

# Member Toolkit to Advance the Equitable Distribution of Donor Milk



**We believe in a world where  
all infants have access to  
human milk through support  
of breastfeeding and use of  
pasteurized donor human milk.**



*Mobilizing the Healing Power of Donor Milk*

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# Health Equity and How It Applies to Nonprofit Milk Banking.<sup>1</sup>

The World Health Organization defines health equity as the “absence of unfair and avoidable or remediable differences in health among social groups.” It calls for just opportunities, conditions, resources, and power for all people to be as healthy as possible. This requires the elimination of obstacles to health, such as poverty and discrimination, and their consequences. These consequences can include perceived and real powerlessness and lack of access to good jobs with equitable pay, good quality education and housing, safe neighborhoods, and high-quality, safe, easily accessible healthcare.

Health inequities are produced and sustained by deeply entrenched systems that intentionally and unintentionally cause stress, silence people, and prevent them from reaching their full potential. To address health inequities, we must develop anti-oppressive and antiracist policies and practices that acknowledge the deep harms that have been caused, both historically and in the present day, here in North America and worldwide. HMBANA looks forward to working toward a healthcare system that is fully accessible to all regardless of race, gender, ability, immigration status, class, sexual orientation, and gender identity.

Equity can be understood as both a process and an outcome. It involves sharing power with people to codesign interventions and investing and redistributing resources to the greatest need—explicitly considering how racism, gender and class oppression, ableism, xenophobia, and English language supremacy impact outcomes.

Equity-centered solutions in healthcare include but are not limited to:<sup>2</sup>

- Ending segregated healthcare that is reinforced by payer exclusion



- 1 It is very important to note the critical distinction between for-profit and nonprofit efforts to supply human milk in the United States. There are many for-profit companies marketing human milk, human milk fortifiers, etc. Because these companies are for-profit, their responsibility is ultimately to the bottom line. HMBANA is an association of nonprofit milk banks, and this toolkit is designed based on the operations of member banks in the United States. Because HMBANA banks use a nonprofit model, they can prioritize equity, providing sliding scale/charity care and advancing research and advocacy efforts while maintaining fiscal health and ensuring safety and quality. HMBANA milk banks explicitly do not pay donors to ensure that donations of human milk never take away from the needs of the donors’ own infant(s). Further, HMBANA members prioritize keeping donations as local as possible so that donors are supporting needs in their own communities rather than having their donations extracted. It is deeply important for all recipients of human milk, especially including the institutions purchasing it, to consider the ethical and moral implications for how the milk is sourced and who the ultimate beneficiaries are.
- 2 Portions are adapted from the American Medical Association’s Organizational Strategic Plan to Embed Racial Justice and Advance Health Equity.

- Ending segregated healthcare that is reinforced by systemic racism
- Establishing national healthcare equity and racial and gender justice standards, benchmarks, incentives, and metrics
- Ending the use of race-based clinical decision models (including calculators)
- Eliminating all forms of discrimination, exclusion, and oppression in all facets of education, training, hiring, matriculation, and promotion supported by:
  - Mandatory antiracism, antisexism, and antihomophobia structural competency and equity-explicit training and competencies for all trainees and staff
  - Publicly reported equity assessments for healthcare institutions
- Preventing exclusion of and ensuring just representation of Black, Indigenous and Latinx people in healthcare training and education as well as in leadership and decision-making positions
- Ensuring equity in innovation, including design, development, implementation, and dissemination, along with supporting equitable innovation opportunities and entrepreneurship
- Solidifying connections and coordination between healthcare and public health
- Acknowledging and repairing past harms committed by institutions

# Best Practices for Implementing Health Equity Work at Member Banks

Just over half of HMBANA member banks report being highly engaged or engaged in their own health equity work while the others report being interested or highly interested in implementing best practices toward health equity. Member milk banks identify staff time, staff size, and availability of data as the top three obstacles to furthering their equity work, based on a 2023 internal HMBANA survey. A further important distinction is that some member banks are hospital-based and thus bound by the policies and practices of those larger institutions. Both HMBANA as a membership association and individual milk banks are and have been primarily white-led. Truly [engaging in equity work as white-led organizations](#) requires awareness, humility, and accountability.

