



# Advancing Care, Improving Lives



**Boston  
Children's  
Hospital**

Gastroenterology,  
Hepatology & Nutrition



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**The Division of Gastroenterology, Hepatology and Nutrition** at Boston Children’s Hospital, led by **Scott B. Snapper, MD, PhD**, (Chief) and **Jenifer Lightdale, MD, MPH**, (Associate Chief) provides a full range of services for patients with gastrointestinal (GI), hepatobiliary, pancreatic, and nutritional problems. We provide evaluation for comprehensive gastrointestinal disorders, including those that affect the pancreas, liver, gallbladder, esophagus, stomach, small intestine, and colon, as well as evaluation for nutritional concerns such as obesity, malnutrition, and feeding disorders. Our skilled team of physicians, nurses, social workers, psychologists, dietitians, and other clinicians provides compassionate, coordinated care to children of all ages and their families.



Scott Snapper, MD, PhD



Jenifer R. Lightdale, MD, MPH

## Locations of care

### **Boston Children’s Hospital**

300 Longwood Avenue  
Boston, MA 02115

**617-355-6058**

[bostonchildrens.org/gastro](http://bostonchildrens.org/gastro)

[BCHgastro@childrens.harvard.edu](mailto:BCHgastro@childrens.harvard.edu)

In addition to the Boston, Massachusetts campus, we offer appointments in:

- Brockton
- Lexington
- Milford
- North Dartmouth
- Norwood
- Peabody
- Waltham
- Weymouth
- Wilmington
- Worcester

### **International referrals**

For families residing outside of the United States, please contact Boston Children’s International Health Services:

**+1-617-355-5209**

[bostonchildrens.org/international](http://bostonchildrens.org/international)

[international.center@childrens.harvard.edu](mailto:international.center@childrens.harvard.edu)

## Division highlights

Ranked among the top four gastroenterology divisions in the nation by *U.S. News & World Report* since 2009.

- 60,000 outpatient visits and 9,500 procedures performed each year
- 64 GI physicians with sub-specialty expertise, as well as more than 80 dietitians and 35 advanced practice clinicians
- Four winners of the Shwachman Award, the highest honor bestowed by NASPGHAN

## Research

The basic research program focuses on the study of epithelial cell/developmental biology, neurobiology, and mucosal immunology in infection, inflammation, host defense, and gastrointestinal tract development. The clinical research program focuses on nutritional epidemiology, inflammatory bowel disease (IBD), celiac disease, esophageal disorders, congenital enteropathies, liver and biliary disorders, pancreatic disorders, allergic diseases, polyposis syndromes, aerodigestive disease, motility, and “functional” disorders. We have many clinical trials under way testing cutting edge therapies to treat IBD, liver and biliary disorders, intestinal failure, motility disorders and allergic gastrointestinal diseases.

## Quality

Our division has clinically meaningful, impactful, and transparent quality assurance and performance improvement programs that align with our enterprise goals. This year, our emphasis was on patient access, development of best practices, and improvement in the care of medically complex patients, while continuing to focus on our hospital culture of safety and high reliability.

## Training

Our fellowship training program in pediatric gastroenterology is one of the largest in the country and has been continuously supported by an NIH T32 training grant for more than 30 years. It is based at Boston Children’s Hospital, a world-renowned, free-standing pediatric hospital located adjacent to the main campuses of Harvard Medical School and the Harvard School of Public Health. Detailed information about the program can be found at [bostonchildrens.org/GIfellowship](http://bostonchildrens.org/GIfellowship).

## Adolescent Weight Loss (Bariatric) Surgery Program

The experts in the nation's first accredited Adolescent Weight Loss (Bariatric) Surgery Program at Boston Children's Hospital are dedicated to addressing the unique needs of children, teens, and young adults who are candidates for weight loss or bariatric surgery. As obesity takes a toll on many aspects of a child's well-being, our program provides a coordinated approach to providing proven surgical and medical weight loss approaches, along with nutritional, psychological, and emotional services. This allows us to treat the whole child in order to achieve long-lasting results.

### Our philosophy

Our philosophy is that weight loss surgery should only be considered after all other attempts at reaching a healthy weight have failed. That's why the journey begins with our clinicians conducting a thorough evaluation of each patient and providing families with the education and support appropriate for their specific situation. For children, teens, and young adults who have tried unsuccessfully to lose weight following a medically supervised plan for at least six months, weight loss surgery may be the safest and most effective approach.

### Leading the way in clinical care

Our comprehensive services include:

- surgical consultation and evaluation
- medical evaluation and treatment recommendations for obesity-related health problems
- oversight of pre-operative diet and education
- adjunctive weight loss medication management
- minimally invasive surgery
- nutritional counseling
- exercise support
- psychological support
- support groups
- long-term follow-up

By tailoring our strategy for each individual and their family, we can help them achieve the best results.

### Our clinical team

The clinicians in the Adolescent Weight Loss (Bariatric) Surgery Program come from a range of disciplines, but all share the desire to help our patients achieve optimal health. Our multidisciplinary team includes physicians, psychologists, nurses, and dietitians who work together to support patients throughout their surgical journey and beyond, helping them adopt a healthy diet and exercise plan.

### Contact us

**617-355-2458**

[bostonchildrens.org/bariatric](https://bostonchildrens.org/bariatric)  
[bariatric@childrens.harvard.edu](mailto:bariatric@childrens.harvard.edu)



Brian Carmine, MD



Camilla Richmond, MD, MA

## Aerodigestive Center

The Aerodigestive Center at Boston Children's Hospital sees children who have trouble swallowing or breathing or who have related gastrointestinal issues in addition to respiratory symptoms. Established in 2006, the center is one of the oldest and largest in the country and is the only one in which the interplay between motility and the airway is assessed. With the highest volume of pediatric patients in the U.S., we have the extensive experience necessary to care for kids with both common and rare disorders involving the respiratory and digestive systems. These include functional and structural disorders of the upper gastrointestinal tract and lungs due to congenital or developmental abnormality or injury, swallowing dyscoordination, feeding problems, genetic diseases, and neurodevelopmental disability.

