



# WALK FOR HOPE

## TOGETHER, WE WILL CURE IBD.

Children's Hospital of Philadelphia's (CHOP) Walk for Hope, hosted by the IBD Family Research Council, raises funds to transform care through research for children with inflammatory bowel disease (IBD).

This day of celebration includes a 5K run/2K walk, activities, dancing and lots more!

100% of donations to Walk for Hope fuel over 30 active IBD research studies at CHOP. We are on a mission to find a cure and create hope for patients like YOU!



### JOIN US AT THE NEXT WALK FOR HOPE

*Scan this QR code to submit your name and email address, and we'll send you information about the next Walk for Hope.*

 **Children's Hospital  
of Philadelphia®**

**IBD**  
*Family Research Council*

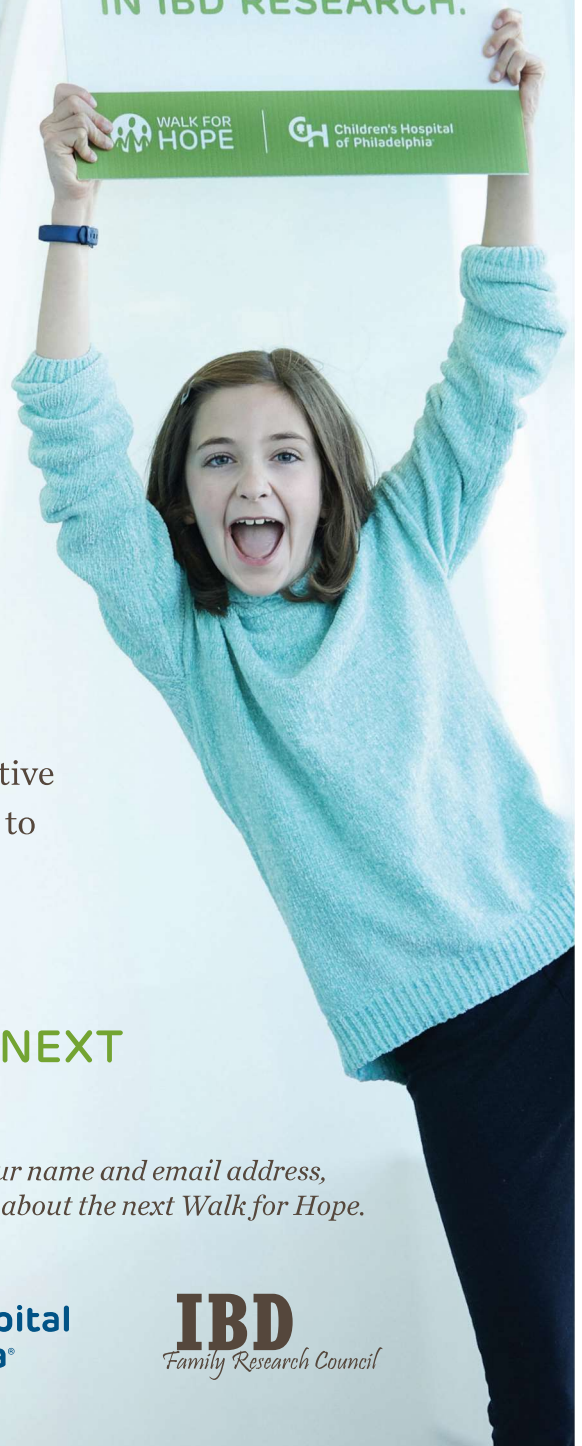
HELP CREATE  
BREAKTHROUGHS  
IN IBD RESEARCH.



WALK FOR  
HOPE



Children's Hospital  
of Philadelphia





# JOIN US VIRTUALLY!

## IBD Education Class

**WHEN:** Every first Wednesday of the month  
2:30 – 4 p.m.

**HOW:** Via an interactive online platform

- Learn about inflammatory bowel disease
- Ask questions about your specific concerns
- Suitable for all ages
- Taught by representatives from the IBD nursing team, dietitians, social workers, psychologists and child life specialists

**RSVP:** [IBDcenter@chop.edu](mailto:IBDcenter@chop.edu) or 215-590-7423

Once you register, we will email you the link to join the class

## IBD Action Plan

### **Feeling Good** - Green Zone: No or minimal symptoms

- Pain is absent or tolerable; at your baseline
- Bowel movements are normal for you; no pain or blood when going to the bathroom
- Energy level is good; you're able to attend school and do activities/hobbies
- Appetite is good; you're able to eat all meals and snacks

### **Take Action!**

- Use a hot pack or take Tylenol for your pain.
- Check for blood in toilet or on toilet paper.
- Stay active in school and social activities.
- Eat a balanced diet - avoid your trigger foods.
- Take your medicines every day.
- Attend your doctor's appointments.

### **Feeling Bad** - Yellow Zone: Mild symptoms are present or starting to increase

- An increase in bowel movements, lasting over 24 hours
- A change in the look of stools and/or streaks of blood or mucus, lasting over 24 hours
- Feeling like you have to run to the bathroom
- An increase in mild belly cramping or rectal pain
- A pattern of waking up early or overnight with bowel movements, lasting over 24 hours
- Energy level is decreased; you're able to attend school but are tired by the afternoon
- Loss of appetite; able to eat 75% of meals and snacks

### **Take Action!**

- Use your pain management strategies.
- Avoid your trigger foods.
- Take a nap after school or skip practice today.
- Decrease screen time.
- Keep your stress level down. Do deep breathing.
- Take your medicines every day.
- Tell your caregiver about your symptoms.
- Consider contacting your IBD Doctor for the next steps via MyCHOP or phone.

