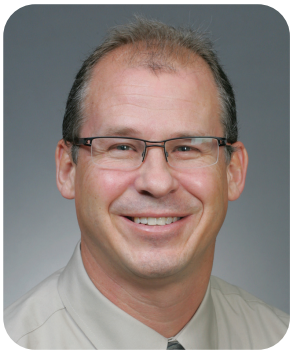
Children's Mercy KANSAS CITY

FOCUSING ON INNOVATIVE RESEARCH AND COMPREHENSIVE CLINICAL CARE



A MESSAGE FROM Craig Friesen, MD

Past Division Director, Gastroenterology
Associate Director of Research; Co-Director of Abdominal Pain Program

As I step down as the Division Director, I am so proud of how our team has responded to the challenges of the pandemic while maintaining our commitments to holistic care, translational research, and educating the next generation of specialists. In 2021, we provided more than 22,000 outpatient visits with more than 10,000 of these being provided in one of our 22 multidisciplinary and interdisciplinary programs. While clinically busy, we also maintained our commitment to the generation of new knowledge with the publication of 68 peer-reviewed manuscripts.

We are delighted to share the 2021 highlights from our division, shining a spotlight on several of our multidisciplinary programs and some of our research accomplishments.

Ding-You Li, MD, PhD, is serving as the Interim Division Director, Gastroenterology, as of Fall 2021.

2021 HIGHLIGHTS

BEST CHILDREN'S HOSPITALS U.S.News & WORLD REPORT GASTROENTEROLOGY & GI SURGERY 2021-22

Ranked #32 in Pediatric Gastroenterology and GI Surgery by U.S. News & World Report.

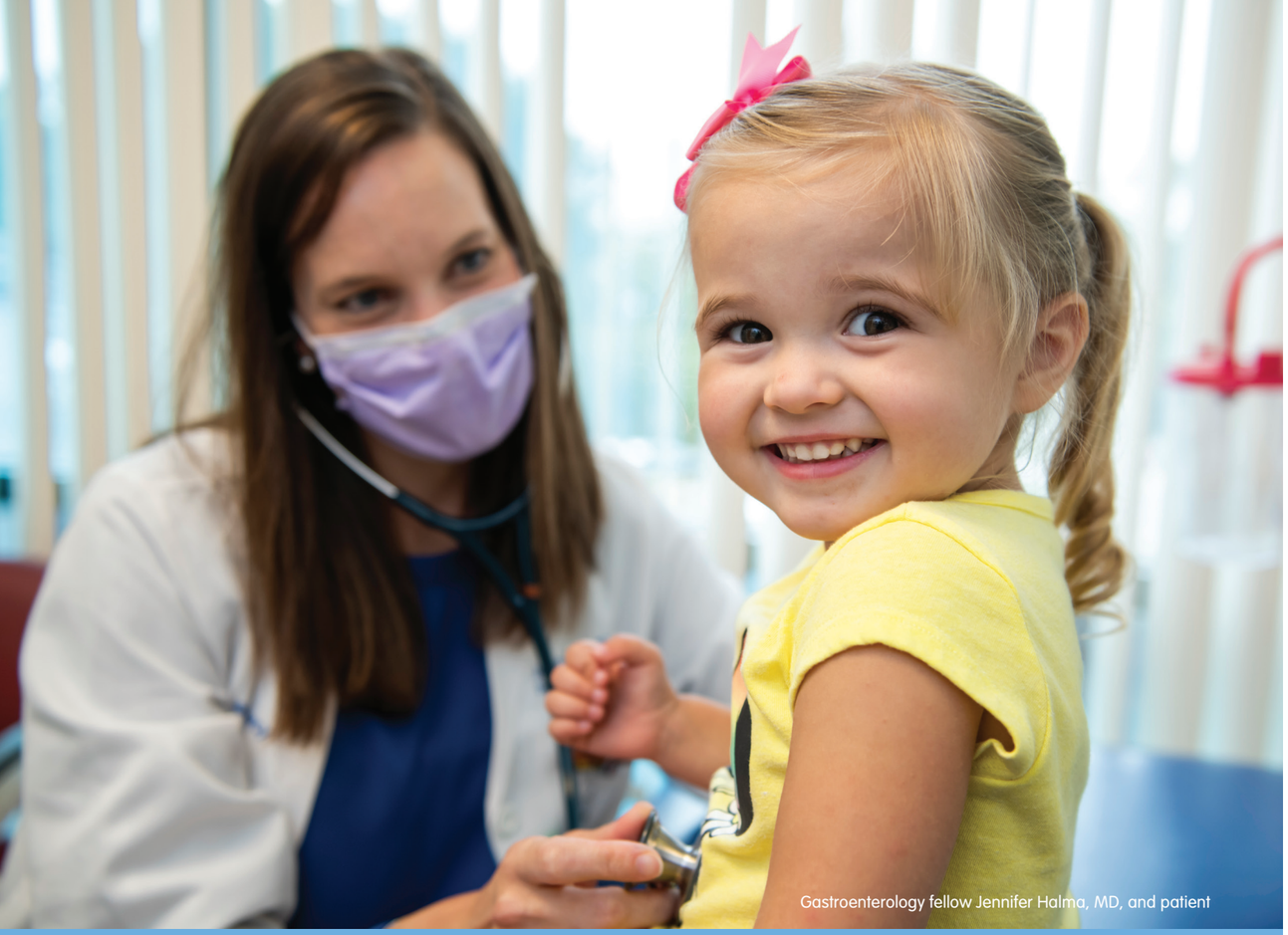
Rachel Chevalier, MD, received a two-year **NASPGHAN Foundation/ NASPGHAN George Ferry Young Investigator Development Award**, providing her with a **$150,000 grant for EoE research.**

