NASPGHAN Personal IBD Notebook

This Notebook Belongs To:

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Main Hospital _____

GI Attending _____
Telephone # _____
_____

GI Fellow _____
Telephone # _____
_____

GI Nurse Practitioner_____
Telephone # _____
_____

Primary Physician_____
Telephone # _____
_____

Pharmacy Phone #_____

Pharmacy Fax #_____

NASPGHAN
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

APGNN
The Association of Pediatric Gastroenterology and Nutrition Nurses

CDHNF
Children's Digestive Health and Nutrition Foundation

Founded in 1973, the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) is the professional organization of 1000 specially trained physicians expert in inflammatory bowel disease and other disorders of the gastrointestinal tract, liver and nutrition. The mission of NASPGHAN (pronounced nás-pa-gan) is to be a world leader in advancing the science and clinical practice of pediatric gastroenterology, hepatology and nutrition in health and disease. NASPGHAN is committed to improving the health and well being of children and adolescents with Crohn's Disease and Ulcerative Colitis, which are also called inflammatory bowel disease (or IBD for short). NASPGHAN has an Inflammatory Bowel Disease Committee, a Professional Education Committee and a Public Education Committee. Through these committees, the physician members of NASPGHAN work to improve the medical care of children with IBD. They are writing a book for parents whose children have IBD, writing clinical guidelines to guide physicians in the best care of children with IBD, improving research in pediatric IBD, as well as developing, producing and distributing this NASPGHAN Personal IBD Notebook. See *http://www.naspghan.org*.

Founded in 1998 by NASPGHAN, the Children's Digestive Health and Nutrition Foundation (CDHNF) was established to promote and develop funds for research and education to improve the health of children with digestive and nutritional disorders. The mission of the Children's Digestive Health and Nutrition Foundation is to fund and promote research and educational programs that will advance the creation, application, and dissemination of knowledge of gastrointestinal, hepatobiliary, pancreatic and nutritional disorders in children, including Crohn's Disease and Ulcerative Colitis; to identify, encourage, support, and coordinate scientific and professional study of these pediatric disorders; to strengthen the role of pediatric gastrointestinal and nutritional scientists as leaders in research and education in these medical and health care fields; to evaluate and improve the quality and availability of medical care for children with digestive disorders; and to support the research and educational programs of NASPGHAN. See *http://www.cdhnf.org.*

The formation and ongoing purpose of The Association of Pediatric Gastroenterology and Nutrition Nurses (APGNN) is to promote the professional development and recognition of pediatric nurses as experts in their field; and to promote excellence in the care of families with children with gastrointestinal and nutritional illness. Nurses in APGNN are specially trained and experienced in the care of children and adolescents with Crohn's Disease and Ulcerative Colitis. See *http://www.naspghan.org/sub/apgnn.asp*.

The NASPGHAN Personal IBD Notebook is supported by a generous grant from Procter & Gamble Pharmaceuticals

Introduction

Growing up can be difficult. Childhood and the teenage years are filled with changes that can be very hard on even the healthiest of people. When a child or adolescent is sick the changes can be even more difficult, and may make the child angry at their current situation and fearful of the future. A child with a possible lifelong disease like inflammatory bowel disease (IBD) has extra needs that fall on the entire family. The responsibilities can seem overwhelming for everyone. At first the child's family and medical team take on most of the responsibilities, but as the child grows older their family and medical team must let the child take on more and more responsibility, looking ahead to when they will eventually leave home.

To help make growing up with IBD easier, we have created a personal IBD notebook. The notebook was originally the idea of a young man with IBD, who found out how important it was to know about your disease, and have a way to pass on information about your disease history. During a trip to another country, he became sick, and was unable to get in touch with his doctor back home. It was days before he could get vital information to the doctors taking care of him. He designed this notebook to help prevent this from happening to anyone else.

The notebook will be a place to store information about your child's medical history as well as information about their daily life. By keeping the notebook up to date, you will always have information about your child's disease when you need it—whether you are traveling, seeing a new doctor, or when they leave home as adults. By working with your child to keep the notebook up to date, everyone in the family will learn about their disease, and hopefully feel more in charge of the whole process. We want you to be an important part of the medical team that takes care of your child.

Please take a few moments now to read through the notebook and become familiar with its contents. Understand what information is required to complete your notebook, and what information you need each time you visit your doctor's office. With time, your notebook will begin to fill up with information; as this happens you can transfer some of the older contents into your own folders at home. This notebook should accompany you on your trips to the doctor and when you travel away from home; let the notebook worry about your disease so you do not have to.

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Every patient must be an active member of the medical team. The most important job a patient has is to know their medical history. Remembering your history can be even more difficult for a person with a lifelong disease. It is also more important for a patient with a lifelong disease to remember their history, because it affects all future decisions in their care.

The hospital records provide a good outline of the patient's medical history. However, some of the more personal information a patient might feel is important is not always present. Medical information might also be missing in an emergency away from home. This patient management system will contain all the information necessary for successful medical treatment, no matter what the situation is.

In this section of the notebook you will find sections in which to store copies of your medical records, and areas to add your own more personal notes. The more completely you fill out the sections, the easier you will make things for yourself during periods of illness. Organization and information can be your best friends during times of illness.

