

POLICY MAKERS TOOLKIT



amplify, educate, advocate



Maria was 34 years old when she died.

Hyperemesis Gravidarum affects 3-10% or 6+ million women globally and leads to numerous pregnancy complications, including death.

1 MOM is 2 Many works to eradicate preventable maternal and fetal morbidity and mortality resulting from HG. Together with our partners, we strive to promote standardized treatment and assessment for improved outcomes through policy and advocacy.

WHAT IS HYPEREMESIS GRAVIDARUM (HG)?

- » HG is a debilitating and **potentially life-threatening pregnancy disease** that may cause weight loss, malnutrition, and dehydration due to severe nausea and/or vomiting with potentially adverse consequences for mothers and children.
- » According to recent research, **10% to over 22% of pregnant women** take medication for nausea and vomiting of pregnancy, yet only 3% are properly diagnosed with HG.
- » HG is the **leading cause for hospital and emergency visits in early pregnancy**, and the second leading cause overall, costing over \$3 billion annually plus outpatient care and therapeutics.
- » HG accounts for over **425,000 emergency and inpatient visits** compared to 149,000 for preeclampsia, 18,000 for sepsis, and 8,000 for cardiomyopathy (HCUP 2014).
- » **1 in 3 babies does not make it to term**

due to miscarriage, stillbirth, unwanted termination, and premature delivery.

- » **Maternal complications** can include gastrointestinal and esophageal damage, liver and kidney failure, preterm birth, placental abruption, sepsis, preeclampsia, embolism, PTSD, and perinatal mood and anxiety disorders (PMADs).
- » **Fetal complications** can include restricted growth, neurodevelopmental disorders (Sensory, Learning, Autism, Conduct), and cardiometabolic disease and mental health issues in adulthood.
- » HG is related to genes GDF15 & IGFBP7.

“When we talk about Maria, the women that were on the HER forums when she died still cry. That it could have been any of us is true, but more so, the tears are now filled with anger as well as grief. **Maria’s death was preventable.**”

“ Our family will forever feel incomplete without her and her children. It’s tragic. If only we had been given information about possible pregnancy complications or she had been given prenatal vitamins with thiamin in the hospital daily, we may not have lost the three of them.”

POLICY INITIATIVES

1 MOM will focus nearly 20 years of effort to advocate for federal and state policies to improve outcomes for those suffering with HG and associated complications, and thus support the long-term health of survivors and their children.

Policy Goal #1 – Advocate for Access to Care

Access to equitable, high-quality and consistent maternal care for all mothers is critical to women who suffer with HG and associated comorbidities. 1 MOM will:

1. Advocate for maternal access to quality health insurance through private insurers, and public programs like Medicaid.
2. Collaborate with state and federal agencies to integrate HG resources into programs offering health care and support to moms and babies.
3. Support legislation that protects current maternal health care programs and funding, expands maternal health care coverage, improves quality of care and addresses racial, ethnic and socioeconomic disparities.

Policy Goal #2 – Amplify the Voices of Women through Research

As of 2020, HER has received no federal funding for any HG research although we have found the likely genetic cause of HG, GDF15, and identified many adverse outcomes in mother and child. HG also contributes to many conditions like encephalopathy, preeclampsia, liver and kidney failure, sepsis, hemorrhage, thromboembolism, and preterm birth.

Effective treatment and management of HG can decrease the overall cost of maternal care and reduces the occurrence and severity of high-cost comorbidities in the short and long term. 1 MOM will:

1. Advocate for federally funded research of HG to identify effective treatments and optimize maternal and fetal outcomes.
2. Improve existing maternal morbidity and mortality research to ensure HG is reflected in the critical data needed to develop effective prevention and treatment strategies.

Policy Goal #3 – Educate Providers and Patients

Proactive and aggressive treatment can alleviate some of the misery and lessen the negative impact of HG, as well as prevent the progression of HG into other serious maternal health conditions. 1 MOM will:

1. Offer resources to increase provider awareness about the signs and symptoms of HG and its contributions to other pregnancy complications.
2. Partner with maternal and fetal health societies and governmental agencies to ensure HG resources are promoted and implemented.
3. Advance the appropriate utilization of medical treatment to prevent potentially devastating consequences of HG, including life-threatening comorbidities.

