



DigestiveHealth Matters

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Happy Tummies, Happy Holidays

Compiled by: IFFGD Staff, the International Foundation for Functional Gastrointestinal Disorders (IFFGD), Milwaukee, WI

Extra helpings of travel, food, and stress make the holidays a trying time of year for everyone, especially if you have a digestive disorder. In this article we revisit suggestions for how to make your holidays less likely to lead to digestive upset.

Healthy Thinking During the Holidays

Everyday life is challenging enough if you suffer from a digestive disorder. Add the obligations, food focus, and travel issues associated with the holiday season, and it can be easy to feel anxious and overwhelmed. Barbara Bradley Bolen, Ph.D., offers suggestions for reducing the impact during the holidays.

Practice active self-care. These skills will help you to keep your focus on you own well-being rather than getting caught up with all of the tasks that this time of year seems to require:

- Plan ahead – It can reduce stress. What will you need to feel most comfortable? How would you handle needing to leave a function early if you don't feel well.
- Practice relaxation exercises – Relaxing your body is helpful in managing symptoms.
- Practice kind and gentle feeding – Eat small meals during the day and stick to foods you know are safe.
- Remind yourself that you do not have to do it all and that it is okay to take a pass on perceived obligations.

Travel Tips with Bowel Disorders

Travel can be very difficult for many people with irritable bowel syndrome (IBS) or other bowel disorders who fear they may not be able to control their symptoms when away from home. If you are one of these people, here are some travel tips designed to help you avoid or manage symptoms and help create a sense of being more in control when traveling.

- Allow enough time to get to the airport on time without worry. When traveling to and from your destination, bring an extra bag with a change of clothes in the event that your luggage is lost.
- Carry a “survival kit” with you. Choose something you are comfortable with, such as a computer bag, briefcase, large purse, or backpack. Throughout your trip, always have a change of clothes with you, and bring a small supply of tissue in case there's none available when you are out.
- Traveling by plane can be difficult for those who suffer from unpredictable symptoms. Ask to sit as close to a restroom as possible. Also, sit on an aisle for easy and fast access so you will not have to ask others to move.
- If you use a medication, divide it into two containers; keep one in your hotel room and one with you at all times.
- Avoid foods and beverages that you know can aggravate your symptoms.

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This Holiday Season, give a gift to help raise critical awareness about the medical needs and challenges faced by those with a chronic digestive disorder and help us move towards a better future for all affected.

Give the gift of digestive health at www.iffgd.org/make-a-donation

Happy Tummies, Happy Holidays

- If you are making a long drive to get to and from your destination, know how much distance there is between rest areas or highway exits with available restrooms. Map your walking and driving routes ahead of time and determine how to get from point A to point B as quickly and directly as possible.

Travel Tips with Gastroparesis

Crystal Zaborowski Saltrelli, C.H.C., offers suggestions for traveling with gastroparesis that make it possible to enjoy time away with family and friends without compromising symptom management.

Before You Go

- Be sure to take your needs into account when making travel arrangements.
- Keep a list of gastroparesis-friendly foods that you know you can safely eat.

Travel Day

- Regardless of how you're traveling, bring your own food and pack twice as much as you think you'll need.

Delays are unpredictable and you can never be sure to find gastroparesis-friendly options along the way.

- You may find that you're more prone to motion sickness than you were prior to having gastroparesis. Have a variety of nausea remedies on hand, just in case.

Once You Arrive

- Continue to follow your regular schedule, both in terms of diet and lifestyle activities. For example, if you typically exercise in the morning, plan that into your daily routine.
- Maximize nutrition in every bite you take. This is not the time to consume empty foods that fill you up without providing any nutrients. Without proper nutrition, you're less likely to have the energy to fully enjoy your trip.

Tips for Avoiding Holiday Heartburn

- Don't lie down within 3 hours of eating. That's when acid production is at its peak, so schedule an earlier meal and avoid bedtime snacks.

- Be extra cautious around the holiday foods that most commonly aggravate symptoms: chocolate, caffeine, onions, fried or fatty foods, alcoholic beverages and even peppermint may cause reflux.

- Serve light appetizers. Fatty foods like chips, dips, and cheeses are slow to empty from the stomach and more likely to aggravate symptoms.

- Stay active. Stick with your exercise routine during the holidays, as weight loss can help alleviate symptoms of gastroesophageal reflux disease (GERD).

- Slow down. Physical exertion after a meal can lead to reflux.

