

BFREE NEWSLETTER

Breastfeeding Resiliency, Engagement, and Empowerment (BFREE)

"Empowering parents to breastfeed every step of the way"

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Letter from the Editor

Dear BFREE Coalition & Community Members,

Happy summer from the BFREE Team! We hope you and your families are continuing to stay safe while enjoying the warmer weather. We are especially pleased to present the July issue of our newsletter, featuring our first-ever video content. In this issue, we are highlighting the breastfeeding experiences of mothers with disabilities, focusing particularly on the Deaf community.¹ Mothers with disabilities face added barriers in finding breastfeeding support, often due to the inaccessibility of resources, or due to a lack of knowledge about their individual needs among health professionals. We are grateful to all of the mothers and birth workers who shared their stories in this issue, and especially to everyone involved in video production and editing.

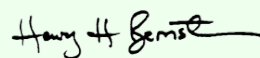
First, we hear from Drs. Tiffany L. Panko, Shazia Siddiqi, and Jason Rotoli, all members of the board of Partners in Deaf Health, a nonprofit Deaf health advocacy group seeking to improve access to health information in American Sign Language (ASL). They call attention to the need for more ASL-fluent lactation consultants, which stems from a shortage of inclusive, video-based training. Next, we asked the co-founders/co-owners of Hand Waves Birth Services, LLC, Ally Balsley and Brittany Noschese, about their own birth experiences and current work to bridge the gap between deaf/signing mothers and the birthing community.

Lastly, we are so excited to share our Mother's Perspective video, featuring the story of Alfia and her three children. We are especially grateful to Tara Tobin-Rogers and Kim Hirschberger, both Program Managers at Deaf Health Services at Northwell, for their incredible support in our first-ever video production.

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,



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



¹ Throughout this issue, we defer to the usage of our interviewees in determining when to use "Deaf," which refers specifically to participants in Deaf culture and the Deaf community, vs. "deaf," which typically refers to individuals who do not have the ability to hear.

*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.

Success Spotlight

The BFREE Team is happy to celebrate Brentwood Public Library and Bay Shore Brightwaters Rescue Ambulance, Inc., for achieving Breastfeeding Friendly recognition! We would like to thank our site champions Xibelualka Solis of Brentwood Public Library and Dana Dequatro of Bay Shore Brightwaters Rescue Ambulance, Inc., for working tirelessly to support their employees and members of the community during these difficult times.



We would also like to spotlight the Kiddy Cove Group Family Daycare. Though we were unable to collaborate in-person, we worked with the directors of these day care homes (including Deidre Brown-Aguilar) via Zoom to initiate and complete the breastfeeding designation process. We would also like to thank the Child Care Council of Suffolk and Division of Nutrition - Child and Adult Care Food Program (CACFP) for their help and unending support of the BFREE Team! A list of child care centers and day care homes that are Breastfeeding Friendly and participate in CACFP in New York State can be found at:

https://www.health.ny.gov/prevention/nutrition/cacfp/breastfeeding_homes/

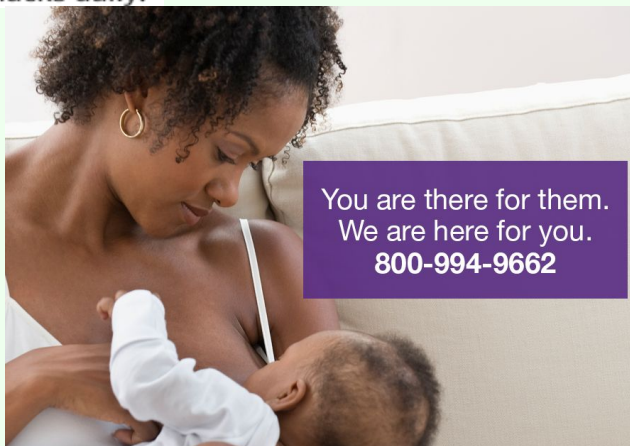


This work is supported by a NYSDOH “Creating Breastfeeding Friendly Communities” grant, which aims to expand community-based breastfeeding partnerships and reduce disparities in the rates of breastfeeding across New York State. Congratulations to all for being recognized for your hard work, and we thank you so much for collaborating with our team!



**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



You are there for them.
We are here for you.
800-994-9662

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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 new 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 last November 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 continue to spotlight [Sandy McCabe](#) and [Lizeth Villa](#) for participating in radio show interviews about breastfeeding in Spanish with La Fiesta 98.5! We are grateful for their 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. If you would like to listen to their interviews, please click on their names.

Subcommittee for Spanish-Speaking Communities

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Cielito Peterson
Marleny Taveras
Lizeth Villa

Join us for BFREE Baby Cafés!

