



THIRD INTERNATIONAL CONFERENCE ON END OF LIFE LAW, ETHICS, POLICY, AND PRACTICE

#ICEL3

MARCH 7-9, 2019

Convention Center Het Pand, Onderbergen 1, 9000 Ghent, Belgium





WELCOME






It is a great honor and pleasure to welcome you to the **Third International Conference on End-of-Life Law, Ethics, Policy, and Practice** in this old Dominican monastery located in the heart of Ghent. This historical building on the banks of the river Leie, near the medieval port with the guildhalls as its remnants is now the culture and congress centre of Ghent University and houses several museum collections, exhibition rooms kept in the original state, and a top-restaurant.

Belgium's **End-of-Life Care Research Group** of Vrije Universiteit Brussel & Ghent University is proud to present a thought-provoking program on a broad range of end of life issues. You can find the **full programme** on the next page, followed by a handy **venue guide** (p10), the biographies of our **plenary speakers** (p12) and a convenient **map** with directions to the conference reception on Thursday and the dinner on Friday (p16). The **abstract book** can be found at icel3.org/abstract-book.

As you know, ICEL is a multidisciplinary, multisectoral, and multinational conference, with presenting disciplines including, but not limited to, law, medicine, nursing, philosophy and bioethics, and sectoral representation spanning practitioners, academics, NGOs, and regulators and policy-makers. We will engage with empirical evidence about, and legal and ethical analysis of, many of the most pressing and vexing issues of our time. Leading experts from around the world will present on their findings. As a participant, you will engage with others who are wrestling with the challenges of end of life care. An overview of all **participants** can be found at the end of this booklet (p20).

We look forward to this two-and-a-half-day deep dive into stopping/not starting potentially life-sustaining treatment, palliative sedation, medical assistance in dying, and the next generation end of life issues. We would like to thank our sponsors and partners (p18), all the members of the Scientific and Organizing Committees (p19) and Ghent University for making this conference possible.

Do not forget to **take your time to get lost in the historic centre of Ghent**, explore the museums, enjoy our culinary talent and throw yourself into the bustling nightlife. Below are 5 tips on what to see and do around the conference venue.

-  1. Admire the newly renovated masterpiece 'Adoration of the Mystic Lamb' in St-Bavo's Cathedral.
-  2. Take a trip around the city by boat.
-  3. Discover the different architectural types of the City Pavillion. With its elements of gothic and renaissance in just one building, it is one of the most spectacular buildings in Ghent.
-  4. Relive the history at the 12th century Castle of the Counts. Right outside you'll find the Tierentyn Mustard show where they still pour the mustard right in front of you.
-  5. Ghent is the first city in Flanders that organized 'Thursday Veggieday' to stimulate people to go meat-free one day a week. Find all the best vegetarian restaurants in the Ghent Veggie Guide.

But this is just the beginning: discovering Ghent means this and so much more! Find out why Ghent is Europe's best kept secret on **visit.gent.be**.

On behalf of the Scientific Committee and Organizing Committee,



Kenneth Chambaere, Chair



Luc Deliëns, Co-chair

PROGRAMME

THURSDAY 7 MARCH, 2019

08.00-09.00 REGISTRATION & WELCOME COFFEE ENTRANCE HALL & KAPITTELZAAL

09.00-09.30 OPENING REFTER (PLENARY HALL)

- 09.00-09.10 Welcome by the Chair of the Scientific Committee - Kenneth Chambaere (BE)
- 09.10-09.30 Introduction by Jean-Jacques De Gucht (BE) - Member of the Flemish Parliament (Liberal Party)

09.30-12.00 PLENARY 1: LATEST DEVELOPMENTS IN ASSISTED DYING AROUND THE WORLD REFTER (PLENARY HALL)

Chair: Kenneth Chambaere (BE)

- 09.30-10.00 Developments in European countries - Agnes van der Heide (NL)
- 10.00-10.30 Recent developments and the future of MAiD in Canada - Jocelyn Downie (CAN)
- 10.30-11.00 A review of developments in Australia - Lindy Willmott (AUS)
- 11.00-11.15 Comfort Break
- 11.15-12.00 Gobal Panel - Moderator Freddy Mortier (BE) - Members: Agnes van der Heide (NL), Jocelyn Downie (CAN), Lindy Willmott (AUS), Luc Deliens (BE) & Thaddeus Pope (USA)

12.00-13.00 LUNCH KAPITTELZAAL

13.00-14.30 PARALLEL SESSIONS 1

Refter (Plenary Hall)	Zaal Rector Vermeylen (2 nd floor)	Oude Infirmierie (2 nd floor)	Priorzaal (1 st floor)
<p>MAiD in Canada 2 years of experience Chair: Stefanie Green (CAN)</p> <p><i>Stefanie Green, Ellen Wiebe, Shanaaz Gokool, Tanja Daws (CAN)</i></p>	<p>ASSISTED DYING & IDEOLOGY Chair: Freddy Mortier (BE)</p> <p>Euthanasia embedded in palliative care? <i>Jan Bernheim (BE)</i></p> <p>Pillarization' as/and biopolitics. Institutional shaping of the requests for euthanasia in Belgium: a sociological approach <i>Natasia Hamarat (BE)</i></p> <p>Euthanasia in Italy: A battle between religion and secularism <i>Johannes Agterberg (IT)</i></p>	<p>CAPACITY Chair: Constance MacIntosh (CAN)</p> <p>Cognitive Distortions and Capacity in MAID Requests where Mental Illness is Present <i>Justine Dembo (CAN)</i></p> <p>Executive dysfunction and capacity for medical decision-making in MAID Requests <i>Lilian Thorpe (CAN)</i></p> <p>Rights! Freedom! Autonomy! Capacity? <i>Peter Saul (AUS)</i></p> <p>A new law in Taiwan: the convergence of legal capacity and mental capacity in Patient Autonomy Act <i>Wan-Ting Hsieh (TWN)</i></p>	<p>SELECTED THEMES Chair: Thaddeus Pope (USA)</p> <p>Bioethical and legal dilemmas on hunger strike in prison settings <i>Maria Ciruzzi (ARG)</i></p> <p>VSED for Advanced Dementia Patients in the US <i>Robert Rivas (USA)</i></p> <p>Primum non nocere: medical liability in end-of-life scenarios <i>Vera Lúcia Raposo (CHN)</i></p>

14.30-15.00 COFFEE BREAK KAPITTELZAAL

15.00-16.30 PARALLEL SESSIONS 2

Refter (Plenary Hall)	Zaal Rector Vermeylen (2 nd floor)	Oude Infirmierie (2 nd floor)	Priorzaal (1 st floor)
<p>ROLE OF PROFESSIONALS IN ASSISTED DYING Chair: Thierry Vansweevelt (BE)</p>	<p>ASSISTED DYING: DEVELOPMENTS IN BELGIUM & THE NETHERLANDS Chair: Bregje Onwuteka-Philipsen (NL)</p>	<p>PROMOTION OF ADVANCE CARE PLANNING Chair: Agnes van der Heide (NL)</p>	<p>ACCESS TO ASSISTED DYING Chair: Luc Deliens (BE)</p>
<p>Making Sense of Medical Aid in Dying: how physicians in Québec (Canada) experience MAiD in relation to the ordinary practice of medicine <i>Samuel Blouin (CAN)</i></p> <p>The physician's role in medical aid-in-dying: perspectives from Vermont <i>Mara Buchbinder (USA)</i></p> <p>Clinicians' perspectives, and willingness to participate in voluntary assisted dying in Victoria, Australia <i>Karen Detering (AUS)</i></p> <p>Health Care Professionals' Perspectives on Medical Assistance in Dying <i>Hope Fast (CAN)</i></p>	<p>Slippery slope in the Netherlands? <i>Laura De Vito (NL)</i></p> <p>Study on denied requests for euthanasia submitted at the End-of-Life Clinic <i>Caroline Van den Ende (NL)</i></p> <p>Factors associated with requesting and receiving euthanasia: A nationwide mortality follow-back study with a focus on psychiatric disorders, dementia and an accumulation of health problems related to old age <i>Kirsten Evenblij (NL)</i></p> <p>Euthanasia in Belgium: Shortcomings of the law and its application and of the monitoring of practice <i>Sigrid Sterckx (BE)</i></p>	<p>Transforming Advance Care Planning Australia, a collaborative national effort <i>Linda Nolte (AUS)</i></p> <p>Advance directives: What does a campaign of loco-regional public debates reveal of citizens' perception of them? <i>Stéphanie Pierre (FR)</i></p> <p>The cost-effectiveness of advance care planning for older adults with end-stage kidney disease <i>Marcus Sellars (AUS)</i></p>	<p>Assisted dying laws in Victoria: Restricting discussions about end of life options <i>Lindy Willmott (AUS)</i></p> <p>The Waxing and Waning of the Informed Consent Principle in the Law Governing End of Life Decision-making in Canada <i>Thomas McMorrow (CAN)</i></p> <p>Deployment of 'the dying': Voluntary assisted dying in the Australian state of Victoria <i>Courtney Hempton (AUS)</i></p> <p>Representing the collective voice of the newly emerging MAiD community in Canada <i>Liana Brittain (CAN)</i></p>

16.30-16.45 Comfort Break

16.45-17.45 PLENARY 2: CONSCIENTIOUS OBJECTION REFTER (PLENARY HALL)

Chair: Thierry Vansweevelt (BE)

16.45-17.15 Let Thy Conscience Be Thy Guide—But Whose Conscience Wins? Personal and Institutional Objections to Providing MAiD - Daphne Gilbert (CAN)

17.15-17.45 Conscientious objections: Can health institutions legally refuse end-of-life care treatments? Sylvie Tack (BE)

18.00-20:00 RECEPTION AT GHENT TOWN HALL

Stadhuis Gent, Botermarkt 1, 9000 Ghent



PROGRAMME

FRIDAY 8 MARCH, 2019

08.30-09.00 WELCOME COFFEE KAPITTELZAAL

09.00-10.30 PARALLEL SESSIONS 3

Reffer (Plenary Hall)	Zaal Rector Vermeylen (2 nd floor)	Oude Infirmierie (2 nd floor)	Priorzaal (1 st floor)
<p>WITHHOLDING & WITHDRAWING TREATMENT Chair: Ben White (AUS)</p> <p>Withdrawing and withholding treatment in a post-best interests world <i>James Cameron (AUS)</i></p> <p>Medical futility at the end-of-life: an Australian policy analysis <i>Eliana Close (AUS)</i></p> <p>To eat or to die: a crucial dilemma in Elderly <i>Véronique Fournier (FR)</i></p> <p>The Vincent Lambert case: An illustration of the limits of an EoL law to resolve all ethical clinical issues <i>Denis Berthiau (FR)</i></p>	<p>VIEWS ON END-OF-LIFE TREATMENT Chair: Joachim Cohen (BE)</p> <p>Staff Positions on End-Of-Life Treatment in patients with incurable diseases <i>Rina Gabison (ISR)</i></p> <p>Non-beneficial treatment at the end of life in a palliative care population with cancer: a systematic review of reasons <i>Marleen Moors (NL)</i></p> <p>What do people with life-limiting illness considering euthanasia/assisted dying think about treatments at the end-of-life? <i>Jessica Young (NZ)</i></p> <p>Medical Futility Dispute Resolution Options in the United States: Law & Ethics Fundamentals <i>Thaddeus Pope (USA)</i></p>	<p>ADVANCE DIRECTIVES Chair: Eliana Close (AUS)</p> <p>Legal and ethical challenges of new media in advance directives <i>Hui Yun Chan (UK)</i></p> <p>Doctors' perspectives on adhering to advance care directives when making medical decisions for patients with chronic disease: an interview study in a Melbourne metropolitan hospital <i>Karen Detering (AUS)</i></p> <p>Prevalence of advance care directives among older Australians accessing health and residential aged care services: multi-centre audit study <i>Linda Nolte (AUS)</i></p> <p>The association between knowledge of end-of-life options and attitudes and behaviors regarding advance directives in Switzerland: Evidence from a National Population-based Study <i>Sarah Vilpert (SWI)</i></p>	<p>ASSISTED DYING IN PSYCHIATRY Chair: Jocelyn Downie (CAN)</p> <p>When Unbearable Suffering Incites Psychiatric Patients to Request Euthanasia: a Qualitative Study <i>Monica Verhofstadt (BE)</i></p> <p>Public and physicians' support for euthanasia in people suffering from psychiatric disorders: A cross-sectional survey study <i>Kirsten Evenblij (NL)</i></p> <p>Perspectives from mental health professionals in Saskatchewan, Canada about the potential expansion of Medical Assistance in Dying to patients with mental illness <i>Cadence MacPherson (CAN)</i></p>

10.30-11.00 COFFEE BREAK KAPITTELZAAL

11.00-12.00 PLENARY 3: NUTRITION AND HYDRATION AT THE END OF LIFE

REFTER (PLENARY HALL)

Chair: Constance MacIntosh (CAN)

11.00-11.30 Withdrawing Clinically Assisted Nutrition and Hydration: New Supreme Court decision and professional guidance in England and Wales - Celia Kitzinger (UK)

11.30-12.00 VSED Divulged: Legal, Ethical, and Clinical Status of the Voluntarily Stopping Eating and Drinking Exit Option - Thaddeus Pope (USA)

12.00-13.00 LUNCH KAPITTELZAAL

13.00-14.30 PARALLEL SESSIONS 4

Refter (Plenary Hall)	Zaal Rector Vermeylen (2 nd floor)	Oude Infirmerie (2 nd floor)	Priorzaal (1 st floor)
PALLIATIVE SEDATION Chair: Karen Detering (AUS)	ASSISTED SUICIDE VS SUICIDE Chair: Greg Mewett (AUS)	END OF LIFE ISSUES IN DEMENTIA Chair: Lara Pivodic (BE)	SELECTED THEMES Chair: Aline De Vleminck (BE)
<p>Palliative sedation at the end of life: state-of-the art, challenges and opportunities for improvement <i>Lenzo Robijn (BE)</i></p> <p>Deep and continuous sedation until death : A first national retrospective survey in France <i>Sandrine Bretonnière (FR)</i></p> <p>Development of an information leaflet for palliative sedation <i>Frank Spichiger (SWI)</i></p>	<p>Understanding the concept of suicide in an age of assisted dying (a global issue through the lens of Canadian experience) <i>Jocelyn Downie (CAN)</i></p> <p>Suicide prevention in an age of medical assistance in dying: a Canadian perspective <i>Mona Gupta (CAN)</i></p> <p>Suicide or not suicide: how people involved in conversations about assisted suicide distinguish assisted suicide from suicide in Switzerland <i>Samuel Blouin (CAN)</i></p>	<p>Termination of life based on a written request: what do the Regional Review Committees say? <i>Laura De Vito (NL)</i></p> <p>Views on assisted dying for people with dementia: a Netnographic approach <i>Aida Dekhoda (NZ)</i></p> <p>Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies <i>Marcus Sellars (AUS)</i></p> <p>Moral Distress and Autonomy at the End of Life <i>Dena Davis (USA)</i></p>	<p>Dying on an emergency department and the decisions at the end-of-life <i>Annelies Vermeir (BE)</i></p> <p>Access to Home Palliative Care: pilot project in Portugal <i>Guida Da Ponte (POR)</i></p> <p>Knowledge and attitude to end of life choices including medical assistance in dying (MAiD) in marginalized indigenous and non-indigenous people in Canada <i>Ellen Wiebe (CAN)</i></p> <p>Restricted palliative care <i>Marius Ciurlionis (LIT)</i></p>

14.30-15.00 COFFEE BREAK KAPITTELZAAL

15.00-16.00 PLENARY 4: PRESSURE POINTS IN END-OF-LIFE DECISION MAKING

REFTER (PLENARY HALL)

Chair: Joachim Cohen (BE)

15.00-15:30 Dementia, capacity and advance directives: current developments in the Netherlands
Bregje Onwuteaka-Philipsen (NL)

15.30-16.00 Palliative sedation as an alternative to assistance in dying? - James Downar (CAN)

16.00-16.15 Comfort Break

16.15-17.45 PARALLEL SESSIONS 5

Reffer (Plenary Hall)	Zaal Rector Vermeylen (2 nd floor)	Oude Infirmierie (2 nd floor)	Priorzaal (1 st floor)
<p>From legislative provisions on End of Life to application on clinical grounds: Which ethical challenges? A European - French, German, Italian - comparative perspective Chair: <i>Véronique Fournier (FR)</i></p>	<p>Issues of Overlap between "Suicide" and "Physician Aid in Dying" Chair: <i>Margaret Battin (USA)</i></p>	<p>STATISTICS FOR ASSISTED DYING Chair: <i>Kenneth Chambaere (BE)</i></p>	<p>DEFINING DEATH Chair: <i>James Downar (CAN)</i></p>
<p><i>Véronique Fournier (FE), Gerald Neitzke (GER) & Renzo Pegoraro (IT)</i></p>	<p><i>Margaret Battin (USA), Joachim Cohen (BE), Jocelyn Downie (CAN), Agnes van der Heide (NL), Ellen Wiebe (CAN) & Lindy Willmott (AUS)</i></p>	<p>Completion of medical certificates of death after an assisted death: An environmental scan of practices <i>Janine Brown (CAN)</i></p> <p>An Analysis of Euthanasia Statistics in Various Countries <i>Miho Tanaka (JPN)</i></p> <p>Drugs used for euthanasia: A repeated Population-Based Mortality Follow-Back Study in Flanders, Belgium <i>Sigrid Dierickx (BE)</i></p> <p>Medical Assistance in Dying in Canada: An assessment of the evidence with respect to advance requests, mature minors, and where a mental disorder is the sole underlying medical condition <i>Mona Gupta (CAN)</i></p>	<p>Consensus, controversies and dilemmas concerning the definition of death in the USA <i>Betty Levin (USA)</i></p> <p>Brain Death and the Law: Hard Cases and Legal Challenges <i>Thaddeus Pope (USA)</i></p> <p>Final death <i>Helen Towers (USA)</i></p>

18.30-20.30 CONGRESS DINNER AT GHENT CITY MUSEUM

STAM, Godshuizenlaan 2, 9000 Ghent

Free museum visit from 18:00 (until midnight).

Welcome drink from 18:30.

Congress dinner starts at 19:00.



