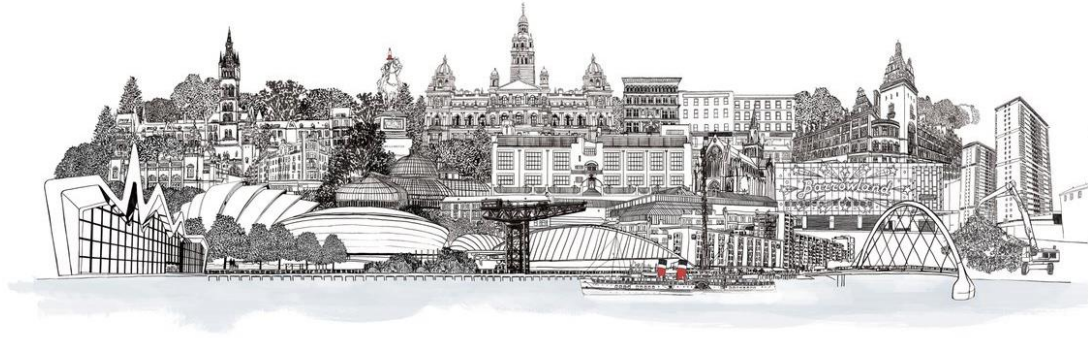


# EWOPA

European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure  
48<sup>th</sup> Annual Meeting, Glasgow, Scotland, UK, September 7-9, 2017

jointly with the  
50<sup>th</sup> Anniversary Meeting of the European Society for Paediatric Nephrology (ESPN)



## Programme

Dochart Room, Scottish Event Campus (SEC), Glasgow

### Thursday, September 7, 2017

**16:30 Opening of the 48<sup>th</sup> Annual Meeting of EWOPA**  
*Christopher Reid, Dirk Bethe, Robert Novo, Lore Willem*

**16:35-18:25 Transplantation**

*Chairpersons: Elizabeth Hunter, Christopher Reid*

16:35 **Patients experience of transplant**  
*Elizabeth Hunter*

16:50 **Parental experience of paediatric kidney transplantation**  
*Stacie Bowden*

17:20 **Executive functioning following paediatric kidney transplantation**  
*Michaela Hartmann*

17:40 **To transplant or not to transplant: The case of B., a 17y old Turkish girl with diabetes Type 1 and CKD V**  
*Lore Willem, Katrien Van der Vaerent, Ariadne Van Hulle*

18:10 **Living related renal transplantation from grandparental donors to paediatric recipients**  
*Maria Scanes*

**18:30-19:30 EWOPA Welcome Reception**

### Friday, September 8, 2017

**08:30-10:10 Spiritual and Health Beliefs**

*Chairpersons: Claire Dempster, Dirk Bethe*

08:30 **Working with fixed or core beliefs - yours or mine?**  
*Claire Dempster, Rukshana Shroff, Amy Barber, Eileen O'Neill*

08:50 **Spiritual beliefs: problem or opportunity?**  
*Maria Scanes, Claire Dempster*

**09:10 Break-out groups**

**10:10 Coffee Break**

**10:40-11:50 Non-Adherence and Complex Cases**

*Chairpersons: Dirk Bethe, Robert Novo*

**10:40 Medication non-adherence is a leading modifiable cause for renal graft loss in childhood - a large center study.**

*Nabil Melhem*

**11:00 How to work effectively as an MDT with a complex teenager waiting for a kidney using a BioPsychoSocial Model?**

*Sophie Velleman, Jonathan Ford*

**11:30 Accompanying services within the Interdisciplinary Approach towards the Paediatric Nephrology Patients (Case Presentation)**

*Hasmik Tadevosyan*

**11:50-13:00 Joint Session with 22nd Annual Meeting of Paediatric Nephrology Nurses**

*Chairpersons: Roy Connell, Christopher Reid*

**11:50 Outpatient nephrotic syndrome with physician and nursing consultant**

*Marjoleine van der Zijde, Marja Kensellar*

**12:10 To safeguard or not to safeguard?**

*Tracy Daglar*

**12:35 Transplanting a child with severe autism, a positive experience for all**

*Ellen Samuels*

**13:00 Lunch**

**14:20-15:00 Creative projects I**

*Chairpersons: Arvind Nagra, Lore Willem*

**14:20 How the Finnish kidney and liver association supports renal sick children, adolescents and their families**

*Marjukka Miettinen*

**14:40 Ziezon, national network. Joint effort in education for sick children**

*Gabrielle Bakhuis, Astrid Möls*

**15:00 Coffee Break**

**15:30-17:00 Joint session with ESPN – Lomond Auditorium**

*Chairpersons: Christopher Reid, Alan Watson*

**15:30 History and current state of psychosocial care in paediatric nephrology**

*Dirk Bethe, Christopher Reid*

**16:00 More than just IQ – specific neurocognitive difficulties in children with chronic renal failure and kidney transplantation**

*Jenny Prüfe*

**16:15 The sibling voice - the impact of transplantation on siblings**

*Grainne Walsh*

**16:30 Renal replacement therapy in children with a severe mental disability**

*Lore Willem, Elena Levtchenko*

**17:05-17:30 Creative projects II**

*Chairperson: Arvind Nagra*

**17:05 Harvey's Gang**

*Malcolm Robinson & patient M.*

**19:30 EWOPA Dinner at Restaurant "Metropolitan"**

## **Saturday, September 9, 2017**

### **08:30-09:50 Ethical questions regarding treatment decisions**

*Chairpersons: Lore Willem, Claire Dempster*

08:30 **Ethical dilemmas in kidney transplant with living parent donor for child with short life expectancy**

*Nancy Kamphuis-Serpa*

08:45 **Making difficult decisions together**

*Fiona Bathgate, Claire Dempster*

09:00 **Break-out groups**

09:50 **Coffee break**

### **10:10-11:10 Quality of Life**

**11:30-11:45** *Chairpersons: Dirk Bethe, Lore Willem*

10:10 **Health-related quality of life with CKD, comparisons between parents and child reports**

*Helena Öborn*

10:25 **How are children on dialysis faring psychosocially?**

*Claire Dempster*

10:40 **Psychological wellbeing of children with CKD**

*Charlotte van Herzele*

10:55 **Stress, anxiety and depression in parents of children with chronic kidney disease**

*Elke de Bruyne*

### **11:10-11:30 EWOPA Business Meeting**

11:30 **Health - related quality of life in children with CKD**

*Caroline Anderson*

11:45 **Coffee break**

### **12:00-13:25 Transition**

*Chairpersons: Robert Novo, Jenny Prüfe*

12:00 **A virtual hospital - an e-health tool for adolescents with severe chronic health conditions**

*Anna Tornivuori*

12:20 **Successfully implementing transition by addressing common misconceptions and use of 'Ready Steady Go' programme**

*Arvind Nagra*

12.45 **Transition from Paediatric to Adult Nephrology units in France**

*Robert Novo*

13:10 **TransNephro-EURO, a transition survey**

*Lars Pape, Jenny Prüfe*

**13:25 Good-bye and invitation to EWOPA 2018!**

**13:30 End of meeting**

## Presenters and Chairpersons

Anderson, Caroline, Specialist Paediatric Dietitian, Southampton, United Kingdom  
Bakhuis, Gabriele, Hospital Teacher, Nijmegen, The Netherlands  
Bathgate, Fionna, Clinical Psychologist, London, United Kingdom  
Bethe, Dirk, Clinical Psychologist, Heidelberg, Germany  
Bowden, Stacie, Psychologist, London, United Kingdom  
Connell, Roy, Nurse, Nottingham, United Kingdom  
Daglar, Tracy, Nurse, Liverpool, United Kingdom  
De Bruyne, Elke, Psychologist, Ghent, Belgium  
Dempster, Claire, Family Therapist, London, United Kingdom  
Hartmann, Michaela, Medical Student, Hannover, Germany  
Hunter, Elizabeth, Clinical Psychologist, Glasgow, United Kingdom  
Kamphuis-Serpa, Nancy, Social Worker, Nijmegen, The Netherlands  
Melhem, Nabil, Paediatric Nephrologist, London, United Kingdom  
Miettinen, Marjukka, Self-Help Activist, Helsinki, Finland  
Möls, Astrid, Hospital teacher, Nijmegen, Finland  
Nagra, Arvind, Paediatric Nephrologist, Southampton, United Kingdom  
Novo, Robert, Paediatric Nephrologist, Lille, France  
Öborn, Helena, Nurse, Stockholm, Sweden  
Pape, Lars, Paediatric Nephrologist, Hannover, Germany  
Prüfe, Jenny, Psychologist, Hannover, Germany  
Reid, Christopher, Paediatric Nephrologist, London, United Kingdom  
Robinson, Malcolm, Biomedical Scientist, Southampton, United Kingdom  
Samuels, Ellen, Nurse, London, United Kingdom  
Scanes, Maria, Nurse, London, United Kingdom  
Tadevosyan, Hasmik, Hospital Teacher, Yerevan, Armenia  
Tornivuori, Anna, Nurse, Helsinki, Finland  
Van der Zijde, Marjoleine, Nurse, Rotterdam, The Netherlands  
Van Herzeele, Charlotte, Psychologist, Ghent, Belgium  
Velleman, Sophie, Clinical Psychologist, Bristol, United Kingdom  
Walsh, Grainne, Nurse, London, United Kingdom  
Watson, Alan, Paediatric Nephrologist, Nottingham, United Kingdom  
Willem, Lore, Clinical Psychologist, Leuven, Belgium

## Scientific Committee

Reid, Christopher, EWOPA Coordination Group, Chairman  
Dirk Bethe, EWOPA Coordination Group  
Robert Novo, EWOPA Coordination Group  
Annika van Schantz, EWOPA Coordination Group  
Lore Willem, EWOPA Coordination Group

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