

Women In Need Of Help & Hope, The Losses Of HG

Kimber MacGibbon, RN

Founder HER Foundation

Good morning. It is an honor to have this opportunity to speak to you today.

I would like to ask you to imagine a town with tens of thousands of pregnant women. Then imagine this town was threatened by a lack of food and water for weeks, possibly even months. The media immediately would focus on the area and report the risks of loss in these women, not to mention the critical need for adequate nutrition. No doubt most observers would be appalled by the lack of provision and compassion. These women would obviously become a top priority for relief efforts.

Yet who is coming to the rescue of tens of thousands of pregnant women afflicted each year with Hyperemesis Gravidarum (HG) – the overlooked pregnancy disease? The debilitating nausea and vomiting caused by HG makes eating and drinking next to impossible for these pregnant women. They begin to feel trapped in their homes, unable to work, and totally dependent on those around them for weeks or even months, as a result of severe dehydration and starvation.

Few acknowledge their poor state, while others downplay their suffering. Even health professionals are often uneducated on HG management, and fail to respond with the correct diagnosis, much less compassion and proactive care. These women are desperate for help and hope. You can hear this in the voice of one woman grieving the losses of HG. "I made it only to the 7th week, then I ended it. I was violently ill... like nothing I had ever experienced before, I had very low blood pressure, 59/39 at one point, a uterine hemorrhage, and a kidney infection, and [I was] vomiting 15-20 times a day. I was on 6 different anti-nausea drugs, and they did nothing."

The suffering of these women is immense and the compassion virtually non-existent. Yet, the availability of information on the critical importance of nutrition during pregnancy is practically unlimited and impossible to ignore. Almost every magazine print articles on the subject. Even medical journals and associations acknowledge this fact. The American Dietetic Association's position on pregnancy health begins with these statements:

It is the position of the American Dietetic Association that women of childbearing potential should maintain good nutritional status through a lifestyle that optimizes maternal health and reduces the risk of birth defects, suboptimal fetal growth and development, and chronic health problems in their children. [slide]

Despite statements like this and the enormous amount of research to the contrary, women with HG are still told their malnourished state for months on end will not harm their child, perhaps in part due to a lack of information on how to manage such patients. Consequently, women's symptoms are often minimized or dismissed as exaggerations, further limiting the care they receive.

Marcie from Denver, CO described the ignorance of health professionals like this. "I was vomiting up to 70x a day... and received fluids but no medication. Routinely they would wake me up at 3 o'clock in the morning to weigh me. During this... a nurse actually suggested I have an abortion. [The doctor] told [me] to... eat mashed potatoes... I was sent home with a pamphlet on nutrition for pregnant women, the physician was not at all empathetic and gave me a pseudo lecture on what to eat and what not to eat, as if I could eat at all!"

Marcie suffered immensely from starvation, and it is likely her child did as well. Fewer than 15-20% of affected women receive nutritional support, in part due to risks and costs. However, we know without a doubt that lack of nutrition and stress during pregnancy DO adversely affect the child and this cannot be ignored any longer.

Jacqueline described the effect of HG like this: "I was hospitalized [from] 5 ½ weeks [until] 17 weeks with admissions till delivery, the emotional [and] physical toll were horrific. [I was] vomiting 70+ times a day, nose bleeds, torn esophagus,

burst blood vessels in my eye... I gave up work, couldn't walk, couldn't eat, and lost approximately 30 pounds. I looked like a skeleton and felt... like I was dead... I was so depressed after having [my son] I couldn't work till he was 7 months old... My son has special needs.”

Our research is the first to report that the percent of weight women lost during pregnancy is proportional to the risk of neurodevelopmental and behavioral disorders. In other words, as women lose more weight, they have a greater chance of adversely affecting their child's health. Other research clearly demonstrates that the effects of suboptimal nutrition and even emotional stress may not appear until the child reaches later life, however in some, it is evident in infancy. These women are sacrificing their health, and risking the health of their child, yet the medical community is taking little interest in improving the care of women with HG.

Still, some who are diagnosed and treated proactively, will progress to a severe state due to the ineffectiveness of current treatments for HG. Most medications offered are beneficial in fewer than 20% of women, and the few that are most beneficial, are very expensive which prohibits them from being prescribed or covered by insurance. These women will often suffer in silence as their bodies and babies are exposed to the risks of multiple medications that fail to offer relief. They are too ill to advocate for themselves. Lack of knowledge about effective care means too many women are not offered treatment at all. In addition, no drug

is FDA approved for HG treatment and the research on the risks of available medications is minimal, leaving women with guilt and fear over potential harm to their unborn child, and practitioners hesitant to prescribe anything.