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**Feeling worse!** - Red Zone: Yellow Zone symptoms present for *more than 2 days* or worsening symptoms:

- Ongoing belly or rectal pain or new rectal drainage
- Blood in most bowel movements
- Diarrhea or increase in bowel movements
- Vomiting lasting more than 3 hours or vomit that is green (bile)
- Fever (greater than 101 F) with an unknown source (no recent sick contacts)
- Missing school or too tired for activities
- Loss of appetite; able to eat only 50% meals and snacks
- New symptoms: rashes, mouth sores, red/swollen eyes, joint pain/swelling

**Take action!**

☎ **Call your IBD Doctor **today**** (do not use MyCHOP)

○ **My IBD Doctor:** \_\_\_\_\_ # \_\_\_\_\_

☎ Weekends/evenings - call 215-590-1000 and ask to page the GI Fellow on call.

☎ *To make an appointment, call 215-590-3630.*

☎ To schedule an appointment for infusions in the GI Suite, call 215-590-3326.

☎ Contact your primary care doctor for general health questions or symptoms not related to IBD.

○ **My Primary Care Doctor:** \_\_\_\_\_ # \_\_\_\_\_

☎ **For Medical Emergencies, call 911!**





# IN THE ZONE

## IBD Action Plan

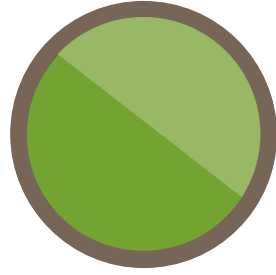


### GO ZONE

- Little/no pain
- Normal bowel movements
- Good energy level
- Good appetite

### TAKE ACTION!

- Use a hot pack or take Tylenol® for your pain.
- Check for blood in toilet or on toilet paper.
- Stay active in school and social activities.
- Eat a balanced diet. Avoid your trigger foods.
- Take your medicines every day.
- Go to your doctor appointments.

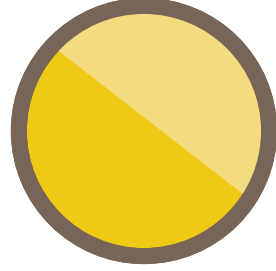


### SLOW DOWN ZONE

- Pain is present
- More/change in bowel movements
- More blood in bowel movements
- Running to the bathroom
- Waking up for bowel movements
- Low energy
- Loss of appetite

### TAKE ACTION!

- Use your pain management strategies.
- Avoid your trigger foods.
- Take a nap after school or skip practice today.
- Decrease screen time.
- Keep your stress level down. Do deep breathing.
- Take your medicines every day.
- Tell your caregiver about your symptoms.
- Consider contacting your IBD doctor for the next steps via MyCHOP or phone.



### STOP ZONE

- Worsening pain
- Diarrhea
- Vomiting
- Fever
- Blood in most bowel movements
- Missing school
- Severe loss of appetite
- New symptoms: rashes, mouth sores, red/swollen eyes, joint pain/swelling, rectal drainage

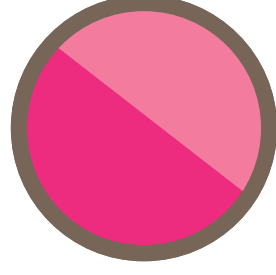
### TAKE ACTION!

Call your IBD doctor today (do not use MyCHOP).

My IBD doctor: \_\_\_\_\_

# \_\_\_\_\_

- Weekends/evenings: Call 215-590-1000 and ask for the GI fellow on call.
- Appointments: Call 215-590-3630
- For medical emergencies, **call 911!**



## **Very Early Onset Inflammatory Bowel Disease**

### **What is VEO-IBD?**

VEO-IBD is **very early onset** inflammatory bowel disease (IBD). It occurs in children less than 6 years of age who develop IBD. This chronic disease causes inflammation in the gastro-intestinal (GI) tract. There may be periods of no symptoms (remission) as well as periods of inflammatory symptoms (flare-ups).

### **How is VEO-IBD different from IBD?**

VEO-IBD is IBD that develops in infants and younger children.

IBD includes: ulcerative colitis (UC), Crohn's disease (CD) and indeterminate colitis (IBD that has features of both UC and CD). In all age groups, IBD can look and behave differently in the individual patients.

Children with VEO-IBD are not classified as UC or CD in the early stages of the diagnosis, because the disease can change and look very different over the first few months and even years. In some children, the diagnosis remains indeterminate IBD even as the child becomes older.

### **What causes VEO-IBD?**

The cause of VEO-IBD is different for every child and many times is unknown.

A combination of factors cause VEO-IBD, including genetics, the immune system, and the environment. The environment may include food, water, antibiotics, viruses, bacteria (and more), and also all of the bugs that live in the gut.

In very rare instances, there can be one gene or immune defect that causes VEO-IBD. This is not common. In these children, discovering the gene or immune defect helps the medical team treat the specific defect. Very often, we do not discover one cause for VEO-IBD.

### **How is VEO-IBD diagnosed?**

- Medical history
- Clinical symptoms
- Lab tests
- Endoscopy
- Colonoscopy
- Imaging tests
- Genetic tests

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#### **What is the treatment for VEO-IBD?**

Each treatment plan is specialized and unique. Treatment options include nutritional therapy, medications, and sometimes, surgery.

Some children with VEO-IBD are treated with different medications than the older patients. This is because some children with VEO-IBD have different symptoms and findings than older patients. In addition, in very rare cases, the immune system and genetics play a bigger role in the disease than older patients and different therapies are needed.

Medication, routine lab work and regular medical appointments help stop symptoms, prevent flare-ups, and heal the GI tract. Currently, for most patients, there is not a cure for VEO-IBD. However, with treatment, VEO-IBD will not interfere in a child's development, school activities or social interactions. There are no limits to what children with VEO-IBD can do or become.

#### **Who will take care of my child's VEO-IBD?**

The VEO-IBD team at Children's Hospital of Philadelphia (CHOP) includes:

- Gastroenterologists
- Immunologists
- Registered Dietitians
- Registered Nurses
- Behavioral Psychologists
- Social Workers
- Child Life Specialists

#### **For additional questions or concerns:**

Contact CHOP's VEO-IBD Program at 215-590-7423.

