

Constipation 101

Transcript of a TrisomyTalk.com video presentation
for parents of children with trisomy 18, 13 and related disorders

By Ann Barnes, RN with Terre Krotzer, TrisomyTalk Host

Thank you, Terre Krotzer, for providing SOFT with Trisomy Talk Webinars. What a great use of technology. Terre is the mother of 14 year old Krissy who has trisomy 18 and she invited me to talk about constipation, a common problem for those with trisomy 18, 13 and many with related disorders. The presentation text follows, but be forewarned; it contains more detail about your bowels than you ever wanted to know!

It was our beloved daughter, Megan (1985-2004), who brought us to SOFT in 1987, where we met and still continue to meet other families who share about living with their children with trisomy 18, 13 and related disorders. Like Megan who was born with trisomy 18, these children teach others about their specific syndrome and care needs through their parents. Megan never had a surgery for her bowels. However she still needed help to maintain regular bowel function throughout her life, and she benefitted from the long - term care of a pediatric gastroenterologist and the nutritionist who worked with him.

My background is in healthcare, primarily as a pediatric registered nurse (RN) and I also earned the title of *stay-at-home mom* during those years when our 3 oldest children were young, plus the years prior to home health care for Megan, our youngest. So this talk/article about constipation is presented from the perspective of being a mom, who has been there, and as a nurse, with the insight gained from other SOFT families and the SOFT Surgery Registry.

This information is not a substitute for your doctor's advice. Any ideas that interest you should be discussed with your child's health care provider as to the appropriateness for your child.

This presentation/article discusses:

- What is constipation
- The lower digestive tract
- What causes constipation
- Comorbidities (other health issues occurring at same time) and common associations
- Possible complications
- The treatment goal
- Laxative types and other approaches

What is Constipation?

Constipation is a common problem for the general population of all ages; so common **that doctors generally prescribe laxatives without testing for possible reasons.** In the USA, constipation accounts for 3-5% of pediatric office visits and 25% of referrals to gastroenterology specialists. But the incidence of constipation for children with neurodevelopmental disabilities is 74%, much greater than the general population (www.DDHealthInfo.org). At one of the early SOFT conferences in Rochester, NY, Dr. Gregory Liptak, Neurodevelopmental Pediatrician, the physician who took care of one of SOFT's well-known long-term survivors, described constipation as *a delay or difficulty in passing a stool for two weeks*

or more which is a description that likely encompasses all SOFT children (and quite possibly many listeners/readers of this presentation).

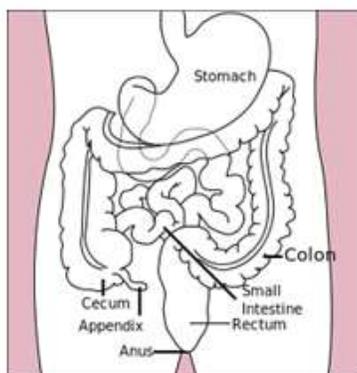
Be aware that chronic constipation is a symptom of an underlying problem. Understanding the challenges and causes could help find relief for your child. Children with trisomy 18, 13 and some with related disorders have problems **related to intake of nourishment and output of stool**. Coordination of muscles used to suck (or chew), swallow and breathe affects intake. Feeling the urge to go, bearing down with abdominal muscles to push, and relaxation of the pelvic floor muscles to let stool out, affects output.

Constipation occurs when stool accumulates in the rectum and becomes dry, impacted and/or difficult to expel which may lead to 3 or more days between bowel movements. Normal frequency of bowel movements in a healthy newborn is 2-3 times per day, decreasing with age to once daily for those greater than 3 years old. Small firm stools, appetite decrease, and fretfulness are some of the signs of constipation. Loose stool or diarrhea might be a sign of stool moving around an impaction. In most cases constipation is diagnosed as a **functional constipation** which might be of short duration with treatment and behavior modifications, but can recur or become chronic. A functional disorder refers to an altered way the body functions, not caused by abnormality or illness. Only 5% of constipation cases are due to anatomical or organic causes for the population in general but for those born with multiple anomaly disorders like trisomy, the incidence might be greater. The SOFT Surgery Registry lists numerous kinds of surgeries involving the bowel for those with trisomy 18, 13 and related disorders.