History Overview

Date of diagnosis: _____
Physician who made diagnosis: Dr._____ Hospital _____

Procedures Performed: *Procedures that should be listed here include colonoscopies, upper endoscopies, x-rays, and surgeries.*

- *Insert copies of the reports from these procedures in the Procedure Records Section*

Procedure	Date Performed	Location	Reason for Procedure & Results of Procedure

Hospitalizations

- *Insert copies of your discharge letters in the Correspondence & Appointment Records Section*

Date Admitted	Date Discharged	Location	Reason For Admission	Discharge Instructions

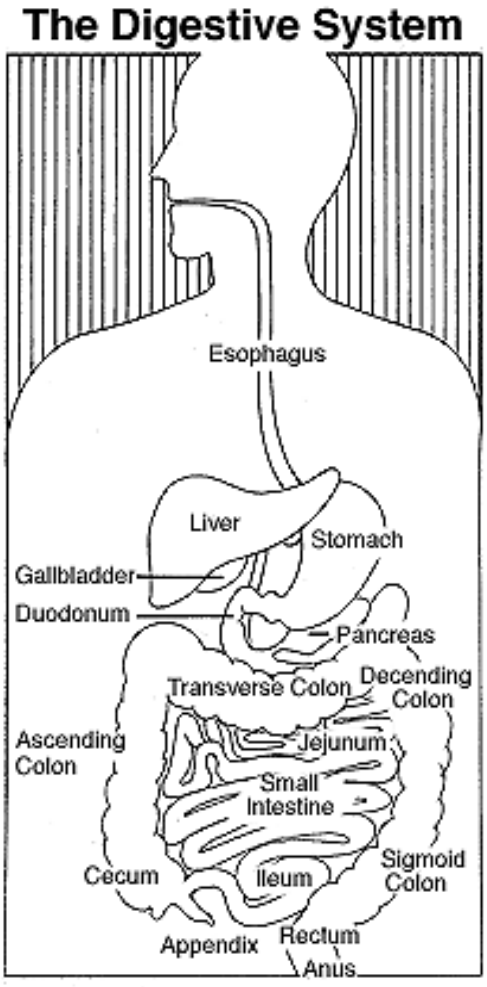
Medical and Environmental Allergies: *Please include any reactions you have had to medications, foods, or environment.*

Allergy To	Date Identified	Reaction and Treatment

Additional Medical Conditions

Condition	Date Diagnosed	Who Manages This Condition	Treatment for Condition
		Dr _____ Hospital _____	
		Dr _____ Hospital _____	
		Dr _____ Hospital _____	
		Dr _____ Hospital _____	
		Dr _____ Hospital _____	
		Dr _____ Hospital _____	
		Dr _____ Hospital _____	
		Dr _____ Hospital _____	
		Dr _____ Hospital _____	

Disease Location



Doctor's use colonoscopies, x rays, and other procedures to identify where in your digestive system your disease is located. Record on the chart below where, how, and when the location of your disease was identified

Location	How, When Identified
	Date_____ Procedure_____
	Date_____ Procedure_____
	Date_____ Procedure_____
	Date_____ Procedure_____
	Date_____ Procedure_____
	Date_____ Procedure_____
	Date_____ Procedure_____
	Date_____ Procedure_____

Extra-intestinal Problems:

Problems with IBD often occur outside of the digestive system (extra-intestinal). The most common problems are listed below. If you have had any of these problems, please indicate when and/or where these problems occur.

Problem	When or Where Does the Problem Occur
High Fevers	
Mouth Sores	
Joint Pain	
Skin Rashes	
E Nodosum (red, painful lumps)	
P Gangrenosum (skin ulcers)	
Eye Problems (uveitis)	
Perianal Disease	

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Medical Therapy Records

When you start a new dose of a drug you are currently on, please record the stop date and then on a separate line the start date of the new dose.

5-ASA Therapy

- *These include: Asacol, Pentasa, Azulfidine, Colazal, Rowasa, Canasa, and Dipentum*

Medication	Date Started	Date Stopped	Dose	Precautions Side Effects Allergic Reactions

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Antibiotic Therapy

- *These include: Flagyl, Cipro, or other antibiotics used to treat your IBD.*

Medication	Date Started	Date Stopped	Dose	Precautions Side Effects Allergic Reactions

Steroid Therapy

- *These include: Prednisone, Budesonide, Medrol, or Methylprednisone*

Steroid	Dose	Date Started	Date Stopped	Problems Side Effects Allergic Reactions

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Immunomodulator Therapy

- *These include: 6-MP, Azathioprine, or Methotrexate*

Medication	Date Started	Date Stopped	Dose	Precautions Side Effects Allergic Reactions

Biologic Therapy

- *These include: Infliximab (Remicade), CDP-571, Natalizumab (Antigren), D2E7 (Humira)*

Infusion Date	Dose	Weight	Pre-Medication (Tylenol, benedryl, medrol etc)	Problems During Infusion

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Other Prescription Medical Therapies

- *These include: Other therapies such as Cyclosporine, Thalidomide, Entanercept, Mycophenolate Mofetil, Tacrolimus or medications you may have received as part of a clinical trial.*

Medication	Date Started	Date Stopped	Dose	Precautions Side Effects Allergic Reactions

Nutritional Therapies: *Please record in this table any use of nutritional therapies such as NG Tube Feeds. Record how it is delivered (tube feeding, can) and any notes about the therapy (problems, suggestions, etc)*

Type	Date Started	Date Stopped	Amount	How is it Delivered and Notes About Therapy

Non Prescription Therapies: *Please record in this table any use of other treatments (fish oil, probiotics, prebiotics etc), over the counter medications (vitamins, Imodium etc), or use of specialists (acupuncture, yoga, massage etc)*

Therapy	Dose	Date Started	Date Stopped	Notes Regarding Therapy

Additional Information: *Use this space to record any additional info regarding your medical therapy.*

Correspondence and Appointment Records

Correspondence includes any form of communication with the hospital, doctors, or nurses such as letters, e-mails, or faxes.

