Volume 6 Issue No.1 April 2022

BFREE Newsletter

Breastfeeding Resiliency, Engagement, and Empowerment

"Empowering parents to breastfeed every step of the way"

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Letter from the Editor

Dear BFREE Coalition & Community Members,

Happy Spring from the BFREE Team! We hope you and your families are continuing to stay safe as we go into the warmer weather. We are especially pleased to present the April issue of our newsletter.

We are highlighting the breastfeeding experiences of mothers battling cancer, specifically breast cancer, and those who have achieved remission. These mothers face added barriers in finding breastfeeding support, often due to misinformation, or due to a lack of knowledge about their individual needs. We are grateful to all of the mothers and organization advocates who shared their stories and experiences in this issue.

First, we highlight efforts to connect with our Spanish-speaking communities across Long Island. Next, we spotlight Bay Shore and Hauppauge WIC, as well as John Jermain Memorial Library for achieving breastfeeding friendly recognition. Then, we hear from Latina Sister's Support Inc., an organization that strives to "make a difference in the lives of those diagnosed with breast cancer." They call attention to the need to reduce disparities in healthcare and share information about breastfeeding reducing the risk of breast cancer development.

Lastly, we are so excited to share our Mother's Perspective section. Here, Lisa Cassenti shares her journey of motherhood and breastfeeding, including the impact her breast cancer diagnosis had on this. This story offers information and insight into the life of a mother breastfeeding while battling cancer.

As always, we are sincerely appreciative to all of this edition's contributors, to the entire BFREE Steering Committee for its active engagement and sage advice, and to each of you, our many collaborators, for your collective passion in support of breastfeeding. Please email us at BFREE@northwell.edu to share feedback and any potential contribution ideas for future newsletters!

Sincerely,

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Henry Bernstein, DO, MHCM, FAAP Principal Investigator Creating Breastfeeding Friendly Communities



^{*}The BFREE Team understands that the language around breastfeeding can be very gendered and risks alienating marginalized populations. While we are encouraging more inclusive language, such as "parents" over "mothers", "partners" over "fathers", and "human milk" over "breast milk", we also wanted to stay true to the voices that generously contributed to this newsletter. We hope to continue educating ourselves and expand the inclusivity of our work to promote healthy infant feeding for all parents.

Connecting With Our Spanish-Speaking Community

The BFREE Team remains grateful to Yezenia Chaparro (CBC), Paola Duarte (CLC), Sandy McCabe (IBCLC), and Fadhylla Saballos-Tercero (IBCLC) for participating in our ongoing Spanish Baby Cafés to promote services that are culturally and linguistically competent. We would also like to thank our Subcommittee for Spanish-Speaking Communities for recommending this valuable initiative and for working tirelessly to advocate for the community!

The BFREE Team established this cross-collaborative subcommittee in November 2020 to actively engage our community members, partners, and stakeholders in an effort to improve our outreach strategies and cultural competence toward Latinx communities. Finally, we'd like to spotlight Dr. Christian Suri for participating in a radio show interview about breastfeeding in Spanish with La Fiesta 98.5! We are grateful for his valuable insight and for our partnership with La Fiesta 98.5, which expands our capacity to promote healthy infant feeding among Latinx communities across Long Island.

This work is supported by a NYSDOH "Creating Breastfeeding Friendly Communities" grant, which aims to expand community-based breastfeeding partnerships and reduce disparities in the rates of breastfeeding across New York State.

Congratulations to all for being recognized for your hard work, and we thank you so much for collaborating with our team!

Subcommittee for Spanish-Speaking Communities

Wendi Andria
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Check out our website for more resources: https://www.bfreecoalition.org
Visit us on Facebook at: https://www.facebook.com/BFREE.Coalition/

This project is supported by NYSDOH Grant #530390. The content of this newsletter is the responsibility of the Contractor and does not necessarily represent the opinions and interpretations or policy of the New York State Department of Health.





Success Spotlight

The BFREE Team is happy to celebrate Hauppauge and Bay Shore Women, Infant, and Children (WIC) on becoming Breastfeeding Friendly! We would like to thank our site champion Lauren Brand for putting in a great amount of effort to support her employees and members of the community during these difficult times.





Pictured are the lactation spaces at Bay Shore WIC (left) and Hauppauge WIC (right).

