

Cambridge University Press

978-1-108-49987-3 — Human Germline Genome Modification and the Right to Science

Edited by Andrea Boggio , Cesare P. R. Romano , Jessica Almqvist

[Table of Contents](#)[More Information](#)

## Contents

<i>List of Figures</i>	<i>page</i> xiii
<i>List of Tables</i>	xiv
<i>Notes on Contributors</i>	xv
<i>Foreword</i>	
Bartha Knoppers	xxvii
<i>Preface</i>	xxix
<i>Acknowledgments</i>	xxxiii
<i>List of Abbreviations</i>	xxxv
<b>1 Introduction</b>	<b>1</b>
<i>Andrea Boggio, Cesare P. R. Romano, and Jessica Almqvist</i>	
I The Science	3
II Methodology	15
<b>2 The Governance of Human (Germline) Genome Modification at the International and Transnational Level</b>	<b>22</b>
<i>Cesare P. R. Romano, Andrea Boggio and Jessica Almqvist</i>	
I Key Terms and a Quick Primer of International Law and International Human Rights Law	23
II International Bioethics Law	30
III Applicable International Human Rights Standards	53
IV Conclusions	78
<b>THE REGULATION OF GENOME MODIFICATION AT THE NATIONAL LEVEL</b>	<b>81</b>

<b>PART I NORTH AMERICA</b>	<b>81</b>
<b>3 The Regulation of Human Germline Genome Modification in Canada</b>	<b>83</b>
<i>Erika Kleiderman</i>	
I Introduction	83
II The Regulatory Environment	84
III Oversight Bodies and Funding for Research on Human Germline Modification	90
IV Substantive Provisions	91
V Current Perspectives and Future Possibilities	100
<b>4 The Regulation of Human Germline Genome Modification in the United States</b>	<b>103</b>
<i>Kerry Lynn Macintosh</i>	
I The Regulatory Environment	104
II Substantive Provisions	122
III Current Perspectives and Future Possibilities	126
<b>5 The Regulation of Human Germline Genome Modification in Mexico</b>	<b>129</b>
<i>María de Jesús Medina Arellano</i>	
I Introduction	129
II The Regulatory Framework	130
III Oversight Bodies for Research on Human Germline Genome Modification	143
IV Funding	145
V The Specific Regulatory Environment	147
VI Current Perspectives and Future Possibilities	152
<b>PART II EUROPE</b>	<b>153</b>
<b>6 The Regulation of Human Germline Genome Modification in Europe</b>	<b>155</b>
<i>Jessica Almqvist and Cesare P. R. Romano</i>	
I Introduction	155
II The Council of Europe	157
III The European Union	179
IV Conclusions	212

Cambridge University Press

978-1-108-49987-3 — Human Germline Genome Modification and the Right to Science

Edited by Andrea Boggio , Cesare P. R. Romano , Jessica Almqvist

Table of Contents

[More Information](#)

## Contents

ix

7	<b>The Regulation of Human Germline Genome Modification in the United Kingdom</b>	217
	<i>James Lawford Davies</i>	
	I Introduction	217
	II A Short Overview of the UK Legal System	217
	III The Regulatory Environment	219
	IV Substantive Provisions	226
	V Current Perspectives and Future Possibilities	232
8	<b>The Regulation of Human Germline Genome Modification in Germany</b>	241
	<i>Timo Faltus</i>	
	I Introduction	241
	II The Regulatory Environment	242
	III Substantive Provisions	251
	IV Current Perspectives and Future Possibilities	264
9	<b>The Regulation of Human Germline Genome Modification in Belgium</b>	266
	<i>Guido Pennings</i>	
	I Introduction	266
	II The Regulatory Framework	267
	III Substantive Provisions	273
10	<b>The Regulation of Human Germline Genome Modification in Sweden</b>	281
	<i>Santa Slokenberga and Heidi Carmen Howard</i>	
	I Introduction	281
	II The Overall Regulatory Environment	282
	III The Specific Regulatory Environment	299
	IV Current Perspectives and Future Possibilities	306
11	<b>The Regulation of Human Germline Genome Modification in the Netherlands</b>	309
	<i>Britta van Beers, Charlotte de Kluiver, and Rick Maas</i>	
	I Introduction	309
	II The Regulatory Framework	311

