NEW!

You, Me AND IBD

An Educational IBD Magazine for
Children, Teens and Parents

What's Inside

robbie's rainbow.ca

ABOUT US

Robbie's Rainbow is a registered Canadian charity comprised of patients, parents, gastroenterologists and members of the public. Our organization came together to provide children with IBD access to critical treatments, diagnostic testing, education, mentorship and support. We recognized that children were not able to access the most impactful treatments for their disease due to lack of private and public health coverage. We believe research plays a vital role and look to researchers to find a cure to this debilitating disease. Today, we have a website that provides information to the public on our goals and how to get involved. It provides IBD families with valuable resources and a parent support network. We also have an ambassador program that brings IBD children and their parents together, so we all have the opportunity to build relationships with those who fully understand living life with a chronic illness.

MISSION

Robbie's Rainbow is a registered children's charity dedicated to improving the health and quality of life of children and families living with Crohn's disease and ulcerative colitis.

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ROBBIE'S RAINBOW AFFILIATES

The Canadian Digestive Health Foundation
www.CDHF.ca

Welcome to...

our latest edition of You, Me and IBD.

We have curated a variety of articles on topics relevant to children, teens and parents on IBD, sharing insights and strategies to manage IBD in a positive and proactive way. You will find easy to follow recipes created by our expert registered dietitian and fun activities to provide an additional level of enjoyment for our younger readers, we strive to offer something interesting and engaging for all.

You can trust and have faith in our educational materials as our articles are both written and reviewed by experts in the field of pediatric gastroenterology and nutrition. We aim to touch upon the many aspect of life with IBD, bringing thoughtful, expert and positive insights that add value and guidance.

The mission of our organization, Robbie's Rainbow, is to enhance the quality of life of children, teens and families affected by IBD in providing articles, information and resources that support the quest for knowledge.

This is a pivotal year for our organization as we turn 10 years old. We have accomplished so much in our first decade, having raised over half a million dollars in funding for research and compassionate funding for children in need of therapies, diagnostics and care not covered by provincial and private health plans.

You, Me AND IBD

An Educational IBD Magazine for Children, Teens and Parents

As we move into our next decade, we are thrilled to share with you our collaborative partnership with the Canadian Digestive Health Foundation (CDHF). The CDHF has over 20 years experience in helping improve the quality of life of Canadians affected by digestive diseases. We are excited to work with the CDHF on new initiatives and have the opportunity to share a larger stage nationally.

If this is your first time reading You, Me and IBD, we are delighted that you are joining us as a reader. Should you be a long-time reader of our magazine, we thank you for your confidence and support over the years, and we look forward to sharing many more editions of You, Me and IBD together.

ABOUT OUR PARTNER

CDHF Canadian Digestive Health Foundation

The Canadian Digestive Health Foundation (CDHF) is Canada's trusted resource on digestive health. CDHF is committed to providing useful, up-to-date information and research to help Canadians better manage digestive conditions and live healthier lives.

CDHF's primary mission is to reduce the pain and suffering and improve quality of life by providing trusted, accessible, and accurate information about digestive health and disease.

Additionally, the Canadian Digestive Health Foundation is committed to empowering all Canadians to manage their digestive health with confidence and optimism.

CDHF is the official foundation of The Canadian Association of Gastroenterology (CAG). Over 1100 members including gastroenterologists, surgeons, pediatricians, basic scientists and nurses comprise the Association.

CAG provides professional gastroenterological education and funding opportunities for gastrointestinal health and disease research, and more recently, has advocated for improved timeliness and quality of digestive health care for Canadians.

Learn more on CDHF's website: CDHF.ca

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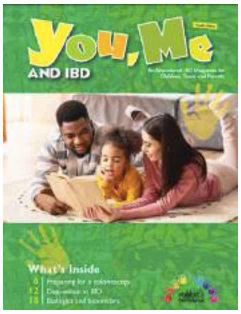

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Digestibles Healthy Lifestyle Choices

The Deal with Diet & Nutrition

Did you know "diet" and "nutrition" are two different things?

- Diet refers to the food we eat
- Nutrition means properly absorbing food to stay healthy

IBD can affect the amount of nutrients your digestive system absorbs, so it's important to ensure you are getting the essentials. There's no evidence to suggest that certain foods or diet causes, manages or prevents IBD. However, a well-balanced diet with an adequate intake of protein, carbohydrates, fats, vitamins and minerals is necessary for proper nutrition.

It is important that you don't exclude food groups from your diet without first talking to your doctor or a registered dietitian. IBD is different in every patient, and there is no specific diet that will work the same way for everyone. Talking to a dietitian is the best way to determine strategies that are best suited for you and your health needs.

Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5449130/

Sports and Fitness

Stay active, do the things you love and take part in the sports you enjoy – or try something new! There may be days when IBD symptoms like fatigue or pain, prevent you from engaging in physical activity – and this perfectly OK! If this occurs, don't push yourself! Mild to moderate exercise can help reduce IBD symptoms, decrease stress, and improve bone density – so talk to your doctor about an exercise routine that would work best for you!

Rest Up!

It's important to ensure you are getting the rest and sleep you need. There are a number of studies that show a lack of sleep can increase inflammation, as well as your mood and mental health.

Tips for Catching Z's

Reading a magazine or listening to music in bed can be a great way to wind down from a long day. It's good to be mindful of screen time before bed. If you choose to watch your favourite TV show, or scroll through Instagram at nighttime, try cutting off screen time 1 hour before bed. These distractions can stimulate your brain and keep you up, which might stand in the way of you get those much needed 8-10 hours of sleep at night!

By Dr. Nick Carman,

Fecal Calprotectin Testing & IBD

What is fecal calprotectin (fcal)?

Calprotectin is a protein complex found in white blood cells (most commonly neutrophils) that has antimicrobial properties. It is normally released by the cells as part of the body's inflammatory response.

People with IBD have inflammation in the intestine, so calprotectin is released into the gastrointestinal tract when there is active inflammation.

What is fecal calprotectin (fcal) testing?

The great thing about calprotectin is that we can measure it in the stool, and use it as a non-invasive measure of disease activity along with symptoms and blood tests. When IBD is under good control, very little calprotectin is released, but when the disease is active more calprotectin is generated. We can, therefore, use it to measure how well a treatment is working.

Why is fecal calprotectin (fcal) testing important?