We would also like to spotlight John Jermain Memorial Library for becoming Breastfeeding Friendly! Though we were unable to collaborate in-person, we worked with Wonda Miller, the Assistant Director of the library, via Zoom to initiate and complete the breastfeeding recognition process.



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Office on Women's Health National Breastfeeding Helpline: 1-800-994-9662

Call anytime M-F 9am-6pm to talk with a health information specialist in English or Spanish

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Latina Sister's Support Inc.







About Us

Latina Sister's Support Inc. was founded to make a difference in the lives of those diagnosed with breast cancer as well as any other type of cancer. We currently provide awareness, education, referrals, and support. Our goal is to achieve health justice for all women at risk of living with cancer. Our organization is devoted to make a difference in the community. We provide the highest quality referral programs that benefit all residents in Suffolk, Nassau County, and surrounding areas.

Our mission

- Reduce the disparities in access to quality care.
- Educate, encourage, empathize and empower our Hispanic/Latina Sisters and their families faced with breast cancer diagnosis and survivorship.
- Provide workshops, medical support, professional support, community awareness events, and shared individual testimonies.
- Engage our sisters and serve as a living portrait of hope. We believe that a woman lifted by others is stronger than a woman who stands alone.

Our Vision

Reduce the disparities in access to quality health care and breast cancer awareness amongst Hispanic/Latina women and their families.

We are a resource of knowledge about programs and services for wellbeing and survivorship after breast cancer, and other cancer diagnoses.

Our Education about Breast Cancer and Breastfeeding

Mothers that breastfeed have a lower risk of developing breast cancer in their lifetime and there is a significant decrease for mothers that breastfeed longer than six months. Breastfeeding reduces estrogen levels which reduces breast cancer cell growth. Also, breastfeeding can prevent ovulation causing a reduction in ovarian cancer risk.

Breastfeeding can reduce the risk of cancer in children. When a child receives breastmilk, they boost their immune system, and they are less likely to develop diabetes later in life.

Reference:

MD Anderson Cancer Center, & Cordeiro, B. (2014, October 9). Breastfeeding lowers your breast cancer risk. MD Anderson Cancer Center. Retrieved March 28, 2022, from https://www.mdanderson.org/publications/focused-on-health/breastfeeding-breast-cancer-prevention.h19-1589046.html

Breastfeeding and Breast Cancer Screening

Selected points from the *Academy of Breastfeeding Medicine*'s Clinical Protocol #34, by Helen M. Johnson, MD, and Katrina B. Mitchell, MD

Breast cancer can cause reduction in milk production due to certain medications or therapies and overall lactation capacity because of surgery or other interventions. Women with a breast cancer diagnosis need individualized support in making decisions about infant feeding. The *Academy of Breastfeeding Medicine* has published a useful set of guidelines for clinicians supporting breastfeeding women with a breast cancer diagnosis. Some are included here, and we encourage readers to consult the full article for more information. To read more please click <u>here</u>.

DOs

- Breastfeed or express breast milk
 before a screening.
- Make an individualized decision to screen while breastfeeding.
- Be informed on donor milk if electing to wean
- Be monitored closely when a breast cancer survivor and breastfeeding because of potential reduced milk production.

DON'Ts

- DO NOT abstain from routine breast cancer screening. (All radiologic modalities used for breast cancer screening are safe during lactation.)
- DO NOT expect full milk production after total mastectomy, breast conservation therapy (partial mastectomy and radiation), or chemotherapy.

OTHER NOTES

- Chemotherapy: diminished milk production from both breasts may occur.
- Chemotherapy, targeted anti-HER2 therapy, and endocrine therapy: likely require discontinuation of breastfeeding.
- Breast cancer diagnosed up to 5 years postpartum is generally more aggressive than other presentations of this malignancy.

Johnson HM, Mitchell KB; Academy of Breastfeeding Medicine. ABM Clinical Protocol #34: Breast Cancer and Breastfeeding. Breastfeed Med. 2020;15(7):429-434. doi:10.1089/bfm.2020.29157.hmj

When Mastitis May Not Be the Problem; A Story about **Breastfeeding and Breast Cancer** by Lisa Cassenti

"She said that my

daughter was not

gaining enough weight

to solely breastfeed and

that I needed to

consider formula."

Before I begin, may the stories and words I share serve you and your community for the highest good. Please share my story with those who you feel can benefit. Our stories are powerful and they are gifts that we can give freely so that others can learn from our experiences.