Lower Digestive Tract (consists of the small and large intestine and rectum)

Lower Digestive Tract

https://en.wikipedia.org/wiki/Gastrointestinal_tract



The Small Intestine: In this slide the faded lines connected to the bottom of the stomach, show the beginning of the small intestine. The small intestine mixes digestive enzymes with food residue and absorbs nutrients. It ends at the cecum which is the beginning of the large intestine. The large intestine is also known as the colon.

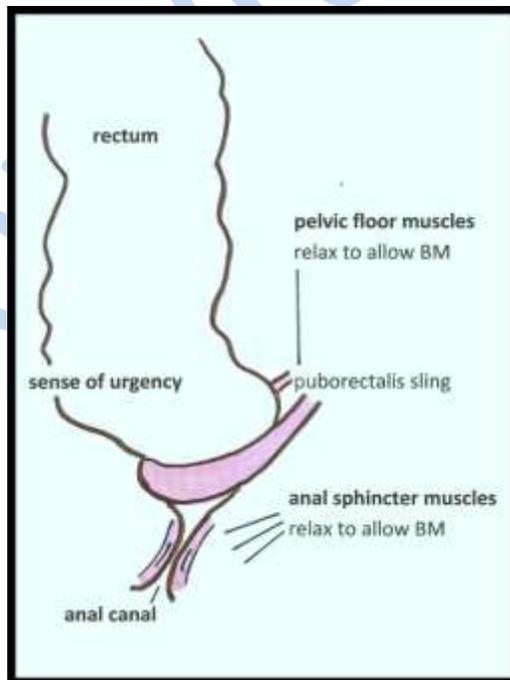
(The small intestine is composed of 3 parts (not labeled in the slide), starting with the **duodenum where many different enzymes from the stomach, liver, gall bladder and pancreas mix with food consumed to aid digestion. Next in the upper portion of the twisted area, is the **jejunum** which absorbs nutrients such as proteins, carbohydrates, amino acids and more and last the **ileum**, (lower portion of the twisted area) which absorbs mainly B12, as well as water soluble vitamins, bile salts and other nutrients not yet absorbed.)*

Nourishment moves from the stomach to and through the small intestine, to the beginning of the large intestine, called the ascending colon. The undigested nourishment residue then moves up the ascending colon, across the transverse colon and down the descending colon to the rectum. The small intestine is called small because the diameter is less than the diameter of the large intestine. However, on average the small intestine measures 3 -1/2 times the length of an adult person's height.

The **large intestine (colon)**, about 5 ft long in an average adult, is a tube-shaped muscle. Short segments of this muscle contract to move food residues back and forth for **water extraction**. Periodically **strong** contractions begin in the ascending colon and move progressively, pushing food residue toward the rectum. If these strong contractions fail to occur, it causes **slow transit constipation (STC)**. The slower food residue moves, the dryer it becomes. Before moving to the next slide pay attention to the location of the rectum and anus, bottom center of the lower digestive tract.

Side View of Pelvic Floor Muscles

The diagram below is a close-up side view of the rectum and anus showing the pelvic floor muscles highlighted in pink. These are the muscles that must relax to allow a bowel movement.



Side view of muscles that relax (by phasic contractions) to allow a BM

(The **pubo-rectus sling is a pelvic floor muscle looped around the base of the rectum that relaxes to open so stool can move into the anal canal. The anal canal has 2 sets of muscles; voluntary external sphincter muscles & involuntary internal sphincter muscles that surround the anal canal.)*

If these muscles, pictured in the slide, fail to relax, then **pelvic floor dysfunction**, also called **outlet dysfunction**, occurs. **Anorectal Manometry** testing can be done to evaluate constipation or fecal incontinence.

Causes of constipation:

There are numerous causes of constipation. Listed are causes that might relate to a child with trisomy 18 or 13.

- **Inadequate fluid intake or dehydration** is likely the most common reason for constipation in all persons. For those with trisomy 18 or 13 feeding and fluid intake problems and tolerance issues with volume make it difficult to be adequately hydrated. But a word of **caution: if there is a possibility your child is in heart failure or being treated for heart failure, check with your doctor before attempting to increasing fluids.**

*Research results from a survey of nearly 10,000 **adults** about fiber, exercise, fluids and constipation published in ([American Journal of Gastroenterology, May, 2013](#)) found that **low liquid consumption** remained **a predictor of constipation.***

- **Lack of exercise-** The activity level of those with full trisomy 18 or 13 is insufficient to help prevent constipation, and laxatives are needed. Low muscle tone or motor abnormality affects GI motility.
- **Lack of upright positioning-** It is hard to push out a stool when lying on your back. **Sitting upright on a potty chair** helps when bearing down for a bowel movement. Those not yet old enough for a potty chair can be aided, while lying on their back, by flexing their knees to the chest and giving a little pressure to the soles of the feet. My daughter, Megan, began using a special needs potty chair when 3.5 years old. Routine timing for sitting on the potty chair after feeds and sleep, along with a lot of praise, resulted in 75% voiding and 80% BM on the potty success.
- **Medications-** Be aware that **medicines might contribute to constipation problems.** Drugs for reflux, seizures, heart failure, pain, supplements of iron or calcium and many anticholinergics which dry secretions and slow digestion, list constipation as a side effect. Ask your doctor about possible side effects and interactions of all the medications your child takes, even those taken by nebulizer. **Do not discontinue or change a medication without talking to your doctor.**
- **Electrolyte abnormalities-** Misuse of laxatives can cause electrolyte abnormalities such as excess calcium or too little potassium which contribute to constipation and possibly other health concerns. Laxatives will be discussed in more detail later in this presentation.
- **Lack of strong colon contractions result in slow colon transit (SCT)** - An early symptom of SCT is delayed passage of meconium (dark sticky stool) beyond 24 hours of age in the newborn. A **nuclear transit study** can help confirm suspected SCT. Care is managed with laxatives and/or enemas and careful diet under the long-term guidance of a pediatric gastroenterologist but

if there is no improvement then surgeries such as **colon resection, colostomy or cecostomy** might be considered. [Pediatric Surgery Update, *Slow Transit Constipation*, 2012 Coqui.Net.] These surgeries for children with trisomy 18, 13 and related disorders, and numerous other reported GI surgeries for abnormality or blockage can be seen in the SOFT Surgery Registry at www.trisomy.org. For example:

- **Colostomy** 4 children with trisomy 13, and 3 with related disorders
 - **Cecostomy** 1 child with trisomy 13
 - **Intestinal Resection** 9 with trisomy 13, and 5 with trisomy 18
(of these, 3 with trisomy 13 specified **colon resection**)
- **Outlet muscles failing to relax** causes pelvic floor dysfunction, also called outlet dysfunction. Dysfunction occurs when an urge to have a BM is felt, but the pelvic floor muscles fail to relax; or **tighten instead of relaxing**. Supporting your baby in a warm bath might relax the anus and produce a BM... **in the bath!** *Stimulating the anus gently using a lubricated old fashioned rectal thermometer is another suggestion you can ask your doctor about.* Technology provides a number of tests to confirm a dysfunction diagnosis.
 - **An anatomical malformation of the anus contributes to difficulty in having a bowel movement.** A malpositioned or funnel shaped anus was found in 10-50% of cases of t18 studied by KL Jones in the well-known medical genetics text book *Smiths Recognizable Patterns of Human Malformation*. Multiple anomalies of every organ system have been noted in Jones' studies of children with trisomy 18 and trisomy 13. However an infant may be born with several anomalies, yet another with only a few. The SOFT surgery registry shows:
 - **Anal plasty** 6 with related disorders, 1 with trisomy 18, and 1 with trisomy 13
 - **Rectum reconstruction** 1 with mosaic trisomy18
 - **Fear of having a BM** happens when a child experiences pain with a BM or anxiety as might occur when potty training. The urge to have a BM happens when nerve endings in the rectum detect fullness. The child who fears a BM can tighten the anal sphincter muscles and withhold the movement. This exacerbates the problem by backing the stool up and stretching the rectum with accumulation and **the urge sensation dulls**. The stool sits longer in the rectum, continues to dry, becoming more difficult to pass. The medical term for this is **Functional Fecal Retention**.
 - **Certain foods** such as cheese, bananas, rice, and whole cow's milk can contribute to constipation. For infants, a transition from breast to formula often begins constipation issues. The child's health care provider or nutritionist can provide information about formulas, foods and constipation.

