**Rare Genetic Disease Program
September 12, 2019**

**InterContinental Hotel
Room 204**

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| Registration, Breakfast and Visit Exhibits | 7:00-7:30 am |  |
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|  | **7:30-8:00 am**  | **History of dialysis and new advancement in management of phosphorus?Marcos Rothstein MD, FACP** **Medical Director, Dialysis Services** **Washington University** **St. Louis, MO** |
| Introduction  | **8:00-8:05 am** | **Dr. Rupesh Raina and Dr Charles Kwon and Dr Hany Aly**  |
| Welcome by the Chairman, Department of Nephrology, Cleveland Clinic | **8:05-8:10 am** | **Dr. Robert Heyka** |
| Welcome by Chairman of University Hospitals Cleveland Medical Center  | **8:10-8:15 am** | **Dr. Srinivas**  |
| FSGS Section | **Chairs: Dr. Warady, Dr. Heyka, & Dr. Srinivas** |
|  | **8:15-8:45 am**  | **Advances in FSGS TherapyWilliam E. Smoyer, M.D., F.A.S.N.****C. Robert Kidder Chair****VP and Director, Clinical and Translational** **Research****The Research Institute at Nationwide Children's Hospital****Professor of Pediatrics, The Ohio State University** |
|  | **8:45-9:05 am** | **Role of Lipopheresis in FSGS: is this an option for resistant FSGS and posttransplant FSGS?****Dr. Rupesh Raina****Adult-Pediatric Kidney Disease/Hypertension****Associate Professor of Medicine****Director of Research Akron Nephrology Associates****AGMC, Cleveland Clinic, Cleveland, Ohio****Staff at Akron Children's Hospital, Akron, Ohio****Case Western Reserve University Cleveland, Ohio** |
| Coffee Break | **9:05-9:15 am**  |  |
| ADPKD | **Dr. Christina Nguyen, & Dr. Kwon** |
|  | **9:15-9:35 am**  | **Advances in ADPKD Treatment****Katherine M. Dell MD****Professor of Pediatrics, Case Western Reserve University****Vice Chair of Research, Pediatric Institute****Center for Pediatric Nephrology****Cleveland Clinic Children’s** |
| Uric Acid | **Dr. Negrea and Dr. Priya Kalahasti** |
|  | **9:35-10:10 am**  | **Urate Nephropathy Chronic gout and cross talk with kidney****Brian Mandell, MD, PhD****Department Rheumatologic and Immunologic Disease** **Cleveland Clinic**  |
| aHUS | **Dr. Somyer, Dr. Bagga, and Dr. Buchman** |
|  | **10:10-10:35am**  | **aHUS a Genetic Disease: recent advancement in diagnosis and treatment.****Christoph Licht, MD****Professor of PediatricsUniversity of TorontoThe Hospital for Sick Children** |
| Coffee Break |
|  | **10:40-10:50 am**  | **aHUS Alliance and Role of Patient Advocacy****Linda Burke aHUS Alliance NGO** |
|  | **Dr. Raid Bou Matar, Dr Shroff and Dr. Licht**  |
|  | **10:50-11:20 am**  | **Orphan Drugs Challenges in Developing WorldArvind Bagga MD, FAMS, FIAP, FISN****Professor****ICMR Center for Advanced Research in Nephrology****Department of Pediatrics****All India Institute of Medical Sciences****New Delhi, India** |
|  | **11:20-11:40 am**  | **Visits booth to discuss new studies enrollment** |
| Alport’s  | **Dr. Kwon, Dr. cha, and Dr. Shroff** |
|  | **11:40-12:00 pm** | **Alport’s Foundation and it Role in AwarenessLisa Bonebrake NGO****Director of Communication & Patient Engagement****Alport Syndrome Foundation** |
| Lunch Symposium  | **12:00 pm** |
|  | **Dr. Warady and Dr. Shroff**  |
|  | **12:30-12:50 pm** | **Hyperoxaluria and approach to treatment****Timothy E Bunchman MD****Pediatric Nephrology Richmond, VA** |
| Rickets | **Chairs: Dr. Safadi & Dr. Kusumi** |
|  | **12:50 -1:10 pm** | **X-Linked Hypophosphatemic RicketsJohn D. Mahan, M.D.****Professor, Department of Pediatrics, Program Director, Pediatric****Residency Program, Program Director, Pediatric Nephrology****Fellowship Program, Vice Chair for Education, The Ohio State** |
|  | **1:10-1:35 pm** | **Approach with CystinosisJoshua J. Zaritsky, MD** **Division Chief, Division of Pediatric Nephrology, Department of Pediatrics****Nemours/Alfred I. duPont Hospital for Children** |
|  | **1:35-2:00 pm** | **ACTH is it an option of treatment of drug Resistant Nephrotic syndrome?****Nelson Kopyt, D.O., FASN, FNKF, FACP, Chair, Section of Nephrology and Hypertension****Department of Medicine****Lehigh Valley Hospital and Health Network****Allentown, Pennsylvania** |

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| **Hands-on Workshops in Amphitheater Side A on September 12** |
| 2:30 PM  | Simulation Session D: ECMO and CRRT-Case Based Simulation-Protocol Based CRRT Prescription – **Dr. Cha**  |
| Simulation Session E: Peritoneal Dialysis – PD Catheter Insertion and Prescription and Case Based Simulation for Approach to Peritonitis – **Dr. Warady and Dr. Kusumi**  |
| Simulation Session F: Hemodialysis and SLED-HD Prescription and Case Based Approach - **Dr. Shroff and Dr. Bagga** |
| Simulation Session G: Case Based Discussion: Inborn Errors of Metabolism and Prescription for High Flow CRRT – **Dr. Bunchman and Dr. Nguyen**  |
| 4:30 PM  | Q&A  |
| 4:45 PM  | Adjourn  |

**Friday, September 13, 2019**

**General Session**

**7:00 am Registration, Continental Breakfast, and Visit Exhibits**

**8:00 am Welcoming Remarks**

**Session A**

**Moderator: Hany Aly, MD, MSHS**

**8:15 am HIF Stabilization in the Prevention of ROP**

**Jonathan Sears, MD**

**9:00 am Imaging Infants with Retinopathy of Prematurity with Optical**

**Coherence Tomography**

**Xi Chen, MD, PhD**

**9:45 am Break**

**Session A**

**Moderator: Raina Rupesh, MD**

**10:00 am Neonatal AKI- Advancement and Update-Case Based Approach**

**Presenters**

**Bradley A. Warady, M.D.**

**Director, Division of Pediatric Nephrology**

**Director, Dialysis and Transplantation**

**Children’s Mercy Kansas City**

**Professor of Pediatrics**

**UMKC School of Medicine**

**Rukshana Shroff, MD, FRCPCH, PhD,**

 **Consultant in Pediatric Nephrology**

**At Great Ormond Street Hospital for Children in London UK,**

**Associate Professor at University College London.**