We are nationally recognized for conducting clinical research to improve care for children with intestinal, liver, esophageal and nutritional disorders, as evidenced by our presence at the **2021 NASPGHAN Annual Meeting.** Our participation included **7 oral presentations, 7 posters, 1 invited lecture** and **1 award.**

Jennifer Schurman, PhD, and her team of psychologists created the **Comfort Promise plan** to make needle procedures more comfortable for children.

Our transplant team welcomed a new Section Chief of Transplant Surgery, Co-Director of the Brendan Tripp Elam Transplant Center – **Bhargava Mullapudi, MD.** Our transplant team also **received patent approval** for work related to their publication: Coexpression of FOXP3 and a Helios isoform enhances the effectiveness of human engineered regulatory T cells.

Thomas Attard, MD, and team led the creation of **guidelines for transition of care** in children and adolescents with **hereditary polyposis syndromes.**



Gastroenterology fellow Jennifer Halma, MD, and patient

2021 By the Numbers

22,369 visits (excluding procedures)

4,977 procedures

- **10** colon catheter placements
- **1,353** colonoscopies
- **3,495** EGDs
- **70** flexible sigmoidoscopies
- **14** suction rectal biopsies
- **10** endoscopic retrograde cholangiopancreatographies (ERCPs)
  New program for 2021
- **25** enteroscopies

46 faculty members

Medical

23 physicians

17 APRN providers

Psychology

6 PhD providers

4 multidisciplinary clinics (abdominal pain, celiac disease, inflammatory bowel disease, feeding)

46% of visits were provided via telehealth in 2021.

CLINICAL EXCELLENCE SETTING NEW STANDARDS OF CARE

IBD: Family Engagement and Transition

The Inflammatory Bowel Disease (IBD) program offers multidisciplinary, collaborative care focusing on the whole child and their family. IBD Medical Director Julie Bass, DO, works closely with the IBD Patient Family Advisory Committee (PFAC), in which family members and care providers work together to improve outcomes. Parents meet as a group every other month and one to two parents attend monthly IBD Clinical Quality Improvement meetings. Dr. Bass is also the Engagement Physician Lead for ImproveCareNow, a collaborative community where patients, parents, clinicians and researchers work together to improve treatment for children with IBD.

Transitioning from pediatric to adult care is a critical, and often challenging, step for these patients. The IBD Young Adult Clinic was developed in 2017 by Michele Maddux, PhD, Director of Medical Transition. This clinic occurs twice monthly and provides transition support, education and planning for patients 17 and older, with the goal of helping young adult patients successfully transfer to adult care by their 22nd birthday. Dr. Maddux is also involved in ImproveCareNow and is leading a multisite collaborative study examining perceived barriers toward transition, as well as seeking qualitative feedback from parents and patients regarding clinical interventions needed to address transition barriers.