Comorbidities: possible coexisting conditions/diseases related to constipation

- **Hirschsprung's disease** occurs when some of the nerve cells in the intestine are missing or do not form properly during pregnancy. The missing nerve cells interrupt signals from the brain telling the walls of the intestine to move food forward (peristalsis). These babies are unable to have normal BMs, are constipated, and develop partial or complete blockage of the bowel. 25% of intestinal obstruction in all newborns is caused by Hirschsprung's disease. Delayed passing of meconium (dark sticky stool) in the 1st 24-48 hours of life is a major symptom. 80% show

symptoms in first 6 weeks of life but if only a short segment of intestine is affected the child might not show symptoms for months or years. Symptoms in the older child mimics other illnesses; constipation gets worse, loss of appetite, delayed growth, and small watery stools. Testing is done by x-ray, barium enema and biopsy. Treatment depends on the extent of the problem but if bowel obstruction happens, a surgical bowel resection (removal of affected intestine) and a colostomy are usually necessary. With a colostomy the end of the remaining healthy intestine is brought through an opening in the abdomen. Stool will pass through the opening into a bag. This might be temporary or permanent. Hirschsprung's disease has been mentioned by a few SOFT parents. Find more information about Hirschsprung's at www.trisomy.org > Resources.

- **Meckel's Diverticulum (MD)** is an outpouching or bulge in the lower part of the small intestine. MD is the **most common genetic gastrointestinal GI anomaly** at birth affecting 2-3 % of the population but it is not a problem for most and does NOT necessarily need treatment. Symptoms usually occur in the 1st year of life but can happen in children and adults. MD can secrete acid and cause ulcers and bleeding. Bowel obstruction is possible, occurring more often in older children. If bleeding develops abdominal surgery or laparoscopic surgery can remove the diverticulum and the intestinal ends are sewn together. MD has been reported by a few SOFT parents. It is noted in Smith's Recognizable Patterns of Human Malformation as occurring in less than 50% of persons with t13 and 10-50% of those with trisomy 18. Find more information about MD at www.trisomy.org > Resources.
- **Neurodevelopment disability or neurological impairment** can affect GI motility and a person's awareness of urgency, as well as their brain and gut response.
- **Spina bifida** occurs in less than **10% of those with trisomy18, and <50% in trisomy 13**. A neurogenic bowel has loss of normal bowel function because of nervous system impairments and cannot tell the brain when it is full resulting in slow peristalsis
- **Hypothyroidism** can be detected by Newborn screening which is mandated in most states or if a child develops symptoms when older, by blood draw. The incident of Hypothyroidism is 1/4000 newborns. Symptoms include bradycardia (slow pulse), excessive sleep, and constipation. Recently two SOFT mothers reported a diagnosis of hypothyroidism in their child; one with trisomy 18 and the other had mosaic trisomy 18. And a few others commented on Facebook that their child was being treated for hypothyroidism.
- **Illness** - (nausea, vomiting, fever, poor appetite, fatigue) contributes to dehydration

Common Associations: other health issues that might be related

- **Gastroesophageal Reflux (GERD)** due to an increase in abdominal pressure can result in pulmonary aspiration
- **Discomfort** interfering with appetite and sleep results in poor weight gain & irritability.
- **Slow gastric emptying** can be related to laxative abuse
- **Cramping**

Possible complications: need the care of a medical provider

- **Pulmonary aspiration** can be caused by GERD and result in aspirational pneumonia
- **Anal fissures** from straining to push out hard stool cause small tears and bleeding
- **Megacolon** is a stretched colon filled with stool which decreases the urge sensation
- **Volvulus** is a loop of bowel twisted on itself which may result in necrosis and bowel blockage
- **Fecal Impaction** is a dry, hard immobile lump of stool in rectum
- **Encopresis** is soiling of underwear/diaper when stool seeps around an **impaction**
- **Seizure** – If your child has seizures, an increase in frequency can be a symptom of constipation
- **Urinary tract infection (UTI)** can be related to constipation. 25% of girls with UTI have constipation issues. The bladder and rectum are in close proximity. A full/distended rectum presses on the bladder, preventing the bladder from filling as much as normal and also interferes with the bladder emptying completely. Retained urine is a predisposition to urinary tract infection (UTI). **Vesico ureteral reflux** of the retained urine in the bladder, backing up through the ureters into the kidneys, could eventually damage the kidneys.

The Treatment Goal & Common types of Laxatives:

Goal for those with trisomy 18 or 13: to soften stool so it is painless to pass

It is important to learn about the Common types of laxatives. The following discusses types of laxatives in more detail including three hyperosmotic laxatives.

- **Bulk forming** (Fiber) - considered safest to use long term but can be counterproductive.
- **Stimulant** (irritant) – harshest; not recommended for long term use
- **Stool softener**
- **Lubricant**
- **Osmotic** - considered safe for long term maintenance
 - **Saline**
 - **Hyperosmotic**

Some laxatives are available by prescription only but most are over-the-counter (OTC) products. A number of them are mentioned in this paper, but not all. Ask your child's health provider about any laxatives you're considering using for your child, even the OTC products. They all have the same purpose but work differently and have possible side effects.

Laxative Types (Bulk forming; Stimulant)

Bulk Forming Fiber supplements must be given with extra water or they will be counterproductive causing gas, discomfort and worsen constipation. The fiber fluffs up with water making the stool softer. OTC Fiber supplements such as *Maltsupex* for infants <4 mo; and *Benefiber* for older children are used for mild constipation and considered safest for long term maintenance but can **interfere** with some **medication absorption**. These products are **not a good choice for those who have difficulty taking adequate fluids**. Persons who have intestinal strictures or possible adhesions from a prior surgery should let their health care provider know and discuss possible risk before using fiber supplements.

Stimulant laxatives irritate the walls of the small intestine and colon. This causes the muscles to contract, propelling contents forward but might cause diarrhea, dehydration, and loss of electrolytes. Stimulants usually contain senna (*Senokat*) or cascara (*castor oil*) that occur naturally in some plants or

contain bisacodyl (*Dulcolax*), a product which evacuates the colon but has no action in the small intestine. Stimulant laxatives are considered the **harshest** of laxatives and are for occasional use or for disimpaction, if a child becomes impacted. Stimulants may stop working if used daily or damage the colon, making constipation worse, and are **not recommended for long term use**.

Laxative Types (Stool softener; Lubricant)

Stool Softener contains docusate, a wetting agent that allows water and fats to get into the stool. *Colace* is a stool softener that does not force a BM but might take 1-2 weeks of use for effect. Stool softeners are commonly used to soften stool temporarily, such as after surgery, childbirth or for occasional constipation. Caution: **do not use stool softens with mineral oil or certain medications**.

Lubricants grease the stool to help it slip thru the GI tract. *Mineral oil* is a commonly known lubricant but its use is **not recommended for infants and neurologically impaired children as it is associated with aspiration and lipid pneumonia**.

Laxative types - (Osmotic - Saline)

Osmotic laxatives are considered safe for long term maintenance - Osmosis is movement of fluid through a semipermeable membrane from a low solute area to a high solute area. There are two kinds of osmotic laxatives; Saline and Hyperosmotic.

Saline - Saline laxatives contain non absorbable ions that remain in the colon and draw water in by osmosis, softening the stool. The most commonly used (*Milk of Magnesia*) has a chalky taste and might alter electrolytes or interfere with certain medications. It is used for occasional constipation. It should be **used with caution in infants and anyone with renal (kidney) impairment**.

Laxative Types – (Osmotic - Hyperosmotic)

Hyperosmotic- (*Lactulose*) - This prescription drug is a man-made non-absorbable sugar that draws body fluid into the colon, lowers pH (acidifier) and increases bowel movements but it can sometimes cause gas, bloating and abdominal discomfort. It is for short term use in those greater than 6 months old and is one of the commonly prescribed laxatives considered **safe for children under 2 years of age**. My daughter, Megan, took lactulose in her early years.

