



THE EMPOWERMENT ZONE

VOLUME 18, ISSUE 2, MAY 2018

A PUBLICATION OF



Join us on Facebook!

In This Issue...

From the Desk
of Roberta KestenbaumCover

Options for Bowel
ManagementPages 2, 3

SBRN Spring Walk for Page 4
Empowerment

SBRN Tricky Tray RafflePage 5
at Spring Walk for Empowerment

SBRN Welcomes TracyPage 5
to the EZ and Golden Girls

Hollydell Ice Skate Social RecapPage 6

Healthy Living for College Students. Page 7

NJ DDD Releases New ManualPage 7
for their Supports Program

84 Park Avenue, Suite G-106
Flemington, NJ 08822
908-782-7475
info@thesbrn.org
www.thesbrn.org

From The Desk Of *Roberta Kestenbaum*



Spring has finally sprung and with warm weather on our minds, we are in the midst of planning for our **10th annual Walk for Empowerment** on Sunday, **June 10** at Roosevelt Park in Edison. Come join us for a fun-filled day of entertainment, refreshments and activities. Most importantly, we will stroll and roll around the pond to raise awareness of spina bifida!

We will also have a tantalizing **Tricky Tray Auction**, which is looking better than ever! We have many items, including sports memorabilia, an American Girl doll, an overnight stay at Mohegan Sun, wine tasting, tickets for museums and theme parks, restaurant certificates, gift baskets and more! You could be a winner!

Please consider **raising funds** for SBRN. This is an important fundraiser for our Family Support services. You can ask your friends and family members to donate or come up with creative ways to bring in money: hold a bake sale or sell crafts, have a yard sale or even collect loose change!

Check our website (www.thesbrn.org) for information, registration and pledge pages. We hope to see you there!



*“Just a few
of our
Tricky Tray
items”*

OPTIONS ...for Bowel Management

Most people living with spina bifida have some loss of bowel control (neurogenic bowel), including difficulties with emptying (constipation) and/or leakage of feces (incontinence). Problems arise due to limited sensation when the bowel is full, as well as lack of control over sphincters. Bowel management plans are important to develop and maintain throughout the lifespan.

The **goals** of a bowel management program are to help predict and control when bowel movements happen and to ensure complete elimination to reduce the risk of constipation, incontinence or other related issues.

Step-Wise Approach

Everyone's bowel program is unique to them and it may take a little time to determine what works best. Usually a step-wise approach is recommended, starting with the least invasive techniques before resorting to more invasive procedures such as surgery.

Diet and Fluids – Often the first thing to try, before moving to pharmacological interventions, is changing your diet and taking in more fluids. As part of any healthy diet, eating more foods high in fiber, such as fruits, veggies, beans, whole wheat pastas and breads, may help stool pass more easily. In contrast, foods like bananas, white rice and cheese may be constipating. Keep in mind, though, that people react to foods differently, so what may be stimulating to some, may be constipating for others. It's a good idea to add food items slowly until the stool is a good consistency. It is also important to add more **water** (not sugary drinks!) into your daily routine to ensure that you are well hydrated, especially when increasing fiber. Keeping a food diary may help you discover which foods are helping and which are hurting.

Oral Options: Stool Softeners & Laxatives – **Stool softeners** (such as Colase) can help by increasing the amount of water drawn into the colon and moistening the stool. **Oral laxatives** can make the stool bulkier and/or softer. Metamucil is a psyllium fiber laxative, which is used to bulk up the stool and move things along more quickly. It is important to increase fluid intake to avoid worse constipation. Miralax is an osmotic laxative, which increases the fluid retained in the stool to soften it. All of these are mild and may take a few days to help. Stimulant laxatives, on the other hand, which are more powerful, should be used short-term if recommended by your healthcare provider.

Digital Stimulation – For this technique, the person or a caregiver inserts a gloved, lubricated finger into the rectum and uses a circular motion to help relax the muscles and sphincters in order to reduce resistance to

the passage of stool. It is important to be gentle when doing this and short fingernails are a must. It may take a minute or two for the sphincter to relax. The procedure can be repeated after 15-20 minutes if it has not been effective.

Rectal Options: Suppositories & Mini-Enemas – Inserting **suppositories** helps draw water into the rectum and soften stool. Suppositories are mild and can be used daily if needed or with stool softeners or laxatives. In general, solid glycerin suppositories do not melt well for people with spina bifida, so liquid glycerin suppositories may be more helpful. **Mini-enemas** (brand name: Enemeez), which can help clean out the lower colon, are also mild and can be used daily.