#### **Additional Resources about Very Early Onset Inflammatory Bowel Disease:**

<https://www.chop.edu/centers-programs/very-early-onset-inflammatory-bowel-disease-veo-ibd-program>

## **Nutrition and Inflammatory Bowel Disease**

Adequate nutrition is necessary to support growth and development for children with inflammatory bowel disease (IBD). Good nutrition can lead to better disease outcomes.

### **Why is nutrition important?**

Poor nutrition can occur when there is not enough energy consumed from food. This may be due to symptoms including loss of appetite, abdominal pain, mouth sores, diarrhea or poor absorption of carbohydrates, protein, fat, vitamins, and minerals.

Poor nutrition can lead to:

- Poor disease outcomes
- Decreased adult height
- Poor bone health
- Low weight

Good nutrition can:

- Decrease symptoms
- Improve vitamin and mineral balance
- Improve growth, weight, and development

### **How can food be used as medicine?**

There is no diet that can cause or cure IBD, but certain diets can be used to help treat IBD. Speak to your health care provider for more information. Nutrition needs are different based on age and gender. A child's activity level and disease may also affect nutrition. If your child is experiencing an increase in symptoms, we may recommend a modified diet including well-cooked vegetables and peeled fruits. Diet and IBD continues to be an active area of research at Children's Hospital of Philadelphia (CHOP) and other organizations.

### **Aim for a balanced diet that includes all food groups:**

- Fruits and vegetables
- Whole grains (whole wheat, brown rice, quinoa, and oatmeal)
- Lean proteins (yogurt, eggs, chicken, fish, nut butters, and beans)
- Dairy (as tolerated)
- Water

### **Limit the following foods:**

- Processed and smoked meats (deli meats, hot dogs, and sausages)
- Frozen meals and microwavable dinners
- Red meat
- High-fat, greasy foods (fast food)
- Packaged foods with a long shelf life
- "Added" sugars (high fructose corn syrup)
- Artificial sweeteners, including sugar alcohols (reduced-calorie sweeteners, such as erythritol, maltitol, sorbitol, Stevia, and xylitol)
- Sugar sweetened beverages (juices and sports drinks)

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Your child should avoid whole nuts, large seeds, and popcorn if they have a narrowing of the intestine (called a "stricture") from inflammation or scar tissue. Speak to your health care provider if you are unsure whether your child has a stricture. Small seeds, such as those found in strawberries and cucumbers, are okay to eat.

#### **What is a processed food?**

A processed food is considered a food that has been changed from its natural state. Processed foods often contain food additives that are used to preserve a product's shelf life.

#### **Why are vitamins and minerals important to children with IBD?**

Decreased bone mineral density is common in children with IBD. It is important to ensure adequate intake of calcium. Additional supplementation of nutrients including vitamin D, iron, folic acid, and calcium may be needed. Children should eat a healthy diet high in lean protein, fruits, vegetables, and whole grains.

#### **How can I improve my child's nutrition?**

Your child should eat slowly, chew food well, and listen to their body to determine what foods they can tolerate and what foods to avoid. Nutritional formula (commercial liquid supplements) and homemade smoothies are good sources of energy. Tube feedings may be needed to provide additional calories to help your child gain weight. Discuss nutrition concerns and goals with an IBD dietitian.

#### **Label reading tips:**

- Look for sources of added sugar in food and sports drinks (table sugar and syrups).
- Aim for foods with fewer ingredients on the food label.
- Avoid ingredients you do not recognize or are difficult to pronounce.
- Avoid foods with high amounts of sodium (used to preserve a food) and food dyes (used to artificially color food).

#### **Label reading practice:**

Below are two Nutrition Facts labels of different brands of vanilla bean ice cream. If you had the option to pick between the two brands, we recommend Brand #2 because it contains fewer ingredients.



**Brand #1:**

<b>Nutrition Facts</b>		
Serving Size 1/2 cup (66 g)		
Servings Per Container 12		
<b>Amount Per Serving</b>		
Calories 130		
Calories from Fat 70		
		% Daily Value
Total Fat	7 g	11%
Saturated Fat	4.5 g	23%
Trans Fat	0 g	
Cholesterol	25 mg	8%
Sodium	50 mg	2%
Total Carbohydrates	16 g	5%
Dietary Fiber	0 g	0%
Sugars	12 g	
Protein	2 g	4%
Vitamin A 6%      Vitamin C 0%		
Iron 0%              Calcium 8%		
<b>Caffeine:</b> 0 mg to 0 mg		
<b>Ingredients:</b> Milk, Cream, Corn Syrup, Sugar, Whey, Nonfat Milk, Cellulose Gel, Cellulose Gum, Vanilla, Mono & Diglycerides, Carrageenan, Vanilla Bean.		
<b>Contains:</b> Milk		
<b>Additional Info:</b> Gluten-Free, Caffeine-Free		

**Brand #2:**

<b>Nutrition Facts</b>		
Serving Size 1/2 cup (69 g)		
Servings Per Container 14		
<b>Amount Per Serving</b>		
Calories 150		
Calories from Fat 80		
		% Daily Value
Total Fat	9 g	14%
Saturated Fat	5 g	25%
Trans Fat	0 g	
Cholesterol	50 mg	17%
Sodium	45 mg	2%
Total Carbohydrates	16 g	5%
Dietary Fiber	0 g	0%
Sugars	15 g	
Protein	3 g	7%
Vitamin A 6%      Vitamin C 0%		
Iron 0%              Calcium 10%		
<b>Caffeine:</b> 0 mg to 0 mg		
<b>Ingredients:</b> Milk, Cream, Skim Milk, Sugar, Egg Yolks, Natural Vanilla Extract & Vanilla Bean Specks.		
<b>Contains:</b> Eggs, Milk		
<b>Additional Info:</b> Gluten-Free, Caffeine-Free		

**How do I schedule an outpatient nutrition appointment?**

- To schedule an appointment at the Buerger Center, call the Center for Pediatric IBD at 215-590-7423.
- To schedule an appointment with a dietitian in Abington, Exton, King of Prussia, Princeton, or Voorhees call central scheduling at 215-590-3630.
  - We try to coordinate visits with your child's gastroenterologist and dietitian.