## INTERNAL BEST PRACTICES:

These best practices are potential ways to begin thinking about and designing health equity policies and practices. Each member milk bank is situated in its own unique geographic and cultural context. Only through genuine engagement in these contexts can health equity policies and practices be designed uniquely for [each member bank](#).

- Mission, vision, and value statements that reflect dedication to advancing equity
- A clearly defined equity statement that is publicly visible
- Policies that use inclusive language and address specific barriers for all stakeholders
- Digital and print communications that use inclusive and diverse language and images that include racial, economic, gender expression, and religious diversity
- Collection and tracking of demographic information from donors
- Board and staff demographics that mirror milk bank communities served
- Implementation of a sliding fee scale and/or charitable care program for caregivers with financial barriers to accessing donor milk
- Online and print materials in multiple languages
- Multilingual staff who can screen donors, talk with recipients, and conduct community outreach
- Equity work that is embedded in the strategic plan
- Identification of potential allies in the community (e.g., breastfeeding organizations, public health institutions, religious communities, racial justice organizations) and the best ways to participate in their work
- Creation of a community advisory board or council

## EXTERNAL BEST PRACTICES

- Work toward better understanding disparities in the distribution of donor milk by collaborating with healthcare institutions receiving donor milk, local researchers, and other advocacy organizations with the goal of collecting demographic data.
- Develop a research agenda to better understand barriers to and opportunities for the equitable distribution of donor milk; partner with universities and other research entities to implement that agenda.
- Advocate for insurance coverage of donor milk, focusing on Medicaid coverage at the state and federal levels.
- Partner with associations such as America's Essential Hospitals to continue to better understand the barriers to hospitals relying on primarily Medicaid revenue to implementing donor milk programs.

- Partner with Indian Health Service clinics and hospitals as geographically appropriate to support breastfeeding programs and establish donor milk programs in tribal communities.
- Create new and amplify current public education campaigns to raise the visibility of donor milk to new birthing people and to potential new donors.
- Utilize grassroots organizing strategies to bolster efforts toward equitably distributing donor milk.
- Collect stories and feedback from donors, recipients, healthcare professionals, and others involved in milk banking to inform advocacy, organizing, and public education efforts.

# General Messaging Tips to Support the Equitable Distribution of Donor Milk

No two communities' advocacy campaigns will look exactly alike. But while the picture may vary from place to place, there are some best practices for crafting an effective message. These tips can be used in your communications with policymakers and the general public to ensure that your message is both heard and well received.

## KNOW YOURSELF

Before taking on legislative advocacy, first evaluate yourself as a messenger. What are your strengths and weaknesses? What issues are you an expert on? Which policymakers or constituencies will be most receptive to your advocacy? How will others perceive your interests and biases? Use your self-reflection to guide your role and to help you identify when it would be more effective to ask others to step in.

## KNOW YOUR AUDIENCE

When engaging in a legislative advocacy campaign, you will be in touch with a diverse group of people who may not all share your values and interests. Before communicating, be sure to know with whom you are talking. What existing biases or ideas might they have about your issue? Are they familiar with donor milk? Do they value racial and gender equity? Are they singularly focused on business interests? It is helpful to tailor the way you talk about your bill in light of your audience so that you can draw their attention to your shared values rather than your differences.

## TELL A STORY

Advocacy campaigns are not won on facts and figures. Far more important are the stories we tell. Sharing stories can make even the most complicated of issues come to life for the public and policymakers. Personalize your language and provide examples as often as possible; your messages will be more memorable.

## BLAME BROKEN SYSTEMS, NOT PEOPLE

Great stories often have heroes and villains, so when messaging for legislative advocacy, be sure you're leading your audience to the right villain. Keep the focus on the system that is not performing as it should and not on individual people. Policymakers or members of the public who did not breastfeed or provide human milk to their children can be valuable allies if you don't inadvertently alienate them.

