

Presenters and Chairpersons

Almeida, Paulo - Paediatric Psychologist, Porto, Portugal
Batte, Suzanne - Social Worker, Nottingham, UK
Bayliss, Linda - Clinical Psychologist, London, UK
Bethe, Dirk - Psychologist, Heidelberg, Germany
Caldas Alonso, Alberto - Paediatric Nephrologist, Porto, Portugal
Cochat, Pierre - Paediatric Nephrologist, Lyon, France
Davis, Cara - Specialist Clinical Psychologist, Bristol, UK
Flinter, Frances - Clinical Geneticist, London, UK
Gagné, Joanne - Social Worker, Montreal, Canada
Heath, Jennifer - Clinical Psychologist, Nottingham, UK
Hoque, Victoria - Senior Play Specialist, London, UK
Kachere, Rose - Higher Level Teaching Assistant, London, UK
Levtchenko, Elena - Paediatric Nephrologist, Leuven, Belgium
Lugasi, Tziona - Clinical Psychologist, Montreal, Canada
Muhammad, Shahid - Registered Scientist, Bristol, UK
Novo, Robert - Paediatric Nephrologist, Lille, France
Prüfe, Jenny - Psychologist, Hannover, Germany
Reid, Christopher - Paediatric Nephrologist, London, UK
Santos Amorim, Priscila - Educational Counsellor, Salvador da Bahia, Brazil
Schnarwyler, Beatrice - Paediatric Nurse Specialist, Zürich, Switzerland
Sparta, Guiseppina - Paediatric Nephrologist, Zürich, Switzerland
Tadevosyan, Hasmik - Teacher, Yerevan, Armenia
Tainio, Juuso - Doctor in Training (Paediatrics), Helsinki, Finland
Tavares, Claudia - MD, Porto, Portugal
Teixera, Ana - Paediatric Nephrologist, Porto, Portugal
Tjaden, Lidwien - MD PHD Student, Amsterdam, The Netherlands
Van Herzele, Charlotte - Psychologist, Gent, Belgium
Von Schantz, Annika - Unit Manager, Helsinki, Finland
Wallace, Dean - MD, London, UK
Walsh, Grainne - Children's Transplant Clinical Nurse Specialist, London, UK
Willem, Lore - Clinical Child and Adolescent Psychologist, Leuven, Belgium

Organizing Committee

Ana Teixeira, Porto
Christopher Reid, EWOPA Coordination Group, Chairperson
Dirk Bethe, EWOPA Coordination Group
Beatrice Schnarwyler, EWOPA Coordination Group
Annika von Schantz, EWOPA Coordination Group
Robert Novo, EWOPA Coordination Group

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EWOPA

European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure

45th Annual Meeting

September 18-20, 2014

Porto, Portugal, Alfandega Congress Centre

Jointly with the

47th Annual Scientific Meeting of the European Society for Paediatric Nephrology (ESPN)

Programme

Thursday, September 18

11.00 – 14.00	Joint Symposium EWOPA/ESPN
D. Maria Hall	
11.00 – 12.30	Part I, Chair Persons: Christopher Reid, Pierre Cochat
	Christopher Reid <i>Overview of EWOPA History, Activity, Priorities</i>
	Pierre Cochat <i>Global International Issues in Paediatric Nephrology</i>
	Dirk Bethe <i>Nonadherence: Very Common, Often Frustrating, Always Complex</i> <i>– Update on the Phenomenon, the Etiology And Adherence Support Measures</i>
	Frances Flinter <i>Ethical Issues of Genetic Testing and Diagnosis</i>
12.30 – 13.00	Lunch Break
13.00 – 14.00	Part II, Chair Persons: Elena Levtchenko, Alberto Caldas Alonso
	Lidwien Tjaden et al. <i>Long-Term Quality of Life and Social Outcome of Childhood End-Stage Renal Disease</i>
	Guiseppina Sparta et al. <i>Neurodevelopmental Long-term Outcome in Children after Hemolytic Uremic Syndrome</i>
	Charlotte van Herzele et al. <i>Cortical Arousals and Periodic Limb Movements During Sleep are Associated with Lower Quality of Life in Children with Monosymptomatic Nocturnal Enuresis</i>
	Juuso Tainio et al. <i>Health-Related Quality of Life, Sexual Health, and Mental Well-Being in Young Men After Pediatric Renal Transplantation</i>
14.00	End of Joint Symposium EWOPA/ESPN

