DIGESTIVE HEALTH MATTERS

DECEMBER 2021

YOU ARE NOT ALONE



NORTON EDUCATION SERIES EVENTS

Pgs. 18-19

See pages 18-19 for a recap of the 2021 NES event and details about the upcoming 2022 IBS NES event in Chicago

GASTROINTESTINAL PATIENT EDUCATION

GERD pgs. 10-11
Gastroparesis pgs. 14-15
Constipation pgs. 16-17
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VIEW UPDATED PATIENT RESOURCES

Pg. 8-9

In 2021, IFFGD unveiled an easy to navigate, user friendly series of websites.

WWW.IFFGD.ORG

PUBLICATION BY IFFGD

BECAUSE DIGESTIVE HEALTH MATTERS

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About IFFGD

In 2018
Ceciel Rooker becomes President of IFFGD

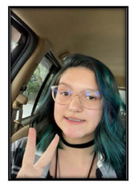

Ceciel Rooker
President and Executive Director


Jamie DuMont
Director of Operations


Emily Taylor
Director of Patient Engagement


Hayley McCorkle
Public Relations Manager


Alyssa Sutton
Project Coordinator


Yoshi Rooker
Media Intern

Our Mission

Our mission is to inform, assist, and support people affected by gastrointestinal (GI) disorders.
IFFGD was founded in 1991 by one person struggling with the challenges imposed by a chronic GI disorder. Many others, from all walks of life, have joined with us.

We work with patients, families, physicians, nurses, practitioners, investigators, regulators, employers, and others to broaden understanding about GI disorders, support or encourage research, and improve digestive health in the adults and children.

Our Goals

- Ensure IFFGD is the source for patients to get accurate and up-to-date information on their gastrointestinal illness
- Heighten awareness and offer education for patients with functional GI and motility disorders and undeserved or rare GI diseases
- Find innovative ways to engage patient advocates
- Engage younger clinicians and researchers to increase their interest in functional GI and motility disorders and undeserved or rare GI diseases
- Expand IFFGD internationally
- Collaborate with like-minded organizations to help advance the science and treatment of functional GI and motility disorders and under-served or rare GI diseases
- Increase IFFGD's advocacy presence
- Ensure that IFFGD has the resources needed to accomplish our mission

The International Foundation for Gastrointestinal Disorders (IFFGD), is a Public Charity designated under the U.S. IRS code 501(c)(3). We are a registered nonprofit education and research organization.

Logos: then and now



First used in 1992 in the premiere issue of *Participate*, IFFGD's original Newsletter



In 1994, we changed our logo and added our name



In the Fall of 1996, we changed our name from the International Foundation for Bowel Dysfunction to the International Foundation for Functional Gastrointestinal Disorders



In 2015, Cole Norton, son of Nancy and Bill Norton, and previous employee at IFFGD, redesigned the logo for a new modern look



In 2021, we commissioned this special logo to commemorate our 30th Anniversary

The Nancy Norton Story



In some ways my life has become very unique. Let me begin by assuring you that I consider myself to be a very fortunate individual and, in many ways, as one friend has described it, "I have a big life," a life that I never envisioned for myself. However, there were days when I felt that I would never leave my home, I felt that my life was over. I could not imagine how I could continue on in life as a person living with bowel incontinence.

In 2014
Nancy Norton received the DDNC lifetime service achievement award

Not everyone has been as fortunate as I in the ability to cope and manage incontinence. Bowel or bladder incontinence is a 24-hour, seven day a week challenge. One never escapes it, for many it is even in our dreams.

In 1985 with the delivery of my son, I sustained a 4th degree laceration. I subsequently had two repair surgeries that were unsuccessful in restoring continence. My life changed in one moment of time, from a continent person with a full life, anticipating the birth of my son with an expectation that both mother and child would do well, to a life that no longer holds any spontaneity but rather a life that is focused on control.

Incontinence that results from vaginal delivery is something that was seldom discussed in 1985 and unfortunately, we have not made much progress in including it in discussions with pregnant women today.



Bill and Nancy Norton

On October 2, 1991, Nancy Norton and her husband Bill started the International Foundation for Bowel Dysfunction, now known as the International Foundation for Gastrointestinal Disorders.

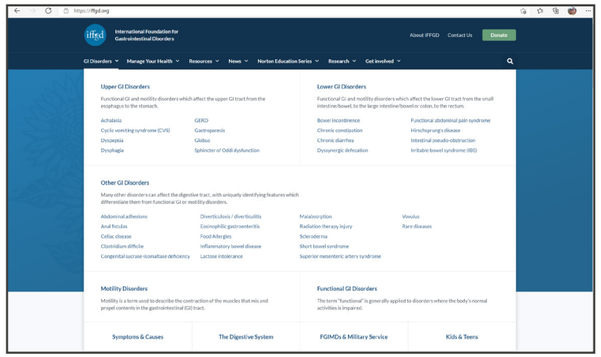
In a career spanning almost three decades, Ms. Norton served in several prominent professional societies, providing a voice on behalf of patients. Her roles have included:

- Chair, Digestive Disease National Coalition (DDNC) 1997–2007
- Council Member, NIH National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Advisory Council Term: 2001 to 2005
- Commissioner, National Commission on Digestive Diseases, National Institutes of Health (NIH). Term: 2006–2008
- Member, Advisory Committee to the Director of the Office of Research on Women's Health (ACRWH), National Institutes of Health (NIH). Term: 2006-2010
- Presenter, National Institutes of Health (NIH) State-of-the-Science Conference on Prevention of Fecal and Urinary Incontinence in Adults, addressing The Impact of Fecal and Urinary Incontinence on Health Consumers – Barriers on Diagnosis and Treatment and The Patient's Perspective. December 10–12, 2007
- Planning Committee. Endpoints and Outcomes Conference 2009: Optimizing Clinical Trials in FGID. Rome Foundation
- Member, Patient Reported Outcomes (PRO) Consortium, IBS Working Group, Critical Path Institute. Term: 2009–2017
- Committee Member. Rome III: The Functional Gastrointestinal Disorders. Working Team on Gender, Age, Society, Culture, and the Patient's Perspective
- Committee Member. Rome Working Team on Severity
- Planning Committee, NIH State-of-the-Science Conference: Cesarean Delivery on Maternal Request
- Panel Member, NIH State-of-the-Science Conference, Endoscopic Retrograde Cholangiopancreatography (ERCP) for Diagnosis and Therapy
- Council Member, National Digestive Disease Information Clearinghouse (NDDIC)
- Committee Member, Institute for Clinical Research and Education, American College of Gastroenterology (ACG)
- Ex-Officio Executive Committee Member, Functional Brain-Gut Research Group (FBG)
- Advisory Board Member, UNC Center for Functional GI & Motility Disorders
- Advisory Board Member, Simon Foundation for Continence



Bill and Nancy Norton with their son, Cole Norton

Educational Resources



The International Foundation for Gastrointestinal Disorders (IFFGD) offers a place you can go to find help and support. We provide information and tools on a wide range of topics for patients and their families, healthcare providers, and anyone interested in chronic gastrointestinal disorders.

Click here ➡ ***Visit the Publications Library***

Publications Library
On our main website, www.iffgd.org, you will find our publications library with over 300 brochures, fact sheets, and articles. This resource is uniquely devoted to providing reliable information to the public, with most of the information in our library written by medical professionals from around the world.

Social Media
Social media are still one of the top sources in which patients receive medical information. As part of our efforts to maintain a presence on social media worldwide, we actively share reliable educational resources, promote awareness, and mobilize action to advocate for those living with chronic gastrointestinal disorders on Facebook, Twitter, Instagram, LinkedIn, and YouTube. We have built our social following base to 13,711 across all platforms.

- Facebook (@IFFGD)
- Twitter (@IFFGD)
- LinkedIn (International Foundation for Gastrointestinal Disorders)
- Instagram (@digestivehealthmatters)
- YouTube (IFFGD)

Click here ➡ ***Visit IFFGD's YouTube Channel***

IFFGD also hosts educational programs such as Advocacy Events, Patient Education Symposia (Norton Education Series), IFFGD Podcasts, Patient Illness Experience Interviews, GI News Interviews, and much more. These recordings are conducted throughout the year in collaboration with the leading medical professionals in the field. The individual videos are available on IFFGD's YouTube Channel at www.YouTube/IFFGD.com to educate the public about GI disorders and the impact that they have on so many patients, family, friends, and caregivers.

e-Newsletters
A great way to stay connected with IFFGD and keep up to date with news and events of interest to the GI community is by subscribing to our ***free*** monthly eNewsletter.

In 1992 the first printed newsletter, *Participate* was published.

Click here ➡ ***Subscribe to our e-Newsletters***

By subscribing, you will

- Receive the latest information about research, care, and treatment published in our eNewsletter.
- Be a part of a community of support with others who understand and share common concerns.
- Stay up-to-date about IFFGD events, awareness programs, clinical trials, and education programs.

Click here ➡ ***Visit IFFGD's Research Study Listing***

Research Study Listing
Participation in clinical studies or trials offers one way to help advance research into gastrointestinal (GI) disorders. IFFGD hosts a list of clinical studies, in adults and children, that are seeking participants. A description of the study purpose and contact information is included. If you would like to see what research studies are available for your gastrointestinal illness, visit the IFFGD research studies listing on www.iffgd.org.

