



Breast/Chestfeeding in the US: A Listening Session with National Advocates

In honor of National Women and Girls HIV/AIDS Awareness Day (#NWGHAAD), we're bringing together US-based organizations to discuss and share updates about their work to expand knowledge around breast/chestfeeding with HIV, promote provider support for parents living with HIV, change policies to reflect current evidence – and how you can get involved.

Join us on Zoom or live on our Facebook page: facebook.com/thewellproject

Wednesday, March 16, 2022 | 1:30 - 3:00 PM EST



Register Now!! bit.ly/NWGHAAAD2022

This webinar is part of The Well Project's BEEBAH (Building Equity, Ethics, and Education on Breastfeeding and HIV) initiative. To learn more, please visit: bit.ly/BEEBAH



Chat Log (Abridged)

00:16:00 **Olivia G. Ford (she/they) - The Well Project:** To join the Infant Feeding listserv, drop your email here *or* email me at oford@thewellproject.org!

00:16:20 **Olivia G. Ford (she/they) - The Well Project:** Register for the perinatal roundtable here! <https://ucsf.zoom.us/meeting/register/tJcoc-yqqz8jH9AtZmzgH726jYPSv-thYEKN>

00:22:27 **Olivia G. Ford (she/they) - The Well Project:** Expert consensus statement: <https://www.thewellproject.org/hiv-information/expert-consensus-statement-breastfeeding-and-hiv-united-states-and-canada>

00:22:32 **Catherine Hanssens:** And please let me/CHLP know of any providers you encounter who are NOT supportive of women living with HIV who choose to breastfeed. Chanssens@hivlawandpolicy.org

00:24:45 **Pamela Morrison:** Jenna, great trip through memory lane! I would love some of the links to those activities and presentations etc to share with my British colleagues

00:25:39 **Singh Robert B.:** Why it is call also chest feeding.

00:26:25 **Jenna Conley:** Of course, Pamela! this links to most of the work I mentioned: <https://www.thewellproject.org/hiv-information/breastfeeding-chestfeeding-and-hiv-supporting-informed-choices>

00:27:04 **Vickie Lynn (she/her/hers):** Singh, it is a term that is inclusive for all who feed and nurture their child by feeding them milk from their chest.

00:27:25 **Vickie Lynn (she/her/hers):** Bodyfeeding is another term used.

00:29:09 **Singh Robert B.:** okay, will that be the milk that only comes from the woman's breast?

00:30:21 **Vickie Lynn (she/her/hers):** A person's breast, yes.

00:30:29 **Heather O'Connor:** Some lactating individuals do not identify with having breasts and therefore use the term "chestfeeding" or "bodyfeeding".

00:32:23 **Singh Robert B.:** okay, thanks a lot I do not wish to speak I am beginning to come to terms with these new terminologies. I can see I am way behind with regards to the terminologies.

00:32:55 **Heather O'Connor:** That's totally fine! These are safe spaces to learn and grow! :)

00:33:03 **Vickie Lynn (she/her/hers):** Thank you Heather - I miss spoke

00:33:43 **Heather O'Connor:** No you didn't, Vickie! Was just trying to further elaborate. <3

00:33:50 **Vickie Lynn (she/her/hers):** Thank YOU!!

00:34:08 **Krista Martel (she/her), The Well Project:** Deb has been one of the amazing provider allies working hard for many years for women and better/more support!

00:37:23 **Krista Martel (she/her), The Well Project:** Please be sure to read Ci Ci's blog from 2019 where she talks about her experience not being able to breastfeed her son (now 11): <https://www.thewellproject.org/a-girl-like-me/aglm-blogs/liquid-gold>

00:37:56 **Krista Martel (she/her), The Well Project:** And her blog from 2022 and recent experience with her newborn: <https://www.thewellproject.org/a-girl-like-me/aglm-blogs/gold-ish-liquid>

00:39:21 **Singh Robert B.:** do you work with men or male partners along with the person who want to do breast or chest feeding?

00:41:21 **Krista Martel (she/her), The Well Project:** Here is a link to the BEEEBAH programming Ci Ci spoke about - which we will add this webinar to, as long as many other programs as they are developed: <https://www.thewellproject.org/hiv-information/beeabah-building-equity-ethics-and-education-breastfeeding-and-hiv>

00:41:22 **Heather O'Connor:** There are many things a male partner can do to support a lactating partner and often these options are explored and practiced with a lactation consultant.

00:44:48 **Singh Robert B.:** Is there a lot of women living with HIV need to do breast or chest feeding ? From my experience the medical community is not likely to support this cause.

00:44:50 **Krista Martel (she/her), The Well Project:** We have created a list of supportive providers in the US- and would like to continue to add to it - so please fill out the form if you would like to be added, or share with your networks: <https://www.thewellproject.org/hiv-information/list-us-based-providers-who-support-informed-infant-feeding-choices-parents-hiv>

00:54:57 **Catherine Hanssens:** www.hivlawandpolicy.org

00:56:50 **Bose Oladayo:** Yes so true our story our life.

00:59:37 **Pamela Morrison:** Yep. I've been advocating for breastfeeding in context of HIV since 1995!

00:59:41 **Heather O'Connor:** Your earrings are fierce, Catherine!

01:01:32 **Catherine Hanssens:** There is almost no funding for legal and policy advocacy on this issue.

01:01:54 **Olivia G. Ford (she/they) - The Well Project:** Keep dropping your questions in the Q&A box - or raise a hand and we will bring you off mute to speak your question!

01:03:00 **Bose Oladayo:** I remembered, how happy mothers with HIV were, when it was announced that women living with HIV can breastfeed their babies in the clinic where I access treatment for HIV almost 10 year ago.

