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The arrival of spring always brings renewed energy and optimism as the days get longer with ample sunshine. At the Institute, our efforts continue to focus on solidifying, improving and focusing the depth of our programs. We are excited that our patients on the northeast side of the metropolitan area will be able to receive outpatient endoscopy care at our new Redmond Ambulatory Surgery Center. We welcome the addition of Shelley Cathrea to the Swedish Digestive Health Institute (SDHI) team as our new executive director. Shelley is a familiar face to SDHI, having served as the Swedish Gastroenterology director several years ago and she's excited to return to and lead the Institute. We also invite you to join *Team Swedish - Just Doo It* as they attempt to repeat as fundraising leaders for the Crohn's and Colitis Foundation on June 12, 2021.

In this edition, we return to Ms. Brianna Nelson and Dr. Kunjali Padhya to bring more focus on how the High-Risk GI Cancer Screening Clinic manages patients with Lynch syndrome. From the surgical side, we explore with Dr. John Griffin one of the alternatives to permanent ileostomy — the ileo-anal pouch. Lastly, we spend time with super sleuth Dr. Chris Carlson who leads our GI team learning about diagnosing lesions in the small bowel with enteroscopy.


As always, we hope you find something in this edition that is applicable to improving the health of your patients.

Brian Louie, Jack Brandabur and Shelley Cathrea





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Lynch syndrome, a family affair

Historically, Lynch syndrome has been the cause of cancer-related deaths across generations of affected families. This inherited cancer syndrome increases the risk of developing colorectal and other cancers including endometrial, ovarian, renal pelvis/ureter, bladder, gastric, liver, kidney, brain and some types of skin cancers.

Named after Henry Lynch, M.D., for his early work with affected families, Lynch syndrome puts patients at risk of being diagnosed with cancer at a younger age by up to 60 percent, depending on the specific mutation, before general screening is recommended. But with genetic testing and regular screenings, cancer can be caught at an earlier stage before it threatens a patient's life.

While the majority of diagnosed cancer is not linked to a hereditary condition, "Lynch syndrome is not rare," says genetic counselor Brianna Nelson, MS, LCGC. "It can affect 1 in 350 people." And for each person diagnosed, there's a whole family that could be impacted.

That's why she and gastroenterologist Kunjali Padhya, M.D., want to ensure referring providers know the clues that can point to Lynch syndrome, and when to refer a patient for genetic testing.

Different mutations, different risks

Five different mutations can lead to Lynch syndrome, all related to DNA mismatch repair. During cell division, the mismatch repair system functions like a spellchecker, flagging errors to be corrected. The mutated version is less effective at spellchecking DNA, and errors can build up over time and lead to cancer.

Not every person with Lynch syndrome will end up with cancer, but regular screenings are the best way to ensure anything that arises will be caught early. The exact schedule of screenings will depend on which of the five mutations a patient has. (See the chart on the following page for the top cancer risks for each mutation.) That's why getting genetic testing is a critical step to managing Lynch syndrome.

"Almost all patients with Lynch syndrome can expect that they will be receiving frequent colonoscopies," says Dr. Padhya. Through genetic testing, patients can find out their particular mutation and the accompanying risks. Those at a higher risk with the MLH1 and MSH2 mutations might start at age 20 or 25, as opposed to patients with PMS2 or MSH6 who might wait until age 30. Dr. Padhya takes the mutation type and other information she knows about a patient and coordinates

the timing and referrals for all the screenings a patient will need.

Dr. Padhya and her colleagues at the Swedish Digestive Health Institute handle upper endoscopies and colonoscopies. (See our winter 2020 issue to learn about Twistle, which guides patients through colonoscopy preparation.)

But Lynch syndrome is also associated with other cancers, including endometrial, ovarian, renal pelvis/ureter, bladder, gastric, liver, kidney, brain and some types of skin cancers. To ensure patients get all the screenings they need, Dr. Padhya coordinates with other providers. "At the High Risk GI Cancer Screening Clinic, we direct traffic for sending referrals and ordering and monitoring so that all the other screenings are done," she says.

