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Curriculum Vitae

Heidi Carmen Howard
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Senior researcher, Centre for Research Ethics & Bioethics, Uppsala University, Sweden
Associated Researcher, Ethics and Society Group, Wellcome Trust Genome Campus, UK

PERSONAL INFORMATION

Citizenship: Canadian
Languages: Native French and English speaker; fluent Spanish; basic Dutch

RESEARCH THEMES

I lead a multidisciplinary group (Bioethics, Sociology, Philosophy, Law) working on the ethical, legal, social, and policy aspects of new technologies, especially in genetics and genomics. In particular, we use multi- and interdisciplinary approaches with a large emphasis on empirical research to study the challenges and implications of novel technologies (e.g. gene editing, next generation sequencing) and approaches and their responsible translation for end users and society. Projects include themes such as commercial genomics and direct-to-consumer genetics, biobanking, public health genomics, participant-centric research initiatives, public engagement, how best to merge different stakeholder voices in policy, and conceptual issues related to risk information and uncertainty in genetics and genomics.

EDUCATION

2008 MSc Bioethics, *Summa cum laude,* Katholieke Universiteit Leuven, Belgium

2004 PhD Genetics, Dean's Honour List, McGill University, Canada

1996 BSc Biology, Distinction, McGill University, Canada.

Previous POSITIONS

2013-2014 Assistant Professor (tenure track), Bioethics, Radboud University Medical Centre, Nijmegen, The Netherlands

2011- 2013 Senior Research Fellow, Bioethics, Institute for Biomedical Ethics, University Basel Switzerland & INSERM, Université Toulouse III, Paul Sabatier, Toulouse, France (Marie Curie FP7)

2009-2011 Postdoctoral Fellow, Bioethics, (Marie Curie FP7) KU Leuven, Belgium

2004- 2007 Postdoctoral Fellow, Genetics, Psychiatric genetics, Centre for Genomic Regulation, Barcelona, Spain & Douglas Hospital, McGill, Canada

FUNDING

2,5 million Euro/25 million SEK = total won in competitive grants since 2004

2018-2021	Swedish Research Council Grant: Ethical, legal and social issues of gene editing.	4 800 000 SEK (500 000 € 750 000 CAD)
2017-2021	European Commission, Science with and for Society (SWAFs-18) Consortium on Ethics of new technologies (SIENNA) PI of genomics work package. www.sienna-project.eu	820 000 € (1.200 000 CAD) of a 3 mil Euro grant
2014-2015	Belgian Government BELSPO award (declined, country-dependent)	200 000 € (300 000 CAD)
2013-2014	Research Foundation Flanders (FWO) Pegasus Postdoctoral fellowship, (declined, country-dependent)	240 000 € (360 000 CAD)
2011-2012	Académie Suisse des Sciences Médicales, Banking together: sharing biological samples among Swiss researchers, Co-applicant, University of Geneva and University of Basel	40 000 CHF (52 000 CAD)
2011-2013	Marie Curie (European Commission FP7) career development award, Humanities panel	240 000 € (360 000 CAD)
2009-2011	Marie Curie (European Commission FP7) career development award, Life science panel	220 000 € (330 000 CAD)
2007-2008	Erasmus Mundus Fellowship, Master of Bioethics, European Commission	20 000 Euro (30 000 CAD)
2004-2006	Canadian Institute of Health Research fellowship	120 000 CAD
2005-2007	Spanish Ministry of Science and Technology, *Juan de la Cierva* postdoctoral award	36 000 Euro (54 000 CAD)
2004	Catalonia Government Ministry of Universities, Research and Information Societypostdoctoral award	14 000 Euro (21 000 CAD)

PUBLICATIONS (total 72, H-Index 23)