## CENTER ON IMPACTED COMMUNITIES

The work you are doing to advance human milk feeding is for real families in your community, and your advocacy should reflect that. As you begin to build your campaign, make sure that your coalition includes those who will be directly impacted by the bill and your efforts:

- Do not invite impacted community members to join you just for the photo opportunity. Truly centering their voices means offering a seat at the table in partnership for the long run.
- Support for human milk feeding is a bipartisan issue. However, some may be hostile to the deeply held values and personal identities that have led you and your coalition partners to support human milk feeding. Become knowledgeable about the policymakers you are lobbying to ensure that you and your partners are comfortable engaging before participating in a meeting. Take care not to pressure a coalition member to engage in a situation that might cause them harm.
- If you are unable to find impacted community members who are eager to join your coalition, do not carry on. Pause and take some time to reevaluate your strategy and network.

## USE COMPETITIVENESS TO YOUR ADVANTAGE

Policymakers look to other states for examples of legislative successes and horror stories. Play to policymakers' sense of competitiveness by encouraging them to not let your state fall behind its neighbors. Highlight the policies of neighboring states. Try to make comparisons with states that are politically and geographically similar.

## KEEP IT SIMPLE AND BRIEF

Communicate in language that is approachable, easy to understand, and as succinct as possible. Often, lawmakers and members of the public are considering your message along with hundreds of other messages, and attention spans are limited. While long, detailed reports might be useful to reference, be sure you have points that summarize their findings in a way that is easy to quickly understand. Part of keeping things simple means translating the technical language of public health, medical practitioners, and lawyers into language that everyone can understand.

## TALKING POINTS TO SUPPORT EQUITABLE DISTRIBUTION OF DONOR MILK

- Human milk as a child's first food is universally recommended by all major medical associations.
- Human milk as the first food lowers babies' risk of illnesses such as ear, skin, and respiratory infections, diarrhea, and vomiting as well as longer-term conditions such as obesity, type 1 and type 2 diabetes, and asthma.
- Some birthing parents are unable to supply human milk to their babies for many reasons, including illness and premature birth.
- When the birthing parent's milk is unavailable for any reason, donor milk is the best alternative.
- Donor milk is milk from screened donors through a nonprofit milk bank accredited HMBANA.
- Donor milk is the standard of care for premature babies unable to receive milk from the birthing parent; prematurity disproportionately impacts Black, Indigenous, and People of Color populations.
- Essential hospitals (those that rely on greater than 75% of their revenue from Medicaid) are less likely to use donor milk.
- Data from the Centers for Disease Control and Prevention (CDC) in 2015 shows that the use of the birthing parent's own milk and donor milk were lower in hospitals located in zip codes with higher percentages of Black residents.
- Lack of Medicaid and other insurance coverage is a barrier to accessing donor milk (portions adapted from [Winning New Rights for Lactating Workers: An Advocate's Toolkit by Worklife Law](#)).



# Designing a Law for Medicaid Coverage and Creating a Campaign

One meaningful and achievable step toward increasing equity in access to donor milk in states is to advocate for a law that ensures Medicaid coverage of donor milk.

## DECIDING TO MOVE FORWARD

While ensuring Medicaid coverage is an important step toward ensuring equitable access to donor milk, it is important to acknowledge that designing a law and creating a campaign requires human and financial capacity and resources. This toolkit provides information and resources about coalition-building, community engagement, and potential allies—work that can increase capacity and that requires capacity to begin and continue. Before beginning a campaign like this, do your best to understand how things work in your state—what, if any, work is already ongoing; what costs are associated; what length of time it might take; and, if you're successful, what resources need to be dedicated to implementing the law.

## UNDERSTANDING MEDICAID

Medicaid is a jointly funded partnership between states and the federal government that provides healthcare to America's poor. States are in charge of managing their specific programs. Medicaid covers some of a state's low-income population through federally mandated services, but each state sets the bar for qualifying for assistance in their state; consequently, not everyone with an income below the federal poverty line receives Medicaid support.

