



THE EMPOWERMENT ZONE

VOLUME 19, ISSUE 3, SEPTEMBER 2019

A PUBLICATION OF THE



Join us on Facebook!

In This Issue ...

- From the Desk of Roberta Kestenbaum..... *Cover*
- Why are Women with *Pg 2, 3, 4*
Disabilities Less Likely to Get Breast Cancer Screening?
- Empowerment Retreat for..... *Pg 5*
Adults with Disabilities Flyer
- Don't Fall for that Scam..... *Pg 6, 7*
- Congratulations Millie,..... *Pg 7*
Ms. Wheelchair NJ 2019

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

From The Desk Of

Roberta Kestenbaum



* Summer is nearing its end, fall is approaching, cooler weather is on the horizon and many students are going back to school. For adults, it's time to celebrate the end of summer with our annual **Adult Empowerment Retreat** for adults over 21 with disabilities. The Empowerment Retreat is a 3 day event offering interactive workshops on topics such as wellness, relationships and advocacy, physical and artistic activities along with social opportunities and making new friends. The Retreat will be held from September 20-22 at Crowne Plaza Edison. See page 5 for details.

The Retreat will be facilitated by Ms. Wheelchair NJ 2019, Millie Gonzalez, a long-time volunteer with SBRN and current Board Chair. In keeping with her Ms. Wheelchair platform, the theme of this year's retreat is: #LiveFiercely through Self-Care. See page 7 to learn more about Ms. Wheelchair NJ.



* Also in this issue (pages 2-4), we discuss the importance of getting regular breast cancer screenings. Women with disabilities are less likely to receive mammograms due to numerous barriers, yet it is extremely important not to overlook or put aside this important preventative measure. It could save your life!

* Have you ever received a phone call or letter offering you something that seems too good to be true or threatens you with loss of services or insurance? Do they ask for money or for personal information? It may very well be a SCAM. We discuss different types of scams that are often targeted at people with disabilities, and what you can do to protect yourself (pages 6-7).

Why are Women with Disabilities Less Likely to Get Breast Cancer Screening?

THE REALITY

Finding breast cancer early increases the chance of survival and getting screened regularly is the best way to find breast cancer early when it is most treatable, according to the Centers for Disease Control & Prevention (CDC).



Women with disabilities are just as likely to be at risk for breast cancer, but they are less likely to have received a mammogram to screen for breast cancer. According to the CDC, in 2016, 74% of U.S. women 50 – 74 years with a mobility disability had a mammogram within the past two years, compared to 80% of women without a disability. Although the rates have gone up over the past several years, it still remains that **over ¼ of women with disabilities do not receive regular mammograms**. Research also suggests that the more severe the disability, the less likely women are to receive mammograms (Taouk, Fialkow & Schulkin, 2018).

THE BARRIERS

Why are people with disabilities less likely to get mammograms? Multiple reasons! Women with disabilities cite several obstacles to getting regular mammograms, including lack of accessibility, financial concerns, lack of transportation, too many other appointments, and healthcare providers' attitudes.

Accessibility – Lack of accessibility can affect many aspects of the process. The medical building where the screening takes place needs to be wheelchair accessible, as do the examination room and the dressing room. The screening equipment itself needs to be wheelchair friendly or other accommodations need to be offered. The machine needs to be able to lower to the height of a seated woman. Positioning can sometimes be difficult and uncomfortable. Women in wheelchairs may have difficulty getting close enough to the machine, all while keeping their head, shoulders and arms out of the way. Transferring to another type of chair or having an additional person help position and hold limbs out of the way may help.

Financial Concerns– Women with disabilities are more likely to be living below the poverty level and to be uninsured or underinsured. Studies have shown that women with disabilities and no medical coverage are considerably less likely to receive a mammogram than those with public or private insurance (Todd & Stuijbergen, 2012). [See Box for information on obtaining free mammograms.]

If You Can't Afford a Mammogram

Many states have programs that help people who cannot afford screenings and who do not have health insurance get breast cancer and other types of cancer screenings at no cost. In New Jersey, the New Jersey Cancer Education and Early Detection (NJCEED) Program offers comprehensive screening services for breast, cervical, prostate and colorectal cancer in all 21 counties. They can provide education, outreach, early detection, case management, screening, tracking and follow-up. To be eligible, you must be at or below 250% of the poverty level and be uninsured or under-insured. Call 1-800-328-3838 to see if you qualify and to find free screening services.

Transportation – Just getting to the appointment can be a major obstacle. Accessible transportation is not always available at the times needed and it can be difficult and unpleasant to use. What should take a short amount of time to travel may wind up being hours with long wait times and inconvenient options. Specialized transportation sometimes requires scheduling days in advance and may get cancelled at the last minute. Other options may be too expensive.