That can include blood and urine tests looking for early signs of anemia, kidney dysfunction and abnormal cells. And women are referred to gynecologic oncologists for endometrial biopsies, and eventually a discussion about having a hysterectomy after age 40, or when the patient is done having children.



Kunjali Padhya, M.D.



Brianna Nelson, MS, LCGC

Here at the Swedish Digestive Health Institute, the High-Risk GI Cancer Screening Clinic monitors patients with Lynch syndrome and other inherited cancer syndromes to give them the best shot at a healthy future. The clinic can be reached at 206-215-4250. See our winter 2020 issue for more information.

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Lynch syndrome, a family affair (continued)

To test or not to test

In the past, the cost of genetic testing has presented a significant barrier to patients. But that's changing, as the price has come down significantly. Insurance will often cover the cost of testing for patients with a significant family history of cancer, but even for patients who don't meet the criteria for coverage, multi-gene panels, which can identify Lynch syndrome mutations along with other hereditary cancer syndromes, can be ordered by a genetic counselor at Swedish for around \$250 in Brianna's experience.

And with the Covid-19 pandemic, genetic counselors are seeing patients virtually and using saliva tests that can be taken at home. "We're trying to make testing as easy as possible for patients," says Brianna.

So, who should be referred for genetic testing? One good indicator is a family history with three or more relatives with colon or uterine cancer. By asking a few questions about a patient's family history, primary care providers can uncover patterns that point to a hereditary cancer syndrome. Once a patient is identified, genetic counselors will take a thorough family history and decide which, if any, tests a patient needs.

If a patient's family member is diagnosed with Lynch syndrome, they should then be tested as well. The syndrome follows a dominant autosomal inheritance pattern, which gives each family member a 50 percent chance of inheriting the mutation regardless of gender. But not all families with Lynch syndrome will have a clear history of cancer. Depending on the mutation, the risk of cancer can be less. But unfortunately, that also means that patients might not find out about the syndrome until after they are diagnosed with a cancer.

That's why a diagnosis of colon or uterine cancer under the age of 50 can also trigger genetic testing. And if a patient finds out they have Lynch syndrome, they should be encouraged to share that information with family members who could also be affected.

A life-saving referral

Primary care physicians have a critical role to play in identifying patients who might have Lynch syndrome or another genetic cancer syndrome. One quick question about family history can start the process of a patient being diagnosed, which will give them the tools to live a healthier life with regular cancer screenings.

"The referral to genetic testing is relatively painless. It doesn't take up that much of a patient's time and could end up identifying things that will save their life," says Dr. Padhya. "And when you think of all the family members who could also be affected, we could potentially prevent a lot of cancers that might otherwise be missed."

Refer patients for genetic testing when:

- They are diagnosed with colorectal or uterine cancer under the age of 50
- They have one relative diagnosed with colorectal or uterine cancer under the age of 50
- They have two or more relatives diagnosed with colorectal or uterine cancers at any age
- A family member is diagnosed with Lynch syndrome

Swedish Cancer Genetic Counseling and Testing can be reached at 206-215-4377. ■

TOP CANCER RISKS FROM EACH LYNCH SYNDROME MUTATION

	MLH1	MSH2 and EPCAM	MSH6	PMS2	General population lifetime risk
Cumulative risk for diagnosis through age 80					
Colorectal	46 - 61%	33 - 52%	10 - 44%	8.7 - 20%	4.2%
Endometrial	34 - 54%	21 - 57%	16 - 49%	13 - 26%	3.1%
Ovarian	4 - 20%	8 - 38%	≤1 - 13%	3%	1.2%
Renal pelvis and/or ureter	0.2 - 5%	2.2 - 28%	0.7 - 5.5%	≤1 - 3.7%	—
Bladder	2 - 7%	4.4 - 12.8%	1 - 8.2%	≤1 - 2.4%	2.4%
Gastric	5 - 7%	0.2 - 9%	≤1 - 7.9%	No data	0.9%