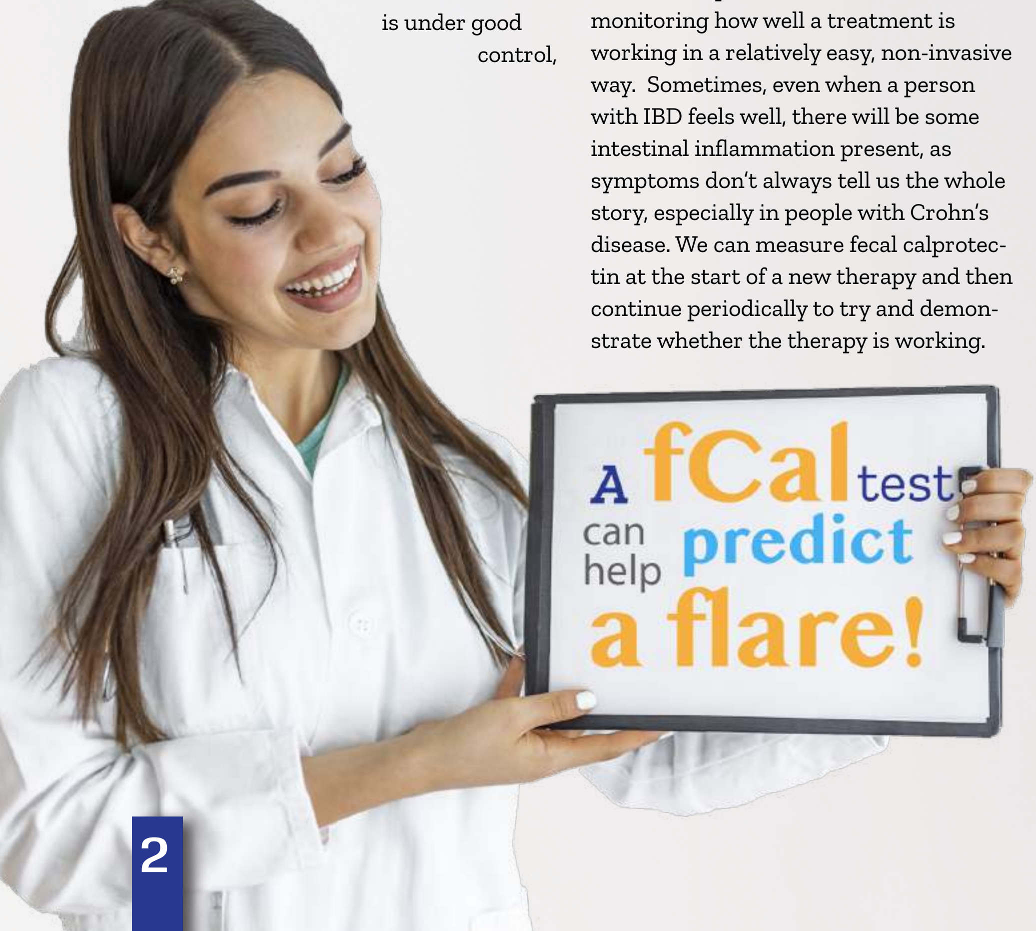
Your IBD care team will order a fcal test for a few reasons including differentiating IBD from irritable bowel syndrome (IBS), monitoring disease activity, monitoring response to treatment, determining whether your bowel has healed and predicting relapse. I think the most important role for fcal is in monitoring how well a treatment is working in a relatively easy, non-invasive way. Sometimes, even when a person with IBD feels well, there will be some intestinal inflammation present, as symptoms don't always tell us the whole story, especially in people with Crohn's disease. We can measure fecal calprotectin at the start of a new therapy and then continue periodically to try and demonstrate whether the therapy is working.

Periodic testing might help avoid frequent colonoscopies, which aren't the most fun tests to undertake! If things are going well, we should see an overall decrease in the fcal over time. It is therefore important to perform this test when your doctor or nurse asks, as it can give us insightful information regarding how well your IBD is controlled, which might even prevent a flare!

How is the fecal calprotectin (fcal) test performed?

Historically we have been able to perform fcal testing through a hospital or local lab, where a stool sample is collected and either brought or sent to the lab by the patient for processing, with the results then forwarded to the physician. If the sample is sent to a lab for processing, we expect a result in a week or so. These tests have sometimes been unavailable in some parts of the country, but availability is increasing. However, depending on where you live, neither private nor public insurance will cover this test – and it costs $200!

More recently, a home kit known as IBDoc is available, and the test can be performed from home and uploaded by a smartphone app (iOS or Android) to your physician. This involves taking a stool sample, placing it in the IBDoc kit, and using your phone's camera (through the app) to take a photo of the cassette. You then immediately get a result, which is then automatically and securely uploaded to your IBD care team.



What do the fecal calprotectin (fcal) test results tell you?

As fcal is essentially a way of measuring the amount of white blood cells in the intestine, it can be used as a test to tell us how much inflammation is present. If IBD is in remission, there should be minimal inflammation in the intestine, and so the calprotectin will be low. In this case, we can usually be confident our treatment plan is working. If IBD is active and there is inflammation present, the calprotectin will be elevated. We can, therefore, use it as a way to know if there is active inflammation, prompting us to re-evaluate things and potentially adjust our treatment plan. These adjustments could be as simple as changing the dose or frequency of medication or could involve recommending an entirely new treatment, so it is always important to discuss any potential changes with your IBD physician.

Are fecal calprotectin (fcal) measurements reliable?

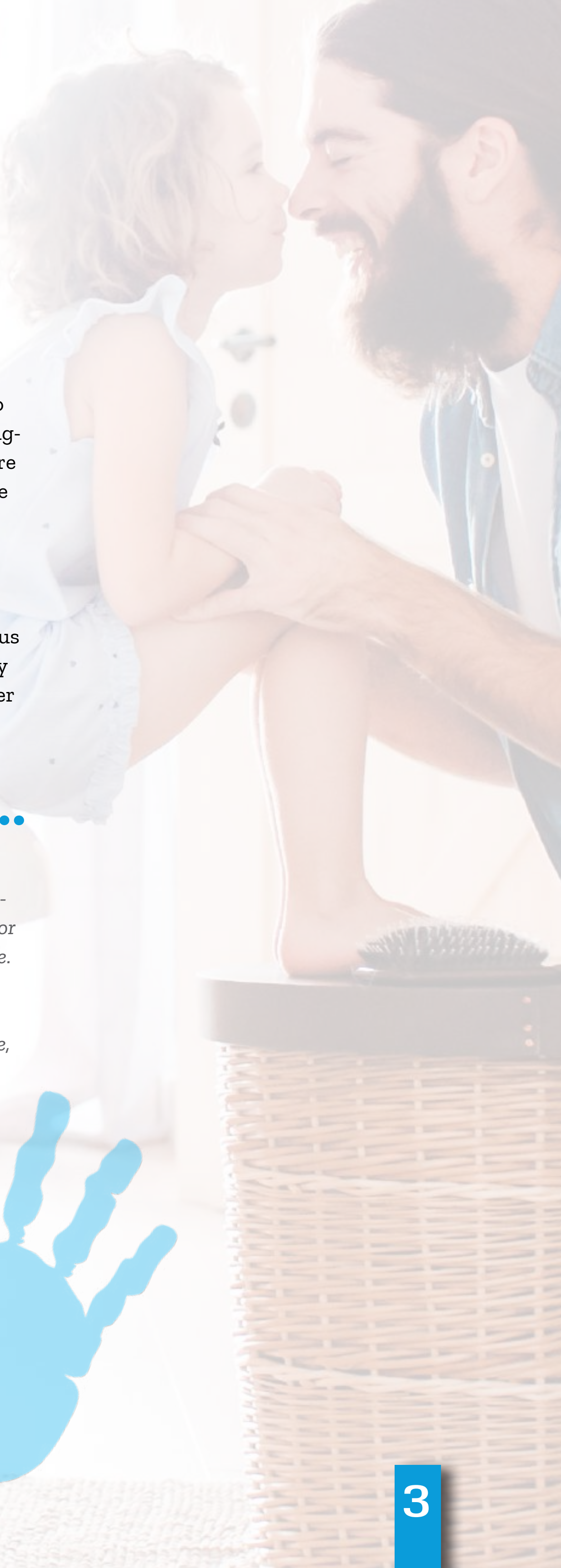
Calprotectin is not a perfect test, but for most patients, it provides valuable information about disease activity in addition to other tests that the IBD physician would order. In scientific terms, research has shown that it is much more sensitive than specific. Meaning, if the test is normal, it's doubtful that there is inflammation present in your bowel. However, about 20-25% of fcal tests might be positive even when there is no inflammation in your bowel. So, we don't panic when we get a positive test – we look at it together with all the other information we gather from patients and their lab work. Also, the utility of fcal is different for different people. It depends somewhat on what type of IBD a person has and where the inflammation is in the intestine, so it is important to discuss the role of fcal with your IBD physician.