Led by **Rachel Rosen, MD, MPH**, our team of clinicians includes pediatric experts from many different specialties, including gastroenterology, pulmonology, feeding therapy, otolaryngology, and complex care pediatrics. Together, we provide comprehensive and personalized treatment plans for patients and families.

### Leading the way in innovation

The clinicians in the Aerodigestive Center are leaders in pediatric aerodigestive research and innovation. We are the only aerodigestive center to be funded by the National Institutes of Health.

Highlights of our accomplishments include:

- Spearheading the use of blended diets in gastrostomy tubes to treat GI and respiratory diseases.
- Pioneering the use of motility testing in children with respiratory symptoms, including post-lung transplant patients.
- Promoting oral feeding, even in patients who aspirate all textures, which improves feeding outcomes.
- Reducing gastrostomy tube placement in aspirating patients to fewer than 5 percent of all patients hospitalwide.

- Developing a rapid NG-tube-wean-to-oral-feeding program.
- Eliminating the use of the LLMI and "red airways" as a test for GERD.
- Broadening the BRUE evaluation to include video fluoroscopic swallow studies.
- Participating in consensus guidelines for diagnosing and managing GERD, the management of children with esophageal atresia, and the utility of esophageal motility testing in children.
- Educating parents of patients with NG tubes in the SIM lab.
- Validating novel technology such as FLIP and mucosal impedance testing in the evaluation of aerodigestive patients.
- Measuring pharyngeal and esophageal bolus flow and its relationship to airway disease.

### Contact us

**617-355-0897**

[bostonchildrens.org/aerodigestive](https://bostonchildrens.org/aerodigestive)



Rachel Rosen, MD, MPH

## Avoidant/Restrictive Food Intake Disorder (ARFID) Program

The Avoidant/Restrictive Food Intake Disorder (ARFID) Program at Boston Children's Hospital is one of the only multidisciplinary programs in the country specifically devoted to caring for patients between ages 6 and 18 who have difficulty eating or feeding.

### Leading the way in clinical care

Our team of specialists in gastroenterology, adolescent medicine, nutrition, and mental health evaluates every child and develops a comprehensive care plan. This plan is aimed at improving the patient's nutritional intake to achieve healthy growth and address nutritional deficiencies.

Our team also provides education and support to help kids and teens eat healthy, balanced meals without discomfort, as well as psychosocial support to help families navigate the social challenges associated with ARFID.

Our base of expertise ensures that families have all the tools they need to support their child's physical and psychological well-being. We offer access to a broad set of experts, including:

- Physicians who specialize in gastroenterology and nutrition, adolescent medicine, and eating disorders
- Psychologists who specialize in behavioral therapy and cognitive behavioral therapy for ARFID
- Clinical nutritionists who specialize in caring for children and adolescents with ARFID

Our team works with families to determine the best plan of care for each child. Our goal is to ensure that the patient has a thorough evaluation and an action plan in place that is best for both the family and the child.

### Contact us

**617-355-6341**

[bostonchildrens.org/arfid](http://bostonchildrens.org/arfid)



Elana Bern, MD



## Center for Advanced Intestinal Rehabilitation

Because children with short bowel syndrome lack sufficient intestinal function to grow and develop, they require specialized nutrition support, often including tube feedings or intravenous nutrition.

Multiple operations, nutritional therapies and medications are required to manage the condition. The skilled clinicians in the Center for Advanced Intestinal Rehabilitation (CAIR) at Boston Children's Hospital have decades of experience treating children with short bowel syndrome, setting the standard of care for managing this complex problem.

Led by **Christopher Duggan, MD, MPH, and Tom Jaksic, MD, PhD**, our team of clinicians includes pediatric experts from many different specialties who work together to provide comprehensive and personalized treatment plans for patients and families.

### A clinically proven approach

At CAIR, "multidisciplinary" isn't just a marketing buzzword. Our team includes clinicians from multiple specialties, including surgery, gastroenterology, nursing, nutrition, social work, behavioral psychology, speech and language pathology and pharmacy. This team approach has been clinically proven to improve outcomes: Our survival rate for patients with short bowel syndrome is more than 90 percent and is among the best reported in the world. Our multidisciplinary approach has also been linked to lower rates of central catheter-associated bloodstream infections and other improved outcomes.

### Leading the way in innovation

Since its inception, CAIR has been among the most prolific centers for research on short bowel syndrome and related topics. We have published papers on a wide variety of subjects, including predictors of parenteral nutrition weaning, survival outcomes, leading-edge nutrition management, infection management, micronutrient deficiencies, and more.

### Highlights include:

- Development by **Tom Jaksic, MD, PhD**, and **Heung Bae Kim, MD**, of the serial transverse enteroplasty (STEP) procedure, a surgical technique that lengthens the intestines of children with short bowel syndrome. Our clinicians have successfully performed many of these procedures, establishing Boston Children's as one of the preeminent hospitals in the world for the treatment of short bowel syndrome.
- Use by Mark Puder, MD, PhD, and Kathleen Gura, PharmD, of Omegaven, a fish oil-based emulsion that appears to help treat liver disease resulting from total parenteral nutrition. Boston Children's has the longest track record of Omegaven use, which has been approved by the U.S. Food and Drug Administration.
- CAIR researchers have found that a substantial proportion of infants with intestinal failure can achieve enteral autonomy, particularly those with underlying NEC, preserved ileocecal valve, and longer bowel length.

**(Continued)**

- With partners in industry and other centers, Christopher Duggan, MD, MPH, and colleagues were among the first to study and use Teduglutide, a GI-specific hormonal therapy designed to improve intestinal absorption and reduce the need for parenteral nutrition.
- Lissette Jimenez, MD, MPH, is leading a multicenter study of the long-term effects of this medication, and Alexandra Carey, MD, is studying a once-weekly formulation of a related medication.
- CAIR researchers have published data on the prevalence of certain complications and comorbidities in children with intestinal failure, including patterns of growth, dietary intake, small bowel bacterial overgrowth, eosinophilic inflammation, and metabolic bone disease.