Following this page

- *Insert copies of your correspondence with your GI Team*
- *Ask your doctor for copies of his correspondence: including discharge summaries from the hospital, and if your doctor agrees, letters to other doctors summarizing your visits to the office.*
- *Please place all of these correspondences in order starting with the most recent*

Appointment Record

Date	Height and Weight	Reason for Visit	Treatment Plan
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change________________________________ ______________________________________

<u>Appointment Record</u>

Date	Height and Weight	Reason for Visit	Treatment Plan
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
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	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________
	Ht_____ cm Wt_____ kg ❑ Increase ❑ Decrease	❑ Change in health ❑ Check Up ❑ Other	❑ No change ❑ Change______________________________ _________________________________

Procedure Records

Following this page

- Please place copies of reports from Colonoscopies, Upper Endoscopies, X-Rays, and Surgeries
- Please place these records in order beginning with your most recent procedure.

Lab Test Records

Following this page

- Please insert copies of the results from your blood tests, stool cultures, and any other lab work.
- Please place these records in order starting with your most recent laboratory test.

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Home Life

Having an illness does not require that a child stop doing the things they enjoy. What having an illness requires is that the child must start planning ahead about things in their daily life, such as travel or school. At first this planning might be difficult, however, with time it will become much easier and will help to give you a more normal and safe life.

In this section of the notebook you will find information about how to live with this illness outside of the doctor's office. For younger patients this section will help parents organize and record information about their child's life at home. After time this section will be a space for the growing patient to record their own opinion. One day you will even be able to use the information in the notebook to help create the safe environment you enjoyed as a child, wherever life takes you.

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SCHOOL

It is your decision who you let know about your disease. In situations such as school, even if you do not want any special arrangements made for you, it may help to decrease your stress to at least know what options are available to you. School is another area of your life that will require planning ahead and organization, your two best allies when dealing with the stresses of IBD.

It might be beneficial for you to contact your school before starting and learn their policies about special circumstances, their health care services, and what resources might be available to you. Never assume that certain activities are beyond your reach. Most likely these activities can be done, if you make the appropriate people aware of your condition. If your school does not offer any services, check with your state department, as they may be able to help you.

Here are some tips for students to consider when entering school:

- Special bathroom passes can usually be secured for students with IBD, and special accommodations can sometimes be arranged (such as a private bathroom in your college dorm room). At the very least, plan ahead for bathroom trips.
- Many schools will provide note takers for students who have trouble getting to class; check with your school for what services it offers students with special circumstances. Again, never assume that something is beyond your reach.
- Don't sacrifice meals at the expense of school, keep handy some calorie supplements that can be "meals in a can" in case you find yourself rushed or at the library late.
- Always keep extra medication on you at all times.
- Make your teachers aware of your circumstances before the semester starts, so hopefully they will understand if you are absent or late.

SCHOOL RELATED TELEPHONE NUMBERS

_____

_____

_____

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TRAVEL TIPS

Our Tips

- **Never put your medication or important information in luggage that leaves your possession. When traveling by plane, bring your meds and your notebook with you in your carry-on luggage.**
- Be careful of the water! Always drink bottled water wherever you go. Every country has different bacteria that their native digestive tracts are used to, while yours may not be.
- Beware of exotic foods. Your digestive system may not easily handle such changes in diet, so check with your doctor before you leave if you want to sample the local cuisine.
- Make sure you have appropriate accommodations, such as bathrooms for long trips.
- Bring toilet paper or wipes with you, don't get stranded empty handed (companies make handy travel packs of 10 wipes that can fit into a pocket).
- Be knowledgeable of some basic language in the country you are visiting: especially phrases like "where's the bathroom" or words like "hospital, pharmacy, and doctor". Consider keeping a cheat sheet in your wallet.
- Keep a few handy nutritional supplements around in case you find yourself in need of a meal while in transit. This is probably not the best time to be skipping a meal.
- **BRING YOUR NOTEBOOK!**

Your Tips

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DIET AND NUTRITION

During the course of your disease, you may encounter foods that you do and do not tolerate well. Please record below any of these foods or other tips you may accumulate that help you with your diet. For example: if you are lactose intolerant, an easy way to see if your foods contain any dairy is to look for a "D" on the label. You may even want to keep track of some of the recipes that you have enjoyed on the following pages.

Your Tips

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Recipes

Rice Flour Pancakes (serves 4)

1 cup rice flour
1 tbs. sugar
2 tsp. baking powder
1/2 tsp. salt
1 cup rice or soy milk
1 egg, lightly beaten
2 tsp. olive oil or vegetable oil
1 cup maple syrup

Sift the rice flour, sugar, baking powder and salt together in a bowl. Beat in the rice milk or soy milk until the mixture has a smooth consistency. Add the beaten egg and olive oil or vegetable oil and mix until just blended.

Heat a non-stick griddle to 375 degrees or until it is hot enough that drops of water splashed on the griddle bounce and sizzle. Lightly oil the pan. Ladle the pancake mixture onto the griddle to form 4 inch cakes.

Turn the cakes once the bottom has browned and bubbles appear on the tops. Cook the cakes for an additional two minutes. Serve the pancakes with warmed maple syrup. Recipe will yield 12 pancakes

http://www.colitiscookbook.com/

Erin's B-4 scope Orange Smoothie

All right, we all know how it feels before we have a scope, no foods, only clear liquids and pulp free OJ. Well here is something that makes life a little easier for those one or more days that we have to go without eating.

Ingredients

- pulp free Orange Juice
- crushed ice
- sugar

Directions
In a food processor or blender add the crushed ice (it has to be in small pieces or it won't work well) and Orange Juice. Process until smooth. Then add sugar to your own preference. Put the lid back on the blender or processor and process a few more seconds until mixed. This drink is not exactly clear but contains ingredients that we are allowed to have before your scope. ENJOY!!!

http://pages.prodigy.net/mattgreen/smoothie.htm

Your Recipes

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Your Recipes

Should I Call My GI Team ?

