The Division of Pediatric Gastroenterology at Children’s Mercy is nationally recognized for pioneering groundbreaking approaches in treatment and for conducting research to improve the effectiveness of care for children. The division stands out with its unique biopsychosocial approach to treatment and research in abdominal pain, inflammatory bowel disease, intestinal rehabilitation, liver transplantation, liver disease, chronic constipation, celiac disease and feeding disorders. This approach provides an integrated model of care for patients.

Specialized programs for hereditary polyposis, motility disorders and other diseases put Children’s Mercy at the forefront of pediatric gastroenterology. Working with the Genomic Medicine Center at Children’s Mercy, the division also is conducting genetic testing and research to transform care for children with rare syndromes.

TOP-RANKED PROGRAM
Among the top pediatric gastroenterology programs in the nation, according to U.S. News & World Report.

2019 BY THE NUMBERS

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Published Manuscripts</td>
<td>48</td>
</tr>
<tr>
<td>Published Book Chapters</td>
<td>6</td>
</tr>
<tr>
<td>International and National Presentations (24 Oral and 30 Posters)</td>
<td>54</td>
</tr>
<tr>
<td>Multidisciplinary Programs</td>
<td>22</td>
</tr>
<tr>
<td>Outpatient Visits (Excluding Procedures)</td>
<td>19,198+</td>
</tr>
</tbody>
</table>

The Children’s Mercy Pediatric Neurogastroenterology program is among a handful of comprehensive pediatric motility centers in North America, and one of a select few utilizing an interdisciplinary approach to care.
RESEARCHING EARLY STAGE FATTY LIVER DISEASE AND DRUG METABOLISM

It is well known that medication dose adjustments are needed for patients with advanced liver scarring and liver failure because, in advanced disease, the liver is unable to process medications efficiently. Valentina Shakhnovich, MD, Children’s Mercy Gastroenterologist, Clinician-Scientist and Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine; Research Assistant Professor of Pediatrics, University of Kansas

School of Medicine, is the only NIH-funded pediatric gastroenterologist and clinical pharmacologist in the country. She is now investigating early stage fatty liver disease and drug metabolism.

Dr. Shakhnovich recently received a K23 Career Development Award from the National Institutes of Health to investigate the effect of early stage fatty liver disease on drug metabolism and medication efficacy in children. The goal of her research is to find out if medication dose adjustments are needed for children with fatty liver disease, the number-one pediatric liver disease in the U.S.

Recent NIH Award: K23 Career Development Award from the NIH, nearing $1 million dollars in funding over the next five years.

INVESTIGATING WAYS TO IMPROVE MEDICATION ADHERENCE FOR CHILDREN WITH IBD

Medication adherence is a significant problem for patients with pediatric inflammatory bowel disease, with prevalence rates ranging from 50-88%. That issue has long interested Michele Maddux, PhD, Clinical Psychologist at Children’s Mercy and Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine, and is the reason she is conducting an innovative evaluation of the feasibility and efficacy of training gastrointestinal providers to deliver adherence-focused interventions during routine medical care.

Her research is measuring patient adherence via self-report and electronic monitors, plus all patient visits are being audiotaped. The long-term objective of Dr. Maddux’s research is to incorporate adherence-focused prevention

and intervention into standard pediatric GI practice in order to improve the overall health and quality of life for youth with inflammatory bowel diseases. Ultimately, her findings could have implications for other medical subspecialties where medication adherence is an issue.

UTILIZING BIG DATA TO HELP ANSWER RESEARCHERS’ QUESTIONS

Thomas Attard, MD, Pediatric Gastroenterologist and Medical Director of Endoscopy, is leading efforts among his colleagues in the Division of Pediatric Gastroenterology at Children’s Mercy, utilizing big data resources to ask and answer important questions that could have an impact on clinical care for all children.

These databases, such as the Health Cost and Utilization Project (HCUP), are highly sophisticated resources that provide the patient numbers and detail necessary to look into a wide range of issues in a powerful and efficient manner.

Utilizing big data has led the Children’s Mercy researchers to study and recently publish papers on topics as diverse as pediatric proton pump inhibitor use and fracture risk; a comparison between gastrostomy technique outcomes; and the epidemiology of pediatric cholecystitis-related admissions in the U.S., among many others.

DIAGNOSING AND MANAGING CELIAC DISEASE

The Celiac Program at Children’s Mercy Kansas City provides a comprehensive multidisciplinary approach to care for children with celiac disease or non-celiac gluten sensitivity. The program diagnoses approximately 150 children with the disease each year, and because it is a lifelong condition, follows them annually until they transition to adult care.