My journey to becoming a mother was not an easy one. I was told by a world-renowned reproductive

endocrinologist that there was no way that I would become pregnant naturally. I followed all of his recommendations to prepare my body for pregnancy before beginning in-vitro including yoga, acupuncture,

nutritional changes, and several supplements for me and my partner (including CoQ10 and DHEA). I visualized my baby in my uterus and told myself daily in the mirror, "I am pregnant."

Before beginning in vitro, a miracle happened; I spontaneously and naturally became pregnant!!! I gave birth to the love of my life, my daughter, Lianna Marie, on 1/10/2018. Until she was placed on my chest for the first time, I had no comprehension of how much I was capable of loving someone with every fiber of my being.

When pregnant and in order to prepare for breastfeeding, I took a breastfeeding class at the hospital.

Although this helps you in understanding breastfeeding positions, and how to start on the breast that your baby last breastfed on, it does not prepare you in the ways that I had hoped. I was told that I would have access to a Lactation Consultant (LC) at the hospital to be sure that my baby had the proper latch, etc.

In reality, when I first was given my baby to begin to breastfeed for the colostrum to come

> in, I had ABSOLUTELY NO IDEA what I was doing. I had NO IDEA that I needed to give my baby a "mouthful of breast" for her to properly latch on. I put my nipple in her mouth and she reflexively sucked, but she did not have a proper latch. Before long, my nipples became sore, painful, and even began to bleed.

Before we were discharged 2 days later, my daughter's weight had dropped from 5 lbs., 7 oz. to under 5 lbs. and she was diagnosed with "failure to thrive." The nurse who came in to provide discharge instructions spoke with me and my partner in a serious tone as she handed me formula. She said that my daughter was not gaining enough weight to solely breastfeed and that I needed to consider formula.

My daughter was only two plus days old at that point. What message was the hospital giving me and my daughter's father about breastfeeding?

What about "the breast is best?" What about nipple confusion at the age of 2 days old? That conversation alone placed fear and doubt in my new mama brain and spurred on multiple disagreements between me and my daughter's father about breastfeeding. Breastfeeding is difficult enough without adding more pressure and taking away support that may have been there. I believe this set us up for difficulties in breastfeeding before we even left the hospital.

When my daughter was one month of age, I separated from my daughter's father. Just prior to our separation, I had made an appointment with IBCLC, Jennifer Giordano of "Latch with Love." I feel grateful and blessed every day that Jenn came into our lives. Right away, she was able to teach me how to help Lianna latch on my breast. She understood how important breastfeeding was to me

and my daughter and educated me on a way that I could give Lianna what she needed through breastfeeding. This involved an intense way of feeding called "The Triple Feed."

I would breastfeed Lianna, then give her expressed milk, and then pump. It also involved me to get a new "breast friend," a medical grade breast pump. That pump went EVERYWHERE with us! "Have pump, will travel."

Jenn also gave me and Lianna an invaluable resource; a breastfeeding mama group that met weekly! I WAS NOT ALONE!

I was not the only one who was struggling, tired, crying over the triple feed and dreaming of washing pump parts. I could share in a safe, non-judgmental space, laugh, and cry with these mamas and their babies! Community is POWERFUL, HEALING, and FILLS YOUR CUP (and your breasts).

Around 7-8 months of age, Lianna began to empty my breasts fully and she was getting what she needed! Hallelujah!

It was sunshine and rainbows! Triple-feed no more, but I continued to pump to store frozen breastmilk for the future.

When Lianna was 9 months old, I felt a nodule between my left armpit and breast. I was almost certain that it was the beginning of mastitis as I had experienced that before. The nodule did not go away and I started to experience sharp shooting



"Community is POWERFUL, HEALING, and FILLS YOUR CUP (and your breasts)."

pains in my left breast that took my breath away.

On 11/5/2018, I was told that I had breast cancer and it had spread to at least one of my lymph nodes. Before I walked out the doors of Fortunato, I had an appointment with an oncologist booked that afternoon.

I called Jenn Giordano for an immediate consult with her and we cried HARD! I had to wean Lianna ASAP so that I could begin treatment.



Jenn intuitively knew that weaning needed to start that day (or I would be subconsciously trying to get every ounce of breast milk into my daughter to what could be my detriment).