All of us at IFFGD wish you a happy holiday season this year!

Adapted from IFFGD Publications by Barbara Bradley Bolen, Ph.D., Crystal Zaborowski Saltrelli, C.H.C., Nancy J. Norton, and Linda Pribek.

Your gift means a lot to us, and all of those affected by a chronic digestive disorder.

www.iffgd.org/make-a-donation

Give today and
download our printable art.

-our Thank you for your support.



"Wedded to Spring"
Art by Norton Shigematsu
(Nortonshigematsu.com)



Medical & Research News

IBS Associated with Vitamin D Deficiency

The authors of a randomized, double-blind pilot study of 51 individuals with irritable bowel syndrome (IBS) found to have low levels of Vitamin D suggest that the impact of IBS on quality of life may be heightened by Vitamin D deficiency. They suggest that individuals with IBS might benefit from screening and possible supplementation.

Source: Tazzyman S, et al. *BMJ Open Gastroenterol.* November 2015.

New Drug Study Reports Improvement of Symptoms of IBS-C

On December 9, 2016 Synergy Pharmaceuticals announced results from the first of two randomized, double-blind, placebo-controlled Phase 3 clinical trials evaluating the efficacy and safety of the new drug, plecanatide, for the treatment of IBS with constipation (IBS-C). The drug was more effective than placebo in improving the number of complete spontaneous bowel movements and relieving abdominal pain in patients over a trial period of 12 weeks. The study involved 1,135 adult patients with IBS-C. The most common adverse event was diarrhea, which occurred in less than 4% of patients.

Medical News from ACG 2016

The following are a selection of research studies presented as abstracts at the 2016 American College of Gastroenterology (ACG) meeting, an annual conference for medical professionals.

The data and conclusions presented here should be considered *preliminary* until published in a peer-reviewed journal.

Chronic Constipation and IBS

In two randomized, double-blind, controlled Phase 3 clinical trials two different doses (3 mg and 6 mg) of the drug plecanatide compared with placebo were found to increase complete spontaneous bowel movements and improve stool consistency, bloating, and straining in 2,683 patients with chronic idiopathic constipation (CIC) over a study period of 12 weeks. Improvements were maintained throughout the treatment period. The drug was well tolerated, with diarrhea (7.1%) and urinary tract infection (2.2%) being the most common adverse effects. While not currently approved in the U.S. by the Food and Drug Administration (FDA), plecanatide is currently under review for CIC and irritable bowel syndrome with constipation (IBS-C).

Opioid-Induced Constipation

Two Phase 3 clinical trials involving over 1,000 individuals with opioid-induced constipation (OIC) found the drug naldemedine compared with placebo to increase the number of spontaneous bowel movements within 4–24 hours of initial dose in OIC patients with chronic non-cancer pain over a study period of 12 weeks. Gastrointestinal symptoms were the

most frequently reported adverse events.

Gastroparesis

While the drug aprepitant (Emend) was not found in a clinical trial to meet the primary study endpoint of improving nausea better than placebo in 126 individuals with gastroparesis, researchers suggest that there is cause to investigate the drug further. Among participants, aprepitant (125 mg daily) was found to result in a greater decline in average daily hours of nausea experienced and was found to improve other measures of symptom severity over a study period of 4 weeks. Aprepitant is currently approved by the FDA for the treatment of nausea in chemotherapy patients and those coming out of surgery

Eosinophilic Esophagitis

Findings of a ten year retrospective study of 59 adult patients with eosinophilic esophagitis (EoE) suggest that most patients experience a resolution of symptoms and minimal disease impact on quality of life a decade after first diagnosis. Reduced EoE-related quality of life was trivial to minimal in 57% of patients, mild in 18%, moderate in 16%, and severe in 9%. After 10 years, 31% were not on EoE therapy, 63.8% were taking proton pump inhibitors (PPIs), and 6.8% were taking steroids.

C. difficile Infection

A nationwide retrospective study of 38,409 patients with *Clostridium difficile* (*C. difficile*) infection admitted to U.S. hospitals in 2013 found that one in five patients were readmitted within 30 days. Risk factors for readmission included female sex and initial discharge to home rather than to other healthcare facilities.

Medical News Reported at the 2016 FNM Meeting

The following are a selection of research studies presented as abstracts at the August 2016 Federation of Neurogastroenterology and Motility (FNM) meeting in San Francisco, CA, an international conference for medical professionals.

The data and conclusions presented here should be considered *preliminary* until published in a peer-reviewed journal.

