

# Cancer in People with Intellectual Disabilities

**May 18, 2020: Conference**

**May 19, 2020: Workshops**

Frambu Resource Centre for Rare Disorders, Norway

## Program Conference May 18

- 08.30 – 09.15 Registration at Frambu and connection of video studios  
Coffee, tea, water and fruit
- 09.15 – 09.30 **Welcome**  
Kristian Kristoffersen, Frambu Resource Centre for Rare Disorders  
Kari Midtbø Kristiansen, Norwegian National Advisory Unit on Ageing and Health  
Daniel Satgé, Association Oncodéfi, France  
Heidi E. Nag, Frambu, chair of the conference day
- 09.30 – 10.15 **“My own experience of cancer”**  
Anette Reiersen and service provider Adela Kalbarczyk, Norway
- 10.15 – 10.30 Break
- 10.30 – 11.30 **Session 1: Epidemiology**  
Cancers in people with moderate, severe and profound intellectual disability  
Daniel Satgé  
  
Epidemiology of demise because of cancer in individuals with and without intellectual disabilities  
Maarten Cuypers
- 11.30 – 11.45 Coffee, tea, water and refreshments
- 11.45 – 13.00 **Session 2: Cancer screening and early diagnostics**  
A project seeking to increase participation and understand informed decision making of bowel, breast and cervical screening using intervention-based initiatives within the community  
Alison Milne and Dr Rosemary Millar  
  
Reporting progress and showcase two videos:  
Norma Muir and four service users, Beanie Heggarty, Philip McArthur, Natasha Hogg, Tommy Doyle
- 13.00 – 14.00 LUNCH**

- 14.00 – 14.45 **Session 3: Communication**  
Coping with cancer and how to break bad news  
Irene Tuffrey-Wijne
- Cancer communication tools in Norway  
Stine Skorpen
- 14.45 – 15.00 Coffee, tea and water
- 15.00 – 15.45 **Session 4: The cancer journey**  
Supporting people with an intellectual disability during cancer treatment  
Deborah de Jonge and Jackie Rooney
- Liaison nurses to ease the cancer journey in establishment for people with intellectual disabilities  
Manon Vulcano
- 15.45 – 16.00 Coffee, tea, water and cake
- 16.00 – 16.45 **Session 5: Cancer pain**  
Cancer pain in people with intellectual disabilities: assessment and management  
Nanda de Knecht
- 16.45 Goodbye to those who are leaving Frambu
- 17.30 Outdoor activities and barbecue dinner for guests at Frambu

## Program Workshops May 19









Coffee, tea and water is served during the workshop sessions






- 09.15 – 09.20 **Welcome and practical announcements**  
Stine Skorpen, Norwegian National Advisory Unit on Ageing and Health, chair of the workshop day
- 09.20 – 09.45 **Opening lecture**  
Ole Alexander Opdalshei, Assistant Secretary General of the Norwegian Cancer Society
- 09.45 – 11.15 **Workshop 1**  
Palliative care and ways to discuss death and dying  
Diane Willis
- 09.45 – 11.15 **Workshop 2**  
The role of the family when someone with intellectual disability has cancer  
Irene Tuffrey-Wijne and Monica Hennem Steen (mother)
- 11.15 – 12.15 **Poster session**
- 12.15 – 13.15 LUNCH**
- 13.15 – 14.45 **Workshop 3**  
Genetics in cancer linked to people with intellectual disability, everything you always wanted to ask about genetics but were afraid to ask  
Raoul C M Hennekam
- 13.15 – 14.45 **Workshop 4**  
Obstacles in the “cancer journey” for people with ID, known issues and how can we reduce some of the obstacles?  
Grethe Skorpen Iversen, Deborah de Jonge and Jackie Rooney
- 14.45 **Goodbye**  
Closing remarks and a discussion of aims and goals for International Society on Cancer in People with Intellectual and Developmental Disability (ISCIDD)  
Daniel Satgé  
Stine Skorpen  
Heidi E. Nag, on behalf of Frambu
- 15.00 Coffee, tea, water and a light handheld meal
- 15.30 – 17.00 Steering group meeting on Conference 2022

We reserve the right to make changes in the program

## Chairs, lecturers and workshop managers

	<p><b>Heidi E. Nag</b>            Chair of the conference day, Frambu Resource Centre for Rare Disorders, Norway. Special educational advisor at Frambu since 2005. PhD student on Smith-Magenis syndrome and challenging behaviour.</p>
	<p><b>Anette Reiersen</b>            User voice, Norway  <b>Adela Kalbarczyk</b>            Service provider/carer, Department of Hannestad Tune, Norway</p>
	<p><b>Daniel Satgé MD, PhD</b>            Oncofeff, association dedicated to the best care of cancer in people with intellectual disability, Montpellier, France</p>
	<p><b>Maarten Cuypers</b>            Postdoctoral Researcher at Radboud University Medical Center in Nijmegen, Netherlands. Project on cancer epidemiology in people with intellectual disabilities</p>
	<p><b>Alison Milne</b>            Detect Cancer Early Manager, NHS Lothian, Scotland</p>
	<p><b>Dr Rosemary Millar</b>            Cancer screening coordinator Public Health consultant NHS Lothian, Scotland</p>
	<p><b>Norma Muir</b>            Senior Care &amp; support worker/Service User Involvement Co-ordinator, Support-Works, City of Edinburgh Council, Scotland</p>

	<p><b>Service users:</b> Natasha Hogg, Beanie Haggarty, Philip McAtear and Tommy Doyle</p>
	
	<p><b>Irene Tuffrey-Wijne</b> Professor of Intellectual Disability and Palliative Care. Faculty of Health, Social Care and Education, Kingston and St George's, University of London, England</p>
	<p><b>Stine Skorpen</b> Nurse Consultant, Chair of the workshop day, Norwegian National Advisory Unit on Ageing and Health</p>
	<p><b>Nanda de Knegt</b> Visiting postdoctoral at VU University, Department of Clinical Neuropsychology, Amsterdam, the Netherlands. Psychologist and research coordinator in Prinsienstichting, care center for people with intellectual disabilities, Purmerend, the Netherlands</p>
	<p><b>Ole Alexander Opdalshei</b> Assistant Secretary General of the Norwegian Cancer Society</p>
	<p><b>Diane Willis, PhD</b> Edinburgh Napier University, Scotland</p>
	<p><b>Raoul C M Hennekam, MD PhD</b> Professor of Pediatrics and Translational Genetics, Amsterdam, the Netherlands</p>

	<b>Monica Hennum Steen</b> User voice, mother
	<b>Deborah de Jonge</b> , Clinical Specialist for Additional Needs, Clatterbridge Cancer Centre NHS Foundation Trust, England, UK
	<b>Jackie Rooney</b> , Head of Safeguarding, Clatterbridge Cancer Centre NHS Foundation Trust, England, UK
	<b>Grethe Skorpen Iversen</b> , Palliative care nurse, Regional Centre of Excellence for Palliative Care, Haukeland University Hospital, Bergen, Norway
	<b>Manon Vulcano</b> , liaison nurse for Oncodefi Association in Montpellier, France

**Any questions?**

Please contact us on e-mail:  
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