

1ST EUROPEAN TRANSITION SYMPOSIUM / LAUSANNE, SEPTEMBER 14TH 2018

FINAL PROGRAM

Thursday 13th of September, 19h – Speed-networking dinner

8:00-8:15		Welcome & coffee
8:15-8:30	Presentation of the symposium	Joan-Carles Surís & Christina Akre
8:30-9:15	KEYNOTE SESSION 1: "LA SUITE-NECKER": AN INNOVATIVE TRANSITION CARE PROGRAM FOR TEENAGERS AND YOUNG ADULTS WITH RARE OR CHRONIC DISEASES	Nizar Mahlaoui Pediatric Immuno-Hematology and Rheumatology Unit, Fench Reference Center for Primary ImmunoDeficiencies, Necker Enfants Malades University Hospital, Imagine (Institute for Genetic Disorders). Paris, France.
9:15-10:30	Session 1: Clinical and evaluation abstracts	Moderator: Christina Akre
1.	COHORT STUDY OF 130 PATIENTS WITH JUVENILE IDIOPATHIC ARTHRITIS DURING TRANSITION FROM PEDIATRIC TO ADULT CARE	Debrach AC ¹ , Beaumel A ² , Rougelot A ² , Hofer M ¹ , Couret M ¹ , Larbre JP ² , Coury F ² ¹ Centre Hospitalier universitaire Vaudois, Department of Rheumatology, Lausanne, Switzerland; ² Hospices Civils de Lyon, Centre Hospitalier Lyon Sud, Department of Rheumatology, Pierre-Bénite. France
2.	TRANSITION PROGRAM IN PEDIATRIC CARDIOLOGY	Geiser VG, Sekarski NS, Gendre CG Pediatric cardiology unit, Lausanne University Hospital. Lausanne, Switzerland
3.	KIDSETTRANSPLANT: A SERIOUS GAME TO PREPARE THE TRANSITION OF CHILDREN WITH LIVER DISEASE OR AFTER LIVER TRANSPLANTATION	McLin VA ¹ , Steiner M ¹ , Geissbühler A ² , Spahni S ² , Wildhaber BE ¹ Swiss Pediatric Liver Center, University Hospitals of Geneva. Geneva, Switzerland
4.	POLYARTICULAR JUVENILE ONSET ARTHRITIS AT TRANSITION PERIOD: SCREENING OF ANTINUCLEAR ANTIBODIES MAY BE USEFUL!	Coury F, Freychet C, Cabrera N, Duncan A, Rey B, Belot A, Coutant F, Fabien N, Zomaleto Z, Larbre JP Rheumatology Department, Lyon Sud Hospital, 69310 Pierre Bénite; Department of Pediatrics, Nephrology and Rheumatology, Hôpital Femme Mère Enfants, 69 Lyon. France
5.	JUVENILE ONSET ARTHRITIS AT TRANSITION: CHECK FOR NAIL PSORIASIS!	Righetti M, Remy Piccolo V, Freychet C, Beaumel A, Belot A, Duquesne A, Villani A, Lohse A, Larbre JP, Coury F Rheumatology Department, Lyon Sud Hospital, 69310 Pierre Bénite; Department of Pediatrics, Nephrology and Rheumatology, Hôpital Femme Mère Enfants, Lyon; Rheumatology Department, Belfort Hospital. France
6.	TRANSITION TRAINING FOR STAFF IN PAEDIATRIC PALLIATIVE CARE	Mills, A.