Source: National Comprehensive Cancer Network

A life-changing alternative to ileostomy

When patients are so sick that their colon must be removed, most of them think they will have to live with an ileostomy for the rest of their lives. But a life-changing procedure offered at Swedish allows patients to forgo the ostomy bag after a transitional healing period and eliminate waste in a relatively normal way. This procedure turns the lower end of the small bowel into a structure known as an ileo-anal pouch or “J-pouch.”

When other therapies aren’t enough, patients with ulcerative colitis or Crohn’s disease can find symptom relief through colon removal. Another reason a patient might need a colectomy is a hereditary condition such as FAP or HNPCC that almost invariably leads to colon cancer. In this case, colectomy is life-saving.

The J-pouch option can relieve patients of the hopelessness and depression that often accompanies an ostomy bag. “I’ve had patients tell me they’d rather die than have a bag on the belly,” says Dr. John Griffin, a colorectal surgeon. Indeed, over a quarter of ostomy patients experience depression, anxiety and hopelessness, and many have suicidal thoughts. Creating the J-pouch is a tried-and-true procedure, but many people don’t know about it.

Surgeons create the J-pouch by curving the lower end of the small intestine back on itself into a “J” shape. The J’s upward curve creates a reservoir that helps store waste until the patient is ready to eliminate it through an opening at the bottom. This opening allows waste to pass through the anus so patients can use the toilet in a relatively normal way. Even when surgeons must remove a patient’s rectum, they can usually preserve the sphincter muscles associated with the anus, giving patients some bowel control.

The journey to the J-pouch takes place in several phases. The process starts with colon removal, followed by one or two more surgeries, each several months apart. Remarkably, surgeons can remove the colon laparoscopically. “You can do it with four small, one-centimeter incisions. And that’s it. It’s amazing,” Griffin says. Patients aren’t any happier about the idea of a torso-long scar than they are about an ileostomy bag, he notes, and the minimally invasive approach is a “real game-changer.” Swedish uses both laparoscopic and robotic techniques for colectomy.

Griffin, who has been with Swedish since 2016, says that about 80 percent of patients who need a J-pouch have ulcerative colitis (UC). UC patients are generally good candidates for a J-pouch procedure. Griffin notes that the J-pouch is not recommended for patients with Crohn’s.

Patients need an ileostomy during the healing period that follows the surgeries leading to a J-pouch. The ostomy is easier to accept when they know it’s likely temporary. Griffin says a healthy, well-maintained ostomy can be a good bridge between surgeries. Swedish employs a nurse educator who helps patients with ostomies, whether temporary or permanent, have a better experience.



John Griffin, M.D.

Approaching normalcy

People with ulcerative colitis suffer from chronic abdominal pain, bouts of fever, fatigue and inadequate bowel control. Many move their bowels more than two dozen times a day. Removing the colon relieves these miserable symptoms. But, as Griffin tells his patients, “It doesn’t necessarily get you back to how God made you.” Patients with a J-pouch may need to move their bowels four to six times a day. For most people, that might seem like an inconvenience, but it’s an improvement for UC patients.

Side effects and complications

Following a colectomy, physicians should watch for symptoms of dehydration. The colon plays a significant role in absorbing water into the body. Without it, patients may not get all the fluids they need. Griffin estimates that 30 to 40 percent of colectomy patients readmitted to the hospital are treated for dehydration. Patients can avoid dehydration by drinking a lot of fluids, especially electrolyte solutions. Fortunately, Griffin says, “at about six weeks there are changes in the small bowel, and it becomes much more efficient at absorbing water.”

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A life-changing alternative to ileostomy (continued)

Sometimes the completed J-pouch becomes inflamed, a condition called pouchitis. Ironically, pouchitis mimics the symptoms UC patients hoped to leave behind with a colectomy. Griffin says pouchitis follows the “rule of thirds.” About a third of J-pouch patients will experience pouchitis. A third of those will need medical treatment (such as antibiotics or antidiarrheals). And a third of those on pouchitis medications (about five percent of all J-pouch patients) do not respond to drugs. That small group of people, says Griffin, generally ends up with an ileostomy. The bottom line is that the J-pouch succeeds in 95 percent of patients.

Prevention

There are promising ways to treat UC to help avoid surgery altogether. Biologics can often control symptoms enough to prevent surgery in patients with UC. “If they come in and they haven’t been treated with biologics, I almost always send them to GI to have them treated,” says Griffin. Some probiotics can also reduce UC symptoms, even to the point of remission. When avoiding surgery is not possible, probiotics and prebiotics such as dietary fiber can help make the J-pouch more sustainable in up to 85 percent of patients.

Contraindications

Contraindications for the J-pouch solution include Crohn’s disease, constipation, bowel incontinence **not** caused by UC, obesity and very tall patients, since a long torso makes it more difficult for the small bowel to reach the pelvis.

Obesity is a challenge because the mesentery (which carries the intestines’ blood supply) shortens when it becomes fatty. Since surgeons can’t stretch blood vessels, the mesentery limits the small bowel’s reach into the pelvis. Griffin says there are ways around this, and he has had success scoring the mesentery’s surface to lengthen it, and other maneuvers. “If you can reach the pubic bone comfortably, you usually have enough length to hook up,” says Griffin.

While not every patient is a good candidate for a J-pouch, it’s essential to consider this option when planning to remove the colon. The J-pouch helps to restore some measure of normalcy, which can transform a patient’s emotional well-being in the years to come. ■

SBE: An endurance race for diagnostic results

Small bowel enteroscopy (SBE) is the marathon event of the gastrointestinal world. This procedure lasts longer than its more common cousin, the colonoscopy, and is riskier. But it allows physicians to view the entire small bowel without surgical incisions, a plus for patient recovery.

In his nearly eight years at Swedish, gastroenterologist Dr. Christopher Carlson has a strong track record as an SBE marathoner, performing most SBE procedures done at Swedish. He likes to focus on one thing for long periods, and the more complicated SBE procedures can run up to three hours.

What is SBE?

Gastroenterologists perform SBE using a long endoscope (200 centimeters), compared with 170 centimeters for a colonoscopy. The SBE scope, about the diameter of a child’s toy marble, incorporates two

balloons, one at the front and one at the back, which can be inflated to help move the scope along or secure it in place. Because SBE is invasive, it involves an anesthesiologist, with the patient receiving either deep sedation or general anesthesia.

In an upper, or antegrade SBE, the scope enters through the patient’s mouth and traverses the stomach to reach the small intestine. In a lower, or retrograde SBE, the scope enters through the rectum and traverses the large intestine to reach the small intestine.

SBE, like a colonoscopy, is used for visual diagnosis with a video camera. Like a colonoscopy, SBE can be used to biopsy masses and remove polyps. SBE can also inject contrast into the bile ducts or pancreas to assist with diagnostic imaging in patients with altered anatomy; this is known as enteroscopy-assisted ERCP (endoscopic retrograde cholangiopancreatography).

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SBE: An endurance race for diagnostic results (continued)

Indications for SBE

A patient might need an SBE procedure if there are signs of occult bleeding, such as iron deficiency anemia not attributable to another cause, or blood in the stool. Another common indication is an obstruction, especially one that shows up on a CT scan.

Reconnaissance increases success

SBE is most useful when the gastroenterologist performing it goes in equipped with reconnaissance data. If the gastroenterologist knows the suspected problem and its location, SBE is far more effective as a diagnostic tool. On average, says Carlson, SBE yields a diagnosis about 70 percent of the time.

It's common to conduct a capsule endoscopy before performing an SBE. The patient swallows a pill-sized capsule that houses a video camera, so the gastroenterologist can later watch the capsule's progress on a video screen and identify potential problems. Occasionally, especially in bowel obstruction or Crohn's disease cases, the capsule gets stuck and must be retrieved using SBE. Capsules are retained just over one percent of the time, varying based on patient condition.

Additionally, some patients have an upper and lower endoscopy before the SBE to assess for more common causes of anemia or bleeding.

Images from CT scans, radiology images, or capsule endoscopies help the gastroenterologist know what to target during the SBE procedure.

Color photos and time stamps from capsule endoscopies are especially helpful, as they impart greater precision to the SBE road map. Such prior knowledge can decrease the time needed for the procedure and increase the diagnostic yield. Otherwise, says Carlson, "It's like being in a corn maze."

What the SBE finds

The procedure's diagnostic payoffs help balance its risks. SBE allows diagnosis and treatment of conditions "when there is simply no other way to get there," says Carlson.

- **Vascular Ectasia:** This occurs when blood vessels in the small intestine become thin-walled and rise to the surface, where they bleed. These lesions can result in profound anemia, especially if the patient is taking anticoagulant medications.

- **Strictures:** Narrow spots in the bowel can be symptomatic of Crohn's disease, but NSAIDs (such as ibuprofen) may also cause strictures. The SBE can expand strictures using a balloon passed through the scope, giving the patient relief.
- **Cancer:** Includes gastrointestinal stromal tumor (deep within the jejunum), small bowel adenocarcinoma, carcinoid tumor and lymphoma.
- **Ulcers:** SBEs can biopsy ulcers and help diagnose Crohn's disease.
- **Polyps:** SBEs can remove polyps and deliver them for further analysis.
- **Foreign objects:** An SBE procedure might also retrieve medical equipment such as video capsules or surgical stents trapped in a patient's small intestine.



Christopher Carlson, M.D.

Risks

The most severe risk of SBE is perforation. Although the procedure is still considered relatively safe, the perforation risk is about 0.4 percent on average. By comparison, extensive studies on colonoscopies (at least 50,000 cases each) found that the colonoscopy perforation rate ranged from 0.005 percent to 0.085 percent. Perforation during SBE is about 10 times more frequent than during colonoscopy.

The perforation risk during SBE varies widely depending on patient condition and where the scope enters the body. Antegrade, or upper SBE, carries the lowest risk of perforation, 0.2 percent. Retrograde, or lower SBE has the highest risk, 1.1 percent.

Carlson says some diseases indicate that an SBE could predispose patients to perforation, especially patients with existing damage to the small intestine or altered anatomy from resectioning or ostomy. In patients with altered anatomy, the perforation risk is much higher than average, three percent overall. And retrograde SBE with altered anatomy has been shown to carry a perforation risk as high as 10 percent.

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SBE: An endurance race for diagnostic results (continued)

A somewhat surprising risk of SBE is pancreatitis (in about 0.2 percent of patients). As the scope and balloons snake through the bowel's loops, they compress and stretch the intestine. It's possible this pressure can cause trauma to the pancreas's body and tail.

Bleeding occurs less than one percent of the time post-SBE and is usually not serious. Depending on the procedure's details, it could be hard to tease out whether the bleeding resulted from the SBE or from the condition itself, says Carlson.

Since retrograde SBE typically views less of the small bowel and is riskier, physicians are more likely to perform antegrade SBE. But this creates another potential side effect — a sore throat. About half of upper enteroscopy patients experience pain or discomfort in the throat

following the SBE, and about 5 percent of those need a numbing spray to combat throat pain, says Carlson.