Hepatology: Investigation of Tregs

Ryan Fischer, MD, collaborated with researchers from the University of Kansas Medical Center to investigate the utility of engineered "anti-inflammatory" regulatory T cells (Tregs) to prevent disordered inflammation. The overexpression of important transcription factors, including FOXP3 and Helios, allows these Tregs to control the immune response in a mouse model of graft-versus-host disease. The efforts have resulted in patented cell-based technologies and ongoing exploration of Treg therapy in models of autoimmune disease and transplant rejection. This research was partially funded by the Tripp Family Foundation.

Colorectal: Multidisciplinary Care

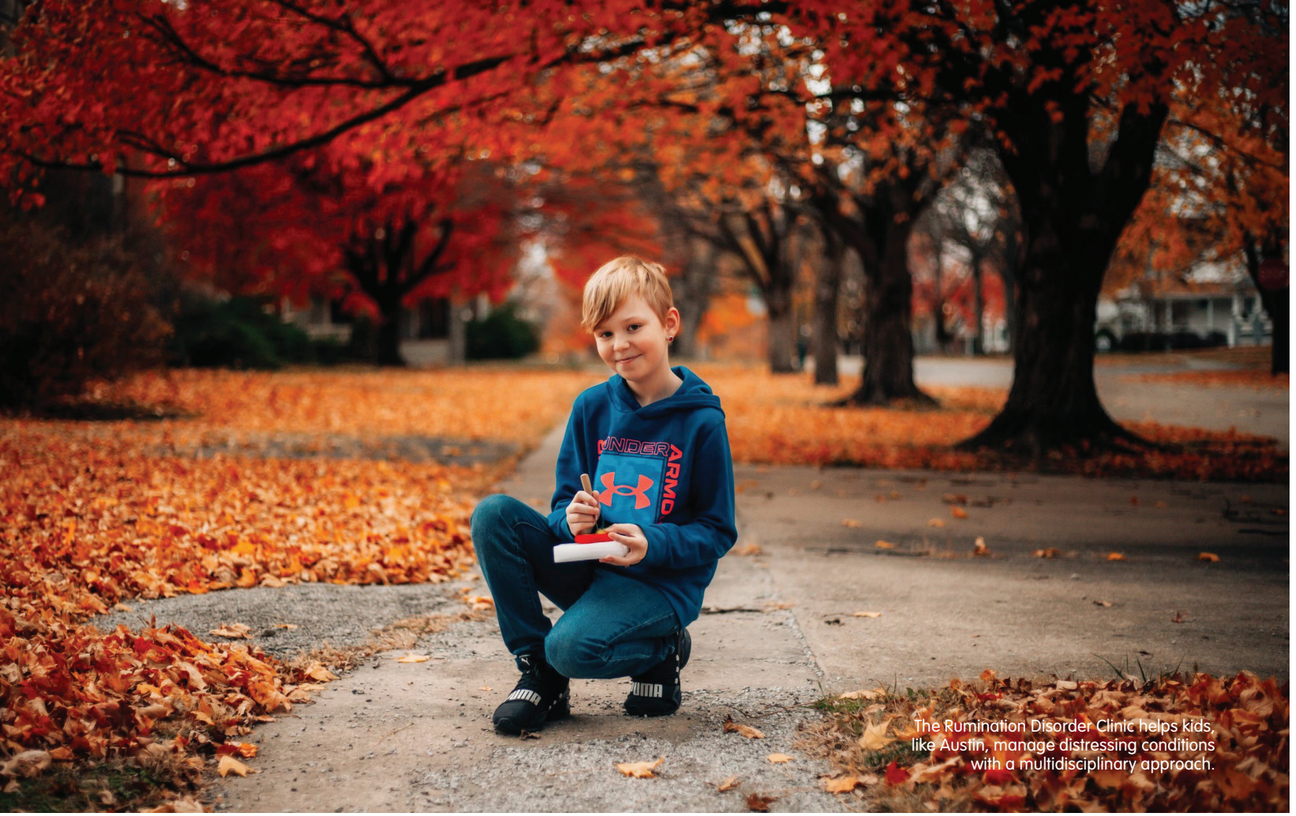
The Comprehensive Colorectal Center (CCC) provides multidisciplinary care for children with colorectal conditions. One unique aspect of the CCC is a focus on mental health, with an embedded pediatric psychologist, Christina Low Kapalu, PhD, on the team. Dr. Low Kapalu and colleagues recently published a systematic review of the psychosocial and behavioral factors that impact the quality of life of patients with anorectal malformations and Hirschsprung disease. Dr. Low Kapalu specializes in helping patients and their families cope with the challenges of living with a chronic condition. Other specialties in the CCC include Gastroenterology, Urology, Colorectal Surgery, Nutrition and Gynecology.

