| Study title | PI | Description of Study |
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| Clinical Features and Long-term Outcomes of Tubulointerstitial Nephritis (TINU) | Darcy Weidemann | This is a multi-center retrospective cohort study of children ages 1-21 years old with either suspected or confirmed tubulointerstitial nephritis (TINU). Owing to its exceptionally rare nature, existing literature is mostly limited to single center cohorts with small sample sizes, short duration of followup, and/or lack of long-term followup with relevant kidney-related outcomes. We aim to describe the clinical features, treatment regimens, and long-term outcomes of children with TINU. |
| COntemporary Infant and Neonatal Dialysis Study (COINED) | Melissa Muff-Luett | COntemporary Infant and Neonatal Dialysis Study (COINED) is a multi-center retrospective study seeking to evaluate current neonatal dialysis practices including the incidence of neonatal dialysis, the characteristics of neonates receiving dialysis, dialysis modalities utilized and transitioned between, complications and outcomes. The goal is to provide data for best care practices in this small but complex patient population. The study requires a single data entry record per patient enrolled and is not an ongoing registry. |
| OPKO Vitamin D study | John Mahan | |
| Identifying Barriers to Phosphorus Binding Medication Compliance in Pediatric Dialysis Patients- Questionnaire Development and Feasibility | Alison Schoch | There is a need to identify barriers with taking Phosphorus Binding medication in our pediatric dialysis population. Phosphorus binder administration is different than other medications due to its inconsistent schedule so previously developed questionnaires don't identify all barriers these patients may have. We are hoping to develop a questionnaire to help identify these patients' barriers so we can better focus our interventions to help compliance. |
| Evaluation the Social Impacts of Covid-19 on the Pediatric Transplant Community | Namrata Jain | We are interested in evaluating the social impacts of COVID 19 in pediatric nephrology. We aim to evaluate changes in obesity patterns, change in insurance status, change in # of rejection episodes, changes in the # of social work/psychology referrals and #nutrition consultations, as well as changes in our patients' home location. This is a retrospective study, with no funding, and does not require IRB approval. Data is inputed via a case report form (CRF). |
| Impact of C. difficile Infection in Renal Transplant Recipients | Avi Traum | |
| VUR in Pediatric Kidney Transplant | Namrata Jain | This is a multicenter study to assess if allograft outcomes are affected by either the presence of asymptomatic/symptomatic VUR or the procedures used to correct the VUR. We are looking at both patients who had abnormal bladders and those with "normal" bladders prior to kidney transplant. This study requires IRB approval and DUA. Redcap at Boston Children's Hospital. This study is unfunded. |
| Pediatric Glomeruli w/ Crescents | Guillermo Hidalgo | |
| DoNUT Project | Simone Sanna-Cherchi | Congenital anomalies of the kidney and urinary tract (CAKUT) account for 40-50% of pediatric kidney failure worldwide, with significant implications for cardiovascular morbidity and mortality. Genetic factors play a significant part in the development of CAKUT. The DevelOpmeNt of the Urinary Tract (DONUT) study has the following aims: 1) study the clinical characteristics of CAKUT patients with known disease mutations to give us new insight into kidney development, pathobiology, and conduct genotype-phenotype correlations; and 2) discovery and validation of new genetic factors predisposing to development of CAKUT in a well-phenotyped North-American cohort. |
| Iron Study In Non Dialysis CKD Pts | Rasheed Gbadegesin | |
| Impact of BMI listing requirements on Pediatric Transplantation | Rachel Engen | An exploratory study to assess practice patterns regarding BMI requirements for pediatric kidney transplant candidates, assess the number of affected patients for future study, and identify outcomes of children who are declined for transplant due to BMI. The study combines a survey component (no IRB) and an optional patient-level component (IRB required, no DUA required by receiving site). Estimated time is <5min for the survey and <15min per patient for the optional data collection. |