**Contact us**

**617-355-5275**

[bostonchildrens.org/cair](http://bostonchildrens.org/cair)

[cair@childrens.harvard.edu](mailto:cair@childrens.harvard.edu)



Christopher Duggan,  
MD, MPH



Tom Jaksic, MD, PhD

## Center for Childhood Liver Disease

The Center for Childhood Liver Disease at Boston Children's Hospital specializes in helping infants, children, adolescents, and young adults who have a wide variety of liver, gallbladder, and bile duct disorders, as well as liver masses and tumors. As an advanced training center for pediatric liver disorders and transplants, we have access to state-of-the-art equipment and services, as well as investigational drug therapies currently in clinical trials.

Led by **Scott A. Elisofon, MD**, the center offers expertise in hepatobiliary disease and many specialized procedures. For example, our experts have decades of experience performing endoscopic retrograde cholangiopancreatography (ERCP) procedures to determine specific diagnoses and perform specialized therapeutics. We also offer elastography and have performed thousands of studies in this area.

### Our clinical team

- board-certified transplant hepatologists
- gastroenterologists/endoscopists
- surgeons
- nurses and nurse practitioners
- interventional radiologists
- social workers
- dietitians
- liver pathologists

In addition, we collaborate with multiple specialty centers and programs at Boston Children's to care for patients with complex conditions or multiple diagnoses, including:

- Liver Transplant Program
- Intestinal and Multivisceral Transplant Program
- Inflammatory Bowel Disease Center
- Cystic Fibrosis Center
- Metabolism Program
- Center for Advanced Intestinal Rehabilitation

- Pancreatic Disorders Program
- Dana-Farber/Boston Children's Liver Tumor Center
- Boston Adult Congenital Heart Disease program/Fontan program

We also provide expert second opinions for patients from across the country and around the world.

### Leading the way in innovation

The physicians, nurses, and researchers in the Center for Childhood Liver Disease are dedicated to participating in clinical trials and research to find better diagnostic and therapeutic options for childhood liver diseases. We are one of just a few pediatric hospitals in the country to do so.

Our areas of study include treatment trials for hepatitis B and C, Alagille syndrome, and biliary atresia. In addition, we study cystic fibrosis liver disease and fatty liver disorders, as well as evaluation of ultrasound-based imaging technology (FibroScan, transient elastography) as a way to non-invasively assess a child's liver scarring.

Our physicians are often asked to contribute to pediatric guidelines to help other doctors and nurses diagnose and treat many chronic conditions.



Scott A. Elisofon, MD

### Contact us

**617-355-5837**

[bostonchildrens.org/liver](https://bostonchildrens.org/liver)

## Center for Nutrition

The Center for Nutrition at Boston Children's Hospital specializes in treating infants, children, adolescents, and young adults who have a wide variety of nutritional needs. As an advanced training center for pediatric nutrition, we have access to state-of-the-art equipment and services, as well as investigational nutritional therapies currently in clinical trials.

Led by Director **Christopher Duggan, MD, MPH**, Associate Director **Bridget Hron, MD, MPH** and Clinical Nutrition Director **Coleen Liscano, MS, RD, LDN, CNSC**, the center offers expertise in malnutrition, obesity, growth failure, intravenous (IV) nutrition, intestinal failure, inborn errors of metabolism, and home parenteral nutrition. Our consultative services include a comprehensive nutrition assessment and the development of a care plan appropriate for age, optimal growth and development, and quality of life for each child and family. Our dietitians and clinicians are also actively involved in research, collaborating with doctors around the world to learn more about even the rarest conditions. With more than 60 highly specialized registered dietitians, the Center for Nutrition has the expertise to help manage the nutritional status of a child with many different types of conditions.

Our team of physicians, nurses, pharmacists, and dietetic technicians are dedicated to helping children with common or complex gastrointestinal, liver, and nutritional problems. We can help children with inflammatory bowel disease, celiac disease, eosinophilic gastrointestinal disorders, and short bowel syndrome, among other diagnoses. In addition, we offer several specialized programs, including:

- Home Parenteral Nutrition Program: Designed for children who require intravenous or parenteral nutrition (PN) and hydration support at home
- Growth & Nutrition Program: Designed specifically to help children under 6 who are struggling with feeding or weight gain

- Center for Advanced Intestinal Rehabilitation: Focused on the treatment and understanding of short bowel syndrome

We perform advanced assessment procedures in our state-of-the-art Nutrition Assessment Laboratory. Our experts have decades of experience in performing indirect calorimetry, the gold standard for measurement of energy expenditure. Indirect calorimetry has guided nutrition, metabolic, and respiratory strategies in the ICUs, medical floors, and in the outpatient setting for many years at Boston Children's Hospital and has allowed us to identify metabolic state and tailor nutritional prescriptions in our most complicated patients.

### Our clinical team

- gastroenterologists certified in nutrition (National Board of Physician Nutrition Specialists)
- registered dietitians
- dietetic technician
- pharmacists
- nurses and nurse practitioners
- researchers

### Contact us

**617-355-4677**

[bostonchildrens.org/nutrition](http://bostonchildrens.org/nutrition)



Christopher Duggan,  
MD, MPH



Bridget Hron, MD

## Celiac Disease Program

Each year, the Celiac Disease Program at Boston Children's Hospital provides care for hundreds of children with celiac disease and gluten sensitivity. Our multidisciplinary approach focuses on accurate diagnosis and management with specialized education and support to help children and their families successfully navigate the challenges of celiac disease at all stages of child development.

Our core philosophy is that every child with celiac disease can thrive on a gluten-free diet with ongoing and developmentally appropriate support from their medical care team and within their community. We strive to help children with celiac disease maintain gluten avoidance while reducing psychosocial stressors associated with the burden of gluten exposure risk in everyday life.

Our highly experienced team includes gastroenterologists, dietitians, clinical social workers, nurses, and community advocates. We work collaboratively to provide comprehensive care to children, adolescents, and young adults living with celiac disease.

### Leading the way in clinical care

We provide diagnostic testing and ongoing management of celiac disease to children with celiac disease and gluten sensitivity. We see new patient consultations and second opinion cases from throughout New England and other national and international locations.

### Highlights include:

- Long term monitoring for comorbidities and complications of celiac disease (including non-responsive celiac disease, other autoimmune diseases, food-related anxiety, and disordered eating).
- First in the nation to offer specialized group nutrition education classes on the gluten-free diet.