Polyposis: Multipronged Approach

The Polyposis Center, under Director Thomas Attard, MD, aims to improve treatment of hereditary polyp syndromes by utilizing a multipronged approach. One element is more education for providers who rarely encounter these conditions. Last year, Dr. Attard founded the Polyposis Special Interest Group at NASPGHAN 2020 and was lead author on treatment guidelines used by the American College of Gastroenterology and the European Society of Gastrointestinal Endoscopy. The Center has shown that advanced endoscopic techniques can reduce the need for surgery and is trialing food supplements that could decrease the likelihood of polyps becoming cancerous.

NASPGHAN Award for EoE Research

Rachel Chevalier, MD, recently received a two-year NASPGHAN Foundation/NASPGHAN George Ferry Young Investigator Development Award, which is given to support a commendable research project studying gastrointestinal conditions or nutritional disorders in children. Dr. Chevalier's project focuses on eosinophilic esophagitis (EoE), a disease of the esophagus often triggered by a reaction to certain foods. The condition is managed through elimination diets or corticosteroids, including oral budesonide. Dr. Chevalier will analyze the factors that lead to patients failing to reach remission with budesonide therapy, with a long-term goal of better predicting therapeutic response to budesonide and improving EoE treatment.



The Rumination Disorder Clinic helps kids, like Austin, manage distressing conditions with a multidisciplinary approach.

RUMINATION DISORDER CLINIC: AUSTIN'S STORY

Rumination Disorder Clinic

The Rumination Disorder Clinic is one of the nation's only interdisciplinary programs for children and teens with rumination disorder, a GI condition that causes the backward flow of recently eaten food from the stomach to the mouth, where it is re-swallowed or spit out. Rumination can be triggered by underlying GI conditions, such as reflux, viral illness, or allergies, as well as by stress. Initial treatment includes GI testing as well as assessment for possible emotional or behavioral factors. Long-term management includes both medical and behavioral health therapies such as medications, biofeedback therapy, and stress management training.