Click here ➡ ***Visit IFFGD's Dietitian Listing***

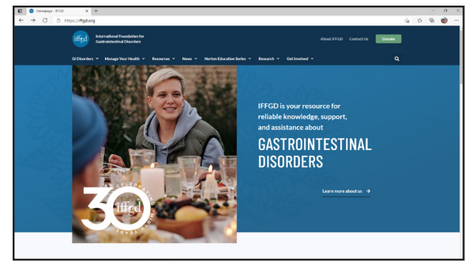
Dietitian Listing
IFFGD strives to add resources that are valuable to patients. With the growing need for diet and nutritional support and education for patients with gastrointestinal disorders, we created a dietitian listing. These healthcare providers work specifically with patients with GI disorders in the areas of diet and nutrition. We have over 100 dietitians that can be searched by GI disorder and geographic location. Specifics such as insurance requirements, telehealth appointment options, and contact information are provided.

Website Update
We believe finding the information you need on gastrointestinal (GI) disorders is vital. Therefore, in April 2021, we redesigned seven of our websites to make searching for content faster, easier to access, and more user-friendly. You can stay informed on clinical trials, upcoming events and medical and treatment news. We will continue to update the content on our websites to provide you with the most up-to-date information on GI disorders.

In 1997 the first website, iffgd.org, was created

Outside of IFFGD's main website, we also have nine other websites with information dedicated to a specific gastrointestinal illness or symptoms.

- aboutConstipation.org
- aboutGastroparesis.org
- aboutGERD.org
- aboutGIMotility.org
- aboutIBS.org
- aboutIncontinence.org
- aboutKidsGI.org
- losninosyGI.org
- YouandConstipation.org

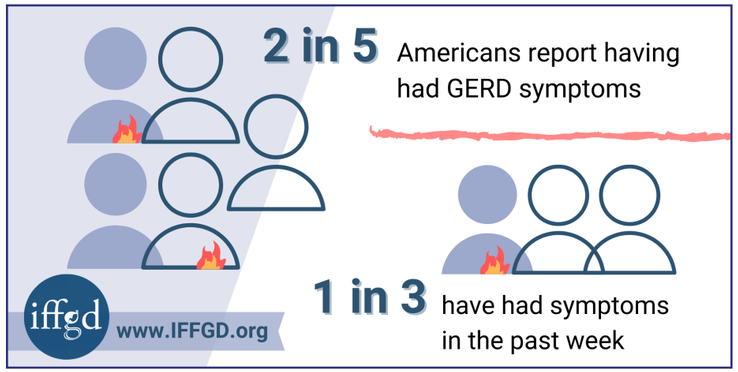


Gastroesophageal Reflux Disease (GERD)

Introduction

Heartburn is a very common symptom that either you or someone you know likely experienced within the last week. A recent population-based survey showed that 2 of 5 Americans reported GERD symptoms in the past, and 1 of 3 had symptoms in the past week. GERD is thought to affect an estimated 18 to 28% of Americans, making it the most prevalent gastrointestinal (GI) disorder in the country. It is also the most common diagnosis encountered in the gastroenterology clinics with nearly 8.9 million visits in 2009. However, the true prevalence of this disorder could be even higher given most individuals have access to over-the-counter acid suppressive medications (such as proton pump inhibitors [PPIs]) and typically try self-treatment first. The mean direct cost to diagnose and treat a patient with typical GERD in the first year of evaluation is $971 per patient with annual national expenditure ranging from $9.3 billion to 12.1 billion. Whereas the evaluation and treatment of atypical symptoms associated with GERD has averaged out to $5,438 per patient in the first year with the estimated annual cost being five times that of typical GERD at $50 billion.

Click here ➡ *Visit www.aboutGERD.org*



What is GERD?

GERD is a condition where stomach contents flow back (reflux) into the esophagus causing troublesome symptoms and/or possible damage to the esophagus. The esophagus is the muscular tube that connects the mouth and the stomach, allowing food to pass into the stomach. Heartburn and/or regurgitation are common symptoms associated with GERD. Patients generally describe heartburn as a burning sensation behind their breastbone in their chest that might radiate towards their neck and throat. Occasional reflux of stomach (gastric) contents is a normal physiological process that often occurs after meals. Physiological processes include all body functions that contribute to sustaining life.

GERD occurs when this reflux is frequent enough to cause symptoms. Although heartburn and/or regurgitation are the typical symptoms associated with GERD, some patients may develop other symptoms such as hoarseness, chronic cough, feeling that there is a lump, or foreign body stuck in the throat, and throat clearing. These symptoms are considered as extra-esophageal manifestations of GERD, or symptoms that occur outside of the esophagus. Other symptoms may include epigastric pain, chest pain, and sleep abnormalities. Epigastric pain is defined as pain or discomfort in the area below the ribs and in the center of the upper abdomen.

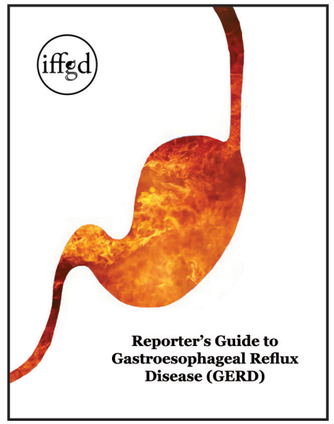
In 1998
IFFGD designated the week of Thanksgiving in November as GERD Awareness Week on the National Health Awareness Calendar

Typical Causes of GERD and Heartburn

The cause of GERD depends on many factors and is influenced by many physical characteristics. These include the pressure of the lower esophageal sphincter, the presence of a hiatal hernia, esophageal motility, and the ability of the lining of the esophagus to protect against reflux. The lower esophageal sphincter is the muscle that separates the esophagus from the stomach, acting as a valve that prevents stomach contents from moving up into the esophagus. A hiatal hernia occurs when a small portion of the upper stomach pushes up through the diaphragm into the chest. The diaphragm is the muscular, internal separation between the chest and abdomen. Esophageal motility refers to the movement of food through the esophagus, resulting from coordinated muscle contractions.

Increased number of momentary lower esophageal sphincter relaxations can lead to harmful stomach contents entering the esophagus, and might account for 48-73% of GERD symptoms. Anatomical factors like the presence of hiatal hernia or an increase in pressure in the abdomen, as seen in obesity, can also increase episodes of reflux events. In fact, obesity is not only associated with an increased risk of developing GERD symptoms, but also erosive esophagitis and esophageal carcinoma. Other risk factors for development of GERD symptoms include age ≥50 years, tobacco use, consumption of excess alcohol, and pregnancy.

Click here ➡ *Visit IFFGD's GERD Awareness Resources*



There are 3 subtypes of GERD:

- Non-erosive reflux disease (NERD) – Defined as abnormal esophageal acid exposure based on pH testing, but without esophageal mucosal injury on endoscopy.
- Erosive reflux disease (ERD) – Defined as endoscopic evidence of reflux related mucosal injury.
- Barrett's esophagus – Replacement of the normal lining of the esophagus with lining of the stomach and cells that are typically seen in the small bowel. Developing this condition can lead to an increased risk of cancer of the esophagus.

Adapted from IFFGD's Reporters Guide to Gastroesophageal Reflux Disease (GERD). Written by Ronnie Fass, MD, Professor of Medicine at the University of Arizona and Dhyanesh Patel, MD, Assistant Professor of Medicine at Vanderbilt University Medical Center

Click here ➡ *Read IFFGD's GERD Reporters Guide*

Symptoms of GERD

Two common symptoms that people may experience are heartburn and acid regurgitation (refluxed material into the mouth). Other symptoms may also occur, these include:

- Difficulty or pain when swallowing
- Excessive belching – loud gas passing from the stomach and out the mouth
- The feeling of food sticking in the esophagus
- Chronic sore throat or irritated larynx
- Inflammation of the gums
- The erosion of tooth enamel
- Hoarseness – a change in voice that sounds raspy or strained
- A sour or bitter taste in the mouth

Patient Engagement



In 2006 IFFGD brings patients together on Capitol Hill for the first time

Patient Panel

In 2018, the IFFGD Patient Panel was formed. It includes patients, family members, and friends interested in helping shape IFFGD's future by providing input on IFFGD programs and services and by participating in IFFGD-sponsored events. The panel currently consists of over 2100 individuals from around the world and continues to grow.

To actively engage and understand new patient panel members, IFFGD launched a survey of the Patient Panel in January of 2020. The survey characterizes panel members' GI disorders, geographical locations, and interests in IFFGD activities such as advocacy, sharing experiences, volunteering, advisory opportunities, and research. Also in 2020, IFFGD began screening members of our Patient Panel for opportunities to work with our Industry Council, other nonprofit organizations, medical societies and others to provide feedback and input about their illness experience as a patient with a chronic GI condition. As a result, we have been able to connect several patients with companies interested in incorporating the patient voice in their activities. Moving forward, we will continue to collaborate with the Patient Panel to help us determine the current unmet needs of the digestive health patient community and how IFFGD can best meet these needs.

