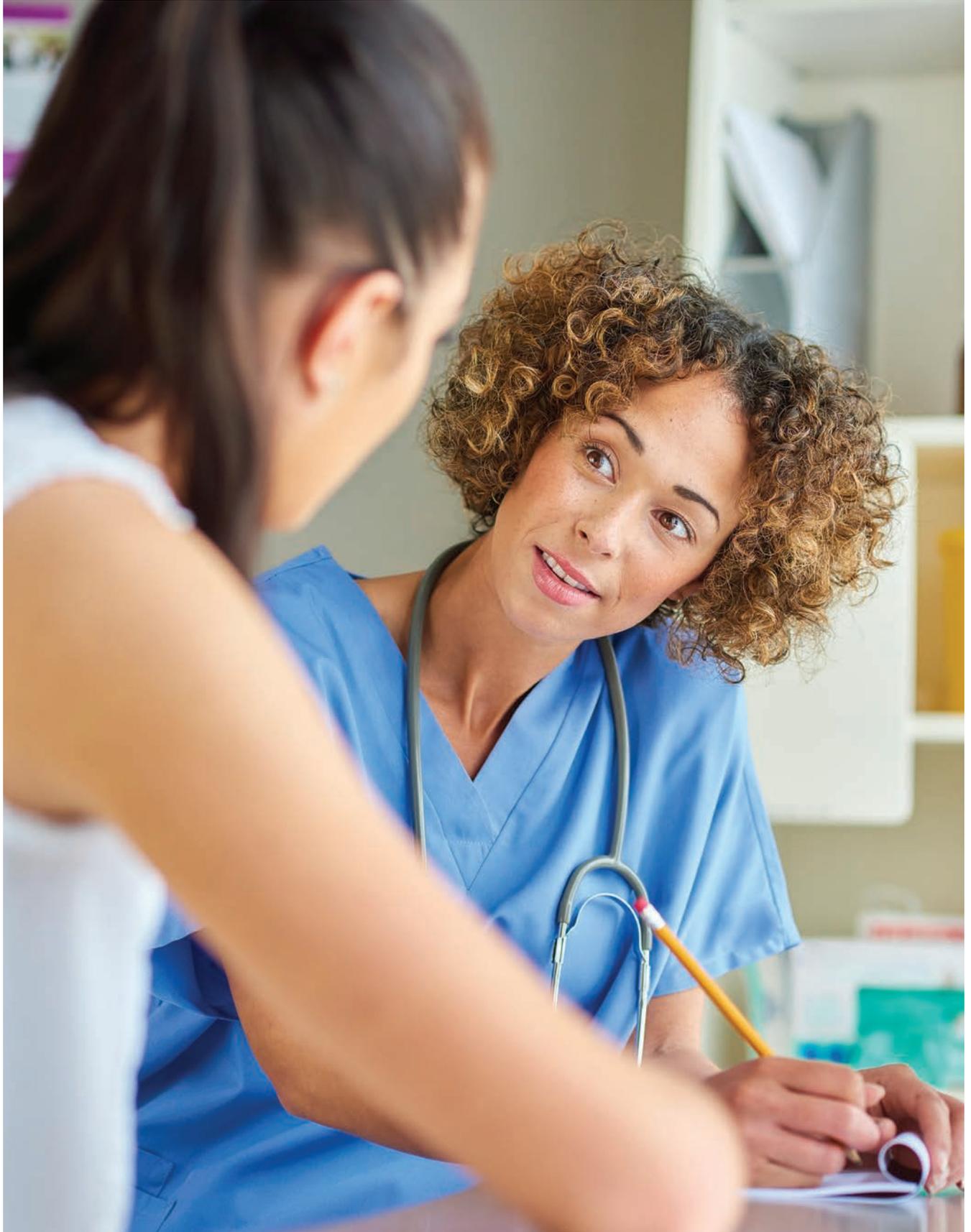




Health Maintenance for Pediatric IBD Patients

Discussion guide for parents



Inflammatory bowel diseases (IBD), including Crohn's disease and ulcerative colitis, can have a tremendous impact on the health of your child. This discussion guide highlights some of the things that you can look out for and do, to keep your child's health on the right track. Speak with your child's healthcare provider to see what steps you can take together to ensure the health of your child—now and in the future.

Vaccinations

Your body's immune system is what keeps you healthy and protects you from becoming sick or catching something like a cold or the flu. Some of the medications that your child takes for their IBD may weaken their immune system, making it easier for them to get common and uncommon infections. To protect your child against these infections, it is very important for them to be up-to-date on their vaccinations.

Children with IBD should generally follow the recommended vaccination schedule of the American Academy of Pediatrics (www.aap.org). However, there are a few important points to remember about vaccines for children with IBD:



Live vaccines are **not** recommended for IBD patients taking certain medications that weaken the immune system. Some vaccines are only available with weakened live virus. However, these kinds of vaccines can cause infections in anyone that takes certain medications, such as: prednisone, azathioprine (Imuran®, Azasan®), 6-mercaptopurine (6-MP, Purinethol®), methotrexate (Trexall®), adalimumab (Humira®), adalimumab-atto (Amjevita®), adalimumab-abdm (Cytezo®), certolizumab (Cimzia®), golimumab (Simponi®), infliximab (Remicade®), infliximab-dyyb (Inflectra®), infliximab-qbtx (Lxifi®), infliximab-abda (Renflexis®), ustekinumab (Stelara®), vedolizumab (Entyvio®), tacrolimus (Prograf®), infliximab-axxq (Avsola™), or any other medications that weaken the immune system. This also includes patients who took these medications within the past three months or plan to take them in the next four to six weeks. You should discuss with your healthcare provider whether it is safe for your child to receive these kinds of vaccines. For an updated list of recently approved IBD medications, please visit <http://www.crohnscolitisfoundation.org/assets/pdfs/recently-approved-treatments.pdf>.

Live virus vaccines include:

- Rotavirus (RotaTeq®)
- Intranasal flu vaccine (FluMist®)—The nasal spray version is a live virus vaccine. The injected vaccine (shot) is not a live vaccine.
- Measles, Mumps, Rubella (MMR)
- Chicken pox (Varicella, Viravax®)
- Shingles (Zostavax®)
- Smallpox
- Yellow Fever
- Oral Polio—The version taken by mouth is a live virus vaccine. The standard injected vaccine (shot) is not a live virus vaccine.

Inactivated vaccines are recommended for all patients with IBD, regardless of the medications they are taking. Inactivated vaccines are not live, and include:

- Diphtheria (DTaP, Tdap)
- Haemophilus influenza (HiB)
- Hepatitis A (Havrix®, Vaqta®, Twinrix®)
- Hepatitis B (Recombivax HB®, Twinrix®)
- Human Papillomavirus (HPV) (Gardasil®, Cevaxix®)
- Meningitis (Meningococcus) (Menactra®, Menveo®)
- Pertussis (DTaP, Tdap)
- Pneumonia (Pneumococcus) (Pneumovax 23, Prevnar 13)
- Tetanus (DTaP, Tdap)
- Polio: The version given as a “shot” or injection is an inactivated vaccine.
- Flu vaccine (Influenza): The version given as a “shot” or injection is an inactivated vaccine. It is recommended annually.

Your child should be tested for hepatitis B and tuberculosis (TB) **before** taking any anti-TNF medications, such as infliximab (Remicade®), infliximab-dyyb (Inflectra®), infliximab-qbtX (Lxifi®), infliximab-abda (Renflexis®), adalimumab (Humira®), adalimumab-atto (Amjevita®), adalimumab-abdm (Cytezo®), certolizumab (Cimzia®), golimumab (Simponi®), ustekinumab (Stelara®) and vendolizumab (Entyvio®). If your healthcare provider finds that your child is not immune to hepatitis B, the hepatitis B vaccine may be given. Even if initial TB testing is negative, your child may receive continued annual TB monitoring for as long as she/he is on the medication.

IBD patients on medications that suppress the immune system should receive the pneumonia vaccine between the ages of two years and older. There are two types of pneumonia vaccines, Prevnar 13 and Pneumovax 23. Prevnar 13 is typically given to all children in infancy as a three dose series. For children ages two to five years who have not completed the series, or have not received Prevnar 13, they should complete the series. Pneumovax 23 is given once, then repeated five years later as long as on immune suppression. However, there must be a minimum of eight weeks between receiving Prevnar 13 and Pneumovax 23. For children two years and older, if previously unvaccinated with Prevnar 13, they should receive it once followed by Pneumovax 23 at least eight weeks later.



Pneumovax 23 should be repeated every five years as long as on immune suppression.