Is it Diarrhea or Impaction?

When there is frequent constipation, fecal matter can become impacted (large clumps of stool form) in the intestine. Water is drawn out of the stool and reabsorbed into the body, making the stool very hard and difficult to move. When this happens, new matter sometimes flows around it and leaks due to a weak external sphincter, making it look like diarrhea. This is sometimes called paradoxical diarrhea. **It is important for healthcare providers who are not experienced with neurogenic bowel to realize that when a person with spina bifida has diarrhea, it may be caused by impaction and it needs to be cleaned out.**

Rectal Options: Enemas – An enema is used to flush out stool by injecting water through the rectum into the bowel. A cone enema system, where a small lubricated cone is inserted into the rectum and then warm liquid (water or saline) is pushed through it, is commonly used by people with spina bifida. Cone enema supplies are often covered by insurance if prescribed by a doctor. It may take a while to figure out timing and how much liquid is most effective. A **balloon enema** program is similar to the cone enema system, except it uses a latex-free foley catheter with a balloon which can be inflated in the rectum to prevent water from coming back out. This system may require additional training.

A more recent option in the US is an anal irrigation system, **Peristeen**, which is designed to allow the individual to use it independently. The catheter is easier to insert and inflate. This system does require training by approved healthcare professionals, and it is sometimes hard to get insurance to cover it and provide the materials, but that is becoming easier.

Surgeries – Surgical options are usually considered the last resort after trying less invasive techniques. However, if the other techniques are not working, doctors may recommend surgical intervention. In these procedures, surgeons create a duct from the top of the colon (large intestine) to outside of the abdomen (belly) so that individuals can flush the bowel more directly.

In the **MACE (or ACE)** procedure, a stoma (opening) is created for easy access into the colon, often using the appendix as the duct, in order to wash out the bowel. The stoma is often hidden in the belly button, but can be placed in other parts of the belly. A catheter is inserted

into the stoma, through the appendix and into the colon to flush it out with water, usually on a daily basis.

A **cecostomy** is similar, but instead of using the appendix as a duct, the surgeon inserts an artificial tube from the skin of the abdomen to the cecum (top of the colon.) The cecostomy tubes need to be changed every 6-12 months. The cecostomy is less invasive than the MACE, and it is reversible.

These procedures can make bowel flushes easier to do independently and less messy. However, as with any surgery, there are risks involved and should be discussed carefully with your doctors.

Some Tips for Timing Bowel Management

- Schedule your bowel routine at the same time every day.
- Eat and drink about 20-30 minutes before your routine to get the digestive system working.
- Perform your bowel routine at least once every two days. (Discuss with your doctor.)
- Relax and take your time. Try to avoid straining.
- Use proper positioning. Sit upright if you can and/or use properly fitting equipment.
- Shift your position at least every 15 minutes.

(Adapted from the *Bowel Management Booklet*, Christopher & Dana Reeve Foundation.)

This article is based on information from the following sources:

Bowel Management Booklet (2017), Christopher & Dana Reeve Foundation, <https://www.christopherreeve.org/living-with-paralysis/health/secondary-conditions/bowel-management>

Bowel Management for Spina Bifida – An Unofficial Guide by and for Parents and Adults with SB, <https://spinabifidabowelmanagement.com/>.

Evaluation and Treatment of Neurogenic Bowel Dysfunction – A Review (2016), Kumar, L., Athanasakos, E., & Emmanuel, A.V., *European Neurological Review*, 11(2). <http://www.touchneurology.com/articles/evaluation-and-treatment-neurogenic-bowel-dysfunction-review>.

This information is presented for the purpose of education and is not meant as a substitute for medical advice or care from a physician or other healthcare providers. Contact your healthcare provider with questions about care.

REGISTRATION IS OPEN!

10th Annual Spring Walk for Empowerment



TO BENEFIT THE CHILDREN
AND FAMILIES WE SERVE



DATE: Sunday, June 10, 2018
TIME: Registration Begins at 10:00 AM
WHERE: Roosevelt Park
151 Parsonage Rd., Edison, NJ
WHAT: Stroll & Roll, Tricky Tray Raffle,
Activities and Refreshments



HOW CAN YOU HELP?



