

First International Symposium on Cancer in Persons with Intellectual Disability



Bordeaux ● Limoges ● Montpellier ● Nîmes ● Toulouse



February 5th

8H15 – Opening session

Gilles Favre – Head of Cancéropôle GSO
Claudia Ferrari – French National Cancer Institute
Jean-Bernard Dubois – Oncodefi président
Marie-Odile Réthoré – Honorary President, Scientific introduction

9H15 – Cancer in people with intellectual disabilities

Moderators: Jean-Bernard Dubois and Henny van Schrojenstein Lantman de Valk

My own experience of cancer – Amanda Cresswell, introduced by Irene Tuffrey-Wijne (London, England)

Frequency and distribution of cancers in people with intellectual disability – Daniel Satgé (Montpellier, France)

10H40 - coffee break



Cancer frequency and features at diagnosis in persons with intellectual disability – the Hérault study – Aude Jouinot, Brigitte Trétarre and Daniel Satgé (Montpellier, France)

Professional guidelines for cancer screening in people with intellectual disability in the Netherlands Henny van Schrojenstein Lantman de Valk (Nijmegen, Netherlands)

12H00 - Buffet

13H30 – Breast cancer in women with intellectual disabilities

Moderators: William Jacot and Gérald Frangin

Breast cancer features at diagnosis in women with intellectual disability, a French hospital study – Daniel Satgé and William Jacot (Montpellier, France)

"Going to breast cancer screening". A film explaining breast cancer screening to women with intellectual disability in Norway – Stine Skorpen (Tonsberg, Norway)

Women be healthy: a promising new community-based intervention - Susan Parish (Waltham, United States)

The breast cancer screening journey in women with severe and profound intellectual disabilities in Scotland – Diane Willis (Glasgow, Scotland)

16H20 - Coffee break



16H40 – Other cancers in women and in men with intellectual disabilities

Moderators: Diane Willis and William Jacot

Overview of ovarian cancer in women with intellectual disability – Daniel Satgé (Montpellier, France)

Cervical cancer screening in women with intellectual disability – Susan Parish (Waltham, United States)

Testicular cancer in men with Down syndrome – Shaista Hafeez (London, England)

18h30 – Welcome reception by Helene Mandroux Major of Montpellier

February 6th

8H30 – Colon cancer in persons with intellectual disabilities

Moderators: Marc Ychou and Susan Parish

Colon cancer in persons with intellectual disability. Frequency, risk factors, prevention and screening – Diane Willis (Glasgow, Scotland)

Colon cancer in persons with intellectual disability, a French national study – Sophie Bourgaire! (Marseille, France)

Colon cancer screening is difficult. An exemplary institutional success – Marie-Claude Ligier, Daniel Satgé (Saint-Etienne, France)

10H00 - Coffee break



10H20 – Cancer in children with intellectual disabilities

Moderators: Nicolas Sirvent and Motoi Nishi

What do we know about cancer in children with intellectual disability? – David Malkin (Toronto, Canada)

Cancer in children with intellectual disabilities, general introduction and data from the Hokkaido Registry – Motoi Nishi (Tobetsu, Japan)

Leukemia in children with Down syndrome – Johan Hitzler (Toronto, Canada)

12H10 - Buffet

14H00 – Communicating with persons with intellectual disabilities who have cancer

Moderators: Susan Parish and Stéphane Culine

Should we tell him that he has cancer? New guidelines for breaking bad news to people with intellectual disability – Irene Tuffrey-Wijne and Amanda Cresswell (London, England)

Using pictures and story-telling to support communication about cancer with people with intellectual disability – Irene Tuffrey-Wijne (London, England)

Norwegian booklet presenting the cancer journey to adults with intellectual disability who will be treated for cancer – Stine Skorpen (Tonsberg, Norway)

16H00 - Coffee break



16H20 – Pain and palliative care in persons with intellectual disabilities

Moderators: Irene Tuffrey-Wijne and Bernard Azéma

Pain and coping with pain – Marc Zabalía (Caen, France)

Anticipation and expectations of persons with intellectual disability facing the idea of a serious disease and the idea of death – Anne Dusart (Dijon, France)

Recognizing people with intellectual disabilities who will die from cancer in the near future – Henny van Schrojenstein Lantman de Valk (Nijmegen, Netherlands)

The development of European norms for palliative care of people with intellectual disabilities – Irene Tuffrey-Wijne (London, England)

18H10 – Presentation of selected posters

February 7th

8H30 – What cancers in people with intellectual disabilities tell us about cancer and about intellectual disability?

Moderators: Daniel Satgé and Marjolijn Jongmans

Germline mutations in "oncogenes" causing intellectual disability: an unexpected link – Gijs WE Santen (Leiden, Netherlands)

Down syndrome tumor profile and molecular events do not support the somatic mutation theory of cancer – Daniel Satgé (Montpellier, France)

Possible Japanese racial predisposition for particular tumors in Edwards syndrome – Motoi Nishi (Tobetsu, Japan)

10H00 - Coffee break



10H20 – Actuality of biological research on cancer in persons with intellectual disabilities

Moderators: Gijs WE Santen and Vincent Cavallès

Down syndrome and cancer, the role of the calcineurin-NFAT signaling pathway – Sandra Ryeom (Philadelphia, United States)

Cancer risk in patients with Noonan syndrome – Marjolijn Jongmans (Amsterdam, Netherlands)

Cognition and oncogenesis in the RASopathies – Eric Legius (Leuven, Belgium)

The fragile-X protein and breast cancer spreading – Claudia Bagni (Leuven, Belgium)

12H20 – Buffet

14H00 – Social Science

Moderators: Didier Truchot and Alain Leplège

Social science research on people with intellectual disability and cancer – Patrick Devlieger (Leuven, Belgium)

Ethnographic study of the experiences of people with intellectual disability who have cancer – Irene Tuffrey-Wijne (London, England)

Quality of life and quality of care for persons with intellectual disabilities – Alain Leplège (Paris, France)

Effectiveness of a smoking cessation program for persons with intellectual disabilities – Anne Stoebner-Delbarre (Montpellier, France)

16H10 - Coffee break



16H30 – round table: lay the foundations for a learner society

17H30 – Closing remarks by Jean-Bernard Dubois