Bone Health

Active IBD can affect the normal development of your child’s bones in many ways. Active IBD can:

- Slow down bone growth and affect the structure of the bones
- Delay puberty, which is a time of rapid bone growth
- Decrease energy levels and physical activity, which are important for normal bone and muscle development
- Decrease appetite, which means your child might not be eating enough foods that contain the nutrients their body needs to build muscles and bones
- Stop your child from eating certain foods that are high in vitamin D (like milk, cheese, and yogurt), which the body needs to absorb calcium from the diet
- Prevent the intestines from absorbing the nutrients it needs to form bones and muscles

Who is at risk for low bone mass?

Research has shown that children with IBD who have disease that remains active for long periods of time may have poor nutrition, delays in growth and

puberty, low levels of certain blood proteins (like albumin), and thinner, shorter bones. Taking steroids (like prednisone) for more than three months can also affect bone formation and growth. If your child is experiencing any of these things, they should be tested for low bone mass.

How do we measure bone mass?

There are several ways to measure bone mass. The most common is called a bone density scan (also referred to as “dual X-ray absorptiometry” or DXA). This test takes an X-ray of the whole body using a very low dose of radiation. It takes about 10 minutes, and is completely painless.

How often should my child be tested?

Your child’s healthcare provider may request that their bone density be checked when they are diagnosed with IBD. If their bone density is not normal, they may be retested no sooner than six months later to see if the medications and/or improved nutrition are having a positive impact on their bone density.

What if my child has low bone mass or low bone density?

There are many ways to improve your child’s bone density. However, the best method depends on your child’s specific situation. Therefore, you should talk to your child’s healthcare provider about the best way to deal with it. Options could include the following or a combination of the following:

- Getting your child’s IBD under control with other medications, without using steroids
- Optimizing their nutrition
- Using calcium and vitamin D supplements (if vitamin D level is low)
- Encouraging exercise that involves walking, running, and jumping (called weight-bearing exercises)

In some cases, it is helpful to partner with a pediatric endocrinologist to make sure that the low bone mass is not caused by something else, like another condition or disease.

Your child’s bones and muscles are important. Work with your healthcare provider to ensure that your child will reach their full growth potential!

Pubertal Development

Having IBD, along with poor nutrition, may delay puberty in boys and girls. As a result, a young girl’s

first menstrual period may be delayed, and periods may be skipped or become irregular. In some patients, symptoms (such as diarrhea and abdominal pain) may become worse just before or during menstrual periods. If you have concerns about your child’s pubertal development, discuss them with your child’s pediatrician or pediatric gastroenterologist.

Colon Cancer

Colon cancer is a cancer that starts in the colon (also known as the large intestine). There is an increased risk in anyone who has IBD that involves the colon—this includes people with ulcerative colitis and people with Crohn’s disease of the colon (Crohn’s colitis). The risk of colon cancer starts to increase around eight to 10 years after IBD symptoms appear, and increases more quickly after that. While this may sound scary, colon cancer is highly treatable when caught early. Keeping your child’s IBD under control and ensuring a healthy lifestyle can play a key role in decreasing their risk of colon cancer. Follow these recommendations to lower the risk:

- **Get tested.** Most colon cancers that are caught early are completely treatable. For this reason, screening for colon cancer is the best way to reduce the risk of colon cancer. Your child should start getting colonoscopies eight to 10 years after they first started experiencing IBD symptoms,



with a follow up colonoscopy every one to two years after that. Talk to the healthcare provider about when and how often your child should get a colonoscopy.