Please consider fundraising for SBRN! There will be prizes for the top fundraisers! You can create a pledge page online at www.thesbrn.org, and ask friends and family to donate. Or, you can collect cash and checks and bring them with you to the walk. **Any amount is appreciated!!**



Registration and Sponsorship information is on our website

www.theSBRN.org • 908-782-7475 • info@thesbrn.org

Thank You to our Sponsors!



Participate in SBRN's TRICKY TRAY RAFFLE at our
SPRING Walk for Empowerment
to benefit the children and families we serve



You Could Be A **WINNER!**



PREVIEW



- » *American Girl Doll*
- » *Overnight Stay for 2 at the Mohegan Sun*
- » *QVC Studio Tour for 6 Guests*
- » *Unionville Vineyards - wine tasting & tour for 8*
- *Vine Restaurant - 3 course dinner for 2*



AND MUCH MORE!

Museums - Restaurants - Sports Memorabilia - Theaters

Register to Participate on Sunday, June 10th - www.thesbrn.org

SBRN welcomes Tracy to the EZ and the Golden Girls

Empowerment Zone

We'd like to welcome Tracy W., our newest writer for the *Empowerment Zone*. Starting with our next issue, Tracy will contribute her thoughts and ideas and she hopes that you will share your views as well. In her own words:

Hello, let me start by introducing myself. My name is Tracy. I am a young woman with Spina Bifida. I started writing for The Spina Bifida Resource Network a few years ago and was doing it for quite some time before I felt I had to let it go. After awhile of being away something inside brought me back and I am super excited that it did. Not only did it give me the chance to express myself but also hopefully it will give you all an opportunity to express yourselves on a variety of everyday topics through the eyes of people with Spina Bifida. My hope in doing this is that it will keep us all feeling empowered thus: The Empowerment Zone.

Golden Girls Teleconference

Tracy will also be joining Sonya for the peer-led teleconference group, the "Golden Girls." This group meets the first Wednesday of every month at 8:00 p.m. Join in to discuss topics of interest to women living with disabilities. Sonya and Tracy are looking to make some changes so join in and let your voice be heard!

Next Meeting: Wednesday, June 6, 8:00 pm – 9:00 pm

Call in: 877-724-3207 (toll free) or 605-468-8003 (local)

Participant Code: 915942#



2018 Adult Empowerment Retreat
Details Coming Soon!

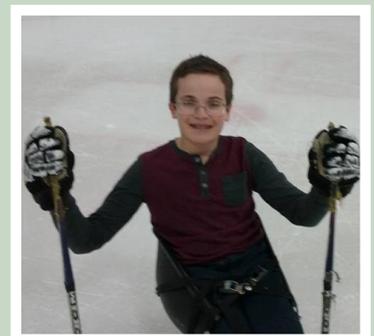
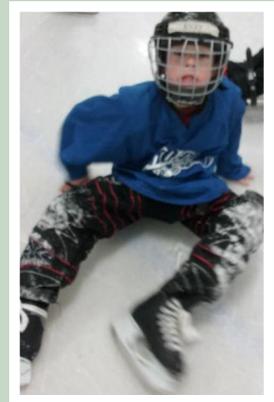
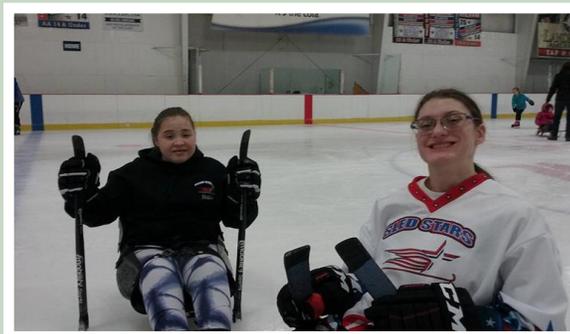
SBRN AND HOLLYDELL ICE ARENA'S "ICE SKATE SOCIAL"

The Spina Bifida Resource Network held its annual "Ice Skate Social" at Hollydell Ice Arena in Sewell, NJ on St. Patrick's Day on March 17th. This free event is a Fun Day for people of all abilities to enjoy and have fun on the ice in wheelchairs, skates and sleds. Participants enjoyed DJ Dave who entertained everyone with songs and games on the ice.



Participants enjoyed lunch, interacting with friends and meeting new people and having a great deal of fun for the afternoon.

A *Special Thank You* to **Nancy Andrelczyk** for her dedicated time in coordinating and organizing this annual event! SBRN also greatly appreciates the hospitality of the Hollydell Ice Arena.



