

# The Empowerment Zone

A publication of the SPINA BIFIDA RESOURCE NETWORK

Volume 18, issue 1, February/March 2018

84 Park Avenue, Suite G-106 Flemington NJ 08822 Web: [www.theSBRN.org](http://www.theSBRN.org) Email: [info@thesbrn.org](mailto:info@thesbrn.org) Office Phone: 908.782.7475 Fax: 908.782.6102

## In This Issue . . .

From the Desk of Roberta Kestenbaum . . . . . *cover*

When Your Day Comes . . . . . *Pages 2, 3, 4, 5*  
*Submitted by Theresa Feighery*

Advocacy and Your Rights . . . . . *Pages 2, 3, 4*

Golden Girls Teleconference . . . . . *Page 5*



Join us on Facebook!

SBRN Upcoming Events . . . . . *Page 6*  
*Hollydell Ice Skate Social, Walk for Empowerment, Adult Empowerment Retreat*

Community Support Group . . . . . *Page 6*

What to Know About the Flu . . . . . *Page 7*

From The Desk Of

*Roberta Kestenbaum*



A great big thank you to all of our supporters for our year-end campaign and throughout the year for all of the support at our events! Thanks to our very generous donors, we are proud to continue providing support services, hosting conferences and retreats, organizing fun activities, offering teleconferences and tele-support groups and providing resources.

Although we will soon no longer be receiving funding from the State of NJ for our Family Support Services, our services will continue as they were. Those whom we serve should not notice any changes in service delivery. So if you need assistance with catheterization techniques or bowel management plans, you would like someone to teach your child's school personnel about spina bifida or you have other questions or needs, be sure to give us a call!

We also have some fun events coming up! (See *page 6* for info on our events and others).

Our annual **Hollydell Ice Skate Social** is right around the corner. Join us on March 17 (St. Patrick's Day!) at the Hollydell Ice Arena for a fun day on the ice where everyone is welcome.

Our annual **Walk for Empowerment** is scheduled for June 10, 2018 at Roosevelt Park in Edison, NJ. We had such a fun time at Roosevelt Park strolling and rolling around the pond that we are doing it again!

We will be scheduling the **Adult Empowerment Retreat** for the end of the summer. More details to follow soon!

As we move forward, we are modernizing!  
We are introducing our **new updated logo**  
and we will soon be updating our website as well.

Stay tuned!



## WHEN YOUR DAY COMES *submitted by Theresa Feighery*

As the hit song from Ruby & the Romantics goes, our day will come. That R&B 60's hit pertained to love, but for those of us living with a disability, it could hold another, hopeful meaning. Perhaps "our day" is a time when discrimination, both blatant and insidious, will have been eradicated. As far-fetched as that may seem, think of life before the ADA and how much has changed. Yes, unemployment is obscenely high, inclusion in housing and education has a long way to go, and ride-sharing companies, by not providing wheelchair accessibility, have subverted the tremendous achievements made with traditional taxis by advocates such as United Spinal. The outlook may seem bleak, but there is hope, hope that our day will come.

Fighting the government and institutions representing education and business is daunting, but doable. Determined individuals and activist groups have proved that over and over again. But the attitudes and outlooks of regular folk make for an entirely different mountain to climb. It is far more difficult to change hearts and minds, which is the other side of the coin when considering if our day will come. Sooner or later, an individual with a mobility disability will face discrimination. If you find that an obvious statement, then it's happened to you, if not, I now can regretfully say that your day will come.