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# POPS REFERRAL PROGRAM

Peer program offers practical support for families living with IBD

*Katherine, 9, treated for IBD, with her mother*

Learning your child has inflammatory bowel disease (IBD) can be a scary and challenging time. CHOP's Center for Pediatric Inflammatory Bowel Disease provides a Peers Offering Practical Support (POPS) program to parents and guardians who have children diagnosed with IBD.

**The POPS Program provides practical, nonclinical support to help families cope with their child's diagnosis.**

*In the POPS Program, families may discuss:*

- A pediatric IBD diagnosis and what it means for your child's life — today and in the future
- General support, including explaining IBD to younger children and encouraging teens to make healthy choices for their medical condition
- Tackling life with IBD: school, social life, sports and college

You may connect by phone, text, email or in person with a POPS member, depending on your preferences.

An experienced social worker will partner with you through POPS to provide a better understanding of the program's advantages and how you can use it to help your children.

 **Children's Hospital  
of Philadelphia®**  
Center for Pediatric  
Inflammatory Bowel Disease

**LEARN MORE OR SIGN UP**  
267-426-9589  
[chopibdgroup@email.chop.edu](mailto:chopibdgroup@email.chop.edu)

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# ANXIETY, DEPRESSION AND DAILY ACTIVITIES IN GI PATIENTS

Anxiety, depression and difficulty completing daily tasks are common in children and adolescents with gastrointestinal (GI) conditions. Identifying and treating these concerns can improve your child's ability to cope with their medical condition and live life to the fullest.

We want to provide the best care for your child, so we now ask all patients 8 years and older to complete brief questionnaires about their experience with anxiety, depression and completing daily tasks. This will be done on a computer while your child is waiting to be seen at their appointment.

We will review the answers carefully. If your child expresses concern about how they are feeling, your GI team will talk with them further and help to figure out next steps. If we have concerns about your child's safety, our team will discuss them with you. Your child's answers may be viewed by their medical team at CHOP but will not be shared with anyone else.

It is important that your child is allowed to complete the questionnaires on their own, and that their answers are not influenced by anyone else.

## **What is Aromatherapy?**

Aromatherapy uses oils from the roots, leaves, seeds, or blossoms of certain plants to help boost a person's mood or make them feel better. These are called essential oils. Aromatherapy can help your child feel better when they are sick or hurt and promote the health of body, mind and spirit. Each oil works in different ways.

### **How does aromatherapy work?**

Some experts believe that aromatherapy works because tiny particles of the essential oil “turn on” smell receptors in the nose. Once these receptors are turned on, they send signals to the brain. The brain sends messages to areas of the nervous system that control mood and perception of symptoms such as pain and anxiety.

### **What conditions can be treated by aromatherapy?**

Different essential oils have different chemical properties. Some help with relaxation and decreasing stress and others may support a positive mood and increase digestive comfort.

### **Is aromatherapy safe?**

It is important to talk with your healthcare provider before you begin using essential oils with your child. According to the National Institute of Health's Center for Complementary and Integrative Health, essential oils have few harmful side effects. They can make some conditions or illnesses worse. Some essential oils can react with certain medications.

When essential oils are placed directly on the skin, they can cause irritation. It is very important to mix (dilute) essential oils in oil or lotion before applying them to the skin.

To use essential oils safely:

- Only buy pure essential oils that include
  - the Latin name of the oil
  - the part of the plant it came from
  - how it was obtained (Steam, distilled or cold pressed)
  - what country it came from
- Keep essential oils away from the eyes.
- Keep oils away from fire or flame.
- **Do not** allow your child to swallow essential oils.

People with certain health conditions should not use or handle essential oils until they check with their healthcare provider. Some of these conditions include:

- Lung conditions such as asthma
- Allergies
- Pregnancy
- Seizure disorder
- Heart conditions and high blood pressure
- Certain types of cancer

51:B:06

### How is aromatherapy performed?

Aromatherapy can be used in different ways.

- **Pre-filled Sniffer (Inhaler):** Allows your child to breathe in essential oils through his nose.
- **Room Diffuser:** A diffuser is a machine that releases particles of the essential oil throughout a room, similar to a vaporizer. It should only run 30 minutes or less at a time.
- Essential oils can be mixed with oil or lotion then massaged into the skin.
- Sometimes essential oils are placed into bath water but they should be properly diluted first in either Epsom salts, baking soda or vegetable glycerin. (Sold at health food stores)

Essential oils should never be swallowed or taken internally.

### How often can we use aromatherapy?

Aromatherapy by inhalation can be used as often as needed and tolerated. If you are using other methods of application of the oils, it is important to follow instructions from a professional and always dilute the oils before applying to the skin.

### Does aromatherapy take the place of traditional medicine?

Aromatherapy is **not** a substitute for medical care provided by a healthcare professional.

Please talk to your health care provider if you would like to learn more about aromatherapy. Our staff can help you decide if aromatherapy might be a helpful addition to your child's care plan.



## Acupuncture

### **What is acupuncture?**

Acupuncture is a therapy that is believed to use the body's natural healing ability to reduce pain and improve functioning. In acupuncture, very fine needles, slightly thicker than a human hair, are inserted into specific points in the body called acupoints.

### **How does acupuncture work?**

We don't fully understand how acupuncture works. Scientists believe that when the acupoints are touched on the patient's body, the patient's nervous system will release chemicals, such as endorphins, in the body. These chemicals may promote the body's natural healing ability, reduce pain, and promote physical and emotional well-being.