Hyperosmotic- (*Pedi-Lax* formerly called *Babylax*) is also an anal-rectal irritant - This OTC product is a liquid glycerin suppository provided in a soft tube applicator. Insertion of *Pedi-Lax* irritates the anal canal, draws water into stool and prompts a BM in less than an hour (In my experience *Pedi-Lax* liquid glycerin suppositories are more effective than hard glycerin suppositories and results took only about 15 minutes). It is used for occasional constipation of 2-5 year olds; if under 2 years check with your doctor. *Babylax* was effective even when my daughter was much older. **Dr John Carey, medical advisor for SOFT, advises all parents to check with their child's doctor before using *Pedi-Lax***.

Hyperosmotic- (*Miralax*) contains Polyethylene Glycol (PEG) 3350 and it is available with or without electrolytes. *MiraLax* without electrolytes is discussed here as it is considered “**the Gold Standard of Treatment**” for children with constipation (personal communication, Dr John C Carey, 2013) It is a tasteless powder, easily mixed with water or juice, making a high-solute solution and does not cause **tolerance** (the need for increased doses). A recent article by Walia in *Practical Gastroenterology* describes PEG 3350 without electrolytes as absorbable in only trace amounts with a very low risk of electrolyte imbalance. This OTC product for adults with occasional constipation and medical procedure preparations has been prescribed off label to children for more than a decade. **If your child has a**

history of kidney disease, bowel obstruction or irritable bowel let your child's health provider know before using this product. My daughter used Miralax with success when in her teens.

Recently, an alarmist ad about MiraLax raised concerns with Facebook moms of children with trisomy conditions. And one SOFT mom shared that her daughter experienced “dangerous and lasting side effects” from increased doses of MiraLax prescribed by different GI doctors. Concerns about *MiraLax Polyethylene Glycol (PEG) 3350* can be found in news articles, ads, and consumer complaints to the FDA. See <http://FDA.gov>. The FDA scrutinized PEG-3350 for neuropsychiatric events and made a decision in 2011 of “no action necessary at this time based on available information”. Walia et al notes that the therapeutic safety of PEG 3350 for treatment of chronic childhood constipation and impaction has been demonstrated in many studies. [Walia et al 2013 *Chronic Constipation in Children: An Overview*. Practical Gastroenterology, Nutrition Issues in Gastroenterology, series#119]

Laxative Types – (Combination)

Combination laxatives Combination OTC products for constipation combine two or three different-acting laxatives but most contain a **harsh stimulant laxative** and long term use is a risk for possible colon damage. An example is **Peri-colase** which contains a stool softener and a stimulant.

Other Approaches to Constipation

Enemas - There are different types of enema solutions with different modes of action. Enemas should only be used with caution, under the guidance of your child's health care provider, as enemas can deplete a baby of electrolytes and alter body fluids in children. This is especially true of tap water enemas. [Marks JW, 2012. Constipation, MedicineNet.com, WebMD]

Power Pudding is a home remedy for constipation that one SOFT teen is given daily. Dr Liptak, at his SOFT conference workshop in Rochester, mentioned that power pudding was a mixture of prune juice, bran, cool whip and apple sauce. Joe Graedon of Peoples Pharmacy provides a slightly different recipe in his constipation information for **adults**. Mix 1 cup unprocessed wheat bran, 1 cup applesauce, $\frac{3}{4}$ cup prune juice - the mixture will be very thick and needs to be refrigerated. This high-fiber mixture **must be taken with plenty of fluid** and used daily. **It doesn't work instantly**. Graedon recommends Power Pudding for **adults** beginning with 1-2 tablespoons daily, if no results in a week increase by 1 tablespoon. Do not exceed 6 tablespoons daily. **If you wish to try Power Pudding ask your child's doctor if it is appropriate to your child's needs and about how much to give your child.**

Dark corn syrup/kayro syrup is a non-absorbable sugar that holds onto water. It is an old remedy for mild constipation in infants but botulism was a concern in the older product. The current corn syrup product contains less sorbitol (non-absorbable sugar) thus it is less effective for treating mild constipation in infants, and it is no longer considered a potential source of botulism. There is disagreement in the health profession about the use of dark corn syrup for mild constipation in infants.