1. G Samuel, **HC Howard**, M Cornel, C van El, A Hall, F Forzano, and B. Prainsack. A response to the forensic genetics policy initiative's report "Establishing Best Practice for Forensic DNA Databases", in press, Forensic Science International: Genetics, https://www.sciencedirect.com/science/article/pii/S1872497318302710
2. DF Vears, E Niemiec, **HC Howard**, P Borry, How do consent forms for diagnostic high-throughput sequencing address unsolicited and secondary findings? A content analysis, in press, Clinical Genetics, doi.org/10.1111/cge.13391, https://onlinelibrary.wiley.com/doi/10.1111/cge.13391
3. Anna Middleton, Emilia Niemiec, Barbara Prainsack, Jason Bobe, Lauren Farley, Claire Steed, James Smith, Paul Bevan, Natasha Bonhomme, Erika Kleiderman, Adrian Thorogood, Christoph Schickhardt, Chiara Garattini, Danya Vears, Katherine Littler, Natalie Banner, Erick Scott, Nadezda V Kovalevskaya, Elissa Levin, Katherine I Morley & **Heidi C Howard** 'Your DNA, Your Say': global survey gathering attitudes toward genomics: design, delivery and methods Pers. Med. 15, NO. 4 https://www.futuremedicine.com/doi/10.2217/pme-2018-0032
4. **Howard HC**, van El CG, Forzano F, Radojkovic D, Rial-Sebbag E, de Wert G, et al. One small edit for humans, one giant edit for humankind? Points and questions to consider for a responsible way forward for gene editing in humans. Eur J Hum Genet. 2018;26(1):1-11.
5. de Wert G, Pennings G, Clarke A, Eichenlaub-Ritter U, van El CG, Forzano F, et al. Human germline gene editing: Recommendations of ESHG and ESHRE. Eur J Hum Genet. 2018.
6. De Wert G, Heindryckx B, Pennings G, Clarke A, Eichenlaub-Ritter U, van El CG, et al. Responsible innovation in human germline gene editing: Background document to the recommendations of ESHG and ESHRE. Eur J Hum Genet. 2018.
7. **Howard HC,** Iwarson E, Mapping Uncertainty in Genomics, Journal of Risk Research, 2018, 21:2, p.117-128
8. Middleton, A.; Mendes, Á.; Benjamin, C. M., **Howard, HC**, Direct to consumer genetic testing - where and how does genetic counselling fit? Personalized Medicine, 2017, 14,3 249-257, doi.org/10.2217/pme-2017-0001
9. Niemiec E, Vears DF, Borry P, **Howard HC**. Readability of informed consent forms for whole-exome and whole-genome sequencing. J Community Genet. 2017.
10. Kalokairinou L, **Howard HC**, Slokenberga S, Fisher E, Flatscher-Thoni M, Hartlev M, et al. Legislation of direct-to-consumer genetic testing in Europe: a fragmented regulatory landscape. J Community Genet. 2017.
11. Niemiec E, Kalokairinou L, Howard HC, Current ethical issues in health-related direct-to-consumer genetic services and the impact of the IVD Regulation, Pers. Med. 2017
12. Kalokairinou L, Borry P, **Howard HC**. Regulating the advertising of genetic tests in Europe: a balancing act. J Med Genet. 2017;54(10):651-6.
13. **Howard HC**, Mascalzoni D, Mabile L, Houeland G, Rial-Sebbag E, Cambon-Thomsen A. How to responsibly acknowledge research work in the era of big data and biobanks: ethical aspects of the Bioresource Research Impact Factor (BRIF). J Community Genet. 2017.

14. Henneman L, Borry P, Chokoshvili D, Cornel MC, van El CG, Forzano F, et al. Responsible implementation of expanded carrier screening. Eur J Hum Genet. 2017;25(11):1291.
15. Borry P, Bentzen HB, Budin-Ljosne I, Cornel MC, **Howard HC**, Feeney O, et al. The challenges of the expanded availability of genomic information: an agenda-setting paper. J Community Genet. 2017.
16. Oliveri S, **Howard HC**, Renzi C, Hansson MG, Pravettoni G. Anxiety delivered direct-to-consumer: are we asking the right questions about the impacts of DTC genetic testing? J Med Genet. 2016;53(12):798-9.
17. Niemiec E, **Howard HC**. Ethical issues in consumer genome sequencing: Use of consumers' samples and data. Appl Transl Genom. 2016;8:23-30.
18. Niemiec E, Borry P, Pinxten W, **Howard HC**. Content Analysis of Informed Consent for Whole Genome Sequencing Offered by Direct-to-Consumer Genetic Testing Companies. Hum Mutat. 2016;37(12):1248-56.
19. Henneman L, Borry P, Chokoshvili D, Cornel MC, van El CG, Forzano F, Francesca Forzano, Alison Hall, **Heidi C Howard**, Sandra Janssens, Hülya Kayserili, Phillis Lakeman, Anneke Lucassen, Sylvia A Metcalfe, Lovro Vidmar, Guido de Wert, Wybo J Dondorp, Borut Peterlin, et al. Responsible implementation of expanded carrier screening. Eur J Hum Genet. 2016;24(6):e1-e12.
20. Severin F, Borry P, Cornel MC, Daniels N, Fellmann F, Victoria Hodgson S, **Howard, H.C**..... Points to consider for prioritizing clinical genetic testing services: a European consensus process oriented at accountability for reasonableness. Eur J Hum Genet. 2015;23(6):729-35.
21. L Kalokairinou, **HC Howard,** P Borry, Current developments in the regulation of direct-to-consumer genetic testing in Europe (2015) Medical Law International, dec 2015
22. **Howard HC**, Knoppers BM, Cornel MC, Wright Clayton E, Senecal K, Borry P, et al. Whole-genome sequencing in newborn screening? A statement on the continued importance of targeted approaches in newborn screening programmes. Eur J Hum Genet. 2015;23(12):1593-600.
23. Dondorp W, de Wert G, Bombard Y, Bianchi DW, Bergmann C, Borry P, et al. Non-invasive prenatal testing for aneuploidy and beyond: challenges of responsible innovation in prenatal screening. Eur J Hum Genet. 2015;23(11):1592.
24. Dondorp W, de Wert G, Bombard Y, Bianchi DW, Bergmann C, Borry P, et al. Non-invasive prenatal testing for aneuploidy and beyond: challenges of responsible innovation in prenatal screening. Eur J Hum Genet. 2015;23(11):1438-50.
25. Pinxten W, **Howard HC.** Ethical issues raised by whole genome sequencing. Best Pract Res Clin Gastroenterol. 2014;28(2):269-79.
26. Kalokairinou L, **Howard HC**, Borry P. Science and Regulation. Changes on the horizon for consumer genomics in the EU. Science. 2014;346(6207):296-8.
27. Pascal Borry, Davit Chokoshvili, Emilia Niemiec, Louiza Kalokairinou, Danya Vears, and **Heidi Carmen Howard** Current ethical issues related to the implementation of whole exome and whole genome sequencing, *in press*, chapter for Movement Disorder Genetics, edited by Dr. Jose Bras and Susanne A. Schneider
28. Elke Sleurs, Louiza Kalokairinou, **Heidi C. Howard** and Pascal Borry, "Promotion and sales of self-tests on the Internet" *In press*, Routledge Handbook of Medical Law and Ethics, edited by Y. Joly and B. M. Knoppers