- One-on-one celiac disease-specific nutrition consultation with registered dietitians with specialist expertise in gluten-free diets.
- Developmentally targeted workshops for ongoing education and support as children learn to manage their gluten-free diet independently.
- Specialized education and support services for children with both Type 1 Diabetes Mellitus and celiac disease.

### Leading the way in innovation/research

Our treatment of celiac disease is informed by our research which is helping to advance understanding of celiac disease development, diagnosis, and management. Recent and current projects include:

- Characterization of the epidemiology of non-responsive celiac disease in children.
- Clinical trials of the use of gluten immunogenic peptides for monitoring gluten-free diet adherence.
- Leading the development of a standardized gluten exposure risk assessment for children following a gluten-free diet.
- Application of modern molecular and image analysis methods to interpret small intestinal biopsies from patients with celiac disease.
- Evaluation of noninvasive biomarkers of celiac disease activity for diagnosis and follow-up.

**(Continued)**

### Leading the way in support, education, and advocacy

We recognize the importance of connecting families to learn from one another. That's why we run the **Celiac Kids Connection**, the only celiac disease support group solely focused on kids and families. Our group, which includes nearly 500 families living with this disease in New England and across the country, provides a networking community of support, education, and advocacy for families with children diagnosed with celiac disease.

Patient and family engagement is a key element of our Celiac Disease Program. In addition to the Celiac Kids Connection support group, our offerings include:

- Weekly school support sessions to help families set up a 504 plan for their child at school.

- Weekly new-to-celiac family meet-up opportunities.
- Peer-to-Peer Support and Parent-to-Parent Support.
- A monthly e-newsletter and quarterly printed newsletter.
- Ongoing medical education activities, including a multidisciplinary case conference series.
- Cooking and nutrition education classes.
- Food and self-advocacy focused storytimes for young children.
- Food assistance program for families experiencing food insecurity.
- Monthly educational webinars for patients and families.

#### Contact us

**617-355-6058**

[bostonchildrens.org/celiac](http://bostonchildrens.org/celiac)



Alan Leichtner, MD,  
MSHPEd



Jocelyn Silvester, MD,  
PhD



Dascha Weir, MD

## Colorectal and Pelvic Malformation Center

The clinicians in the Colorectal and Pelvic Malformation Center at Boston Children's Hospital specialize in caring for infants, children, and adolescents with complex colorectal and pelvic conditions. From surgical expertise to skilled medical management of colorectal and pelvic conditions, we provide expert, compassionate care.

Led by director and lead surgeon **Belinda Dickie, MD, PhD**, our team of gastroenterologists includes Samuel Nurko, MD, MPH, and Claudio Morera, MD, who work along side a comprehensive team of pediatric experts from surgery, urology, gynecology and more. We work together to provide comprehensive and personalized treatment plans for patients and families.

The Colorectal and Pelvic Malformation Center sees children with a range of colorectal and pelvic conditions, including:

- anorectal malformations
- cloacal deformities
- cloacal exstrophy
- Hirschsprung's disease
- intractable constipation
- intractable fecal incontinence
- rectal prolapse

### Leading the way in clinical care

Because a child's needs may change over time, we offer state-of-the-art evaluation and treatment options, as well as care for developmental and ongoing needs. Our patients have access to treatment with minimally invasive and robotic procedures not typically offered elsewhere, in addition to outpatient medical care such as our intensive bowel management program. We also partner with Boston Children's Motility and Functional Gastrointestinal Disorders Center for expert evaluation when appropriate, using anorectal manometry, colonic manometry, colonic transit studies, and other tests.

Our skilled clinicians are experienced in the latest treatment approaches for colorectal and pelvic malformations, including:

- Pull-through procedure, a surgical technique used to treat Hirschsprung's disease. In most cases, our surgeons can perform this procedure with minimally invasive techniques, often entirely through the anus to prevent scarring.
- Posterior sagittal anorectoplasty (PSARP), a type of pull-through procedure that treats anorectal malformations. This technique surgically creates a child's anus within their sphincter muscle.
- Medical management, including medications and injections of botulinum toxin (Botox) into the anal sphincter.
- Bowel management for children who are unable to anticipate or control their bowel activity, which can help reduce the likelihood of accidents.

### Contact us

**617-355-8664**

[bostonchildrens.org/colorectalpelvic](https://www.bostonchildrens.org/colorectalpelvic)  
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Belinda Dickie, MD, PhD



Samuel Nurko, MD, MPH



Claudio Morera, MD

## Congenital Enteropathy Program

The Congenital Enteropathy Program at Boston Children's Hospital is one of just a few programs in the world that specializes in caring for children with chronic infantile-onset congenital diarrhea. Many of our patients have severe diarrhea or are unable to absorb nutrients leading to malnutrition, electrolyte derangements, and/or dehydration. Children often have undergone multiple previous tests that have failed to identify a cause.

Our multidisciplinary team takes a supportive, family-centered approach to care for children. Through comprehensive evaluations and second opinions, our goal is to provide a more precise diagnosis of the underlying cause of GI symptoms, including exploring genetic causes, and we create an individualized treatment plan to improve children's overall quality of life. We partner closely with the Home Parenteral Nutrition Program to provide additional therapy and resources for kids and families who need this support.

### Leading the way in innovation

Our team is at the forefront of research aimed at better understanding possible genetic mutations in severe diarrheal diseases and congenital enteropathies. Once a mutation is identified, we can investigate how it causes disease and seek ways to counteract its effects.

Because these conditions are so rare, we collaborate with the multicenter Pediatric Congenital Diarrhea and Enteropathy (PediCODE) Consortium to learn more about how these conditions progress, understand the underlying genetics and biology, and develop new therapies. To date, scientists have identified as many as 45 genes that cause different types of congenital diarrhea and enteropathy. As we add to this list, we will be able to provide families with precise, rapid diagnoses, and better-customized treatments.

Thanks to advances in stem-cell and gene-editing technologies, our researchers use patient-specific "mini intestines" that model the disease in the lab. This allows us to investigate the disease at a cellular level and rapidly test potential drugs to see if they can reverse the effects of the disease.