- A double-blind, controlled, crossover study of 16 patients with clinically suspected **rumination syndrome** concluded that the drug baclofen – through its effect on lower esophageal sphincter pressure – reduced symptoms more effectively than placebo.
- Motility changes were observed and measured in a study that looked at 41 patients suffering chronic constipation with **fecal evacuation disorders** whose symptoms improved after biofeedback therapy (two sessions per day for 2 weeks).
- A study of 101 adult patients with **cyclic vomiting syndrome (CVS)** found that these individuals have poor health related quality of life relative to the general US population. Major factors driving the poor quality of life scores in this population included anxiety and depression. The authors urge a biopsychosocial care model for CVS patients with co-existing factors such as anxiety, depression, and pain.
- A study of 16 patients with **IBS** and 20 healthy controls given infusions of different FODMAP food components found fructans (a polymer of the fructose molecule) compared to glucose induced higher symptom ratings of cramps and flatulence in healthy controls and especially in individuals with IBS. Fructans are found in foods such as agave, artichokes, asparagus, leeks, garlic, onions, jicama, and wheat.
- A study of 516 patients with **gastroparesis** and 195 with **chronic unexplained nausea and vomiting (CUNV)** concluded that abdominal pain and overlapping non-abdominal pain (migraine headache, endometriosis, fibromyalgia, chronic fatigue syndrome, and interstitial cystitis) were important burdens for patients. Patients with co-existing migraine headaches had the highest disease burden scores. The findings draw attention to the need for a multidisciplinary approach in the management of pain for these patients.

Probiotics Found Not to Improve GI Symptoms Better Than Placebo in Non-Patients

Bifidobacterium infantis 35624, a probiotic often used as part of a treatment plan for patients with IBS, was found not to improve gastrointestinal symptoms of abdominal discomfort and bloating better than placebo in a randomized, double-blind trial of 275 mostly female individuals recruited from the general population who experienced symptoms over the prior 3 months but who had not seen a physician and had not received prescription medicine for their symptoms over the prior year. While symptom improvement was seen over the 6-week study period, no significant differences were seen between the probiotic and the placebo groups. The authors suggest that this may be explained by the high placebo effect and the lower impact of functional bowel symptoms in the non-patient population.

Source: Ringel-Kulka T, et al. *Am J Gastroenterol*. [Epub ahead of print]

IBS Symptoms in Patients with IBD in Remission Associated with Chronic Fatigue

In a preliminary report, presented as a poster at the December 2016 Crohn's & Colitis Foundation of America Clinical and Research Advances in IBD conference in Orlando, FL, of a 20-year study that followed 470 Norwegian patients with inflammatory bowel disease (IBD), researchers from Norway concluded that their findings show IBS symptoms in IBD patients who are in remission are associated with a higher prevalence of chronic fatigue. Among 264 patients with IBD in remission, those who also experienced symptoms of IBS (n = 68) were more likely to have chronic fatigue (37%) than those without IBS symptoms (15%). Female gender was another risk factor for chronic fatigue. Women with IBS symptoms were found to experience chronic fatigue more than men with IBS symptoms (44% compared with 33%).

Eluxadoline (Viberzi) Effective in the Relief of IBS-D Symptoms

Twice daily eluxadoline was found to improve stool consistency and reduce abdominal pain as well as frequency and urgency of bowel movements better than placebo in a randomized, double-blind study of 2,427 adult men and women with diarrhea predominant IBS (IBS-D). Sustained efficacy of the drug was demonstrated over a period of 6 months. The most common adverse events were constipation and nausea.

Source: Lembo AJ, et al. *New Engl J Med*. January 2016.

IFFGD Industry Council

Formed in 1998, the IFFGD Industry Council facilitates communication with the Council participants – helping us make the needs of people with functional GI and motility disorders known to the companies with the means and interest to develop treatment products and services. While we do not endorse any specific product or company, we thank the IFFGD Industry Council participants for helping support the mission of IFFGD.