It is expected that there will be times you will have to call your GI Team. It would be fantastic if your team was always available to take your call, but the reality is that you are not their only patient. You should discuss when and how to reach someone with your GI Team so that you know what to do when the time comes. Specifically, you should ask your team the following questions:

- *For what type of problems would you like me to call?*
- *What number do I call during usual business hours?*
- *What number do I call after business hours and on weekends?*
- *Who should I call for non-urgent problems such as lab results, prescription refills or school notes?*
- *How long does it usually take to get a call back?*

In some practices, secretaries or nurses may handle non-urgent calls. If you feel that you must speak with the physician on the team, you should make that clear when you leave your original message, so that multiple people do not have to call you back.

Emergency or urgent calls deal with problems that need to be addressed more quickly. If you believe you are having an emergency or urgent problem, you should make the team aware of this from the start. If you are having an emergency and cannot reach a member of your GI Team, you may need to be seen by your primary doctor or in an Emergency Room.

When you call your GI Team about your health, you should think about symptoms in terms of how they have changed for you. It is helpful for your GI Team to know how long you have had symptoms, if they are worsening, or changing in any way. You should become aware of what your “baseline” health is and know when it changes. The bigger the change, the more urgent your phone call becomes; learn to listen to your body!

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IMPORTANT NUMBERS

Hospital Main Operator	
Emergencies	410-328-0812
GI Appointments	410-328-6749
Nutrition	410-328-0812
Satellite Office Appointments	UCMC 410-879-7730
Endoscopy Suite	410-328-5923
DEXA scans	410-328-3335
Lactose breath tests	410-328-6749
Biopsy and Lab Test Results	410-328-0812
Prescription Refills	410-328-1072
GI Fax numbers	
Outpatient	410-328-1072
GI main fax number	410-328-1072
Endoscopy	410-328-1072
Referrals	410-328-1072
Subspecialty Telephone Numbers	
Adolescent Medicine	
Allergy (Immunology)	
Cardiology	
Connelly Resource Center for Families	
Dermatology	
Diagnostic Center	
Emergency Department	
Endocrinology	410-328-3410
General Surgery	410-328-5730
Home Care	
Nephrology (Renal)	
Neurology	
Ophthalmology	
Orthopedics	
Otolaryngology (ENT)	
Pharmacy (outpatient)	
Physical therapy	
Pulmonary	
Psychiatry	

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Radiology	410-328-5775
Radiology File Room	
Rheumatology	410-328-6749 (410-992-7440)
Social Work	
Urology	

Financial questions

Business Office	

Additional numbers

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PLAN FOR MEDICAL EMERGENCY

Before traveling discuss with your doctor how best to handle a medical emergency in the area to which you are traveling. Please record below your doctor's suggestions, as well as important numbers in the area to which you are traveling (doctors, hospitals etc)

PLAN

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NUMBERS

International Association for Medical Assistance (716) 754-4883

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HOSPITALIZATION

During the course of your care you might have to spend time overnight at the hospital for tests, for special treatment of your disease, or for surgery. The hospital may seem like a strange and unfamiliar place, but if you know what to expect, your stay can be a lot more pleasant for everybody. We have included some tips that patients have given us that made their stay in the hospital more comfortable, and we have left space for your to write your own tips.

Our Tips

- Leave all valuables at home as they may be lost in the shuffle, but do bring some cash ($30) to pay for minor expenses you may have while hospitalized.
- Bring comfortable clothes, and make sure to bring clothes for any type of temperature as it can go from hot to cold depending on where you are. Slippers are also great to help you feel at home.
- Lifesaver candies are great to have especially when you are not allowed to eat solid food.
- Bring your own bathroom accessories unless you do not mind using the ones that the hospital provides.
- Bring telephone numbers and addresses of people you might want to contact, as well as writing materials to make notes about questions you have for doctors and to record information.
- Bring your medications with you. If the hospital does not have your medication they will dispense yours until they do.
- Bring some reading/entertainment materials like magazines or a walkman. Patients can often bring their video games to hook up to hospital televisions, as well as videotapes to watch on hospital VCRs.
- Read the pages about “Your GI Team”. You should also familiarize yourself with the schedule that you will have in the hospital. Sleeping can be difficult so know when you can, and when you might be woken up.
- Some hospitals have a library of information for patients and their families including Internet access, journals, and videotapes. Ask your nurse about these resources.

Your Tips

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YOUR GI TEAM

Hospitalization can be a time of many concerns and questions for families. We realize that families are sometimes overwhelmed by the large medical team found in some hospitals. We hope that the following information is helpful in understanding the roles of the people you **may** meet while in the hospital; it will explain who's who on your medical team and what to expect from the various physicians and nurses involved in your child's care.

Attending Physician: The Attending Physician is the senior physician who oversees all children admitted to the hospital on the "GI service." The Attending Physician on service may not be the physician who cares for your child in the outpatient setting, but will be in close communication with your outpatient team. Each Attending physician has completed medical school (4 years), Pediatric Residency (3 years) and specialty Fellowship training in Pediatric Gastroenterology (3 years). The Attending Physician will see and examine each patient every day at a bedside visit (rounds) with the team and is ultimately responsible for each child's care. An Attending Physician will perform GI procedures (sometimes assisted by one of the Fellows) and will oversee the general plan with the team. If the admission extends over a weekend you may meet more than one Attending Physician. Discharge and homecare arrangements will also be discussed with your outpatient team.