Our team has also authored updated guidelines for evaluating congenital diarrheas, which appear in the *journal of Gastroenterology*.

### Contact us

**617-355-3658**

[bostonchildrens.org/enteropathy](https://bostonchildrens.org/enteropathy)  
[enteropathy@childrens.harvard.edu](mailto:enteropathy@childrens.harvard.edu)



Jay Thiagarajah, MD, PhD



Lissette Jimenez, MD, MPH



# Eosinophilic Gastrointestinal Disease Program

The Eosinophilic Gastrointestinal Disease Program at Boston Children's Hospital is a multidisciplinary program that treats children and adolescents with eosinophilic gastrointestinal disorders (EGIDs), including eosinophilic esophagitis (EoE), eosinophilic gastritis, eosinophilic colitis, food protein-induced enterocolitis syndrome (FPIES), mast cell disorders, and autoinflammatory conditions associated with allergies.

## Leading the way in clinical care

Our team understands the challenges facing children living with an allergic gastrointestinal disease. As a leader in the diagnosis, treatment, and research of pediatric EGIDs, our program provides comprehensive care for patients from across the U.S. and around the world.

Our goal is to improve the quality of life for patients and families affected by EGIDs. We offer:

- Complete evaluation and treatment for children and adolescents who have been diagnosed with an EGID
- Diagnostic testing including blood work, endoscopy, allergy testing, and radiology testing
- Nutrition evaluation and dietary guidance by a dietitian with expertise in food allergies and GI disorders
- Education and support for the patient and family
- School/camp advocacy to educate teachers and caregivers
- Follow-up care via phone, in-person appointments and, in some circumstances, telemedicine
- Assistance coordinating appointments for families traveling from out of state to our hospital in Boston
- Opportunities for participation in clinical research

## Our clinical team

The pediatric specialists in the Eosinophilic Gastrointestinal Disease Program have advanced training and experience both in their field

and in caring for children. Having a team of these experts gives patients the best and most complete care possible. Our highly trained team includes:

- Board-certified pediatric gastroenterologists that specialize in EGIDs
- Board-certified pediatric allergists that specialize in EGIDs
- Occupational and speech therapists who specialize in feeding problems associated with EGIDs
- Psychologists
- Registered dietitians
- Social workers
- Child life experts

Our clinicians also have expertise in other rare allergic gastrointestinal disorders, such as:

- Mast cell activation disorders
- Systemic mastocytosis
- Food protein-induced enterocolitis syndrome (FPIES)
- Alpha gal allergy
- Collagenous gastritis

## Contact us

**617-919-9958**

[bostonchildrens.org/egid](https://bostonchildrens.org/egid)  
[EGID@childrens.harvard.edu](mailto:EGID@childrens.harvard.edu)



Elizabeth Hait, MD, MPH



Erin Syverson, MD

## Esophageal and Airway Treatment Center

The Esophageal and Airway Treatment (EAT) Center at Boston Children's Hospital is dedicated to the care of infants, children, and young adults with complex esophageal and airway problems. For our team, these very rare conditions are not rare at all. When it comes to treating these complex conditions, we are the most experienced institution in the world. Our goal is to help every child achieve a healthy esophagus and airway.

Led by **Peter Ngo, MD, and Benjamin Zendejas-Mummert, MD, MSc**, our world-renowned multidisciplinary team consists of experts from surgery, gastroenterology, pulmonology, anesthesia, otolaryngology, endocrinology, cardiology, feeding, nursing, and social work. Together, we provide comprehensive and personalized treatment plans for patients and families.

Depending on the patient's unique situation, we may recommend approaches such as:

- surgical procedures for esophageal concerns, such as the Foker process and jejunal interposition
- surgical procedures for vascular rings and chest wall abnormalities
- long-term medical management
- endoscopic dilation
- endoscopic incisional therapy
- endoscopic vacuum therapy

### Leading the way in innovation

Boston Children's is home to the world's most extensive pediatric hospital research enterprise.

The researchers and clinicians in the EAT Center have published papers on a wide variety of subjects, including the surgical treatment of long-gap esophageal atresia and severe tracheomalacia, minimally invasive procedures for esophageal strictures, and more.

### Contact us

**617-355-3038**

[bostonchildrens.org/eat](http://bostonchildrens.org/eat)

Highlights include:

- Outcomes data for the Foker process, a revolutionary procedure that encourages natural growth and strengthening of a child's existing esophagus. Boston Children's has the most extensive experience in the world in performing the Foker process.
- The finding that posterior tracheopexy is effective in treating severe tracheomalacia with significant improvements in clinical symptoms and degree of airway collapse on bronchoscopy.
- The largest retrospective review to date of patients with postoperative recurrent and acquired TEF following esophageal atresia repair. These findings provide a new categorization for postoperative TEF that helps clarify the diagnostic and therapeutic challenges for management.
- Outcomes that demonstrate that the jejunum can be used as an esophageal graft even in very difficult cases with failed multiple earlier operations for correction of EA/TEF.
- The finding that esophageal dilation with balloon or savory dilators are equally safe and effective for the treatment of anastomotic strictures associated with esophageal atresia.



Peter Ngo, MD,



Benjamin Zendejas-Mummert, MD, MSc

# Fecal Microbiota Transplantation (FMT) and Therapeutics Program

The Fecal Microbiota Transplantation (FMT) and Therapeutics Program at Boston Children's Hospital was one of the first in the country to provide fecal transplants tailored specifically for pediatric patients. It's also currently one of only a few programs in New England that offers this innovative treatment for children.

Our expertise in FMT treatment and research draws patients from across the United States and from around the world to the program for evaluation and/or treatment.

## Leading the way in innovation

Under the leadership of **Stacy A. Kahn, MD**, our clinicians are on the forefront of research in this area.

Some highlights of these efforts include:

- Conducting a variety of studies to further advance our understanding of the potential fecal transplant holds for a number of conditions.
- Creation of a national pediatric database with collaborators from across the U.S. and Canada to study FMT in children.
- Leading the largest clinical study to date looking at the safety and efficacy of FMT in children with recurrent *Clostridioides difficile* (C. diff). The findings, reported in *Clinical Gastroenterology and Hepatology*, reveal positive outcomes in 87 percent of the pediatric patients with very few adverse events reported.

