Healthy intestinal villi, like those seen here, help with nutrient absorption. With celiac disease, eating foods containing gluten causes an immune response that damages the villi.
Family focused

Our celiac disease program combines the latest medical advances with a comprehensive approach

BY THOMAS T. SATO, MD

Historically, pediatric gastroenterologists have been able to diagnose and treat celiac disease and gluten sensitivity, but focused expertise in the field has allowed Children’s Hospital of Wisconsin to develop a comprehensive program at the Bonnie Lynn Mechanic Celiac Disease Clinic.

The process begins with a definitive diagnosis through endoscopy and biopsy. Through one-on-one educational sessions with a dietitian, we then teach patients and their families how to prevent exposure to gluten-containing foods.

Because dietary and lifestyle changes involve the entire family, we take a multidisciplinary approach, engaging clinical therapists as needed. In addition, we examine cultural, ethnic and socioeconomic aspects of dealing with the disease.

Children’s is actively pursuing improved science in this area. We are building a database registry and tissue/blood bank to advance understanding of celiac disease. We also are researching inflammatory signatures in patients with celiac disease and type 1 diabetes.

Celiac disease is a debilitating condition that can be wholly abated by a gluten-free diet. We are excited to be able to help more young people make the lifestyle changes required to restore their best quality of life.

Best,

Thomas T. Sato, MD, FACS, FAAP
CEO, Children’s Specialty Group
Pediatric general and thoracic surgeon, Children’s Hospital of Wisconsin
Senior Associate Dean of Clinical Affairs, Professor of Pediatric General and Thoracic Surgery, Medical College of Wisconsin
Changing for the better
Quick referring provider surveys give the chance to provide specialty-specific feedback

In 2017, more than 400 referring providers completed a survey telling Children’s Hospital of Wisconsin about their impressions of our care and how we’re partnering with them. The results told us where we’re succeeding, and they also guided us in making changes to improve communication and access.

“Our next step is getting specialty-specific and ultimately provider-specific feedback,” said Carey A. Ehler, MD, a neonatologist at Children’s Hospital of Wisconsin, director of provider engagement and experience for Children’s Specialty Group, and associate professor of Neonatology at the Medical College of Wisconsin. “In order to make effective change moving forward, we need to know where to focus our time and resources.”

COMING TO YOUR INBOX
Our new effort is a focused survey of only seven to eight questions that you will receive by email after you refer a new patient to certain specialties. You will only receive one survey per specialty each month. Survey questions will vary by specialty.

WE’RE ALL EARS
Each survey takes about two minutes to complete and yields valuable insights. “The data will help us target any interventions we need to make within that specialty. It will also help us identify how we can share best practices across specialties,” Dr. Ehler said.

As a result of referring provider feedback, we developed the CHW Refer app. Use it to search for Children’s specialists, check appointment availability, review medical care guidelines and much more.

The bottom line is that Children’s wants to hear what you have to say, and we hope to make the referral process as convenient as possible. “We are grateful for the partnerships we have with our referring providers, and their feedback guides our quest for continuing improvement,” Dr. Ehler said. “I hope you will continue to come forward with concerns and guidance.”

Carey A. Ehler, MD

Pediatric Rounds 2018 Reader Survey by the numbers

MORE THAN 50%
read all or most of the magazine.

Thank you to everyone who completed our reader survey. You told us exactly what you think about Pediatric Rounds, and your feedback will help shape our content for the better.

90% consider Pediatric Rounds a good or excellent source of useful information.

26% have shared an issue with colleagues or office staff.
Same fetal care, new location

The Fetal Concerns Center’s new clinic space streamlines care and collaboration

On June 4, the Fetal Concerns Center began seeing patients in its new clinic space on the second floor of Children’s Hospital of Wisconsin, conveniently located right across the hall from the Herma Heart Institute.

Founded in 2000, the Fetal Concerns Center specializes in diagnosis, treatment and care coordination for women with high-risk pregnancies and fetal anomalies. The new clinic space includes five consultation rooms and six exam rooms where ultrasounds and echocardiograms are performed.

According to Fetal Concerns Center Program Director Kristi Rapp, having this designated space within the hospital allows for more streamlined care and collaboration among physicians, as well as more comfort and convenience for families.

Learn more about the Fetal Concerns Center at chw.org/fetalconcerns.
Many different conditions can affect a child’s liver, ranging from an infection to a chronic disease to a genetic condition. When this vital organ is damaged, it can lead to liver failure and the need for a liver transplant. Our Liver Disease and Transplant Program has a strong track record of successfully managing all types of liver disorders. “We treat the whole scope, from the fairly simple to the most complex liver problems,” said Grzegorz W. Telega, MD, a board-certified hepatologist, program director of Liver Transplant Hepatology at Children’s Hospital of Wisconsin and professor of pediatric gastroenterology at the Medical College of Wisconsin.