GI Fellow: GI fellows are pediatricians who are specializing in pediatric Gastroenterology. Each GI Fellow has completed medical school and a 3-year pediatric residency program. The GI Fellow works closely with the Attending Physician, residents and nurses to provide care to your family. A GI Fellow evaluates children admitted to the GI service, supervises the residents, develops plans and also performs various GI procedures under the supervision of the GI Attending.

Resident: Each resident is a medical school graduate who is completing a 3-year pediatric training program. Each child admitted to the GI service may be assigned a resident who performs an admission physical examination and review of history, as well as daily follow up of physical examination, symptoms and other problems, assists in scheduling of tests, ordering of medications and the development of a daily plan. Residents are in the hospital 24 hours per day on a rotating basis to monitor ongoing problems, to evaluate newly admitted children or to intervene in emergency situations.

Senior Resident: The senior resident is in the 2nd or 3rd year of the 3-year pediatric training program and directly supervises the other residents and provides general pediatric consultation to the team. The senior residents teach and supervise the other residents and are in turn supervised by GI Fellows and Attending physicians.

Nursing Staff: The nursing staff on inpatient units is specifically educated around the care of children with GI disorders. The staff will implement the plan of care for your child while they are in the hospital. They will also provide the education needed to care for your child at home. Each patient is assigned **a Primary Nurse (PN).** A primary nurse addresses the primary needs of a patient and family by coordinating and collaborating with the entire multi-disciplinary team. The primary nurse develops and implements a plan of care, while also attending to any problems that may arise. This provides direct and consistent care for your child. The primary nurse will keep the nurses on the patient's team updated with the plan of care. From admission to discharge the primary nurse will utilize all resources available to provide holistic care.

Advanced Practice Nurses (APN) work closely with the physicians and nurses to ensure that all your child's needs are addressed before discharge to home. APNs have a graduate degree in nursing and a wealth of experience in the care of children with gastrointestinal and nutritional problems. They may also coordinate specific care needs and education that you need before going home.

Consulting services: Additional teams may be involved in your/your child's care as needed. If consultation from another specialty group is needed, that team may include additional Nurses, Residents, Fellows and Attending Physicians who work together.

Your family: We consider your family to be key members of the health care team. We welcome and encourage your participation and questions. Brief questions and reviews of plans can often be answered during the morning rounds with the whole team. If you have more involved questions, please inform the doctors on rounds who will set up a time to come back for more detailed discussion. If you are not present on rounds, the nurse can contact a team member to arrange a meeting. If the admission is a brief one for testing only, results and a further plan may not be available at the time of your child's discharge but will be discussed at the next appointment with your outpatient Gastroenterology attending physician.

Medical Release Forms and Letters

A recent law called the Health Information Portability & Accountability Act (HIPAA) has resulted in changes regarding who can view your child's personal health information. Many of these changes will result in your having to sign waivers to release your child's personal health information, whether to their school, to their camp, or to another doctor's office. It is useful to keep track of these waivers, so please insert them into the binder following this page, along with copies of the letters, so that they are available if misplaced.

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SPECIAL INSTRUCTIONS

During the course of your care you might receive special instructions regarding preparation for procedures, tube feedings, or information regarding research studies you agree to participate in.

Following this page

- Please insert all of these informational packets/sheets after this page.

List of Common IBD Medications (by Trade Name)

Trade Name	*Generic Name*	*Foreign Name*	*Dosage Forms*	*Medication Class*
Anusol-HC Ointment	Hydrocortisone		Ointment (1%, 2.5%)	Corticosteroid
Anusol-HC Suppository	Hydrocortisone		Suppository (25 mg)	Corticosteroid
Asacol	Mesalamine		Tablet (400 mg)	5-ASA
Azulfidine	Sulfasalazine	Salazopyrin	Tablet (500 mg)	5-ASA
Canasa	Mesalamine		Suppository (500 mg)	5-ASA
Cipro	Ciprofloxacin		Capsule (250 mg)	Antibiotic
Colazal	Balsalazide		Capsule (750 mg)	5-ASA
Cortenema	Hydrocortisone		Enema (100 mg/60 ml)	Corticosteroid
Cortifoam	Hydrocortisone		Rectal Foam (10%)	Corticosteroid
Deltasone	Prednisone		Tablet (2.5,5,10,20 mg)	Corticosteroid
Dipentum	Olsalazine		Tablet (250 mg)	5-ASA
Entocort EC	Budesonide		Capsule (3mg)	Corticosteroid
Flagyl	Metronidazole		Tablet (250 mg)	Antibiotic
Folex	Methotrexate		Tablet (2.5 mg),	
			Injection (25 mg/ml)	Immunomodulator
Imuran	Azathioprine		Tablet (50 mg)	Immunomodulator
Medrol	Methylprednisolone		Tablet (2,4,8,16,32 mg)	Corticosteroid
Mexate	Methotrexate		Tablet (2.5 mg),	
			Injection (25 mg/ml)	Immunomodulator
Neoral	Cyclosporine		Capsule(25,100 mg),	
			Liquid(100mg/ml)	Immunomodulator
Pediapred	Prednisolone		Liquid (5 mg/5 ml)	Corticosteroid
Pentasa	Mesalamine		Capsule (250 mg)	5-ASA
Prelone	Prednisolone		Liquid (15 mg/5 ml)	Corticosteroid
Prevacid	Lansoprazole		Capsule (15, 30 mg),	
			Liquid (1 mg/ml)	Acid Blocker
Prilosec	Omeprazole		Capsule (10, 20 mg)	Acid Blocker
Proctofoam-HC	Hydrocortisone		Rectal Foam (1%)	Corticosteroid
Purinethol	Mercaptopurine		Tablet (50 mg)	Immunomodulator
Remicade	Infliximab		Injection (100 mg)	Biologic Agent
Rheumatrex	Methotrexate		Tablet (2.5 mg),	
			Injection (25 mg/ml)	Immunomodulator
Rowasa	Mesalamine		Enema (1 gram)	5-ASA
Zantac	Ranitidine		Tablet (150 mg),	
			Liquid (15 mg/ml)	Acid Blocker