WE LOOK FORWARD TO SEEING EVERYONE ON THE ICE NEXT YEAR!

Sharing Knowledge about Healthy Living with College Students

As part of our mission, SBRN provides **community prevention education**. In our newest program, **“Healthy NOW, Healthy LATER”**, we train college students to provide peer to peer education about the benefits of healthy living NOW to prevent birth defects LATER. Our work is supported by the State of New Jersey’s Office for the Prevention of Developmental Disabilities.

We focus on the health benefits of: (1) vitamins and minerals (including folic acid), (2) maintaining a healthy weight from healthy diets, (3) being careful about alcohol consumption, and (4) how men’s diet and weight are important too. We’ve been to campuses all over New Jersey and have been delighted to work with dozens of students who have enthusiastically become spokespeople. These students have then shared the information with hundreds of other students in our effort to promote healthy living!

Please contact us if you would like to learn more about our program or would like to get involved.

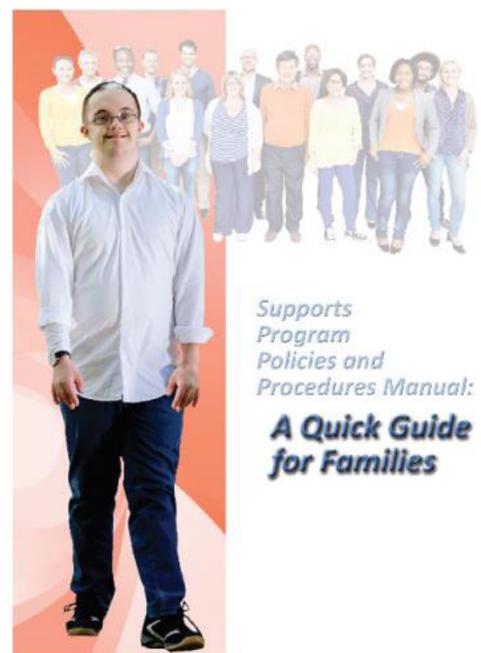


SBRN’s Prevention Coordinator Zara DeJesus (center) joins with nursing students from Raritan Valley Community College to educate students about healthy living.

NJ DDD Releases New Manual for their Supports Program

The New Jersey Division of Developmental Disabilities (DDD) is in the process of moving all eligible persons to their new Supports Program. This program is for adults age 21 and older with disabilities who are eligible for Medicaid and are living with their families or in other non-licensed settings. The Supports Program provides Employment/Day Services and a variety of Individual/Family Support Services that individuals can choose.

In collaboration with the NJ Regional Family Support Planning Councils, the Division has developed [The Supports Program Policies and Procedures Manual: A Quick Guide for Families](#) to assist families in gaining a basic understanding of the Supports Program. The Manual provides information on eligibility, the role of the Support Coordinator, choosing Service Providers, description of Services and more. The Manual is available on DDD’s website.





84 Park Avenue, Suite G-106
Flemington, NJ 08822

NON-PROFIT ORG.
U.S. POSTAGE
PAID
FLEMINGTON, NJ
PERMIT NO. 376

Millie Gonzalez
Chairman of the Board
mgonzalez@thesbrn.org

Roberta Kestenbaum, PhD, MSW
Executive Director
rkestbaum@thesbrn.org

Michelle Tomaszewski
Family Support Coordinator
mtomaszewski@thesbrn.org

Zara DeJesus
Family Support Coordinator, Bilingual
zdaniels@thesbrn.org

Barbara Dombroff, RN
Family Support Nurse
bdombroff@thesbrn.org

Jeremy Cantilina
Business Manager
jcantilina@thesbrn.org

Laura Larice
Editor, Administrative Assistant
llarice@thesbrn.org

The mission of the Spina Bifida Resource Network is to empower the lives of people with Spina Bifida, and promote the prevention of Spina Bifida, through advocacy, education, collaboration, public awareness, research and programs.

We provide individualized services in the home and community, including care coordination, trainings by nurses, advocacy in the schools, financial assistance and educational and recreational events.

*For more information contact our office at
info@thesbrn.org, or call 908.782.7475.
We welcome the opportunity to hear from you.*

The information and other materials contained in this newsletter individually and collectively are provided for educational and informational purposes only and are not a substitute for legal, medical advice or treatment. Neither recommendations nor endorsements are implied.