Silver lining

Telemedicine has surged during the COVID-19 pandemic, and Carlson says pre-procedural video visits with patients have been so helpful that he'd like to continue them after the pandemic. He has consulted with pre-SBE patients as far away as the Olympic Peninsula and eastern Washington without bringing them to Seattle for an office visit. The SBE procedure may be a marathon for the gastroenterologist, but it shouldn't be for the patients. Every bit of reconnaissance helps with SBE, and video visits are a silver lining in the pandemic cloud. ■

PROVIDER PROFILE: MOHIT GIROTRA, M.D, FACP

Dr. Mohit Girotra was recruited to the Swedish Digestive Health Institute from the University of Miami School of Medicine in Florida, where he was an Associate Professor and Director of Endoscopy in the Division of Gastroenterology/Hepatology.

After finishing medical school at Christian Medical College in India, Dr. Girotra trained at the Johns Hopkins/Sinai Internal Medicine Program, where he developed his passion for GI, and also became invested with American College of Physicians (ACP) serving as Co-Chair for ACP-Chief Residents Association. He then completed his GI fellowship at the University of Arkansas for Medical Sciences (UAMS), where he stayed on as faculty (Assistant Professor), before pursuing a therapeutic endoscopy fellowship at the Stanford University in California, where he acquired a wide range of endoscopic skills for expert management of biliary and pancreatic diseases along with GI oncology.

Dr. Girotra has been actively involved in education/mentoring and takes pride in helping his residents/fellows excel academically. He is also passionate about research, having won several research recognitions (Mendeloff award and ACP Maryland Research Award) and has authored over 100 peer-reviewed articles. His clinical and research interests include therapeutic pancreatico-biliary endoscopy (ERCP, EUS), advanced luminal endoscopy, emerging technologies and endoscopic innovation.

Dr. Girotra embraces several key/leadership roles in GI professional societies. In ACG, after participating in "Training" and "Digital Communications/Publications" committees, he currently serves on the "Practice Parameters Committee." In AGA, he serves on the "DDW Abstract Committee" and in ASGE, he serves as the "Co-chair of Lower-GI section." He has also served as Co-Director of the ACG 2nd Year Fellows Course, and is currently serving as elected National Secretary of Foundation of Interventional and Therapeutic Endoscopy (FITE).

Dr. Girotra considers himself fortunate for receiving opportunities to work with acclaimed investigators and clinical mentors, who helped shape his career, and strives to extend the same quality of mentorship to coming generations of gastroenterologists. Importantly, this mentorship and collaboration allows Dr. Girotra to provide high quality, evidence-based and compassionate care to his patients at Swedish. ■



Mohit Girotra, M.D., FACP

“Team Swedish, Just Doo It!”, regional fundraising champions, walks again this year, at CCF “Take Steps” for Crohn’s and Colitis



The Swedish pediatric and adult gastroenterology groups have formed “**Team Swedish, Just Doo It!**”, to proudly support the “Take Steps” walk-a-thon fundraiser on June 12, 2021. For 10 years in a row, Team Swedish has walked to show how much they care for their patients and community, and to demonstrate commitment to the Crohn’s & Colitis Foundation (CCF). The Pacific Northwest CCF is an exceptionally active chapter whose mission is to cure Inflammatory Bowel Disease (Crohn’s disease and ulcerative colitis, collectively known as IBD) and improve the quality of life in children and adults.

Swedish’s team has always had spirit! Altogether, Swedish has raised over \$41,000 since 2012. This year, we’ve set our goal higher than ever, and hope to raise more than \$7500 as part of our steadfast commitment towards helping the CCF fund pioneering research that leads to groundbreaking treatments, public and professional education, and support for our patients. Year after year, Team Swedish is honored as the top fundraising team amongst all regional hospital and medical groups. We hope to remain the undefeated “GI Cup Champions” and encourage you to support our efforts. By doing so, you too will experience a sense of celebration and connection, feeling empowered that by taking steps for cures, you’ll also have made a difference in the lives of so many.

For more information, or to register for the ‘Take Steps’ fundraiser’ visit the Crohn’s & Colitis Foundation at <https://www.crohnscolitisfoundation.org>. ■