List of Common IBD Medications (By Generic)

Generic Name	*Trade Name*	*Foreign Name*	*Dosage Forms*	*Medication Class*
Azathioprine	Imuran		Tablet (50 mg)	Immunomodulator
Balsalazide	Colazal		Capsule (750 mg)	5-ASA
Budesonide	Entocort EC		Capsule (3mg)	Corticosteroid
Ciprofloxacin	Cipro		Capsule (250 mg)	Antibiotic
Cyclosporine	Neoral		Capsule (25, 100 mg), Liquid (100 mg/ml)	Immunomodulator
Hydrocortisone	Anusol-HC Ointment		Ointment (1%, 2.5%)	Corticosteroid
Hydrocortisone	Anusol-HC Suppository		Suppository (25 mg)	Corticosteroid
Hydrocortisone	Cortenema		Enema (100 mg/60 ml)	Corticosteroid
Hydrocortisone	Cortifoam		Rectal Foam (10%)	Corticosteroid
Hydrocortisone	Proctofoam-HC		Rectal Foam (1%)	Corticosteroid
Infliximab	Remicade		Injection (100 mg)	Biologic Agent
Lansoprazole	Prevacid		Capsule (15, 30 mg), Liquid (1 mg/ml)	Acid Blocker
Mercaptopurine	Purinethol		Tablet (50 mg)	Immunomodulator
Mesalamine	Asacol		Tablet (400 mg)	5-ASA
Mesalamine	Canasa		Suppository (500 mg)	5-ASA
Mesalamine	Pentasa		Capsule (250 mg)	5-ASA
Mesalamine	Rowasa		Enema (1 gram)	5-ASA
Methotrexate	Folex		Tablet (2.5 mg), Injection (25 mg/ml)	Immunomodulator
Methotrexate	Mexate		Tablet (2.5 mg), Injection (25 mg/ml)	Immunomodulator
Methotrexate	Rheumatrex		Tablet (2.5 mg), Injection (25 mg/ml)	Immunomodulator
Methylprednisolone	Medrol		Tablet (2,4,8,16,32 mg)	Corticosteroid
Metronidazole	Flagyl		Tablet (250 mg)	Antibiotic
Olsalazine	Dipentum		Tablet (250 mg)	5-ASA
Omeprazole	Prilosec		Capsule (10, 20 mg)	Acid Blocker
Prednisolone	Pediapred		Liquid (5 mg/5 ml)	Corticosteroid
Prednisolone	Prelone		Liquid (15 mg/5 ml)	Corticosteroid
Prednisone	Deltasone		Tablet (2.5,5,10,20 mg)	Corticosteroid
Ranitidine	Zantac		Tablet (150 mg), Liquid (15 mg/ml)	Acid Blocker
Sulfasalazine	Azulfidine	Salazopyrin	Tablet (500 mg)	5-ASA

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List of Common IBD Medications (By Medication Class)

Medication Class	*Trade Name*	*Generic Name*	*Foreign Name*	*Dosage Forms*
5-ASA	Asacol	Mesalamine		Tablet (400 mg)
5-ASA	Azulfidine	Sulfasalazine	Salazopyrin	Tablet (500 mg)
5-ASA	Canasa	Mesalamine		Suppository (500 mg)
5-ASA	Colazal	Balsalazide		Capsule (750 mg)
5-ASA	Dipentum	Olsalazine		Tablet (250 mg)
5-ASA	Pentasa	Mesalamine		Capsule (250 mg)
5-ASA	Rowasa	Mesalamine		Enema (1 gram)
Acid Blocker	Prevacid	Lansoprazole		Capsule (15, 30 mg), Liquid (1 mg/ml)
Acid Blocker	Prilosec	Omeprazole		Capsule (10, 20 mg)
Acid Blocker	Zantac	Ranitidine		Tablet (150 mg), Liquid (15 mg/ml)
Antibiotic	Cipro	Ciprofloxacin		Capsule (250 mg)
Antibiotic	Flagyl	Metronidazole		Tablet (250 mg)
Biologic Agent	Remicade	Infliximab		Injection (100 mg)
Corticosteroid	Anusol-HC Ointment	Hydrocortisone		Ointment (1%, 2.5%)
Corticosteroid	Anusol-HC Suppository	Hydrocortisone		Suppository (25 mg)
Corticosteroid	Cortenema	Hydrocortisone		Enema (100 mg/60 ml)
Corticosteroid	Cortifoam	Hydrocortisone		Rectal Foam (10%)
Corticosteroid	Deltasone	Prednisone		Tablet (2.5, 5, 10, 20 mg)
Corticosteroid	Entocort EC	Budesonide		Capsule (3mg)
Corticosteroid	Medrol	Methylprednisolone		Tablet (2,4,8,16,32 mg)
Corticosteroid	Pediapred	Prednisolone		Liquid (5 mg/5 ml)
Corticosteroid	Prelone	Prednisolone		Liquid (15 mg/5 ml)
Corticosteroid	Proctofoam-HC	Hydrocortisone		Rectal Foam (1%)
Immunomodulator	Folex	Methotrexate		Tablet (2.5 mg), Injection (25 mg/ml)
Immunomodulator	Imuran	Azathioprine		Tablet (50 mg)
Immunomodulator	Mexate	Methotrexate		Tablet (2.5 mg), Injection (25 mg/ml)
Immunomodulator	Neoral	Cyclosporine		Capsule (25, 100 mg), Liquid (100 mg/ml)
Immunomodulator	Purinethol	Mercaptopurine		Tablet (50 mg)
Immunomodulator	Rheumatrex	Methotrexate		Tablet (2.5 mg), Injection (25 mg/ml)