The Affordable Care Act (ACA) provided states an opportunity to expand their Medicaid coverage to many more residents in need. Under the expanded Medicaid program, residents' household income must be below 138% of the federal poverty level, which increased the number of enrollees who qualified for support. The change in healthcare coverage provided a significant increase in aid to individuals who had been unable to afford basic healthcare. During the first three years of the extended Medicaid program, as an incentive for states to adopt the plan, the federal government covered 90% of the shared [cost](#). Due to the politicization of the ACA, not all states adopted Medicaid expansion. Subsequently, the U.S. Department of Health and Human Services concluded that Medicaid expansion cost more than anticipated. Pew Charitable Trust has found in a recent study that Medicaid is the most significant expense in some states after K-12 education, with the number of enrollees continually increasing (Glans, 2020). States and the federal government share costs for the safety net program, and as the federal share of costs decreases, states must take on more of the cost burden (Glans, 2020).

There are vast differences in how individuals qualify for Medicaid, how healthcare is delivered and organized, and what additional services are covered across the country. Medicaid is expensive, and state budgets are not equally equipped to handle the financial burden of expanding services for their citizens (McKillop & Carges, 2018).

Understanding waivers in Medicaid expansion is essential for successful policy change.

Waivers are a mechanism negotiated through the U.S. Department of Health and Human Services, which allows states to customize their Medicaid programs with entitlements such as coverage for donor milk for premature infants. The allowance for waivers was passed as an amendment to the Social Security Act and has been part of the American social safety net for decades. A state's ability to fund the additional programs that a waiver might make possible is dependent on the state's financial health and the size of its eligible Medicaid population, both of which have significant impacts on the health and human service policy decisions of state leaders (McKillop & Carges, 2018). With the federal government's waiver approval, each state can create its own customized Medicaid program, to some extent, as long as their plan includes federally mandated services and remains financially balanced with the prescribed FMAP rate. Because of revenue shortfalls and budgetary constraints, some states will not have the resources to expand coverage without federal assistance, and this must be taken into account when advocating for Medicaid funding policy change (Mitchell, 2018).

## **SAMPLE MEDICAID LANGUAGE**

It's important to remember that legislative processes often involve compromise and that there can be unexpected opportunities to introduce and advance legislation. Having language ready and ensuring that the language is exactly where you want to start is key. Here is sample language from [The Milk Bank in Indiana](#).

## **SAMPLE LANGUAGE FOR DONOR MILK**

Coverage for Inpatient and Outpatient Donor Milk

Medicaid and every health insurance policy that provides pregnancy-related benefits and is delivered, issued, executed, or renewed on or after the effective date of this section shall provide coverage for the use of donor milk, as medically prescribed, and are subject to the following conditions:

- (1) The covered person is a child under the age of 12 months based on that child's gestationally corrected age.
- (2) The donor milk is obtained from a milk bank that meets quality guidelines established by the Human Milk Banking Association of North America.
- (3) The infant's mother is medically or physically unable to produce maternal breast milk or produce maternal breast milk in sufficient quantities to meet the child's needs or the maternal breast milk is contraindicated.
- (4) Pasteurized human donor milk has been determined to be medically necessary in a child who exhibits one or more of the following:

- (i) An infant birth weight below 1,800 grams
- (ii) A congenital or acquired condition that places the infant at risk for development of necrotizing enterocolitis
- (iii) Infant hypoglycemia
- (iv) A high risk for development of bronchopulmonary dysplasia or retinopathy of prematurity
- (v) A congenital or acquired gastrointestinal condition with long-term feeding\_or malabsorption complications
- (vi) Congenital heart disease
- (vii) An organ or bone marrow transplant
- (viii) Sepsis
- (ix) Congenital hypotonias associated with feeding difficulty or malabsorption
- (x) Renal disease requiring dialysis in the first year of life
- (xi) An immunologic deficiency
- (xii) Neonatal abstinence syndrome
- (xiii) Any other serious congenital or acquired condition for which the use of donor milk is medically necessary and supports the treatment and recovery of the child

## LOBBYING AND UNDERSTANDING THE RULES

Few efforts can change the landscape as quickly as passing a law—but legislative advocacy comes with a new set of responsibilities for organizations. A common belief is that nonprofit 501(c)(3) organizations are not allowed to engage in any lobbying. Actually, most are legally permitted to do so, but there are limits to this permission under U.S. tax law and some state and local laws. Likewise, many foundation grant awards prohibit the use of grant funds for lobbying activities. It is therefore critically important to understand what constitutes lobbying and what does not as well as the rules to follow when you engage in lobbying. This section provides key considerations and links to reliable guides on this topic.

