My name is Marlena Fejzo and I am a science advisor for the HER Foundation. I have a Ph.D. in human genetics from Harvard University and am a faculty researcher with joint appointments at UCLA and USC. I have published papers on my genetic studies of many diseases of women including ovarian cancer, breast cancer, and multiple sclerosis and I discovered the first gene involved in uterine fibroids. I am also a mother of an 8 year old boy born of an HG pregnancy, and 3 year old twin girls born via a surrogate mother. In 1999 I lost a baby in the 2nd trimester due to HG. HG has changed my life - my family and my career.

More than 1 out of 4 HG pregnancies are aborted, die, or do not make it to term. We do not know what the long term effects are of prolonged starvation, dehydration and exposure to antiemetic drugs on the babies that do survive HG. HG is the 2nd leading indicator for hospitalization during pregnancy and yet very little research dollars are spent on it. Drug companies and universities virtually stopped supporting HG research or drug development after babies were born without their limbs when thalidomide was given to treat HG in

the 1950s. We need funding for a national campaign and national support to get the research going again.

Because the cause of HG is currently unknown, there is an urgent need for more research in this area so that therapies can be developed to treat the cause of the disease rather than the symptoms. I am devoted to studying and helping find the cause of HG, which I hope will lead to more effective treatments for this devastating disease. Working closely with the HER Foundation, we have found strong evidence that HG is a genetic disease. We plan to identify the genes that increase the susceptibility to this disease. Such identification will shed light on the true biological pathways involved in HG. It will tell scientists how to develop effective therapies that treat the cause of the disease rather than the symptoms.

Approximately 20,000 babies are lost annually in the US from HG pregnancies. This research will be a first step in putting an end to this devastatingly high number of fetal deaths. It will enable us to prevent this poorly understood disease that effects too many of us:

families, initially thrilled to be pregnant, whose lives are suddenly turned upside down, suddenly forced to take medications designed for cancer patients, some who have to make the hardest decision of all, to abort in order to survive, and others still, like myself, who don't abort but whose babies die anyway.

Please allow me to summarize briefly what HG is by explaining what happened to me in 1999. Just 5 weeks into my pregnancy, I was hospitalized with severe dehydration. My doctor sent me home with a bottle of pills and the first and last picture of my healthy baby. I spent the next two months day and night fighting off nausea and vomiting so extreme I couldn't eat or drink anything – not even a sip of water. I had numerous other symptoms as well, including rashes and blisters, but the overwhelming problem was the constant vomiting. I became so weak from losing an excessive amount of weight and was so nauseated that I was not able to leave my bed, even to use the bathroom. I could not even turn to my side, let alone sit upright without vomiting. My doctor had Zofran, a medicine that is used to prevent vomiting during chemotherapy, pumped into my leg and later moved to IV in my arm when there wasn't any fat left in my thigh to

absorb the drug. And later, after weeks and weeks of utter starvation, too weak to talk, having to use a buzzer to communicate the need for a bedpan or Zofran change, I was put on 7 different drugs at once as a last attempt to try to get me to be able to eat. Nothing worked. When my veins became too thin to retain an IV, they inserted a PICC line into my chest. Ultimately I started hemorrhaging, and, in a wheel chair, unable to walk or even sit upright, I listened as my doctor told me I looked like I had been through a war and that my 15 week old fetus was dead. HG was 10 unbearable weeks of constant suffering, horrifying for me, horrifying for my family, and deadly for my innocent, unborn child.

When I recovered, I was shocked to learn that there was so little scientific research on HG. With your help, I hope that we can correct this and help find a proper treatment or a cure for this terrible disease. The cost of my HG pregnancy that ended in fetal death was over 200,000 dollars. The cost of a genome scan to localize HG-susceptibility genes is approximately twice that amount. How many more babies have to die before we realize that an investment in HG research will save money and lives?

Thank you very much for your time.

If asked: Genetic Linkage analysis is a valuable technique to localize genes for a wide variety of medically relevant diseases that have not yielded to molecular or biochemical analyses and was first shown to be a successful approach when the gene for Huntington's disease was identified by this method in 1983. Since then, the technique has been used to search for genes for many diseases of unknown etiology.

The estimated cost for enrollment, recruitment, and DNA sample collection is approximately =$66.24/participant X 1,000 =$66,240.

Estimated cost for genome scan (provided by CIDR)=$446/sample 400 markers X1,000=446,000.

Estimated cost for fine-mapping and candidate gene sequencing=446,000?.

If you have HG, there is a 20% chance your sister will also have HG.

If you have HG, there is a 15% chance your mother also had HG. If

you and your sister have HG, you have about a 50% chance of having a mother who had HG as well. If you have HG there is a 33% chance you have an affected relative (sister, mother, grandmother, aunt, or cousin) who has had HG.