Click here ➡ ***Join the Patient Panel***

Patient Advisory Committee

Launched in 2018, the IFFGD PAC continues to be a valuable source of information and support for the Foundation. Members contribute to the development of our programs and services by sharing their perspectives on the unmet needs of their communities, offering input on proposed IFFGD programs and initiatives, and acting as ambassadors in their communities. A total of 17 individuals represent a diverse range of diagnoses, geographic locations and backgrounds comprise this exciting new committee. The PAC were essential in the planning of our 2020 and 2021 Virtual Advocacy Events by assisting with the selection of the subject matter for the educational videos and suggesting ideas for how to best function in a virtual environment.

IFFGD is greatful to our PAC members. Our current members are:

Alyssa
Amber
April
Brittany
Brooke
Caroline
Cate
Claudia
Debbie
Jason
Kat
Kim
Melissa
Nina
Swapna
Timothy
Trisha

IFFGD Focus Groups

Focus Groups are designed to take a qualitative approach to understand areas of gap needs within the community. At IFFGD, we firmly believe in the statement, "If you want to end with patients, then you must start with patients." With that in mind, IFFGD created open and ongoing patient lead focus groups, which provide us with the unique opportunity to reveal vital information and detailed insights from a diverse group of patients living with chronic gastrointestinal (GI) diseases.

Health Disparities and Inequalities Focus Group: This focus group was designed to better understand what patients believe are the disparities and inequalities in health care today. We hope that through conversations with patients and with feedback, we can develop educational tools to help patients advocate for themselves during appointments to ensure they receive equitable care. We also hope to gain insight on key points that we can present to legislators about how they can help eliminate gaps in health care. This is not going to happen overnight. But working together, we will equip ourselves to take baby steps in this journey alongside patients living with chronic GI diseases.

Awareness Committee: Public awareness is critical to advance research and improve care for people affected by FGIMDs. The more we spread the word and talk openly about these conditions, the greater our ability is to connect with people who can invest in research activities and gain a stronger commitment from the industry to develop new treatment options. Our Awareness Committee members volunteer their time and skills to help us generate ideas to raise awareness and develop awareness campaigns for IBS Awareness Month in April, Gastroparesis Awareness Month in August, GERD Awareness Week during the week of Thanksgiving and Constipation Awareness Month in December. These individuals serve as the face of our GI community and continually work to build unique awareness campaigns tailored to amplify the voice of the patient community.

Click here ➡ ***Join a Focus Group***

Patient Advocacy

Digestive health advocacy through IFFGD brings concerned parties together to ensure that we carry clear, impactful messages. Adding your voice to this growing chorus helps expand critical research, initiate important legislation, and facilitate the development of new treatment options. It can be as simple as sending an email or making a call to a legislative office.

In 2006, IFFGD began regularly bringing the gastrointestinal illness community to Washington DC to work together to raise awareness about and advocate for the need for research into safe and effective treatments, and cures and better pateint access to diagnostics and treatments.

In late summer 2022, IFFGD will again sponsor and coordinate a Virtual Advocacy Event. Patients, caregivers, and other members of the digestive health community will be invited to watch to learn about current research activities from invited Federal agency representatives and educate their legislators on Capitol Hill through calls and emails. Advocates will be informed on talking points related to Federal funding for NIH-sponsored research and will be encouraged to ask their Members of Congress to advance the following policy priorities:

- Provide increased funding to NIH and proportional funding increase to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for FY 2022,
- Support the Stimulating Peripheral Activity to Relieve Conditions (SPARC) initiative at the NIH,
- Support Gulf War Illness research at the DoD and VA, and
- Support the continuation of the new competitive program at the Centers for Disease Control and Prevention (CDC) to address public and professional awareness of chronic health conditions and GI illness.

Gastroparesis (GP)

In 2016 IFFGD designated August as Gastroparesis Awareness Month on the National Health Awareness Calendar

Click here ➡ ***Visit www.aboutGastroparesis.org***

Introduction

Gastroparesis (GP) is a condition of slowed stomach emptying with no intestinal blockage. Healthcare providers often refer to this as delayed gastric emptying. This is referred to as a motility disorder where the stomach does not empty food as quickly as it should. The results are often symptoms of nausea, vomiting, fullness, abdominal pain and weight loss amongst others. Motility describes the movement of food and fluids through the gastrointestinal (GI) tract. GP has a significant impact on GI tract motility and is a debilitating condition. The resulting symptoms with GP can vary from mild to severe and in some patients can be life-threatening due to secondary conditions such as malnutrition.

Subsets of Gastroparesis

There are three specific groups of gastroparesis causes, but many rare causes also exist.

Idiopathic Gastroparesis

This is the most common subset of gastroparesis. The term idiopathic simply means that there is no known cause of the disease. An average of 30% to 50% of patients with gastroparesis have a diagnosis of idiopathic gastroparesis. Certain infections such as viral infections, especially in kids, have been related to idiopathic causes of GP. Certain drugs can delay stomach emptying. Sometimes the potential cause is not found.

Diabetic Gastroparesis

Diabetes mellitus is a disorder in which the body does not produce enough or respond normally to insulin. Insulin is a hormone released by the pancreas that regulates blood sugar. This condition causes higher than normal levels of sugar in the blood. Diabetic GP occurs when slow emptying of the stomach occurs in people with diabetes.

About 25% of GP patients are diagnosed with diabetic gastroparesis. This can affect people with either type 1 or type 2 diabetes. In patients who develop diabetic GP, symptoms usually continue, even if sugar levels become controlled.

Post-surgical Gastroparesis

Post-surgical GP can occur when surgery changes the stomach. This can be through damage to nerves or the formation of scar tissue damage to the stomach. The vagus nerve, if damaged, is often believed to be the cause in patients who suffer from GP symptoms. The vagus nerve originates in the brain and extends to control major body organs such as the heart, lungs, upper GI tract, and other organs in the chest and abdomen.

Diagnosing Gastroparesis

Diagnosis of GP may begin with various tests. This will determine if there is anything preventing the stomach from emptying properly. These tests will find if the GP symptoms are caused by another condition. This may include imaging tests (such as CT scans or x-rays), and an upper endoscopy. An endoscope, a long flexible tube with a camera and light on the end, is used in an endoscopy. An endoscopy involves placing this tube in the mouth, down the esophagus, and into the stomach and duodenum. The duodenum is the first part of the small intestine. This tube has a camera and light on the end allowing the healthcare provider to see inside your GI tract and make sure an ulcer, cancer or other findings are not the reason for the symptoms being experienced.

Your healthcare provider will decide what test is right for you. This decision is based on the severity of your symptoms, any medications you take, availability of the tesing in your area, and other medical conditions you have. The following tests are commonly used in the diagnosis of GP. Drugs (medications) that are being taken should also be reviewed prior to testing as some of them may interfere with test results.

- *Gastric emptying scintigraphy* (GES) – GES involves eating a meal with a small amount of radioactive substance. This allows images to be taken during digestion, determining the rate of stomach emptying. The test can take between 2 and 4 hours to complete.
- *Wireless motility capsule* – This is a piece of equipment in the form of a pill. This pill is swallowed and then travels though the GI tract. Information is collected by wearing a receiver over 5 days that records the data. This test measures the amount of time the GI tract takes as it moves contents through the gut.
- *Gastric emptying breath test (GEBT)* – This test is performed using breath samples that are collected. To begin the test, the patient eats a meal that contains a nonradioactive ingredient. This allows the food to be tracked and measured in your breath over a few hours.

Treatment of Gastroparesis

Careful discussion between patients and their healthcare providers will help find the treatment options that are best for each person. Treatment may include one of more of the methods below but is not limited to these. Treatment of GP will vary from person to person. The table does not include all drugs available but can be used as a guide to help discuss treatment options with your healthcare provider.

Adapted from IFFGD Fact Sheet 565 written by Baharak Moshiree MD MSc and Mackenzie Jarvis PA-C, DMs, at Atrium Health In Charlotte NC, and Marissa Lombardi, IFFGD.

Click here ➡ ***Read Full Fact Sheet***

Drug	Brand name examples
Antiemetics	
Ondansetron	Zuplenz®, Zofran®
Trimethobenzamide	Tigan®
Promethazine	Phenergan®
Prochlorperazine	Compazine®
Granisetron	Kytril®
Proton Pump Inhibitors	
Pantoprazole	Protonix®
Rabeprazole	AcipHex®
Omeprazole	Prilosec OTC®, Zegerid OTC®, OmePPi®
Prokinetics	
Metoclopramide	Reglan®, Metozolv ODT®, Gimoti®
Erythromycin	Erythrocin®, EryPed®
Azithromycin	Zithromax®, Z-Pak®
Domperidone	Motilium®
Prucalopride	Motegrity®
Tegaserod	Zelnorm®
Bethanechol	Duvoid®, Urecholine®, Myotonachol®

Gastroparesis Symptoms

- Abdominal pain – dull to sharp pain in the upper stomach area that occurs inside the belly, often in the stomach or intestines.
- Nausea – a feeling of sickness felt in the abdomen, stomach, chest, or head that includes feeling the need to vomit.
- Vomiting – bringing food back up from the stomach into the mouth.
- Early satiety – feeling full after only a small amount of food.
- Reflux – a burning feeling in the esophagus. The esophagus is the tube that connects the mouth and stomach.
- Regurgitation – bringing contents up through the esophagus from the stomach.
- Losing weight without intentionally trying to.