Tuesdays

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

6-7pm (Spanish): <http://bit.ly/bfreebabycafe>

7-8pm (English): <http://bit.ly/bfreebabycafe>

Thursdays

10-11am (Spanish): <http://bit.ly/bfreebabycafe>

11am-12pm (English): <http://bit.ly/bfreebabycafe>

Prenatal Classes (Caring for Two)

1st Thursday of Every Month

10am-12pm

(English, Spanish translation available)

<http://bit.ly/bfreebabycafe>

Check out our website for more resources: <https://www.bfreecoalition.org>

Visit us on Facebook at: <https://www.facebook.com/BFREE.Coalition/>

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Creating
Breastfeeding Friendly
Communities



Cohen Children's
Medical Center
Northwell Health™

Supporting the Deaf Community: Do They Have Access to Breastfeeding Resources?

By: Tiffany L. Panko, MD, MBA; Shazia Siddiqi, MD, MPH; Jason Rotoli, MD, MS
Board members of Partners in Deaf Health

The deaf community in the United States is heterogenous with differing health needs, levels of access to care, and levels of medical knowledge. Yet, the community remains unified by a shared primary language, American Sign Language (ASL), shared norms, and common life experiences. As a linguistic minority group, they are at increased risk for lower health literacy and experience barriers in accessing equitable health resources. For example, deaf women are more likely to have fewer prenatal visits and are less satisfied with their prenatal care.^{1,2}

Dr. Tiffany Panko, currently the director of the Deaf Health Lab at RIT/NTID³ and board member of Partners in Deaf Health, supported a research project focused on women's health conducted by colleagues at the University of Rochester early in her career. In this study, Chin et al. showed that there are unique characteristics of the deaf community, such as valuing open communication, which can foster healthier and longer breastfeeding habits by providing the information women need to overcome the initial struggle of learning how to breastfeed with a new baby.⁴ However, they also found that deaf women were more likely to have shorter breastfeeding duration if they did not have access to providers in their native language.

One of the ways birthing people get this information is via doulas, whose value in the delivery room and in providing support for the new challenges of parenthood has been gaining recognition in the deaf community. There is a great need for more doulas and lactation consultants who are deaf and/or ASL-fluent. Fortunately, over the last decade, we have seen a rise of deaf or ASL-fluent doulas but the same has not been true for lactation consultants. The lack of deaf or ASL-fluent lactation consultants could be due, in part, to the shortage of certificate-granting organizations that provide accessible training with videos in ASL and courses with sign language interpreters.

The issue of needing more inclusive videos on health information is not new. Partners in Deaf Health, Inc. (PDH) is a non-profit volunteer Deaf health advocacy group in Rochester, NY. PDH is run by Deaf and hearing ASL-fluent people dedicated to improving access to health information for the Deaf community in their native language. One way PDH does this is by supporting a monthly series in ASL, called Deaf Health Talks, on a national platform.

The Deaf Health Talks is a collaboration with the University of Michigan Department of Family Medicine and MI Deaf, a health promotion organization similar to PDH based in Michigan, to provide health information presented by deaf and/or ASL-fluent individuals virtually via Zoom or Facebook. Recent topics included COVID impact in women and children and emergency access to medical and dental care. In September, Drs. Tiffany Panko and Shazia Siddiqi will discuss the "fourth trimester" of pregnancy (the 12 weeks after child birth).

To better serve the deaf community, healthcare providers need to be cognizant of how to communicate effectively with deaf people during what can be one of the most challenging times of their lives after giving birth. In doing so, providers can maximize health information sharing for deaf parents. Ultimately, this can allow parents to focus on having a happy breastfeeding experience as they are transitioning into parenthood.

1 O'Hearn, A. (2006). Deaf women's experiences and satisfaction with prenatal care: a comparative study. *medical care*, 12, 13.

2 Gichane, M. W., Heap, M., Fontes, M., & London, L. (2017). "They must understand we are people": Pregnancy and maternity service use among signing Deaf women in Cape Town. *Disability and health journal*, 10(3), 434-439.

3 Rochester Institute of Technology / National Technical Institute for the Deaf

4 Chin, N. P., Cuculick, J., Starr, M., Panko, T., Widanka, H., & Dozier, A. (2013). Deaf mothers and breastfeeding: do unique features of deaf culture and language support breastfeeding success?. *Journal of Human Lactation*, 29(4), 564-571.

Spotlight on Hand Waves Birth Services

Interviewees: Ally Balsley & Brittany Noschese

What is Hand Waves Birth Services, LLC and how did it come to be?

Hand Waves Birth Services, LLC was co-founded and co-owned by two Deaf birth workers in 2016. The challenges we faced from our first childbirth experiences inspired us to be where we are now with Hand Waves Birth Services. The birthing world lacked information and resources in American Sign Language (ASL). The information mediated from the medical system to deaf/signing individuals was usually superficial and lacking depth which resulted in the deaf/signing community being deprived of information and having their options taken away.

From our personal experiences with our first births in 2013, we faced challenges of not knowing that we had options and that we were able to make decisions in our journey rather than following the expectations of the society or the medical system. With the lack of knowledge and accessibility of understanding information in our primary language of ASL, we faced barriers and frustrations in our birth options and recovery. We wanted to prevent this experience from happening to the other individuals by providing information and sharing resources in ASL. We were not aware of any other Deaf birth workers at the time. We are passionate about building a bridge between the birthing world and the deaf/signing community as well as birth justice.