29. Louiza Kalokairinou, **Heidi C. Howard** and Pascal Borry "Direct-to-consumer genetic testing", Encyclopedia of Life Sciences, Wiley, edited by D. N. Cooper
30. **Heidi C. Howard**, Sigrid Sterckx, Julian Cockbain, Anne Cambon-Thomsen, Pascal Borry, The convergence of direct-to-consumer genetic testing companies and biobanking activities, invited chapter in "Messiness of Convergence" Routledge 2014 (EGN book series),
31. Borry P, Shabani M, **Howard HC**. Is There a Right Time to Know? The Right Not to Know and Genetic Testing in Children. J Law Med Ethics. 2014;42(1):19-27.
32. Borry P, Rusu O, Dondorp W, De Wert G, Knoppers BM, **Howard HC**. Anonymity 2.0: direct-to-consumer genetic testing and donor conception. Fertil Steril. 2014;101(3):630-2.
33. Y. Su, P. Borry, I.C. Otte, **HC Howard**, *"It's our DNA, we deserve the right to test!"* A content analysis of a petition for the right to access direct-to-consumer genetic testing, Personalized Medicine, 2013, 10:7, 729-739
34. van El CG, Cornel MC, Borry P, Hastings RJ, Fellmann F, Hodgson SV, et al. Whole-genome sequencing in health care. Recommendations of the European Society of Human Genetics. Eur J Hum Genet. 2013;21 Suppl 1:S1-5.
35. van El CG, Cornel MC, Borry P, Hastings RJ, Fellmann F, Hodgson SV, et al. Whole-genome sequencing in health care: recommendations of the European Society of Human Genetics. Eur J Hum Genet. 2013;21(6):580-4.
36. Sterckx S, Cockbain J, **Howard HC**, Borry P. "I prefer a child with ...": designer babies, another controversial patent in the arena of direct-to-consumer genomics. Genet Med. 2013;15(12):923-4.
37. **Howard HC**, Swinnen E, Douw K, Vondeling H, Cassiman JJ, Cambon-Thomsen A, et al. The ethical introduction of genome-based information and technologies into public health. Public Health Genomics. 2013;16(3):100-9.
38. **Howard HC**, Borry P. Survey of European clinical geneticists on awareness, experiences and attitudes towards direct-to-consumer genetic testing. Genome Med. 2013;5(5):45.
39. Colledge F, Elger B, **Howard HC**. A review of the barriers to sharing in biobanking. Biopreserv Biobank. 2013;11(6):339-46.
40. Borry P, Shabani M, **Howard HC.** Nonpropositional content in direct-to-consumer genetic testing advertisements. Am J Bioeth. 2013;13(5):14-6.
41. Borry P, Rusu O, **Howard HC**. Genetic testing: anonymity of sperm donors under threat. Nature. 2013;496(7444):169.
42. **Howard HC**, Borry P. To ban or not to ban? Clinical geneticists' views on the regulation of direct-to-consumer genetic testing. EMBO Rep. 2012;13(9):791-4.
43. **Heidi Carmen Howard**, Julie Latour , Justin Vanderschuren et Pascal Borry, Définition et enjeux éthiques des tests génétiques offerts en accès libre, *Revue Générale de Droit Médical* (2012) Mars, numéro 42
44. **Howard HC,** Borry P. Is there a doctor in the house? : The presence of physicians in the direct-to-consumer genetic testing context. J Community Genet. 2012;3(2):105-12.
45. Ros Hastings, Guido de Wert, Brian Fowler, Michael Krawczak, Eric Vermeulen, Egbert Bakker, Pascal Borry, Wybo Dondorp, Niels Nijsingh, David Barton, Jörg Schmidtke, Carla G. van El, Joris Vermeesch, Yrrah Stol, **Heidi Carmen Howard**, and Martina C. Cornel. The changing landscape of genetic testing and its impact on clinical

and laboratory services and research in Europe *European Journal of Human Genetics,* (Sept 2012) 20, 911-916 | doi:10.1038/ejhg.2012.56

