

ESPN VIRTUAL MEETING PROGRAMME

September 18th 2020 Time Zone: Central European Time (CET)

RECORDATI RARE DISEASES	
IMPROVING SUPPORT FOR CYSTINOSIS PATIENTS BY OPTIMISING COMMUNICATION CHANNELS	11:00 - 12:00
Introduction to the value of a multidisciplinary team approach to the care of the cystinosis patient - Jun Oh	11:00 - 11:05
How does communication benefit your patient? - Jun Oh - Fionna Bathgate What are its characteristics? 	11:05 – 11:25
 How members of the multidisciplinary team communicate differently How optimal communication offers best support for your patient 	
Cystinosis & Me: a new tool in patient communication - Detlet Bockenhauer Encouraging patient empowerment 	11:25 – 11.45
 Improving overall patient compliance Integrating with an adolescent's daily life" 	
Conclusion - Detlef Bockenhauer – Jun Oh	11:45 – 11:50
Q&A	11:50 - 12:00
Coffee Break	12:00 - 12:05
Alnylam [®] Industry Symposium II	12:05 – 13:05
OXALATE – FROM TOXIC AGENT TO PREDICTIVE MARKER IN PRIMARY HYPEROXALURIA TYPE 1 (PH1)	12.05 - 13.05
Welcome & introduction - Jun Oh	12:05 – 12:10
 Excess oxalate: The damage and the consequences - Oliver Devuyst The harm caused by elevated levels of urinary oxalate (UOx) Differences between primary and secondary hyperoxaluria The clinical benefits of lowering UOx and plasma oxalate (POx) in patients with PH1 Utilising UOx and POx to predict outcome and measure treatment effect 	12:10 – 12:30
The management of high oxalate in PH1 - Sally-Ann Hulton • Current treatment strategies	12:30 – 12:50
New treatment approaches in development for PH1	12 50 12 05
Q&A	12:50 – 13:05
Coffee Break	13:05 – 13:10
Chiesi Industry Symposium III	
Mind the gap: planning for long-term success in cystinosis care Gema Ariceta	13:10 - 13:30
Coffee Break	13:30 - 13:35
	10.00 10.00
advicenne Industry Symposium IV	
Long-term outcomes of dRTA	13:35 – 13:55
Detlef Bockenhauer Moderated by Rezan Topaloglu	
BREAK	13:55 - 14:15

Introduction and Welcome	
Rezan Topaloglu (ESPN President)	14:15 - 14:20
Dieter Haffner (ESPN Assistant President)	
"COVID-19 and its impact on pediatric nephrology"	
Giovanni Montini	14:20 - 14:50
moderated by Martin Christian	
Coffee Break	14:50 - 14:55
"State of the art in nephrotic syndrome"	
Arvind Bagga	14:55 – 15:25
moderated by Francesco Emma	
Coffee Break	15:25 - 15:30
"Linking glomerular disease and basement membrane biology"	
Rachel Lennon	15:30 – 16:00
moderated by Elena Levtchenko	
Coffee Break	16:00 - 16:05
"Renal replacement therapy: a historical perspective"	
Otto Mehls	16:05 – 16:35
moderated by Franz Schaefer	
Videos in memory of Michel Broyer, Lluis Callis, Karl Schaerer	16:35 – 16:45
Coffee Break	16:45 - 16:50
ESPN General Assembly	
Concluding comments and welcome to new ESPN Council members & Results of Research Grants Applications	
Rezan Topaloglu (ESPN President)	16:50 - 17:15
Dieter Haffner (ESPN Assistant President)	
ESPN 2021 Amsterdam video presentation	17:15 - 17:25