

# BFREE Newsletter

Breastfeeding Resiliency, Engagement, and Empowerment

"Empowering parents to breastfeed every step of the way"

## In This Issue

Success Spotlight pg. 2

Connecting With Our Spanish-Speaking Community pg. 3

Expert Panel Discussion on Chocolate Milk pg. 4

Congenital Disorders and Breastfeeding pg. 5

Interview with Lyssa Lamport pg. 7

Parent's Perspective pg. 9

## Letter from the Editor

Dear BFREE Coalition & Community Members,

Happy fall from the BFREE Team! We hope you and your families are continuing to stay safe as the weather gets cooler. We are especially pleased to present the October issue of our newsletter.

We are highlighting the breastfeeding experiences of parents who have children born with congenital disorders, such as cleft lip and palate as well as tongue-tie (ankyloglossia). These parents face added barriers in finding breastfeeding support. We are grateful to all of the parents and organization advocates who shared their stories and experiences.

First we spotlight Northwell Health Physician Partners Family Medicine at Islandia, Sachem Public Library, and the Salvadoran Consulate for achieving breastfeeding friendly recognition. Next, we highlight efforts to connect with our Spanish-speaking communities in our region. Then, we highlight our expert panel discussion on the documentary Chocolate Milk. Then, we include a brief background on our topic this month, congenital disorders and breastfeeding. We would like to thank Dr. Lee Smith, Dr. Rachel Ruotolo, and Dr. Nicholas Bastidas for their help and expertise in providing information for this section.

Subsequently, we hear from Lyssa Lamport, MS, RD, CNSC, who is a Neonatal Nutritionist. She discusses how to make sure children with cleft lip/palate are receiving adequate nutrition. In addition, we are excited to share our Parent's Perspective. For this column, we are sharing the story of Beatriz Martine whose daughter was born with tongue-tie. She shares the difficulties she faced breastfeeding her child and explains her decision to have her child receive a procedure to release the tongue-tie.

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](mailto: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



\*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 Northwell Health Physician Partners Family Medicine at Islandia in Islip, Sachem Public Library in Holbrook, and the Salvadoran Consulate in Brentwood for achieving Breastfeeding Friendly recognition! We would like to thank our site champions Ashleigh Yancigay at Islandia Family Medicine, Kristen Stroh at Sachem Public Library, and Jocelyn Abigail Santana Perla at the Salvadoran Consulate for putting in a great amount of effort to support their employees and members of the community during these difficult times.



Pictured are community members at Salvadorian Consulate Library. With our BFREE team members are Jocelyn Abigail Santana Perla - Consul at Salvadoran Consulate, Dajuon Strange, Cleopatra Panagiosoulis.

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!



Pictured are community members at Sachem Public Library. With our BFREE team members are Kristen Stroh - Assistant Director, Thomas Lohr - Vice President of the Library Board of Trustees, and Neely McCahey - Library Director.



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Helpline: 1-800-994-9662

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talk with a health information  
specialist in English or Spanish



Pictured are community members at Northwell Health Physician Partners Family Medicine at Islandia. With our BFREE team members are Ashleigh Yancigay, Karina, Diana, and Jennifer



# Connecting With Our Spanish-Speaking Community

The BFREE Team remains grateful to Yezenia Chaparro (CBC), Paola Duarte (CLC), Sandy McCabe (IBCLC), and Marta Blanco (CLC) 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. We'd like to spotlight Marta Blanco, Lead Bilingual Nutritionist at Cornell Cooperative Extension, and Andrea Alexandra Escobar Castillo, Administrative Assistant at the Salvadoran Consulate, for participating in radio show interviews with La Fiesta 98.5! Marta Blanco discussed the Cultural Influences on Breastfeeding in our Latino Community, and Andrea Alexandra Escobar Castillo explained the Salvadoran Consulate's motivation to support breastfeeding. 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.

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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Yezenia Chaparro  
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Michelle Katzow  
Yvette Molina  
Cielito Peterson  
Marleny Taveras  
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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.

# Chocolate Milk



## *Virtual Film Screening and Panel Discussion*

At the end of August, in honor of National Breastfeeding Month and Black Breastfeeding Week, the BFREE Team hosted a free virtual film screening and panel discussion of the Chocolate Milk documentary.

