



SPINA BIFIDA CLINIC NEWSLETTER

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Monday and Wednesday.

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If you have received this newsletter by mail and wish to receive it electronically, call or email Mimi, and she will add you to the Spina Bifida Clinic email list.

SEND US YOUR IDEAS FOR THE NEXT NEWSLETTER

We encourage your comments and input. Please contact us to share your story or if you have a question or concern you feel should be addressed in an upcoming issue of the Spina Bifida Clinic Newsletter. We look forward to hearing from you!

Update from Mimi Ardis

Happy Spring, everyone. Here's hoping we never have the pleasure of encountering another polar vortex and that sunshine will warm our souls!

The times they are a-changing... I'm sure by now you all have heard that Dr. Reid is retiring. Her last day in clinic will be June 28, with her official retirement date July 1. While I am so very excited and happy for her, I also know she will be dearly missed by the patients and co-workers who got to know Dr. Reid over the last 20 years.

With Dr. Reid's retirement, there will be some pretty major changes coming to not only Urology Clinic but to Spina Bifida Clinic. There is a plan in the works for coverage of the Spina Bifida Clinic and those patients. At this time the specifics have not been confirmed, but I will keep you all informed as it gets worked out.

We had another successful GoBabyGo build on March 30. Five more children received modified battery-operated cars allowing them to explore their worlds, engage their curiosity and expand their minds. We are planning another build in July or August. If you would like us to include your child, please contact me. I have several families on my radar and will be contacting them in the next one to two months.

In other news, Peristeen (anal irrigation system) is being successfully used by 12 patients affiliated with OSF HealthCare Children's Hospital of Illinois and Spina Bifida Clinic. Good news..... Illinois Public Aid will now be covering the cost of Peristeen so I may be reaching out to some of you.

Thanks to Dr. Sue Caldecott-Johnson, the clinic now has five pairs of virtual reality units! While attending a conference, she learned of a program called Starlight Xperience who was taking applications to receive free VR units. We got lucky and were picked. You can play games or explore different environments/locations (I took a trip to Mt Everest). They are pretty amazing, help ease some of the boredom and add a fun distraction to clinic. ~Mimi



Oh, POOP!

Let's talk about a subject that most people are uncomfortable with but one that is so very important: poop! We all do it, some better than others, and people with spina bifida generally don't do it well. People with spina bifida have neurogenic bowels as a result of their spinal cord lesion. The lesion disrupts the nerves that control the bladder and bowel resulting in loss of sensation and motor control. The denervation (loss of nerve) also causes a decrease in muscle action of the bowel, resulting in constipation. Constipation in turn can cause urinary tract infections, incomplete bladder emptying or inability to urinate, leakage/incontinence of stool around hard stool and anal fissures.

BOWEL MANAGEMENT

Goals of bowel management:

1. Promote social continence, especially of school-age children
2. Minimize constipation
3. Encourage bowel emptying at appropriate time and place
4. Prevent leakage/incontinence between stools (often results from constipation)
5. Avoid complications from poor bowel routine (UTIs, skin breakdown, anal fissures)

Tips on how to manage bowels:

1. **Have a set schedule.** This is probably the single most important thing to do: be consistent. Get your body in a routine and try to follow it as closely as possible.
2. **Sitting on the toilet and pushing** is often helpful even if you/your child does not have good sensation. Do this 30 to 60 minutes after evening meal allowing peristalsis (involuntary muscle contractions) to help move the stool through the bowel. Prop feet on a stool with knees higher than the belly button. If your child does not know how to push, teach them by having them blow bubbles, blow a pin wheel, grunt, laugh, cough, or purse their lips and blow. Limit time on the toilet to 10 minutes.
3. **Add a probiotic daily** to the diet as they naturally stimulate peristalsis. Yogurt is the best natural probiotic. Other foods containing natural probiotics include: sauerkraut, kimchi (a Korean dish of fermented veggies), kefir (a fermented milk drink) and tempeh (a Southeast Asian soy product).
4. **Increase fluid intake**, especially water! This is essential to keep stool soft. Our bodies absorb water from stool. The longer stool sits in the intestine, the more water is absorbed. The more water that is absorbed, the harder stools become. Hard stool not only causes constipation, it is more difficult to pass and can cause many complications.
5. **Eat a high fiber diet.** Fiber adds bulk to stool which expands abdominal walls causing peristalsis. Foods high in fiber include: beans, whole grains, apples, pears, prunes, raspberries, peas and broccoli. Be sure to drink plenty of water when increasing fiber. Bulking up stool without being hydrated does the opposite – it causes constipation.
6. **Eat foods rich in magnesium.** Magnesium also increases peristalsis. Foods high in magnesium include: nuts, almonds, peanuts, cashews, whole grains, brown rice, beans, seeds and green leafy vegetables.
7. **Eat a full meal instead of grazing.** A full meal stimulates “food dumping” and peristalsis.
8. **Keep active and exercise if possible.** Exercise increases peristalsis which improves transit time of stool in the intestines. Again, stay hydrated with exercise and drink lots of water.

