



Maternal Health Advocacy Guide



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Table of Contents

Introduction.....	4
Supporting Your Leadership.....	4
Intended Audience.....	4
How to Use this guide.....	5
Interactive State Map Resource Center.....	5-6
Family Resources.....	7-12
Providers as Resources.....	7
Near Miss Survivors.....	8-9
Public Resources.....	9-10
Advocacy and Legislative Resources.....	10-12
Conclusion and Next Steps.....	14
Works Cited.....	15-20

Introduction

Health care information and legislation can be challenging and confusing to understand. Recently, state and federal governments, hospitals, and community partners have implemented new initiatives to improve the state of maternal and family care in the United States (U.S). The U.S. faces a maternity health crisis and the system for caring for childbearing families is not conducive to optimal outcomes. These initiatives and pieces of legislation can be difficult to navigate. Therefore, we need to better support consumers (childbearing families, friends, concerned citizens) to be aware of the state of maternity care, current and pending legislation at the state and federal levels, how to make impactful changes in their community, and make their voices heard. March for Moms provides this targeted guide to assist families in their advocacy journey to ensure that all families in the U.S. can grow with dignity and support.

Supporting Your Leadership

March for Moms realizes that delving into the world of advocacy is intimidating, but you made the first courageous step forward by utilizing this guide. Although it may not feel this way now, you are a leader and change maker in your community. You chose to become active and we are here to support your journey. Now, more than ever, families' voices are a crucial part of ensuring systematic changes occur.

Intended Audience

Expecting Families: Any member of an expectant family desiring to further their understanding of the state of maternal care in the U.S. and impact change at the state or federal level.

Near Miss Survivors (& Caregivers): Any survivor of a near death experience during childbirth and/or their caregiver interested in driving awareness of support material/organizations, legislation, advocacy efforts and instructions for action for

consumers who want to challenge poor care or outcomes experienced in pregnancy, childbirth, and/or postpartum period.

How to Use This Guide

Healthcare is ever changing and becoming more complex. Many stakeholders have already ideated on how to improve the health of families in the U.S. and how to combat issues such as rising maternal mortality. Thus, it is important for you to be able to advocate for changes you support as they can impact you, your family, and community.

The guide is intended to provide you with information and statistics regarding maternal mortality and the initiatives both on the state and federal levels that have been undertaken to address it. The resources found here can help you evaluate your community. Lastly, you can use this guide to advocate for yourself or your family with the help of our How To section, which includes step by step guides on how to reach out to your legislator or member of the community, how to convey your message in a succinct and organized way, and utilize social media to keep your message relevant.

Interactive State Map Resource Center

Utilize our **Interactive State Map Resource Center** to familiarize yourself with statistics on:

- 1. Overall Health by State**
- 2. US Maternal Mortality Rate**
- 3. US Maternal Mortality Legislation by State**
- 4. Medicaid Expansion by State**
- 5. Does my State Participate in the Alliance for Innovation on Maternal Health Program?**
- 6. Does my State Have a Perinatal Quality Collaborative?**

How Do I View the Maps?

The content begins with an overview of the state of health in the US and transitions to maternal mortality. Next, you will see more detailed policies and newly passed legislation as well as programs designed to address maternal mortality.

Each map is accompanied by a description to help you understand the content. As you view the maps, feel free to hover over and click on specific states to gain further information. If your state has fact sheets or website links to specific programs, you can access them by clicking on the state. Additionally, at the bottom of each map you will find the following options:

1. **Share**– use and share the content on social media and/or in your advocacy efforts. Make sure to tag us @MarchforMoms #BeyondMothersDay
2. **Download** the content of each map using this option.
3. **Full screen**– use this option to enlarge the map for a closer look!

How Do I Use the Maps in my Advocacy Work?

The topics and data displayed by the interactive maps are key contributors to maternal mortality or efforts to combat it. As you prepare to meet with your elected official, think about what topic you would like to address. For example, many states are considering legislation to extend Medicaid coverage (i.e. insurance coverage) to women for up to a year postpartum. We know that improved access to health care can prevent tragic outcomes. In order to come prepared to your meeting, view the Medicaid Expansion by State Map to familiarize yourself with statistics in your state and/or look at states that are doing well with this legislation.

Once you have a grasp of the statistics, connect it to your personal story! Remember that you do not have to be a statistician to make a point about maternal health. Feel free to print the resources you gather from the maps to appointments as a reference.

Resources

The following section will help you gather further information on how to prepare for a positive experience and empower you to advocate for yourself if you or your family had a bad experience or outcome.

Providers as a Resource

Maternal health providers (midwives, obstetricians, and family practice physicians) are a great source of information and should have the answers for questions you may ponder during the prenatal AND postpartum experiences. Additionally, providers should be supportive during any unforeseen events during labor and postpartum period. You and your family have the right to a debrief of the events that happened and resources to help you understand your particular experience.

Providers are advocates. They advocate to ensure their patients are cared for on a daily basis. You may explore advocacy with your provider by **asking if they participate in any advocacy efforts to improve maternal health at the hospital or community level?**

The National Partnership for Women and Families provides excellent resources for families to enable you to advocate for the best care.

- [What to Ask a Physician Who May Provide Your Maternity Care](#)
- [What to Ask a Midwife or Other Maternity Care Provider Who May Attend Your Home Birth](#)
- [What to Ask a Midwife Who May Provide Your Maternity Care](#)

Resources for Near Miss Event Survivors

For every American woman who dies from childbirth, 70 nearly die. That adds up to more than 50,000 women who suffer "severe maternal morbidity" from childbirth each year, according to the Centers for Disease Control (CDC) and Prevention. A patient safety group, the Alliance for Innovation on Maternal Health, came up with an even higher figure. After conducting an in-depth study of devastating complications in hospitals in four states, it put the nationwide number at around 80,000. The CDC data shows considerable racial/ethnic disparities in pregnancy-related mortality exist. During 2011–2016, the pregnancy-related mortality ratios were:

- 42.4 deaths per 100,000 live births for black non-Hispanic women.
- 30.4 deaths per 100,000 live births for American Indian/Alaskan Native non-Hispanic women.
- 14.1 deaths per 100,000 live births for Asian/Pacific Islander non-Hispanic women.
- 13.0 deaths per 100,000 live births for white non-Hispanic women.
- 11.3 deaths per 100,000 live births for Hispanic women.

A Near miss individual is defined as a very ill, pregnant, or recently delivered person who nearly died but survived a complication during pregnancy, childbirth, or within 42 days of termination of pregnancy. The most common events that occur surrounding childbirth are hemorrhage, cardiovascular complications (eclampsia, pre-eclampsia, i.e. uncontrolled high blood pressure), infection, and postpartum mood disorders.

How Do I Know if I am a Near Miss Survivor?

Speak to your provider, mental health counselor, family and friends. Sometimes it can take time to understand and process a birth experience and everyone's story is different.

You are not alone.

Near Miss Resources

- Faces of Postpartum is a project supporting families across the childbearing spectrum. The objective of this project is to offer a safe space for every woman, person who carried, and/or adopted a child to come together and open up about motherhood, parenthood, gender, race, class issues, sexuality, breastfeeding, abortion, relationship, birth, adoption, near-miss experiences, mental health, illness, and loss.
- 2020 Mom is an organization that focuses on a range of disorders including depression, anxiety and psychosis and can occur within pregnancy or the postpartum period (together often referred to as the perinatal period). Maternal near miss events can cause significant mental distress. When left untreated, these thoughts can cause devastating consequences for the mother, her baby, her family and society. You can

browse through their [awareness materials](#), [hospital programs](#) that help women with mental health disorders, and [advocacy materials](#).

- [Amniotic fluid embolism or AFE](#) is a life-threatening, acute and unexpected birth complication that can affect both mother and baby. The AFE Foundation is an organization that supports those affected by AFE and their families. Their [resources](#) help [families in crisis](#), [AFE survivors](#), and those that are [grieving from a loss](#) of a loved one due to an AFE.
- [The Prevention and Treatment of Traumatic Childbirth \(PATTch\)](#) is an organization that aims to expand awareness and advance knowledge about traumatic birth and its adverse impact on all childbearing people and babies.
- [Maternal Near Miss Facebook Group](#) is specifically for Maternal Near-Miss Survivors. Maternal near miss events are often unexpected and may leave the survivor feeling isolated and alone. This is a safe place where survivors find comfort and offer support as we journey toward healing together.
 - Note that information shared via a Facebook group, even a "closed" Facebook group, should not be considered private. Any health information shared by individuals via Facebook is not protected under federal health privacy law such as HIPAA. Please only share information on social media that you would be comfortable publishing publicly.

Family Resources

These resources come from government agencies to private non profit organizations to help you gather more information.