- Participation in an NIH-funded American Gastroenterological Association (AGA) FMT Registry, which is the first prospective study to examine the long-term safety of FMT in adults and children.
- Leading the first international guidelines on the use of FMT in children.
- The Boston Children's Hospital FMT and Microbial Therapeutics Program continues to lead the field through innovative clinical and translational research.

## Second opinion program

Clinicians in the FMT Program have provided second opinions for patients and providers seeking FMT for the treatment of C. diff and other conditions.

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Stacy A. Kahn, MD

## Growth and Nutrition Program

The Growth and Nutrition Program at Boston Children's Hospital provides care for young children with malnutrition or who are at risk for malnutrition.

### Leading the way in clinical care

Established in 1984 and currently led by **Sarah Fleet, MD**, we are one of the first multidisciplinary programs in the country specifically devoted to feeding and malnutrition in early childhood. Through a partnership with the Massachusetts Department of Public Health Bureau of Nutrition, we use a multidisciplinary approach to helping our patients with their feeding difficulties and ensure they are getting adequate nutrition. Our specialists conduct a thorough evaluation and develop a family-centered plan to improve growth, replete nutrient deficiencies, improve oral acceptance, and develop healthy feeding behaviors.

We treat patients who have poor growth for a variety of reasons, including prematurity, delayed feeding skills, aversion, reflux, allergic colitis, picky eating, developmental disorders, and other feeding difficulties. We also care for children who require nasogastric or gastrostomy tubes.



Sarah Fleet, MD

### Community Partnership

Our program uses a bio-psychosocial model to care for our patients and work with their families. We work closely with community agencies to provide care that supports patients in their home, daycare, or school, and we are able to visit these venues to observe the feeding environment and inform the plan of care.

### Our clinical team

Our multidisciplinary experts include:

- gastroenterologists
- nurse practitioners
- dietitians
- speech and language pathologists
- psychologists
- lactation consultants
- visiting nurses
- social work

### Contact us

**617-355-6058**

[bostonchildrens.org/growth](https://bostonchildrens.org/growth)

## Home Parenteral Nutrition Program

The Home Parenteral Nutrition Program (HPN) at Boston Children's Hospital takes a family-centered approach to treating infants, children, and young adults who require intravenous (IV) or parenteral nutrition (PN) and hydration support at home.

Led by **Alexandra Carey, MD**, our team of clinicians includes pediatric experts from many different specialties who work together to provide comprehensive and personalized treatment plans for patients and families/caregivers.

### Improving quality of life

The goal of our program is to improve the quality of life for children and families/caregivers while at the same time helping to improve their nutritional status and overall function. Although complex, with proper care management and close collaboration with care providers and families/caregivers, we aim to provide comprehensive care outside the hospital, ensuring needs can be met from the comfort of home.

### Leading the way in clinical care

Established in 1981, our program is one of the top centers of its kind in the world. We have taken care of hundreds of infants, children, and adolescents and played a key role in setting standards of excellence in the field. We currently follow over 150 patients on home parenteral nutrition in our program.

### Our partners and clinical team

We work closely with Boston Children's Center for Advanced Intestinal Rehabilitation (CAIR), Motility and Gastrointestinal Disorders Center, Intestine and Multivisceral Transplant Program, and the Dana-Farber/Boston Children's Cancer and Blood Disorders Center, as well as other

centers and programs, to offer a comprehensive set of services for children on home parenteral nutrition and support for their families and caregivers.

We provide:

- Expertise in rare nutritional disorders associated with intestinal failure (e.g., short bowel syndrome, Hirschsprung's disease, intestinal dysmotility, congenital diarrhea or enteropathies, and mitochondrial disorders).
- On-call telephone and telehealth consultation services, supported in part by remote patient monitoring technology (TytoCare™) after the global COVID-19 pandemic forced the abrupt transition of in-person clinic visits to a virtual platform. Remote patient monitoring allows for accurate and validated vital sign and nutritional assessment by the caregiver which is shared asynchronously or in real-time with the medical team.
- Parenteral nutrition and central line care simulation experiences.
- Extensive discharge teaching (5-session teach) for patients, families/caregivers initially discharged with PN.
- Innovative intravenous lipid strategies including SMOFlipid® and Omegaven®.
- Decades of experience with strategies for central-line infection prevention, including 70% ethanol locks, and a new therapy, KiteLock 4% (tetrasodium ethylene diamine tetra acetic acid), through a compassionate use access protocol under Mark Puder, MD, PhD, and Kathleen Gura, PharmD. Investigation of this and other new lock

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therapies was prompted after the FDA granted an Orphan Drug Designation through the Unapproved Drug Initiative for dehydrated ethanol resulting in dramatically increased price of ethanol which reduced access to ethanol lock therapy nationwide.

- Intravenous iron therapy to reduce or prevent the need for blood transfusions.
- Dedicated HPN pharmacists with a focus on reviewing PN prescriptions, navigating PN component shortages, and screening for discrepancies between prescribed and actual HPN solutions.

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Alexandra Carey, MD

## Inflammatory Bowel Disease Center

The Inflammatory Bowel Disease (IBD) Center at Boston Children's Hospital is a leading program in the U.S. for the treatment of Crohn's disease and ulcerative colitis in children, teens, and young adults. Our team of skilled clinicians has decades of experience treating common and complex forms of the disease, including very-early-onset IBD (VEO-IBD). We provide primary IBD care as well as complex second opinions and consultative care to patients in New England, throughout the Northeast, as well from National and International locations. We care for over 1,500 unique patients yearly with >4000 patient visits yearly.

