

Bartha Maria Knoppers

SECTION A: Individual information

A.1. Personal information

Name	Bartha Maria Knoppers
Post or Position	Full Professor
Employer, Research Institution or Affiliation	Director, Centre of Genomics and Policy Canada Research Chair in Law and Medicine Faculty of Medicine, Department of Human Genetics Medical Scientist, Department of Medical Genetics, Research Institute McGill University Health Centre McGill University

A.2. Short Biography

Bartha Maria Knoppers, PhD (Comparative Medical Law), holds the Canada Research Chair in Law and Medicine (Tier 1: 2001 -). She is Director of the Centre of Genomics and Policy, Faculty of Medicine, Department of Human Genetics, McGill University.

Former Chair of the International Ethics Committee of the Human Genome Project (HUGO), (1996-2004), she was a member of the International Bioethics Committee of the United Nations, Educational, Scientific and Cultural Organization (UNESCO) which drafted the *Universal Declaration on the Human Genome and Human Rights* (1993-1997). In 2007, she founded the international Population Project in Genomics and Society (P³G) and CARTaGENE Québec's population biobank (20,000 indiv.). Former holder of the Chair d'excellence Pierre Fermat (France: 2006-2008), she was named Distinguished Visiting Scientist (Netherlands Genomics Initiative) (2009- 2012) and received the ACFAS prize for multidisciplinary (2011). She is Chair of the Ethics Working Party of the International Stem Cell Forum (2006 -), Co-Chair of the Sampling/ELSI Committee of the 1000 Genomes Project (2008 -) and a member of the Scientific Steering Committee of the International Cancer Genome Consortium (ICGC) (2009-).

She holds four Doctorates Honoris Causa, is Fellow of the American Association for the Advancement of Science, of The Hastings Center (Bioethics) and of the Canadian Academy of Health Sciences (CAHS) and Officer of the Order of Canada and of Québec. She also received an award "Prix Montreal In Vivo: Secteur des sciences de la vie et des technologies de la santé".

SECTION B: DISCLOSURES

B.1. Financial Interests

Please provide information on financial interests that could be perceived to influence the responsibilities and decision making process of the Independent Panel. This should include financial relationships with GSK and other pharmaceutical or biotechnology companies within the last 3 years. It should include:

- *Board memberships*
 - Chair, P3G Board;
 - Member RSSPQ
- *Consultancies*
 - Roche-Genentech (Ethics);
 - Pfizer (Ethics);
 - Merck (Ethics)
- *Employments*
 - (2011 -) Associate Member, Faculty of Law, McGill University
 - (2011 -) Medical Scientist, Department of Medical Genetics, Research Institute, MUHC
 - (2009 –) Full Professor, Faculty of Medicine, McGill University
 - (2009 –) Director, Center of Genomics & Policy, Fac. of Med., Dept. Of Human Genetics, McGill University
 - (2001 – 2009) Full Professor, Faculty of Medicine, University of Montreal
 - (1996-2009) Full Professor, Faculty of Law, University of Montreal
 - (1990-1995) Associate Professor, Faculty of Law, University of Montreal
 - (1985-1990) Assistant Professor, Faculty of Law, University of Montreal
- *Grants/grants pending*

SELECTED GRANTS CURRENTLY HELD (All grants represent operating funds; amount/year)

- Cell-based Regenerative Medicine: New Challenges for EU Legislation and Governance (FP7) (EUCeLEX). \$37,000. 2013-2017.
- Canadian Partnership for Tomorrow (CPT) Project – Ethics, Legal & Social Issues (ELSI) Standing Committee. \$90,000. 2013-2017.
- Personalised Risk Stratification for Prevention and Early Detection of Breast Cancer. \$158,902. 2013 to 2017.
- Enhanced CARE for RARE Genetic Diseases in Canada. \$89,899. 2013 to 2017.
- Networks of Centres of Excellence (NCE): Grant. From Biobanking to International Governance: Fostering Innovation in Stem Cell Research. \$75,666. 2011 to 2014.
- European Commission (The), 7th Framework Programme: Grant. Biobank Standardisation and Harmonisation for Research Excellence in the European Union (BioSHaRE-EU). \$73,844. 2010 to 2014.
- FRSQ : Grant. Réseau de médecine génétique appliqué (RMGA). \$60,352. 2010 to 2014.
- Government of Canada: Grant. Canada Research Chair in Law & Medicine (Tier 1). \$200,000. (2008-2009). 2010 to 2017.
- CIHR: Grant. CIHR team of prediction and communication of familial risks of breast cancer. \$93,552. 2008 to 2013.
- Canadian Partnership Against Cancer: Grant. Canadian Partnership for Tomorrow Project (ELSI). \$114,611. 2008 to 2013.
- CIHR: Grant. A Research and Knowledge Network on Genetic Health Services and Policy:

- building on the APOGEE-Net and CanGeneTest experiences. \$10,000. 2008 to 2013.
 - NCE: Grant. The Stem Cell Research Environment: Drawing the Evidence and Experience Together. \$280,666. 2008 to 2013.
 - CIHR: Grant. CIHR Team in Community Genetics (ECOGENE-21). \$68,173. 2007 to 2012.
 - Medical Research Council of Canada (MRC): Grant. The International Stem Cell Forum Ethics Working Party. \$65,217. 2009 to 2013.
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- *Patents (planned, pending or issued)*
 - None

 - *Royalties*
 - None

 - *Stocks or shares (including options)*
 - None

B.2 Other Real or Potential Conflicts of Interest

Please provide any other (e.g. non-financial) real or potential conflicts of interest that could be perceived to influence the responsibilities and decision making process of the Independent Panel. For example potential biases based on pre-existing personal views, academic or commercial competition, personal relationships or institutional affiliations.

Answer: None