### **What conditions can be treated by acupuncture?**

Scientific studies have shown that acupuncture can be an effective treatment for pain and nausea. While acupuncture is sometimes used to treat other conditions, there is less information about its effectiveness. You can speak with one of our providers to determine if acupuncture may help your child.

### **How is acupuncture performed?**

Acupuncture will be performed in a gentle and safe manner.

### **Before Treatment:**

- Your child's Health Care Team will talk with you about your child's health problem and then decide if acupuncture therapy is appropriate for your child.
- We may ask about your child's daily activities and what they like.
- We may check your child's pulse and do a brief physical examination.

### **During Treatment:**

- Your child will be offered a gown, towel or sheet for comfort. We may use a blanket or heat lamp to help keep your child warm during the treatment.
- We will ask your child to lie down.
- We will decide which points on the body to use, based on the problem being treated.
- We will insert needles into acupuncture points. We may need to insert needles into areas of the body away from the affected area to get the best results.
- The needles usually stay in place for 10 to 20 minutes. It is very important for your child to lie still during this time to allow your child's body time to stimulate its natural healing ability.
- At the end of the session, the needles will be removed.

Some children may find it hard to lie still during the session. If for some reason your child is unable to lie still, we will not proceed with acupuncture in order to protect your child's safety.



### 51:B:01

#### **Who will perform my child's acupuncture treatment?**

Your child's treatment may be done by a physician acupuncturist or a licensed acupuncturist.

#### **How many treatment sessions are needed?**

The exact number and schedule of treatments depends on your child's symptoms. Most patients require 6 to 12 treatment sessions. Sometimes two sessions per week will be needed to show relief of symptoms. The acupuncturist will work with you and your child to develop a unique treatment plan.

#### **How long are typical treatment sessions?**

The first session usually lasts 60 minutes. Follow up sessions usually last about 30 minutes or less.

#### **Is acupuncture safe?**

Acupuncture is safe when performed by properly trained providers. Serious side effects are very rare. The Acupuncture Program at CHOP is closely managed to ensure your child's safety. Our acupuncturists are skilled in caring for children, and are trained in decreasing any anxiety or fear associated with the needles used for acupuncture.

#### **Does acupuncture have side effects?**

Your child may feel energized by treatment, or more relaxed or drowsy after treatment. When the needles are inserted, your child may feel pressure at the acupuncture point. Sometimes your child may have minor bleeding or bruising at the site where the needle was inserted.

#### **Is acupuncture painful?**

Most children have little to no pain and report less than 2 out of 10 on a pain scale. Some patients may feel a gentle pinch when the needle is inserted, others feel a tickle.

#### **Does acupuncture replace traditional medicine?**

Acupuncture is **not** a substitute for medical diagnosis and treatment. Our staff can suggest ways to include acupuncture in your child's care plan. Please talk to your medical provider about whether acupuncture should be considered for your child.

Please share any questions or concerns about acupuncture with your child's care team.

## Yoga

### **What is yoga?**

The word “yoga” itself means, “union or to unite”. Yoga focuses your attention on your breath and your body at the same time. Yoga can help to improve health and wellbeing (physical, emotional, mental and social) through the regular practice of postures and poses (asana), breathing exercises, relaxation and meditation.

### **How does yoga work?**

Yoga poses can enable you to stretch or build certain muscle groups, increase flexibility, and help your brain make more serotonin. Serotonin is a chemical that makes you feel calmer, more upbeat, and boost overall well-being. When you move your body into different yoga postures and focus on your breath, you can begin to feel better connected to your body.

### **Which health conditions might be improved by yoga?**

As research shows, the practice of yoga and meditation can improve your overall health and can offer support to people with almost any health condition, either physical or psychological. We often modify poses or use props to make the practices safe and effective and strive to create personalized yoga sessions to support your child, regardless of age or health conditions.

### **What happens during a yoga session?**

Yoga may be done in one-on-one or group sessions.

Each yoga session is altered to meet the needs and ability of the individual.

### **A yoga session could include:**

- Breathing exercises and/or relaxation
- A physical warm up
- Yoga postures, movements, or stretches
- Relaxation and/or meditation.

Meditation is offered in age and developmentally appropriate ways. Meditation can be used to focus the mind on a specific thought, images, or ways to direct the breath. It can help an individual to relax, support sleep, and decrease anxiety.

The length of each personalized or group yoga session is determined based on the age, health, and interest of your child. Sessions can last from 25-60 minutes.

## 51:B:04

### **When may my child start participating in yoga sessions?**

- Your child's Health Care Team will talk with you about your child's health and then determine if a yoga session is appropriate for your child.
- We may ask about your child's daily activities and preferences.
- We may do a brief physical assessment and partner with other members of your child's healthcare team to ensure yoga is a good fit for your child.

### **Who will perform my child's yoga session?**

Your child's yoga session will be led by a certified children's yoga teacher with extensive experience working with children with a variety of health conditions and needs across various life stages.

### **How many yoga sessions are needed?**

The exact number and scheduled sessions depend on your child's symptoms and interest in participating in yoga sessions. Yoga is a practice that can be continued throughout life as means of on-going support and overall well-being. A specialized plan for your child's yoga practice will be determined by your medical team, the yoga instructor, and your child/family.

### **What are the potential benefits of yoga?**

In recent years, there have been a growing number of well-designed studies into the health benefits of yoga. These studies show that the practice of yoga is safe, useful and appropriate for a wide range of conditions and life-stages. It is important to make adjustments of the yoga postures to meet a person's physical and developmental abilities. Adjustments of the yoga postures are done under the supervision of a certified yoga teacher.

With regular practice, yoga has been linked to:

- Improved fitness and well-being
- Weight loss
- Stress relief and relaxation
- Increased sense of calm
- Improved immunity
- Greater ability to focus attention
- Increased energy
- Increased flexibility and strength

### **Is yoga safe?**

Yoga is safe when taught by a properly trained provider. Serious side effects are rare. The Yoga Program at CHOP is closely managed to ensure your child's safety and sense of accomplishment. Our instructors are skilled in caring for children, and are trained in making participation in yoga achievable, fun, and supportive of your child.

Please talk to your medical provider if you are interested in a personalized yoga session or consult for your child. We invite you to share your questions about yoga and this supportive care option with your child's care team.



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Revised 6/21  
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## Tools to Help with Stress: Breathwork

**Breathwork** (Pranayama) is a general term for mindfully changing your breathing. When you breathe in (inhale) using your belly and breathe out (exhale) slowly, it can help you to relax. Try these simple breathing techniques the next time you are feeling overwhelmed, anxious or stressed. Stay focused and practice the breaths 3-5 times each. Increase the number of breaths by one breath every couple of days. You can stop at any time. If you feel dizzy or nauseous, **stop** and take a break.

**Balloon Breath:** Make a circle with your hands, make the circle bigger when you inhale, and then make the circle smaller when you exhale.

- Pretend to blow up a balloon with slow, controlled breaths.
  - Breathe in through your nose to fill your lungs and belly. Focus on filling your belly. Your shoulders should only move a little bit.
  - Breathe out slowly through your mouth to blow up the imaginary balloon. You could use a real balloon to do this exercise.

**Belly Breathing:** Breathe slowly in through your nose, and then out through your mouth.

- Breathe in through your nose. Allow the breath to go down into your belly and flow out through your mouth.
- Notice the way your belly rises and falls when you breathe in and breathe out.
  - If you lie down you could place a small toy on your belly to see it rise and fall.
- Let your thoughts come and go. Notice your breath as it enters your nose, travels to your belly, filling it with a sense of calm and peace.
- Notice your breath bring an even rhythm as you breathe in and breathe out. Focus on your breath, focus on its pathway as it enters your body and fills you with peace.
  - If this makes you more anxious, take a break and try again later.

**Bee Breath:** Making a buzzing sound while you exhale can help you to relax.

- Sit tall and straight.
- Relax your shoulders and face.
- Take a long, slow deep breath in through your nose and then breathe out slowly while you make the buzzing sound of a bee. Try to make your buzz long and slow.
- Notice the vibration in your lips, and in your mind. How does it feel?
- Now, try it with your eyes and ears closed so you can hear the sound from the inside.
- Take a moment, close your eyes and then cover your ears. You do not have to close your eyes.
- Take a long, slow breath in and then breathe out making a long, slow buzz or hum.



51:B:19

**For older children and adults:**

**Alternate Nostril Breathing:** Sit straight and tall in a comfortable position. Try to release any tension in your face by thinking about softening it.

- Close your eyes or gaze softly down the tip of your nose. Think about releasing tension from your jaw.
- Let your left hand rest on your lap.  
Close off your right nostril with your thumb and breathe in through your left nostril.
- Use your index finger and close off the left nostril. Breathe out through the right nostril.
- Breathe in through your right nostril while keeping your left nostril closed.
- Switch fingers, close off the right nostril with your thumb and breathe out through the left.
- Start by trying to do three complete cycles of breaths in and out. You may add cycles if it feels good. Stop whenever you like.

If you or your child continue to experience anxiety or stress, it is important that you call and speak with your health care provider. If you feel you or your child are in immediate danger, please call 911 or go to your nearest emergency room.

**For more information and resources see the Integrative Health Website:**

<https://www.chop.edu/centers-programs/integrative-health/health-resources>



<https://www.chop.edu/centers-programs/integrative-health/therapeutic-breathing-video-series>



At Children's Hospital of Philadelphia (CHOP), Channel 54 has Integrative Health Content.

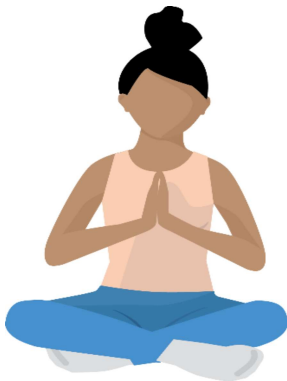

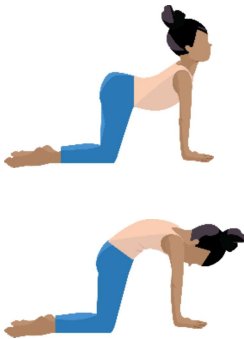


Written 5/20



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## Tools to Help with Stress: Yoga

You can try these gentle yoga poses to help decrease anxiety. You and your child can do them together. Remember, yoga should not hurt. Some poses may not work for you as shown. If you have any questions, please email [integrativehealth@email.chop.edu](mailto:integrativehealth@email.chop.edu) and a yoga therapist will reach out to you to offer some guidance within 48-72 hours.

Yoga Posture	Benefit	Visual	Instruction
<b>Easy Pose</b>	Be at rest and start to notice your breath.  Stretches knees and ankles.		Sit down.  Cross your legs in front of you.  Place your hands gently on your knees with your palms facing down.  If you are comfortable here, go ahead and begin to trace circles in the sky with your nose. Do that about 3-5 times. Next, breathe in, touch your right ear to right shoulder, breathe out and touch your left ear to your left shoulder.
<b>Butterfly Pose</b>	Stretches and relaxes thighs.  Opens hips and increases flexibility.		Sit down.  Place your hands on your knees.  Uncross your legs and bring the bottoms of your feet together in the shape of a diamond.  Relax and breathe.
<b>Cat/Cow</b>	Stretches the back and neck.  Creates a connection with breath and movement of the spine.  Stretches the front of the torso and the neck.		Get up on your hands and knees.  Breathe in as you gently arch your back, open your chest, drop your belly and gaze towards the sky.  Breathe out as you round your back and allow your head to drop down to look at floor. (Look like a hissing cat)

## 51:B:20

<b>Child's Pose</b>	<p>This is a resting pose. Notice how your chest expands and feel it on your legs.</p> <p>Stretches knees, ankles and opens hips.</p>		<p>Come down to hands and knees.</p> <p>Spread your knees wide but keep your toes touching.</p> <p>Bring your forehead down to the ground with your arms reaching out in front of you.</p> <p>If this is too big of a stretch, you can rest your body over a pillow or allow your forehead to rest on a yoga block.</p>
<b>Rest Pose</b>	<p>This is a resting pose. You can stay here for as long as you like. You may want to cover with a blanket to stay warm or roll a small towel underneath your knees.</p>		<p>Lay on your back. Rest your arms by your sides with your palms facing up. Feet can fall outwards.</p> <p>Close your eyes, and allow your body to relax.</p>

### Mudra for Relaxation and Restoration:

Mudras are hand shapes that can be done while seated or lying down. They help direct energy in the body. Mudras will help you feel more relaxed. They can be held while doing some deep breathing for as long as feels good to you. It could be as short as 5 breaths or as long as 5 minutes or even longer if you want.