For those of you who have stared into the eyes of discrimination, perhaps you'll ask what took me so long to come to this realization. Perhaps I am oblivious or just plain lucky, but it is true that I do not take offense easily, which may be a good thing since I live and work in the boogie-down Bronx. In a prior job as a customer rep, I worked amongst the crowd at Yankee Stadium for four seasons—believe me, it paid to have things roll off my back. In fact, I had been spilled down my spine on a few occasions, one time intentionally! Luckily, an NYPD officer nabbed the drunken fan before he emptied his cup and marched him out of the ballpark (no, I didn't press charges). A more common indiscretion involved patrons pushing my chair from behind until ordered to stop. Perhaps draining one's wallet for parking, beer, and a hot dog drove patrons a little nuts. And then there were the endless remarks, which no doubt you've heard, but I mostly ignored, except on bad days when I disposed of them with a snappy comeback. "How fast does that thing go, honey?" "Lie down and I'll run you over so you can see for yourself, pal." Or how about: "Stay positive, sweetie." "Gee thanks, mister, you saved me because I was just heading to the bathroom to blow my brains out."

### Which Laws Protect Against Discrimination?

There are laws to protect your rights at the federal, state and local level. These laws can be extremely complicated, but it helps to know the basics and then you can research how it relates to your particular situation.

#### Federal Acts:

- The **Americans with Disabilities Act (ADA)** prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications.
- The **Fair Housing Act** prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, and national origin.

#### New Jersey State Law:

- **The New Jersey Law Against Discrimination (N.J.S.A. 10:5-12) (LAD)** makes it unlawful to subject people to differential treatment based on many factors, including mental or physical disability, and perceived disability. The LAD prohibits unlawful discrimination in employment, housing, places of public accommodation, credit and business contracts. There are regulations that explain that a place of public accommodation must make reasonable modifications to its policies, practices or procedures to ensure that people with disabilities have access to public places.

*Continued from Page 2*

Crip experience often brings each of us to a point where we become steeled against ignorant behavior, having developed a certain immunity to insult. But when conduct crosses the line, I am here to tell you that there is something you can do about it—legally. And it won't cost you a dime. The surprise for me—no, make that shock—did not involve anything that went down in the rough-and-tumble hood, but in a place near and dear to my heart, the beautiful North Country of New York State.

I have visited Lake George every summer of my life. It is close, inexpensive, and offers unique contrasts of commercial and country, indoor and outdoor, shopping and serenity.

Throw in mini-golf (there is an ADA accessible course, run by a Vet!), parasailing, Six Flags, music (tons of it, mostly free), county fairs, and kayaking. You can even have a Last of the Mohicans experience, since much of the Leatherstocking Tales are set right there. But don't take my advice, listen to Thomas Jefferson: "Lake George is without comparison, the most beautiful water I ever saw." Or perhaps drive another scenic 80 miles and visit an Olympic village—Lake Placid. In other words, name your pleasure or your poison, but if you are still not convinced by my travelogue, how about taking in the last HoJo's restaurant in the country? Fried clams and 28 flavors—now that's a retro experience.

### **What are My Rights with Regard to Businesses and other Public Accommodations?**

According to NJ's Law Against Discrimination (LAD), Public Accommodations, including shops, restaurants, resorts, camps, entertainment places, banks, professional offices, medical facilities, state and local government agencies, and public transportation, are prohibited from discriminating based on disability in providing goods or services or in permitting people access. They are also required to provide reasonable accommodations to give people with disabilities access to their facilities, goods and services, unless needed accommodations would impose an undue hardship on their operations. Individuals and businesses may not refuse to contract with you or otherwise do business with you because of your disability.

Disability-based harassment in public accommodations and business transactions is unlawful. It is unlawful for any proprietor, employee or agent of a business or other public accommodation to harass you or permit others to harass you because of your disability; this includes making or permitting derogatory comments about your disability or about people with disabilities, or permitting people to interfere with your use of the premises or facilities because of your disability.