| Utility of the Renasight™ Kidney Disease Gene Panel in the Pediatric Nephrology Population | Christine Sethna and Ashley Gefen | The study will create a multicenter registry of Renasight™ genetic testing results in pediatric nephrology patients with suspected genetic kidney disease to determine the diagnostic yield and clinical utility of Renasight™. De-identified data of patients who underwent Renasight™ genetic testing will be captured retrospectively and entered into REDCap. A cross-sectional survey of physicians will be conducted to determine whether genetic testing results changed management for each patient enrolled in the registry. Reimbursement: $400/site, $50/patient enrolled. |
| Infectious Disease counseling & delays pre/post kidney transplant | Taylor Heald-Sargent | |
| Behavioral health Services available within Pediatric Nephrology Practices | Anne Dawson | |
| Differentiating Pediatric aHUS from other TMA processes | Arash Mahajerin | This study aims to evaluate admission characteristics, e.g. laboratory values and vital signs, for pediatric patients presenting with concern for thrombotic microangiopathy (TMA) to identify if significant differences exist between atypical Hemolytic-Uremic Syndrome (aHUS) and other TMA conditions (e.g. thrombotic thrombocytopenic purpura). In addition, therapies utilized and 6 and 12 month outcomes including genetics will be described for patients with aHUS. |
| Covid 19 effect on Renal Disease | Guillermo Hidalgo | |
| Tacrolimus in the Treatment of Pediatric Steroid Resistant Nephrotic Syndrome | Avi Traum | |
| XLH Patient Clinical | John Mahan | |
| GNOM kids study | Kouri | The GNOM Study is the Genetics of Membranous in Children Study. This study is a collaboration of the PNRC and Dr. Krystof Kiryluk's lab at Columbia University. The aim is to identify genetic susceptibility loci and novel biomarkers, such as serum antibody levels, in children with primary membranous nephropathy. It requires only a blood draw from the patient. |
| Bio-repository for Children with Recurrent FSGS following Transplantation | Tarak Srivastava | The basis for recurrence of FSGS following kidney transplantation remains unknown. The biorepository study will collect 10 mL blood (in 3 separate tubes), 30 mL urine and clinical data in RedCap to study the genetic basis for risk of FSGS recurrence in Dr. Gbadegesin's laboratory and for putative circulating permeability factor in Dr. Srivastava's laboratory. The goal is to enroll 25-30 children with and 25-30 children without recurrence of FSGS following transplantation. |
| Complement Pathway Abnormalities in Post – Infectious Glomerulonephritis (PIGN) | Rahul Chanchlani | This study aims to compare the clinical features, genetic defects and outcomes in children with typical and atypical PIGN |
| Genetic, Genomic & Biomarker Studies of Henoch-Schonien Purpura & IgA Nephropathy in Kids (GiGA) | Krzystof Kiryluk | The GIGA-kids Study (Genomics of IgA-related disorders in kids Study) is a multicenter collaborative study based at Columbia University and sponsored by the PNRC. The study aims to recruit over 1,000 children with IgA nephropathy or Henoch-Schönlein purpura (with or without nephritis) for the purpose of genetic, genomic and biomarker studies. IgA nephropathy represents the leading cause of kidney failure among young adults. Henoch-Schönlein purpura is a related disorder with skin manifestations that frequently leads to nephropathy in children. Our prior genetic studies suggest that patients carrying more risk alleles have an earlier onset of disease. Accordingly, GIGA-kids extends our genetic investigations to pediatric patients, aiming to validate the known disease markers and to discover new genetic and biochemical predictors of disease that may be specific to children. For more information, please see www.gigakids.org |
| SSNS GWAS Study | Rasheed Gbadegesin | |
| KidCOM | Christoph Licht | KidCOM (www.kidcom.ca) is one of the largest (pediatric) international registries & biorepositories of patients with aHUS and IC-MPGN/C3G, including 17 pediatric centers across 3 countries (Canada, United States, and Australia). The main goal of KidCOM is to monitor natural outcomes, treatment responses and biochemical markers in patients with aHUS IC-MPGN/C3G as specific examples of complement-mediated renal diseases to extend our understanding of the underlying pathophysiology, and to develop specific treatment strategies, and thus advance patient outcomes. |
| Probiotics in Kidney Transplant: Survey | Sarah Kizilbash | |