46. Zawati MH, Borry P, **Howard HC**. Closure of population biobanks and direct-to-consumer genetic testing companies. Hum Genet. 2011;130(3):425-32.
47. Su Y, **Howard HC,** Borry P. Users' motivations to purchase direct-to-consumer genome-wide testing: an exploratory study of personal stories. J Community Genet. 2011;2(3):135-46.
48. **Howard HC**, Joly Y, Avard D, Laplante N, Phillips M, Tardif JC. Informed consent in the context of pharmacogenomic research: ethical considerations. Pharmacogenomics J. 2011;11(3):155-61.
49. **Howard HC**, Borry P. Europe and direct-to-consumer genetic tests. Nat Rev Genet. 2011;13(2):146; author reply
50. **Howard HC**, Borry P. Direct-to-consumer pharmacogenomic testing. Pharmacogenomics. 2011;12(10):1367-70.
51. **Howard HC**, Avard D, Borry P. Are the kids really all right? Direct-to-consumer genetic testing in children: are company policies clashing with professional norms? Eur J Hum Genet. 2011;19(11):1122-6.
52. Borry P, Henneman L, Lakeman P, ten Kate LP, Cornel MC, **Howard HC**. Preconceptional genetic carrier testing and the commercial offer directly-to-consumers. Hum Reprod. 2011;26(5):972-7.
53. Knoppers BM, Avard D, **Howard HC**. Direct-to-consumer genetic testing: driving choice? Expert Rev Mol Diagn. 2010;10(8):965-8.
54. **Howard HC**, Knoppers BM, Borry P. Blurring lines. The research activities of direct-to-consumer genetic testing companies raise questions about consumers as research subjects. EMBO Rep. 2010;11(8):579-82.
55. Borry P, **Howard HC**, Senecal K, Avard D. Health-related direct-to-consumer genetic testing: a review of companies' policies with regard to genetic testing in minors. Familial Cancer. 2010;9(1):51-9.
56. Borry P, Cornel MC, **Howard HC**. Where are you going, where have you been: a recent history of the direct-to-consumer genetic testing market. J Community Genet. 2010;1(3):101-6.
57. **Howard HC**, Borry P. Personal genome testing: do you know what you are buying? Am J Bioeth. 2009;9(6-7):11-3.
58. Sénécal, K, Borry, P, **Howard HC**, Avard, D. Les tests génétiques offerts directement aux consommateurs : vue d'ensemble des normes et politiques applicables (2009) GenEdit,1-14
59. Borry P, **Howard HC**, Senecal K, Avard D. Direct-to-consumer genome scanning services. Also for children? Nat Rev Genet. 2009;10(1):8.
60. P. Borry and H**C Howard.** DTC genetic services: A look across the pond *Am. J. of Bioethics*. 2008, 8(6):14-16
61. Steiger H, Richardson J, Joober R, Mimi Israel , Kenneth R Bruce , N M K Ng Ying Kin , **Howard HC** , Anestin A, Dandurand C, Gauvin L Dissocial behavior, the 5HTTLPR polymorphism, and maltreatment in women with bulimic syndromes. Am J Med Genet B Neuropsychiatr Genet. 2008;147B(1):128-30.
62. Richardson J, Steiger H, Schmitz N, Joober R, Bruce KR, Israel M, Gauvin L, Anestin AS, Dandurand C, **Howard H**, de Guzman R.. Relevance of the 5-HTTLPR