Amber D., from WI illustrated this conundrum. “HG started around 4 wks but was not diagnosed until around the 10th week. Here I am pregnant and taking Zofran, a cancer drug for nausea and on TPN, another treatment for cancer. And the real kicker is they put me on the cancer floor in the hospital because the maternity ward was full....”

Consequently, about 10%, or upwards of 12,000 wanted pregnancies are terminated each year so mothers can avoid enduring months of misery or possibly damaging their child for life. This is a choice no mother should have to make. These women face great risk, many unknowns, and many losses. We need the medical community to realize the suffering of these women and the impact on future health, as well as work with the HER Foundation on an effective treatment protocol to ensure all women are given adequate and consistent care.

Often as a last resort, health professionals hospitalize an estimated 60,000 [CDC] women annually for HG at a cost of a half billion dollars [HCUP]. After receiving IV fluids and sometimes medication, they are sent home with minimal support. That is over 164 women every day. At least twice that many women will endure HG but, due to the trend toward outpatient care, receive complex in-home

care by family or semi-skilled nurses who are often unqualified or uneducated on preventing potentially life-threatening complications. Other women will miscarry or terminate their pregnancy before a proper diagnosis is given.

Not surprisingly, we receive email from people every year who lose loved ones to HG, including one from Serpil who wrote "My best friend (24 years old) died from what I believe was HG. She died over a year ago and her condition went undiagnosed for 7 months before she died." And another from a mother who said "My 19 year old daughter died on March 19, 2002... She was 13 weeks pregnant... and had been to the hospital twice the week before and diagnosed with Hyperemesis Gravidarum." These deaths are almost always preventable with aggressive care. As you can see, millions of dollars and even lives could be saved each year through greater research and awareness.

How many women does this affect? The incidence of HG is unknown, but is much greater than the estimated 1-3% of pregnant women, which represents only women admitted as inpatients to the hospital. It is likely that someone you know has suffered in silence or felt the stigma among other pregnant women. Statistical information is critical to realizing the impact of this disease, yet the data on HG is outdated, inaccurate and generally limited to small populations. Consequently, as you have heard, HG is misunderstood, misdiagnosed and medically mismanaged.

The cost of HG beyond medical care is incalculable, and their suffering impossible to quantify. Mothers face major lifestyle changes due to significant physical debility, in addition to the financial strain of lost employment and required domestic assistance. This can have a devastating impact on families.

Ruth, from Newport Beach, CA lost her job to HG at a critical time. “[HG went] undiagnosed and all I was offered was Phenergan and bed rest. I missed 2 months of work... I was wrongfully terminated for missing so much work, causing me to lose my income and my health insurance mid-pregnancy.”

The overall psychosocial stress on the entire family cannot be ignored and is greatly underestimated. Some women report abandonment and abuse by their partner, and trauma in their children who fear their death. The residual effects are unknown.

Juliette P., from PA described the impact on her family like this: “I entered this pregnancy believing that pregnancy was a healthy and natural life change and not an illness... [but] I couldn't go to work... my husband had to help to bathe me because I was so weak... since I lost over 30 pounds... my father [came daily] to care for me and... take me to my appointments... My sisters shopped for food...”

Women with HG lose so much during their pregnancies, yet much of it can be prevented or at least minimized if health professionals and families are given tools to manage and support a mother with HG.

Many of the coping and survival strategies for HG that we offer women come from personal experience. With my first HG pregnancy in 1998, I found very little information on the topic of hyperemesis, and despite being a registered nurse, I knew nothing about the disease. My midwife had little explanation of it and only offered a one page pamphlet on morning sickness which did not apply.

Furthermore, I was too sick to research HG, and too sick to remedy the inadequacy of my care, so I suffered greatly, emotionally and physically, for my entire pregnancy. Having HG is like enduring months of endless food poisoning with excessive fatigue, weakness, dizziness, starvation pangs, and an inability to care for even one's self. The relentless vomiting can leave you feeling as though you were suffocating repeatedly – a very traumatic experience.