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Transition Lead and Senior Physiotherapist LauraLynn Children's Hospice. Dublin, Ireland

7. NO REASON TO BE COMPLACENT: FIRST RESULTS OF A MIXED-METHODS CONTROLLED EVALUATION STUDY INTO TRANSITION PROGRAMMES IN DUTCH DIABETES CARE

van Staa AL, Peeters MAC, van der Slikke CMM, de Kruif-Hoek E, Bronner MB
 Research Centre Innovations in Care, Rotterdam University of Applied Sciences. Rotterdam The Netherlands

8. MEDICAL CARE OF UNACCOMPANIED MINORS AT THE GENEVA UNIVERSITY HOSPITALS: A QUALITATIVE STUDY TO EXPLORE THE CHALLENGES OF THEIR TRANSITION TO MAJORITY

Pernin T^{1,2}, Dominicé Dao M², Chamay Weber C¹, Narring F¹
¹Adolescents and Young Adults Program, Geneva University Hospitals; ²Primary Care Division, Geneva University Hospitals. Geneva, Switzerland

Discussion

10:30-10:45

Break

10:45-12:00 **Session 2: Program description abstracts**

Moderator: Anne-Sylvie Ramelet

9. DEVELOPING AND STANDARDISING ADOLESCENT TRANSITION SERVICES IN EPILEPSY CARE IN IRELAND- A COORDINATED, SYSTEMATIC APPROACH

Owen. Y
 National Childrens Hospital Group and Epilepsy. Ireland

10. THE PASS'ÂGE: A MULTIPURPOSE DEDICATED SPACE TO IMPROVE TRANSITION

Romier M¹, Larbre JP², Desombre H³, Durieu I⁴, Duquesne A¹, Lega JC⁴, Revol O³, Belot A¹
¹ Pediatric nephrology, rheumatology, dermatology unit, Hôpital Femme-Mère-Enfant, 69500, Bron; ² Rheumatology department, Centre Hospitalier Lyon Sud, 69310, Pierre-Bénite; ³ Department of Child Psychiatry, Hôpital femme-Mère-Enfant, 69500, Bron; ⁴ Department of Internal Medicine, Adult Cystic Fibrosis Care Center, Centre Hospitalier Lyon Sud, 69310, Pierre-Bénite. France

11. AN OVERVIEW OF RARE DISEASES TRANSITION NETWORKS IN FRANCE IN 2017

Gatipon-Bachette E.^{1,3}, Dion L.^{1,3}, Cazenave A.^{1,2,3}, Crétole C.^{1,2,3,4}
¹ Rare diseases health network : NeuroSphinx Filière, ² Rare diseases reference Network MAREP (Ano Rectal Malformations and Pelvic rare diseases), ³ Assistance Publique – Hôpitaux de Paris, ⁴ UMR 1163 INSERM. France

12. BUILDING A TRANSITION PROGRAMME FOR YOUNG PEOPLE WITH CHRONIC CONDITIONS

Jacquín, P¹, Limbourg, A²
¹Adolescent medicine unit, Robert-Debré University Hospital; ²AD'VENIR transition unit, Robert-Debré University Hospital. Paris, France

13. CO@CH: AN APP-BASED INTERVENTION TO SUPPORT PARENTS OF ADOLESCENTS WITH CHRONIC ILLNESS DURING TRANSITION

Akre C, Barrense-Dias Y, Suris JC
 University Institute of Social and Preventive Medicine, Lausanne University Hospital, Lausanne, Switzerland

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14. TEN STEPS TRANSITION TO ADULT SERVICES: AN INNOVATIVE PATHWAY FOR IMPROVING TRANSITION TO ADULT SERVICES FOR YOUNG PEOPLE INCLUDING THOSE WITH MULTIPLE COMPLEX LONG TERM CONDITIONS

Rogers J, Brook L
Alder Hey Children's NHS Foundation Trust. Liverpool, United Kingdom

15. TRANSITION WEBSITE - A NEW TOOL FOR HEALTH PROFESSIONALS, YOUNG PEOPLE AND THEIR PARENTS

Hanghøj S; Boisen KA
Center of Adolescent Medicine, Department of Paediatrics Adolescent Medicine, Copenhagen University Hospital Rigshospitalet. Copenhagen, Denmark

Discussion

12:00-13:00

Lunch

13:00-14:15 **Session 3: Program and research abstracts**

Moderator: Michael Hauschild

16. TRANSITION SHOULD INCLUDE OUT-OF-HOSPITAL SUPPORT

Gosse, AMG
Director of Dessine-Moi Un Mouton. Paris, France

17. WHAT IS THE IMPACT OF A STRUCTURED HEALTHCARE PATHWAY DEDICATED TO PATIENTS IN TRANSITION ON THEIR LONG-TERM FOLLOW-UP?

