



Hosted by Cystinosis Ireland for Cystinosis Network Europe

Saturday 25th April 2020
Starts 1200 Irish Time / 1300 CET
Please check your timezone

Keynote Speaker
Dr Stephanie Cherqui
UCSD



Please check your own time zone

SESSION 1: *12 noon to 13.00 Irish Time / 13.00 to 14.00 CET*
Cystinosis and its management

Introductions

Cystinosis and its management

Prof Elena Levchenko – Conference Scientific Chair
Head of Department of Paediatric Nephrology
University Hospitals Leuven Belgium



Cystagon and Procysbi – How they work, why they are important and potential new treatments

Prof Donald Cairns
Head of School of Pharmacy and Life Sciences
Robert Gordon University Aberdeen



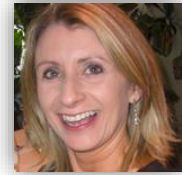
BREAK

SESSION 2: *13.00 to 14.00 Irish Time / 14.00 to 15.00 CET*
Educational issues
Maintaining your mental health



Working with schools - a shared language for cystinosis

*Dr Joyce Senior
Educational Psychologist; Asst Professor of Education and Director;
Professional Doctorate in Educational Psychology
University College Dublin*



Maintaining your mental health - for people with cystinosis and for carers

*Dr Siobhán MacHale
Consultant Liaison Psychiatrist;
Dept of Psychiatry Beaumont Hospital
Senior Lecturer RCSI
Dublin*



BREAK

SESSION 3: 14.00 to 15.00 Irish Time / 15.00 to 16.00 CET The Eyes

Ocular complications of cystinosis

*Dr Rachel Bishop, MD, MPH,
Staff Ophthalmologist (contractor)
National Eye Institute, National Institutes of Health,
Bethesda, Maryland,*



A possible new method of delivery cysteamine to the eyes

*Dr Anuj Chauhan
Department Head of Chemical and Biological Engineering; Colorado School
of Mines*



BREAK

SESSION 4: 15.00 to 16.00 Irish Time/ 16.00 to 17.00 CET Muscles and Bones



The emerging concept of 'cystinosis metabolic bone disease'

Prof Justine Bacchetta, MD, PhD
Professor of Pediatrics, Head of the Pediatric Nephrology and Rheumatology Unit, Vice Chair of the Department of Pediatrics, INSERM Research Unit 1033, Lyon University Hospitals



Benefit of exercise in cystinosis, some exercises to do at home to keep muscles healthy and new research on Galileo training boards for cystinosis

Christian Köppl
Physiotherapist at the Centre of Social Paediatrics in Traunstein, Germany.



BREAK

SESSION 5: *16.00 to 17.00 Irish Time / 17.00 to 18.00 CET*
Kidney Transplant: planning, procuring and preservation
Pregnancy in women with cystinosis
Male Fertility in cystinosis

Kidney Transplant: planning, procuring and preservation

Prof Paul Grimm
Professor of Pediatrics; Medical Director, Pediatric Kidney Transplant Program; Dept of Pediatric Nephrology Lucile Packard Children's Hospital; Stanford University School of Medicine





Pregnancy in women with cystinosis

*Dr Aude Servais
Senior Nephrologist
Dept of Adult Nephrology and Transplantation
Necker Hospital
France*



Male fertility in cystinosis

*Dr Ahmed Reda
KU Leuven
Belgium*



BREAK

SESSION 6: *17.15 to 18.45 Irish Time / 18.15 to 19.45 CET*
Latest Research in Cystinosis

Overview of the Latest Research

*Dr Patrick Harrison
Department of Physiology
University College Cork*



KEYNOTE ADDRESS 17.30 Irish time/ 18.30 CET

Clinical Trial for Autologous Transplantation of Gene-Corrected Hematopoietic Stem Cells for Cystinosis

*Dr Stephanie Cherqui
Associate Professor in Department of Pediatrics
Division of Genetics, University of California San Diego*





The Discovery and Development of CF10 – a cysteamine prodrug to improve the lives of those with cystinosis

Prof Herbie Newell

Professor of Drug Development at the University of Sunderland and Emeritus Professor of Cancer Therapeutics at Newcastle University, England



A No-Nonense Approach to Cystinosis - New treatment potential

Prof Paul Goodyer

Professor of Pediatrics and Human Genetics; McGill University Health Centre, Montreal



A novel urine test for in-home, needle-less assessment of kidney injury and transplant rejection

Prof Minnie Sarwal

Professor in Residence, Surgery, Medicine, Pediatrics, (UCSF); Medical Director, Kidney Pancreas Transplant Program, Director; Precision Transplant Medicine, San Francisco



BREAK

SESSION 7: 19.00 to 20.00/ 20.00 to 2100 CET **The Expert Panel**

Open Q & A with our speakers from today and joined by Dr Katharina Hohenfellner, Germany and Dr Atif Awan, Dublin

Without funding and donations this conference could never take place. We would like to thank all our supporters.