polymorphism and childhood abuse to increased psychiatric comorbidity in women with bulimia-spectrum disorders. J Clin Psychiatry. 2008;69(6):981-90.
63. **Howard HC**, Borry P. Direct-to-consumer genetic testing: more questions than benefits? Personalized Medicine. 2008;5(4):317-20.
64. Bory P, **Howard HC**. In response to: Howard HC, Borry P: direct-to-consumer genetic testing: more questions than benefits? Personalized Med. 5(4), 317-320 (2008) - Response from the authors. Personalized Medicine. 2008;5(5):425-6.
65. Steiger H, Richardson J, Joober R, Gauvin L, Israel M , Kenneth R Bruce , N M K Ng Ying Kin , **Howard HC** , and Young SN, The 5HTTLPR polymorphism, prior maltreatment and dramatic-erratic personality manifestations in women with bulimic syndromes. J Psychiatry Neurosci. 2007;32(5):354-62.
66. **Howard HC**, Dupre N, Mathieu J, Bouchard JP, Rouleau GA. [Severe neuropathy with agenesis of the corpus callosum]. Med Sci (Paris). 2003;19(4):414-6.
67. Dupre N, **Howard HC**, Mathieu J, Karpati G, Vanasse M, Bouchard JP, et al. Hereditary motor and sensory neuropathy with agenesis of the corpus callosum. Ann Neurol. 2003;54(1):9-18.
68. Dupre N, **Howard HC**, Rouleau GA. Hereditary Motor and Sensory Neuropathy with Agenesis of the Corpus Callosum. In: Adam MP, Ardinger HH, Pagon RA, Wallace SE, Bean LJH, Stephens K, et al., editors. GeneReviews((R)). Seattle (WA)2003.
69. **Howard HC**, Mount DB, Rochefort D, Byun N, Dupre N, Lu J, et al. The K-Cl cotransporter KCC3 is mutant in a severe peripheral neuropathy associated with agenesis of the corpus callosum. Nat Genet. 2002;32(3):384-92.
70. **Howard HC**, Dube MP, Prevost C, Bouchard JP, Mathieu J, Rouleau GA. Fine mapping the candidate region for peripheral neuropathy with or without agenesis of the corpus callosum in the French Canadian population. Eur J Hum Genet. 2002;10(7):406-12.
71. Morton CC, Christian SL, Donlon TA, Driscoll DJ, Fink JK, Gabriel JM, Gotway, J.M. Greally, M.P. Hitchins, **HC Howard**, Y. Ji, S. Leonard, T. Lerner, E. Magenis, S. Malcolm, T. Ohta, S. Rainier, M. Rees, B. Riley et al Report of the fourth international workshop on human chromosome 15 mapping 1997. Cytogenet Cell Genet. 1999;84(1-2):12-21.
72. Xie YG, Rochefort D, Brais B, **Howard H,** Han FY, Gou LP, et al. Restriction map of a YAC and cosmid contig encompassing the oculopharyngeal muscular dystrophy candidate region on chromosome 14q11.2-q13. Genomics. 1998;52(2):201-4.

ACADEMIC RESEARCH STAYS (visiting fellow)

EURAC Biomedicine Group, Bolzano, Italy, July 2017, host Dr Deborah Mascalzoni

Sanger Institute Welcome Trust, Cambridge/Hinxton, UK, February 2016, March 2017, host Dr. Anna Middleton, from 2018- current, associated fellow

KULeuven Centre for Biomedical Ethics and Law, Nov. 2015, host, Prof. Pascal Borry

Mcgill University, Centre for Genomics and Policy, Autumn 2008, Summer 2010, ongoing visits, visiting fellow, Host Prof. Bartha Knoppers

SELECTION OF INVITED PRESENTATIONS

1. Two example of obtaining input from citizens in Genomics: Your DNA, Your Say, and SIENNA, Belgian Ministry of Public Health and King Beaudoin Foundation, Feb 23, 2018, Brussels, Belgium

2. Bioethics and Genetic Counselling, International Conference on Gene Editing, Hinxton, Uk, Oct 2017

3. Ethical and Governance Issues in Gene Editing, OECD expert meeting, Berlin, July 6-7, 2017, moderator for workshop Session 1, Ethics and Governance in Gene Editing

4. Ethical Issues of New Technologies in Genomics, "Bioethics in the Era of Genomics and Personalized Medicine«, Sarajevo, Bosnia and Herzogovena Unit of UNESCO chair in bioethics meeting, October 28, 2016

5. One small edit for man, one giant edit for mankind? Points and questions to consider for a responsible way forward for gene editing in humans, European Society of Human Genetics annual meeting, Barcelona, May 2016

6. Whole Genome Sequencing in Newborn Screening? European Society of Human Genetics annual meeting, Glasgow, June 2015

7. Ethical and Social issues of Biobanks, Antwerp Institute for Tropical Disease Ethics Course, Antwerp, Belgium, Jan. 2015

8. Ethical, legal and social issues of direct-to-consumer genetic testing, The Swedish Society for Human Genetics, Keynote speaker, Arlanda, Sweden, Jan. 2015

9. *The return of results and direct-to-consumer genetic testing companies*, European COST-Actions, CHIPme conference, Coimbra, Portugal, Oct. 14th-16th, 2014

10. *The experiences and views of health care professionals and researchers regarding the feedback of results in the context of Next Generation sequencing in Oncology*. European Society of Human Genetics Annual Meeting, Milano, June 2014

11. *Direct-to-consumer genetic testing companies and biobanks*, Institue National de la Science and de la Recherche Medicale Workshop, March 24th-26th, 2014

12. *Public Health Genomics: Responsible introduction of genomic based information and technologies in public health*, CHI's Clinical Genomics and Informatics Europe event, Dec 6th, 2013

13. *Consent for whole genome sequencing in newborn screening*, Dutch National Institute for Public Health and the Environment, and Community Genetics, Nov. 13th 2013

14. *Biobanks and databases for rare disorders*, Brocher Foundation Workshop on "Rare Diseases", Geneva, Switzerland, 18-19 April 2013

15. *Direct-to-consumer genome sequencing: the current market and prospects*, Brocher Foundation Workshop on "Data Protection in the era of consumer targeted genome sequencing, Geneva, Switzerland, 4-5 February 2013

16. *Direct-to-consumer genetic testing*, European Commission Joint Research Centre workshop on The Genetic testing offer in Europe, Ispra, Italy, November 19th-20th, 2012