I was a healthy, average weight at the beginning of my pregnancy, then lost three pounds a week until I weighed what I did in early high school. I became so debilitated that I was eventually barely able to sit upright or walk for more than a few minutes. My husband had to care for me daily, and take on all other tasks like errands, meals, cleaning, etc., all while maintaining a demanding, 12 hour per day job. It was a great strain on our new marriage, especially as the medical bills grew. Even he did not fully realize how sick I was and how little control I had

over the ravages of this disease. No one around me understood or knew what to do and eventually it was as though I did not exist to others. The isolation and debility were unbearable and not surprisingly, lead to depression.

It took me months to be able to walk again, and after delivery, I was barely strong enough to lift my newborn son despite physical therapy. It was the most traumatic illness of my life, and was only moderately severe in comparison to others. After three early miscarriages, my second and final term pregnancy was managed proactively and aggressively, but was equally miserable due to the ineffectiveness of most medications. I can only hope this foundation can bring about change so my daughter will not face the trauma of HG as so many do today. At times, I feel guilty for the increased risk my children face for future health issues as a result of the poor nutrition they received in-utero. Each day I am reminded of HG as I watch my son struggle with emotional and developmental tasks other kids his age have mastered, and I face another year battling the resulting chronic fatigue and insomnia. It is hard not to worry about the long-term impact on my children, and what future health issues I may face as well.

However, I am not one to remain a victim. About 5 years ago today, I launched the site www.hyperemesis.org to offer a source of reliable information for those managing HG in hopes that other women could avoid some of the pain and challenges I had endured, including that of a child with special needs. We are

working to improve the care of women with HG so future generations will not only have a chance at life, but also a healthy life. Countless women send us their stories of deplorable care leading to multiple terminations, life-threatening medical complications, and even death. Given the medical technology and information available in the US, HG is one of the worst examples of medical neglect and ignorance in our time. One woman sums it up like this: "...doctors can do operations that you'd never think possible, yet they can't stop [HG]. It's heartbreaking, and soul destroying." Consequently, families are forced to choose against biological children, and women struggle to regain their health and dignity. Today you will hear a fraction of these stories and the hypocrisy of medical care for women with HG.

You may wonder why a woman would get pregnant if she is going to face HG? But, with so little research, no marker has been found to determine which women will have HG, and in which pregnancies. A woman usually has no idea what HG is until she is ill and desperate for information, some never know why they are ill. Contrary to what women are told, our research finds HG recurs in greater than 75% of pregnancies. With the lack of awareness, affected women are often misdiagnosed or disregarded until their symptoms are severe, or they face repeated terminations. Consequently, managing the disease is even more difficult and complications are more frequent.

Not surprisingly, the CDC reports that the rate of pregnancy-related deaths and complications have remained largely unchanged since 1982.¹ [Trend Slide] Hospitalizations for all pregnancy-related complications occurring before delivery account for more than \$1 billion annually.² HG is a leading cause of hospitalization during early pregnancy, and 2nd overall during pregnancy. Total costs of care for HG, including outpatient and home care, clinic visits, medications, and consults likely exceed one billion dollars annually. Yet the research on HG is limited, especially in comparison to other diseases, some of which affect fewer women and can be cured. Consequently, when looking at government health information sites, HG is rarely found in the list of diseases, and management information is virtually non-existent. [show chart]

The enormous losses of HG cannot be measured solely in dollars; however, we know that the health of future generations is determined by the care pregnant women are given today. Ignoring a disease that hospitalizes more women than any other during early pregnancy is costing this country millions, if not billions, of dollars annually. While the trend of increasingly complex medical care at home initially saves money, the risk of complications increases, and the availability of surveillance systems to accurately monitor effectiveness, costs and outcomes decreases. It is painfully obvious that mothers with HG are being neglected by the health care system. Saving dollars today by denying women more expensive, yet more effective medical care will cost us greatly in the years ahead. The

¹ <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5202a1.htm>

² <http://www.cdc.gov/nccdphp/overview.htm>

decisions we make TODAY create a legacy for the next generation, as their health and our economy are determined by us dedicating adequate resources for the care of pregnant women now.

Please help us educate others about this disease, allocate funds for collaborative research, and assist our efforts to collect important statistical data about HG.

Collaboration with larger organizations like the CDC and the NIH is critical to our success. Until significant changes are made, HG will continue to have a major impact on our society and economy. You have an opportunity to change this. We have an impressive team of experts who are preparing for HG research projects.

We are ready and are looking to you for help. Together, we can offer these women hope that the next generation will not have to endure the suffering and losses we have for centuries.

Thank you.