**TEAM APPROACH**
Liver disease can affect a child’s life in significant ways. We use a team approach to provide education, support and ongoing disease management to the patient and family.

Our multidisciplinary team includes nurses who specialize in liver disease, dietitians who frequently work with children with liver disorders, social workers to navigate insurance and school issues, pharmacists who understand how liver disease affects the metabolism of medications, radiologists with special training, pediatric psychologists, transplant surgeons, and two board-certified transplant hepatologists.

“There are about 100 board-certified transplant hepatologists in the country, and we are privileged to have two of those,” Dr. Telega said. “That provides a depth and better understanding of liver disease. It also provides more comprehensive service to the patients when they have people who have more in-depth knowledge of the liver.”

**TRANSPLANT EXPERTISE**
In some cases, a liver transplant may be a child’s best option. Children’s is home to the largest pediatric liver transplant center in Wisconsin and is known as a pioneer in the transplantation field.

“We cooperate closely with other specialties, because liver disease frequently affects other organs or is associated with problems in other organs,” Dr. Telega said. That means maintaining collaborative relationships with cardiology, nephrology, oncology and genetics, among other specialties. In 2012, Children’s successfully performed the state’s first pediatric combined liver and heart transplant and has performed multiple combined liver and kidney transplants with no mortality. “We also performed 10 liver transplants for hepatoblastoma — an aggressive form of liver cancer — with no mortality and no tumor recurrence,” Dr. Telega said.
Is it celiac disease?

Help your patients develop defenses against celiac disease through proper diagnosis and treatment

BY ANKUR A. CHUGH, MD

Celiac disease is the abnormal immune response to the ingestion of gluten (found in wheat, barley and rye). Symptoms within the GI tract can include abdominal pain, diarrhea, vomiting, weight loss and failure to thrive. Extra-intestinal (EI) manifestations can include iron-deficiency anemia, osteoporosis, arthritis, headaches and

Ankur A. Chugh, MD, is the interim director of the Celiac Disease Clinic at Children’s Hospital of Wisconsin and an assistant professor of pediatric gastroenterology at the Medical College of Wisconsin.
What if my patient wants to stop eating gluten?
Obtain the patient’s celiac serologies before they stop eating gluten. This will help clarify if they have celiac disease or gluten sensitivity. If the celiac serologies are abnormal, they should be referred to a pediatric gastroenterologist for a scope. For the scope to be accurate, the patient needs to keep eating gluten. North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) guidelines suggest two pieces of bread a day is enough to have accurate biopsy results.

What if my patient is avoiding gluten?
First, try to understand how much gluten, if any, the patient is consuming. If it’s equivalent to at least two pieces of bread a day, both lab and biopsy results should be accurate. Some gastroenterologists might be OK with doing a scope if the patient is eating at least one cracker a day for three weeks prior to the scope.

At-risk patients for celiac disease

- IgA deficiency: 2%
- Autoimmune thyroiditis: 2–5%
- Turner syndrome: 4–8%
- Idiopathic dilated cardiomyopathy: 6%
- Down syndrome: 5–12%
- Type 1 DM: 3–12%
- Williams syndrome: 6%
- Multiple sclerosis: 11%
- Autoimmune hepatitis: 6–15%
- IgA nephropathy: 4%
- 1st degree relative with celiac disease: 11%
- Addison disease: 6%
- Autoimmune liver disease: 6–8%

The risk of developing celiac disease is increased by the percentages noted for patients with:

- Type 1 DM
- Williams syndrome
- Multiple sclerosis
- Autoimmune hepatitis
- 1st degree relative with celiac disease
- Addison disease
- Autoimmune liver disease
- IgA nephropathy
- Type 1 DM
- Williams syndrome
- Multiple sclerosis
- Autoimmune hepatitis
- 1st degree relative with celiac disease
- Addison disease
- Autoimmune liver disease
- IgA nephropathy

Dermatitis herpetiformis. EI symptoms typically present after the age of 5. GI and EI symptoms typically resolve in 12 to 24 months once the patient is on a gluten-free diet.

How is celiac disease diagnosed?
A typical diagnosis is made with abnormal celiac serologies and an abnormal intestinal biopsy. There are many celiac serologies, which include the anti-gliadin antibody (AGA), deaminitated gliadin peptide (DGP) antibody and tissue transglutaminase (TTG) antibody, all of which have an IgG and IgA test. The sensitivity and specificity of the serologies are different, and as such, current recommendations are to only get the TTG IgA antibody, along with the total IgA. Patients who are IgA deficient may not mount an appropriate TTG IgA antibody response, and in these cases, the TTG IgG antibody should be obtained. For patients under 2 years old, the DGP IgG antibody should be obtained along with the TTG IgA antibody.
If the patient won’t eat any gluten, consider genetic testing for celiac disease. While 20 to 30 percent of the population has genes that put them at risk for celiac disease, the lack of these genes effectively rules it out. Genetic testing, however, can be expensive and may not be covered by insurance, so this should be discussed before ordering the test.