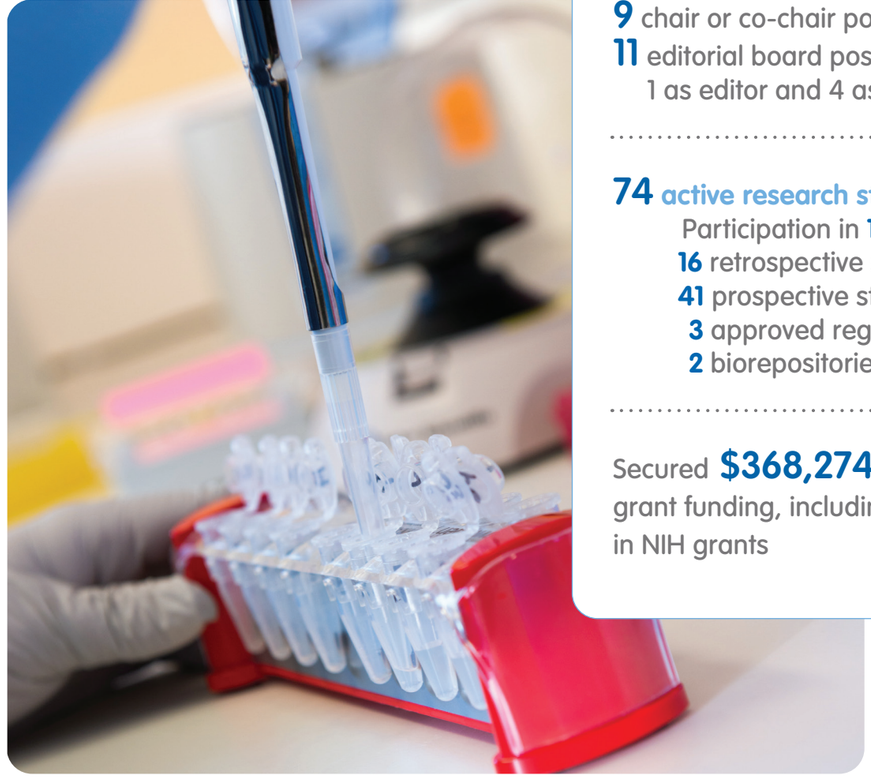
Austin's Story

Eleven-year-old Austin Hasenohr knows firsthand the benefits of the Rumination Disorder Clinic. Late in 2020, Austin became sick, unable to keep any food down. He was diagnosed with inflammation of lymph nodes in a membrane attached to his abdominal wall, but his mother believed there was more going on and drove Austin to the Rumination Clinic, where he was diagnosed with eosinophilic esophagitis (EoE), a chronic inflammatory immune response to allergens. Treating the EoE helped Austin feel better, but regurgitation had become his body's habitual response, and treatment shifted to habit reversal, training his body to keep food down.

Clinical Psychologist Jennifer Schurman, PhD, ABPP, BCB, worked with Austin in the Rumination Disorder Clinic to test different techniques such as singing, sucking on hard candy and chewing gum. Austin became proficient at biofeedback, where patients visualize stress reactions and then calm them with diaphragmatic breathing, progressive muscle relaxation or other tactics. Stress management is critical as well, and for Austin that means having a wide variety of hobbies, including needle felting and dancing. Rumination can be embarrassing, socially isolating and psychologically distressing for kids like Austin. A multidisciplinary approach that addresses both the physical and psychological effects of the disorder, like that at the clinic, leads to more successful long-term management for patients and families.

LEADING THE WAY Through Research

Our team's successes are found where two key commitments intersect: our dedication to discovering new, more effective treatment methods through clinical research and our commitment to providing excellent medical care. We are actively researching in the areas of abdominal pain, inflammatory bowel disease, liver care, polyposis, GI issues in children with autism, and many others. By collaborating with our Genomic Medicine Center's Genomic Answers for Kids study, we are able to diagnose gastroenterology conditions at the genetic level.



By the Numbers

68 publications

36 oral presentations at national or international meetings

Faculty involved in:

47 national committees
9 chair or co-chair positions
11 editorial board positions, including 1 as editor and 4 as associate editors

74 active research studies

Participation in **12** clinical trials
16 retrospective studies
41 prospective studies
3 approved registries
2 biorepositories

Secured **$368,274** in external grant funding, including **$198,274** in NIH grants

RESEARCH HIGHLIGHTS

Dr. Thomas Attard Creates Guidelines for Shift From Pediatric to Adult Care for Youth With Polyp Syndromes

Polyposis Center Director Thomas Attard, MD, and team led the publication of care transition guidelines for pediatric patients with hereditary polyposis syndromes. These patients are particularly vulnerable because of the risk of loss of continuity of care and subsequent poor disease outcomes. The report offers specific recommendations for disease management, covering models of care, providers and socioeconomic factors affecting transition. The authors emphasize the need for early planning, flexibility in the transition process, psychological readiness, communication among team members, and assessing changing insurance coverage. The study was commissioned by the Pediatric Committee of the American College of Gastroenterology.

Attard TM, Burke CA, Hyer W, et al. ACG clinical report and recommendations on transition of care in children and adolescents with hereditary polyposis syndromes. *Am J Gastroenterol*. 2021;116(4):638-646. doi:10.14309/ajg.0000000000001140

Nutrition Task Force Studies Feeding Tube Practices in Pediatric Patients to Guide Transition From Nasogastric to Gastrostomy Tube

Ruba Abdelhadi, MD, CNSC, NASPGHAN-F, was lead author on a report which examined the safety and use of nasogastric tubes (NGTs) and gastrostomy tubes (GTs) in pediatric patients. The survey was done by the ASPEN Enteral Nutrition Task Force Pediatric Work Group and is the first step toward addressing an information gap surrounding feeding tube choices and the appropriate timing of transitioning from NGT to GT feeding. The study defined time frames, parameters, and other decision points that nutrition support professionals can use to guide clinicians and families in the transition from NG to GT feeding.