Chocolate Milk examines how the socioeconomic factors of race and sex influence breastfeeding rates for black mothers in America through the stories of three women.

After participants watched the film, our moderator, Adesuwa Watson, asked questions to our panelists, Dr. Joynetta Bell Kelly, Janice Campbell, and Makeetah Cochy. As the panelists shared their perspectives, we learned about obstacles black and brown parents encounter in working towards their breastfeeding goals. They emphasized that it takes a village of supporters to help breastfeeding parents reach these goals, and they highlighted steps that communities, families, and providers can take to support breastfeeding parents.

We wanted to thank our panelists and moderator for leading an incredible panel and all of the 150+ registrants for the film. We are glad that our event was able to reach such a large number of individuals.

## Panelists and Moderator:



**Joynetta Bell Kelly, DHSc, MA**

is the Vice President of Strategic Community Partnerships. She creates, develops, and leverages relationships across multi-sectoral entities within the partnerships portfolio and builds programs and initiatives to address disparities throughout New York communities.



**Janice Campbell, MSN, RN**

is a Master's prepared Registered Nurse, Ph.D. student, Lamaze Childbirth Educator, and International Board-Certified Lactation Consultant. She is the lactation coordinator at Mount Sinai South Nassau and the founder of the Black Breastfeeding Coalition of NY.



**Makeetah Cochy**

is the newly elected council member of the Long Island Doula Association (LIDA) and an active member of the Black Maternity Wellness Collective (BMWC). She is currently earning her Master's degree in Clinical Mental Health & Counseling at Long Island University.



**Adesuwa I. Obasohan Watson, BA, MPH**

is the Director for the Office of Minority Health with the Suffolk County Department of Health Services, which strives to address health disparities and inequities for racial and ethnic minorities in the County.





# Congenital Disorders and Breastfeeding

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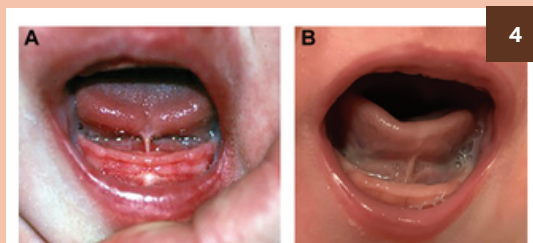
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## Tongue-Tie<sup>1,2</sup>

### What is Tongue-Tie?

Tongue-Tie (or Ankyloglossia) is when "an unusually short, thick or tight band of tissue (lingual frenulum) tethers the bottom of the tongue's tip to the floor of the mouth"<sup>3</sup>

Ankyloglossia is more common in boys and usually runs in families.<sup>3</sup>



**Figure 1.** (A) An example of "anterior" ankyloglossia with the lingual frenulum attaching at the tongue tip, limiting tongue mobility. (B) Posterior attachment of lingual frenulum. Consensus was not reached regarding the definition of "posterior" ankyloglossia. Some in the consensus group would describe this figure as an example of posterior ankyloglossia if there are objective findings of restricted tongue mobility caused by the lingual frenulum.

### How does Tongue-Tie impact Breastfeeding?

A tongue-tie can sometimes impact breastfeeding. The most common complaints that arise from parents who are breastfeeding a child with a tongue-tie are that there is a shallow latch, an inefficient latch, or the child is causing the parent pain.

### How and when is the condition corrected?

The tongue-tie can be corrected by an Otolaryngologist (ENT) though a low-risk procedure called a frenulectomy (or frenectomy), which is where the tongue is released (see picture above). Usually the procedure is done a few days after birth so that the parents can initiate breastfeeding before the procedure occurs. The procedure can be done in office, up until the child is 6 months of age; after that age, the procedure likely has to be done in an operating room with anesthesia. To be eligible for a frenulectomy, there has to be restricted movement of the tongue. For many parent-child dyads, breastfeeding may be improved after this procedure. However, to note, not all parents have a better breastfeeding experience after the tongue-tie is released.