Menesguen F¹, Tejedor I², Malivoir S², Faucher P³, Halbron M⁴, Popelier M⁴, Léger J⁵, Netchine I⁶, Polak M⁷, Bruckert E⁸, Poitou C³, Touraine P²
¹E3M, Pitie Salpêtrière Hospital; ²Department of Endocrinology and reproductive medicine, Center for rare endocrine and gynecological disorders, Pitié Salpêtrière Hospital; ³Department of Nutrition, Pitié Salpêtrière Hospital; ⁴Department of Diabetology, Pitié Salpêtrière Hospital; ⁵Department of Pediatric Endocrinology, Robert Debré Hospital; ⁶Department of Pediatric Endocrinology, Trousseau Hospital; ⁷Department of Pediatric Endocrinology, Necker Hospital; ⁸Department Endocrinology and Metabolism, Pitié Salpêtrière Hospital. Paris, France

18. TRANSITION FOR PATIENTS WITH TYPE 1 DIABETES WITH A DEDICATED TRANSITION NURSE

Turrian M, Emmanouilidis-Bertholet S, Antoniou MC, Bouthors T, Hauschild M
Pediatric Endocrinology and Diabetology Unit, Lausanne University Hospital, Lausanne, Switzerland.

19. IMPLEMENTING AND EVALUATING A PATIENT NAVIGATOR SERVICE IN ALBERTA, CANADA FOR YOUTH WITH CHRONIC CONDITIONS TRANSITIONING TO ADULT CARE

Schroeder J¹, Samuel S², Morrison C¹, Mackie A³, Dimitropoulos G², Tinge K¹
¹Alberta Health Services; ² University of Calgary; ³University of Alberta. Canada

20. TRANSITION FROM CHILD AND ADOLESCENT MENTAL HEALTH SERVICES AND ADULT HEALTH SERVICES IN EUROPE: LESSONS FROM THE MILESTONE PROJECT

de Girolamo G¹, Signorini G¹, Saam M¹ and the MILESTONE group
¹Saint John of God Clinical Research Center. Brescia, Italy

21. EXPERIENCES WITH TRANSITIONAL CARE FOR YOUNG PEOPLE WITH DIABETES TYPE 1: A QUICK SCAN AMONG YOUNG PEOPLE AND THEIR HEALTHCARE PROFESSIONALS

Peeters MAC, Sattoe JNT, Bronner MB, van Staa AL
Research Centre Innovations in Care; Rotterdam University of Applied Sciences. Rotterdam, The Netherlands

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22. PARENTS TO CHRONICALLY ILL ADOLESCENT ARE AMBIVALENT TOWARDS CONFIDENTIAL YOUTH CONSULTATIONS

Thomsen EL¹, Khoury LR², Møller T³, Boisen KA¹

¹Center of Adolescent Medicine, Copenhagen University Hospital; ²Department of Dermatology and Allergy, Herlev and Gentofte Hospital, University of Copenhagen; ³University Hospitals Centre for Health Care Research, Rigshospitalet, University of Copenhagen. Copenhagen, Denmark

23. TRANSITION IS ABOUT PARENTS TOO

Suris JC^{1,2}, Larbre JP³, Hofer M⁴, Hauschild M⁵, Barrense-Dias Y¹, Akre C¹

¹Institute of Social and Preventive Medicine, Lausanne University Hospital, Lausanne, Switzerland; ²General Pediatrics, Lausanne University Hospital, Lausanne, Switzerland; ³Adult Rheumatology, Centre Hospitalier Lyon-Sud, Lyon, France; ⁴Pediatric Rheumatology Unit of Western Switzerland, Lausanne University Hospital and Geneva University Hospital, Lausanne, Switzerland; ⁵Pediatric Endocrinology and Diabetology Unit, Lausanne University Hospital, Lausanne, Switzerland.