GP symptoms can also lead to further health issues that lessen overall quality of life. People that experience nausea, abdominal pain, and early fullness are more likely to develop malnutrition. Malnutrition is when the body does not absorb enough nutrients including vitamins. Any combination of GP symptoms can have an impact on a patient's quality of life and lead to depression, difficulty sleeping, and impaired digestion due to a decreased ability to eat.

Constipation

Constipation is a common gastrointestinal symptom. It affects virtually everyone at some point in their life. Occasional constipation may result from changes in diet or from inactivity and will generally respond to simple lifestyle measures. However, constipation that is chronic (constant or long-lasting) or recurrent may indicate the need to see a healthcare provider for evaluation and treatment.

There is no single, generally accepted definition of constipation. The term "constipation" can refer to different things, such as

- having bowel movements that are hard and difficult to pass,
- having bowel movements less often than usual,
- feeling like you want to have a bowel movement, but cannot,
- feeling that you cannot empty your bowels completely.

Given the various possible definitions of constipation, it is hardly surprising that the reported prevalence of constipation is quite variable. Studies from North America show prevalence rates of 2–27%, with most estimates ranging from 12–19%.

Subtypes of Constipation

Irritable Bowel Syndrome with Constipation (IBS-C)
Irritable bowel syndrome, or IBS, is a common long-term condition that affects many people worldwide. The main symptoms are abdominal pain or discomfort along with changes in bowel habits. A change in bowel habits can be any change from what is normal for you, such as how often you have a bowel movement or what the bowel movement looks like (how watery or solid, its color, how much you expel at a time). Other symptoms may include feeling bloated, having a sense of urgency to run to the bathroom and gas. The abdominal discomfort or pain of IBS can be mild or severe. It might get better or worse if you have a bowel movement, are under stress, or eat certain foods. Or it might not change very much. The gas and bloating of IBS might cause you to pass gas often, or make you feel full in your belly. (See article on IBS, pages 22-23)

Click here ➡ ***Visit www.aboutIBS.org***

Chronic Constipation (CC)?
CC is a long-term bowel problem that affects how your digestive system works. The word chronic means long lasting. A chronic condition lasts for weeks, months, or longer. This is sometimes referred to as chronic idiopathic constipation (CIC) or functional constipation (FC) as well.

Chronic constipation lasts much longer than occasional constipation. You might get constipation when you travel, eat certain foods, or take certain medications. This is occasional constipation because it goes away when you go back to your regular routine.

The main causes of chronic constipation include:

- Problems with the nerves and muscles that control sensation in your lower intestine. This may cause a slow-moving digestive system. Healthcare providers call this "slow transit constipation."
- Problems with the nerves and muscles of the rectum, where your bowel movements leave the body. This is called "dyssynergic defecation (DD)."
- Sometimes, chronic constipation may be caused by getting too little fiber in your diet or needing more physical activity. It may also be caused by medication or by health conditions such as diabetes or an under active thyroid.

Opioid-Induced Constipation (OIC)
OIC is a condition where the medications you take affect how your digestive system works. Opioids are strong pain medicines that can slow bowel movements, causing fewer or more difficulty having a bowel movement than normal. Hence the term "opioid-induced" constipation.

Your healthcare provider might prescribe opioids if you have a condition that causes moderate to severe pain. Healthcare providers may prescribe opioids for pain from a procedure, such as surgery or dental work; an injury or accident; a chronic, or long-lasting, condition that causes pain; cancer or illness at the end of life. While opioids can treat pain effectively, they have known side effects. Between 50 and 80 percent of people who take opioid medicines have constipation.

Opioid-induced constipation can be so unpleasant that you stop taking the opioid medicines. But if they control your pain best, you might not get the pain relief that you need. If constipation becomes severe, your healthcare provider may prescribe medications such as pills, enemas, or suppositories to relieve it.

Click here ➡ ***Learn more about OIC***

How to manage constipation

The best treatment for constipation depends on what is causing it and how your body responds. Exercising and getting more fiber or making other dietary changes might work for you. Or you might need medication. Sometimes keeping track of what you eat and drink and of your bowel movements can help you to better understand what the cause of your constipation might be and if the treatments you are trying are helpful to you.

Click here ➡ ***IFFGD Fact Sheet 147 – Personal Daily Diary***

Your healthcare provider will probably recommend diet changes first. They might first ask what you eat each day and recommend changes. They might also ask you to work with a dietitian. This is a health care professional who specializes in diet and nutrition.

Click here ➡ ***IFFGD Dietitian Listing***

If you have constipation, the recommended treatments include adjusting your diet, fiber intake, and exercise level. If those do not relieve constipation, your healthcare provider is likely to recommend laxatives, and other medicines if laxatives do not work.

You may also have tests to check how your muscles are working when you have bowel movements, and you might work with a physical therapist.

Summary

Learning the cause of your constipation is an important factor in treating it or other conditions you may have that cause your constipation. Whether you have IBS-C, CC, OIC or DD, the right diagnosis helps you and your healthcare provider decide on effective treatment. Tell your provider if you have abdominal pain or discomfort and any sudden changes in bowel movements. They can recommend specific treatments. Working with your healthcare provider is the safest, most effective way to treat constipation and start feeling better.

IFFGD Websites for Information on Constipation

Visit AboutConstipation.org

Visit YouandConstipation.org

Visit AboutIBS.org

December is Constipation Awareness Month
In recognition of 2021 Constipation Awareness Month, IFFGD launched a campaign to educate people on what it is like to live with constipation — using the hashtag **#Understanding Constipation.**

Nancy and Bill Norton Patient Education Series

The mission of the Nancy and Bill Norton Patient Education Series (NES) is to help people who suffer from gastrointestinal (GI) disorders by providing them with practical, medically sound information. By engaging in this educational program, patients will have a greater understanding of living with chronic GI illness and how to better reach their treatment and wellness goals.

In 2020
The Nancy and Bill Norton Patient Education Series was launched

For individuals suffering with chronic illnesses, including chronic GI conditions, self-management interventions play an important role in reducing health care utilization and improving long-term health outcomes for patients. These interventions may include patient education, support for decision-making, self-monitoring of symptoms, adhering to treatment regimens, psychological and social support, and maintaining difficult lifestyle changes. The Nancy and Bill Norton Patient Education Series will provide patients with an educational program that equips them with tools and resources to better help them navigate life.

30th Anniversary Edition of the Norton Education Series

To commemorate IFFGD's 30th anniversary we hosted a very special virtual edition of the Nancy and Bill Norton Patient Education Series (NES). This event was a mix of pre-recorded videos and a live feed, taking place on November 6-7th in Charleston, SC. William Chey, MD chaired the Program Committee with Lin Chang, MD and John Pandolfino, MD serving as Co-Chairs. The Program Committee was joined by Ceciel Rooker, IFFGD President, in co-hosting the event.

This free, virtual two-day event included a keynote lecture, two medical education sessions and six open panel discussion sessions as well as bonus Pediatric Content.

Medical Education Session One: We began each morning with Medical Education Sessions. Day one included information on Pathophysiology and Diagnostics. We learned about the different parts of the gastrointestinal (GI) system and the diagnostic tests often performed when symptoms are present. The talks focused on symptom presentation (what is normal and when to be concerned) and what to expect from a diagnostic workup.

Medical Education Session Two: On day two, we learned about Treatment Options (both pharmacologic and surgical) for disorders within different portions of the gastrointestinal (GI) tract. Also included in this session was information on behavioral treatments, dietary interventions and complementary and alternative medicine for GI disorders.

Open Panel Discussion sessions included presentations from healthcare providers and patients, as well as recorded discussions between the speakers on the panel. There were six open panel discussion sessions covering the following topics: Short Bowel Syndrome (SBS) and Intestinal Failure, Irritable Bowel Syndrome (IBS), Bacteria in the GI Tract (SIBO & H. Pylori), Nausea and Vomiting, Constipation and Diarrhea, and Heartburn and Reflux.

Click here ➡ ***View 2021 Event Videos***

Click here ➡ ***Learn more about the April 2022 IBS Event in Chicago***

NORTON
EDUCATION SERIES

2022

Irritable Bowel Syndrome (IBS) Live Program



In collaboration with Northwestern University, Feinberg School of Medicine, IFFGD will be hosting an in-person Norton Education Series (NES) to help equip people with the tools they need to manage Irritable Bowel Syndrome (IBS).



Program Chair
Darren M. Brenner, MD

Topics to Discuss:

- The Epidemiology, Symptomology, and Strategy of Irritable Bowel Syndrome (IBS)
- Treatment Options for IBS-Mixed and IBS-Constipation
- Treatment Options for IBS-Diarrhea
- Food and IBS – How Can Working with a Dietitian Help?
- Why Should I Work with a Behavioral Therapist?
- Speaker Panel Discussion and Q & A

SCAN TO REGISTER

Email: iffgd@iffgd.org

SATURDAY, APRIL 23, 2022
10 AM - 3 PM

Location: Chicago, Illinois

Creating a Healthcare Team



The most important and proactive step that you can take in your health care journey is assembling a healthcare team, a team that will nourish and support all aspects of your health – with you at the center.