01:09:50 **Olivia G. Ford (she/they) - The Well Project:** YES to the doula model of support/presence! <3

01:10:07 **Bakita Kasadha:** Doulas are fantastic

01:11:23 **Catherine Hanssens:** Also, as everyone knows with medical consent forms, you are not expected to actually read them, and you often experience harassment for trying to read it — and that is something to raise if that kind of form is used against you down the road.

01:12:34 **Grissel Granados:** I think Cynthia was the one who mentioned about consent forms so I am curious in what context she mentioned it

01:12:53 **Catherine Hanssens:** When care is conditioned on signing a consent form, the signature is not “consensual.”

01:15:33 **Catherine Hanssens:** Also pushing back against hospital/facility lawyers who create these stupid forms.

01:16:02 **Olivia G. Ford (she/they) - The Well Project:** Such a phenomenal report!
<https://bixbycenter.ucsf.edu/sites/bixbycenter.ucsf.edu/files/Family%20Justice%20Summit%20Report.pdf>

01:17:28 **Heather O'Connor:** It is also a huge problem that there is no information regarding how to care for a lactating person living with HIV in lactation education. Anytime it is mentioned it is in the context of "DO NOT". Therefore lactation issues become a solid "DON'T DO IT" when issues like mastitis arise. A strategy could be developed with a lactation consultant, but not if they are not educated on what to do and how to do it.

01:17:54 **Dee Conner:** Right Cynthia, and they should not be in fear.. It's their choice..

01:18:22 **Pamela Morrison:** I'm a lactation consultant. We have a duty of care to support a mother's own choices!

01:18:31 **Catherine Hanssens:** Cynthia, so so important — once child protective services gets involved, a parent and their family usually are subjected to endless surveillance.

01:19:12 **Heather O'Connor:** Absolutely! I am speaking specifically to lactation certification courses in the United States. I am not sure whether or not HIV is included in education in the UK.

01:19:15 **Pamela Morrison:** should maybe add, we supply the info, the client makes the choice!

01:19:25 **Lisa Diane White:** HIV stigma/criminalization furthers the perpetuation of a climate of fear. Thank you for these powerful conversations.

01:20:04 **Pamela Morrison:** Exam is international, and HIV is on the topic list.

01:21:55 **Heather O'Connor:** When I completed my breastfeeding certification course, information on how to care for a lactating person living with HIV was not included in the course. The only time it was mentioned was to not allow a mother living with HIV to breastfeed and to make sure donor milk was coming from an HIV negative person.

01:22:24 **Pamela Morrison:** Oh Heather, shocking!

01:23:24 **Heather O'Connor:** Interested to know if more information is included in the IBCLC test... that's something that I don't know. In the US, lactation support is so severely needed, but often not provided at the rate that it should be...especially for folks living with HIV who require a specific treatment plan.

01:23:49 **Pamela Morrison:** Martha, very good points

01:24:28 **Pamela Morrison:** CC so good. Selective risk!

01:25:20 **Bakita Kasadha:** Thank you Martha, Ci Ci and Krista, such important points

01:25:30 **Pamela Morrison:** Heather, maybe we can talk about this more...

01:26:05 **Heather O'Connor:** Yes! Absolutely!

01:27:08 **Heather O'Connor:** A lot of it has to do with the marketing of formula at such a high rate.

01:27:55 **Ciarra "Ci Ci" Covin (she/her):** Our pediatrician gave us a choice of the ARVs Zuri received after birth. 1 or 3 med regimen.

01:27:56 **Pamela Morrison:** Heather, yes Formula is seen as so normal.

01:29:24 **Heather O'Connor:** Right! It is oftentimes immediately offered to mother post-birth and in cases of unnecessary supplementation while mother's milk comes in fully.

01:30:02 **Pamela Morrison:** Deborah, BHIVA in UK only give infant prophylaxis for 4 weeks.

01:30:15 **Heather O'Connor:** ^^^ this!

01:38:06 **Krista Martel (she/her), The Well Project:** Please complete this quick survey!
<https://www.surveymonkey.com/r/NWGHAAD22>

01:38:20 **Finn Schubert:** Catherine, I would like to discuss how we can better engage hospital legal/risk management departments which often become involved in clinical decisions - I will contact you

01:38:26 **Catherine Hanssens:** chanssens@hivlawandpolicy.org

01:38:35 **Bakita Kasadha:** Fantastic discussion, thank you all!

01:38:57 **Pamela Morrison:** Thank you all so much!!!

01:39:01 **Catherine Hanssens:** Finn, please do — just shared my email. I think that’s an important conversation to have.

01:39:04 **Jessica Sanchez:** Thank you!!!!

01:39:07 **Carsen Beckwith:** Thank you all for this wonderful conversation!

01:39:07 **Heather O’Connor:** Thank you so much!!

01:39:10 **Dee Conner:** Thank you ladies!!

01:39:19 **Dee Conner:** Here to support

01:39:23 **Singh Robert B.:** Thanks a million

01:39:23 **Finn Schubert:** Thank you everyone! This was a fantastic discussion!

01:39:44 **Martha Martha Cameron:** This was excellent - thank you so much.

01:39:48 **Zandraetta Tims Cook:** Thank you. Very informative and provocative discussion.

01:40:21 **deborah cohan:**I learned so much today. Thanks everyone! Yes to pushing for guidelines changes and providers taking responsibility for changing the paradigm to one of reproductive justice and autonomy!

01:40:27 **Bose Oladayo:** Thank you so much for all your sharing. I am so inspire.

01:40:29 **Olivia G. Ford (she/they) - The Well Project:** Survey link again!
<https://www.surveymonkey.com/r/NWGHAAD22>

01:40:39 **Nicolette Lovingood:** They need to have more of these talks. Thank you!