### Leading the way in clinical care

Led by **Scott B. Snapper, MD, PhD** (Director), and **Athos Bousvaros, MD, MPH** (Associate Director), the Inflammatory Bowel Disease Center team includes clinicians from a broad range of specialties, including gastroenterology, surgery, radiology, psychology, and social work. Each patient is evaluated by a multidisciplinary team often including GI attending physicians, GI and advanced IBD fellows, advanced practice providers, nurses, and dietitians. Our team approach also offers access to other medical specialists as needed including immunologists, dermatologists, rheumatologists, hepatologists and hematologists. Some specific areas of expertise include access to:

- Educational programs for new IBD patients
- Nutritional therapies
- Yoga and mindfulness programming
- Fecal Microbial Transplantation (FMT)
- Care of college students, care and transitional services for young adults
- Advanced expertise in biologics and small molecule therapies approved for adult IBD and/or other patients with immune-mediated conditions
- Combined surgical/GI clinics for assessment and management of complex cases
- VEO-IBD or Autoinflammatory and Immune Dysregulation Clinic (AIIDC)

- Participation in numerous industry and investigator sponsored clinical trials providing access to novel therapies
- Participation in national IBD quality initiatives (e.g., Improved Care Now)

### Leading the way in innovation

The IBD Center currently leads several pioneering studies on IBD and participates in numerous national and international studies that are funded by grants from the NIH as well as support from foundations, philanthropy, and pharmaceutical companies. We are also the lead U.S.-based location for the VEO-IBD Consortium ([www.veoibd.org](http://www.veoibd.org)), which is comprised of international pediatric gastroenterologists and scientists who are working together to identify the causes of VEO-IBD and to develop new therapies. We have one of the largest pediatric IBD biospecimen repositories in the world. Some areas of research or unique opportunities include

- Determination of effect of IBD medical therapies on surgical outcomes
- Identification of novel genes and molecular pathways associated with VEO-IBD
- Immune, microbial, and genetic studies to define precision medicine approaches for IBD therapy
- Employing multi-omic approaches including single cell and spatial transcriptomics to further define and characterize IBD

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- Development and testing of new IBD medications in novel animal model systems as well as in patients
- Identification of novel diagnostic methods including biomarkers
- Assessment of Vitamin D and bone health in IBD
- Effect of the IBD on cognition and brain health
- Determining the effect of different immunizations and viral infections on children with IBD
- Assessment of environmental exposures on IBD development
- Involvement in several national and international studies (e.g., RISK, PROTECT, GEM, Capture-IBD)



Scott B. Snapper, MD, PhD



Athos Bousvaros, MD,  
MPH

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## Liver, Intestine, and Multivisceral Transplant Program

The Liver, Intestine, and Multivisceral Transplant Program is among the most productive pediatric transplant programs in the Northeast.

Since the inception of these programs in 1984, we have improved the health and quality of life of children of all ages, from infants to young adults. We have a highly skilled group of surgeons, led by our surgical director, **Heung Bae Kim, MD**, and medical directors **Scott A. Elisofon, MD** (liver) and **Christine K. Lee, MD** (intestine). We follow several hundred patients who have undergone transplantation, with excellent patient and graft survival.

### Treating a variety of diagnoses

Our transplant program is able to treat patients with a variety of diagnoses, including:

- Acute liver failure
- Biliary atresia
- Cirrhosis due to:
  - Alpha-1 antitrypsin deficiency
  - Wilson disease
  - Alagille syndrome
  - PFIC
- Portal hypertension/variceal bleeding
- Metabolic diseases:
  - Urea Cycle disorders
  - Organic Acidemias
  - Maple Syrup Urine disease
  - Crigler-Najjar syndrome
  - Primary oxaluria
- Liver tumors:
  - Hepatoblastoma
  - Hepatocellular carcinoma
- Liver disease patients with complex cardiac conditions
- Cystic Fibrosis liver disease
- Short bowel syndrome

Our transplant programs are closely integrated with the Center for Advanced Intestinal Rehabilitation, which provides innovative medical, nutritional, and surgical options for children with intestinal failure, the Motility and Functional Gastrointestinal Disorders Center, and the Liver Tumor Center at Dana-Farber/Boston Children's, which provides children with management of malignant and benign tumors of the liver.

### Providing ongoing support

Long after the transplant and throughout the transplant journey, our team is an ongoing source of support for children and their families. As young transplant recipients transition to adulthood, we continue to work with them on managing their own health care and we teach them how to effectively cope with the challenges of adhering to a medication schedule.

### Leading the way in clinical care

We recognize that every child is different. Therefore, we go to great lengths to provide very personalized care delivered in a way that makes patients and their families comfortable. We also take a collaborative approach to the treatment of every child, working with experts from other Boston Children's Hospital departments.

Over the past decade, our ability to medically

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manage and rehabilitate patients has also dramatically progressed, which means fewer patients are requiring transplants, or are able to wait longer to undergo transplantation.

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**Contact us**



Heung Bae Kim, MD



Scott A. Elisofon, MD



Christine K. Lee, MD

## Motility and Functional GI Disorders Center

The Motility and Functional Gastrointestinal (GI) Disorders Center at Boston Children's Hospital is one of the only centers in the U.S. to offer a unique combination of multidisciplinary programs covering all facets of motility and functional GI disorders. We treat not only a child's condition but also the related symptoms that occur as a result, such as intestinal disability, dizziness, breathing issues, sleep disorders, and pain. While we collaborate with our world-renowned surgical colleagues, when necessary, our GI motility team focuses on the biopsychosocial model: highly precise testing, medicines, and therapies that are alternatives to surgery or complement surgical treatments. Our center provides coordinated evaluation for patients who must travel for specialized testing and treatment.

Led by **Samuel Nurko, MD, MPH** and co-director, **Rachael Rosen, MD, MPH**, the Motility and Functional Gastrointestinal Disorders Center team includes specialists from gastroenterology, pain, surgery, nursing, nutrition, psychology, and social work. Besides diagnosing the underlying problem and controlling GI symptoms, we work together to address all aspects of a child's well-being, including diet, daily function, emotional health, and school reintegration to improve quality of life.

### Advanced motility testing

When symptoms suggest a GI motility or functional disorder, our center provides state-of-the-art advanced evaluation and treatment. We evaluate the most complex patients with underlying primary motility disorders like achalasia, gastroparesis or pseudo-obstruction; congenital malformations, or postoperative problems (such as fundoplication). Tests include:

- high-resolution esophageal manometry with impedance
- high-resolution gastroduodenal colonic and anorectal manometry
- high-definition anorectal manometry wireless motility capsule
- EndoFLIP
- panometry
- advanced radionuclide evaluation

The results of these advanced studies provide new insights into the pathophysiology of motility disorders, and our team has developed new treatment approaches as a result.