Having a chronic health condition can be exhausting. It is easy to feel overwhelmed. Don't worry so much about finding the 'best healthcare professionals'; instead, focus on finding the providers/practitioners who are best for you and the goals you want to reach.

As you build and choose your health care team, I encourage you to:

- Ask questions.
- Understand all aspects of your health condition.
- Listen to your body and trust your intuition.

When you explore your options, write down what you want to doand start making a plan that you can share with your potential team.

Think holistically

Health and wellness aren't only dependent on your physical state. It's easy to consider your healthcare team complete once you have established a relationship with your primary care provider or a specialist. However, western medical professionals alone are not equipped to address all aspects of their patients' health. Even if they wanted to, they would never have the time. These providers are key players on your health care team, and they are critical to your success. However, to tip the scales most in your favor, you'll need to focus on more than just western medicine treatments and protocols. Consider incorporating evidence-based practices and lifestyle modifications that will benefit all aspects of your health and well-being.

Complementary Medicine describes health care approaches that are not part of the traditional Western medicine system but are used together. Complementary therapies are practiced worldwide and are often rooted in alternative medical systems, such as Traditional Chinese Medicine, Ayurveda, and Naturopathy.

The potential benefits of complementary therapies are numerous. These therapies can enhance treatment effectiveness, relieve symptoms, reduce treatment side effects, improve well-being and quality of life. They can reduce pain, anxiety, and depression, relieve stress, enhance cognitive performance, enhance emotional well-being, and reduce inflammation.

Living with a gastrointestinal illness can cause additional stress in life. Stress is a normal emotional and psychological reaction to many things we encounter in our day-to-day lives, but don't underestimate its impact.

Chronic or ongoing stress can cause genuine mental, emotional, and physical problems. Chronic stress can depress our immune system, making us more susceptible to health problems. The good news is, by practicing stress management techniques, you can take control. Consider adding a therapist, social worker, a physical trainer, or a licensed acupuncturist to your team to help you control your stress.

For people living with gastrointestinal conditions, a dietitian may be the most critical team member. What we eat significantly influences our health – for better or for worse. I lived for decades with chronic bronchitis, not understanding I was allergic to milk. It's not just about how much you eat. The types of food you eat play a significant role in your dietary and nutritional health.

Build your team

Once you've learned more about your diagnosis, it is time to make your provider choices. It can be helpful to set up one-on-one consultations. A consult will help you get a better sense of whether you and a provider are a good match. Prepare for your consultation by making out a list of questions and the important qualities to you in a healthcare provider.

Qualifications

- Are you board certified or licensed in your field?
- What is your experience treating others with the same condition(s)?
- Can you provide me with any results or outcomes?

Treatment Style

- Do you like to tackle diseases like mine head-on, or do you typically take a more conservative 'wait and see' approach?
- Will you support integrative treatment approaches, such as complementary therapies and lifestyle modifications, to manage my condition(s)? (for your western medicine providers)
- Will you support my western medical treatment choices and help me manage my disease? (for your complementary and alternative providers)

Communication

- How can I communicate with you outside of appointment times?
- What is your availability?
- Who can I contact with any questions or problems I may experience?

My Team

- Do you have a dietitian/ nutritionist and physical therapist on staff? If not, will you refer me to one?
- Will you help me find a social worker/patient navigator to help guide me through treatment?

Second Opinion

- Will you help me find a healthcare provider to give me another opinion on the best treatment plan for me?

You might want to ask yourself: Did the provider use language I understand and take time to listen to my concerns and answer my questions? What was their communication style?

Choosing Providers and Insurance

A consult may or may not be covered by your insurance or healthcare plan, so ensure you are clear on the costs upfront. There are several factors to consider when choosing which healthcare providers you will include on your health care team.

- Does my insurance or health care plan cover you?
- Will you accept my health care plan?
- Which hospital (if any) do you work with?
- Does my insurance cover the hospital?
- Will I have a case manager to help with insurance questions?
- Will my insurance plan cover your dietitian/nutritionist or other nutrition services provided by your office?
- What should I expect for out-of-pocket costs?

Tips for your journey

- Western medicine truly excels in diagnosing, monitoring, and assessing disease state and progression by using diagnostics, such as laboratory tests and imaging scans. These tests are vitally important throughout your journey, providing objective, biological data on changes in a disease state. Results of these diagnostic tests may help you to understand what is working (and what isn't) in your health care plan and contribute to informed decision-making with your provider(s). Regardless of any other components you choose to include in your health care plan, use the diagnostics that Western medicine offers.
- It is essential to inform each of your healthcare providers about all the treatment approaches you are using.

As you build your health care team, include your support system as a member. No one needs to face a chronic health condition alone. When people with a chronic health condition seek and receive help from others, they often find it easier to cope. Developing and nurturing strong relationships is an important step in healing.

Through the choices that you make in the journey ahead, you have the power to tip the scales in favor of health, well-being, and healing. Don't let anyone convince you otherwise.

Lorren Sandt
Executive Director,
Caring Ambassadors Program
Lorren@CaringAmbassadors.org

Irritable Bowel Syndrome (IBS)

In 1997 IFFGD designated April as Irritable Bowel Syndrome (IBS) Awareness Month on the National Health Awareness Calendar

Click here ➡ *Visit www.aboutIBS.org*

Overview

Irritable bowel syndrome (IBS) affects up 10% of individuals worldwide. IBS affects children and adults of both genders. Although IBS does not shorten a person's life span, it is associated with a large health care and economic burden. Studies have shown that IBS patients have an increased number of health care visits, diagnostic tests, and surgeries. IBS can also severely impact a person's quality of life.

For most, IBS is best understood as a long-term condition in which patients experience reoccurring issues with abdominal pain or discomfort which is associated with their bowel movements. Some patients with IBS, particularly those whose problems started after food poisoning or traveler's diarrhea (post-infectious IBS) can gradually get better over time. Others will have IBS for their entire lives.

Subtypes of IBS

IBS is often categorized based on the most common type of bowel movements experienced. These groups include:

- Irritable bowel syndrome with diarrhea (IBS-D) – symptoms of diarrhea occur most often
- Irritable bowel syndrome with constipation (IBS-C) – symptoms of constipation occur most often
- Irritable bowel syndrome mixed (IBS-M) – symptoms of both constipation and diarrhea occur

Identifying the subgroup of IBS is helpful when deciding which tests and/or treatments are best. The severity of the symptoms should also be considered. Grouping IBS patients by their bowel movement habits is also useful for researchers who are trying to better understand what causes or the best way to care for patients with IBS.

Diagnosing IBS

The medical evaluation of people with suspected IBS can vary a lot between patients. It depends on symptom presentation, age, and overall health of the person as well as the health care practices of the healthcare provider. Generally, the healthcare provider will have a detailed discussion with the patient, do a physical examination and possibly suggest some medical testing to rule out any other possible causes for the symptoms.

There is a collection of symptoms that healthcare providers use to make sure something other than IBS is not causing symptoms. They are often called "Alarm signs" or "Alarm Symptoms". These features include:

- Blood in bowel movements – This blood can be bright red to black in color and may be in or around bowel movements.
- Low blood counts (anemia) – This is determined by blood work or lab tests ordered by a healthcare provider.
- New onset of symptoms over the age of 50.
- Losing weight without trying.
- Diarrhea that wakes you up from sleep at night.
- A family history of IBD, colon cancer, or celiac disease.

These alarm signs are usually not explained by IBS and can represent other medical problems. When these signs and symptoms occur, they should be brought to the attention of a healthcare provider to perform additional tests.

Importantly, even if another diagnosis is made, it may exist along with a diagnosis of IBS. The patient and healthcare provider will then need to decide how to manage coexisting conditions.

Treating IBS

The first line of treatment for IBS includes general measures such as:

- Implementing diet and lifestyle changes, which may be associated with symptoms
- Introducing medications to help manage symptoms
- Establishing an effective relationship between the patient and their healthcare provider
- Obtaining education about IBS

Diet changes

Persons with IBS should consider whether their symptoms are related to what they eat and/or drink. If certain foods trigger or worsen symptoms, reducing or avoiding them can sometimes help. For some patients with symptoms after eating, it may be helpful to eat smaller, more frequent meals.

Click here ➡ *IFFGD Dietitian Listing*

General dietary recommendations include:

- Eating regular meals at a slower pace
- Eating until feeling full and not more
- Drinking at least 8 cups of fluid per day
- Limiting intake of tea and coffee to 2 cups per day
- Reducing intake of alcohol and carbonated or sugary drinks
- Avoiding garlic and onions and any other foods that consistently trigger symptoms

Lifestyle changes

Increased stress may result in the onset or worsening of IBS symptoms and associated non-bowel symptoms such as fatigue or low energy. Proper rest and exercise can help reduce stress levels and positively influence IBS symptoms. Dealing with IBS symptoms is stressful. Learning more about the disorder, communicating effectively with your healthcare provider, and taking a more proactive role in your self-care can reduce that stress and improve control over symptoms.

Medications

If diet and lifestyle changes do not completely relieve IBS symptoms, medications may be helpful. From the start, medications developed for IBS have been created to improve either constipation or diarrhea. However, with increasing knowledge of the causes of IBS we have been able to develop treatments that improve the pain and/or discomfort as well.

Click here ➡ *IFFGD Fact Sheet 168 - Current Pharmacologic Treatments for Adults with Irritable Bowel Syndrome*

Regardless of the treatment selected, it should always be discussed thoroughly between the healthcare provider and the patient.

This helps those with IBS to

- Understand the treatment and why it is being used,
- Be aware of any alternatives if available,
- Understand the risks as well as benefits of the treatment,
- Know what to do if side effects occur or symptoms return.

Adapted from IFFGD Fact Sheet 101 by Lin Chang MD and Douglas Drossman MD.

Click here ➡ *Read Full Fact Sheet*

Symptoms of IBS

Experiencing abdominal pain and/or discomfort with a change in bowel habits is the key symptom of IBS. A change in bowel habits can be any change from what is normal for you, such as how often you have a bowel movement or what the bowel movement looks like (how watery or solid, its color, how much you expel at a time). The pain and/or discomfort is often relieved by having a bowel movement but at times can worsen.

Other common symptoms of IBS can include bloating (a sensation of fullness in the belly), urgency (the need to rush to have a bowel movement), mucus (thick white or yellow liquid) in the stool, and the feeling of incompletely emptying after a bowel movement.

Symptoms can change over time. There can be periods when symptoms get worse as well as periods when symptoms lessen or disappear. In addition, the main type of bowel movements experienced may change over time. For example, some people who suffer mainly from constipation (or diarrhea) may later experience a change to the opposite or develop a mixture of both constipation and diarrhea. Sometimes changes in diet, behavior, or using over the counter remedies or prescription drugs can lead to such changes. Other times, a cause for the change is not known.

Participate in Research

Medicine traces its roots to Hippocrates, a 5th Century BC healer and author of observations such as "above all do no harm" that underpin much of the medical profession's ethical philosophy. During the Age of Enlightenment, physicians, through observation and experiment made discoveries that slowly produced a rational basis for treating and preventing disease.

Early discoveries underlie modern medical treatments. In the nineteenth century, healthcare providers noticed that through hand washing between patients and after surgery the spread of disease was prevented, and this began modern infection control. This and other observations changed the practice of medicine from one rooted in superstition and tradition to a discipline that applied the sciences of anatomy, physiology, bacteriology, and biochemistry.

Despite these advances, there was little progress in the evaluation of medical treatments prior to World War II. Dramatic cures such as the accidental discovery of penicillin and insulin required no research studies. However, this limited the progress of medicine to "accidents" until the development of the Randomized Controlled Trials (RCTs) we have today.

What is a Randomized Control Trial (RCT)?

The full term is randomized, placebo-controlled, double-blind clinical trial. Its central features are that everyone in the research study must have a similar illness and either receive the treatment or procedure being tested or an alternative. This may be a placebo (substance or treatment which is designed to have no therapeutic value) or an actual alternative treatment. The measure of treatment success must be decided in advance; and all the study participants are unaware (blinded) as to whether they are receiving the test treatment or the placebo.

Randomization means that the study patients are randomly selected for exposure to the treatment or the placebo so there is little possibility that the two groups of patients differ in age, sex distribution, or other possible bias. *Placebo-controlled* means that the drug's effect is compared to that of the placebo. To prove effectiveness, the drug must demonstrate statistically better outcomes than the placebo. *Double-blind* implies that neither patient nor treating physician knows whether a treatment or placebo is used.

Click here ➡ ***Learn more about RCTs***

How to get Involved in research?

Clinical studies and/or trials are an important way to learn more about gastrointestinal (GI) illnesses and help find better treatment options. Participation in this type of research offers one way for you to help advance the knowledge of gastrointestinal (GI) disorders.

Click here ➡ ***Learn about current research studies you can participate in***

In 2002 IFFGD published its first research survey

IFFGD Research Awards

IFFGD first offered Research Awards in 2003 and Research Grants in 2007. To date, we have presented forty-five Research Awards or Grants to researchers from around the world.

In 2003 IFFGD presented their first Research Awards

IFFGD Research Awards recognize the accomplishments of investigators who are engaged in significant research in the field of gastrointestinal (GI) disease. Our intent is to encourage the participation of clinicians and scientists in multidisciplinary efforts aimed at advancing the understanding of GI disorders in adults and in children that can ultimately lead to better treatments and cures.

IFFGD Research Grants provide funding for research relevant to understanding and managing gastrointestinal (GI) disorders. Our goal is to support high-quality research that will ultimately lead to improvements in the care of patients with these disorders.

Click here ➡ ***Learn about IFFGD's Research Awards and Grants***

Generally, IFFGD awards competitive research grants when they have raised funds for this designated purpose. Monies for research grants may come from a fundraising event, specific donations from the community or from an industry partner. These grants follow a procedure in which applications are reviewed and scored by a selection committee, which is independent of IFFGD staff. The availability of these grants is announced to the research community through multiple channels.

In August 2021, IFFGD hosted a Virtual Walk "Make Moves for GI Health" to raise funds to support a research grant. With over 100 participants and industry support we were able to secure over $30, 000 from this event which occurred between August 21st through September 4th. We are grateful to all who participated and are beginning to plan a similar event for 2022.

Click here ➡ ***To learn more about the "Make Moves for GI Health" virtual walk***

Click here ➡ ***Visit IFFGD YouTube channel to see where previous IFFGD Research winners are today***

The Need for More Research – How You Can Help

IFFGD participates in and encourages support of scientific research. Although the need has been demonstrated, functional GI, motility and rare GI disorders research remains severely underfunded. There are a growing number of clinicians and investigators who are striving to learn more about these disorders. They need research funding. You can help. Working together, we can change the way these disorders are viewed, managed and treated.

Click here ➡ ***To learn about the need for funding research and how to make a difference***

Ambassador Program

The IFFGD Ambassador Program was created to increase awareness of IFFGD's mission among healthcare providers outside of the United States. In 2019, a pilot program was launched in conjunction with the Latin American Society for Pediatric Gastroenterology, Hepatology & Nutrition (LASPHGAN) and North American Society for Pediatric Gastroenterology, Hepatology & Nutrition (NASPHGAN) for pediatric gastroenterologists in Latin America.

The Latin Ambassador program is currently being overseen by Dr. Miguel Saps in collaboration with Drs. Jose Garza, Samuel Nurko, Leonel Rodriguez and Reinaldo Pierre Alvarez (LASPHGAN President). The primary responsibilities of the Ambassadors are to give lectures on functional gastrointestinal and motility disorders (FGIDs) for pediatrics and distribute information about IFFGD and the resources we have for patients. The committee appoints one Ambassador per country every 2 years.

2019 Latin Ambassadors

- Dra. María Francisca Jaime, Pediatric Gastroenterologist at Clínica Alemana De Santiago, Chile.
- Dr. Mauro Batista De Morais, Full Professor of Pediatric Gastroenterology, Paulista School of Medicine / Federal University of São Paulo, Brazil.
- Dr. Juan Francisco Rivera-Medina, Pediatrician in Gastroenterology, Hepatology and Nutrition National Children's Health Unit Institute in Lima, Peru.
- Dr. Carlos Velasco, Professor, Department of Pediatrics at the Universidad del Valle in Cali, Colombia.
- Dr. Edgar Játiva Mariño MSc. PhD(c), Doctor in Medicine and Surgery, Specialist in Pediatrics, Professor of the Central University of Ecuador.

2021 Latin Ambassadors

- Dr. Ricardo Ariel Chanis, Assistant Clinical Professor Department of Pediatrics. Faculty of Medicine of the University of Panama Aguila, Panama
- Dr. Fernando Alonso Medina, Pediatric Gastroenterologist, Monroy, Colombia
- Dr. Roman Nestor Bigliardi, Head of pediatric gastroenterology, University of Buenos Aires
- Dr. Rodrigo Vazquez Frias, Professor of Pediatrics, National Autonomous University of Mexico

Spanish Resources

IFFGD Latam Twitter and Facebook accounts have been created to increase awareness about the program. The social media accounts help to share Spanish summaries of important articles, information about events, and to get connected to other societies, local family healthcare providers, pediatric residents, and local patient associations. In conjunction with this program, a Spanish translation of the IFFGD website with information on pediatric GI disorders, www.AboutKidsGI.org has been launched as www.losninosygi.org.

Click here ➡ ***Learn about IFFGD's Ambassador Program***

Click here ➡ ***Visit www.losninosygi.org***

Junior Academicians

IFFGD created the Junior Academicians (JA) program to engage junior clinicians and researchers to increase interest in functional GI and motility disorders, as well as underserved or rare GI diseases. The goal of this program is to help raise awareness of these gastrointestinal disorders as well as the resources IFFGD has for the community. This program also helps to develop the thought leaders for the future.

As new IFFGD projects arise, junior academicians serve on project committees with experts in the field. This provides opportunity for their career enhancement as well as builds a strong resource community for the future. Additionally, IFFGD shares information on research funding opportunities with this group. IFFGD also utilizes this group of leaders for the development of future program ideas.

The Junior Academician Program is currently being overseen by Drs. Baha Moshiree, Linda Nguyen, Ali Rezaie, Darren Brenner, and Arthur Beyder.

2021 IFFGD Junior Academicians

Dilpesh Agarwal, Medical College of Wisconsin

Nitin Ahuja, Univ of Pennsylvania

Cara Axelrod, Nova Southeastern University

Kenneth Barshop, Massachusetts General Hospital

Justin Brandler, Michigan Medicine

Helen Burton, Massachusetts General Hospital

Daniel Bushyhead, Houston Methodist Hospital

David Cangemi, Mayo Clinic

Soojong Hong Chae, Univ of South Florida

Walter Chan, Harvard Medical School

Bianca Chang, Cedars-Sinai, LA

Victor Chedid, Mayo Clinic

Austin Chiang, Thomas Jefferson University

Bruno Chumpitazi, Baylor College

Ann Davis, Univ of Kansas

Francis Edeani, Medical College of Wisconsin

Jeanetta Frye, Univ of Virginia

Amanda Glinky, Children's Hospital of New Orleans

Kimberly Harer, Michigan Medicine

John Hollier, Baylor College of Medicine

Kayla Hopkins, Atrium Health

Mackenzie Jarvis, Atrium Health

Lisa Jones, Univ of Wisconsin

Gorav Kalra, Univ of Seattle

Kendra Kamp, Univ of Washington

Su Bin Kim, Cleveland Clinic

Michael Kingsley, VA and U Pitt

David Kunkel, Univ of California

Muriel Larauche, UCLA

Allen Lee, University of Michigan

Lisa Lin, UCLA

Joy Liu, Northwestern University

Alejandro Llanos-Chea, Univ of Miami

Ling Mei, Froedtert Hospital

Stacy Menees, Michigan Medicine

Mulugeta Million, UCLA

Sarvee Moosavi, Univ of British Columbia

Johanna C. Iturrino Moreda, Harvard Medical School

Judy Nee, Harvard Medical School

Leila Neshatian, Stanford

Borko Nojkov, Univ of Michigan

Colleen Parker, Univ of Toronto

Dan Patel, Vanderbilt University

Alice Jiang Van Pelt, Rush Univ

Michael Potter, John Hunter Hospital

Neha Santucci, Cincinnati Children's Hospital

Patrick Sanvanson, Medical College of Wisconsin

Eric Shah, Michigan Medicine

LeAnne Sherwin, Univ of Missouri

Kyle Staller, Harvard Medical School

Andrew Su, UCLA

Elyse Thakur, Atrium Health

Dipesh Vasant, Manchester Univ

Chris Velez, Massachusetts General Hospital

Priya Vijayvargiya, Mayo Clinic

Xiao Jing Wang, Mayo Clinic

Shamaila Waseem, Indiana Univ

Jennifer Wellington, Univ of Maryland

Click here ➡ ***Learn about more about IFFGD JAs***

Diet and GI Health

The influence of diet is unique to each person. There is no generalized dietary advice that will work for everyone. During your appointment with your healthcare provider, they may take a brief dietary history to help identify dietary and/or other factors that may impact symptoms. You can also keep a diary for 2–3 weeks of dietary intake, symptoms, and any associated factors (like daily obligations, stressors, poor sleep, medications) to share with them.

Healthcare providers and patients need to talk about diet. Guidance needs to be provided by a knowledgeable healthcare professional (like a healthcare provider or registered dietitian). They can assess individual circumstances affecting gastrointestinal (GI) illness(s), while helping make sure that nutritional needs are being met through a balanced diet, and healthy eating habits.

In line with our mission, to inform, assist, and support people affected by gastrointestinal (GI) disorders, IFFGD strives to add resources that are valuable to patients. With the growing need for diet and nutritional support and education for patients with gastrointestinal disorders, we created a dietitian listing. These healthcare providers work specifically with patients with GI disorders in the areas of diet and nutrition. We have over 100 professionals that can be searched by GI disorder and geographic location. Specifics such as insurance requirements, telehealth appointment options, and contact information are provided.

Click here ➡ ***IFFGD Fact Sheet 147 – Personal Daily Diary***

Click here ➡ ***IFFGD Dietitian Listing***

How to build your smoothie in your blender

To help your smoothies blend easier and prolong the life of your blender, you should remember to place liquids on the bottom, followed by sweeteners and/or protein powders. Any leafy greens should be placed in next; followed by soft ingredients such as yogurt or nut butters. The last two ingredients to go into the blender are fresh fruits, whole nuts/seeds and then finally anything frozen such as ice or frozen fruit.



Tips:

- Change things up and use different fruits such as pineapple, mango, papaya or peaches
- Almond milk may be used in place of kefir if desired.
- Cut up whole fruit and freeze extra to keep it from going bad. Allow to thaw prior to blending for best results.
- If desired, add 1-2 tsp pure maple syrup for added sweetness

Gut Friendly Recipes

Quinoa Tabbouleh Salad



- 1 cup quinoa, rinsed well
- a pinch of salt, or as desired
- 1 medium lemon, juiced
- 1/3 cup olive oil, infused with garlic
- 1 large cucumber, preferably English, diced
- 1 pint cherry tomatoes, cut into quarters
- 2 medium carrots, grated
- 1 cup parsley, preferably Italian parsley
- 1/2 cup mint, chopped
- 3 bunches scallions, thinly sliced green tops only

Preparation:

1. Bring quinoa and 2 cups of water to boil in a medium saucepan over high heat. Reduce heat to a simmer, cover and cook until most of water is absorbed, about 8 to 10 minutes. Turn off heat and let quinoa rest, covered, for 15 minutes. Fluff with fork. Allow quinoa to cool to room temperature.

2. In a small bowl, whisk lemon juice and garlic infused olive oil. Season dressing as desired with salt and pepper.

3. Combine cucumber, tomatoes, carrots, herbs and scallions in a large bowl, add cooled quinoa and dressing to bowl and stir until combined. Season as desired with salt and pepper.

4. Chill in refrigerator.

Smoothie Recipes

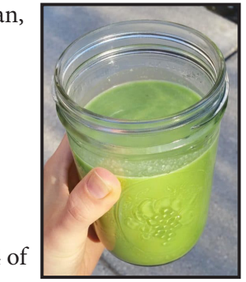
Constipation Smoothie Recipe



- 1/3 cup aloe vera juice
- 1 peeled kiwi fruit
- ½ cup papaya
- ½ cup kefir, plain or vanilla
- ½ cup ice

Banana-pineapple Green Smoothie

This delicious smoothie is vegan, gluten free and made of low-FODMAP ingredients.



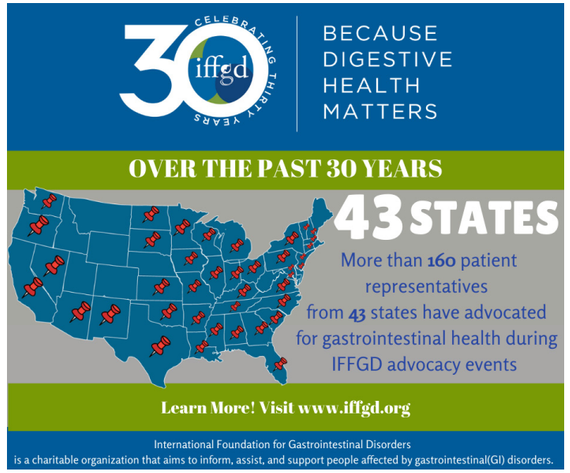
- ½ ripe banana
- ¼ cup frozen pineapple
- 1 cup, loosely packed, spinach
- 1 peeled lemon wedge (1/4 of a lemon)
- 1/2 tablespoon natural peanut butter
- 1/8 teaspoon (or a few dashes) of ground ginger
- 3-4 ice cubes

Four-fruit Chocolate Smoothie



- 2 bananas
- 2 clementines
- 6 frozen cherries
- 8 frozen raspberries
- 1 cup almond milk, unsweetened, can add more or less based on your consistency preference
- 2 scoops Vegan protein, chocolate

IFFGD and Advocacy



Key Legislative Priorities

Each year, IFFGD sets forth its legislative priorities and works with legislators in Washington, D.C. to advance policies that impact the study and treatment of chronic gastrointestinal (GI) diseases. These policies are aimed at expanding and improving GI disease research, patient access to care, and prevention and public awareness of GI conditions.

Research

IFFGD continually encourages sustained and increased funding for the National Institutes of Health (NIH) with each fiscal year. Strengthening the nation's biomedical research enterprise through NIH fosters economic growth and sustains innovations that enhance the health and well-being of the American people. It is vitally important to also ensure proportional funding increases for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which supports basic, clinical, and translational research on aspects of gut physiology regulating motility and clinical trials through the Motility and Functional GI Disorders Program. Gulf War Illness research at the Department of Defense (DoD) and the Department of Veterans Affairs (VA) is important for the GI community. The DoD Gulf War Illness Research Program (GWIRP) and the VA Gulf War Research Program allow talented researchers to work at finding the reasons behind this high prevalence and seek ways to reduce these challenges during future conflicts.

Patient Access to Treatments

IFFGD regularly advocates on the importance of limiting patient out-of-pocket costs and curbing current and future payer tactics to shift costs onto patients. Many patients face financial barriers to obtaining quality care and innovative treatments. IFFGD supports policy and regulations that facilitate patient access to care by strengthening the patient-provider decision-making relationship, limiting patient out-of-pocket spending, and curbing cost-shifting practices by third-party payers, including step therapy, and non-medical switching.

Education and Awareness

Improving education and awareness is a key focus of IFFGD both in advocacy and general resources. The Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC) is a key avenue for improving education and awareness through advocacy. A CDC program focused on surveillance, provider education, and public awareness would increase diagnoses and improve patient outcomes.

Coalition Involvement

The Digestive Disease National Coalition (DDNC) serves as the national voice of the digestive health community by bringing patient organizations, physician societies, and industry partners together around issues of common interest. The DDNC actively works to shape health policy through sustained advocacy and outreach and hosts a two-day public policy forum on Capitol Hill each year.

The functional GI and motility disorders patient community is well represented by the DDNC as IFFGD co-Founder Nancy Norton served as the DDNC's Chairperson for several years and President, Ceciel Rooker, is currently Chairperson for the DDNC.

IFFGD's Leadership with the NIDDK

In October 2001, Nancy Norton was appointed by the NIH Director to a 4-year term on the National Diabetes and Digestive and Kidney Diseases Advisory Council, the advisory body of NIH's National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). In 2020, IFFGD's current President, Ceciel Rooker, was also appointed to this prominent position. This council serves to advise NIDDK about its research portfolio, and to take second-level peer review of research grant applications that have been scored by initial review groups. Council members also serve as liaisons between the research communities they represent and the NIDDK.

Comments and Testimony to Government Agencies

Each fiscal year (FY), Congress decides how much funding to provide federally supported medical research initiatives, what areas of research should be prioritized, and how much funding should be committed towards new drug approval and the monitoring of current treatment options. Whenever appropriate, IFFGD offers testimony, either written or in person before members of Congress, which expresses the needs of functional GI and motility disorder patients and urges additional resources for NIH and FDA.

As part of our continual presence in Washington, DC, and around the United States, whenever appropriate IFFGD offers testimony to the FDA, HHS, and other regulatory agencies. This type of testimony is typically in response to requests for comments posted by agencies within the Federal Register. Through either written or in-person statements, we share the perspective of GI and motility disorder patients. IFFGD urges the consideration of the patient perspective in regulatory decisions and encourages the development of additional resources to help meet their needs.

In 1995 first congressional testimony was submitted by IFFGD

In 2011 IFFGD gave testimony to the US Senate about impacts of GI disorders on veterans

IFFGD's Founding Roots in Advocacy

IFFGD's Founders, Nancy and Bill Norton, have been prominent advocates for the study and treatment of gastrointestinal disorders. Since 1991, they have worked to present the perspective of patients and their needs to the healthcare community.

On behalf of IFFGD, they organized the biennial International Symposium on Functional Gastrointestinal Disorders, a forum for international experts. Over the years they provided testimony to various U.S. Senate and House of Representatives Subcommittees as well as to many federal agencies. Ms. Norton has also been a member in several prominent professional societies, providing a voice on behalf of patients.



Bill Norton testifies before House Appropriations Committee.

United States Federal Agencies

Highlights of GI Research and Regulations within US Government Agencies

The Department of Health and Human Services (HHS) is the U.S. Government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. Their mission is "to enhance the health and well-being of all Americans, by providing for effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services."

The National Institutes of Health (NIH) is a division of HHS. The NIH began in 1887 as a laboratory in New York. Today, the NIH is the focal point for Federal health research. The agency seeks to encourage and support innovative research to protect and improve the health and quality of life for Americans. The NIH works hard to improve research into gastrointestinal (GI) and motility disorders and continues to develop and expand in these areas.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) within the NIH focuses much of their research efforts on GI conditions. As the NIDDK is allotted more research funding, they continue to expand on research through the Motility & Functional Gastrointestinal Disorders Research Program. This program directly improves research for irritable bowel syndrome (IBS), gastroparesis, functional dyspepsia, colonic diverticular disease, swallowing disorders, and gastroesophageal reflux (GERD), among many others.

The Genetic and Rare Diseases Information Center (GARD) is a program of the National Center of Advancing Translational Sciences (NCATS) within the NIH. GARD provides information and resources for those impacted by genetic and rare diseases. GARD works to provide open access to information that is reliable, current, and understandable.

The U.S. Food and Drug Administration (FDA) is another agency within the HHS. They are responsible for protecting the public health by ensuring the safety, efficacy, and security of human and veterinary drugs, biological products, and medical devices; and by ensuring the safety of our nation's food supply, cosmetics, and products that emit radiation.

The Centers for Disease Control and Prevention (CDC) has been using science-based, services to protect public health for over 70 years. Research through the CDC provides science and advanced technology to aid in disease prevention. The CDC has established the Chronic Diseases Education and Awareness Program to improve the lives of those impacted by chronic conditions, including those of the GI tract. This CDC program is focused on surveillance, provider education, and public awareness to increase accurate diagnoses and improve patient outcomes.

The Department of Defense (DoD) conducts important research into medical conditions that impact veterans and active-duty military personnel through its Congressionally Directed Medical Research Program (CDMRP). This program provides significant research into GI disorders. The DoD Gulf War Illness Research Program (GWIRP) allows researchers to work at finding the reasons behind the high prevalence of GI conditions in military service members.

The Department of Veterans Affairs (VA) has a research portfolio that includes GI illnesses impacting Veterans. Between 25-32% of Gulf War veterans continue to experience symptoms associated with their deployment. The Gulf War Research Program allows researchers to work at finding the reasons behind this high prevalence and seek ways to reduce these challenges in the future. The VA also has ongoing research into other GI conditions such as GERD, colon cancer, and C. difficile infections (C-Dif).

Raising Awareness

In 1999
IFFGD released the first nationally televised public service announcement on IBS with CNN

Why Raise Awareness

According to the National Institutes of Health (NIH), approximately 60 to 70 million people are affected by digestive disorders. Public awareness is critical to increase knowledge, advance research, and improve care for people affected by functional gastrointestinal and motility disorders. Raising awareness often translates into larger federal investments in research activities and a stronger commitment from industry to develop new treatment options.

One way IFFGD has helped to raise awareness is by sponsoring events on the National Health Observances Calendar.

In 1997, IFFGD sponsored April as IBS Awareness Month. Up to 45 million people living in the United States suffer from irritable bowel syndrome (IBS). Each year, IFFGD joins patients, family members, and caregivers to increase public awareness about IBS and help to educate the public. The theme for IBS Awareness Month 2021 was "IBS Education" using special messaging and images alsong with the hashtag #IBSeducation.

Click here ➡ ***2021 IBS Awareness Month toolkit***

In 2009, IFFGD sponsored the week of Thanksgiving as GERD Awareness Week. 1 in 5 people suffer from gastroesophageal reflux disease (GERD) in the United States and close to 5 million people are admitted into the hospital each year for chest pains associated with GERD. In recognition of 2021 GERD Awareness Week, IFFGD launched a campaign to acknowledge what it is like to live with GERD day to day — using the hashtag #LivingWithGERD.

Click here ➡ ***2021 GERD Awareness Week toolkit***

In 2016, IFFGD sponsored August as Gastroparesis Awareness Month. In recent studies, gastroparesis, a chronic gastrointestinal (GI) disorder, is estimated to affect 5 million individuals in the United States. This year, in recognition of Gastroparesis Awareness Month, IFFGD will launch a campaign which acknowledges the quality of life for patients and patient story — using the official hashtag #ThisIsGP.

Click here ➡ ***2021 Gastroparesis Awareness Month toolkit***

December is Constipation Awareness Month. For millions of Americans, constipation is not something that just goes away. Chronic constipation affects up to 20% of adults and 16% of children in the United States alone. In recognition of 2021 Constipation Awareness Month, IFFGD launched a campaign to acknowledge how constipation effect each individual different and the impacts on a person's quality of life — using the hashtag #UnderstandingConstipation.

Click here ➡ ***2021 Constipation Awareness Month toolkit***

During each awareness event, IFFGD focuses on important health messages about diagnosis, treatment, and quality of life issues. The goals include improving the understanding of gastrointestinal disorders, helping patients and families manage these conditions, and encouraging preventive strategies. You can help spread the word by downloading and sharing IFFGD's Social Media Toolkit a month before each awareness event. Visit, www.iffgd.org, for IFFGD resources during awareness events.

Acknowledgments

The governing body (Board of Directors) of International Foundation for Gastrointestinal Disorders (IFFGD) is representative of the general public we serve and includes healthcare professionals from various disciplines related to digestive health and incontinence, as well as non-medical professionals from legal and business fields.

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IFFGD Industry Council

In 1998, to enhance the interaction between the gastrointesinaal illness community, the clinicians who care for them and the companies that provide the diagnostics, pharmaceuticals and other products used in their care, we formed the IFFGD Industry Council. The Council facilitates communication between IFFGD and the member companies and ensures that the voice of our patients is heard.

We invite participation from companies with a demonstrated interest in these disorders. *Note that while we are grateful to our Industry Council supporters, we do not endorse any specific product or company.*

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International Foundation for Gastrointestinal Disorders

Our mission is to inform, assist, and support people affected by gastrointestinal (GI) disorders.

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