- [LeapFrog](#) has put together a [2019 survey of hospitals](#) that can help you understand if the hospital provides safe, high-quality care. This tool can be used to identify hospitals in your area and see how they rate for a variety of factors including maternity care. Additionally, Leapfrog has put together

incredibly helpful InfoGraphics to understand C-section rates and a pathway to a healthy birth.

- The Office of Women’s Health has created an all-inclusive resource regarding maternal care, labor, and newborn care. These resources are helpful in understanding how to care for both the mom and the baby during and following birth.
- Centers for Medicare & Medicaid Services is a governmental resource that provides hospital ratings. This can help to provide general information about the facility as well as an understanding of the care they provide. The ratings are also provided in relation to state and national averages which can help when reviewing facilities in your area.

Advocacy & Legislative Resources

In addition to the interactive content provided in this guide we provide you with the following resources to help you with advocacy efforts. Don’t forget to browse our How To: Advocacy Guide for a step by step approach to advocacy.

- The Center For Disease Control and Prevention (CDC) Pregnancy Mortality Surveillance System tracks data and showcases statistics from 1986 to 2018 showing an upward trend of maternal mortality of 7.2 deaths per 100,000 births. This resource also provides statistics based on racial and ethnic disparities as well as cause of deaths.
- The Joint Commission Quality Check will publicly report C-Section rates by July 2020. This will provide additional insights into how hospitals compare against standards that have been monitored since 2010.
- State Maternal Mortality Review Committees (MMRCs) have been established in many states. These committees review cases of death related to pregnancy and postpartum period. The reviews help identify patterns and prevent maternal mortality. A map of all available MMRCs is available and their profiles can provide additional insights to what is occurring on a state level.

- Alliance for Innovation on Maternal Health (AIM) is a national data-driven maternal safety and quality improvement initiative based on proven implementation approaches to improving maternal safety and outcomes in the U.S. The goal is to decrease preventable maternal mortality and severe morbidity across the United States.

AIM works through teams and health systems on the state, national, and hospital levels. The program focuses on the following strategies to increase the safety and quality of care:

- Broad Partnership
- Tools & Technical Assistance
- Implementation Training
- Real Time Data
- Build on Existing Initiatives
- Incremental Bundle Adoption
 - OB Hemorrhage
 - Severe Hypertension/Preeclampsia
 - Safe Reduction of Primary Cesarean
 - Maternal Prevention of VTE
- Incremental Bundle Adoption
 - Maternal Mental Health: Depression and Anxiety
 - Maternal Venous Thromboembolism
 - Obstetric Care for Women with Opioid Disorder
 - Obstetric Hemorrhage
 - Postpartum Care Basics for Maternal Safety
- From Birth to the Comprehensive Postpartum Visit
- Transition from Maternity to Well-Woman Care
 - Prevention of Retained Vaginal Sponges After Birth
 - Reduction of Peripartum Racial/Ethnic Disparities
 - Safe Reduction of Primary Cesarean Birth
 - Severe Hypertension in Pregnancy
- **California Maternal Quality Care Collaborative Maternal Data Center** was created to help monitor and improve the quality of

perinatal care. If you're located in **California, Washington or Oregon** you can see if your hospital participates in the collaborative. Hospitals use the evidence-based quality improvement guides provided by this initiative and record near real-time benchmarking data. In addition to the Quality Care Collaborative you can reference the United States graphic outlined on the March for Moms page to learn about the current status of your state's Quality Care Collaborative.

- Every state has a **Health Agency or Public Health Department** that is focused on the health of the general public and has a specific department that oversees the state's Title V program that focuses on the well-being of mothers and children. **You can locate your local State Health Department Here.**

How To Guides

Now that you have an understanding of the statistics and information it is time to put what you know to use. The two best ways to advocate is to meet with your elected officials and raise awareness. Below you will find two How To Guides on advocacy and social media.

How To: Advocacy

How To: Social Media



Conclusion and Next Steps

Congratulations on beginning your advocacy journey with our guide. Your support for maternity care as well as current and pending legislation at the state and federal levels will make impactful changes in your community. Advocacy work is dynamic thus staying up-to-date on statistics and legislation, building relationships with legislative offices, and amplifying messages on social media is crucial. The resources and guides provided in this guide are meant to be used again and again. Moreover, the instructions we provide can be applied to advocacy for varying issues under the maternal and family health umbrella (see Interactive State Map Resource Center).

Policy changes occur when individuals voice their concerns and demand improvements to care. You, as part of the March for Moms team, are the reason such changes will occur!

Questions?

Please email any feedback, questions or concerns to March for Moms at maternitycaremarch@gmail.com

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20

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