### Care for functional abdominal pain

The Functional Abdominal Pain Program within the Center is focused on school-age children and teens who suffer from disorders of gut/brain interaction or other well-defined "organic" GI illnesses in which pain persists despite a negative evaluation. We supply a full range of support and medical management through medications, behavior modification, nutrition support, pain management, and alternative therapies. Additionally, we offer an IB-Stim program for patients. We also offer rehabilitation through a day program and Lidocaine infusions for severe patient cases. The team can work with schools to help support patients who are missing days in class or other social interactions with peers. Our multidisciplinary approach is associated with a 78 percent improvement in pain and function in the most intractable patients.

### Leading the way in innovation

The Motility and Functional Gastrointestinal Disorders Center performs groundbreaking research studies in several areas related to motility. We are one of the few centers in the

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country with funding from the National Institutes of Health. Our ongoing studies include the development and validation of new techniques to assess motility (like smart pill, panometry, new analysis for high-resolution manometry), and therapeutic trials for the treatment of different gastrointestinal diseases, such as intractable constipation, gastroesophageal reflux disease (GERD), intractable abdominal pain, and gastroparesis

**Highlights include:**

- Discovery of genetic mutations in children with gastroparesis and pseudo-obstruction.
- Identification of mRNA patterns in gastric mucosa of children with gastroparesis, pseudo-obstruction, and constipation.
- Validation of new methods to establish gastric emptying.
- Development of new methods for the study of intestinal motility.
- Study of the mechanisms of fecal continence.
- Study of the role of visceral hyperalgesia in functional bowel disorders and overlapping pain conditions.
- Study of biomarkers to make the diagnosis and treatment of functional pain disorders

more personalized.

- Study to establish the efficacy of open placebo for patients with pain predominant functional GI disorders.
- Study of the mechanisms underlying GERD and functional esophageal diseases.
- Study of esophageal function validating the use of panometry during EndoFLIP.
- Use of functional MRI to understand brain function in patients with pain.

In addition, the motility team has been instrumental in the development of guidelines for the evaluation and treatment of children with motility and functional GI disorders and is an integral part of the Rome Foundation leadership.

**Contact us**

**617-355-6055**

[bostonchildrens.org/motility](http://bostonchildrens.org/motility)



Samuel Nurko, MD, MPH



Rachel Rosen, MD, MPH

# Pancreatic Disorders Program

The Pancreatic Disorders Program at Boston Children's Hospital is the first multidisciplinary program devoted to the care of children with pancreatic diseases in New England and the Northeast. Our program takes a patient-centered approach to effectively manage and treat the vast spectrum of pancreatic disorders in children.

We have experience in treating a variety of pancreatic disorders including:

- congenital malformations
- inflammatory conditions (i.e. acute, recurrent, and chronic pancreatitis)
- exocrine pancreatic insufficiency
- pancreatic trauma
- malignancy
- diseases with associated pancreas pathology (i.e. cystic fibrosis, inflammatory bowel disease, and Shwachman-Diamond Syndrome)

## Leading the way in clinical care

Our program has been recognized by the National Pancreatic Foundation (NPF) as a leader in diagnosing and treating pancreatic disorders for children.

Our clinical research program focuses on therapeutic clinical trials including a current trial on pain management in pediatric acute pancreatitis. In addition, we are a member of the NIH-funded international multicenter research consortium INSPPIRE, whose goal is to further elucidate the mechanisms and natural history of recurrent and chronic pancreatitis in children.

The physicians and providers in our program are active on local, national, and international levels in furthering clinical and basic science research.

## Our clinical team

Our clinical team is known worldwide for their expertise in performing advanced therapeutic endoscopic procedures, including endoscopic

retrograde cholangiopancreatography (ERCP) as well as therapeutic endoscopic ultrasound (EUS).

Some of our comprehensive team includes:

- anesthesiologists
- clinical psychologists
- early intervention specialists
- physicians
- social workers

Our commitment to multidisciplinary collaboration is what allows us to provide a holistic approach and exceptional pancreatic care to all children. The Pancreatic Disorders Program at Boston Children's Hospital has many established relationships to support families.

These relationships include:

- pediatric and adult clinical experts
- clinical and basic science researchers
- community advocates such as the National Pancreas Foundation
- patient support groups

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Amit Grover, MB, BCh, MBChB



Victor L. Fox, MD

## Pediatric Polyposis Program

The Pediatric Polyposis Program at Boston Children's Hospital serves the unique needs of children with the growth of polyps anywhere within their gastrointestinal tract (commonly called polyposis). Most polyps in children are non-cancerous or benign. However, some children who develop polyps have an increased risk of developing gastrointestinal cancers, as well as tumors and cancers in other parts of the body.

With rare exception, complications and cancer risk related to polyposis are largely determined by the named disorder or specific genetic diagnosis and patient age. Therefore, a careful diagnostic evaluation by an experienced team of specialists is essential.

### Leading the way in clinical care

Our program aims to prevent or reduce complications of gastrointestinal polyps, promote clinical and basic research, and educate families and health care providers about polyp-forming conditions, including:

- familial adenomatous polyposis
- juvenile polyposis syndrome
- PTEN hamartoma tumor syndrome
- Peutz-Jeghers syndrome

Gastrointestinal polyps may occur due to an inherited genetic condition. Multiple family members may be affected or at risk. Special DNA tests can be very helpful to identify these individuals within one family so we offer consultation with a genetics counselor or a geneticist as part of the initial evaluation.

### Our clinical team

Led by **Victor L. Fox, MD**, an international authority in diagnostic and therapeutic endoscopy for children, our program offers an extended team of specialists, including geneticists, genetic counselors, surgeons, radiologists, endocrinologists, and social workers. We work closely with the Pediatric Cancer Genetic Risk Program at Dana-Farber Cancer Institute/Boston Children's Hospital. We also partner with specialists at the Center for Cancer Genetics and Prevention at the Dana Farber Cancer Institute and Brigham and Women's Hospital when our patients request transition of care to an adult center and to support the needs of adult family members.

### Contact us

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Victor L. Fox, MD





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