*Please note that this section is included in the Toolkit for general information purposes only and may not reflect recent legal developments. It is not legal advice and is not intended to be a substitute for legal counsel.*

Advocates often struggle with the question of what constitutes lobbying. This is an important question because lobbying activities are subject to IRS regulations and potential recordkeeping requirements. Straightforward resources from Bolder Advocacy can help. Bolder Advocacy is a nonprofit organization that offers workshops and other tools for advocates on nonprofit lobbying, including state-level information regarding

lobbying restrictions. It also provides a help line for legal questions. Visit [bolderadvocacy.org](https://bolderadvocacy.org) to learn more about its offerings.

You also need to comply with the rules of your state and sometimes local jurisdiction, as many states require certain advocates to register as lobbyists and disclose lobbying activities to the state.

## ADVOCACY SOLUTIONS BEYOND LOBBYING

While talking directly to policymakers or encouraging your membership to do so is a highly effective way to influence legislation, lobbying isn't the only way to have an impact on public policy. Organizations or individuals who are not permitted to lobby due to funding or employment rules can shift the political landscape and change narratives, making others' lobbying efforts more effective. And splitting up the work means that groups that can lobby will be able to put more of their focus there.

Here are some concrete actions you can take without lobbying. These ideas are based on the federal definition of lobbying; the rules may be different in your state.

### 1. Collect Stories

Compelling stories are often more persuasive than data or arguments. A collection of stories from directly impacted people or companies is one of the most powerful tools in your toolkit. Partnering with qualitative researchers to collect stories via interviews, journaling, or digital storytelling has historically been used in many facets of healthcare to increase understanding of an issue. Hearing directly from those who have received donor milk, healthcare professionals who prescribe donor milk, and even those who wish they had had access to donor milk can be very powerful. Without lobbying, organizations and individuals can collect and share stories of people who would benefit from the legislation or healthcare institutions that have seen positive results by already providing what the law would require. These stories can be shared in letters to the editor, with journalists covering this issue, in written reports, or with advocates who are engaging in lobbying.

### 2. Conduct and/or Share Research

Like stories, statistics about donor milk in your state can be useful to make clear that equitable access to donor milk is an urgent issue lawmakers need to address. You can identify gaps in current research and partner with universities and others to prioritize research outcomes and to conduct the research. You can share the national data available from the CDC about inequitable access to donor milk and its lifesaving properties, and you can reach out to others in states where Medicaid coverage is available to see if they have research to share about the benefits of passing such a law.

### 3. Inform Decision-Makers and the Public

Your organization can build relationships with policymakers and community leaders to

educate them about why human milk feeding is so important. By raising awareness of how donor milk benefits families, communities, and the state's economy and public health before any bill is discussed, you are laying the groundwork for future legislative advocacy. When legislation is later proposed, you may also be asked for technical information about donor milk, which you can provide without lobbying as long as you do not express a view about proposed or pending legislation. Further, through educating community leaders about donor milk and nonprofit milk banking, they can continue to spread the word in their circles. Often, communities are unaware of even local nonprofit milk banks and the ability to donate and provide donor milk to those in need.

#### **4. Build Membership and Community Capacity**

Many organizations are surprised to learn that asking their members to contact legislators about a bill is lobbying. However, effective organizations can help their members engage in other ways. You can provide training to your membership on the legislative process, provide workshops on communicating effectively, and even host events to help members get to know their elected officials without directing them to lobby for legislation. Organizations can also alert their members of proposed legislation and inform them about the legislation as long as they do not also encourage them to take action.

#### **5. Engage in Administrative Advocacy**

Once a law passes, organizations that cannot lobby can take action to make sure the law goes into effect in a way that benefits the community. Under federal rules, it is not lobbying to seek to influence the implementation of a law, for example by submitting written comments or speaking with enforcement agency officials about how to interpret the law in a way that best benefits families. Other post-passage activities, such as drafting proposed guidance or encouraging a state agency to fast-track implementation, are not lobbying. Even before the passage of a law, it's possible to conduct administrative advocacy activities with the governing state agency to secure coverage for donor milk without passing legislation. For example, some places have seen success with working with their relevant state agencies to create a Medicaid-specific billing code for donor milk and then ensuring that healthcare institutions are aware of the billing code.