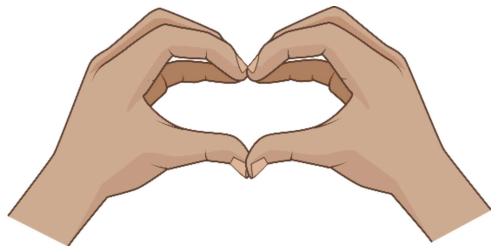
### Gesture of the Earth:

- Curl the pinky and ring fingers toward the palm with the thumbs on top.
- Extend the middle and index fingers straight out in a “V” shape.
- Reach out to each side and touch the tips of the middle and index fingers to the ground.
- Relax the shoulders and sit tall.



## **Gesture of the Open Heart:**

- Hold the hands in front of the heart with the palms facing each other and fingertips pointing upward.
- Interlace the fingers inward so that they slightly cross, with the right pointer finger closest to the heart.
- Stretch the thumbs down to touch at their tips to form a heart shape.
- Relax the shoulders and sit tall.



If you or your child continues to experience anxiety or stress, it is important that you call and speak with your health care provider. If you feel you or your child is in immediate danger, call 911 or go to your nearest emergency room.

For yoga videos while staying in the hospital, tune in to Channel 54.

**For more information and resources, see the Integrative Health Website:**

<https://www.chop.edu/centers-programs/integrative-health/health-resources>



# RE-EEN Smoothie

**RE-EEN Smoothie Study:** The RE-EEN Smoothie Study is recruiting patients newly diagnosed with Crohn's Disease who are interested in using diet to help achieve disease remission. The purpose of the study is to evaluate the use of a whole-food based smoothie as Exclusive Enteral Nutrition for Crohn's Disease. In this study, participants will be randomly assigned to receive either a whole-food based smoothie, or formula as Exclusive Enteral Nutrition (EEN) therapy for Crohn's Disease. Participants will work closely with the study dietician to ensure that all their nutritional needs are met during their participation in the study.

**Eligibility:** 8- 21 years old. Participation will last for 8 weeks and will involve 4 study visits. At each study visit you will meet with the study dietician, complete study questionnaires, as well as have blood, stool, and urine collected. There is an optional follow-up visit at month 8-14. All nutrition visits and lab visits will be paid for by the study. Depending on which treatment group you are randomized to, the study will provide you with formula or money to purchase foods for the smoothie. Additionally, participants will be compensated for their time and effort for the 5 stool samples they provide throughout the study.

**To learn more please contact [IBDresearch@chop.edu](mailto:IBDresearch@chop.edu)**



# INROAD

**INROAD Study:** The INROAD study aims to understand which genes cause IBD and expand on what is known about how IBD affects those with African ancestry. Patients are being recruited within the first two years of diagnosis at their scheduled infusion visits. This study is being done in collaboration with hospitals around the country, and is headed by Emory University in Atlanta, Georgia. Participants will be compensated for their time and effort, upon completion of each visit.

**Eligibility:** Participation in the study will last up to five years and includes an annual collection of blood, stool, and biopsy samples, and a one-time saliva sample at the first visit. All study visits will align with clinically indicated visits already scheduled, and biopsy collection will only occur at scopes that are part of the patient's clinical care.

**To learn more please contact [IBDresearch@chop.edu](mailto:IBDresearch@chop.edu)**

# PIFI/PIDI

**PIFI-PIDI Study:** This study aims to create special tools to measure fatigue and disability in patients aged 2-18. Researchers will talk to patients and their parents to find out what issues matter most and use this information, along with medical records, to design the tools. The goal is to help doctors track these problems better and improve care for children and adolescents with IBD. This study is being done in collaboration with the Shaare Zedek Medical Center. Participants will be compensated for their time and effort, upon completion of the interview.

**Eligibility:** 2- 18 years old. Attend a one time 30–45 minute audio and video recorded interview & review medication and medical history.

**To learn more please contact [IBDresearch@chop.edu](mailto:IBDresearch@chop.edu)**

# Welcome to the MACARONI-23 Study

Thank you for deciding to allow your child to take part in this important clinical research study. This Study Guide will help you understand what you can expect during each of your child's appointments at the study center. You may wish to bring it with you to your child's appointments.



**If you have any questions, please ask a member of the study team. Contact details can be found on the back cover of this Study Guide.**

## About the MACARONI-23 Study

The main purpose of this study is to look at whether 2 study drugs work to treat Crohn's disease (CD) in children.

This study is being done by 2 pharmaceutical companies working together: Janssen Research & Development, LLC, and Eli Lilly and Company.

Your child has been randomly assigned (by a computer) to receive **guselkumab**. This study drug was developed by **Janssen Research & Development, LLC**.

This study will also look at the safety profile of the study drug in children and what the body does to the study drug (this is called "pharmacokinetics").



## About the study drug

Guselkumab is a monoclonal antibody that targets interleukin-23 (IL-23).

- **Monoclonal antibodies** are antibodies that are made in laboratories. They act like the antibodies produced naturally in our bodies that seek out and destroy any substances that the immune system might react to (called antigens).