Other medical issues – Women with chronic disabilities often have many other medical issues that need attention and so preventative measures like breast cancer screenings get put on the back burner. If a lot of time and energy is spent dealing with secondary conditions, such as uti's or pressure sores, preventative measures that aren't critical at that moment may be ignored.

Provider attitudes – Studies and anecdotal reports suggest that providers may influence whether or not women with disabilities get an initial mammogram or return for others. For example, doctors may be less likely to recommend screening to women with disabilities (Taouk et al, 2018). Providers may focus so much on the issues related to the disabilities that they overlook other health aspects not directly related, such as screening for breast cancer.

Additionally, women with disabilities sometimes complain that providers are condescending or that they get irritated when it's more difficult to position someone who has mobility issues (Todd & Stuijbergen, 2012). Women who have a bad experience are less likely to return for another routine visit.

What Can You Do?

Although there may be obstacles, the fact remains that
IT IS VERY IMPORTANT TO GET REGULAR BREAST CANCER TREATMENT.
Despite the barriers, there are steps you can take to minimize the inconvenience and assure that you get the screening that you need.

BE PREPARED

Know your family history. Although most women with breast cancer don't have a family history of the disease, if you do have a family member who has had breast cancer, you have a greater risk and you should let your doctor know.

Speak to your doctor. If they don't mention regular screenings, bring it up yourself. Ask them to recommend a facility that has accessible machines. Make sure that they do a breast exam in the office and ask them about doing breast exams at home: how often, how to do it, what to look for and how can you have someone help if there are mobility issues.



continued on page 4

Call in advance. Ask questions. Lots of them to ensure that the experience will be accessible and as comfortable as possible. Describe your abilities and your concerns.

Make arrangements in advance. Make sure that you leave yourself enough time to arrange for transportation and to have someone accompany you if it would be helpful.

Confirm everything! The day before, confirm your transportation and companion. Be sure to call the screening center to remind them of your needs.

It may seem like a lot of effort, but remember: The earlier that breast cancer is detected, the better the chance for survival. Your life may depend on this screening!

Questions to Ask When You Call to Schedule an Appointment:

- Is the building accessible?
- Are the exam room and the dressing room large enough for a wheelchair or for two people if I need assistance?
- Is the machine adjustable so that I can remain in my wheelchair?
- If I cannot get close enough in my wheelchair, is there a way to transfer me to a different chair?
- Can we schedule the appointment for a longer time if it is needed?
- Can I have someone (either another technician or someone I've brought with me) help me get positioned correctly?
- If you cannot accommodate me, can you recommend a facility that is accessible?

References:

Centers for Disease Control and Prevention (CDC), *Disability and Health Data System (DHDS)*, <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>.

Centers for Disease Control and Prevention (CDC), *Women with Disabilities and Breast Cancer Screening*, <https://www.cdc.gov/ncbddd/disabilityandhealth/breast-cancer-screening.html>.

Denkensohn-Trott, S. (2017) *It's Not Easy, But You Must Get Your Mammogram*, New Mobility, <http://www.newmobility.com/2017/10/you-must-get-your-mammogram/>

O'Brien, D. (2014) *A Mammography Handicap*, PN/Paraplegia News, http://pvamag.com/pn/article/6517/a_mammography_handicap

Taouk, G.H., Fialkow, M.F. & Schulkin, J.A. (2018) *Provision of Reproductive Healthcare to Women with Disabilities: A Survey of Obstetrician-Gynecologists' Training, Practices, and Perceived Barriers*, Health Equity, Vol 2 (1).

Taylor, J. (2016) *Women with Disabilities are more likely to Die of Breast Cancer – Here's Why*, Mic, <https://www.mic.com/articles/134979/women-with-disabilities-are-more-likely-to-die-of-breast-cancer-here-s-why#.IDqazH8FV>.

10 Mammogram Questions for Wheelchair Users (2017), WoMMen, <http://wommen.org.uk/blog/2017/06/14/physically-disabled-ladies-mammogram/>.

Todd, A. & Stuijbergen, A. (2012) *Breast Cancer Screening Barriers and Disability*, Rehabil Nurs, 37(2), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4521895/>.

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.

EMPOWERMENT RETREAT

for Adults with Disabilities

Friday, September 20th through Sunday, September 22nd

Crowne Plaza ~ 2055 Lincoln Highway ~ Edison, NJ



The retreat is a weekend-long interactive and fun event designed for adults 21 years and over with disabilities to explore and experience increased independence, socialization, self-esteem and overall growth.