PROGRAMME

SATURDAY 9 MARCH, 2019

08.30-09.00 WELCOME COFFEE KAPITTELZAAL

09.00-10.30 PARALLEL SESSIONS 6

Reffer (Plenary Hall)	Zaal Rector Vermeylen (2 nd floor)	Oude Infirmierie (2 nd floor)	Priorzaal (1 st floor)
<p>IMPLEMENTATION OF ASSISTED DYING Chair: Sandrine Bretonnière (FR)</p> <p>Developing a medical assistance in dying curriculum in specialty residency training programs <i>Susan Macdonald (CAN)</i></p> <p>Impact of a Unique Canadian approach to Medical Assistance in Dying by Nurse Practitioners in the patient's home environment <i>Calvin Pelletier (CAN)</i></p> <p>Psychiatric Patients Requesting Euthanasia: Initiatives for Sound Clinical and Ethical Decision Making <i>Monica Verhofstadt (BE)</i></p> <p>A regulatory analysis of Victoria's Voluntary Assisted Dying Regime <i>Ben White & Katrine Del Villar (AUS)</i></p>	<p>NEONATES & MINORS Chair: Kim Beernaert (BE)</p> <p>Neonatologists' and neonatal nurses' attitudes towards perinatal end-of-life decisions <i>Laure Dombrecht (BE)</i></p> <p>Every single day we resuscitate her... what are we doing, where are we going? Modifiable factors for improving end-of-life decision making for neonatologists, nurses, and parents in the Neonatal Intensive Care Unit <i>Veerle Piette (BE)</i></p> <p>Age Distinction in Canada's Bill C-14: Necessary or Discriminatory? <i>Kathryn Morrison (CAN)</i></p> <p>The fraught notion of a good death for children: Can a child ever really 'die well'? <i>Bryanna Moore (USA)</i></p>	<p>ASSISTED DYING FROM A RIGHTS PERSPECTIVE Chair: Lindy Willmott (AUS)</p> <p>A re-examination of the compatibility of the English blanket ban on assisted suicide with the prohibition on ill-treatment in article 3 of the European Convention on Human Rights <i>Stevie Martin (UK)</i></p> <p>The semantics of the 'right to assisted dying' <i>Adam McCann (UK)</i></p> <p>Legal change on assisted dying revisited <i>Penney Lewis (UK)</i></p> <p>Right-to-Die Society in Belgium: history & future <i>Marc Van Hoey (BE)</i></p>	<p>POLICY DEVELOPMENT Chair: Mona Gupta (CAN)</p> <p>Policy development in contested spaces: drivers of change and evidence based policy <i>James Cameron (AUS)</i></p> <p>The Voluntary Assisted Dying Act 2017: the role of the public service in significant government reform <i>Jackie Kearney (AUS)</i></p> <p>Minors & MAiD: Canadian Law Reform Process & Debate <i>Constance MacIntosh (CAN)</i></p> <p>Guidelines-based regulation on end-of-life care decisions in Japan <i>Futoshi Iwata (JPN)</i></p>

10.30-11.00 COFFEE BREAK KAPITTELZAAL

11.00-12.15 PLENARY 5: THE LONG-TERM VIEW ON END-OF-LIFE PRACTICE

REFTER (PLENARY HALL)

Chair: Luc Deliens (BE)

11.00-11.30 Ethical reflection on what has passed: predictions for the future - Freddy Mortier (BE)

11.30-12.15 Global Panel: Moderator: Kenneth Chambaere (BE) - Members: Freddy Mortier (BE), Jocelyne Downie (CAN), Bregje Onwuteaka-Philipsen (NL), Ben White (AUS) & Peggy Battin (USA)

12.15-12.30 CLOSING

Closing by Co-Chair of the Scientific Committee - Luc Deliens (BE)

12.30-13.30 LUNCH KAPITTELZAAL

VENUE GUIDE

CATERING AND PLENARY HALL GROUND FLOOR

- enter by the main entrance
- go right
- pass the reception desk
- take the glass door in front of you

KAPITTELZAAL (CATERING)

- enter the open space
- at your left you find the Kapittelzaal

REFETER (PLENARY HALL)

- take the first double door at your left



PARALLEL SESSIONS ROOMS 1ST & 2ND FLOOR

- enter by the main entrance
- go left
- go to the end of the hallway
- take the double glass door

PRIORZAAL - 1ST FLOOR

- by stairs:
 - go to the 1st floor
 - take the glass door at your left
 - enter by the double white door in front of you
- by elevator:
 - take the white door immediately at your right
 - go to the 1st floor
 - turn left around the corner
 - take the glass door at your left
 - enter by the double white door in front of you

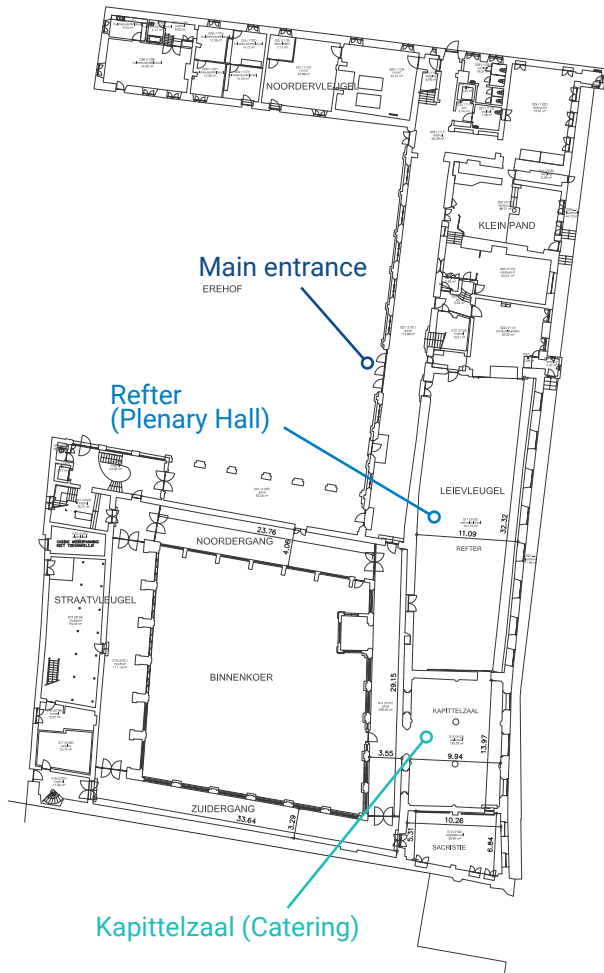
ZAAL RECTOR VERMEYLEN - 2ND FLOOR

- by stairs:
 - take 3x the stairs (up to the 1,5 floor)
 - enter by the brown door at your left (zaal rector vermeylen)
- by elevator:
 - take the white door immediately at your right
 - go to the 2nd floor
 - go right
 - take a few steps down
 - enter by the brown door (zaal rector vermeylen)

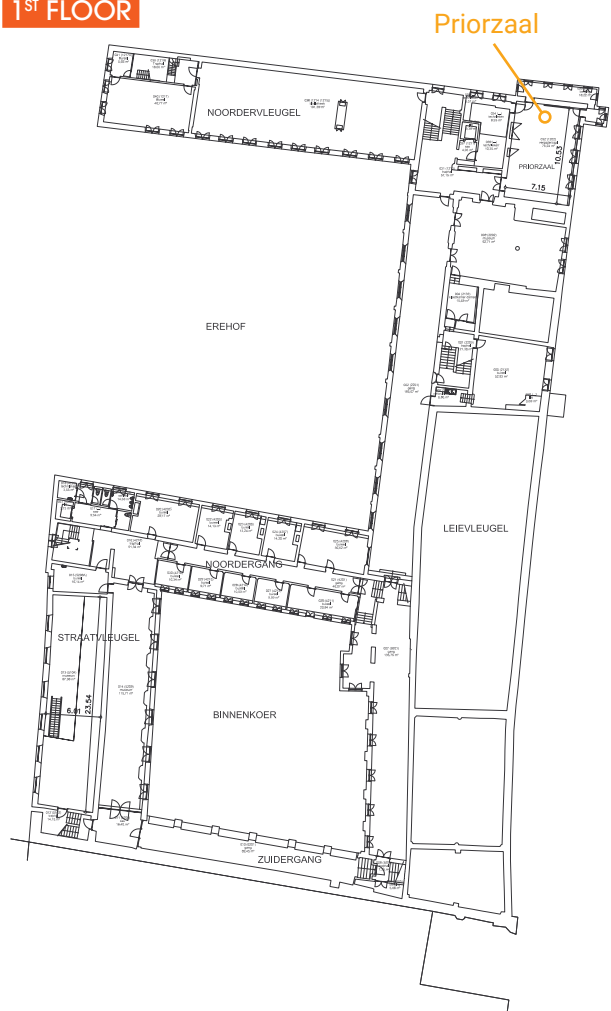
OUDE INFIRMERIE - 2ND FLOOR

- by stairs:
 - go to the 2nd floor
 - take the glass door at your left
 - enter by the double white door in front of you
- by elevator:
 - take the white door immediately at your right
 - go to the 2nd floor
 - turn left around the corner
 - take the glass door
 - enter by the double white door in front of you

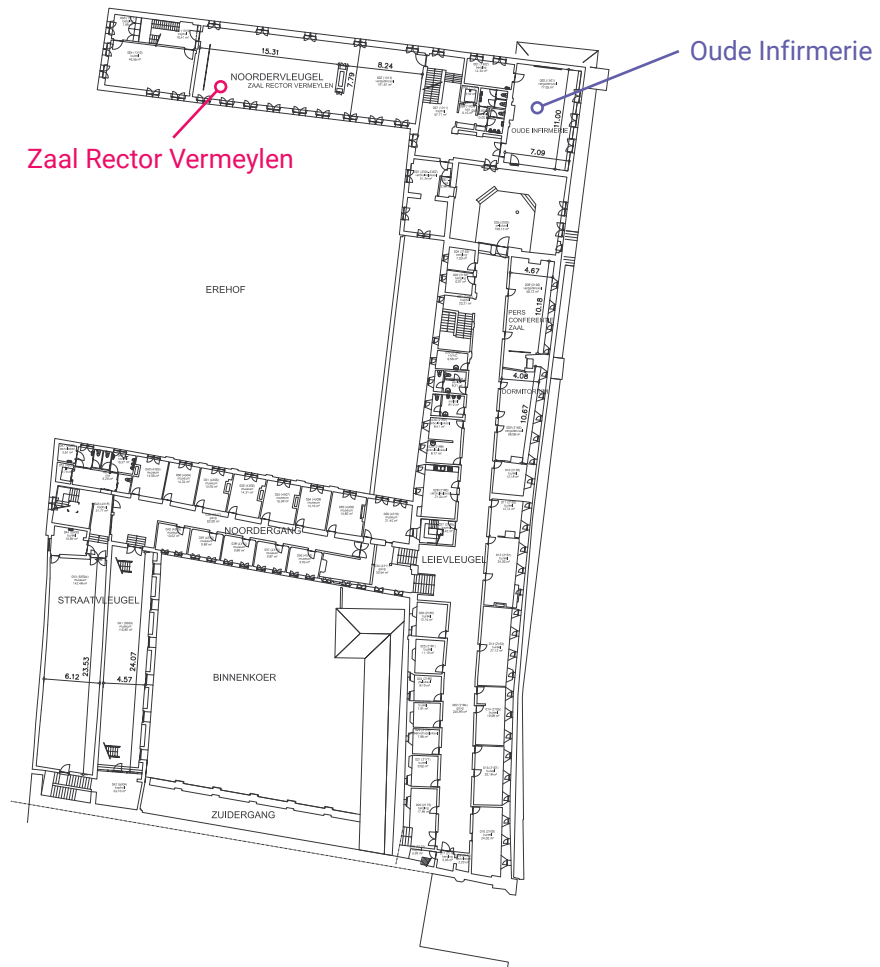
GROUND FLOOR



1ST FLOOR



2ND FLOOR



PLENARY SPEAKERS

MARGARET BATTIN (USA)



Margaret Pabst Battin, M.F.A., PhD., Distinguished Professor of philosophy and medical ethics at the University of Utah, has authored, co-authored, edited, or co-edited some twenty books, including *Drugs and Justice* and *The Patient as Victim and Vector: Ethics and Infectious Disease*; two collections on end-of-life issues, *The Least Worst Death* and *Ending Life*; and a comprehensive sourcebook, *The Ethics of Suicide: Historical Sources*. She is currently completing *Sex & Consequences: A Thought Experiment for Saving the Planet*, about the large-scale reproductive problems of the globe. She has been named one of the “Mothers of Bioethics.”

KENNETH CHAMBAERE (BE)



Prof. Kenneth Chambaere is Assistant Professor at the End-of-Life Care Research Group of the Vrije Universiteit Brussel (VUB) and Ghent University in Belgium. He obtained an MSc in Sociology in 2004 and a Postgraduate in Logic, History and Philosophy of Science in 2005, before obtaining a PhD in Medical-Social Sciences in 2010 studying the incidence and characteristics of various end-of-life practices including euthanasia and palliative sedation. From 2010 to 2016 he was a Postdoctoral Fellow of the Research Foundation Flanders (FWO) devoting his time to empirically studying “slippery slope” phenomena in Belgium and other countries with assisted dying laws. Prof. Chambaere is involved in various research concerning palliative and end-of-life care. He has published over 50 international peer-reviewed papers to date.

JOACHIM COHEN (BE)



Professor Joachim Cohen is a medical sociologist and professor of the End-of-Life Care Research Group of the Vrije Universiteit Brussel and Ghent University. His program of research focuses on end-of-life care and related issues or trends. He graduated in 2001 as a Master in Sociology and in 2007 as a PhD in Social Health Sciences. His research has been awarded with the Kubler Ross Award for Young Researchers and the Young Investigator Award from the European Association of Palliative Care 2010. Both prizes were awarded to him, mainly because of his large-scale cross-national research on end-of-life care. Prof. dr. Cohen has published over 135 articles in international peer reviewed journals and co-edited the Oxford University Press book: “A public health perspective on end of life care”.

JEAN-JACQUES DE GUCHT (BE)



Jean-Jacques De Gucht is a Flemish politician and member of the Flemish Liberal party (Open Vld). He is known for his legislative proposals on ethical issues, with which he consistently shows himself to be a defender of an individual’s right to self-determination. At De Gucht’s initiative, the Euthanasia Act was extended to minors in 2014.

LUC DELIENS (BE)



Luc Deliens, PhD, is Professor of Palliative Care Research, Founding Director of the End-of-Life Care Research Group of the VUB University & Ghent University in Belgium, leading research programs on both palliative care and end-of-life decision making. His team is with about 60 staff people, the country's largest research group on end-of-life care. Back in the nineties, he was the first to conduct a nationwide empirical study on euthanasia in Belgium, published in 2000 in *Lancet*. Internationally, he chairs the European Association for Palliative Care (EAPC) Reference Group on Public Health and Palliative Care and co-chairs the EAPC Research Network and is involved in different on-going EU funded research projects. He successfully supervised over 40 PhDs and is actually supervising about 25 PhD students. He published over 500 papers or book chapters and received several scientific awards for his scientific work. He is also member of the Royal Academy of Medicine of Belgium.

JAMES DOWNAR (CAN)



James Downar is a Critical Care and Palliative Care physician in Ottawa. He graduated from McGill Medical School and completed residency training in Internal Medicine, Critical Care and Palliative Care at the University of Toronto. He has a Master's degree in Bioethics from the Joint Centre for Bioethics at the University of Toronto. He is currently the Head of the Division of Palliative Care at the University of Ottawa, and an Associate Professor in the Department of Medicine. He is the co-chair of the Pan-Canadian Palliative Care Research Collaborative, the chair of the Ethical Affairs committee of the Canadian Critical Care Society, and the co-chair of the Ontario Palliative Care Network's Provincial Education Steering Committee. He has authored more than 60 peer-reviewed publications, has been principal investigator on a dozen peer-reviewed grants, and is a former Associated Medical Services Phoenix Fellow. His research interests include communication and decision-making for seriously ill patients and their families; Palliative Care for the Critically Ill; and Palliative Care for Noncancer Illnesses.

JOCELYN DOWNIE (CAN)



Jocelyn Downie is the James S. Palmer Chair in Public Policy and Law and a Faculty Associate of the Health Law Institute at Dalhousie University. She is also an Adjunct Professor at the QUT Australian Centre for Health Law Research. Her work on end-of-life law and policy includes: Special Advisor to the Canadian Senate Committee on Euthanasia and Assisted Suicide; author of *Dying Justice: A Case for the Decriminalizing Euthanasia and Assisted Suicide in Canada*; and member of the Royal Society of Canada Expert Panel on End-of-Life Decision-Making, the plaintiffs' legal team in *Carter v. Canada (Attorney General)*, the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, and the Canadian Council of Academies Expert Panel on Medical Assistance in Dying.

DAPHNE GILBERT (CAN)



Daphne Gilbert is an Associate Professor at the Faculty of Law, University of Ottawa and a member of its Centre for Health Law, Policy & Ethics. She sits on the Legal Advisory Committee for Dying with Dignity, an organization committed to improving quality of dying and protecting end-of-life rights. A graduate of the University of Manitoba Faculty of Law and Yale Law School, Daphne clerked for Chief Justice Antonio Lamer at the Supreme Court of Canada before her appointment at the University of Ottawa. She teaches in the Public Law area and researches and writes on the constitutional challenges and opportunities in reproductive justice and medical aid in dying.

CELIA KITZINGER (UK)



Celia Kitzinger is Honorary Professor in the School of Law and Politics at Cardiff University where she co-directs the Coma and Disorders of Consciousness Research Centre (cdoc.org.uk). Over the past decade she has worked intensively with families who have a relative in a prolonged disorder of consciousness, including supporting them through court cases. She has co-created, with other members of the research centre, an award winning online resource for these families and is widely involved in training and the creation of e-learning resources. She was a member of the core group that wrote the new professional Guidance on Clinically Assisted Nutrition and Hydration.

CONSTANCE MACINTOSH (CAN)



Constance MacIntosh is the Viscount Bennett Professor of Law at the Schulich School of Law, Canada, and is a long-time member of Dalhousie's Health Law Institute. Her work engages with the intersection of law, policy and governance practices with the well-being of vulnerable populations.

FREDDY MORTIER (BE)



Freddy Mortier is professor of ethics at Ghent University (Belgium) and was vice rector from 2013 to 2017. He teaches general philosophy and bioethics at the faculties of Psychology and Educational Studies, of Medicine and Health Sciences, and at his own faculty. He is a member of the (Belgian) National Advisory Committee for Bioethics and was chairman and/or secretary of several ad hoc working parties in that committee. He is also a member of the Ethics Committee of the Ghent University Hospital and a member of the directing board of viWTA, the Flemish Parliamentary Institute for Technology Assessment. His interests in bioethics are mainly directed at end-of-life research, including the ethics of euthanasia and other end-of-life decisions. Other fields of special interest are the rights of minors in health care and the relation between religion and health care.

BREGJE ONWUTEAKA-PHILIPSEN (NL)



Bregje Onwuteaka-Philipsen is professor of end-of-life research at Amsterdam UMC, location VU University medical center. She leads the research group 'public health at the end-of-life' of the department of public and occupational health and is chair of the Expertise Center for Palliative Care of the VU University medical center. Her research covers the topics of advance care planning palliative care, and end-of-life decision making. She has ample experience in leading large research project such as the studies in which the Dutch Euthanasia Law is evaluated and incidences and circumstances of end-of-life decision-making are studied every 5 years.

THADDEUS POPE (USA)



Thaddeus Mason Pope is Director of the Health Law Institute and Professor at Mitchell Hamline School of Law in Saint Paul, Minnesota (USA). Professor Pope has nearly 200 publications in: leading medical journals, law reviews, bar journals, nursing journals, bioethics journals, and book chapters. He coauthors the definitive treatise *The Right to Die: The Law of End-of-Life Decisionmaking*. And he runs the Medical Futility Blog (with nearly four million page-views). In both his academic scholarship and his policy work, Professor Pope works to calibrate the balance between individual liberty and public health in the end-of-life medical treatment context.

SYLVIE TACK (BE)



Sylvie Tack studied law (2004) and medical-social sciences (2006) at Ghent University. After that she conducted scientific research within the interuniversity project 'Monitoring quality of end-of-life care'. In 2012 she obtained her phd in law with the thesis "Ethical policies on end-of-life decisions in healthcare institutions". Sylvie is currently a practice assistant at Ghent University and guest professor at Antwerp University. In addition to her academic career, Sylvie has been active as a health law lawyer for many years. She followed her training at Prof. Balthazar (Ghent) and was later attached to the Dewallens & Partners (Leuven) law office. In 2010, Sylvie started her own law practice in Knokke (Sanalex advocaten).

AGNES VAN DER HEIDE (NL)



Professor Agnes van der Heide is working at the department of Public health at Erasmus MC, University Medical Center Rotterdam, the Netherlands, since 1994. She is a professor in end-of-life care and decision making. Her studies are focused on epidemiology, health services and legal-ethical aspects in the field of end-of-life care, end-of-life communication and end-of-life decision making. She is and has been principal investigator of many collaborative research projects at the local, national and international level. Currently she supervises about 15 PhD students.

THIERRY VANSWEEVELT (BE)



Thierry Vansweevelt studied law at the UAntwerpen (University of Antwerp). He gained his doctorate in Law with a thesis on "The liability of the doctor and the hospital". As a full professor of the UAntwerpen Thierry lectures on liability law and health law. Between 2003 and 2006 he was dean of the Law Faculty. Thierry Vansweevelt is a member of the Bar of Antwerp as well as the Bar of Brussels. He specialized in medical liability law in which he defends both hospitals, doctors and patients. Insurance law is also close to his heart. He is also devoted to medical law concerning for example the duty of professional confidentiality and euthanasia.

LINDY WILLMOTT (AUS)



Lindy Willmott is a Professor of Law at Queensland University of Technology and a member of the Australian Centre for Health Law Research. Lindy researches and publishes in health law, particularly at the end of life. She has co-authored more than 10 texts and the website 'End of Life Law in Australia'. Lindy is currently undertaking empirical research projects funded by the Australian Research Council and the National Health and Medical Research Council. She co-leads projects to provide legal training to medical specialists about the law at the end of law, and an accredited training program for doctors involved in assisted dying in Victoria. Lindy is a Board Member of Palliative Care Australia and is on the Editorial Board of the Journal of Law and Medicine.

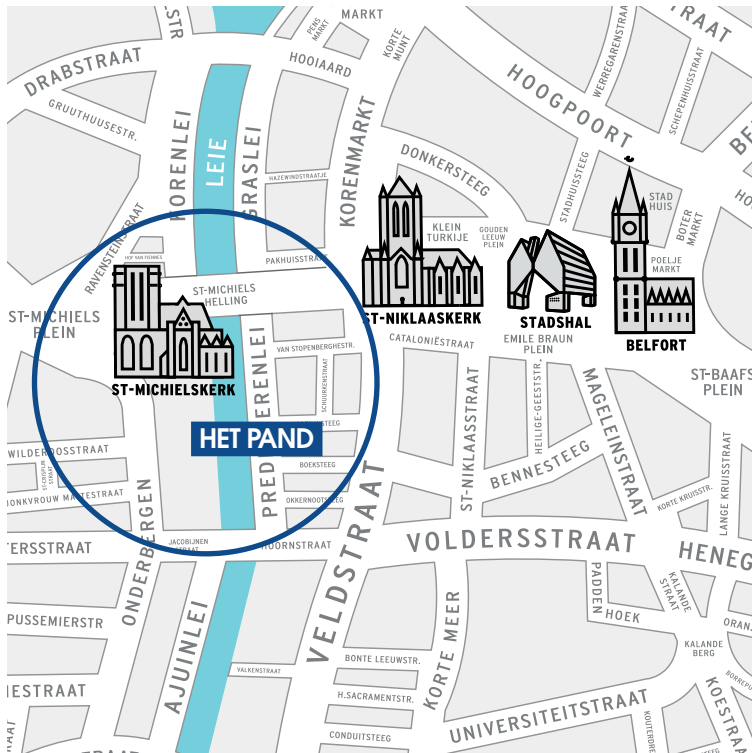
BEN WHITE (AUS)



Ben White is a Professor in the Australian Centre for Health Law Research in the Faculty of Law at the Queensland University of Technology (QUT). Ben graduated with first class Honours and a University Medal in Law from QUT and then completed a DPhil at Oxford University on a Rhodes Scholarship. He is undertaking a program of funded research examining law, policy and practice at the end of life through a series of Australian Research Council and National Health and Medical Research Council grants. He co-leads a project providing training to doctors about end of life law, and another training program for doctors involved in voluntary assisted dying in Victoria.

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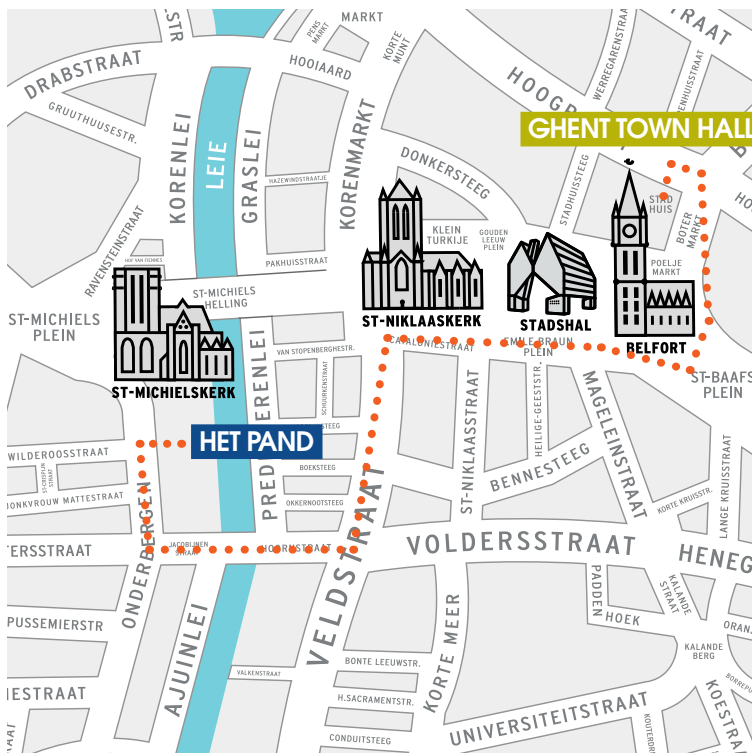
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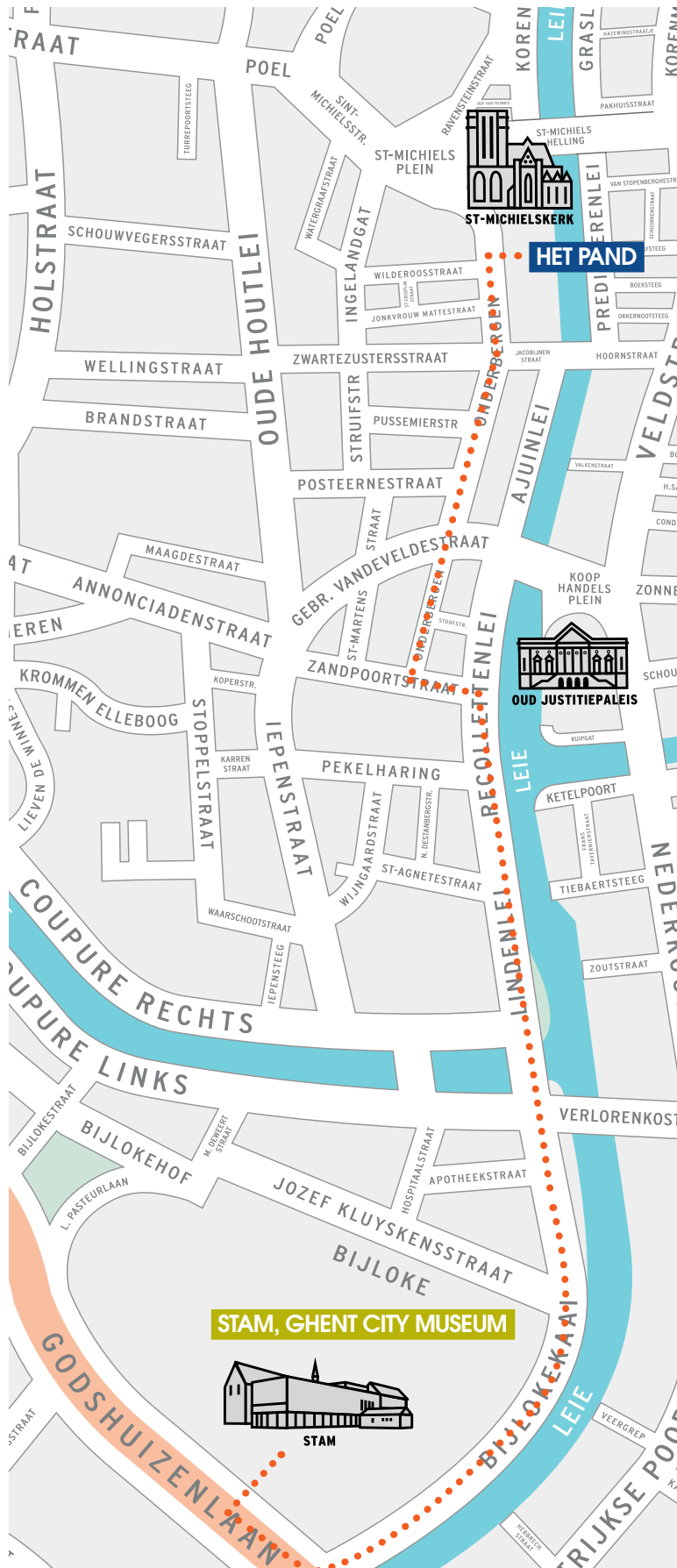
ROUTE 1: GHENT TOWN HALL | WALKING TIME: 8 MIN



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Address: Botermarkt 1, 9000 Ghent
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Time: 18:00-20:00

ROUTE 2: STAM, GHENT CITY MUSEUM | WALKING TIME: 16 MIN



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Address: Godshuizenlaan 2, 9000 Ghent

Date: Friday 8 March, 2019

Time: 18:00-24:00

Welcome drink from 18.30. The dinner starts at 19:00. Conference participants can visit the museum for free from 18:00-24:00

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