Medications used for bowel management:

First Tier/Conservative Treatments

Bulk forming agents: Add fiber to the stool by adding bulk. Again, it is important to drink plenty of fluids while taking these medications. Can be added to liquid or food with little change in taste. These can be used without a physician order/recommendation. *Medications: Metamucil, Fibercon, Benefiber*

The following should be added only after discussing with a physician:

Stool softeners: Encourage bowel movements by helping liquids mix into the stool and help prevent dry, hard stools. *Medications: Colace*

Osmotics: Pull water from the intestines and surrounding tissue resulting in softer stool and increased bowel action. *Medications: Lactulose, Miralax*

Saline laxatives: Encourage bowel movements by drawing water into the bowel from surrounding tissue, which results in soft stool mass and increased bowel action. Not intended for long term use. *Medications: Milk of magnesia in any form, Magnesium citrate, Fleets*

Stimulants: Encourage bowel movements by acting on the intestinal wall to cause irritation, which increases peristalsis. Should not be used if other methods have failed. *Medications: Senna, Ex-lax, Ducolax*

Lubricants: Help soften the stool and ease the passage of stool. Mineral oil is the most common lubricant. Never give mineral oil at bedtime due to risk of aspiration.

Second Tier Treatments: Should be used only under direction of provider

Suppositories: Help stimulate the rectum to push stool out. The rectal vault should be emptied of hard stool prior to inserting a suppository. After inserting the suppository, hold the buttocks together for at least 10 minutes to allow the suppository to work by preventing it from being pushed out.

Medications: Glycerin- lubricates the bowel; Bisacodyl (Dulcolax)-contains a stimulant, wax-based which melt slowly; Magic Bullet- is a bisacodyl suppository that has a water base so it melts faster

Mini Enemas: Similar to suppositories but contain a small amount of liquid. Rectal vault needs to be empty prior to giving. *Medications: Enemeez-prepackaged glycerin with lubricated tip*

Small Volume Enemas: Volume is between 30 to 120 ml (1 to 4 ounces) and given daily to every other day. *Examples: Fleets- come in adult size-120 ml or pediatric size-60 ml; Warm water- 30-60 ml may have soap or mineral oil added*

Digital stimulation, digital evacuation



Third Tier Treatments: Transanal Irrigation (Need provider order)

Large Volume Enemas: needed at times to clean out large amounts of stool. Volume is weight based
Examples: Warm water or saline enemas administered with an enema bag and tubing

Cone enemas: Using a cone irrigator set, a warm water enema is given with the cone acting as a rectal plug to hold in the fluid. Volume is weight based.

Peristeen Bowel Irrigation System: newest treatment although it has been used in Europe for years. This is a procedure that is performed daily (nightly) or every other day (night) on the toilet. It consists of a catheter with a balloon, tubing, a water bag and hand help pump devise. The bag is filled with warm tap water, the tubing primed and the catheter placed in the rectum. The balloon is inflated which allows it to stay in place, then a set amount of water is pumped into the lower colon, flushing the stool out from below (like an enema).

Pros: time effective; convenient-can easily transport system; don't need any additives to the water; and geared toward independence

Cons: cost

Fourth Tier Treatments: These are surgical procedures, so need evaluation by pediatric surgeon

Cecostomy: Surgical placement of a tube placed in the cecum (lower colon). The cecostomy tube exit will sit flush to the skin to the right of the belly button. A flush bag with tap water or normal saline (with or without additives ex: glycerin) is hung up and connected to the cecostomy tube. The fluid flushes out the lower colon from above. It is done on the toilet daily (nightly) or every other day (night) and should take less than 1 hour.