Natural products – are unregulated by the FDA, thus ingredients and strength are not monitored. Be aware that herbal teas may contain stimulant-type laxatives and should not be used long term.

Diet & FLUIDS - consult your child's health care provider or nutritionist about foods, formulas and enteral products for tube feeding, that might help increase stools and be sure to discuss free water needs, especially if adding fiber to your child's diet. Infants with functional constipation frequently respond to treatment with juice that contains sorbitol such as apple, prune or pear. Most children with trisomy 18 or 13 are tube fed or partially tube fed and baby formulas or enteral formulas for tube feeds are available *with or without* fiber. Fiber added Pediasure slowed my daughter's stool output so we switched back to

using plain Pediasure. In hindsight, perhaps she also needed a little extra water. Enteral products for tube feeding contain different amounts of fiber & calorie content. There are more products than in the list below but you can see there is a different calorie and fiber content per product.

Jevity Plus; 1.2 Cal/ml; 12 g. fiber/L
PediaSure with Fiber; 1.0 Cal/ml; 5 g. fiber/L
Kindercal; 1.0 Cal/ml; 6.3g fiber/L

Breast Milk

Breast fed babies are less likely to be constipated than formula fed. However my baby with trisomy18 was breast fed but also treated for colic and constipation. Breast fed infants initially stool more often than those who are formula fed but breast milk is so nutritious that most of it is absorbed and these babies can go a week between bowel movements and as long as the stool is soft, it is not considered constipation. More than a few SOFT moms report success with breast feeding, or pumping breast milk and giving it to their baby thru a feeding tube. One SOFT mom recently commented on Facebook that her breast fed baby had a milk allergy, and she switched to using a soy formula. Soy formula is less constipating than many other baby formulas.

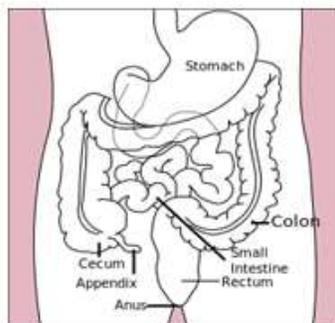
Surgery Approach (when all else fails... a procedure new to SOFT)

Recently, the first cecostomy was reported to the SOFT Surgery Registry.

Cecostomy is a **percutaneous** (meaning through the skin) **tube into the cecum**. See the cecum at the beginning of the large intestine in the slide below. An opening through the skin and abdominal wall into the bowel allows doctor-prescribed solutions to be flushed into the colon to moisten and soften the food residue for passage through the colon to the rectum; like a reverse enema. It takes about an hour to work. **A laxative will still be needed.** Careful attention must be paid to fluids and electrolytes, requiring frequent monitoring by the health care provider. **It is considered a last resort surgery.** A cecostomy surgery is a minimally invasive procedure and requires site care similar to a gastrostomy.

Surgery

- **Cecostomy** – percutaneous tube into cecum (1st part of large intestine)



For years, **the most asked SOFT question** was about *how to treat constipation?* But this was before MiraLax. Thus MiraLax has likely been prescribed and helped many SOFT children.

Laxatives and fiber (*with adequate fluids*) are effective in improving bowel movement frequency unless the constipation is caused by an underlying disorder or a slow colon transit problem. [DDHealthInfo.org] When soft stool is achieved it is important to continue daily maintenance to prevent reoccurrence of constipation. **(Laxatives for daily maintenance might be prescribed at a different dose or be a different laxative than what was initially prescribed to relieve the problem, particularly if the child was impacted. Be sure to clarify name and dose of medication for daily maintenance with your child's doctor.)* Constipation is a lifetime concern for those with trisomy 18 and trisomy 13. Other moms can be a helpful resource. But remember to talk with your doctor about ideas or suggestions, even those presented in this article!

**addition to Trisomy Talk presentation*

Questions? Email Ann Barnes: fbarnes@nc.rr.com

Constipation 101 TrisomyTalk transcript by Ann Barnes, posted to Support Organization for Trisomy 18, 13 and Related Disorders (SOFT) website www.trisomy.org

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