17. *Direct-to-consumer genetic testing companies and biobanks*, Messiness of Convergence Workshop, ESRC, Edinburgh, Sept. 27-28, 2012

18. *Ethical, Legal, and Social Issues of Direct-to-Consumer Genetic Testing*. Invited by: Ethos Plateforme interdisciplinaire d'éthique, Interface Sciences-Société, Université de Lausanne, Switzerland, July 1st, 2012

19. *Direct-to-consumer Genomic Testing: where have we been? Where are we going?,* Symposia, 11th Congress of Bioethics, International Association of Bioethics, 2012, Rotterdam, the Netherlands,

20. *Criteria for responsible introduction of genome-based-technologies and information into public health care,* European Meeting on Psychosocial Aspects of Genetics 2012, Nürnberg, Germany, June 23rd-26th, 2012

21. *Ethical, Legal, and Social Issues of Direct-to-Consumer Genetic Testing*. BGI Genomics, International Conference on Genomics in Europe, Copenhagen, Denmark, 24-26 May 2012

22. Tales from Many Lands: Direct-to-consumer Genetic Testing in Europe and the USA. Swiss Society of Medical Genetics annual meeting, Basel, Switzerland, April 12th, 2012

23. Ethical, Legal, and Social Issues of Direct-to-Consumer Genetic Testing. Medical Genetics Department Computational Biology Group, University of Lausanne, Swiss Institute of Bioinformatics, April 4th, 2012

24. *Ethical, Legal, and Social Issues of Direct-to-Consumer Genetic Testing*. Department of Genetic Medicine and Development, University of Geneva Medical School, March 27th, 2012,

25. *Ethical Aspects of Whole Genome Sequencing.* Invited by: Prof. Dr. Anne Cambon-Thomsen, European project GEUVADIS FP7 Coordination Action annual meeting. Nov. 29th, 2012

26. *Tests Génétiques en accès libre: Enjeux Ethiques*, Forum Étudiants, Université de Toulouse, Toulouse, Dec 2 2011

27. *Ethical Legal and Social Issues of Genomics*, Nyon Hospital Clinical Ethics Education, Nyon, Switzerland, Nov. 7, 2011

28. *Direct-to-consumer genetic testing; an overview*, 4th International and interdisciplinary congress on the pharmaceutical life cycle, the medicine life: conception, usages, and environment, University of Paris 8, 1-3 Sept. 2011

29. *A qualitative analysis of European clinical geneticists' views of direct-to-consumer genetic testing,* Interdisciplinary Symposium "Genetics as Culture in a Consumerist Age" Innsbruck, Austria, October 27-29th, 2011

30. *What do European Clinical Geneticists think about direct-to-consumer genetic testing?* Working group meeting of the "Tests génétiques en vente libre sur internet: ressorts, développements et consequences d'une offre en émergence » projet, Toulouse, June30-July 1 2011

31. *Survey of European clinical geneticists on awareness, experiences and attitudes towards direct-to-consumer genetic testing*, ESHG meeting, Amsterdam, May 28-31, 2011

32. *Ethical, Legal and Social Issues in Quality Assurance*, Public Health Genomics European Network II Meeting, Sevilla, October 14-15 2010

33. *Consommateurs ou participants à la receherche?,* INSERM Seminar Series, Oct. 1 2010, Université de Toulouse, Équipe 4: Génomique et santé publique

34. *Ethical Aspects of Direct-to-consumer genetic testing*, Summer Institute 2010: "Genetics, Ethics and Clinical Translation", Egmond aan Zee, Netherlands

35. *Direct-to-consumer genetic testing: the European Regulatory Landscape,* Genome Canada, Genomics Public Policy and Society meeting, Ottawa, Canada, June 29, 2010

36. *Direct-to-consumer genetic testing companies: what are their policies regarding testing in minors?* European Society of Human Genetics Conference, Gothenburg, Sweden, June 12-15, 2010

37. University of Padova (Padova,Italy); Public Health Genomics: What it is and what it isn't.

Erasmus Mundus Masters of Bioethics, May 2009

38. *Ethical Issues in Direct-to-Consumer genetic testing for pharmacogenomics*, European Summer University Technologies and Health : Law and Ethics (6-8 July 2009) Namur, Belgium

39. Introduction to Direct-to-Consumer Genetic Testing, European Society of Human Genetics Conference, Vienna, Austria, June 22-25, 2009

40. Masters Course on Medical Law, Université de Montréal, October 2009, Ethical, Legal and Social Issues of DTC GT

41. Erasmus Mundus Masters of Bioethics, KU Leuven, November 2009 & 2010, Research Methods

SELECTION OF PUBLISHED ABSTRACTS (for poster presentations)

HC Howard and P Borry, A qualitative analysis of European clinical geneticists' views of direct-to-consumer genetic testing, Amercian Society of Human Genetics 61th Annual Meeting, Montreal, Canada, October 11-15 2011