Abdelhadi RA, Rempel G, Sevilla W, et al. Transitioning from nasogastric feeding tube to gastrostomy tube in pediatric patients: A survey on decision-making and practice. *Nutr Clin Pract*. 2021;36(3):654-664. doi:10.1002/ncp.10603

Institutional Support is Critical for Building a Multidisciplinary Care Model for Pediatric Inflammatory Bowel Disease

Clinical Psychologist Jennifer Schurman, PhD, and Associate Director of Research Craig Friesen, MD, co-authored a commentary highlighting key considerations to gaining institutional support for a multidisciplinary care program for pediatric inflammatory bowel disease (IBD). Based on their significant experience in building successful integrated care models within the field of pediatric gastroenterology, the authors specifically recommend the inclusion of a psychologist in pediatric IBD care, citing the biopsychosocial nature of IBD. The report includes the need to address finances at the program level and reviews the benefits of collecting and reporting program data to support projections and demonstrate outcomes.

Schurman JV, Friesen CA. Leveraging institutional support to build an integrated multidisciplinary care model in pediatric inflammatory bowel disease. *Children (Basel)*. 2021;8(4):286. Published 2021 Apr 8. doi:10.3390/children8040286

Study Evaluates the Effect of Hepatic Steatosis on Drug Metabolism

More than half of all medications prescribed to children are processed in the liver through drug metabolizing pathways in the cytochrome P450 family. Although it is well established that moderate to severe liver damage affects drug metabolizing capacity in the liver, the effect of increased liver fat (i.e., hepatic steatosis) on drug metabolism is unknown. This leaves a critical information gap for the 40%-85% of children with obesity who are affected by hepatic steatosis, an early form of non-alcoholic fatty liver disease (NAFLD). Valentina Shakhnovich, MD, an NIH-funded pediatric gastroenterologist and clinical pharmacologist, is investigating how hepatic steatosis affects cytochrome P450 function and whether medication dose adjustments are needed for children with obesity and early stage NAFLD.

NOTABLE PUBLICATIONS

Slowik V, Lerret SM, Lobritto SJ, Voulgarelis S, Vitola BE. Variation in immunosuppression practices among pediatric liver transplant centers - Society of Pediatric Liver Transplantation survey results. *Pediatr Transplant*. 2021;25(2):e13873. doi:10.1111/petr.13873
Voytek Slowik, MD, et al. published a study examining the immunosuppression (IS) protocols of pediatric liver transplant centers to better understand variabilities and similarities among peer institutions. Though many practices are similar, the study found areas of wide variability, and serves to guide prospective research linking IS practice to outcomes.

Morrow R, Funk R, Becker M, et al. Potential role of methotrexate polyglutamates in therapeutic drug monitoring for pediatric inflammatory bowel disease. *Pharmaceuticals (Basel)*. 2021;14(5):463. Published 2021 May 14. doi:10.3390/ph14050463
Ryan Morrow, MD, and collaborators published a study highlighting a potential role for methotrexate polyglutamates (MTX-Glu) in treating pediatric inflammatory bowel disease (IBD). Results of this research, the first to study MTX in pediatric IBD, suggest that higher short-chain MTX-Glu levels may be associated with IBD treatment response to MTX in children.

Friesen HJ, Rosen J, Low Kapalu C, et al. Mucosal eosinophils, mast cells, and intraepithelial lymphocytes in youth with rumination syndrome. *Neurogastroenterol Motil*. 2021;33(10):e14155. doi:10.1111/nmo.14155
Children's Mercy gastroenterology researchers participated in a collaborate study of antral and duodenal biopsies and cell densities in youths with rumination syndrome. Their findings suggest a potential role for inflammation in the pathophysiology of rumination syndrome. Future studies may help identify if treatment targeted at these cells is beneficial for patients.