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GLOSSARY

MEDICAL TERMS & HOSPITAL ABBREVIATIONS

Abscess	A pocket or collection of pus.
Albumin	A protein that is measured in blood tests. The level is a good indicator of overall nutrition.
5-aminosalicylic acid (5-ASA)	The active component of mesalamine.
Anemia	Lower than normal amounts of hemoglobin in the red cells of the blood.
Ankylosing Spondylitis	A form of spinal arthritis that strikes some people with IBD, and which sometimes causes fusion of the joints of the spine.
Arthralgia	Pains in the joints, frequently experienced by persons with IBD.
Arthritis	Inflammation of a joint, accompanied by pain, swelling, heat, or redness.
Aseptic Necrosis	A complication of the prolonged use of high-dose steroids, in which one or both of the hip joints may suddenly undergo massive deterioration.
Autoimmunity	An inflammatory reaction to one's own tissues.
Barium Enema	An x-ray examination of the colon and rectum after liquid barium has been infused through the rectum.
BE	See barium enema.
BID	Twice a day (Latin: bis in die).
Biopsy	A small piece of tissue taken from the body for examination under the microscope.
BP	Blood pressure.
C&S	Culture and sensitivity (test for bacteria in blood and urine samples).
CAT Scan	See CT scan
CBC	Complete blood count. A type of blood test.
CD	An abbreviation for Crohn's disease.
Clinical	Involving the direct observation and treatment of patients.
Colectomy	Removal of part or all of the colon.

Colon	The large intestine.
Colonoscopy	A test in which a flexible, lighted tube is inserted through the rectum to examine the colon.
Colostomy	A surgically created opening of the colon to the abdominal wall, allowing the diversion of fecal waste.
Comprehensive Metabolic Panel (CMP)	A lab test which allows for the measurement of 12 blood chemistries from a single blood sample.
CT Scan	Abbreviation for Computed Tomography Scan. A specialized type of x-ray study.
CXR	An abbreviation for chest x-ray.
Discharge Summary	A summary dictated by your physician during or after the hospital stay, including any tests or operations performed, laboratory data, your condition on discharge, and plans for follow-up care.
Distal	Closer to the anus; downstream.
Distension	An uncomfortable swelling in the abdomen, often caused by excessive amounts of gas and fluids in the intestine.
Dx	An abbreviation for diagnosis.
Dysplasia	Alterations in cells that may predict the development of cancer.
E. nodosum	See Erythema nodosum
ECG (EKG)	Electrocardiogram.
Edema	Accumulation of excessive amounts of fluid in the tissues, resulting in swelling.
Elemental Diet	A specially prepared liquid meal that is hypoallergenic.
Electrolytes	Acids, bases, and salts essential for maintaining life.
Endoscopy	The examination of the inside of a hollow organ, such as the bowel, using special lighted tubes.
Erythema Nodosum	Red swellings occasionally seen on the lower legs during flareups of Crohn's disease and ulcerative colitis.
ESR	Erythrocyte sedimentation rate. A type of blood test.
Exacerbation	An aggravation of symptoms or an increase in disease activity; a relapse.
Excision	Surgical removal.
Febrile	Running a fever.
Fissure	A crack in the skin; usually near the area of the anus in Crohn's disease.

Fistula	An abnormal connection between two locations in the body, such as loops of intestine, or between the intestine and another structure, such as the bladder,vagina, or skin.
Folic Acid	One of the vitamins responsible for the maintenance of red blood cells.
Fulminant	Disease that develops with extreme rapidity.
Gastroenterologist	A physician specially trained in the diagnosis and treatment of patients with gastrointestinal disease.
GI	Abbreviation for gastrointestinal.
Granuloma	Microscopic collections of cells characteristic of Crohn's disease.
Gut	General word for intestine or bowel.
H&H	Abbreviation for hemoglobin & hematocrit.
H&P	Abbreviation for history and physical examination.
HCT	Abbreviation for hematocrit.
Hematocrit	A measure of the number of red blood cells. Low levels are seen with anemia.
Hemoglobin	The molecule in red blood cells that carries oxygen. Low levels of hemoglobin result in anemia.
Hemorrhage	Abnormally heavy bleeding.
Hemorrhoids	Painful, dilated veins of the lower rectum and anus, sometimes seen as a complication in persons with IBD.
Hgb	Abbreviation for hemoglobin.
History and physical examination	Contains your complete medical history as told to the admitting resident, as well as results of physical examinations.
HPI	History of present illness.
Hyperalimentation	A means of supplying patients with additional nutritional support by vein so that their nutritional requirements are met. Also known as total parenteral nutrition (TPN).
IBD	Abbreviation for inflammatory bowel disease.
IBS	Abbreviation for irritable bowel syndrome.
Idiopathic	Of unknown cause.
Ileoanal Anastomosis	A newer operation for ulcerative colitis (also known as the pull-through) in which an internal pouch is created after colectomy. Because the rectal tube is retained, the patient continues to evacuate through the anus.