- **Take IBD medications.** The risk of colon cancer may be lower in people whose IBD is better controlled with medications. However, there is no research that shows one medication is better than another at preventing colon cancer. Therefore, be sure your child is taking their medications as prescribed by their healthcare provider.
- **Eat a well-rounded diet.** A well-rounded diet, with lots of fruits and vegetables, is associated with a lower risk of colon cancer in people without IBD. High fiber diets appear to have a benefit as well. These diets are generally recommended, but check with the healthcare provider to see if a high fiber diet is right for your child, particularly if they have Crohn's disease, because roughage (the undigested part of fiber) can be a problem if they have a narrowing of their intestines (known as a stricture).
- **Eat less red and processed meats.** Eating lots of red meat or processed meats (ex. hot dogs, ham, bacon, sausage, and some deli meats) may be associated with an increased risk of colon cancer. This does not mean that your child can't eat meat, it just means they should eat it in moderation. Some experts recommend limiting red and processed meats to one to two times per week.
- **Get enough vitamin D.** Low levels of vitamin D have been linked to inflammation in the intestines and colon cancer. Taking vitamin D supplements to keep your child's vitamin D level normal is recommended. At this time, it is unclear whether having vitamin D levels above normal is helpful. It is important to speak with your child's healthcare provider before you give your child any supplements.
- **Avoid tobacco.** Tobacco is known to increase the risk of several types of cancer, including colon cancer. This is true for all types of tobacco, including smoking, chewing tobacco, dip, and second-hand smoke.
- **Exercise.** Regular physical activity is associated with a lower risk of colon cancer.
- **Your child should get screened more frequently if they have primary sclerosing cholangitis (PSC).** PSC is a disease of the liver that causes scarring of the bile ducts. The risk of colon cancer is much higher in people with PSC. For this reason, it is recommended that those with PSC should get a colonoscopy one to two years after diagnosis and continue screening every one to two years.



Skin Cancer

There are two main types of skin cancer, melanoma and non-melanoma skin cancer (NMSC). People with IBD have an increased risk of melanoma. Anti-TNF medications like infliximab (Remicade®), infliximab-dyyb (Inflectra®), infliximab-qbtx (Ixifi®), infliximab-abda (Renflexis®), adalimumab (Humira®), adalimumab-atto (Amjevita®), adalimumab-abdm (Cytezo®), and certolizumab (Cimzia®) are associated with an increased risk of melanoma. Azathioprine (Imuran®, Azasan®) and 6-mercaptopurine (6MP or Purnethal®) are both associated with an increased risk of NMSC, also known as basal or squamous cell cancers. If your child is taking any of the medications listed above, an annual skin exam by a dermatologist is recommended.

The good thing is that skin cancer is mostly preventable. Ultraviolet (UV) light damages the skin and is the main cause of skin cancer. The two biggest sources of UV light are sunlight and tanning beds. Avoiding UV light is the best way to prevent skin cancer. If your child is exposed to the sun,

experts recommend using sunscreen with an SPF of 30 or above, and reapplying every two hours. Using indoor tanning beds is not recommended.

Cervical Cancer

Women with IBD are at greater risk of cervical cancer. At this time, we do not know if the higher risk is related to IBD, medications to treat the diseases, or a combination of both. A vaccine is now available to prevent human papillomavirus (HPV), the virus that causes most forms of cervical cancer. The American Academy of Pediatrics now recommends this vaccine for all children (girls and boys) as part of the routine schedule of vaccinations. HPV vaccination is recommended for all pediatric IBD patients. The HPV vaccine is safe for IBD patients taking medications that suppress the immune system. The HPV vaccine requires three doses for immunocompromised patients, no matter the age, and can be started as early as nine years old.

Tobacco Use

Current smokers have twice the risk of developing Crohn's disease than those who have never smoked. For those with Crohn's disease, smoking increases the risk of disease flares and the risk of surgery. If your child smokes, they should consider joining a program to help them quit or talk with their healthcare provider about using anti-smoking agents, such as a nicotine patch or medications. A resource that can help: http://www.cdc.gov/tobacco/quit_smoking/cessation/index.htm

Even being around tobacco smoke increases the risk of Crohn's disease or more severe disease. Therefore, caregivers of pediatric patients with Crohn's disease should stop their tobacco use.

Electronic cigarettes (known as e-cigarettes) may also contain chemicals that are harmful to your child's health. Avoidance is strongly recommended as e-cigarettes can be just detrimental to health as tobacco.