- QOL Medical, LLC
- Shire
- Ironwood Pharmaceuticals, Inc.
- Allergan

Congenital Sucrase-Isomaltase

Deficiency (CSID) – CSID is a genetic disorder that affects a person's ability to digest certain sugars. Symptoms usually begin in childhood and typically include stomach cramps, bloating, excess gas production, and diarrhea. Recent studies suggest that CSID may be more common than currently estimated. Newer genetic tests and more accurate noninvasive breath tests may lead to more accurate prevalence studies and diagnosis of less typical cases. Learn more at IFFGD.org/other-disorders/congenital-sucrose-isomaltase-deficiency-csid

Linaclotide for IBS-C or Chronic Idiopathic Constipation – Linaclotide (Linzess/Constella) is a prescription drug to relieve symptoms in people who have irritable bowel syndrome with constipation (IBS-C), or chronic idiopathic constipation. In studies, patients taking linaclotide experienced improvement in multiple symptoms including pain or discomfort, bloating, and bowel function. Learn more at IFFGD.org/news/industry-treatment-news/linaclotide-linzess

Participants Sought for Linaclotide Study for IBS-C in Children –

Participants sought for a multicenter, randomized, double-blind, placebo-controlled safety and efficacy study of a range of linaclotide doses administered orally to children, ages 7 to 17 years, with IBS-C. The purpose of this study is to evaluate the safety and efficacy of linaclotide for the treatment of **IBS-C in children ages 7–17 years**. For more information on this Phase II study, visit www.marco-polostudies.com or phone 888-609-3456.

Participants Sought for Linaclotide Study for Functional Constipation in Children –

Participants sought for a multicenter, randomized, double-blind, placebo-controlled, parallel-group, safety and efficacy study of a range of linaclotide doses administered orally to children, ages 6 to 17 years, who fulfill modified Rome III Criteria for child/adolescent functional constipation. The purpose of this study is to evaluate the safety and efficacy of linaclotide for the treatment of **functional constipation in children ages 6–17 years**. For more information on this Phase II study, visit www.marco-polostudies.com or phone 888-609-3456.

Eluxadoline for IBS-D –

Eluxadoline (Viberzi) is a drug FDA approved in 2015 for treatment in adult men and women of diarrhea and abdominal pain associated with diarrhea predominant irritable bowel syndrome (IBS-D). It works by decreasing bowel activity. Learn more at IFFGD.org/news/industry-treatment-news/eluxadoline

Teduglutide for Short Bowel Syndrome (SBS) –

Teduglutide (Gattex®/Revestive®) is a drug for the treatment of SBS, a rare condition related to poor absorption of nutrients. It typically occurs in people who have had half or more of their small intestine removed who may then need to use

parenteral nutrition (PN) and intravenous (IV) fluids, the slow infusion of a solution of nutrients and fluids into a vein. Gattex works by regenerating cells in the intestinal lining, slowing down transit through the gut and increasing blood flow, and allowing for increased nutrient absorption. In studies, the drug was associated with achieving and maintaining clinically meaningful reductions in PN and IV fluid volume in adult subjects with SBS. Learn more at IFFGD.org/news/industry-treatment-news/Gattex

Participants Sought for Study of Teduglutide for Treatment of

Pediatric SBS – Participants sought for a SBS research study for children up to 17 years of age on PN. The aim of the study is to increase absorption of nutrients which may result in decreased PN support. For more information on this Phase III study email clinicaltransparency@shire.com, and refer to its ClinicalTrials.gov identifier: NCT02682381.

Participants Sought for Long-Term Study of SBS – Participants of any age are being sought for a long-term research study of patients with SBS. For more information email to clinicaltransparency@shire.com, and refer to its ClinicalTrials.gov identifier: NCT01990040.

Study of Oral Budesonide for

Treatment of EoE – Eosinophilic Esophagitis (EoE) is a chronic immune system disease. It can cause inflammation and lead to difficulty swallowing (dysphagia). Participants are sought for a study in adolescents and adults with EoE to measure the histologic response and determine if any reduction in dysphagia is achieved. Learn more at IFFGD.org/news/industry-treatment-news/eosinophilic-esophagitis-study

H.R 2311 Recap

Thanks to the efforts of advocates across the country, H.R. 2311 currently has 12 cosponsors in the U.S. House of Representatives. The bill was originally introduced and sponsored by Congressman F. James Sensenbrenner (WI, 5th District).

Other Representatives who have signed on in support of H.R. 2311 are:

- Andre Carson (IN, 7th District)
- Zoe Lofgren (CA, 19th District)
- Gwen Moore (WI, 4th District)
- David Young (IA, 3rd District)
- David Loebsack (IA, 2nd District)
- Keith Rothfus (PA, 12th District)
- David Joyce (OH, 14th District)
- Sean Duffy (WI, 7th District)
- Eliot Engel (NY, 16th District)
- Mark Pocan (WI, 2nd District)
- Ron Kind (WI, 3rd District)
- Joyce Beatty (OH, 3rd District)

Cosponsors help H.R. 2311 and other pieces of legislation introduced in the House become law by acting as champions for the legislation they support and helping it move forward through the legislative process.

