

HER Foundation

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It's Not Morning Sickness...It's Much, Much Worse

MOMS AND EXPERTS MEET ON CAPITOL HILL, GIVE VOICE TO OVERLOOKED PREGNANCY DISEASE

Hyperemesis Gravidarum Supporters Call on Congress for Federally Funded Research on National Women's Health and Fitness Day

WASHINGTON (September 28, 2005) - Moms and experts converged on Capitol Hill today, National Women's Health and Fitness Day, for a Congressional Briefing with the non-profit Hyperemesis Education and Research Foundation (HER Foundation) and members of Congress to garner attention and federal research support of hyperemesis gravidarum (HG) – the overlooked pregnancy disease. Sponsored by U.S. Rep. Dave Weldon, M.D. (FL-15) and U.S. Rep. Xavier Becerra (CA-31) the briefing underscored the need for improved research and statistical data to better understand and treat HG – the leading cause for hospitalization in early pregnancy at a cost of \$500 million annually.

Despite the impact of the disease, HG research is limited and inconclusive causing the disease to be medically misunderstood, misdiagnosed and mismanaged. Though its total incidence is unknown, approximately two percent of U.S. pregnant women are hospitalized for HG each year. However, health professionals state that most HG patients are never admitted to the hospital with the current trend in care; therefore, these women are never counted.

"HG is a serious pregnancy disease that causes untold suffering among affected women," said Congressman Weldon. "I am hopeful that this briefing will foster heightened awareness of the disease and strengthen our commitment to better addressing HG."

Marked by rapid weight loss, malnutrition, dehydration and severe, unrelenting nausea and vomiting, HG, unlike morning sickness, can lead to serious complications for mothers and their unborn children. Various research shows the disease increases the risk of miscarriage, premature delivery and low birth weight. While its treatment has been documented for centuries, HG's cause is still unknown, leading some health professionals to mistakenly treat the disease as a psychological disorder or common morning sickness, delaying vital medical care.

"Mothers who suffer from HG are often unable to eat or drink for extended periods of time causing substantial weight loss at a time when nutrition is so vitally important," Congressman Becerra said. "Recognizing that proper and adequate nutritional habits are critical during pregnancy, it is concerning that more is not known about the long-term effects of suboptimal nutrition on babies born to HG mothers."

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A debilitating disease with both short and long-term physical, emotional and financial impacts, HG turns what should be a joyous experience for expecting mothers into a nightmare. Consequently, families choose against future biological children or even terminate *wanted* pregnancies due to inadequate treatment, health concerns or desperation to end the misery. Many women report feeling isolated and alone, often unable to leave their homes, as family, friends, co-workers and even health care providers minimize or downplay their symptoms.

Attendees heard such stories today from both mothers and experts experienced with the disease, including:

- Aimee Brecht-Dosher, M.D., OB/Gyn and HG survivor, Ventura, CA
- Andrea Taylor, HER Foundation volunteer online forum administrator, HG survivor, Post Falls, ID
- Ann Marie King and Jeremy King, HER Foundation co-founders, HG survivors, Leesburg, VA
- Karen Dunlap, HER Foundation volunteer, HG survivor, Allen, TX
- Kathleen and Paul Essig, HER Foundation volunteers, HG survivors, White Plains, MD
- Kimber MacGibbon, RN, HER Foundation founder, HG survivor, Boring, OR
- Larisa Kalife, M.D., internal medicine, HG survivor, Cheviot Hills, CA
- Marlena Schoenberg Fejzo, Ph.D., faculty researcher with joint appointments at UCLA and USC, HG survivor, Los Angeles, CA
- Shari Munch, Ph.D., MSW, LCSW, assistant professor, School of Social Work Rutgers University, Somerset, NJ
- T. Murphy Goodwin, M.D., professor and chief of maternal-fetal medicine, University of Southern California (USC)

"Health professionals have long thought HG is likely related to an overdrive of pregnancy hormones; however, the fact that HG frequently recurs in subsequent pregnancies and has a strong familial linkage suggests genetics play a role," said **T. Murphy Goodwin, M.D., University of Southern California** and briefing keynote speaker. "Dr. Roberto Romero of the Perinatal Research Branch of the NICHD and Dr. Duane Alexander, director of the NICHD, were among the first to recognize the need to fund research in this area, contracting with USC to begin a research program in this area. These seed funds must be extended and expanded to make up for years of neglect in research on hyperemesis. USC, in cooperation with the HER Foundation, has already identified key areas for research including genetic studies, drug effectiveness and effects of suboptimal nutrition, but collaboration with larger research organizations like the CDC and the NIH is critical to our success in truly understanding the disease."

Five years ago today, Kimber MacGibbon, RN, frustrated by the lack of information and support available during her first HG pregnancy in 1998 launched www.hyperemesis.org. Jeremy King contacted MacGibbon in 2002 when his wife was battling a life threatening HG pregnancy. He and his wife, Ann Marie, later helped MacGibbon create the HER Foundation, which received official non-profit status in 2003. The HER Foundation continues to be the No. 1 resource worldwide for HG, as well as the only center solely dedicated to coordinating and advancing research on HG.

"HG is an important women's health issue that we can not afford to ignore, its impacts are far too great for this generation and those to follow," said MacGibbon, HER Foundation founder. "Most of the women who contact us are eager to participate in research, but we lack the necessary funding. Federal research dollars are needed to offer these women the help and hope they deserve."

Primary diagnostic criteria for HG include weight loss of more than 5 percent of pre-pregnancy weight, ketosis (an indication of acute starvation), recurrent dehydration and debility. While common morning sickness typically subsides after the first trimester, HG may not lessen until mid-pregnancy and may persist until late pregnancy or delivery.

No drug is FDA approved for HG treatment. Research on the risks of available medications is minimal, leaving pregnant women with guilt and fear over potential harm to their unborn children, and health care practitioners hesitant to prescribe anything. The HER Foundation is working in collaboration with health professionals to establish a standard HG treatment protocol for hospitals and emergent care centers to ensure consistent, adequate care.

About HER Foundation

The HER Foundation is a 501 (c)(3) not-for-profit organization with the mission to provide **education and support** to those seeking effective management strategies for Hyperemesis Gravidarum (HG)—a debilitating pregnancy disease marked by rapid weight loss, malnutrition, dehydration and severe, unrelenting nausea/vomiting. Founded in 2003 by fellow HG survivors Kimber MacGibbon, RN, and Ann Marie King and her husband Jeremy, the foundation serves as a support network and voice for HG sufferers and their families. HelpHER.org is the leading source of HG information, with more than a quarter million worldwide visits last year. Through its collaboration with health professionals, educational outreach and online forums, the HER Foundation works to **improve understanding**, diagnosis and treatment of HG and the **impact** it has on pregnant women and their children. For more information, visit **www.HelpHER.org**.