Is a scope really necessary to diagnose celiac disease?
The European guidelines indicate that the diagnosis of celiac disease can be made with elevated celiac serologies >10x normal, positive celiac genetics and a positive anti-endomysial antibody (EMA), a very specific test for celiac disease. However, NASPGHAN recognized the European criteria without affirming it, citing celiac disease as a lifelong diagnosis with concomitant disorders, such as H. pylori and eosinophilic esophagitis, that can be diagnosed on biopsy.

My patient was diagnosed with celiac disease. What’s next?
The physician making the diagnosis should educate the patient and their family about the disease and refer them to a dietician to learn about the gluten-free diet. The gluten-free diet is difficult, and it can take time for patients and families to learn and strictly follow.

Celiac serologies (TTG IgA) should be checked three to six months after diagnosis to ensure they are improving, and annually after that. The 2016 NASPGHAN guidelines suggest additional labs be obtained at diagnosis (CBC, LFTs, calcium, thyroid, vitamin D, iron) and annually thereafter (CBC, vitamin D, thyroid); however, they acknowledge that these recommendations are based on expert consensus opinion rather than strong evidence. In addition, a recent study suggests that even if lab abnormalities are detected, they resolve within one year of being on a gluten-free diet.

My patient is asymptomatic. Do they need a gluten-free diet?
The short answer is yes. Untreated celiac disease can lead to both GI and EI symptoms down the road. Symptoms such as osteoporosis, iron-deficiency anemia and short stature can develop. In addition, the risk of intestinal lymphoma, while low, is increased by about three to six times in patients with untreated celiac disease.

Who needs to be screened for celiac disease and how often?
First-degree relatives of patients with celiac disease should be screened. European guidelines suggest starting with celiac genetics because, if they are negative, you can stop screening. However, not all insurance covers genetic testing for celiac disease, and siblings of patients with celiac disease often have the genetics that put them at risk for celiac disease, making the test less helpful. Another option is to obtain the TTG IgA every three years, or sooner if symptoms
The Neurogastroenterology, Motility and Autonomic Disorders Program at Children’s Hospital of Wisconsin offers one of the world’s largest teams of experts in the diagnosis and treatment of these disorders. Families from around the United States and beyond seek treatment at Children’s because of our team’s deep level of expertise, high volume of patients with motility disorders and cutting-edge diagnostic tools.

Children’s is recognized as a Gastrointestinal Motility Center of Excellence by the American Neurogastroenterology and Motility Society. In addition, ours is one of the few pediatric programs in the nation that specializes in autonomic disorders that have a gastrointestinal component.

For example, our Cyclic Vomiting Syndrome Program is the first and largest program to focus on treating children who are experiencing severe, recurring vomiting episodes.

We offer a full range of state-of-the-art testing and treatment options, including manometry studies and gastric pacing. Our comprehensive, interdisciplinary approach incorporates the expertise of pediatric specialists across many specialties, including general surgery, neurology, genetics, nutrition, immunology and behavioral health. These specialists use the best, safest equipment for kids, including imaging and scoping equipment that is the right size for children.

In addition, our team is actively involved in research on functional GI, motility and autonomic disorders, which deepens our understanding of how to best treat these conditions.

Learn more about the Neurogastroenterology, Motility and Autonomic Disorders Program at chw.org/neurogi.

Manu Sood, MD, our medical director of gastroenterology, is one of Children’s many experts in diagnosing and treating motility and autonomic disorders.
develop, once the patient is 3 years old. High-risk patients should also be screened for celiac disease according to their society guidelines.

What if the celiac serologies do not correspond with the intestinal biopsies?
Not all elevations in TTG IgA are celiac disease, and not all villous atrophy is celiac disease. In these patients, potential celiac disease and other etiologies need to be considered. These patients should be referred to a pediatric gastroenterologist with expertise in celiac disease.

What about gluten sensitivity?
The number of people in the United States (without celiac disease or wheat allergy) who are avoiding gluten is going up significantly. People are doing this for perceived health reasons or because it makes them feel better. The literature on gluten sensitivity in pediatrics is limited. The prevalence is variable, and there are no biomarkers, guidelines or treatment recommendations. Some new literature indicates that fructans, a carbohydrate found in many foods that contain gluten, may be the cause of irritable bowel symptoms rather than gluten. Patients on a gluten-free diet should take a multivitamin.