#### References

- 1.Smith, L. (2022, September 15). Personal communication [Microsoft Teams].
- 2.Ruotolo, R. (2022, September 27). Personal communication [Microsoft Teams].
- 3.Mayo Clinic Staff. "Tongue-Tie (Ankyloglossia)." Mayo Clinic, Mayo Foundation for Medical Education and Research, 15 May 2018, <https://www.mayoclinic.org/diseases-conditions/tongue-tie/symptoms-causes/syc-20378452>.
- 4.Messner, A. H., Walsh, J., Rosenfeld, R. M., Schwartz, S. R., Ishman, S. L., Baldassari, C., ... & Satterfield, L. (2020). Clinical consensus statement: ankyloglossia in children. *Otolaryngology–Head and Neck Surgery*, 162(5), 597-611.

# Congenital Disorders and Breastfeeding

## Cleft Lip and Palate<sup>1,2</sup>

### What is Cleft Lip and Cleft Palate?

The CDC states that "a cleft lip happens if the tissue that makes up the lip does not join completely before birth. This results in an opening in the upper lip. A cleft palate happens if the tissue that makes up the roof of the mouth does not join together completely during pregnancy." <sup>3</sup>

The CDC reports that about 1/1600 babies each year are both with cleft lip and palate; 1/2800 are born with just cleft lip; and 1/1700 are born with cleft palate.



4

### How and when are these conditions corrected?

These conditions are corrected surgically. For a cleft lip, infants can receive surgery between 3 and 6 months; cleft palate is usually repaired when the child is between 6 and 12 months

### How does Cleft Lip and Palate impact Breastfeeding?

Especially given that these conditions cannot be surgically corrected right away, children with cleft lip and/or palate can experience difficulties breastfeeding. First, having a gap in the lip and/or palate, makes it hard for the baby to form a seal around the nipple and suckle effectively. This could mean milk is not effectively moving down the throat and providing nourishment to the child. Second, given the lack of a good seal, children with these conditions also likely swallow a large amount of air while feeding. Thus, it is necessary to burp the child more often. Children with cleft lip (compared to children with cleft palate) may have an easier time breastfeeding given that the breast is flexible and can conform to the baby's mouth. However infants with both cleft lip and palate will have a harder time feeding, and it is unlikely that parents will be able to successfully supply their child with a sufficient amount of milk by only feeding their child on the breast.

### In what ways can Parents facilitate Breastfeeding?

To help the milk go down the throat more easily, changing the child's position can help. For instance, a child can be put in the "straddle" position or in the "modified football" hold for feeding. Additionally, to make suckling more efficient, using the "dancer hand" hold helps to stabilize the jaw. To note, when a cleft lip is present, milk is likely to leak from the baby's nose regardless of the position, but if this happens, this will not harm their health and can simply be cleaned. Given that it is unlikely infants with cleft palate will get all the milk they need from breastfeeding alone, pumped/expressed milk can be provided to the child through use of a specialized bottle. Two examples are the Haberman feeder/Medela special feeder and the Dr. Brown Specialty Feeding System. These bottles only require the bottle's nipple to be compressed and then gravity takes care of delivering the milk to the infant, thus no sucking is needed. Cross cut bottle nipples can increase the flow of milk and reduce the amount of suction required from the baby. These bottles/tools allow for parents to still supply their child with breastmilk even if the child cannot nurse on the breast. Ultimately, parents should work with a specialized cleft lip/palate care team who can provide personalized help with feeding.

#### References

1. Bastidas, N (2022, September 19). Personal communication [Email].
2. Ruotolo, R (2022, September 27). Personal communication [Microsoft Teams].
3. "Facts about Cleft Lip and Cleft Palate." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 28 Dec. 2020, <https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html>.
4. Ruotolo, R (2022, September 22). [Before and after photo of child with a cleft ]. Retrieved from <https://www.instagram.com/p/Ciy555gregE/>

# Babies with Cleft Lip/Palate Can Breastfeed, Too

We sat down with Lyssa Lamport, MS, RD, CNSC, a Neonatal Nutritionist with extensive experience working with parents of babies with cleft lip/palate.

**BFREE Team:** What challenges do children with cleft lip and cleft palate face regarding nutrition?

**Lyssa:** When we get these babies the first step we have to do is figure out how to feed them. Can they breastfeed? Can they use a bottle? Do they have to use a tube? Can the tube go through the nose? Does the baby need a special mouthpiece? The degree of the anomaly is going to decide how we feed the baby. There are a lot of steps and people that are involved in making this decision - including the parents, neonatologist, speech pathologist, ENT (ears, nose, throat), oral and plastic surgeons. As a neonatal nutritionist I come in once we know it's okay to start feeding the baby and how we are going to feed the baby. Then, I do a nutrition assessment to see if the baby is small, large, and if the baby had anything going on during pregnancy that could impact the baby's ability to successfully feed or to grow.