How does this help me, the patient?

I think the most important way calprotectin helps patients is assisting in recognizing intestinal inflammation early. This can help us make changes to treatment before the development of significant symptoms, and to ensure we are maintaining good control of the disease over time.

Calprotectin is another tool in our ever-increasing arsenal to help us keep on top of inflammation in IBD. It gives us early information about disease activity without invasive testing, which together provides us with the ability to make changes to hopefully prevent relapses and improve quality of life.

Dr. Nicholas Carman contributed to the content and review of this article for accuracy and balance. We thank Dr. Carman for his time and contribution to our magazine. Dr Nicholas Carman, Bsc, MBBS, FRACP, is a Pediatric Gastroenterologist (GI) in the IBD program at the CHEO IBD Centre, is Director of Advanced Diagnostics and Therapeutics and Assistant Professor of Pediatrics at the University of Ottawa.



Connection, Communication & Honesty

By Katie McBeath, Teaches Grades 7-9

Every day you send your child off to school, you are handing over precious cargo, with strong hopes that their day will be full of new opportunities. Likewise, as a teacher, every day, I welcome children into my classroom and hope for the same! When your child has a chronic disease, such as Inflammatory Bowel Disease (IBD), there are additional challenges for both parties to make each day positive for your child. When striving for success, we must work together to ensure your child feels safe and successful at school.

The first step to ensure support at school is to make a genuine connection with those that will be interacting with your child throughout the day. In our digital world, it is all too easy to send an email; but health is personal and a face-to-face meeting early in the school year will make the connection you will need to know that your child's health story is heard. It would be advisable not to simply 'drop-in'. Contact the teacher by phone or email and request a meeting, stating that you would like to share some health information about your child. Invite all school staff that will be in contact with your child, or be sure to request that the information gets passed on to other staff members at the school. Arrive at the meeting with paper copies of information about your child's disease, symptoms and strategies you have found helpful. Be sure to provide space and time for the teaching staff to ask questions for clarity.

Decide on an appropriate communication plan between the school, teachers and yourself, along with how the teacher and your child will communicate, including building self-advocacy strategies for your child.

> "Some of my students do not need to ask to go to the bathroom"

Once the groundwork of information has been laid out, it is important your child feels comfortable navigating IBD symptoms in the school environment every day. Having your child establish a subtle form of communication with their teacher is a great way to build comfort and trust within the school environment. For example, some of my students do not need to 'ask' to leave the room to use the washroom.

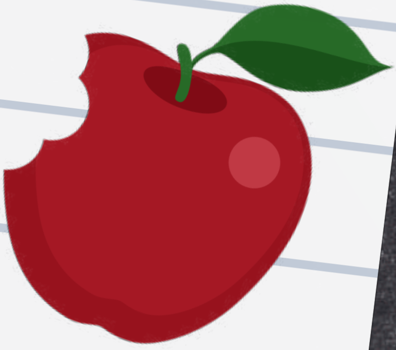
Instead, they place a small item on their desk, indicating to me that they have gone to the washroom.

This signal is helpful on days when your child needs to maake multiple trips. As parents, you might have suggestions for this, and depending on their age, your child may also have ideas of how your child would like to have a sort of 'secret code' in school. Another important element of communication is for you to keep the teacher informed of day-to-day issues that may affect your child's engagement at school.

A flare, for example, can be exhausting and distracting; it is helpful for teachers to know your child is experiencing a flare so that they can modify their expectations and provide extra emotional support when needed.

As trained teaching professionals, we have a background in educating young minds. Still, we are also willing to learn and adapt to support your child and family as you navigate the education system with IBD.

Ultimately, parents and teachers have the same clientele and information is power!



My Crohn's journey

By David McGuire

Strength and Conditioning Coach at SMART Fitness,

Hi! My name is David and I'm 27 years old. I was diagnosed with Crohn's disease when I was 18. It all started with abdominal pain and frequent trips to the bathroom and progressed to rapid weight loss.

I lost about 45 lbs. in 3.5 months. As a high school student, this played a massive role on my self-esteem because I didn't understand why I couldn't stop my body from feeling ill. The care I received upon diagnosis seemed very slow at first, probably because I felt so poor. That was, until I was placed on a biologic.

This treatment worked for about 10 years. Flash-forward to the summer of 2019, and I was experiencing more abdominal pain, but it was different than usual flare-ups. I ended up requiring my first surgery: a right hemicolectomy (removing the right side of the colon and attaching the small intestine to the remaining portion of the colon), caused by 2 fistulas. The rest of 2019 and into 2020 have been a slow and tedious process of trial and error; finding what food and lifestyle choices now work for my body, as well as managing a new biologic.

> **"During my post-surgery recovery, exercise helped keep me motivated."**

I work as a strength and conditioning coach and have a degree in Kinesiology. I understand and see the benefits of exercise with my clients, and definitely understand the same benefits to be true for those with IBD.

I love the sport and art of powerlifting and bodybuilding. Being able to lift weights, to see myself getting stronger over time and growing larger definitely helps combat negative feelings and self-doubt associated with feeling ill.

Throughout my battles with Crohn's disease, I have always been surrounded by a strong support system, from my family to close friends. I try to be mindful, keeping a positive mindset, being active and willingly saying "no" to the foods I want, but my body doesn't respond well to.

If I can leave one message to those just diagnosed or struggling through a hard time in their IBD journey: remember, it will get better! There is a light at the end of the dark tunnel. You can, and you will improve your health. It can be difficult when others don't understand what is happening, because you look fine on the outside. This is okay, you need to accept this. Not everyone will understand what is happening to your body. But you do! Listen to your body, accept it and love who you are becoming.

Follow David on Instagram: @smartfitness1992

Convenience is a factor when choosing a BIOLOGIC

By Karen Frost

There are differences among biologic treatments, including how they are manufactured and prepared, how they are administered, how frequently they are taken, and how they affect a patient's lifestyle.

Pediatric gastroenterologists want to ensure their patients have access to the best therapy necessary to successfully manage inflammatory bowel disease (IBD). Whether your child or teen will be new to a biologic or needs to consider moving onto a second or third biologic therapy, the quest to learn more about the safety, efficacy, cost and convenience of treatment begins.

