociopolitics and Law of Compulsory DNA Testing of Refugees</i>, (2013) 8:2 <i>UMass Law Review</i>, 466.</p> <p>Some of his most recent publications include: Dove E. S., Knoppers B. M., Zawati M.H. “Towards an Ethics Safe Harbor for Global Biomedical Research” (2014) 1:1 <i>Journal of Law and the Biosciences</i> 3; Dove E.S., Ozdemir V. “Global Bioethics: When International IRB Collaboration Confronts Local Politics” (2014) 14:5 <i>American Journal of Bioethics</i> 20; Dove E. S., Tasse A. M., Knoppers B. M. “What are some of the ELSI Challenges of International Collaborations Involving Biobanks, Global Sample Collection, and Genomic Data Sharing and How Should they be Addressed?” (2014) 12(6) <i>Biopreservation and Biobanking</i> 363-4.</p> |