The breast cancer had thrived on estrogen and progesterone. Breastfeeding would only increase hormone production and "feed" the cancer. I told Jenn that I needed to honor mine and Lianna's breastfeeding journey before it ended. I wanted to celebrate it and grieve the loss of breastfeeding via photographs. That day, Jenn connected me to Jessica Sullivan of Jessica Michelle Photo. A few days later, Jessica photographed me and Lianna breastfeeding in the rocking chair that my grandma rocked me in, at Avalon Nature Park in Stony Brook. In one photograph, Jessica asked me to look far into the future. I pictured myself and Lianna looking at these photographs far into the future while we were both in abundant health, seeing how STRONG we both were and are TOGETHER.

I am grateful and blessed to say that I got to give Lianna breastmilk past the one year mark due to breastmilk that my cousin, Rachel Grimmer, donated to us. It is the greatest gift we have ever received! I am over-joyed to share that I am now living abundantly healthy and my life has changed in unimaginable and positive ways. Lianna is 4 years old. She is wise beyond her years as I included her openly in my breast cancer journey and she has seen my transformation every step of the way. She wants me to get blue nipples when I am ready for that part of reconstruction.



Before I leave you, here are a few resources for you. Feel free to get in touch with me by going to: https://www.lisacassenti.com You can download my Free Ebook, "10 Tips to Becoming and Empowered Thriver" there as well as get a link to a monthly virtual support group that I co-founded called, "The Breast Connection." We focus on being proactive with your breast and overall health. Although we have many members who are breast cancer thrivers, we welcome everyone! Thank you for your time and always remember what a rock star mama you are!

Lisa Cassenti's Takeaways from Her Journey:



Know the **possible barriers of breastfeeding** before you begin the journey.

Know your **family history of breast cancer** and discuss with your doctors, reproductive endocrinologist, and OB/GYN prior to pregnancy and breastfeeding if possible.





Find your tribe in a **supportive community** and find a **lactation consultant**.

Do **frequent self breast exams** (and have your partner do them on you, too).





Celebrate your breastfeeding journey, whatever it looks like.

Advocate for your rights as a breastfeeding mama so that you can pave the way for yourself and other mamas.



babycafé





FREE VIRTUAL BREASTFEEDING SUPPORT

breastfeeding support groups for expecting and new parents (and their families)! Sessions are available in English and Spanish. Sessions entirely in Spanish are led by bilingual and bicultural lactation professionals.

Join any session by:



ZOOM LINK http://bit.ly/bfreezoombaby<mark>ca</mark>fe

Sessions in English:

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Every Tuesday 6 to 7 pm



PHONE +1-646-568-7788 (Meeting ID: 923 0683 0122



FOLLOWING OUR FACEBOOK PAGE https://www.facebook. com/BFREE.Coalition

HOSTED BY lactation professionals (IBCLCs, CBCs, CLCs). Any questions/technology concerns? Email BFREE@northwell.edu





Creating Breastfeeding Friendly Communities

babycafé



BFREE: BREASTFEEDING RESILIENCY, ENGAGEMENT, AND EMPOWERMENT

APOYO VIRTUAL GRATUITO PARA LA LACTANCIA

¡Todos estan invitados a grupos de apoyo a la lactancia materna GRATUITOS y semanales para las futuras y nuevas madres (y sus familias)! Sesiones están disponibles en inglés y español. Sesiones completamente en español son dirigidas por profesionales en lactancia bilingües y biculturales.

Únase por:



EQUIPOS DE ZOOM http://bit.ly/bfreezoombabycafe

Sesiones en Inglés:

Todos los martes 7pm-8pm Todos los jueves 12pm-1pm

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SIGUIENDO EN NUESTRA PÁGINA DE FACEBOOK com/BFREE.Coalition

Dirigido por profesionales en lactancia (IBCLCs, CBC<mark>s, CLCs). Si tiene preguntas o</mark> necesita ayuda con la conexión, escriba al email BFREEenorthwell.edu necesita ayuda con la conexión,





NEW YORK STATE Breastfeeding Friendly Communities



Tuesdays

1:30-3pm (English): http://bit.ly/sshbabycafe

6-7pm (Spanish):

http://bit.ly/bfreezoombabycafe

7-8pm (English):

http://bit.ly/bfreezoombabycafe

Thursdays

12-1pm (English):

http://bit.ly/bfreezoombabycafe

Join us for BFREE Prenatal Class (Caring for Two)!

1st Thursday of Every Month 12-1:30pm (English, Spanish translation available) http://bit.ly/bfreezoombabycafe





To learn more about the BFREE Team and to access our free resources, please click below:



