

Genetic Discrimination Observatory

6th Annual Scientific Meeting 2025 - 2026

Date: December 10-11, 2025

7:00 a.m. to 10:00 a.m. EST

8:00 p.m. to 10:00 p.m. EST

Location: online

Zoom link: <https://mcgill.zoom.us/j/86142069598?pwd=iMAf5d9OI5wDinaJtz7E4BYdaQo4pf.1>

Meeting ID: 861 4206 9598

Passcode: GDO2025

Note: presentations (not the discussions) will be recorded unless a speaker requests otherwise.

Aim of the meeting:

- Exchange knowledge and research findings about genetic discrimination, AI, and its impacts
- Update members on the progress of GDO activities
- Set a collaborative research agenda for 2026

For any logistical challenge, please contact:

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Day 1: December 10, 2025

| Time | Agenda item | Chair/Presenter | Jurisdiction | Affiliation |
|-------------------|--|--|--------------|---|
| 7:00-9:30 | | | | |
| 7:00-7:15 | Welcome & Introduction | Yann Joly, Prof. | Canada | Centre of Genomics and Policy, McGill University |
| 7:15-7:45 | GDO 2025 in review | Song Lingqiao, Dr. | Canada | Centre of Genomics and Policy, McGill University |
| 7:45-8:00 | Coffee & Networking Break | | | |
| 8:00-10:00 | Presentations & Discussions | | | Chair: Donrich Willem Thalidar, Prof. |
| 8:00-8:30 | Positioning Genetic Data Privacy within the Indian Legal Framework: An Analysis | Athira, P.S., Prof. | India | Centre for Intellectual Property Rights, National University of Advanced Legal Studies |
| 8:30-9:00 | Insurance, Genetics and Risks of Genetic Discrimination: Survey of Ukrainian Doctors (Geneticists) and Genetic Counsellors | Mykhailo Arych, Prof. | Ukraine | National University of Food Technologies |
| 9:00-9:30 | The DNA Battlefield: From Epigenetic Scars to a Genetic Geneva Convention | Thalia Arawi, Prof. | Lebanon | T2P Regional Center for Health Ethics Training & Consultancy |
| 9:30-10:00 | Genetic Discrimination in Health Insurance: A Chinese Perspective | Lingqiao Song, Dr. Hongjie Man, Prof. | China | Centre of Genomics and Policy, McGill University; The Institute for Health Law and Policy Studies, ECUPL |

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| 20:00-22:00 | | | | |
| Chair: Yann Joly | | | | |
| 20:00-21:00 | Spotlight: Keynote Presentation | | | |
| | <i>Past, Present, and Future of Genetic Non-discrimination Ethics and Law</i> | | | |
| | Speaker: Mark A. Rothstein, Prof. Affiliation: Institute for Clinical and Translational Science, University of California, Irvine, U.S. | | | |
| 21:00-22:00 | Presentations & Discussions | | | Chair: Yann Joly |
| 21:00-21:30 | The Legislative Ban on Genetic Discrimination in Australian Life Insurance: Progress and Updates | Jane Tiller, Dr. , Researcher | Australia | School of Public Health and Preventive Medicine, Monash University |

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| 21:30-22:00 | GD under Japan's <i>Genomic Medicine Promotion Act</i> and Forthcoming Government-Sponsored Research | Kaori Muto, Prof. | Japan | Department of Public Policy, Human Genome Centre, the Institute of Medical Science, The University of Tokyo |
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Day 2: December 11, 2025

| Time | Agenda item | Chair/Presenter | | Affiliation |
|-------------------|--|----------------------------|-----------------|---|
| 7:00-10:00 | | | | |
| 7:00-10:00 | Presentations & Discussions | | | Chair: Lingqiao Song |
| 7:00-7:30 | Regulation of AI and Genetics in the Global South: Issues of Genetic Discrimination and Inequity | Kshitij Kumar Singh, Prof. | India | Campus Law Centre, Faculty of Law, University of Delhi |
| 7:30-8:00 | Genetic Privacy and Discrimination Laws in Practice - the Case of 23andMe | Anya Prince, Prof. | U.S. | College of Law, University of Iowa |
| 8:00-8:30 | Investigative Genetic Genealogy: Mapping the Risks and the Legal Landscape | Taner Kuru, LL.M., Lawyer | The Netherlands | Tilburg Institute for Law, Technology, and Society (TILT), Tilburg University |
| 8:30-9:00 | Gene editing, disability and genetic discrimination - law and policy concerns | Aisling De Paor, Prof. | Ireland | Dublin City University |
| 9:00-10:00 | GDO 2026 Action Plan (closed session, open to GDO committee members and collaborators) | | | |
| 9:00-9:15 | Introduction | Yann Joly, Prof. | Canada | Centre of Genomics and Policy, McGill University |
| 9:15-10:00 | Open Discussion | All | | Centre of Genomics and Policy, McGill University |

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| 20:00-22:00 | | | | |
| 20:00-21:00 | Presentations & Discussions | | | Chair: Anya Prince |
| 20:00-20:30 | Genetic Discrimination in Singapore: Current Landscape and Future Directions | Jeanette Yuen, MSc. CGC | Singapore | National Cancer Centre Singapore |
| 20:30-21:00 | Risk of False Positives for Genetic Discrimination | Misha Rashkin, MSc. CGC | U.S. | Department of Cancer Genetics, Stanford Cancer Centre |
| 21:00-21:15 | Coffee & Networking Break | | | |
| 21:15-22:00 | Discussions & Planning | | | |
| 21:15-22:00 | Discussion & Wrap-up | Yann Joly, Prof. & Song Lingqiao | | Centre of Genomics and Policy, McGill University |
| 22:00 | Meeting close | | | |