- **IL-23** is a naturally occurring **protein** found in the body that is involved in inflammatory processes, including inflammation of the bowel. Guselkumab targets a specific part of a protein in IL-23 to block its action.

- The study drug will be given by injection into a vein (intravenously) and/or under the skin (subcutaneously) during the study.



The image depicted contains models and is being used for illustrative purposes only.



## How long will my child be in the study?

- Your child will be in the MACARONI-23 Study for about 1.5 years.

## Welcome to the U-Astound Study

Thank you for deciding that your child will take part in this important clinical research study.

This Study Guide will help you understand what to expect during your child's visits to the research center. You may wish to bring it with you to your child's visits.



**If you have any questions, please ask a member of the site staff. Contact details can be found on the last page of this guide.**

## About ulcerative colitis

Ulcerative colitis (UC) is the name given to inflammation in the lining of the large intestine. UC is a long-term (chronic) condition and there is no known cure.

Symptoms of UC in children may include:

- bloody diarrhea
- cramping
- tiredness
- weight loss.



These symptoms come and go at random. UC can have a major impact on your child's daily life, and can even affect their growth.

## About the U-Astound Study

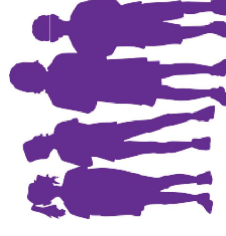
The U-Astound Study will look at a potential new medication ("the study medication") for children and teenagers with moderate to severe UC.

The main goals of this study are to find out if the study medication is safe and if it works in treating UC. The study will also look at how the study medication is broken down in the body (called "pharmacokinetics," or PK). PK testing is important to check if the doses of the medication are safe and to see if they work.

The U-Astound Study will include about 110 children and teenagers, 2–17 years of age, who have already received treatment for UC.

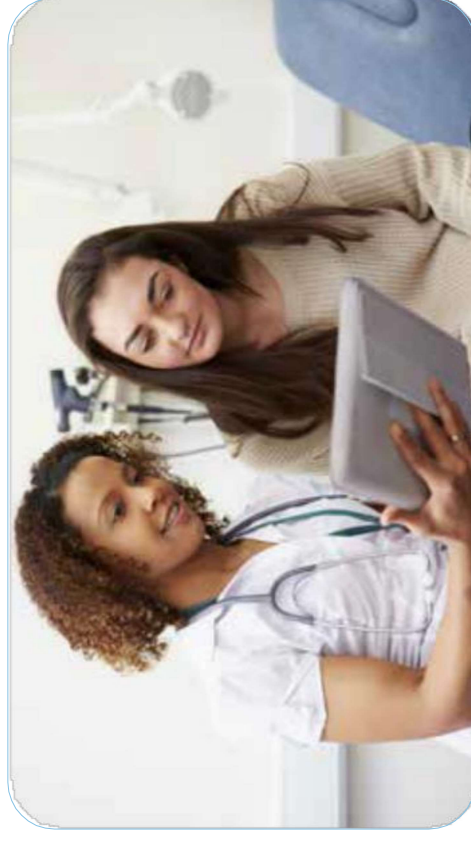
110

children



2–17

years of age



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# Cameo

- **Cameo Study:** This NIH-funded study hopes to identify factors behind why certain children with Crohn's who are treated with anti-TNF biologics experience intestinal healing and why others do not.
- **Eligibility:** 6-17 years old, suspected to have or is diagnosed with Crohn's MRE imaging, anti-TNF as starting therapy or within 180 of different initial treatment, available for year-long follow up

To learn more please contact [IBDresearch@chop.edu](mailto:IBDresearch@chop.edu)

# Capture

- **Capture Study:** CAPTURE IBD (Cohort for Pediatric Translational and Clinical Research in IBD) is a new study that seeks to address gaps in current pediatric IBD research. The study is seeking applicants for a patient and caregiver advisory council that will advise study leadership. If you are a primary caregiver (18+) to a pediatric IBD patient, or you are a pediatric patient aged 16 and older diagnosed with IBD you are eligible to apply.
- **Eligibility:** Ages between 4 and 21
  - IBD diagnosis( CD, UC, or IBD Unclassified) and clinical suspicion of active disease
  - Patients for whom there is not high suspicion of intestinal inflammatory disorder and undergoing clinically diagnostic colonoscopy with biopsy to serve as non- inflamed control participants

**To learn more please contact [IBDresearch@chop.edu](mailto:IBDresearch@chop.edu)**



# IBD Medication Registry

- **IBD Medication Registry:** An Observational Study of the Natural History of Therapy in the Management of Pediatric Patients with Inflammatory Bowel Disease. The primary objective is to evaluate change in disease activity in children and adolescents with IBD starting new IBD therapy.
- **Eligibility:** Males or females less than 18 years old with confirmed diagnosis of CD, UC or IBD-U starting a new therapy prescribed by CHOP physician.

To learn more please contact [IBDresearch@chop.edu](mailto:IBDresearch@chop.edu)

# Ulcerative Colitis?

**The RAVANS study is designed to assess the safety and effectiveness of auricular stimulation using the Cala RAVANS device in pediatric and young adult patients with Ulcerative Colitis.**

## **What is a clinical research study?**

Clinical research studies look for new ways to progress science and develop potential treatment options. They are designed to test the safety and effectiveness of investigational therapies to understand if these potential treatments can be used in the future.

## **Could the RAVANS study be an option for you?**

The study may be option for you if you:

- have been diagnosed with Ulcerative Colitis
- are between 10-39 years old
- are experiencing Ulcerative Colitis symptoms

## **What to do if you are interested?**

If you'd like to learn more about the RAVANS study, please email the study team at [KLacey2@northwell.edu](mailto:KLacey2@northwell.edu).

Please remember that contacting the team does not mean you have to join the study.

A new clinical research study exploring a non-pharmacologic therapy for pediatric and young adult patients with active Ulcerative Colitis.