 **BOOK YOUR ROOM at the Crowne Plaza!**

Phone: 732-287-3500 or 866-279-4813

Come for a day or stay for the weekend.

Join us for our end-of-summer interactive conference!

Topics may include:

Health & Wellness • Recreation
Dating • Relationships • Art
Advocacy • Independence and more!

For more information & to register, go to
<https://www.thesbrn.org/news-and-events/retreat/>

Questions? Email mgonzalez@thesbrn.org or call (908) 782-7475

DON'T FALL FOR THAT SCAM!



If you've ever been scammed, cheated or had your identity stolen through a phone call, a mailing, email or other source, you know how stressful and upsetting it can be. You may feel embarrassed (though you shouldn't –some of these scams are very clever and elaborate), you may feel less secure and you may be very frustrated about losing money or your identity. The best thing you can do to protect yourself is to learn about what scams are out there and be very careful about what information you give out. Here are some common scams targeting individuals with disabilities and tips for what you should do.

CURRENT SCAM

Recently, there's been a scam going around that targets people with Medicare. In this scam, the person is offered DNA testing that can identify health risks and illnesses. The scammers say that the tests are covered by Medicare, but they usually are not covered. The scammers are trying to get your personal information to either scam Medicare or to try and get money from you. What should you do if someone offers you free genetic testing? Don't do it unless your doctor has requested the testing. And don't give out your Medicare numbers or any other personal information. If you think your Medicare number has been stolen or misused, call Medicare and they can give you a new number.

SCAMS TARGETING PEOPLE WITH DISABILITIES

People with disabilities can be targeted in specific ways by scammers. For example, a scammer may call or email a person pretending to be from Social Security, Medicaid, Medicare or the Internal Revenue Source. They may try to scare the person by claiming that their benefits will be lost, or they may try to "help" by offering help getting additional benefits. The scammer will likely ask for personal information, such as social security number, date of birth or bank account information. Once they have this information, they can steal your identity or even get into your accounts and divert funds.

Another scam aimed at people with disabilities is one where scammers offer the opportunity to make money, particularly through work from home programs. These scammers may be seeking personal information such as a social security number to begin employment, or they may ask you to send a fee to cover initial costs for materials and trainings. Then you may never hear from them again.

Scammers may also try to get personal information by pretending that they will help with applications for disability benefits or claims. Other scams that are common include offering bargain price insurance, free delivery of groceries or free prescription drugs for participating in a study. While some may be legitimate, many of these unsolicited offers are just looking to get personal information for identity theft.

continued on page 7

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.

What Can You Do?

The Federal Trade Commission offers some tips:

- **Be skeptical!** Question anyone who contacts you out of the blue and offers you something or suggests that you are losing benefits. Try to verify who they are and who they represent. Ask them to give you a phone number or web address that you can check to see who they are and who they work for. Ask for an email address and make sure that it is a legitimate address for the agency that they say they work for. You can also ask them to put their offer into writing.
- **Don't trust caller ID.** Caller ID numbers are very easy to fake and may not be real.
- **Don't give personal information.** Never give your social security number or account numbers to anyone who contacts you unless you have verified who they are. Be very wary if they keep insisting.
- **Don't wire or send money.** Never send cash or checks unless you know for sure who you are sending it to. If they tell you that you have to do it immediately, don't trust them.
- **Report anything you think is a scam.** You can contact the Federal Trade Commission at www.ftccomplaintassistant.gov or (877) 382-4357, or the federal government at www.usa.gov/stop-scams-frauds.

Protect yourself: It's better to be safe than sorry!

Resources:

Booth, J., *Scams Against Disabled People Affect More than Finances*, <https://www.disabilityadvisor.com/scams-against-disabled-people-affect-more-than-finances/>.

Federal Trade Commission, www.consumer.ftc.gov.

Mueller, K.P, *Say no to that cheek swab: DNA testing scam targets seniors on Medicare*, <https://www.nj.com/advice/2019/08/say-no-to-that-cheek-swab-dna-testing-scam-targets-seniors-on-medicare.html>.

Congratulations Millie, Ms. Wheelchair NJ 2019!



In July 2019, Millie Gonzalez, Ms. Wheelchair New Jersey 2019, competed in the Ms. Wheelchair America 2020 competition in Arkansas, running on her platform of #LiveFiercely through Self-Care. She was one of the top 5 finalists!

Throughout the year, Millie has been using her platform to:

- improve emergency preparedness, response and recovery for people with disabilities;
- empower disabled people to practice self-care; and
- amplify the voices of the disabled population by promoting increased awareness and understanding of disability culture and etiquette among the general public.



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 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.