**BFREE Team:** Is it safe for an infant born with a congenital anomaly to breastfeed?

**Lyssa:** Safety and ability are two different things. The baby's safety is the priority. As far as the physical act of breastfeeding, we are going to have speech pathology come in along with the lactation and possibly ENT team to evaluate the baby and see if the baby can even get on the breast or get a good seal. This is because we don't want these babies to choke or have such a difficult time trying to breastfeed that they develop food aversions, feeding difficulties, or poor feeding behaviors over the next few months. If the baby has a cleft palate and you put a breast in their mouth and they can't get a good seal that can be very frustrating for a hungry baby. It can also be frustrating for the mother, who sees that breastfeeding might not be working. We don't want to set anyone up to fail or feel frustrated. Can a baby at some point successfully breastfeed? I want to say yes - that is the goal, but it may not be the initial feeding option. Breastfeeding may be something you need to build towards.

**"Never assume that a mother never wanted to breastfeed or doesn't want to breastfeed because there may be something wrong with the baby's mouth. It is important to work with the parents and their feeding plan - it makes everybody happy - including the baby and mom." - Lyssa Lamport**

# Babies with Cleft Lip/Palate Can Breastfeed, Too

continued...

**BFREE Team:** What strategies can parents of children with cleft lip/palate use to ensure their children are being well-nourished and who can they reach out to?

**Lyssa:** For starters, parents should talk to their pediatrician first. Additionally, when a baby is born, regardless of any anatomical issues or diseases, you assess their feeding ability or adequacy just like any other baby - by checking for wet diapers, stooling patterns, and growth. What might be a little different for a baby with cleft lip or palate might be that the mother is breastfeeding exclusively, only a few times a day for the practice of it, or maybe the baby needs to be bottle fed or fed with a specialty feeder or tube. But again, you want to watch their growth. We usually give the parents specific volumes that their baby ought to be drinking in a day for their weight. If we have babies that are just under what they need to to maintain hydration, or they are just at the bare minimum weight, sometimes we will concentrate and enrich the pumped breast milk. Sometimes we also give babies that are exclusively breastfeeding additional breastmilk in a bottle as the supplement - not formula.

**BFREE Team:** How can cleft lip/palate affect parents' decision to breastfeed AND how might it affect breastfeeding?

**Lyssa:** I can imagine how a mom can feel nervous. She might have had a plan to breastfeed but is now unsure if it is possible with her baby's condition. They might be nervous wondering *how do I know my baby is eating enough?* - that is a general question without feeding issues. With cleft lip and palate, now you add another layer. When I approach a parent I ask - *what is your goal? Do you want to breastfeed?* If they say *Yes, that was my plan but...* that is where I say end of story: if you want to breastfeed, that is the goal and we medical professionals want to find a way to get you to that goal. We are not setting an unrealistic expectation but instead saying, *I want to get you there as best as I can.* Usually, in the beginning - based on the assessment of the baby's ability to breastfeed I would encourage the mom to start pumping, especially if we know they can't initially breastfeed. I would have these moms keep working with the lactation team as long as possible, encouraging them to seek support from people who will give them that support.

**BFREE Team:** If cleft lip/palate are corrected, what are the immediate effects on nutrition and breastfeeding?

**Lyssa:** Usually we can start feeding the baby right after the procedure, although it might be initially by bottle or tube. The only thing to watch out for is say the baby is first feeding with a specialty bottle and doing okay. After you surgically fix the anomaly, feeding might feel very different and be a little confusing for the baby. In these cases, we just need to be patient until they get used to feeding post-operation. For example, many of our NICU babies feed with a narrow system or a different type of system and often struggle with the larger, retail style bottle systems that mimic the breast. To work out those kinks, we have the parents bring in the bottles they were hoping to use and see how the baby is breastfeeding going back and forth between a bottle and breast.