Discussion

14:15-15:30 Session 4: Research abstracts

Moderator: Joan-Carles Surís

24. ADOLESCENTS WITH EPILEPSY AND THEIR ABILITY TO FULFIL THEIR DEVELOPMENT NEEDS

Malkowska-Szkutnik A¹, Kleszczewska D²

¹Faculty of Education, University of Warsaw; ² The Institute of Mother and Child Foundation. Warsaw, Poland

25. HOW THE CYSTIC FIBROSIS (CF) FRENCH CARE CENTERS MANAGE THE TRANSITION FOR ADOLESCENTS TO ADULT CF CARE CENTER? WHAT THE SAFETIM APP (SUIVI DES ADOLESCENTS DES FAMILLES ET DES EQUIPES POUR UNE TRANSITION IDÉALE EN MUCOVISCIDOSE ANALYSE DES PRATIQUES) STUDY TELLS US

Vion Genovese V¹, Perceval M², Durieu I³, Llerena C¹

¹Ped. CF center Grenoble-France, CHUGA Grenoble, Grenoble Alpes University; ² Filiere Muco CFTR, HCL Lyon Grenoble; ³ Adult CF center HCL, Filière muco CFTR, Lyon. France

26. NEEDS ASSESSMENT OF YOUTH WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES ENROLLED IN A TRANSITION CLINIC PROGRAM IN A TERTIARY INSTITUTION, 2015-2018

Cusi, A, Quilendrin, I

University of the Philippines-Philippine General Hospital Section of Developmental and Behavioral Pediatrics. The Philippines

27. EDUCATING FOR CHANGE: THE CHALLENGE OF TRANSITIONING FROM PEDIATRIC TO ADULT CARE

Morsa M, Gagnayre G, Lombraill P

Laboratory of Education and Health Practices (EA3412), University Paris 13. Bobigny, France

28. CONSENSUS GUIDELINES ON THE ELEMENTS TO IMPLEMENT IN TRANSITION FROM PEDIATRIC TO ADULT CARE

Le Roux E¹, Mellerio H¹, Jacquin P², Bourmaud A¹, Guilmin-Crépon S³, Faye A³, Matheron S⁴, Boulkedid R³, Alberti C¹

¹Université Paris Diderot - Sorbonne Paris Cité, INSERM, Unité ECEVE UMR 1123; ²Assistance Publique-Hôpitaux de Paris, Hôpital Robert Debré, Service de Médecine de l'adolescent; ³Assistance Publique-Hôpitaux de Paris, Hôpital Robert Debré, CIC-EC, Unité INSERM CIC 1426; ⁴Assistance Publique-Hôpitaux de Paris, Hôpital Bichat, Service des Maladies Infectieuses et Tropicales. Paris, France

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29. ARE PAEDIATRIC SPECIALIST TRAINEES PREPARED TO MANAGE TRANSITION, WHAT ARE THE KNOWLEDGE GAPS AND HOW CAN TRAINING BE IMPROVED?

Alam S^{1,2}, Thomas S¹, Farr E^{1,2}, van der Voort J^{1,2}

¹ Children's Kidney Centre, University Hospital of Wales, Cardiff; ² School of Paediatrics, Wales Deanery, Cardiff University. Cardiff, UK

Discussion

15:30-16:00

Coffee break

16:00-16:45

**KEYNOTE SESSION 2:
IS HEALTH TRANSITION DEVELOPMENTALLY APPROPRIATE?**

Janet McDonagh

MD FRCP, Senior lecturer. Centre for Musculoskeletal Research, Division of Musculoskeletal and Dermatological Sciences, School of Biological Sciences, Faculty of Biology, Medicine and Health, NIHR Biomedical Research Centre, Manchester University NHS Trust, Manchester Academic Health Science Centre, University of Manchester, UK

16:45-17:00

Conclusions