Pascal Borry, Rachel E. van Hellemondt, Dominique Sprumont, Camilla Fittipaldi Duarte Jales, Emmanuelle Rial-Sebbag, Tade Matthias Spranger, Liam Curren, Jane Kaye, Herman Nys, and HC Howard, Legislation on direct-to-consumer genetic testing in seven European countries, Amercian Society of Human Genetics 61th Annual Meeting, Montreal, Canada, October 11-15 2011

E. Rial-Sebbag, HC. Howard, P. Borry, A. Cambon-Thomsen, P. Ducournau, Freedom to directly access to genetic tests on internet: a part of the right to innovation?
Amercian Society of Human Genetics 61th Annual Meeting, Montreal, Canada, October 11-15 2011

M Ogorelkova, H. Howard, C. Garcia, _A. Navarro_, X. Estivill, 2005. Extensive gene conversion shapes the DNA sequence variability of HBII-52 small nucleolar RNA cluster and leads to rare haplotypes with potential link to eating disorders. *Am. J. Med. Genet. Part-B Neur. Genet. 138B: 83-84.

HC Howard and Pascal Borry, Ethical Issues Surrounding The Research Activities of Companies Selling Direct-to-Consumer Genetic Tests, Amercian Society of Human Genetics 59th Annual Meeting, Honolulu, Hawaii, USA, October 20-24th , 2009.

H.C. Howard, N. Dupre, M.-P. Dube, J. Horst, A. Simonati, J.-P. Bouchard, J. Mathieu, G.A.Rouleau. "Refining the Candidate Interval for Peripheral Neuropathy with or without Agenesis of the Corpus Callosum". *American Academy of Neurology*. Conference, Denver, USA. 2002

H.C. Howard, M.-P. Dubé, C. Marineau, L.K. Casaubon, M. Melanson, I. Lopes-Cendes, E.Andermann, F. Andermann, C. Prévost, J.-P. Bouchard, J. Mathieu, and G.A. Rouleau

(1996) Refining the Candidate interval for peripheral neuropathy with or without agenesis of the corpus callosum European Society for Human Genetics Conference Lisbon, Portugal. 1998

G. Rouleau, H.C. Howard, M.-P. Dubé, C. Prévost, J.-P. Bouchard, J. Mathieu. "Fine Mapping of the Peripheral Neuropathy with or without Agenesis of the Corpus Callosum Locus". Reunion de Génétique Humaine au Québec, *Qui fait quoi*?. 1998, Montreal, Québec

H.C. Howard, M.-P. Dubé, C. Marineau, L.K. Casaubon, M. Melanson, I. Lopes-Cendes, E.Andermann, F. Andermann, C. Prévost, J.-P. Bouchard, J. Mathieu, and G.A. Rouleau (1996) "Peripheral neuropathy with or without agenesis of the corpus callosum: linkage disequilibrium in the French Canadian population of Québec." 46th Annual American Society of Human Genetics Meeting SanFrancisco. October 1996. *Am. J. Hum. Gen*., supp vol 59, pA221

POSITION OF TRUST AND PROFESSIONAL MEMBERSHIPS

- Member of the Public and Professional Policy Committee (PPPC) of the European Society of Human Genetics (Jan 2012- present), https://www.eshg.org/pppc.0.html
- Chair COST ChipMe Work Group 2 (Genomics and Markets), Oct 2015- 2017 http://chipme2.promoscience.com/eng/home.aspx
- ELSI committee member of EIT Health, (April 2016- present), https://eithealth.eu
- Member Scientific Advisory Board of H2020 PhenoMeNal project on e-infrastructure for analysing medical metabolic phenotype data, (Sept. 2015-present) http://cordis.europa.eu/project/rcn/194953_en.html
- Member of the Global Alliance for Genomic and Health Ethics Task Team on public views of data sharing, (Sept 2015- present) https://genomicsandhealth.org
- Member of the Biobanking and BioMolecular Resources Research Infrastructure, BBMRI-ERCI ethical working group, http://bbmri-eric.eu/common-services
- Ethics advisory group for FHU Dijon Hospital project, Leader Laurence Faivre
- Membership to the European Society of Human Genetics (2011- present)
- Advisory board member for the project "Tests génétiques en vente libre sur internet: ressorts, développements et consequences d'une offre en emergence" financed by the French Institut de Recherche en Santé Publique (INSERM), Head researcher: Dr. Pascal Ducourneau
- Advising member of Public Health Genomics European Network II initiative, head researcher: Angela Brand, Workpackage II Quality Assurance

- Presenter and contributor of European Workshop on Genetic Testing Offer in Europe, European Commission JRC Scientific and Policy Reports, 2013, editors Ségolène, A. , Gribaldo, L., Matthijs, G., Borry, P.