Ileostomy	A surgically created opening of the abdominal wall to the ileum, allowing the diversion of fecal waste.
Ileum	The lower third of the small intestine, adjoining the colon.
Ileus	Temporary paralysis of the bowel, often resulting from sugery, abdominal infection, or electrolyte imbalance.
IM	Intramuscular.
Immunology	Study of the body's immune response to disease.
Immunomodulators	Drugs that suppress or amplify the body's immune response.
Incontinence	In IBD, the inability to retain feces, usually because of rectal inflammation.
Inflammatory Bowel Disease	A collective term for Crohn's disease and ulcerative colitis.
Intractable	Unrelieved by medical treatment.
Irritable Bowel Syndrome	Altered motility of the small and large intestine, causing diarrhea and abdominal discomfort. Sometimes mistakenly called "spastic colitis," this condition does not cause inflammation of the colon and has no relationship to IBD.
IV	Abbreviation for intravenous, meaning into a vein.
Lactase Deficiency/ Lactose Intolerance	A condition caused by a decrease or absence of the enzyme lactase, which aids in the digestion of milk sugar (lactose).
Lactose Breath Test	A test involving the drinking of a liquid rich in milk sugar. Breath samples are then taken over a period of time to determine whether there is a deficiency in lactase.
Leukocytosis	An increased number of white blood cells in circulation; an indicator of infection.
Mesalamine drug	The generic name for 5-ASA, a relatively nontoxic and well-tolerated used to treat inflamed intestine.
Motility	Movement of the muscles that propel food through the intestinal tract.
Mucus	A clear or whitish substance produced by the intestine, which may be found in the stool.
Nasogastric Tube (NG Tube)	A thin, flexible tube passed through the nose or the mouth. Used to remove liquids and air that collect in the stomach when the bowel is obstructed or after intestinal surgery, or to deliver nutrients into the stomach.
NPO	Nothing by mouth (Latin: nihil per os).
Obstruction	A blockage of the small or large intestine that prevents the normal passage of intestinal contents.

Occult Blood	Nonvisible blood in the stool, often an indication of disease activity. Simple lab tests can determine the presence of occult blood.
Operative Report	A complete record of any operation dictated by the surgeon after surgery.
Ostomy	The surgical creation of an artifical excretory opening, such as a colostomy.
Pathogen	A bacterium or virus capable of causing disease.
Pathogenesis	The origin and development of disease.
Pathology Report	Results of examination of any tissues removed from your body at operation or biopsy.
Perforation	Formation of a hole in the bowel wall, allowing intestinal contents to enter the abdominal cavity.
Perianal	The area around the anal opening; This area may become inflamed and irritated in persons with IBD.
Peristalsis	Normal rhythmic movements of the stomach and intestine.
Peristomal	The area immediately surrounding the stoma.
Peritonitis	Inflammation of the peritoneum (the membrane enclosing the abdominal organs), usually resulting from an intestinal perforation.
PO	By mouth (Latin: per os).
Proctectomy	Removal of the rectum.
Proctitis	Inflammation of the rectum.
Proctocolectomy	Removal of the entire colon and rectum.
Progress Notes	A daily record of your progress, test results, etc., by the professionals who care for you.
Prolapse	The falling or protrusion of an organ, such as the rectum or stoma.
PRN	As needed (Latin: pro re nata).
Proximal	Closer to the mouth; upstream.
Pyoderma Gangrenosum	A type of sore that sometimes occurs on the extremities of persons with ulcerative colitis or Crohn's disease.
Q4H	Every four hours.
QD	Every day.
QID	Four times per day.
QOD	Every other day.
RBC	Abbreviation for red blood cell.
Regional Enteritis	Another name for Crohn's disease affecting the small intestine.

Remission	A lessening of symptoms and a return to good health.
Resection	Surgical removal of a diseased portion of intestine.
Reservoir	A surgically created pouch, made from the distal ileum, which collects waste.
RX	Medications.
S	Without (Latin: sans).
SBFT	Abbreviation for small bowel follow-through. Used when describing an upper GI study in which barium is followed all the way through the entire small intestine.
SED Rate	See ESR
Short Bowel Syndrome	A condition in which so much diseased bowel has been surgically removed that the remaining intestine can no longer absorb sufficient nutrients.
Sigmoidoscopy	A test in which a lighted tube is passed through the rectum into the sigmoid colon.
Stat	Immediately.
Small Bowel	Small intestine.
Sphincter	A ring of muscle tissue keeping certain sections of the digestive tract (e.g., the anus) closed.
Stenosis	A narrowing of an area (e.g., a segment of intestine).
Stoma	A surgically created opening of the bowel onto the skin, the result of ostomy surgery.
Stricture	A narrowed area of intestine caused by active inflammation or scar tissue.
Strictureplasty	A surgical procedure that widens narrowed areas of intestine (strictures).
Subtotal Colectomy	Removal of part or most of the colon, leaving a part (usually the rectum) intact.
Sutures	Materials used in surgery to rejoin cut tissues and close wounds.
Tenesmus	A persistent urge to empty the bowel, usually caused by inflammation of the rectum.
TID	Three times a day.
TPR	Temperature, pulse, and respiration.
Total Parenteral Nutrition (TPN)	The intravenous infusion of all nutrients through a catheter placed in a large vein near the collarbone. Also known as hyperalimentation.

Toxic Megacolon	Acute dilation of the colon in ulcerative colitis (or occasionally in Crohn's disease), which may lead to perforation.
TX	Abbreviation for treatment.
Upper G.I. Series (UGI)	An x-ray exam of the esophagus, stomach, and duodenum performed in the fasting patients after the ingestion of liquid barium. The duration of the exam can be prolonged to allow for visualization of the entire small intestine, including the terminal ileum. The x-ray is then known as an upper G.I. series with small-bowel follow-through.
US or U/S	Ultrasound.
WBC	White blood cell.
WNL	Within normal limits.
X-ray Reports	Results of diagnostic x-rays.