“ In addition to the physical complications of HG, women reported difficulty with selfcare; and “82.8% of women reported that HG caused negative psychosocial changes, consisting of (1) socioeconomic changes, for example, job loss or difficulties, (2) attitude changes including fear regarding future pregnancies and (3) psychiatric sequelae, for example, feelings of depression and anxiety, which for some continued postpartum.”
– B. Poursharif et al.

MARIA'S STORY

Maria moved to the US from her native Venezuela to marry the love of her life. Three years later, they were pregnant with twins. But HG changed their love story into a devastating tragedy.

She was hospitalized at 9 weeks with sepsis, low sodium levels, dehydration, nausea, vomiting, weight loss, and malnutrition. Her family felt helpless as they watched the vibrant, 34 year old fade into a coma.

At 14 weeks pregnant, Maria's heart failed and she died of profound malnutrition complicated by Wernicke's Encephalopathy (swelling of her brain due to vitamin B1 deficiency), Osmotic Demyelination Syndrome (ODS due to sodium deficiency), and sepsis.

Maria and her twins died of preventable complications of HG. Read our Case Study on Maria: hyperemesis.org/casestudy

“ I wasn't part of HER when Maria died. I didn't know about HG, much less that it killed people even today. But when I joined with my journey, her death was still felt in the forums. I would have been lost without the people in those forums. So many times, they pushed me to get better help, better treatment, better care. I had no idea at the time that just one year before a woman had died with her twins because her doctors were too late. If she had gotten the care that I was told to get, would Maria and her twin babies be here today? I help HER now to make sure there are no more Maria's. Because 1 MOM is 2 Many.

MAKE A DIFFERENCE

General Recommendations

- » Implement the international consensus HG definition to improve diagnosis and tracking of HG cases and costs.
- » Differentiate HG from morning sickness in databases and research projects to improve outcomes data.

Recommendations for Policymakers

- » Support expanded Medicaid coverage and maternal health legislation.
- » Include HG in regulations and legislation.

Recommendations for Policy Advocates

- » Sign the 1 MOM is 2 Many petition.
- » Contact local representatives to advocate for maternal health and HG specific legislation.

Recommendations for Societies & Clinicians

- » Sign up as a 1 MOM is 2 Many Partner
- » Adopt guidelines consistent with HG protocols.
- » Direct women to HER Foundation HG resources.

Recommendations for Health Departments

- » Require providers to submit health care quality metrics specifically addressing management of HG.
- » Encourage the proactive identification and treatment of HG through public health programs.
- » Provide HER Foundation patient resources and encourage participation in HER collaborative research studies.

POLICY INITIATIVES



Learn more about HER's policy and advocacy efforts

PRESS RELEASE: Moms and experts meet on Capitol Hill, give voice to overlooked pregnancy disease



HYPEREMESIS GRAVIDARUM IN THE NEWS

- » [Here's Why The Term "Morning Sickness" Is So Problematic](#) - InStyle Magazine
- » [Hyperemesis Gravidarum: When Morning Sickness Is So Extreme You Can't Function](#) - New York Times
- » [Amy Schumer Is In The Hospital Due To Hyperemesis Gravidarum—But What Is That?](#) - Women's Health Magazine
- » [This Pregnant Woman's Harrowing Experience Highlights the Disparities In Healthcare for Black Women](#) - Shape Magazine
- » [Pregnancy Made me so Sick that I Begged for an Abortion](#) - Metro News

1 MOM is 2 Many to die of malnutrition, sepsis, and neurological complications (Wernicke's encephalopathy, and Central Pontine Myelinolysis) in the 21st century.

LEARN MORE ABOUT 1 MOM IS 2 MANY

Mission

1 MOM is 2 Many works to eradicate preventable maternal and fetal morbidities and mortality as a result of HG. Together with our partners, we strive to promote standardized treatment and assessment for improved outcomes through policy and advocacy.

What we'll do

We educate on the long term, potentially life threatening complications associated with HG. We advocate for policy to implement proactive, standardized

interventions to minimize the suffering and complications related to HG. We amplify the voices of women and families who suffer from preventable, negative outcomes of HG to increase awareness.

What we want to change

Through development of comprehensive assessments, guidelines, and treatments, mothers and babies across the globe will receive the care they need in order to eradicate preventable maternal and fetal morbidity and mortality.



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www.1MOMis2Many.org