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. Levchenko

17:00-17:15 Welcome address
R. Van Damme-Lombaerts, University Hospital Leuven, Belgium

17:15-18:00 0.1 – Keynote lecture: Communication before and with chronic renal failure
J. Steyaert, Catholic University Leuven, Belgium

18:00-18:15 0.2 – Why I am not taking my medicine – a patient’s perspective
M. Tromp, The Netherlands

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. Levchenko – C. Reid

08:45-09:05 1.1 – Mental problems in patients with nephrogenic diabetes insipidus
N. Knoers, UMC St Radboud Nijmegen, The Netherlands

09:05-09:25 1.2 – Cerebellar cognitive affective syndrome: a part of nephronophthisis phenotype?
N. van de Kar, UMC St Radboud Nijmegen, The Netherlands

09:25-09:40 1.3 – Neurocognitive functioning in school-aged cystinosis patients
M.T.P. Besouw, University Hospital Leuven, Belgium

09:40-09:55 1.4 – Joint activities from patients and doctors to establish care for cystinosis patients in Russia
A.N. Tsygin, Institute of Pediatrics NCZD RAMS, Moscow, Russia

09:55-10:10 1.5 – Family education programme nephrotic syndrome - a psychological and educational intervention for children with nephrotic syndrome and their families
M.R. Benz, Dr. von Haunersches Kinderspital, LMU Munich, Germany

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

10:40-11:10 1.6 – Neuropsychological disturbances in nephropathic cystinosis
D. Trauner, UC San Diego, USA

11:10-11:25 1.7 – Steroid-sensitive nephrotic syndrome as a psychosocial burden - Long-term analysis
E.-M. Rueth, University Hospital Erlangen, Germany
### Total care of the child with chronic kidney disease

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<th>Time</th>
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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                                            |
           | 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

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

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<pre><code>       | S. de Geest, University of Basel, Switzerland / Catholic University Leuven, Belgium            |
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| 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                                |
| 14:40-15:30 | 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                                    |
| 15:10-15:30 | 2.5 – Cystinosis: adherence to cysteamine treatment in Benelux  
           | T. Schurmans, Hôpital des Enfants Reine Fabiola, Brussels, Belgium                            |
| 15:30 – 16:00 | Coffee break – Poster viewing – Exhibition                                                   |

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

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| 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                                        |

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

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| 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                             |
**Total care of the child with chronic kidney disease**

16:10-16:15  38.3 – Painful procedures - helping children cope  
*D. Mackinlay, Nottingham University Hospital NHS Trust, United Kingdom*

16:15-16:20  38.4 – 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)

**Saturday 6 June 2009**

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<td>09:00</td>
<td>Quality of life</td>
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<td>09:00</td>
<td><strong>PLENARY</strong> Chair persons: F. Janssen – J. Knoll</td>
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| 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                                                        |
| 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* |
List of posters

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