Pros: successfully cleans out the lower colon

Cons: it is a surgical procedure requiring general anesthesia; the tube needs to be replaced routinely (how often depends on the type of tube); tube can dislodge; can get skin irritation/infections at the insertion site; can be time consuming; have to mix the solution with salt and glycerin

MACE procedure (Malone Antegrade Continence Enema): Surgical procedure where appendix is brought to the skin surface. MACE is flushed in a similar fashion as a cecostomy tube.

Pros: successfully flushes out lower colon; no tube present

Cons: it is a surgical procedure requiring general anesthesia; can become obstructed; risk of infection at site; can be time consuming

I consistently hear that bowel management is easier if stools are hard. The pros to a good bowel program outweigh the cons of chronic constipation. With a little time, perseverance and consistency, you can achieve a doable bowel routine for you and your child.



Meet Brooke Escobar—Licensed Social Worker

Brooke Escobar is a licensed social worker who has served children and families for over 12 years. Brooke earned her graduate degree in social work from Governor State University. She has worked in a variety of child welfare and medical settings, including the Pediatric Emergency Department and outpatient clinics. Brooke believes it to be a gift to come alongside families and individuals to enhance their health, social functioning and overall well-being. She understands how a child's illness or condition affects the entire family and is here to provide counseling, support and solve problems by enabling connection with community and hospital resources.

Funds Available through the Illinois Spina Bifida Association

Did you know that ISBA offers funds for equipment and emergency assistance?

Equipment Fund: Families may request up to \$250 toward out-of-pocket costs for orthotic or other mobility equipment. To qualify, the equipment must be utilized by an Illinois resident with spina bifida. The 2018 ISBA Equipment Fund was made possible by generous gifts from “A Helping Hand” and Kiwanis Clubs. Funds will be available for 2019, check the ISBA website soon!

Emergency Assistance Fund: Illinois residents with spina bifida can apply for emergency financial assistance up to \$500. Money is paid directly to the vendor/supplier and documentation of need is required. Call ISBA at (773) 444-0305 for more information.

Information about ISBA funds is available on their website: www.i-sba.org

Illinois Spina Bifida Association Support Groups

Illinois Spina Bifida Association offers support groups in the following areas/regions:

Peoria, Bloomington-Normal, Rockford, Southern Illinois and Western Illinois

For information contact (773) 444-0305 or info@i-sba.org

STAR Patient—Jamesa Lee

Jamesa Lee was born in January 2004 with spina bifida. In the beginning she faced many challenges, but she has overcome many of them with the help of her family and the OSF Children's Hospital Spinal Bifida Clinic. Today, Jamesa is a part of the Champaign Centennial High School dance team, Centennial Best Buddies, and has received many awards for maintaining a 4.0 GPA.

Jamesa's motto is "I can do all things through Christ who strengthened me".



STAR Patient—Ben Pritchard



Benjamin "Ben" Pritchard recently turned 16 and celebrated doing what he likes best, playing games and eating pizza with his family. The fourth oldest in a family of three sisters and three brothers, Ben has overcome many obstacles to lead a fulfilling life. He was born with spina bifida and has used a wheelchair to aid in his mobility for most of his life. Ben has been active in school starting at a very young age and will be moving into high school in the fall. His family is very inclusive, and they've done a lot together recreationally.

Ben enjoys camping in places like Galena with his family, and they have taken many other trips in the boundary waters of Minnesota and dune beaches of Michigan. In these places, he has enjoyed canoeing, fishing off his grandfather's cabin dock and motor boating on lakes. The Pritchard family have all bicycled as a group utilizing a trailer for Ben. It was common for him to cover 10 miles or longer with them around their hometown and abroad. Hiking is another activity he has done many summers, observing wildlife and enjoying the open air.

Special Olympics is passion of Ben's, and he has been active in the program since 2014. He received several medals for various events, with track being his specialty. He even won a 400m race! Another activity worthy of mention is bowling, which he does frequently with his siblings... often having the high score. Most teenage boys are into video games and movies and Ben is no exception. He likes to play 2-player games with his younger brother, and he is a HUGE FAN of the superhero film genre. It is his dream to one day attend the San Diego Comic Convention to meet his heroes.



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