*\*Lyssa's responses are abridged from the live interview by our BFREE Team.*



# "My Child had Ankyloglossia"

## A parent's perspective on tongue-tie

Twelve weeks ago, Beatriz Martine gave birth to Ariana Martine, her second daughter. Having had her first child a couple of years ago, she felt like she knew what she was getting into.

**Beatriz had breastfed her first child without any issues "but this time around" she states, "was a little different."**

Shortly after giving birth, she placed her baby on her breast and attempted to latch but it took longer than she remembered. "It was definitely more stressful this time around, she would latch here and there and would gum me, it felt like she was biting my nipple. While with my first daughter, I did not have any issue, I could go back and forth with the bottle and nurse with no problem." Since Ariana was unable to fully suck on the baby bottle nipple, she would spill from the sides of her mouth, "it felt like she was spilling .5 to 1 oz each time she had a bottle, which meant I had to pump to make much more for her bottles," Beatriz said. In her gut, she knew something was wrong. After bringing up this issue with nurses and physicians, she found that Ariana had ankyloglossia, or tongue-tie, which is "an unusually short, thick or tight band of tissue (lingual frenulum) that tethers the bottom of the tongue's tip to the floor of the mouth," Ankyloglossia is fairly common within newborns, with 5% of infants having the condition (1).



The doctors recommended a laser frenectomy procedure, a simple surgical procedure where a soft tissue laser is used to vaporize the tissue between the tongue and the floor of the mouth (2). She was worried at first but after some consideration she learnt of the many benefits.

**For the mother "breastfeeding is far less stressful after the surgery," and regarding your child "you also want to think of their future and the speech therapy you'll have to go through and any issues related with feedings," Beatriz said.**

#### References

- 1.Tongue-tie (ankyloglossia): Symptoms, causes & treatment. Cleveland Clinic. (2022, July 16). Retrieved September 28, 2022, from <https://my.clevelandclinic.org/health/diseases/17931-tongue-tie-ankyloglossia>
- 2.Frenectomy: What it is, procedure & recovery. Cleveland Clinic. (n.d). Retrieved September 28, 2022, from <https://my.clevelandclinic.org/health/treatments/22714-frenectomy>

# "My Child had Ankyloglossia"

## A parents perspective on tongue-tie

Immediately after the laser frenectomy, Beatriz resumed her attempts at breastfeeding Ariana. "It made me really happy when I was able to have nursing sessions, even though not 100% yet." Now, post-surgery, Beatriz alternates breastfeeding Ariana directly and through the bottle.

When asked on how she feels about breastfeeding post surgery, she said "hopeful," as Ariana was "barely spilling milk from the sides of the mouth," and that she "keep[s] her on for as long as it feels comfortable". For any mothers thinking of moving forward with a laser frenectomy procedure for their child, "I say go for it. It's a simple procedure and a quick procedure that is less than a minute and avoids all of the speech therapy, feeding issues, and is less stressful for the mom at the end of day," Beatriz recommended.




On advice to all the new mothers out there, "Just trust your gut- trust your mom instinct!" Beatriz assured.

**"The hardest part of this process was to advocate for myself and my child,"**

she confessed. "A lot of times as moms, we feel like we are unheard when we go to the doctors, or when we seek help, especially as first time moms. It feels like the people who we ask for help kind of tend to think that we over exaggerate **But, you know your baby the best, and you are the one feeding so if you think something is wrong, something is probably wrong.**"

**babycafé**


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## FREE VIRTUAL BREASTFEEDING SUPPORT

Everyone is invited to FREE weekly 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.

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**Sessions in English:**  
 Every Tuesday 7 to 8 pm  
 Every Thursday 12 to 1 pm

**Sessions in Spanish:**  
 Every Tuesday 6 to 7 pm

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

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## APOYO VIRTUAL GRATUITO PARA LA LACTANCIA

¡Todos están 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.

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**Sesiones en Español:**  
 Todos los martes 6pm-7pm

**Dirigido por** profesionales en lactancia (IBCLCs, CBCs, CLCs). Si tiene preguntas o necesita ayuda con la conexión, escriba al email [BFREE@northwell.edu](mailto:BFREE@northwell.edu)

  **Creating Breastfeeding Friendly Communities**

## Join us for BFREE Breastfeeding Support Group (Baby Cafés)!

**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:

