BRUGGE
WORLD HERITAGE CITY

Brugge - Belgium

Known as the Venice of the North, Bruges is one of the most beautiful cities in Europe. It was a justified motive that prompted UNESCO in 2000 to include the entire historical city centre on the World Heritage list. Walking along the maze of winding cobbled alleys and romantic canals, you imagine yourself to be in medieval times. The wealth of museums is a striking image of this city's stirring history. Bruges is also home to contemporary culture, such as the new Concert Hall, which is one of the most prominent music complexes in Flanders.
The restaurants in Bruges which offer gastronomic cuisine and the exclusive hotels are a true feast for those who enjoy the good things in life.
www.brugge.be

Venue:
Concertgebouw Brugge
't Zand 34, 8000 Brugge, Belgium
www.concertgebouw.be

Registration:
Via website www.gene-therapy.eu

Contact information organisation:
CONSERT project
Erasmus MC, Hematology dept.
PO Box 2040, 3000 CA Rotterdam
The Netherlands
consert@gene-therapy.eu
www.gene-therapy.eu
Tel +31 - 10 - 704 4729 / 704 3876
Marjolein Krispijn / Leonie Kaptein

CONSERT
gene therapy for inherited diseases

Symposium

The Ethics of Gene Therapy of Inherited Diseases

November 13, 2008, Brugge, Belgium

Concerted Safety and Efficiency Evaluation of Retroviral Transgenesis for Gene Therapy of Inherited Diseases (CONSERT) is an Integrated Project in the Sixth Framework Programme of the European Commission (www.gene-therapy.eu).

This symposium is organised in conjuction with the Annual Congress of the European Society of Gene and Cell Therapy 13-16 November 2008, Brugge, Belgium (www.esgct.org).

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The Ethics of Gene Therapy of Inherited Diseases

Curing severe genetic disorders via genetic modification of somatic cells has been seen as a great challenge for some decades. Clinical studies showed serious risks for the patients but also in some cases efficacy and advantage compared to existing therapies.

This is why planning research in this field of molecular medicine and deciding on the next steps is not only a difficult medical task but also an ethical one. Ethical decision making has to take into account not only what we can learn from clinics and from the labs where safety research is conducted but also what we still have to learn. The ethics of gene therapy has to find a way between false scepticism and excessive optimism.

Michael Fuchs *(chair CONSERT ethics committee)*
Gerard Wagemaker *(coordinator CONSERT project)*

programme

11:00 **Registration**

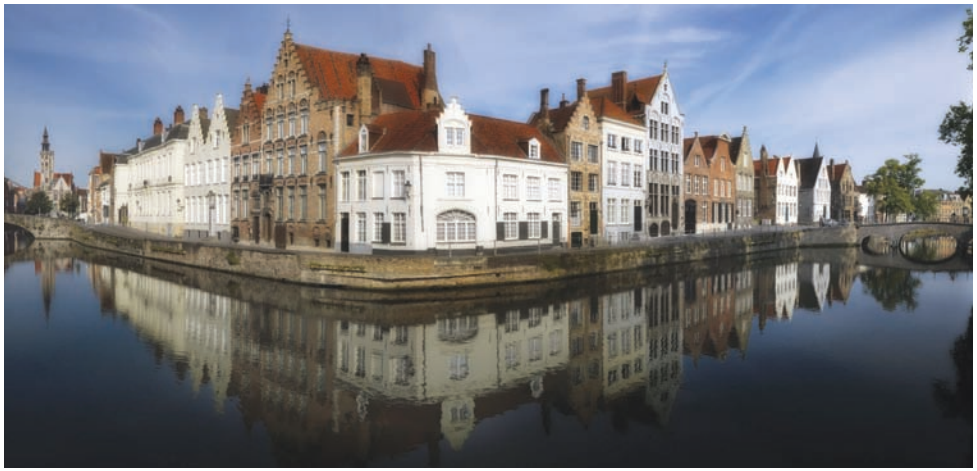
12:00 **Welcome and Introduction**
Gerard Wagemaker *(coordinator CONSERT project)*

12:15 **Keynote**
The Ethics of Gene Therapy and the Difficult Task of Risk Management
Jonathan Kimmelman *(McGill University, Montreal, Canada)*

13:00 **The Experience from Gene Therapy for Inherited Diseases: Choosing Target Diseases and Inclusion of Patients**

- **ADA-SCID**
  Alessandro Aiuti *(San Raffaele Telethon Institute for Gene Therapy, Milano, Italy)*
- **SCID-X1**
  Adrian Thrasher (*UCL Institute of Child Health, London, UK)*
- **Wiskott Aldrich Syndrome**
  Thomas Heinemann *(Institut für Wissenschaft und Ethik, Bonn, Germany)*
- **EB (epidermolysis bullosa)**
  Fulvio Mavilio *(Molecular Medicine S.p.A., Milano, Italy)*
- **Discussion**

14:00 **Break**



14:15 **Risk Perception and Risk Management Strategies**

- **Risks and Risk Perception**
  Gerard Wagemaker *(Erasmus MC, Rotterdam, The Netherlands)*
- **Gene Therapy and Public Perception -** t.b.a.
- **Do We Need a Special Classification of Adverse Events in Gene Therapy?**
  Christopher Baum *(Medizinische Hochschule Hannover, Hannover, Germany)*
- **The Ethics of Gene Therapy – Patient Perspective** - t.b.a.
- **Discussion**

15:15 **From Gene Therapy to Gene Doping in Sports**

- **Can We Still Draw the Line Between Acceptable and Inacceptable Goals of Gene Transfer ?**
  Eric T. Juengst *(Case Western Reserve University, Cleveland, USA)*
- **Lessons to Learn From Research on Doping in Sports**
  Hidde J. Haisma *(University of Groningen, Groningen, The Netherlands)*

16.15 **Break**

16:30 **Ethical Consensus in Somatic Gene Therapy for Inherited Diseases**

- The consensus process of the CONSERT consortium
  Michael Fuchs *(Institut für Wissenschaft und Ethik, Bonn, Germany)*
- General Panel Discussion
- Closing Words

17.45 **End of the Meeting**

Symposium on

The Ethics of Gene Therapy of Inherited Diseases

November 13, 2008, Brugge, Belgium

Family Name	*	
First Name	*	
Title	*	(For example: Prof/Dr/Mr/Mrs/Ms)
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Fax		
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- Please complete all fields marked **(*)** as these are required for administration.
- Registration is free of charge.
- Contact information organisation:

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