Are there new developments for celiac disease?
Lots! There are enzymes (similar to Lactaid) on the market that allow patients to digest small amounts of gluten. These are best used when patients are trying to avoid contamination in their diet, as they do not digest large amounts of gluten. There is a product on the market that can measure gluten in the urine and stool, which can detect or confirm accidental ingestion. There is a vaccine in development that would allow patients to consume small amounts of gluten. There is also a test that might be able to diagnose celiac disease when a patient is not eating gluten. Finally, there are a few drugs in clinical trials that are trying to alter the pathogenesis of celiac disease.

What’s new at Children’s for celiac disease?
We have a dedicated team of 17 pediatric GI providers who are well trained in caring for patients with celiac disease. We also have a team of dietitians, and all our patients diagnosed with celiac disease have a one-on-one education session with one of them. Our guidelines for celiac disease should be available on chw.org in late 2018.

In addition, with Martin J. Hessner, PhD, we have begun translational research attempting to identify a unique inflammatory signature in patients with celiac disease before they develop celiac disease itself. A clinical trial is also underway in healthy children with a sibling affected by type 1 diabetes to determine the role of dietary gluten and other grain proteins as potential risk factors in type 1 diabetes progression. The study is sponsored by the American Diabetes Association and led by Susanne M. Cabrera, MD, a pediatric endocrinologist at Children’s.

**RESOURCES**
Empowering you with resources
Specialty care guidelines now available online

At Children’s Hospital of Wisconsin, we focus on delivering what’s best for children. We know that sometimes what’s best for patients is receiving care close to home from their own primary care physicians.

To support you, Children’s offers specialty care guidelines as well as educational resources for the following specialties:

- Adolescent medicine
- Cardiology
- Child development
- Dental and oral health
- Dermatology
- Diabetes
- Down syndrome
- Endocrinology
- Gastroenterology
- Hematology
- Imaging
- Neonatal and newborn care
- Neurology and neurosurgery
- Orthopedics
- Pain and headache
- Psychology and psychiatry
- Sports medicine
- Surgery
- Urology
- Vascular anomalies

To access specialty care guidelines and resources, visit chw.org/careguidelines.

Clinical trials offer options
Children’s Hospital of Wisconsin trials advance research in cancer and blood disorders

Clinical trials have made tremendous progress in improving treatments and survival rates for children with cancer. By offering a range of clinical trials, Children’s Hospital of Wisconsin gives patients and families more options for fighting cancer and blood disorders.

With the support of the MACC Fund, we are able to offer more than 150 open clinical trials through our own research programs as well as by participating in a number of research consortia. Clinical trials open and close regularly, and new trials are continually in development. For the most current information, contact our Pediatric Cancer and Blood Disorders Clinical Trials Office at (414) 955-4727 or MACCcto@mcw.edu.

Learn more and see a complete list of open trials at chw.org/cancerclinicaltrials.

CME events

Connect with Children’s
CME Dinners
SEPTEMBER 25
CHILDREN’S HOSPITAL OF WISCONSIN KENOSHA CLINIC FUTURE SITE
OCTOBER 23
MILWAUKEE COUNTY ZOO, PECK CENTER
NOVEMBER 14,
OUTEREDGE STAGE, APPLETON
REGISTER: chw.org/connect

The Heart Summit
Management of Complex LV Outflow Tract Disease
OCTOBER 11
CHILDREN’S HOSPITAL OF WISCONSIN, BRIGGS AND STRATTON AUDITORIUM
REGISTER: chw.org/theheartsummit

Adolescent and Young Adult Survivorship Conference
OCTOBER 12
HARLEY DAVIDSON MUSEUM, MILWAUKEE
REGISTER: chw.org/survivorship

Best Practices in Pediatrics and Pediatric Emergency Medicine
FEBRUARY 28–MARCH 2, 2019
WISCONSIN DELLS
REGISTER: chw.org/bestpractices

CONTACT FOR CME EVENTS:
Claire Connelly, (414) 266-6242 or cconnelly@chw.org
Children’s around the state
Find a location near you

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<td>Children's Hospital of Wisconsin-Milwaukee Campus</td>
<td>8915 W. Connell Ct.</td>
<td>Milwaukee, WI 53226</td>
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<td>Children's Hospital of Wisconsin-Fox Valley</td>
<td>130 Second St.</td>
<td>Neenah, WI 54956</td>
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<td>Appleton Clinic</td>
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<td>Delafield Clinic</td>
<td>3195 Hillside Dr.</td>
<td>Delafield, WI 53018</td>
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<td>3365 S. 103rd St.</td>
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<tr>
<td>West De Pere Clinic</td>
<td>1686 Eisenhower Rd.</td>
<td>De Pere, WI 54115</td>
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The locations above are Children’s Clinics. We also see patients in other clinics in the following cities: Fond du Lac, Green Bay, Oshkosh, Racine and Iron Mountain, MI. In addition, we perform surgeries in Marshfield.