Colombo JM, Friesen CS, Garg U, Friesen CA, San Pablo W. Relationships between disaccharidase deficiencies, duodenal inflammation and symptom profile in children with abdominal pain. *Sci Rep*. 2021;11(1):4902. Published 2021 Mar 1. doi:10.1038/s41598-021-84535-9
Jennifer Colombo, MD, et al. published a study evaluating the relationships between disaccharidase deficiencies and symptoms or duodenal inflammation in pediatric patients with abdominal pain. The research found that disaccharidase deficiency cannot be predicted by symptoms in this population. Further studies are needed to assess the clinical significance of disaccharidase deficiency.

Genomic Answers for Kids Advances Rare Disease Research

The Children's Mercy Research Institute has released more than 2,300 pediatric rare disease genomes through its Genomic Answers for Kids (GA4K) program, which makes it one of the largest pediatric rare disease whole genomic datasets ever publicly shared.

To date, more than 3,700 patients have enrolled in the program, which has resulted in more than 18,000 new genomic analyses and more than 600 genetic diagnoses. In addition, the program has advanced research genomic analyses for children of 350 families with more common childhood diseases: cerebral palsy and Down syndrome.

The full pediatric data repository is shared in a real-time web interface through a comprehensive process, which gives researchers and clinicians low-barrier access to processed data with disease prioritized genetic changes.

"Giving access to our data allows researchers to link their own genetic findings so they can accept or reject hypotheses on their gene discoveries," said Tomi Pastinen, MD, PhD, Director, Genomic Medicine Center, Children's Mercy Kansas City. "Data sharing is the only way we'll make headway in the quicker delivery of results that are non-diagnostic today."

The GA4K program has helped hundreds of kids, like Celia, find a genetic diagnosis.

MEET THE TEAM

LEADERSHIP

Ding-You Li, MD, PhD
Interim Division Director, Gastroenterology

MEDICAL FACULTY

Ruba Abdelhadi, MD
Associate Division Director, Education and Professional Development;
Director, Nutrition Support Program

Moises Jimenez Alatorre, MD, PhD

Thomas Attard, MD
Director, Endoscopy Services;
Director, Polyposis Center

Gracielle Bahia, DO

Julie Bass, DO
Director, Inflammatory Bowel Disease Program

Alex Biller, DO

Julia Bracken, MD
Medical Director, Nutrition Services;
Director, Celiac Disease Program

Rachel Chevalier, MD
Associate Program Director, GI Fellowship Program

Katy Clarkston, MD

Jose Cocjin, MD
Chief, Section of Neurogastroenterology and Motility

Jennifer Colombo, MD
Associate Division Director, Clinical Care

James Daniel, MD, FAASLD
James F. Daniel Endowed Chair in Liver Care

Sarah Edwards, DO
Director, Feeding Disorders and Nutrition Program

Dalya El Tawil, MD
Director, Autism Program

Ryan Fischer, MD
Director of Liver Care Center;
Chief, Section of Hepatology and Transplant Medicine

Craig Friesen, MD
Associate Director of Research;
Co-Director of Abdominal Pain Program

Jennifer Halma, MD

Aileen Har, MD

Nadia Hijaz, MD

Tania Hudson, DO

Nadia Ibrahimi, MD
Director, Pancreas Program

Pang Krasaelap, MD

Laurie McCann, DO

John Rosen, MD
Chief, Section of Gastroenterology and Nutrition;
Director, Telemedicine and Outreach

William San Pablo Jr., MD
Director, Intestinal Rehabilitation Program

Kenneth Schmidt, MD

Valentina Shakhnovich, MD

Voytek Slowik, MD
Program Director, GI Fellowship Program

Jeremy Stewart, MD

Fernando Zapata, MD

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Clinical Director, Abdominal Pain Program

Christina Low Kapalu, PhD
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Co-Director, Interdisciplinary Constipation and Incontinence Clinic

Michele Maddux, PhD
Director, Gastroenterology Medical Transition

Jennifer Schurman, PhD
Associate Division Director, Integrative Care and Innovation;
Chief, Section of GI Psychology;
Director, Gastroenterology Research;
Co-Director, Abdominal Pain Program

Laura Slosky, PhD
Co-Director, Interdisciplinary Feeding Clinic

Jamie Ryan, PhD

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