



# 40th European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure

Leuven | Belgium | 4-6 June 2009

*Total care of the child with chronic kidney disease*

## Final programme

### Thursday 4 June 2009

15:00 – 17:00 *Registration*

**17:00 – 18:15 Welcome address & Keynote lecture**

**PLENARY**

**Chair persons: R. Van Damme-Lombaerts – E. Levtchenko**

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|-------------|---|
| 17:00-17:15 | Welcome address<br><i>R. Van Damme-Lombaerts, University Hospital Leuven, Belgium</i>   |
| 17:15-18:00 | 0.1 – Keynote lecture: Communication before and with chronic renal failure<br><i>J. Steyaert, Catholic University Leuven, Belgium</i> |
| 18:00-18:15 | 0.2 – Why I am not taking my medicine – a patient's perspective<br><i>M. Tromp, The Netherlands</i>                                   |

19:00 – 20:30 *Welcome reception – City Hall of Leuven*

### Friday 5 June 2009

**08:45 – 10:10 Neuropsychological aspects of genetic renal diseases – Part I**

**PLENARY**

**Chair persons: E. Levtchenko – C. Reid**

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| 08:45-09:05 | 1.1 – Mental problems in patients with nephrogenic diabetes insipidus<br><i>N. Knoers, UMC St Radboud Nijmegen, The Netherlands</i>   |
| 09:05-09:25 | 1.2 – Cerebellar cognitive affective syndrome: a part of nephronoptosis phenotype?<br><i>N. van de Kar, UMC St Radboud Nijmegen, The Netherlands</i>  |
| 09:25-09:40 | 1.3 – Neurocognitive functioning in school-aged cystinosis patients<br><i>M.T.P. Besouw, University Hospital Leuven, Belgium</i>  |
| 09:40-09:55 | 1.4 – Joint activities from patients and doctors to establish care for cystinosis patients in Russia<br><i>A.N. Tsygin, Institute of Pediatrics NCZD RAMS, Moscow, Russia</i>   |
| 09:55-10:10 | 1.5 – Family education programme nephrotic syndrome - a psychological and educational intervention for children with nephrotic syndrome and their families<br><i>M.R. Benz, Dr. von Haunersches Kinderspital, LMU Munich, Germany</i> |

10:10 – 10:40 *Coffee break – Poster viewing – Exhibition*

**10:40 – 11:55 Neuropsychological aspects of genetic renal diseases – Part II**

**PLENARY**

**Chair persons: N. Knoers – J. Vande Walle**

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| 10:40-11:10 | 1.6 – Neuropsychological disturbances in nephropathic cystinosis<br><i>D. Trauner, UC San Diego, USA</i>  |
| 11:10-11:25 | 1.7 – Steroid-sensitive nephrotic syndrome as a psychosocial burden - Long-term analysis<br><i>E.-M. Rueth, University Hospital Erlangen, Germany</i> |



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- 11:25-11:40 1.8 – A psychological approach, within 4 children with different ages and different preoccupations  
*A.M. Guittard, Hôpital des Enfants, Toulouse, France*
- 11:40-11:55 1.9 – Chronic renal failure and adolescence. About a case : Ella.  
*R. Jean-Dit-Pannel, Université Paris X / Fondation Transplantation, France*

12:00 – 12:30 *Poster walk (chair: T. Schurmans)*

12:30 – 13:25 *Lunch – Exhibition*

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### 13:25 – 15:30 Information – education – compliance **PLENARY** Chair persons: *L. Decorte – E. Reichwald-Klugger*

- 13:25-13:55 2.1 – Impact of health care system related factor on adherence in transplantation: looking beyond the horizon  
*S. de Geest, University of Basel, Switzerland / Catholic University Leuven, Belgium*
- 13:55-14:25 2.2 – Adherence research in adolescents with kidney disease: the past, the present and the future  
*F. Dobbels, Catholic University Leuven, Belgium*
- 14:25-14:40 2.3 – Working with traumatic stress; a case study of working with a 12 year-old girl post kidney-transplant  
*A. Hames, Evelina Children's Hospital, London, United Kingdom*
- 14:40-14:55 2.4 – Non-adherence in adolescent transplant recipients: is patient education practice congruent with health-care providers' beliefs?  
*I.M.S. Aujoulat, Université Catholique de Louvain, Belgium*
- 14:55-15:10 2.5 – Cystinosis : adherence to cysteamine treatment in Benelux  
*T. Schurmans, Hôpital des Enfants Reine Fabiola, Brussels, Belgium*
- 15:10-15:30 2.6 – 30 years of education for children in renal replacement therapy: the cornerstone is team working  
*L. Govaerts, Hospital School Leuven, Belgium*

15:30 – 16:00 *Coffee break – Poster viewing – Exhibition*

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### 16:00 – 17:00 Ethical aspects of genetic diagnosis **PARALLEL** Chair persons: *M. Dehennault – R. Van Damme-Lombaerts*

- 16:00-16:30 3A.1 – Ethical aspects of genetic diagnosis of renal disease in childhood  
*K. Devriendt, Catholic University Leuven, Belgium*
- 16:30-16:45 3A.2 – Best Interests: small children and big decisions  
*C. Jennings, Great Ormond Street Children's Hospital, London, United Kingdom*
- 16:45-17:00 3A.3 – The catharsis and its scarcity  
*P.G. Sallay, Semmelweis University, Budapest, Hungary*

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### 16:00 – 17:00 Workshop: coping with pain: dialogue versus diagnosis **PARALLEL** Chair persons: *A. Demol – K. Lindqvist*

- 16:00-16:05 3B.1 – Coping with needle phobia, thirst and fluid restriction  
*M. Van Zevenhuijzen, ErasmusMC Sophia Children's Hospital, Rotterdam, The Netherlands*
- 16:05-16:10 3B.2 – Painpassport - providing patient directed care by respecting the personal coping strategy of a child  
*A. Kalisvaart, Universal Medical Centre Utrecht, The Netherlands*



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- 16:10-16:15 3B.3 – Painful procedures - helping children cope  
*D. Mackinlay, Nottingham University Hospital NHS Trust, United Kingdom*
- 16:15-16:20 3B.4 – To prepare a toddler for needling his AV-fistula: a team challenge  
*J. Helsen, University Hospital Leuven, Belgium*
- 16:20-17:00 Discussion
- 17:30 – 18:30** *Guided walk in Leuven*
- 19:30** *Conference dinner at Faculty Club (pre-registration required)*

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### Saturday 6 June 2009

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#### **09:00 – 10:45** Quality of life **PLENARY** Chair persons: *F. Janssen – J. Knoll*

- 09:00-09:30 4.1 – Late social rehabilitation after kidney transplantation in childhood  
*M.-F. Gagnadoux, Hôpital des Enfants Malades Necker, Paris, France*
- 09:30-09:45 4.6 – Longitudinal study of quality of life of children with chronic renal failure  
*H. Maxwell, Nottingham University Hospitals NHS Trust, United Kingdom*
- 09:45-10:00 4.2 – Comparison of quality of life perceptions between adolescent renal transplant patients, their parents and healthy controls: a perfect match?  
*L. Decorte, University Hospital Leuven, Belgium*
- 10:00-10:15 4.3 – Outcome of kidney transplantation of pediatric patients after transfer to adult care unit: a single center study  
*M.-J. Clermont, CHU Sainte-Justine, Montreal, Canada*
- 10:15-10:30 4.4 – Quality of life and psychosocial outcome in children on chronic renal replacement therapy in the Netherlands and Belgium  
*W.F. Tromp, Emma Children's Hospital AMC, Amsterdam, The Netherlands*
- 10:30-10:45 4.5 – Family members' experiences of the paediatric renal transplantation process  
*K. Brown, Cardiff and Vales nhs Trust, United Kingdom*

#### **10:45 – 11:15** *Coffee break – Poster viewing – Exhibition*

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#### **11:15 – 12:25** Treatment challenges for children with chronic renal failure **PLENARY** Chair persons: *A. van den Berg – A. Demol*

- 11:15-11:35 5.1 – Living with chronic kidney disease; views of adults who presented with severe chronic kidney disease in infancy  
*D. Mekahli, Great Ormond Street London, United Kingdom*
- 11:35-11:55 5.2 – Tube feeding or supplemental feeding in children with chronic renal failure  
*K. Van der Vaerent, University Hospital Leuven, Belgium*
- 11:55-12:10 5.3 – How do patients and their families like to access dietary information?  
*S. Janes, Birmingham Children's Hospital NHS Foundation Trust, United Kingdom*
- 12:10-12:25 5.4 – Athletic week for children with renal diseases - the experience of 16 years  
*F. Janssen, Hôpital Universitaire Des Enfants Reine Fabiola, Brussels, Belgium*

#### **12:25 – 13:25** *Lunch – Poster viewing – Exhibition*



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### List of posters

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- P.1** - Psychosocial features in a case with polycystic kidney disease and genetic anomaly  
*M.A. Giurgiu, Pediatric Clinic, Pediatric Hospital, Psychology Department, Sibiu, Romania*
- P.2** - Psychosocial nanism in a child with renal function impairment  
*M.A. Giurgiu, Pediatric Clinic, Pediatric Hospital, Psychology Department, Sibiu, Romania*
- P.3** - Psychological status of children and their close relatives in the course of chronic kidney diseases  
*E. Kostadinova, Thracian University, Faculty of Medicine, Stara Zagora, Bulgaria*
- P.4** - Physical activity, physical self-perception, quality of life and locus of control in children with kidney transplants  
*C. Clark, Alberta Children's Hospital/Pediatric Kidney Transplant Program, Calgary, Canada*
- P.5** - Positive outcomes of total care: case presentation  
*L. Sanamyan, DAA, Yerevan, Armenia*
- P.6** - What I have learned at summer camp  
*M-J.Clermont, CHU Sainte-Justine, Montreal, Canada*
- P.7** - *Withdrawn*
- P.8** - Investigation of feelings, concerns, readiness, and self-determination variables in the context of patients' transition from child-centered care to adult centered care  
*T. Lugasi, Université de Montréal, Montreal, Canada*
- P.9** - New world-wide patient-organization on Nephrotic Syndrome presents itself  
*A.M. Voets-van Meel, Nephcure International, Bodegraven, The Netherlands*
- P.10** - Comorbidities and quality of life in children with terminal renal failure - experience of a pediatric center  
*A.V. Bizo, UMF Iuliu Hatieganu" Cluj-Napoca", Cluj-Napoca, Romania*
- P.11** - Summer holiday camp for children with chronic renal diseases - 18 years of experience.  
*T. Schurmans, Hôpital Universitaire des Enfants Reine Fabiola, Brussels, Belgium*
- 3B.1** - Coping with needle phobia, thirst and fluid restriction  
*M. Van Zevenhuijzen, ErasmusMC Sophia Children's Hospital, Rotterdam, The Netherlands*
- 3B.2** - Painpassport - providing patient directed care by respecting the personal coping strategy of a child  
*A. Kalisvaart, Universal Medical Centre Utrecht, The Netherlands*
- 3B.4** - To prepare a toddler for needling his AV-fistula: a team challenge  
*A. Demol, University Hospital Leuven, Belgium*