| 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). We aim to describe the clinical features, treatment regimens, and long-term outcomes of children with TINU. |
| 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. |
| 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 | |
| Covid 19 effect on Renal Disease | Guillermo Hidalgo | |
| Tacrolimus in the Treatment of Pediatric Steroid Resistant Nephrotic Syndrome | Avi Traum/Jill Warejko | |
| 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. |
| 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 | |
| Second Line Therapies in the treatment of BK Viremia/Nephropathy | Avi Traum | The objective of this study is to characterize the response to defined second line therapies in pediatric renal transplant patients with BK viremia and nephropathy. This is a retrospective chart review of kidney transplant recipients with BK viremia and/or nephropathy during the period of 1/1/2012 to 1/1/2022. All pediatric kidney transplant recipients who fulfill the inclusion criteria at participating centers will be included in the study. The primary outcome of interest is the duration of BK viremia after the initiation of a second-line agent. They will also describe the adverse effects to the second-line agents and evaluate the effect of second-line agents on estimated glomerular filtration rate and allograft survival. |
| The Pediatric Lupus Nephritis of Mycophenolate Mofetil (PLUMM Study | Prasad Devarajan/Hermine Brunner | The PLUMM Study is an NIH-funded 1-year 2-part double-blinded placebo controlled 2-arm clinical trial. The study goal to determine the safety and efficacy of MMF dosed as per body-surface area (MMFBSA) compared to pharmacokinetically-guided precision-dosing of MMF (MMFPK) for the treatment of proliferative LN in subjects 8 to <18 years. The primary objective is to evaluate the safety and efficacy of MMFBSA to MMFPK measured by participants with partial renal remission by the end of Part 1 (Week 26). |
| Food and Nutrition Security in Hemodialysis Patients | Neha Pottanat/Elizabeth Onugha | To evaluate the impact of food and nutrition security on phosphorus hemostasis, fluid management, and blood pressure control in a pediatric hemodialysis cohort using food and nutrition screeners. We hypothesize that pediatric hemodialysis patients living in food-insecure households will have higher rates of fluid overload and hyperphosphatemia than those living in food-secure environments. |
| BK Viremia in Pediatric Heart Transplant: A Study on Surveillance Patterns & Impact on GFR | Ruchi Mahajan/Priya Verghese | Survey study to assess screening patterns for BK polyomavirus infection and retrospective data study to analyze GFR patterns in patients who test positive for BK polyoma virus (BKPyV). |
| Kidney transplant outcomes in pediatric patients with tracheostomy: A case series study | Saritha Ranabothu/Avi Traum | The goal of this study is to describe the experience of children with tracheostomies who subsequently undergo kidney transplantation. Our hypothesis is that these patients will have favorable outcomes with regards to allograft function and infectious complications. |
| Defining Post-Kidney Transplant Diabetes Mellitus in Pediatric Recipients Across Transplant Centers | Priya Verghese/Kristy Zeng | This survey seeks to delineate kidney transplant centers' definition, diagnosis, and management of posttransplant diabetes mellitus (PTDM), including diagnostic tests, risk factors for PTDM, and interventions. In addition, the survey explores providers' beliefs and opinions on the diagnosis and management of PTDM. In the last optional section of the survey, we request information on kidney transplant recipients diagnosed per center with PTDM in the last 5 years. |
| Hypercalciuric Hypercalcemia due to CYP24A1, SLC 34A1 and SLC34A3 Mutation-Long term Follow-up, Management and Prognosis | Shelly Levi and Ruth Schreiber | We hypothesize that over time, biochemical parameters, including hypercalcemia, elevated 1,25OH2D, and suppressed PTH, will exhibit improvement. However, hypercalciuria (HC) and the associated risks of nephrocalcinosis (NC), stone disease progression, and potential renal injury will persist. In terms of treatment, we postulate that a low vitamin D diet, meticulous calcium restriction, low-sodium dietary measures, and hyperhydration will be effective treatments. Phosphate supplementation is anticipated to ameliorate rickets and the hypervitaminosis D pathway in patients with SLC34A1/A3 mutations, but may exacerbate phosphate excretion and contribute to the progression of nephrocalcinosis/nephrolithiasis. The use of thiazide diuretics is expected to effectively address hypercalciuria and stone disease, but may worsen total body calcium load (expressed by low PTH/ extrarenal calcifications). |
| Ambulatory blood pressure monitoring thresholds for predicting left ventricular hypertrophy in children age 6-12 years: A Pediatric Nephrology Research Consortium Study | Christine Sethna, Afsana Jahan and Ikuyo Yamaguchi | To determine optimal thresholds of ambulatory systolic and diastolic BP that are associated with the development of LVH in children 6-12 years of age |
| Transplant outcomes in pediatric patients with suboptimal bladder | Saritha Ranabothu and Samhar Al-Akash | The objective of this study is to evaluate transplant outcomes in children who were transplanted with suboptimal bladder. The hypothesis is that transplanted children with sub-optimal bladder have suboptimal graft function and/or survival compared to overall outcome in the published literature, and have higher morbidity related to their urological disease |
| Risk factors for spontaneous resolution versus persistance of childhood idiopathic nephrotic syndrome- a multicenter study | Evgenia Gurevich and Daniel Landau | The aim of the study is to determine whether the resolution of INS is related to the length of the disease or to puberty and sex hormone influences. 1) To determine the duration of illness in childhood INS, based on investigator reported chart reviews, looking for: 1a) The ages of first and last relapse (a relapse will be defined as "last" only if > 2 relapse-free years are documented since that last episode); 1b) The apparent pubertal stage indicators (height velocity, tanner stage, RBC mass, Hgb) at the age of last relapse; 2) To examine potential consequences of long term intermittent CS therapy, such as body mass index, blood pressure, use of steroid sparing agents, and the co-existence of common chronic allergic illnesses, such as atopy, celiac disease and asthma. |
| Provider Survey to Assess Perception of Impact of Pre-transplant hypotension on Transplant Listing Eligibility and Outcomes in Pediatric Patients | Shireen Hashmat and Olga Charnaya | The purpose of this survey is to assess providers' perceptions and practices regarding kidney transplant access and outcomes in pediatric patients with ESKD and chronic hypotension. |
| Multicenter Study of FSGS Recurrence in Pediatric Kidney Transplant Recipients | Olga Charnaya and Ruchi Gupta Mahajan | Identify pathological features on first diagnostic biopsy of FSGS recurrence that have an association with response to therapy and allograft outcome. We will seek to identify specific Class HLA alleles associated with increased risk of FSGS recurrence, and will further elucidate prior report of DQ7 donor/recipient concordance as protective by utilizing HLA-DQαβ heterodimer alleles. |
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