We appreciate the commitment of these House Congressional leaders to functional GI and motility disorders research and improving the lives of all those affected by a chronic digestive condition and hope to have their continued support in the upcoming Congress.

Looking Ahead to the 115th Congress

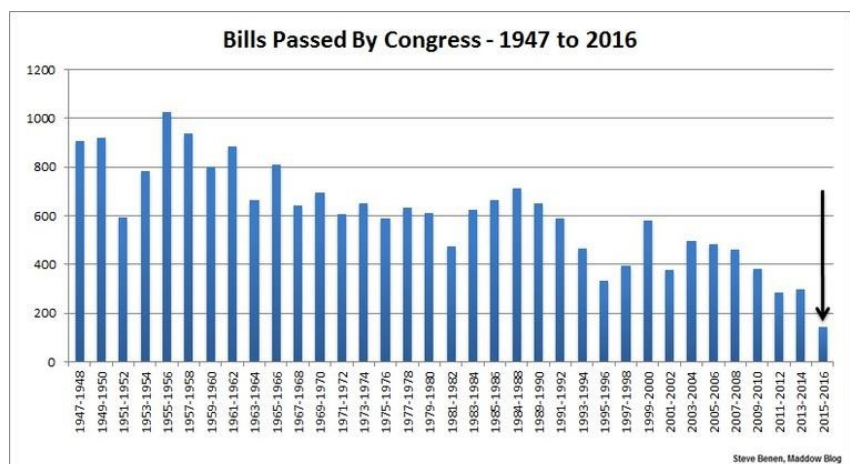
When the 114th Congress is replaced by the 115th Congress on January 3, 2017 *The Functional Gastrointestinal and Motility Disorders Research Enhancement Act* will need to be reintroduced and it will need your continued support.

Every two years in January a new Congress begins with new legislation to consider. Bills introduced in the previous Congress but not acted on or passed can be reintroduced in the new Congress (often with a new number). Then the legislation process starts over again.

The Functional Gastrointestinal and Motility Disorders Research Enhancement Act (H.R. 2311) was introduced in the House of Representatives in the current Congress where it gained bipartisan support from 12 cosponsors. Support in the 114th Congress for H.R. 2311 was propelled by thousands of digestive health advocates from across the country who reached out to their House Representatives on behalf of the bill. They helped raise awareness about functional gastrointestinal (GI) and motility disorders and the needs of patients and families whose daily lives are disrupted by these conditions.

Thank you to everyone who has taken action for this critical legislation. Continued outreach to House Members of Congress from constituents like you is needed in order to increase support for the bill in the House and get it passed into law.

Functional digestive disorders are the most common GI conditions in the general population. Estimates vary, but approximately 1 in 4 people or more in the U.S. have one or more of these disorders – men, women, and children. The conditions account for about 40% of GI problems seen by doctors and other healthcare professionals in the U.S. *The Functional Gastrointestinal and Motility Disorders Research Enhancement Act* aims to help promote awareness of functional GI and motility disorders, expand critical research, initiate important legislation, and facilitate the development of new treatment options for all those affected.



Graphic source: Benen S. MSNBC. *The Maddow Blog*. April 2016. Accessed December 2016.

Members of Congress introduce thousands of bill each year but fewer than 3% have so far been enacted in the 114th Congress. Continued action is needed to ensure that *The Functional GI and Motility Disorders Research Enhancement Act* is passed.

Your Stories

Portraits of Living with a Chronic Digestive Disorder

Sharing your experience of living with a chronic, life-altering condition, such as a functional gastrointestinal (GI) or motility disorder, can provide a therapeutic release for you as well as encourage others who may be suffering to keep fighting.

Jorge

About a week ago during one of my frustrations, I stumbled upon this website. And, I am just astonished at the stories. Even though I know that GI problems occur in a lot of people's lives, reading these stories I can see very vivid images of what all of you are going through.

After my last surgery I have really bad pains in my stomach and lower body. All of this kind of frustrates me but I try to hold my head up high knowing that I don't have a feeding tube, knowing that I don't have a colostomy bag, and that I can also eat. There are always people going through worse so I try to make the best of myself each day.

