

Challenging the Boundaries: Antenatal to Adulthood

25th & 26th April 2024 Midlands Park Hotel, Portlaoise, Co. Laois, Ireland

Day 1 / Thursday 25 April

09:00 Registration, Coffee, **Networking & Poster Exhibition**

10:00 Welcome

SESSION 1

Chair: Dr Hannah Linane, Palliative Medicine Physician and PhD candidate

10:05 It takes a village province: Developing a model for pediatric palliative care in Ontario, Canada

Prof. Adam Rapoport, Medical Director, Paediatric Advanced Care Team (PACT), The Hospital for Sick Children, Associate Paediatric Professor University of Toronto, Medical Director Emily's House Children's Hospice, Toronto

10:55 A Collaborative Approach to Care from **Hospital to Home**

Roscommon Community Palliative Team Martina Kenny, Ursula O'Donoghue, Sarah Banahan, HSE

11:25 Question and Answers

11:35 Stretch, Coffee, Networking & Poster Exhibition

11:55 Opening Address

Stephen Donnelly, TD. Minister for Health

SESSION 2

Chairs: Ms Erin Shepherd, Specialist Children's Liaison Nurse, The Jack & Jill Children's Foundation

Dr Marian Williams, Paediatric Consultant, Paediatric Palliative Care, Belfast Health and Social Care Trust

12:10 Oral Abstract Presentations

1. Clinical Heterogeneity of Adolescent and Young Adult(AYA)Patients Referred to Specialist Paediatric Palliative Care Services in Ireland Dr Hannah Linane

2. Development and psychometric evaluation of the novel Children's Palliative care Outcome Scale (C-POS)

Prof. Lorna Fraser, Professor of Palliative Care and Child Health, King's College London 3. A Comprehensive Assessment of Supportive Care Needs for Parents of Children with Rare Diseases in Ireland - The PNS-RD Study Dr Suja Somanadhan, Universtiy College Dublin

12:46 Questions and Answers

13:00 Lunch, Networking & Poster Exhibition

SESSION 3

Chairs: Ms Erin Shepherd, Dr Marian Williams

14:00 Managing complex symptoms in Adolescents and Young Adults with palliative care needs

Dr Anna-Karenia Anderson Paediatric Palliative Medical Consultant, and Medical Director at Royal Marsden Hospital and Shooting star children's hospice

14:50 Young Person First: Adolescent and Young Adult Cancer

Dr Peter McCarthy, Consultant haematologist specialising in Adolescent and Young Adult (AYA) Cancer

Niamh O'Sullivan, Assistant Director of Nursing (ADON) for Adolescent and Young Adult (AYA) cancer, at Children's Health Ireland (CHI), Crumlin and St. James's Hospital, Dublin

15:10 Navigating palliative care with Adolescents and Young Adults with cancer in Northern Ireland

Lisa Callendar, Teenage Cancer Trust's Teenage and Young Adult Clinical Nurse Specialist- South Eastern Health and Social Care Trust Simon Darby, Social Work Manager-Young Lives vs Cancer (formerly CLIC Sargent)

15:30 Questions and Answers

15:40 Stretch, Coffee, Networking & **Poster Exhibition**

SESSION 4

Chairs: Ms Erin Shepherd Dr Marian Williams

16:00 Oral Abstract Presentations

1. Advanced Care Planning in Adolescents and Young Adults (AYA) with Life-Limiting or Life-Threatening Illness; A Scoping Review Dr Hannah Linane

2. Professionals' discussion of loss and grief with parents of children with life-limiting severe neurological impairment

Elaine Brennan, University College Dublin 3. A prospective review of paediatric trainees exposure to palliative care in Irish hospitals Dr Katie Flinn, CHI Crumlin

16:40 Questions and Answers

16:50 BUMBLEance Presentation

Ian Fallon, General Manager, **BUMBLEance**

17:00 Close

A Multidiciplinary Conference organised by















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Day 2 / Friday 26 April 09:25 Welcome

SESSION 5

Chair: Fiona Woods, Head of Clinical Education. LauraLynn Children's Hospice

09:30 NI Paediatric Palliative Care - Update

Dr David Graham

Consultant Paediatrician (General Paediatrics, Neonatal & Community Paediatrics) & Trust Medical Lead for Paediatric Palliative Care within the Southern Health & Social Care Trust, Co-chair Northern Ireland Paediatric Palliative Care Network

09:50 Update from Republic of Ireland Paediatric **Palliative Care**

Dr Fiona McElligott, Consultant in Paediatric Palliative Medicine Children's Health Ireland and The Rotunda Hospital, School of Medicine, University College Dublin

10:10 Babies, Children and Young People with Life-Limiting Conditions; what does the data tell

Prof. Lorna Fraser, Professor of Palliative Care and Child Health, King's College London

11:00 Questions and Answers

11.10 Stretch, Coffee, Networking & Poster Exhibition

SESSION 6

Chairs: Dr Mary Devins, Consultant in Paediatric Palliative Medicine, Children's Health Ireland at

Ms Paula O'Reilly, Chief Executive Officer, Irish Hospice Foundation

11:30 Antenatal Cardiology

Prof. Orla Franklin

Clinical Associate Professor, Consultant in Paediatric Cardiology, Children's Health Ireland

12:10 Oral Abstract Presentations

1. The holistic needs assessment identifies child and family priorities and offers choice in children's palliative care

Vicky Malik, LauraLynn Children's Hospice 2. Quality Improvement Project: Supporting Antenatal Palliative Care Referral following Life Limiting Fetal Diagnosis

Dr Mairead McGinn, Belfast Health and Social Care Trust

12:35 Questions and Answers

12:45 Parent Presentation: A Mother's Story Vlasta Byrtusová

13:00 Lunch, Networking & Poster Exhibition

SESSION 7

Chairs: Dr Mary Devins, Ms Paula O'Reilly

14:00 Perinatal palliative care: spirituality, care and memory

Dr Daniel Nuzum, Pastoral Care Team Marymount University Hospital and Hospice, Cork and Director of Clinical Pastoral Education, Cork University Hospital

14.30 Byte-sized reflections: Is the tech revolution good or bad for palliative care? Prof. Adam Rapoport

15:00 Questions and Answers

15:15 Abstract prizes & Final Comments

15:30 Close