In addition to a medical provider, families meet with a celiac-focused dietitian at every visit to help achieve a strict gluten-free diet, as well as learn new approaches to cooking, nutrition and wellness. Patients also have access to a pediatric psychologist who addresses the social and emotional impact of this diagnosis, and can help families advocate for school-based services to accommodate a patient’s medical needs. To be certain that all patients have access to nutritious and safe gluten-free food regardless of their economic status, the program has formed a unique partnership with the Food Equality Initiative (FEI), a local gluten-free food pantry.
### PROVIDING AN INTERDISCIPLINARY APPROACH TO PEDIATRIC NEUROGASTROENTEROLOGY

The Children’s Mercy Pediatric Neurogastroenterology program is among a handful of comprehensive pediatric motility centers in North America, and one of a select few utilizing an interdisciplinary approach to care. The program features a pediatric psychologist subspecializing in pediatric motility disorders whose input is integrated into patient clinic visits, contributing to patient success.

Other disciplines involved in the program include pediatric surgery, colorectal surgery, otolaryngology, urology, physical and occupational therapy, nursing, social work and nutrition. The program provides consultations and follow-up for nearly 1,500 patients, and offers testing services to almost 300 patients annually.

This team treats motility problems affecting the entire digestive system, including difficulty swallowing, nausea, vomiting, diarrhea, constipation and abdominal distension. The program also offers access to a comprehensive suite of testing options, including detailed multichannel intraluminal impedance-pH studies, a wireless motility capsule that tracks gastrointestinal transit, and esophageal, antrudoenal, colonic and anorectal manometry studies of intestinal contractility.

### OUTCOMES

The Division of Pediatric Gastroenterology at Children’s Mercy has one of the larger inflammatory bowel disease (IBD) programs in the nation. At Children’s Mercy, the multidisciplinary IBD team includes gastroenterologists, nurse practitioners, a psychologist, a social worker, a nutritionist and researchers.

Children’s Mercy has been recognized as a leader in parent engagement through ImproveCareNow and other national organizations.

### LIVER TRANSPLANT OUTCOMES

More than 110 pediatric liver transplants have been performed since 1999.

Waiting time for liver transplant is shorter than the national average.

- At 30 days, 31.6% of patients have been transplanted vs. the national average of 17.7%.
- At one year, 78.9% of patients have been transplanted vs. the national average of 45.2%.

<table>
<thead>
<tr>
<th>Liver Transplant Program Age &lt; 18 (Pediatric)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Graft Survival</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>1 Month</td>
</tr>
<tr>
<td>1 Year</td>
</tr>
<tr>
<td>3 Years</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Patient Survival</strong></th>
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</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>1 Month</td>
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<tr>
<td>1 Year</td>
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<tr>
<td>3 Years</td>
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</tbody>
</table>

### CHILDREN’S MERCY RESEARCH INSTITUTE

The Children’s Mercy Research Institute (CMRI) at Children’s Mercy Kansas City is an integrated research environment where no boundaries exist between science and medicine. Here, physicians, scientists, academic colleagues and philanthropic partners are collaborating to change the future for children. CMRI areas of emphasis provide the supportive structure for all research conducted at Children’s Mercy. Research may fall under one or more of these areas and include Genomics, Precision Therapeutics, Population Health and Health Care Innovation. To enhance its research endeavors, a new building, future home to the CMRI, is under construction. The institute has been carefully designed so research and clinical care work as cross-functional teams, aligned together, to find answers to pediatric medicine’s most challenging questions.

### Inflammatory Bowel Disease: ImproveCareNow Data as of January 2020

<table>
<thead>
<tr>
<th></th>
<th>Children’s Mercy</th>
<th>Network Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical remission</td>
<td>% of patients in prednisone-free clinical remission</td>
<td>81%</td>
</tr>
<tr>
<td>Adequate nutrition</td>
<td>% of patients with satisfactory nutrition status</td>
<td>91%</td>
</tr>
<tr>
<td>Adequate growth</td>
<td>% of patients with satisfactory growth status</td>
<td>95%</td>
</tr>
<tr>
<td>Data quality</td>
<td>% of registrable population that is registered</td>
<td>100%</td>
</tr>
</tbody>
</table>
MEET THE TEAM

LEADERSHIP
Craig A. Friesen, MD
Division Director, Gastroenterology; Co-Director of Abdominal Pain Program

Nadia Ibrahimi, MD
Director of Pancreas Program

Amy Issa, MD

Panamdeep Kaur, MD

Taina Jausurawong, MD

Ding-You Li, MD, PhD
Chief, Section of Gastroenterology and Nutrition Support Program

Jennifer L. McCullough, MD

Stephanie L. Page, MD
Director of Eosinophilic Esophagitis Program

John M. Rosen, MD
Director of Telemedicine and Outreach

William O. San Pablo Jr., MD

Valentina Shakhnovich, MD
Gastroenterology and Clinical Pharmacology

Voytek Slowik, MD
Associate Director of Fellowship Program

PSYCHOLOGY FACULTY
Amanda D. Deacy, PhD
Clinical Director, Abdominal Pain Program

Rebecca J. Johnson, PhD

Christina Low Kapalu, PhD

Michele Herzer Maddux, PhD
Director of Gastroenterology Medical Transition

Jamie Ryan, PhD

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

Laura Slosky, PhD

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