

KidsFACT: Our New IBD Support Group

Ashley Rogers, MS, RD, LDN



KidsFACT (Kids Fighting Against Crohn's and Colitis Together) is a non-profit support group created by GI FOR KIDS. KidsFACT is for pediatric patients who are diagnosed with Inflammatory Bowel Disease (IBD), including Ulcerative Colitis and Crohn's disease. KidsFACT is dedicated to making strides towards improving the quality of life for those suffering from IBD. KidsFACT's focal point is advancing knowledge to find better treatments and ultimately a cure for IBD. KidsFACT promotes family support, education, and research.

Since our practice is seeing more and more children suffering from IBD, Dr. Al-Tawil feels that it is imperative for patients and their families to have a strong support system and resources in our community. Please visit our website at www.KidsFACT.org or access the website through www.giforkids.com for more information. We also have a discussion forum on the webpage where helpful advice and support from others about IBD is available. Our next support group meeting will be held in the Spring of 2009. Please join us. For additional information contact Ashley Rogers at 865-546-3998 or anrogers@etch.com.



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Happy New Year to all of you!

Gallbladder and biliary disease are conditions in which the flow of bile out of the gallbladder is blocked or slowed due to inflammation, infection, stones, or obstruction of the gallbladder. Our practice has seen an increase in patients with gallbladder or biliary disease over the last several years, which is consistent with national trends. This is most likely due to patients' unhealthy diets and lifestyles, and can also be due to certain medications such as those used for pain. Additional predisposing conditions may result in gallbladder disease in children, such as hemolytic disease and total parenteral nutrition (TPN). Also, gallbladder disease is associated with many other systemic diseases such as autoimmune diseases including Crohn's or Ulcerative Colitis. Diagnosis of gallbladder diseases starts with a patient's history, physical, and basic blood tests. Younger children usually tend to present with nonspecific symptoms, while older children and adolescents typically have classic symptoms such as fatty food intolerance, vomiting, and right upper quadrant pain. Since lab results are often inconclusive for this diagnosis, some patients need radiological evaluations such as ultrasounds, HIDA scans, and functional gallbladder emptying studies. An upper endoscopy and colonoscopy are also used to rule out other conditions such as Crohn's or Ulcerative Colitis. Only a few gallbladder disease patients will require more risky and specific procedures such as endoscopic retrograde cholangiopancreatography (ERCP) and biliary manometry. Dr. Noel, who joined our practice last year, is a nationally known pediatric gastroenterologist with the ability to perform ERCP and biliary manometry in children. Treatment first includes diet modification as well as medication in order to improve hepato-biliary flow. Surgery is only considered an option after these treatment methods fail.

I hope you enjoy this issue. Please contact us with any questions or referrals.

Sincerely,

Youhanna S. Al-Tawil, MD

Fat-Controlled Diet

by Sandy R. Altizer, RD, LDN



A fat-controlled diet is used to limit nutrient losses and/or relieve symptoms caused by fat malabsorption resulting from disease processes or disorders that alter how fat is utilized in the body, such as biliary dyskinesia.

The fat-controlled diet limits total fat intake to less than 20% of total calories. The diet should include a wide variety of fruits, vegetables, lean meats, rice and other grains prepared without additional fat. Milk and milk products as well as meat sources should be low fat. Foods eaten in a restaurant need to be chosen carefully so as to avoid added gravies and sauces and may require special requests regarding preparation.

The level of fat intake is dependent on three things: a) the child's total energy requirements, b) the underlying cause of fat malabsorption, and c) the severity of the symptoms. The caregiver's ability to monitor fat intake needs to be carefully assessed in order to encourage compliance. The food plan needs to be adjusted depending on several factors such as age, developmental stage, and food preferences. Nutritional inadequacy is problematic with this particular diet and nutrient intake should be very closely monitored in order to avoid deficiencies. Consider an over-the-counter supplement, dosed appropriately to age, to augment intake. For infants younger than 2 years, close monitoring by a health care professional is key.

Diets containing 10% or fewer calories from fat are at the highest risk for fatty acid deficiency therefore additional calories in the form of higher carbohydrate foods may need to be included in the diet. Medium chain triglycerides (MCT), in the form of MCT oil, may help with replacing long-chain fats however when consumed in large quantities may promote osmotic diarrhea. Include at least 1% of total calories from linolenic acid and 3% total calories from linoleic acid (such as soy, canola, or safflower oils). Evaluation and treatment, along with close monitoring of dietary needs, will ensure adequate nutrition and proper management of conditions associated with malabsorption of dietary fats.

Biliary Colic, Biliary Dyskinesia & Sphincter of Oddi dysfunction

By Robert Adam Noel, MD



Biliary colic is a recognized source of abdominal pain in both children and adults. Biliary dyskinesia can be a form of biliary colic without cholelithiasis and is assessed by a gallbladder emptying study using cholecystokinin (CCK) stimulation.

The most common symptoms that lead to evaluation for biliary dyskinesia are abdominal pain, nausea, fatty food intolerance, emesis, and diarrhea. Patients with these symptoms will usually get an imaging study of liver and gallbladder and if no stones are found will often be referred for a nuclear medicine study to evaluate gall bladder function. If the gallbladder ejection fraction is less than 35%, the patient may be diagnosed with gallbladder dyskinesia. It is unclear at the present time whether this dysfunction is primary due to gallbladder disease, or a problem with the valve mechanism that in part controls the flow of bile into the intestine known as the sphincter of Oddi, or possibly a problem with the signaling mechanisms that controls bile flow. In pathologic evaluation of gallbladders following cholecystectomy, chronic cholecystitis is found in the range from 40% to 90% of specimens. There is no data on the resolution of cholecystitis using medical or endoscopic therapy. The short term partial to complete resolution of pain ranges from 60% to 90% depending on the study and evaluation period. Of concern in some long term follow up studies is that as many of 40% to 50% of patients have recurrence of abdominal pain. It is therefore important that the pediatric patient be given the best chance of long-term success and an evaluation process that will determine the most prudent approach is used to determine the type of medical or surgical intervention.

Sphincter of Oddi function can be evaluated in select patients with biliary or pancreatic pain. The evaluation of sphincter function is sometimes done by manometry performed in association with an ERCP (endoscopic retrograde cholangiopancreatography). In this study

a special catheter that can measure pressure at the sphincter is introduced into the pancreatic or biliary duct depending on which part of the sphincter muscle that needs to be measured. After the catheter is inserted to a predetermined length into the duct it is slowly withdrawn as pressure measurements are taken. In hypertonic or stenotic sphincters the pressure is higher than 40 mm Hg. The technique is straight forward but complication associated with the procedure can be very serious. In adult studies, ERCP with manometry of the sphincter of Oddi is most useful in patients with type 1 or type 2 sphincter of Oddi dysfunction. Sphincter of Oddi dysfunction (SOD) has been separated onto three different types. Type 1 SOD is characterized by both radiologic and biochemical evidence of SOD in addition to biliary colic symptoms. Type 2 SOD is characterized by either radiologic or biochemical evidence of SOD in addition to biliary colic. Type 3 is associated with biliary colic only with no supporting radiologic or biochemical signs of SOD and is least likely to respond to biliary sphincterotomy. Sphincterotomy of the sphincter of Oddi can be useful in the appropriate patient with elevated manometry pressures to decrease the pressure in the affected duct and to relieve any associated stenosis. However the poorest outcomes are in patients with type 3 SOD, and this procedure in general is not recommended in these patients.

Coping with Pain and Stress Related to Gall Bladder Disease

By Regina M. Hummel, Ph.D.



Pain associated with gall bladder dysfunction is a source of concern for children and parents. It is known that the discomfort associated with gall bladder disease is severe and recurrent. When negative emotions interact with the experience of pain, the outcome is higher levels of subjective distress and diminished use of coping strategies. When the source of pain is unknown, a child is likely to make inaccurate attributions about

their health and well-being. Catastrophizing, or assuming the worst about their health is known to intensify the experience of pain. Once the cause of their symptoms is known however, children can still have difficulty finding ways to cope with the unpredictable nature of this illness. Misguided attempts at problem solving around the causes of the pain can sometimes make their symptoms worse. Failure in the process of problem solving can lead the child to give up trying. This loss of hope and the perception that they have lost all control is another problem for pain management.

Fortunately there are several very effective ways to help children with pain management. Cognitive Behavioral Therapy that incorporates modified diaphragmatic breathing, progressive muscle relaxation and/or guided imagery has been found to be useful and effective in providing children with tools to effectively cope with pain. These strategies focus on developing cognitive distractions for their experience of pain as well as techniques for relaxing their physiology. The goal is to empower the child to be in control of their thoughts regarding their pain. When we can neutralize catastrophic thought processes, emotional well-being will follow.

The key to effective treatment however is early intervention. The sooner a child is given good coping techniques, the better their perception of control of their health and body. Adequate coping with the pain of gall bladder disease allows more time for medication and dietary changes to have an effect and therefore possibly prevent the need for surgery.

MARK YOUR CALENDARS

Support group meeting for those with Celiac disease: March 16, 2009 at 6:00 PM. Location: Meschendorf Conference Room, Koppel Plaza, East TN Children's Hospital Campus. For directions and parking information, please visit the support group's website at www.celi-act.com.

Please keep this resource in mind for any patients you see with Celiac disease.