TEACHING EXPERIENCE

2008- present, Invited lecturer in Bioethics,

Punctual lectures, most often on the bioethics of new technologies in Biology (with a focus on genetics and genomics)
Université de Lausanne, (durative, since 2012), KULeuven, Padova University, Université de Montréal, University of Basel, Université de Toulouse,

2014- present, Punctual Lectures for the Centre for Research Ethics and Bioethics, Department of Public Health and Caring Sciences, Uppsala University

- Introduction to Ethics and Bioethics, undergraduate students in Biological Engineering
- Introduction to Bioethics, Masters Student in Regenerative Medicine
- Bioethics Seminars, cases and discussion, Obligatory professional development course course for Masters and PhD students in Life Sciences

Fall 2013- Spring 2014, Radboud University, 60% teaching Bioethics teaching to Medical and Biomedical students, topics: end of life, (palliative care & euthanasia), neurology (brain death), reproductive technologies (IVF, abortion), Tissue engineering

Full time teaching appointments

August 2001– December 2003, Winter, Autumn 2006, Winter 2007, Autumn 2008 (Total: 10 terms/5 years)

Biology Teacher, Natural Sciences Department, Tenure offered
Marianopolis College, Montreal, Canada.
Courses: *Molecular Biology*, *Introductory Biology*, *Human Biology*
Responsibilities: teaching 3 classes for the entire 16 week semester, including lab teaching and supervision, development and correction of tests, and final exams for over 100 students per semester.
- participation, on average of at least 1 day pedagogical workshop per semester

Winter 1996-2001 Teacher's Assistant, Biology/Human Genetics Departments
McGill University, Montreal, Canada.
Courses: *Human Genetics Applied (177-370B),*
Molecular Biology 177-200A

SUPERVISION OF GRADUATE STUDENTS

Sep 2013- present, PhD co-supervisor, Bioethics, KU Leuven, Louiza Kalokairinou, Ethical, legal and social aspects of direct-to-consumer genetic testing

Sep 2013-June 2014, MSc supervisor, Bioethics, Radboud university, Patrick Miqueu, Ethical issues surrounding patient-centric health research initiatives

Sept 2013- June 2014, MSc supervisor, Bioethics, Radboud university, Emilia Niemic, Consent and whole genome sequence

May 2011- December 2012, co-supervisor, Bioethics PhD Student, Flora Colledge, Barriers to Sharing between Biobanks

2010-2011, supervisor, Bioethics Master Student, Cynthia Chen, Assessment of the ethical component of the ACCE framework to assess genetic tests

2009-2010, co-supervisor, Bioethics Masters student, Yeyang Su, Blog content analysis of users of direct-to-consumer genetic testing services

2009, co-supervisor Bioethics Masters student, Dr. Orpha V. Alonsabe, Postmenopausal pregnancy: a review of medical and ethical issues

2000-2001, supervisor, undergraduate student project, Montreal General Hospital, Jean-Baptiste Rivière, Molecular Genetics of Andermann Syndrome

SELECTION OF REVIEW ACTIVITIES for peer reviewed journals and books

- European Journal of Human Genetics, Nature Publishing
- Journal of Community Genetics, Springer
- American Journal of Bioethics, Primary Research, Taylor & Francis Group
- New Genetics and Society, Routledge
- Ethical Perspectives, Leuven, Belgium,
- Book Proposal Review by Springer: Ethical Challenges in Genomics Research by P. Boddington
- Journal of Public Health Genomics

PUBLIC VULGARISATION ACTIVITIES

- Pharmacogenomics Awareness Day, Montréal, Canada, Feb. 2009
- Invited Guest on CBC NewsWorld (national TV), Montréal, Canada, Oct. 2002
- Invited Guest on Global Morning News Show (regional TV), Montréal, Canada, Oct. 2002

ORGANISATION OF INTERNATIONAL CONFERENCES AND WORKSHOPS

- CHIPME COST Action, Work Group 2 annual meeting, Copenhagen, May 2017
- Brocher Workshop on Postmortem Genetics, Geneva, Nov. 2016
- CHIPME COST Action, Public-Private-Partnerships in Genomics, Sevilla, Oct. 2016

- CHIPME COST Action, Work Group 2 annual meeting, Barcelona, May 2016
- Brocher Workshop on Participant Centred Research Initiatives in Genetic and Genomics, Geneva, Sept. 2015
- Mind The Risk, year 1, concept group workshop, Paris, Nov. 2014
- *Direct-to-consumer Genomic Testing: where have we been? Where are we going?*, Symposia, 11th Congress of Bioethics, International Association of Bioethics, Rotterdam, June 2012
- *International workshop Direct-to-consumer genetic tests: confronting the issues for Europe*, 24/05/2009 during European Society of Human Genetics Conference in Vienna, , May 2009

Interruption of Studies

June 1997- January 1999

In June 1997 my partner experienced a severe traumatic brain injury as a result of an automobile accident. He was left in a coma for four weeks and awoke from the coma unable to do any of the basic activities of daily life, including speaking, walking, or feeding himself. I was his primary care provider from August 1997 until January 1999 and therefore did not work full time on my Ph.D. project. As a result of this accident he has been left with significant handicaps and I continue to be responsible for organizing the activities that make up his ongoing rehabilitation. This has been, without a doubt, the most difficult and humbling yet most meaningful work I have yet had the honor of contributing to.