Eye Health

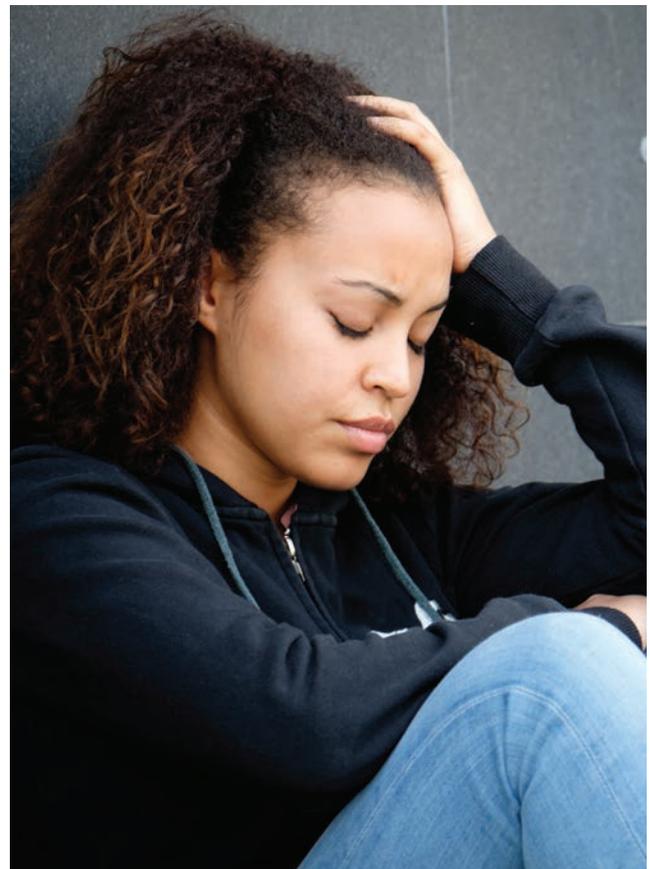
Some people with Crohn's disease or ulcerative colitis may develop eye problems. However, most of these are treatable and do not pose any significant loss of vision. Therefore, an eye exam by an ophthalmologist (a healthcare provider who specializes in diseases of the eye) should be conducted at diagnosis and then every one to two years. If you notice that your child has any type of eye irritation or inflammation, bring it to your healthcare provider's attention.

Psychosocial Health

Children and teens with an illness such as IBD face more challenges and stress than other children their age. They often deal with complicated medications, medication side effects, frequent healthcare provider visits, hospitalizations, blood work, poor growth, delayed puberty, and even surgery. Several studies have shown that many adolescents with IBD are depressed, and when depressed, their anxiety may increase, which can cause their IBD to be more active. Therefore, it is very important to look out for symptoms of depression and anxiety in your child.

Symptoms of depression in children include:

- Sadness or hopelessness
- Irritability, anger, hostility
- Tearfulness or frequent crying
- Withdrawal from friends or family
- Loss of interest in usual activities
- Poor school performance
- Changes in eating or sleeping habits
- No longer enjoying activities that were previously a source of pleasure



If you suspect that your child may be experiencing depression, you should discuss your concerns with your child's physician. Consider working with a local mental health provider who has experience helping children adjust to and cope with a chronic illness. If you are concerned for your child's immediate mental health and/or safety, take him or her to the nearest emergency room immediately.

Self-Management

Sticking to a treatment plan (adherence) can be difficult for both children and adults. Treatment plans are different for each child, but typically include: taking medications as prescribed, following a specific diet, and making and keeping medical appointments as scheduled. Young children need their parents' help with taking medications, eating properly, and attending appointments. However, as children get older, they should gradually start doing these tasks on their own and take greater responsibility for managing their disease. For example, they should learn how and when to take their medications, as well as scheduling their own healthcare provider appointments. Help your child understand why it is important to follow the treatment plan. Figure out ways that you and your child can remember to take medications, such as using a pillbox, taking medication at the same time of day every day, or setting reminders or alarms on a cell phone. Once they start taking on these responsibilities, it is important that you monitor them to ensure that they are following through.

Blood and Stool Tests

It is important that your child gets regular blood and stool tests. How frequently these tests are done depends on your child's disease as well as the medications they are taking. Blood and stool tests may be performed to:

- Check certain levels that suggest if IBD might not be well controlled
- Determine how your child's body is responding to certain medications
- Monitor for unexpected responses to some medications
- Assess for infections
- Help monitor nutritional status and if your child might require additional vitamins and minerals

It is important to get these tests done as often as recommended by your pediatric gastroenterologist.



The Crohn's & Colitis Foundation provides information for educational purposes only. We encourage you to review this educational material with your healthcare professional. The Foundation does not provide medical or other healthcare opinions or services. The inclusion of another organization's resources or referral to another organization does not represent an endorsement of a particular individual, group, company, or product.

Health Maintenance Checklist for Pediatric IBD Patients

Vaccines	Dates Completed
<p>Chicken Pox (varicella) Live vaccine. Not to be used if patient is immunocompromised.* First dose given at approximately one year and second dose at four to six years of age.</p>	
<p>Diphtheria, Tetanus, Pertussis (DTaP, Tdap) Four doses before 15 months of age, fifth dose at age four to six years. Given an additional dose at 11-12 years of age.</p>	
<p>Haemophilus influenza (HiB) Three doses prior to 15 months of age.</p>	
<p>Hepatitis A Two doses are given within six months of each other.</p>	
<p>Hepatitis B Given as a three-dose series (usually within six months). Child should be tested for Hepatitis B before taking any anti-TNF medications. It may be recommended for child to repeat the series if testing shows they are not immune to Hepatitis B after the first series.</p>	
<p>Human Papillomavirus (HPV) Given as a three-dose series (within six months). Recommended for all children (boys and girls). Can be started as early as nine years old.</p>	
<p>Flu (influenza) The flu shot (injection) is recommended every year before flu season (in the Fall or early Winter). The nasal spray version is a live vaccine and should not be given if immunocompromised.*</p>	
<p>Measles, Mumps, Rubella (MMR) Live vaccine. Not to be used if patient is immunocompromised.* First dose at approximately one year and second dose ages four to six.</p>	
<p>Meningitis (meningococcus) Taken one time.</p>	
<p>Pneumonia (pneumococcus) Patients on medications that suppress the immune system should receive the pneumonia vaccine (Pneumovax®) between the ages two years and older. If not previously given, they should receive Prevnar 13 at least eight weeks prior to receiving Pneumovax.</p>	
<p>Polio Three doses prior to 18 months, and a 4th dose at four to six years of age. The polio shot (injection) is recommended. The version taken by mouth (not routinely available in the United States) is a live vaccine and should be avoided if patient is immunocompromised.*</p>	
<p>Travel Vaccines If traveling to an area where certain vaccinations are recommended, check with your healthcare provider before taking any vaccines as some vaccines may be live virus vaccines and should be avoided if patient is immunocompromised.*</p>	

Bone Health	Dates Completed
Height Monitor height growth with your healthcare provider at routine visits.	
Bone Density Test A bone density test (DEXA scan) may be recommended at diagnosis with IBD and every two years after diagnosis. It may be repeated more frequently if initial screening is abnormal.	
Cancer Screening	Dates Completed
Colon Cancer For those with ulcerative colitis or Crohn's disease involving the colon (Crohn's colitis), a colonoscopy should be done eight to ten years after symptoms first appeared, with a follow up colonoscopy every one to three years after that. Sooner if they also have primary sclerosing cholangitis (PSC).	
Skin Cancer Annual skin exam by dermatologist if patient is immunocompromised.*	
Cervical Cancer Annual pap smear if patient is immunocompromised.* Starting at age 21.	
Blood & Stool Tests	Dates Completed
Complete Blood Count (CBC) Completed as frequently as pediatric gastroenterologist recommends.	
Liver Enzyme Tests, Creatinine Completed as frequently as pediatric gastroenterologist recommends.	
Inflammatory Markers (ex. Albumin, Calprotectin, Sed Rate, CRP, Lactoferrin) Completed as frequently as pediatric gastroenterologist recommends.	
Stool & Urine Completed as frequently as pediatric gastroenterologist recommends.	
Eye Health	Dates Completed
Eye Exam At diagnosis, and then every 1-2 years.	
Psychosocial Health	Dates Completed
Depression and Anxiety Children should be screened annually, or when symptoms appear.	

**Immunocompromised patients are those taking certain medications, such as: 6-mercaptopurine (6-MP, Purinethol®), adalimumab (Humira®), azathioprine (Imuran®, Azasan®), certolizumab (Cimzia®), infliximab (Remicade®), methotrexate (Trexall®), prednisone, tacrolimus (Prograf®), ustekinumab (Stelara®), vedolizumab (Entyvio®), or any other medications that weaken the immune system. This also includes patients who took these medications within the past 3 months or plan to take them in the next four to six weeks. For an updated list of recently approved IBD medications, please visit: <http://www.crohnscolitisfoundation.org/assets/pdfs/recently-approved-treatments.pdf>*

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Just Like Me- Teens with IBD. www.justlikemeibd.org

Campus Connection- website for college students with IBD. www.crohnscolitisfoundation.org/campus-connection



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Questions?

Contact the IBD Help Center
Monday–Friday, 9:00 a.m.–5:00 p.m. ET
888-694-8872
info@crohnscolitisfoundation.org

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