# **Community Engagement**

## **BUILDING AN INCLUSIVE AND EQUITABLE COALITION**

As an advocate for change, you can increase your effectiveness by collaborating with others in pursuit of a shared policy goal. Partnership allows you to put forward a common—and therefore more credible—message; increase your access to resources and human networks; expand your knowledge; and tap into diverse areas of expertise

and strengths. But partnerships aren't just strategic tools; they are relationships that require intention and give-and-take. When strong, coalitions can repair or strengthen bonds across racial, socioeconomic, gender, and professional divides that require intent, effort, and action to overcome. At the outset of your campaign, consider conducting a [Racial Equity Impact Assessment](#) to ensure that you've meaningfully evaluated the racial impacts of your legislative policy options.

Be aware that the first step in partnering with others may be taking stock of how your organization, particularly if it is [white-led](#), can better build principles of racial justice and antiracism into its systems. Recognize that this is a lifelong journey, and that the commitment to inclusivity and equity doesn't expire; it also leads to more rewarding and fulfilling work experiences for all.

The process of building and managing coalitions is one place where you can use what privilege you might have to ensure that people of color and other systematically marginalized people can play leadership roles in advocacy campaigns, which will increase their effectiveness. Those closest to the problems are closest to the solutions. Ensuring that these individuals create policy is not only the right thing to do but also results in better policy and stronger, more equitable implementation once the policy becomes law. Diverse membership is the bare minimum to start centering the work in communities that will be impacted by the campaign.

Another core principle is to avoid transactional interactions. To build [authentic and respectful relationships](#), meet early and regularly with groups and leaders you wish to partner with, not only when you want something in return. Leaders who are from dominant groups should be keenly aware of the power dynamics at play and the ways in which we all internalize [oppressive cultural norms](#) in work. Make sure all partners on the campaign don't have just a seat at the table but also a voice and a vote. Doing this requires setting a clear understanding of the coalition, your goals, and decision-making processes. It also requires making sure spaces where policies are developed are accessible and respectful of the experience and expertise of everyone in the room. Exclusionary practices are not just a professional *faux pas*; they harm people and recreate oppressive systems.

## POTENTIAL ALLIES

Human milk feeding has the power to unite people with a broad array of interests and has received bipartisan support in many states. While breastfeeding and donor milk advocates are powerful agents for change, their influence is heightened by working in partnership with advocates from other backgrounds. Be sure to consider which coalitions have been active on other recent legislation impacting maternal and infant health (e.g., paid family leave, maternal health resolutions, paid sick days, etc.).

### Healthcare and Public Health

- American College of Obstetricians and Gynecologists (state chapter)
- American Academy of Family Physicians (state chapter)
- American Academy of Pediatrics (state chapter)

- ZERO TO THREE
- Academy of Nutrition and Dietetics
- State Health Department breastfeeding staff
- Doula and birth worker organizations
- State maternal and infant care committee or coalition

#### **Infant and Child Health**

- March of Dimes (state chapter)
- 1,000 Days
- State organizations working to prevent child abuse
- Association of Maternal & Child Health Programs
- Association of State Public Health Nutritionists

#### **Women's Rights Groups**

- American Civil Liberties Union (state affiliate)
- National Abortion Rights Action League (state chapter)
- Other reproductive justice organizations
- Planned Parenthood (state chapter)
- MomsRising (state/local group)
- YWCA (state/local orgs or board members)
- State or local groups that advocate for women's rights

## **Conclusion**

HMBANA is dedicated to promoting the equitable distribution of donor milk and is actively advancing health equity initiatives through practical approaches. This toolkit provides milk banks and their partners with tangible strategies and tactics designed to mitigate barriers to accessing donor milk. A prominent strategy highlighted within is the advocacy for Medicaid coverage in regions where it is not yet available, enhancing access and distribution equity.

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*Mobilizing the Healing Power of Donor Milk*

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