All I want is a doctor who can sympathize with me and my issues. Whether he or she can help me or not, it is very heartwarming when a doctor does whatever they can. Thank you to all the people who are writing these stories to

Thank you for sharing your stories. It really helped me realize that someone else feels the burden that we have to live with.

help us cope and to give us hope that we will get better and also to do the most with what holds us back.

Stephanie

At the age of 28, after years of pain and discomfort, a gastric emptying test confirmed mild gastroparesis (Gp).

With medication, rest, and lots of family/friends support, I began to recover. Unfortunately, this did not last and I began having severe symptoms including fullness and nausea, barely able to take in fluids.

By accepting what I was going through as a part of my life, I was able to slow down and set priorities. I now focus on managing symptoms through diet, exercise, and reducing stress. I've found other things to focus on in life while continuing to put self-care first. This doesn't mean I don't still have bad days but I have learned how to manage them by not letting the fear take over as well as figuring out what works and what doesn't.

I began writing about my experience on a blog, learning more and more about Gp and how many others were going through similar battles. I'm excited to share and use my experience as a learning tool for others, to focus on the things we can do to help ourselves instead of dwelling on the things we can't. I never would have imagined this would be my life but it hasn't stopped me from continuing to stay positive, hope for a cure someday, and in the meantime live the best life possible.

Anonymous

I bumped into this website in one of several moments of discomfort in my life. I was born with myelomeningocele spina bifida, so I've been dealing with

fecal incontinence my entire life.

I'm actually crying reading some of your posts. For the first time I feel someone is considering this problem as a burden that sometimes is just unbearable. I would like to share my story with you, hoping it might relieve someone else's pain, as your stories just did with mine.

I spent my infancy in and out of hospitals, but it wasn't awful. The real problem came with my early adolescence. I was literally thrown in a world of "normal" people, and I wasn't prepared. The impact this disability had on my personality was immense, massive. It changed me completely. The loneliness, which became an indelible part of me, still takes my breath away. These years have been the most horrible of my life, but I also had the courage to seek some help. I never talked about this disability to anyone. My family cannot even imagine how deep the solitude I dug myself into is.

Two years ago I started psychotherapy. I became aware of the fact that I am mostly afraid of being alone. I realized that I want to learn to love and be loved, and this is something that I always kept out of my life because I was ashamed. I felt inadequate, dirty, guilty (for letting myself be overwhelmed despite that I've seen people going through worse). I was never able to tell my closest friends the real reasons why I never wanted to get close to someone. But, now I want this to change. I injured myself. Now, I want to take care of me, but still I don't see how I can let someone else in this messy life.

Thank you a lot for sharing your stories. It really helped me realize that someone else feels the burden that we have to live with. I wish you all the best.

INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

Our Unique Mission: The International Foundation for Functional Gastrointestinal Disorders (IFFGD) is a nonprofit education and research organization dedicated to informing, assisting, and supporting people affected by gastrointestinal disorders. IFFGD has been working since 1991 with patients, families, physicians, practitioners, investigators, employers, regulators, and others to broaden understanding about gastrointestinal disorders and support research.

Brigitte

7 years ago I had surgery to fix a hiatal hernia. Straight away I was unwell and within 3 months I went back to the surgeon complaining of problems with my bowel. I was told it was because I was still recovering from my operation. The next 5 years were the worst years of my life. I was always sick either vomiting or on the toilet up to 20 times a day, for days at a time. I was given so many diagnoses and given so many diets to try. I was even treated like I was a hypochondriac.

I finally begged a doctor to test if my stomach was working. The next week my world changed forever – I was told I had gastroparesis with zero motility. The doctor said my vagus nerve had been cut when I had my hernia operation.

I spend weeks at a time in the hospital, I can no longer eat, I'm in pain a lot, I take lots of medications, and I am losing my hair.

I wish I had known about this condition years before so I could have learned more about it as it progressed. 18 months on, I am now running a charity to feed people in the community who are also struggling. I wake up each day and remind myself I'm lucky I'm alive and the feeding tube is just part of my life now. I try to fit as much into every day as I can.

It's best to find out as much as you possibly can about this condition and learn to live with it the best way that you can. I don't think my condition can be fixed but you should research every option possible for you to make your life more enjoyable.

Thank you to all the courageous people who have shared your personal account of living with a functional gastrointestinal or motility disorder with us and the digestive health community. Share your story at www.iffgd.org/stay-connected/personal-stories-list

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Phone: 414-964-1799
Email: iffgd@iffgd.org
IFFGD
PO Box 170864
Milwaukee, WI 53217

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