Tell us a little bit about yourself and your role at Hand Waves Birth Services, LLC?

We are mommies of seven children combined residing in Frederick, Maryland. We are Childbirth Educators, Full Spectrum birth workers, and placenta specialists. We currently provide in-person services for local families within a two-hour radius from Frederick, MD, and virtual services for anyone anywhere in the world. In the past five years, we had the honor of being part of many families' sacred journeys. Our goal is to have families feel comfortable in their experiences and to feel confident in making informed decisions. We are also passionate about reproductive and birth justice.

What has been the most rewarding part of working at Hand Waves Birth Services, LLC?

Meeting amazing families and witnessing them find the power that they had all along.

We asked these questions on our Instagram stories, and here are the responses copied and pasted:

What are some unique challenges that deaf and hard of hearing parents face when nursing their babies and what are some techniques or tools that have helped them overcome these challenges?

- No videos/resources in ASL
- Lack of effective & clear information from lactation consultations
- Wish the lactation consultation is deaf or fluent in ASL
- Switching back and forth between the lactation consultation and the interpreter
- Having the lactation consultation talk directly to the interpreter not toward the family
- While I am looking down at my breast and baby, trying to figure out breastfeeding, the LC is talking above my head at the same time, which means I missed everything they are saying.

How can we support deaf and hard of hearing individuals to meet their breastfeeding goals?

Provide information with accessibility at all times: i.e. having a deaf person sign the information in videos, providing subtitles in all videos, being visual on how to nurse by using props & hands-on demonstrations.

- Having a deaf or ASL-fluent lactation consultation
- Support group with [Deaf/Hard of Hearing] (DHOH) nursing parents

What are some common misconceptions about a deaf or hard of hearing parent's ability to successfully breastfeed their child?

The misconceptions come from lack of support and information that would encourage them in being able to breastfeed.

- Anemic baby and the baby wouldn't get enough
- Only one way to nurse
- Their preferred method of nursing is wrong
- That nursing was going to be easy

Mother's Perspective

This issue's Mother's Perspective features the story of Alfia and her experiences breastfeeding each of her three children. The BFREE Team is so grateful for the hard work and dedication of Tara Tobin-Rogers, MS, CI/CT, QMHI-S for producing and editing the video and Kim Hirschberger, MA, CSC for her interpreting.

To access the video, click the linked image below:



Below are several excerpts from Alfia's story. Click on any of the text to read the full transcript!

BFREE Team: Could you talk a little bit about what your pregnancy and birth experience was like for you?

Alfia: Looking back, maybe if I had stuck with breastfeeding longer with my first and second child, **I really see the benefit of it; for their future health, for their behavior, their development.** I think it helps a lot. My mom breastfed me for six months, my sister for eight months and we were fine, so looking back on it, part of my regret is that with my first two children, maybe I should have stuck with it a little longer. It seems, maybe, I gave up too easily on it and I see the results with my third child where I really hung in there and we did it for much longer.

I'm happy I did breastfeed. And in some ways, it helped calm myself. **I recommend to people, do it for a short time and see how you feel. Expose yourself to it and do it for at least for a short time and see what it's like.** I know breastfeeding is a tremendous benefit to the child. I know that and that's something to consider.

BFREE Team: Was there any education that you think you learned between your first two children and your third child that made you want to breastfeed more?

Alfia: I think a lot of women feel like they should know and **there's a sense of guilt or shame and needing to ask for help to do something that's supposed to come naturally.** And I think maybe that was part of my reticence because I did not ask for help.

BFREE Team: Do you think there are any unique challenges, in particular, that deaf and hard of hearing parents face when nursing their babies?

Alfia: You know, with hearing people, from their perspective, I know many of them think, "How can a deaf woman watch her baby? Deaf women shouldn't have babies! You can't take care of them!" And that's a tough misnomer that we've had to face all our lives. **But, we can! We can do it and we do it successfully!**



Upcoming Events & Announcements



EVERY STEP OF THE WAY

National Breastfeeding Month 2021

Image via usbreastfeeding.org/nbm

August is National Breastfeeding Month!

The theme of National Breastfeeding Month 2021 is "Every Step of the Way," with a different observance each week. Follow the links below to read more!

Week 1:

World Breastfeeding Week

Protecting Breastfeeding: A Shared Solidarity

Week 2:

Indigenous Milk Medicine Week

Nourishing Our Futures

Week 3:

Asian American Native Hawaiian and Pacific Islander Week

Reclaiming Our Tradition

Week 4:

Black Breastfeeding Week

The Big Pause: Collective Rest for Collective Power

In recognition of Black Breastfeeding Week, let's celebrate breastfeeding in our diverse communities!

On Wednesday, August 25 from 7-8pm, join BFREE and the Bridgehampton Child Care and Recreation Center to hear a panel of experts share their breastfeeding stories and advice. Click [here](#) to register.

Join on Zoom:

Link - <https://bit.ly/BBWpanel>

Meeting ID - 946 8204 7677

Passcode - 964601

Join by phone:

Phone: Dial 1-888-602-0202

(Passcode: 516-465-5304#)