(Excerpted from the NJ Office of the Attorney General, Civil Rights Fact Sheet)

Having always had nothing but fun and relaxation in the region, two summers ago, in an area near the Vermont border, my Pollyannaish outlook was shattered. How could anything possibly go wrong in Norman Rockwell territory? A drive off the beaten path always made it into my itinerary, so I had decided to venture toward the Green Mountain State for a little maple syrup, homemade fudge, and a leisurely raft ride amongst the evergreens. Dreamy, no? A local recreational sports business offered camping and rental of rafts, tubes, etc. It also provided a van service for pickup from the end of your tour. Perfect! You could begin paddling in New York, float under a picturesque, Currier & Ives covered bridge, and complete your Natty Bumppo journey in the wilds of Vermont. OK, my imagination had been fueled with images of escape from driving the Cross Bronx Expressway every workday, excited to breathe free in God's Country for a few hours. But never did I expect such a reception.

I was greeted with the following: "We do not service the disabled." Well, what do you know, I'd become a time traveler and been transported to Selma, circa 1965. "You can't go down the river in a wheelchair." Actually, I preferred something that floated. And, one more: I was referred to as a child. Of course, a wheelchair user cannot be considered an adult! The proprietors pulled no punches, didn't equivocate, and hit me square between the eyes, except that their repeated statements denying service because of disability were not directed toward me. As you know, people in wheelchairs are not deemed worthy of eye contact and direct conversation, that privilege reserved for the able-bodied. I'll spare you any more of the gory details of the entire encounter, except to say that every faux pas, every insult, and every ILLEGAL discriminatory act occurred in the course of less than five minutes. These troglodytes (and that's putting it kindly) went so far as to order me off

Continued from Page 3

the property and when I didn't move my wheels fast enough, actually called 9-1-1. What do you know, I'd finally made it as a gangbanger, a notorious member of The Spokes, a crew known to repeatedly rollover their victims causing asphyxiation. And wouldn't I have enjoyed that! In a matter of moments, I had gone from being shielded by the police in Yankee Stadium from such maniacs to now having to face down a tin shield and explain why they were nuts, not me. Yes, my day truly had come.

Although I joke, clearly a defense mechanism, emotionally this episode was devastating. After the State Trooper(!) determined I was not a desperado, my vacation had ended—the time had come to return to the peaceful, friendly, accommodating confines of the urban jungle. Yes, give me the poorest congressional district in the country over overalls and livestock. During the first days and weeks after Armageddon, I dealt with my psyche, never even considering any recourse for justice. Like a victim of assault, self-blame creeps into your thoughts, although one and all assured me that these were ignorant individuals (again, putting it kindly). One co-worker, a woman of the South, said I had experienced a Rosa Parks moment (she's the huge R&B fan). Of course this episode in no way compared, but she only meant it as a way to come to terms with the destructive nature of discrimination on individuals and society, no matter its degree or form.

My funk became visible, enough for a friend from table tennis at Burke Rehab in White Plains, NY to question my frame of mind. A blunt individual with a long career at IBM, upon hearing tidbits of the story, exclaimed: "You don't have to take that crap!" He directed me to contact Jim Wiseman, United Spinal attorney and now president of the organization. Mr. Wiseman recommended the state's Division of Human Rights where I could file a complaint and go through a process that would lead to an investigation and possibly a public hearing, all at no cost to me. Wow, perhaps their day had come.

I went through the complaint process, which included refuting the "respondent's" answer with evidence, and then an investigator performed a thorough inquiry. After initially feeling hopeful, I considered the procedure a lost cause because no doubt it would end up as a "she said, he said" standoff. Besides, telling the story was difficult enough and I did not look forward to reliving the whole ugly episode. But I learned that investigators run into denial and deception all the time, and was advised not to lose resolve because the evidence would point to what really had happened.

A short time later I received the result. The investigation had found PROBABLE CAUSE of discrimination, which is a big deal in the law (check that 4th amendment), and it meant the complaint would proceed, possibly to a public hearing. Why possibly? Because a settlement is always in the cards. Here's where it got dicey.

## Whom Should I Contact?

**Speak with the Manager or Owner:** When an incident occurs or there is an issue that you want to address, first determine if there is someone directly related to the situation that you can contact. For example, if you feel that you have been discriminated against at a public accommodation, such as a store or restaurant, you might first want to speak with someone in charge, such as a manager or owner of the business.

**Contact a Legislator for an ally:** In some cases, it might be beneficial to have a public figure on your side to advocate with you or to look into changing a law. To find out who represents you on the federal level, go to [www.congress.org](http://www.congress.org). To see who represents you on the state/local level, visit [https://openstates.org/find\\_your\\_legislator/](https://openstates.org/find_your_legislator/).

**File a complaint with your State Division of Civil Rights:** Every state has its own Office or Division of Civil Rights, who work to enforce the civil rights laws. If you are not able to resolve your dispute with the business that you believe discriminated against you, you can contact your state's civil rights office, which you can find at <http://civilrights.findlaw.com/enforcing-your-civil-rights/state-civil-rights-offices.html>

In **New Jersey**, the Department of Law & Public Safety, through its Division on Civil Rights, is responsible for enforcing the *Law Against Discrimination* (LAD). You can contact the office closest to where you live or where the discrimination occurred to file a complaint. Go to [www.njcivilrights.org](http://www.njcivilrights.org) to find the contact information. If their investigation finds "probable cause", a hearing may be held at the Office of Administrative Law. Alternately, your case may be tried in court.

Continued from Page 4

Unless you have an uncle who worked his way through law school, or have the bank account to hire an attorney, low and behold, the Human Rights Division will appoint one, merely free of charge. Although the Division's lawyers work for little money compared to those corporate types, they juggle a ton of cases at any one time, often involving housing discrimination (my case falls under public accommodation). It took me a while to catch on, but it seems that a Division lawyer, although assigned to your case, works more toward settling without a hearing I'm told this isn't unusual because whether it's a criminal case or someone suing McDonald's, plea bargaining and settling are the order of the day, saving the time and expense of court time. Basically, the assigned lawyer is not going to spend hours reviewing your case and planning a strategy—hey, what do you want for nothing? The good news is that you will have representation at no cost.

In case you're sitting on the edge of your Roho to find out how this all ended, let me point out that each state in the good ole USA will have a Human/Civil Rights Division. Wherever you live, you can file a complaint and see where it takes you. Having your ordeal written up not only seeks justice, but also has a palliative effect. Do I need to say it again? Your day will come. If this route doesn't appeal to you, there's always the possibility of returning to the scene of the crime with scythed wheels (see Ben-Hur). But remember that didn't end too well for Mesalla.

You may have noticed that I never mentioned the name of the business. One, I didn't want to give them the attention, including the negative kind. Truly, they are not worth it. Two, and here's the news flash, my case was "resolved," but not before a long battle of a gag order. They wanted to shut me up. I held out on that issue and won, but still don't want to mention the name of the miscreants. Yes, I could have demanded a hearing and had my say in public, but accepting settlement money alleviated the stress of re-

living a horrible experience. Funny, I really didn't care about the cash, but I bet they sure did. Perhaps they finally got the point. Alright, I still have that Pollyanna side, but they'd be nuts to pull this on someone else—the old deterrent effect.

Excuse my advice and coaching, but isn't it good to know that there is an alternative to doing nothing while suffering silently after facing discrimination in any form and to any degree? When your day comes, maintain hope because "hope is a good thing, maybe the best of things, and no good thing ever dies." I'll let you figure out where that line comes from. You can try to believe me about all this by tuning into Ruby & the Romantics. While listening, remember what I was told: "You don't have to take that crap!"

### Let's Get to Know More About Theresa Feighery

*Theresa attended Henry Viscardi High School in Albertson, Long Island. She was admitted to Edinboro University, PA and graduated with a B.A. Degree in Communications.*

*Theresa has had some interesting job experiences! Previously, Theresa was employed by the NY Yankees as a Customer Services Rep for four consecutive seasons. She currently works for the NYC Department of Environmental Protection as a Clerical Associate.*

*Some interesting tidbits: Theresa enjoys playing table tennis every Saturday at Burke Rehab in White Plains, NY where she has remarked that "everyone is invited!" She is also a Coach for the New Rochelle Little League Baseball, Challenger Division, for children with disabilities.*

*Thank you Theresa for submitting this heartfelt and inspiring story!*

If any readers have a story that you would like to share, contact us at [info@thesbrn.org](mailto:info@thesbrn.org).

## Golden Girls Teleconference

### The Golden Girls are Back!

The "Golden Girls" is a self-guided tele-support group for women of all ages with spina bifida discussing relevant topics such as social issues, relationships, and medical services. Share your story, gather valuable resources and make new friends while enjoying the convenience of simply talking on your phone.



**JOIN THE CONVERSATION by JOINING OUR TELECONFERENCE**

**Hosted by SBRN Member, Sonya Burroughs**

The teleconference is held on the first Wednesday of every month from 8:00 PM - 9:00 PM

Email SBRN at [info@thesbrn.org](mailto:info@thesbrn.org) or call the office at 908-782-7475

# SBRN and COMMUNITY CALENDAR

**REGISTER NOW!**

## SBRN & Hollydell Ice Arena's "ICE SKATE SOCIAL"

**A FREE Annual Event For All Abilities!**

When: Saturday, **March 17, 2018**

Time: 1:00 pm - 3:00 pm

Light Refreshments

Hollydell Ice Arena  
601 Hollydell Dr., Sewell, NJ 08080



**Don't forget  
to register!  
Deadline is  
March 14th**



## A Fun Day for Everyone!



*Registration is required so we can plan for food & ice time for everyone!*

*Call SBRN at 908-782-7475 or register online at [www.theSBRN.org](http://www.theSBRN.org)*



## End of Summer ADULT EMPOWERMENT RETREAT . . . Details Coming Soon!

### SAVE THE DATE

**JOIN US** for our **10th Annual Spring  
Walk for Empowerment**

TO BENEFIT THE CHILDREN AND FAMILIES WE SERVE 



**SUNDAY, JUNE 10, 2018**

Roosevelt Park  
151 Parsonage Rd., Edison NJ

Stroll & Roll • Activities • Refreshments

You could be a WINNER at our Tricky Tray Raffle

Registration and Sponsorship information  
will be available on our website soon!

### Support Group for Women with Disabilities

Our Friend, Marisa Douglas, at the Artemis Center for Independent Living, is hosting a cross-disability support group. Any woman with any type of disability is welcome and encouraged to join.

**When:** Wednesdays from 4:00 pm to 5:00 pm  
**Where:** Artemis Center for Independent Living  
4 East Jimmie Leeds Road  
Galloway, NJ 08205

Come talk about any and all topics  
important to women with disabilities.

Contact **Marisa Douglas, Peer Support Specialist**  
at 609-748-2253 or [mdouglas@artemiscil.org](mailto:mdouglas@artemiscil.org)

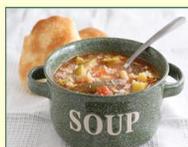
# OH NO! It's **still** Flu Season!

It's still flu season, and this year it is hitting us hard. According to the CDC, this flu season is on track for breaking records and it's still on the rise. This year's H3N2 influenza is a particularly nasty strain that causes more severe symptoms. In New Jersey, this has been one of the worst years for the flu with well over 10,000 cases confirmed (*NJ Department of Health*). Health officials expect this to continue for a while. And, according to the Centers for Disease Control and Prevention (CDC), "Children of any age with neurological conditions are more likely than other children to become very sick if they get the flu." This is particularly the case for those who have trouble with muscle function, lung function or difficulty coughing, swallowing or clearing fluids from airways.

Experts say: **Keep washing your hands!** Also, it's not too late to get a vaccination. Even if you've already gotten the flu, you may get sick again from another strain!

If you or your child with a health condition begins to show symptoms of the flu, it is important to contact the doctor promptly. Your physician may diagnose the flu based on symptoms or s/he may want to test to see if it is the flu. Your doctor then may want to treat the symptoms with flu antiviral drugs. The antiviral drugs can lessen symptoms and reduce the time of sickness. **NOTE:** Antibiotics do not help flu symptoms because they are caused by a virus and not a bacterial infection.

## RECIPE FOR NORTHERN BEAN SOUP



### INGREDIENTS

- 1 pound Great Northern White Beans
- 4 cups Low Sodium Chicken Stock
- 1 whole Onion, Diced
- 2 whole Large Carrots, Peeled And Diced
- 2 stalks Celery, Diced
- Salt And Pepper, to taste
- 4 cloves Garlic, Minced
- 2 Tablespoons Tomato Paste
- 2 whole Bay Leaves

### DIRECTIONS

- Rinse beans and place in bowl covered with water. Soak overnight.
- Drain the beans and place them in a large pot. Add the chicken stock and 4 cups of water. Bring to a boil, then reduce to a simmer.
- Add 2 tablespoons oil to frying pan and cook onions, carrots, and celery about 4 minutes. Season with salt and pepper. Add the garlic and tomato paste and cook for another minute or two. Add the vegetables to the beans. Add bay leaves and give it a good stir.
- Cover and cook on low (to medium-low) until the beans are tender. (About 1 1/2 hours). Remove Bay Leaves when done.
- **Optional:** Cook 1/2 lb. bacon and cut in half inch pieces. Add to soup while cooking.

Recipe can be found on <http://thepioneerwoman.com/cooking/bean-with-bacon-soup/>

**What are symptoms of the flu?** Symptoms usually start suddenly and can include: Fever or chills, cough, sore throat, runny or stuffy nose, body aches, headaches, fatigue, and sometimes vomiting or diarrhea.

For some, serious flu-related problems may occur and you should seek medical assistance right away. Emergency warning signs include: trouble breathing, bluish skin color, not waking up or responding, fever with a rash, returning symptoms that are worse, pain or pressure in the chest or abdomen, dizziness, confusion, or severe vomiting.

**What is the difference between a cold and the flu?** Sometimes it's hard to tell the difference between the common cold and the flu because symptoms are similar. However, they are caused by different viruses. Colds tend to be milder than the flu, and generally include runny or stuffy noses. Also, fever, chills and aches are more likely to accompany the flu, and symptoms come on more quickly with the flu than a cold. Depending on your symptoms, the doctor may want to test for the flu.

**What to do when someone in the family has the flu:** Most importantly, the person should stay home and rest! Caretakers and other family members should avoid close (or face to face contact) with the sick person as much as possible. Everyone should wash their hands after contact with the sick person or their tissues.

The doctor will determine which medications are helpful. Besides medicine for the flu, it may be helpful to take ibuprofen or acetaminophen to reduce aches and fever. (Children should avoid aspirin.) The sick person should stay home from school or work for at least 24 hours after the fever is gone to reduce the risk of infecting others. It is also important to make sure that the sick person is well hydrated and has at least a little bit to eat.

Whether you have a cold or the flu, a nice bowl of hot soup can warm you up and make you feel cozy! Consider making a fresh bowl of **Northern Bean soup** – beans have lots of protein, fiber, iron, folate and Vitamin B1, as well as other vitamins and minerals. The veggies are healthy too and the chicken broth will help you stay hydrated and it may make you feel better!

This article is based on information provided by the CDC ([www.cdc.gov](http://www.cdc.gov)). It 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.



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  
rkestenbaum@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 *SBRN* is a source of **support** and **information** and provides **opportunities** for the Spina Bifida Community to **connect** on a **personal level**.

Our mission is to **EMPOWER** the lives of people living with Spina Bifida through direct service programs, **advocacy**, and **providing information about the prevention** of Spina Bifida.

We are one of the few Spina Bifida organizations nationwide who provide **direct nursing** and social service coordination.

*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.