Cambridge University Press

978-1-108-49987-3 — Human Germline Genome Modification and the Right to Science

Edited by Andrea Boggio , Cesare P. R. Romano , Jessica Almqvist

Table of Contents

[More Information](#)

x

## Contents

III	Substantive Provisions	323
IV	Current Perspectives and Future Possibilities	327
<b>12</b>	<b>The Regulation of Human Germline Genome Modification in Italy</b>	
	<i>Ludovica Poli</i>	
I	Introduction	335
II	The General Legal System	335
III	Regulatory Environment	337
IV	Substantive Provisions	350
V	Current Perspectives and Future Possibilities	356
<b>13</b>	<b>The Regulation of Human Germline Genome Modification in Spain</b>	
	<i>Iñigo de Miguel Beriain and Carlos María Romeo Casabona</i>	
I	Introduction	358
II	The Regulatory Environment	359
III	The Regulatory Environment for Research on Human Germline Modification	368
IV	Current Perspectives and Future Possibilities	378
<b>14</b>	<b>The Regulation of Human Germline Genome Modification in France</b>	
	<i>Alessandro Blasimme, Dorothée Caminiti, and Effy Vayena</i>	
I	Introduction	380
II	The Regulatory Environment	381
III	Substantive Provisions	393
IV	Current Perspectives and Future Possibilities	404
<b>15</b>	<b>The Regulation of Human Germline Genome Modification in Switzerland</b>	
	<i>Alessandro Blasimme, Dorothée Caminiti, and Effy Vayena</i>	
I	Introduction	409
II	The Regulatory Environment	410
III	Substantive Provisions	427
IV	Current Perspectives and Future Possibilities	437

Cambridge University Press

978-1-108-49987-3 — Human Germline Genome Modification and the Right to Science

Edited by Andrea Boggio , Cesare P. R. Romano , Jessica Almqvist

[Table of Contents](#)[More Information](#)

## Contents

xi

<b>PART III ASIA</b>	<b>439</b>
<b>16 The Regulation of Human Germline Genome Modification in Japan</b>	<b>441</b>
<i>Tetsuya Ishii</i>	
I Introduction	441
II The Regulatory Environment	442
III Substantive Provisions	451
IV Current Perspectives and Future Possibilities	461
<b>17 The Regulation of Human Germline Genome Modification in the People's Republic of China</b>	<b>469</b>
<i>Lingqiao Song and Rosario Isasi</i>	
I Introduction	469
II The Regulatory Environment in the PRC	470
III Substantive Provisions	488
IV Current Perspectives and Future Possibilities	497
<b>18 The Regulation of Human Germline Genome Modification in the Republic of Korea</b>	<b>500</b>
<i>Hannah Kim and Yann Joly</i>	
I Introduction	500
II The Regulatory Environment	502
III Substantive Provisions	510
IV Current Perspectives and Future Possibilities	513
<b>19 The Regulation of Human Germline Genome Modification in Singapore</b>	<b>516</b>
<i>Calvin W. L. Ho</i>	
I Introduction	516
II A Brief Overview of Singapore's Legal And Political System	518
III Regulation of Research Involving A Human Embryo, Assisted Reproduction Centres and Non-Human Animals	521
IV Legal and Regulatory Requirements that Apply to Human Biomedical Research Involving Genome Editing in a Non-Clinical Trial Setting	525
V Regulation of Clinical Research	534
VI Current Perspectives and Future Possibilities	537

Cambridge University Press

978-1-108-49987-3 — Human Germline Genome Modification and the Right to Science

Edited by Andrea Boggio , Cesare P. R. Romano , Jessica Almqvist

[Table of Contents](#)[More Information](#)

xii

*Contents*

<b>PART IV OTHER OECD COUNTRIES</b>	<b>541</b>
<b>20 The Regulation of Human Germline Genome Modification in Australia</b>	<b>543</b>
<i>Dianne Nicol</i>	
I Introduction	543
II Regulatory Environment	546
III Substantive Provisions	553
IV Current Perspectives and Future Possibilities	562
<b>21 The Regulation of Human Germline Genome Modification in Israel</b>	<b>568</b>
<i>Vardit Ravitsky and Gali Ben-Or</i>	
I Introduction	568
II The Regulatory Framework	569
III Oversight Bodies for Research on Human Germline Genome Modification	580
IV Current Perspectives and Future Possibilities	581
<b>PART V CONCLUSIONS</b>	<b>583</b>
<b>22 Toward a Human Rights Framework for the Regulation of Human Germline Genome Modification</b>	<b>585</b>
<i>Andrea Boggio, Cesare P. R. Romano, and Jessica Almqvist</i>	
I Evidence	587
II Analysis	597
III Recommendations	611
<b>Index</b>	<b>618</b>