Safety is one of the single most important characteristics driving the choice of drug therapy, and all the biologics used to treat pediatric IBD have excellent safety profiles. Registries have been set into place since the advent of biologic therapies, a practice not done in earlier therapies like steroids or immunomodulators. IBD centres have in place strict pre-biologic screening for patients, including TB status, pertinent immunization check, and chest x-ray to ensure safety and uninterrupted treatment once biologic therapy is initiated.

Efficacy data have been robust. Multiple ongoing trials show response to therapy is achieved in a timely manner, and remission is possible in the long term. With the current treat-to-target models, many practitioners assess for mucosal healing using earlier and/or more frequent re-evaluation colonoscopies, as well as imaging techniques such as an MRI or CT scan.

Cost is a factor, not so much to a young patient, but it is a discussion point for parents. Cost to the patient does factor into a biologic conversation. It is important to share the type of health coverage your child has if any. If you have private insurance, do they charge a co-pay for a biologic prescription, and what biologic manufacturers provide compassionate funding assistance that you can access. These are all factors that weigh heavily in the decision-making process.

QUESTIONS

Below are a few questions to consider asking the GI and IBD nurse:

- Which biologic treatment options are currently available for my child or teen?
- How often will they need to take the biologic?
- How is the medication given, infusion or injection?
- Where is the medication administered?
- How long does it take to receive the medication?
- Based on treatment preferences, which one would best fit your child and your family's lifestyle?

Convenience, is this a factor to consider? ABSOLUTELY.

The convenience of treatment makes a big impact on which biologic a patient chooses; here are a few things to consider.

Some biologics are administered by injection, either once a week or every other week. The gastroenterologist will determine a dosing schedule best suited for your child/teen. It is advised that you chose the same day and time for each dosage, a convenient time based around your child's school, extra-curricular and family schedule. Patients can self-inject or have a home-visit nurse inject. In-home nurses will ask your child a few questions about their general health before administering the injection. Injections can be given in the abdomen or on the front of the thigh; an injection takes 5-10 seconds. Some injectable biologics are shipped to your home or delivered to your teen's post-secondary school residence/ apartment, making treatments accessible and helping maintain an easy injection routine. Also, injectable biologics are portable, so your child can travel with their treatment

anywhere, anytime! Other biologics are administered by infusion.

Your gastroenterologist (GI) will determine the dosing schedule best suited for your child/teen. To begin receiving an infusion biologic, a Patient Support Coordinator will contact you to schedule your child/teen infusion and provide you with a location or locations close to your home. When you arrive at an infusion centre, a nurse will assign your child/teen an infusion chair, ask a few general health questions, insert an intravenous (IV) line then slowly start the infusion. Infusions generally take 3 hours to complete. Before you leave, the nurse will provide you with an appointment card for the next infusion, based on your child/teen's dosing schedule. If you are planning to travel and your trip conflicts with an infusion, a Patient Support Coordinator can work with your GI to provide options to either schedule an infusion before you leave, once you return or even receive an infusion at another centre within Canada. If your teen is going away to college or university, the Patient Support Coordinator can help find an infusion centre close to their school, residence or apartment.

All these components of convenience are part of the patient's decision-making process and are important ones for you, your child/teen, and their GI to consider. The easier it is for your child/teen to take their medication, the more likely they are to keep to a treatment schedule, which can lead to better results, sustained health and remission.

Expressing a preference for a convenient therapy option can help you and your child become more involved in this treatment decision-making process. It will help you determine which treatment is best suited to your child/teen's needs and fits your family's lifestyle and wellbeing.

It's important to ask any questions you may have. If something is not clear, ask for an explanation. Make a list of questions ahead of time to help you remember what to ask.

Having Inflammatory Bowel Disease (IBD) should not define a person! While it sucks that you have it, remember that IBD is only part of you. It is important you make your treatment fit your lifestyle! While there are no cures for Crohn's disease or Ulcerative Colitis, there are many options that will help you live your life optimally! So, when choosing a biologic, do consider convenience as part of your decision-making.

Karen Frost, NP contributed to the content and review of this article for accuracy and balance. We thank Ms. Frost for her time and contribution to our magazine. Karen Frost, BScN, RN (EC), MN, NP-Pediatrics, is a nurse practitioner in the IBD program at the Hospital for Sick Children and has an adjunct clinical appointment in the Faculty of Nursing at the University of Toronto.

Play while you Wait!

WORD SEARCH

p	i	z	z	a	t	p	x	z	o
b	e	f	m	m	d	n	o	r	s
i	h	k	a	d	p	o	b	e	a
l	t	b	c	q	g	o	u	g	n
u	c	w	a	a	h	d	j	r	d
v	y	g	r	s	v	l	n	o	w
d	k	c	o	p	i	e	q	t	i
y	a	z	o	v	w	s	i	o	c
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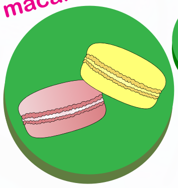
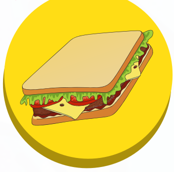
macaroons

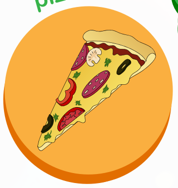


noodles

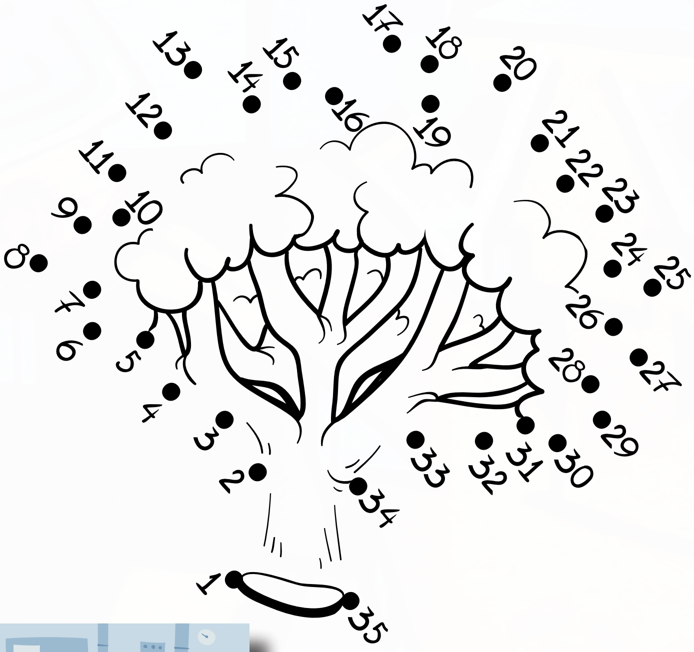
sandwich



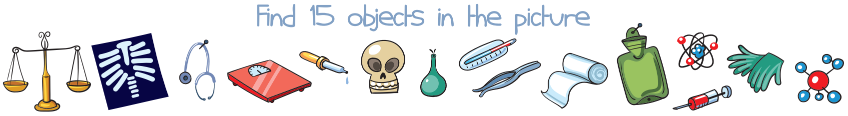
pizza



Broccoli



Find 15 objects in the picture



Healthy RECIPES

Sandra Saville, RD is a Digestive Health Dietitian and President of Microbiome Experts Inc. saville.nutrition@sympatico.ca

Rich in Vitamin D!

Sandra Saville's Crustless Salmon Pie

Preheat oven to 350 degrees F, or bake in the microwave oven.
Lightly oil oven-proof glass like pyrex or a casserole pie plate.

Ingredients:
2 cans salmon (213 g can), drained
3 large eggs, lightly beaten
Dice up your favorite vegetables (onion, mushrooms, peppers)

Method:
In a medium-size mixing bowl lightly beat the eggs with a fork. Add the drained salmon to a bowl and mix well with a fork to break the salmon into small pieces.

Continue stirring well until the mixture is smooth.

Pour the salmon egg mixture into the greased pie plate.

Bake in preheated oven for 35 – 40 minutes, or until the centre is cooked.

The pie can be cooked in a microwave oven on high power for 6 1/2 – 7 minutes, or until the centre is fully cooked.

The crustless salmon pie can be served with pasta and vegetables for a fast meal. Add to a wrap or make as a sandwich or cut into cubes and placed on a salad. You can even add to a kebob with assorted vegetables.

Loaded with Calcium!

Sandra Saville's Calcium Packed Breakfast Smoothie!

Ingredients:

1 banana
1 handful of fresh or frozen spinach OR pureed cooked sweet potato
1/2 cups of frozen black cherries or fresh/frozen mango
1/2 cup of fortified beverage (almond, rice or soy milk)
1 255 ml bottle of chocolate or strawberry high protein Ensure
2 tbsp of smooth peanut, almond or sunflower seed butter
1 tbsp of blackstrap molasses (1 tbsp contains 175mg of calcium!)

Method:

Collect all of your ingrediants, decide which variation you would like to use. Add all ingredients to a blender and blend on 'high' until you achieve desired consistency. If you find the mixture too thick you can add some water to thin it out!

Happy blending!

Reviewed by Sandra Saville, RD of Saville Consulting.

Extra-intestinal Manifestation (EIMs) of IBD

By Melanie Watson

During a clinic appointment, it's pretty standard to share how our gut is feeling and symptoms that you may be experiencing. But, have you ever thought about sharing other changes you've noticed with your body? Changes outside of your gut? If not, it's something worth considering.

You may have heard your gastroenterologist (GI) or IBD nurse mention the term extraintestinal manifestation (extra-intestinal-manifestation) or EIM. EIMs are conditions that affect different parts of the body, outside of the gut, and may be related to your IBD inflammation. The exact cause of EIMs is not completely understood, so more research is needed. EIMs commonly affect the skin, eyes, mouth or joints. Individuals with IBD can experience an EIM prior to their diagnosis, and it's also possible to develop an EIM while in remission.

EIMs can be quite common among pediatric IBD patients. Research has shown that 50% of patients with UC and 80% with Crohn's will develop at least one EIM at some point in living with the disease[1]

Areas most commonly affected by EIMs:

☐ Joints
☐ Skin
☐ Eyes
☐ Mouth
☐ Bones
☐ Anemia

Joints

Joint inflammation or arthritis, pronounced arth-ri-tis, is a common EIM of IBD and typically affects large joints like elbows, wrists, knees and ankles. Arthritis can cause pain, aching, stiffness and swelling in and around the joint(s). [2] Some patients can develop pain and swelling in small joints like the hands, fingers and feet, and others may experience arthritis in their hips or back. Most arthritis symptoms improve once gut inflammation is under control. Some IBD therapies are also used to treat arthritic conditions, which provides added management of symptoms for IBD patients affected by both conditions.

Skin

Erythema nodosum (EN), pronounced era-theema no-dough-sum, is a common condition that affects the fat under the skin. EN appears as tender, red bumps often on the ankles, upper or lower legs, or forearms. The condition is harmless but can be uncomfortable. EN tends to occur during flare-ups and can improve with IBD treatments. [3]

Psoriasis, pronounced sore-rye-a-sis, is another common skin condition. It causes cells to build up quickly on the skins surface, creating small, dry scaling red patches that can be itchy and can appear anywhere on the body. If scratched, these patches may bleed. Topical creams and ointments can be used to treat mild to moderate psoriasis. Photo or ultraviolet light is another therapy used to treat this skin condition. Some IBD medications also treat psoriasis which is an added benefit to those with both conditions.

Mouth

Aphthous stomatitis, better referred to as canker sores or cankers, are one of the most common oral EIMs of IBD. Canker sores are small, often whitish bumps found anywhere inside the mouth. This includes the lips, the roof of the mouth, the cheeks and tongue, and they can be painful. IBD patients who experience cankers tend to get sores when their disease is more active. Sores can be minor and disappear within a week. For some, they can last longer and require steroid treatment.

Eyes

Some IBD patients are affected by eye conditions, with the most common being episcleritis, pronounced ee-pis-kler-itis. This eye condition affects the layer of tissue covering the white outer coating of the eye (also called the sclera), making the eye red, sore and inflamed. Episcleritis may present during an IBD flare and can be treated with cold compresses. In some cases, steroid drops may be required.

Two additional eye conditions linked with IBD are scleritis (skler-it is), inflammation of the sclera itself, and uveitis (u-vee-it is), inflammation of the middle layer of tissue in the eye wall. These conditions are more serious and may lead to vision loss, if not treated.
If you experience eye redness and pain to one or both eyes, contact your health care provider. They may ask you to be assessed by an eye specialist. Both scleritis and uveitis can be treated with steroid drops.

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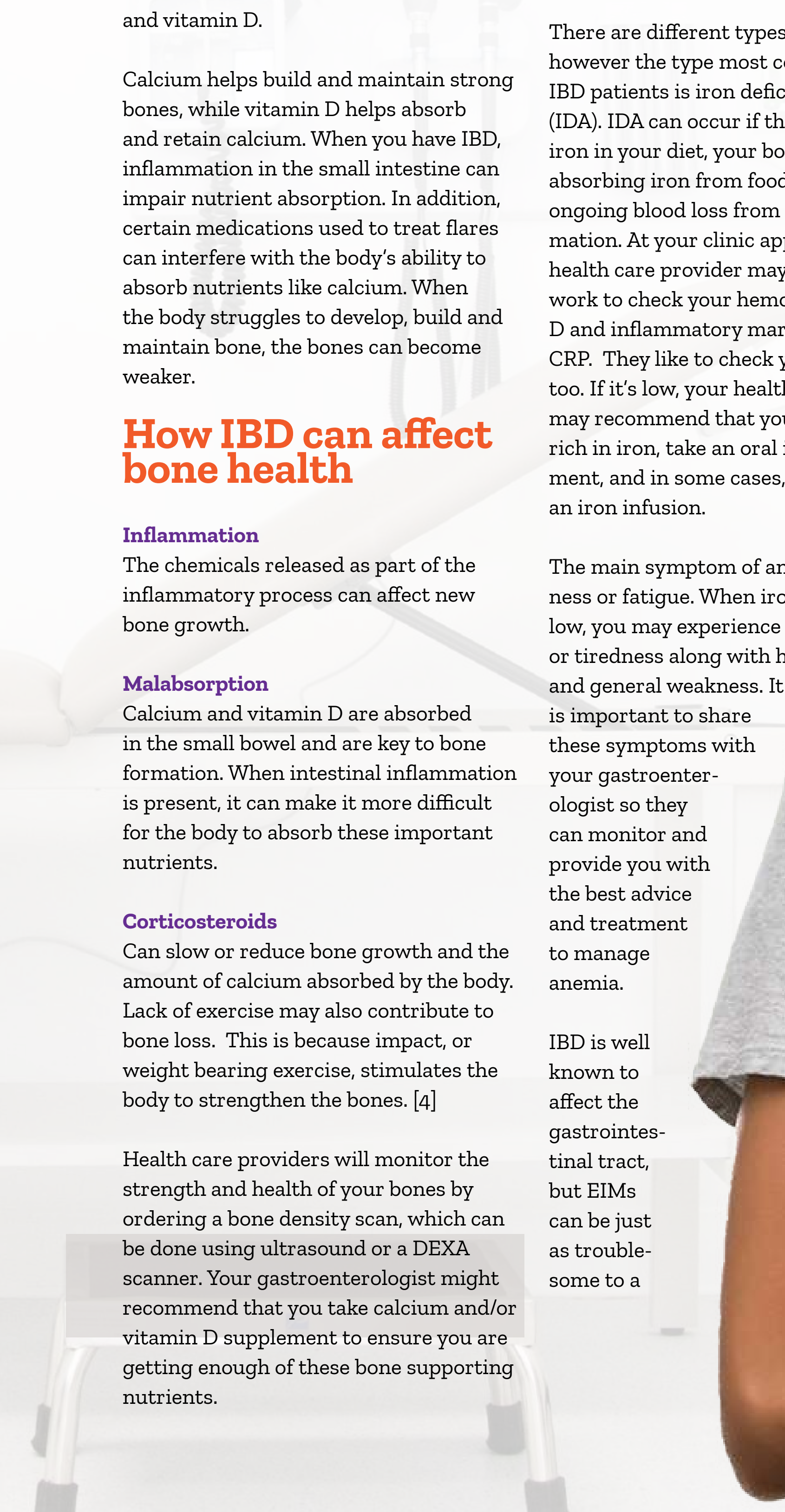
[1] Stawarski A, Iwanczak B, Krzesiek E, et al. Intestinal complications and extraintestinal manifestations in children with inflammatory bowel disease. Pol Merkur Lekarski 2006;20:22-5.
[2] Arthritis society of Canada, What is Arthritis?
[3] Jang et al. EIMs of pediatric IBD
[4] http://www.ibdclinic.ca/what-is-ibd/ibd-and-bones/



Bone Health

Bones play an essential role in our bodies. Not only do they give our body structure, but they also protect our internal organs and store an essential nutrient, calcium. Two important nutrients that contribute to the health of our bones are calcium, and vitamin D.

Calcium helps build and maintain strong bones, while vitamin D helps absorb and retain calcium. When you have IBD, inflammation in the small intestine can impair nutrient absorption. In addition, certain medications used to treat flares can interfere with the body's ability to absorb nutrients like calcium. When the body struggles to develop, build and maintain bone, the bones can become weaker.

How IBD can affect bone health

Inflammation

The chemicals released as part of the inflammatory process can affect new bone growth.

Malabsorption

Calcium and vitamin D are absorbed in the small bowel and are key to bone formation. When intestinal inflammation is present, it can make it more difficult for the body to absorb these important nutrients.

Corticosteroids

Can slow or reduce bone growth and the amount of calcium absorbed by the body. Lack of exercise may also contribute to bone loss. This is because impact, or weight bearing exercise, stimulates the body to strengthen the bones. [4]

Health care providers will monitor the strength and health of your bones by ordering a bone density scan, which can be done using ultrasound or a DEXA scanner. Your gastroenterologist might recommend that you take calcium and/or vitamin D supplement to ensure you are getting enough of these bone supporting nutrients.

Anemia

Anemia, pronounced a-nee-me-a, is another common EIM of IBD.
If you are anemic, it means you have fewer red blood cells and/or lower levels of hemoglobin in your blood. Hemoglobin is a protein found in red blood cells and carries oxygen around the body.

There are different types of anemia, however the type most common among IBD patients is iron deficiency anemia (IDA). IDA can occur if there's not enough iron in your diet, your body has difficulty absorbing iron from food, or you have ongoing blood loss from bowel inflammation. At your clinic appointment, your health care provider may order blood work to check your hemoglobin, vitamin D and inflammatory markers such as CRP. They like to check your iron level too. If it's low, your health care provider may recommend that you eat more foods rich in iron, take an oral iron supplement, and in some cases, may prescribe an iron infusion.

The main symptom of anemia is tiredness or fatigue. When iron levels are very low, you may experience ongoing fatigue or tiredness along with headaches and general weakness. It is important to share these symptoms with your gastroenterologist so they can monitor and provide you with the best advice and treatment to manage anemia.

IBD is well known to affect the gastrointestinal tract, but EIMs can be just as troublesome to a person's overall well-being with dramatic effects on a person's quality of life. It's important to share any symptoms that you may experience outside of your gastrointestinal tract, because they may or may not be related to a flare, and often times are treatable.

* * *

Melanie Watson, NP contributed to the content and review of this article for accuracy and balance. We thank Ms Watson for her time and contribution to our magazine.

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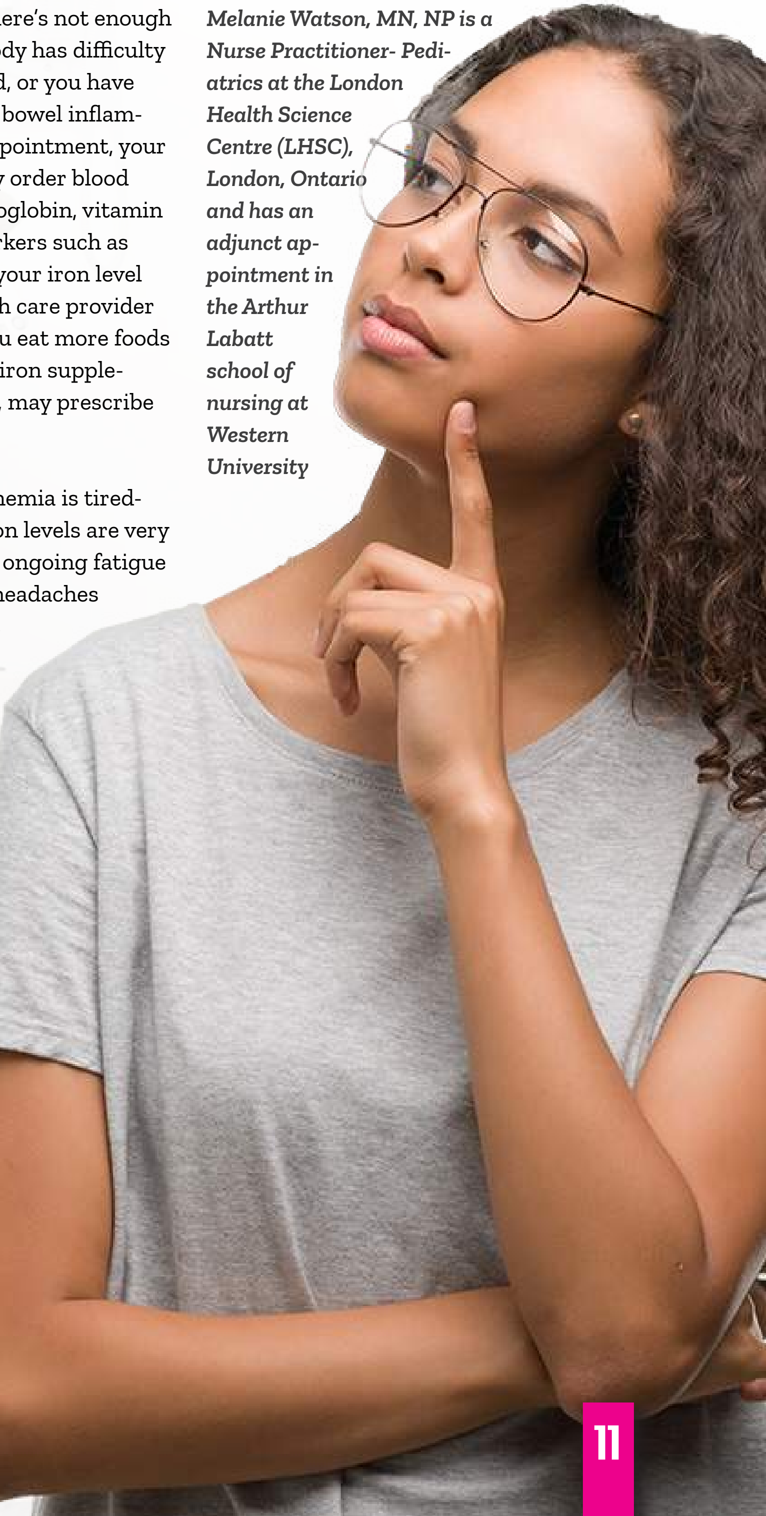


IBD Fatigue in Inflammatory Bowel Disease

Do you sometimes feel like a walking zombie? Drained, with an overwhelming sense of tiredness, lack of energy, or feeling exhausted even after you've had a full night sleep? You are not alone.

When you have Crohn's disease or ulcerative colitis, fatigue can feel physical, mental, or both! You may feel like you've suddenly "hit a wall" and that's a very common feeling.

> **"Fatigue can mean a few different things. It can describe feeling generally tired, or, feeling tired after waking up, or, feeling so tired it's difficult to pay attention."**

The first two tend to be the most common descriptions shared by kids and teens with IBD.

Researchers know that fatigue can affect you physically emotionally, mentally, socially and impact your quality of life. [1] Fatigue is also reported by kids and teens to be a distressing symptom because it's unpredictable and can vary from one day to the next.

Why do I feel this way?

There are a few factors that have been linked to fatigue in Crohn's disease and ulcerative colitis. They include:

Inflammation

If you are in a flare, fatigue might come from your body's response to inflammation.
Several studies have shown a relationship between IBD disease activity and fatigue. Teens with active IBD tend to experience more fatigue than teens with IBD in remission, and teens in remission have fatigue levels higher than teens in good general health.[2]

Nutritional Deficiencies

Vitamin and nutrient deficiencies in those with IBD may be caused by diarrhea or a loss of appetite, which can leave you feeling worn out or tired.

Pain

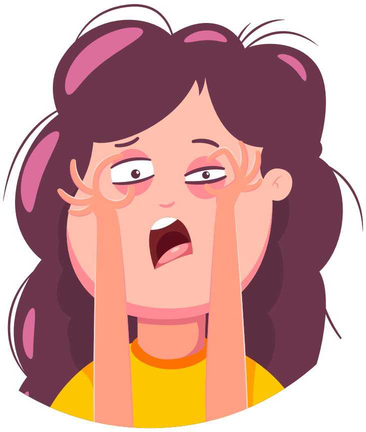
Pain is very common and dealing with pain can be very tiring. If you are experiencing pain, it may be contributing to your fatigue, causing poor sleep, reducing physical activity, and resulting in emotional and psychological distress. Speak to your doctor to identify different ways to manage pain.

Anemia

Anemia can be common for those with IBD. Low iron levels can make you feel tired and affect energy levels.
It's important to ask your gastroenterologist (GI) about your iron levels and take an iron supplement if recommended by your doctor.

If you think you might need more sleep, try:

- ☐ Make sleep a priority, keep a sleep diary
- ☐ Have a nap when you get home from school and on weekends
- ☐ Avoid food and drinks with caffeine in the evening
- ☐ Keep a consistent week-day sleep routine
- ☐ Avoid exercising a few hours before bedtime
- ☐ Shut down the TV and digital devices an hour before bed
- ☐ Have a bath/shower before bed



Medication

Some medications used to manage IBD inflammation may cause side effects like fatigue. Your GI may be able to suggest different ways/times to take your medication so it won't interfere with your sleep.

Before you settle 100% on fatigue being the cause of your exhaustion and tiredness, let's explore one possible culprit, sleep. You might think fatigue or sleepiness are the same, but they're not. We know fatigue refers to those feelings of tiredness or exhaustion usually caused by illness or physical activity; sleepiness is different. Sleepiness is when you feel drowsy and sluggish, and it's hard to keep your eyes open.

> **"Sleep is essential for both mental and physical health."**

On average, children between 6-12 years old need 9-12 hours of sleep and teenagers between 13-18 years old need 8-10 hours to function best.[3] Sleep is food for your developing brain. It fuels your body, helps you grow, plus sleep can help reduce anxiety.

If you've tried changing your sleep habits, and you continue to feel tired and exhausted, fatigue just might be the cause. Remember, everyone is different – If you feel fatigue is affecting how you function during the day or you know fatigue is at play, speak to your GI.
Your IBD healthcare team can help you find strategies to manage fatigue best and get you back to doing the activities that make you happy.

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Dr. Zachos contributed to the content and review of this article for accuracy and balance. We thank Dr. Zachos for her time and contribution to our magazine. Dr Mary Zachos, MD, FRCPC, is a Pediatric Gastroenterologist in the Department of Hepatology and Nutrition, GI Program Director and Associate Clinical Professor at McMaster Children's Hospital in Hamilton, Ontario.

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[1] van Langenberg DR, Gibson PR. Systematic review: fatigue in inflammatory bowel disease. Aliment PharmacolTher. 2010;32:131–143. [PubMed] [Google Scholar]

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[3] https://www.hopkinsallchildrens.org/ACH-News/General-News/The-importance-of-sleep-for-kids
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Mono VS Combo Therapy

By Dr. Cynthia Popalis

A biologic is a type of drug therapy produced from living cells that are made to target specific parts of the immune system. Anti-TNF agents are now common biologic agents used to treat children and teens with inflammatory bowel disease (IBD). These drugs are made from proteins that recognize and bind to specific proteins that are responsible for creating inflammation. Using anti-TNF agents help prevent the attack of healthy cells in the GI tract and control IBD causing inflammation.

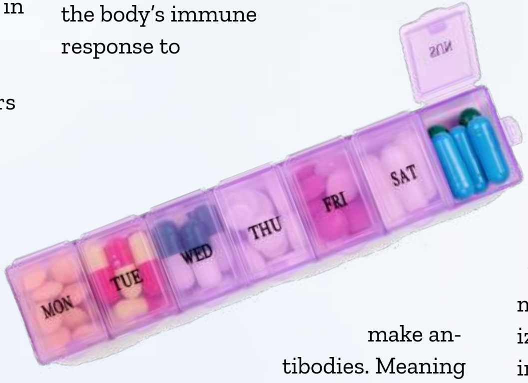
Though anti-TNF agents are very effective treatments, they can stop working in some patients, even if they were helpful in the beginning. This is known as 'secondary loss of response.' This occurs after the body produces antibodies against the drug, which is called 'sensitization'. Once you have been sensitized to the drug, it no longer works well, and your body becomes 'resistant' to the medication. Doctors can help decrease sensitization by monitoring anti-TNF drug levels and combining an anti-TNF agent with an immunomodulator drug (a drug that helps regulate the immune system). We aim to increase 'durability of response' or length of time on an effective drug with these measures.

When an anti-TNF agent is taken alone, with no immunomodulator, we call this "mono-therapy."
And when an anti-TNF agent is combined with an immunomodulator, we call this "combo-therapy".

There is a strategy behind using combo therapy.

'Sensitization' of a biologic agent is thought to occur when the drug level in the body is low. It is thought that if the drug level is zero or close to zero when another dose of medication is given, the body will recognize the drug as foreign and mount an antibody response causing sensitization. Combination therapy is thought to work in different ways. How a drug interacts wxqith your body is unique to each person and can be affected by many factors.

Immunomodulators reduce the body's immune response to make antibodies. Meaning even if the drug level drops before your next dose, an immunomodulator can reduce the possibility of forming antibodies. Immunomodulators also reduce inflammation in the body by using a different pathway than biologic agents. By reducing inflammation, the biologic therapy is not used up as quickly, which helps keep drug levels up and reduces antibody formation.



For patients who have been on a biologic agent previously, this can be a factor that has shown to be most highly associated with 'immunogenicity' or likelihood of developing antibodies. For this reason, we often use combination therapy if it is your second biologic agent. The choice of a biologic agent is also a factor in deciding whether to combine with an immunomodulor.

Different biologic agents have been shown to have differences in rates of sensitizations, even as first-line agents. Among anti-TNFs, some are thought to have lower immunogenicity and are therefore used more often in monotherapy.

When combination therapy is used, it is often dosed at a level patients tolerate well and with few side effects. It is important to let your doctor know if you experience any side effects as there are strategies to reduce symptoms. Patients may also struggle with taking additional medication. Still, rates of sensitization are highest at the beginning of therapy, and combination drug use may only be for a number of months.

Treatment of IBD, including selecting mono or combo therapy, is best personalized to each individual patient, depending on your disease location, disease activity, treatment history and personal preferences. Communicating with your doctor is the best way to determine a personalized treatment plan that best targets your IBD.

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Dr Cynthia Popalis contributed to the content and review of this article for accuracy and balance. We thank Dr. Popalis for her time and contribution to our magazine.Dr Cynthia Popalis MD, FRCPC, is a Paediatric Gastroenterologist at Boomerang Health, SickKids' clinic and Markham, Stouffville Hospital in Markham, Ontario.

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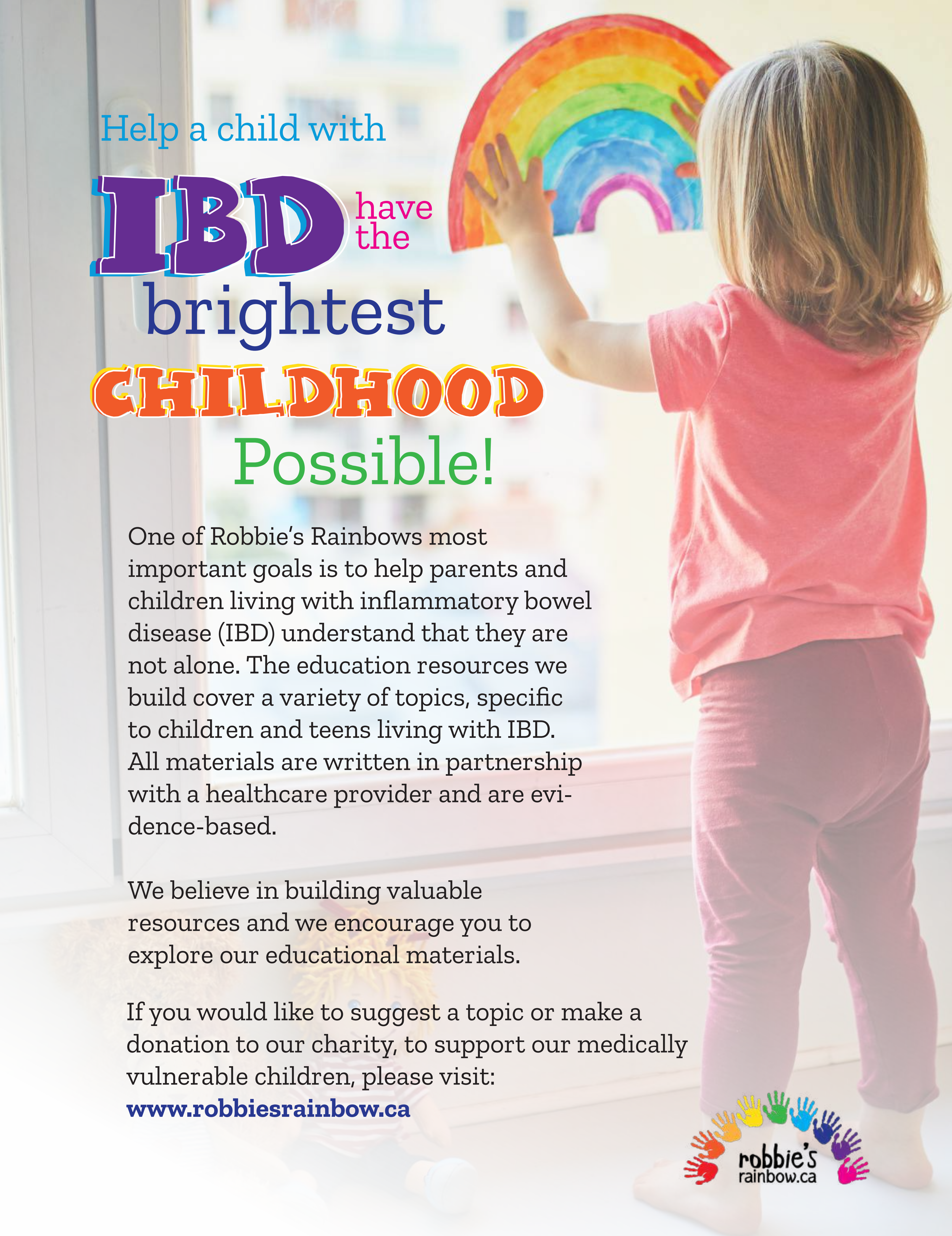

Help a child with IBD have the brightest CHILDHOOD Possible!

One of Robbie's Rainbows most important goals is to help parents and children living with inflammatory bowel disease (IBD) understand that they are not alone. The education resources we build cover a variety of topics, specific to children and teens living with IBD. All materials are written in partnership with a healthcare provider and are evidence-based.

We believe in building valuable resources and we encourage you to explore our educational materials.

If you would like to suggest a topic or make a donation to our charity, to support our medically vulnerable children, please visit:
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