- 14.15 – 14.45**
D. Luis Hall
Genetic Testing and Diagnosis
Chairperson: Christopher Reid
Discussion with Frances Flinter
(Plenary Follow-up)
- 14.45 – 16.30**
D. Luis Hall
Complementary Medicine
Chairperson: Christopher Reid
- Dean Wallace et al.**
What Makes Complementary Medicine “Alternative”?
Workshop
“How Shall We Deal with Complementary Medicine in Paediatric Renal Care?”
(Small groups, facilitators: Christopher Reid, Dean Wallace)
- 19.00 – 21.00**
Welcome Meeting

Friday, September 19

- 09.00 – 11.00**
D. Luis Hall
Various Psychosocial Issues in Chronic Renal Failure
Chairpersons: Dirk Bethe, Ana Teixeira
- 09.00**
Claudia Tavares/Paulo Almeida
Health-related Quality of Life in Children and Adolescents with End-stage Renal Disease – Evaluation of a Portuguese Population
- 09.25**
Jennifer Heath/Suzanne Batte et al.
Psychosocial Treatment of CKD: What Are We doing Right? What Could We Do Better?
- 09.50**
Jenny Prüfe
Cognitive Developments in Children with Renal Failure- First Impressions of the IFB-TX Project: “Opportunities for Life in Pediatric Organ Transplant Recipients”
- 10.15**
Grainne Walsh et al.
The Sibling Voice – The Experience of Kidney Transplantation from the Sibling Perspective
- 10.40**
Priscila Santos Amorim et al.
Meanings of Education for Children and Adolescents With Chronic Renal Failure on Hemodialysis
- 11.00 – 11.30**
Coffee Break
- 11.30 – 13.30**
D. Luis Hall
Ethical Issues
Chair persons: Dirk Bethe, Beatrice Schnarwyler
- 11.00**
Jenny Prüfe et al.
Little Babies and Big Problems – On the Psychosocial Needs of Infants Undergoing Dialysis and Transplantation
- 11.30**
Lore Willem et al.
To Transplant or not to Transplant? Ethical Issues Concerning Kidney Transplantation in Severely Mentally Disabled Children
- 12.00**
Workshop
“Ethical Issues” (Small groups, facilitators: Lore Willem, Beatrice Schnarwyler)
- 13.30 – 14.30**
Lunch Break

- 14.30 – 16.40**
D. Luis Hall
Multidisciplinary Teams, Transition
Chairpersons: Annika von Schantz, Jenny Prüfe
- 14.30**
Joanne Gagné et al.
The Involvement of the Social Worker within the Interdisciplinary Nephrology Team
- 14.50**
Hasmik Tadevosyan et al.
Children with Medical and Educational Needs in Armenia: Building up an Interdisciplinary Team
- 15.15**
Annika von Schantz
How to Build the World’s Best Paediatric Hospital Without Money or Political Support?
- 15.40 – 16.15**
Coffee Break
- 16.15 – 16.40**
Tziona Lugasi et al.
Transition from Child-Centered to Adult-Centered Care in Patients with Renal Transplant or Diabetes: Feelings Towards Transfer and Evolution of Self-Determination and Adherence Across the Transition Process
- 19.00**
EWOPA Dinner at a Restaurant

Saturday, September 20

- 09.00 – 11.00**
D. Luis Hall
Interventions
Chairpersons: Christopher Reid, Suzanne Batte
- 09.00**
Rose Kachere
Inside Out – Assessing the Value of Individual-to-Group School Projects in Supporting Positive Experience of the Public/Private Divide for Dialysis Pupils
- 09.30**
Victoria Hoque
Messy Play with Children on Hemodialysis
- 09.50**
Cara Davis
The Journey of a Looked-after Teenager Through Dialysis, Transplant & Beyond: Reflections on a Long Term Intervention
- 10.30**
Shahid Muhammad et al.
The Lord Mayor of Bristol’s Blood and Organ Donation Campaign in Collaboration with Support Groups and Radio Stations
- 11.00 – 11.30**
Coffee Break
- 11.30 – 11.50**
D. Luis Hall
EWOPA Business Meeting
- 11.50 – 12.50**
D. Luis Hall
Transplant Preparation
Chairpersons: Robert Novo, Grainne Walsh
- 11.50**
Cara Davis et al.
Attempting a Partnership Approach to Transplant Preparation: Involving Children, Young People and Their Families
- 12.20**
Linda Bayliss
Getting Ready for a Transplant: A case Report of Intensive Preparation Work with an Anxious 14 year Old
- 12.50**
End of 45th Annual Meeting of EWOPA