

Jenny Meeden Bailey 5147

February 27, 2014

Re: SUPPORT FOR H.B. No. 5147 CONCERNING CYTOMEGALOVIRUS

Dear Honorable Representatives:

Please pass this important legislation so women will know about simple precautions to take during pregnancy to prevent devastating birth defects and so that newborns who are infected with CMV can have treatment to prevent and treat devastating birth defects. Before I relate my personal story, I am quoting the facts from the CDC and expert doctors in their submissions to your legislature.

The following statistics are from the CDC's website at: www.cdc.gov/cmV

- • CMV is the most common viral infection that infants are born with in the United States.
- • About 1 in 150 children is born with congenital (present at birth) CMV infection. This means that in the United States, about 30,000 children are born with congenital CMV infection each year.
- • About 1 in 750 children in the United States is born with or develops permanent problems due to congenital CMV infection. In the United States, more than 5,000 children each year suffer permanent problems caused by CMV infection.

Dr. Stuart Adler:

“I have studied this topic as an investigator for many years and know that prevention of maternal infection with CMV is in most cases easily preventable using hygienic intervention, if only women were aware of CMV, its effects on the fetus, and how to reduce their risk of infection. “

Dr. Eugene Shapiro:

“Cytomegalovirus (CMV) is the most common cause of hearing loss and neurodevelopmental disabilities in this country, and clinical trials have now shown preventive measures for pregnant women and treatment measures for CMV infected newborns are beneficial.”

Dr. Gail Demmler-Harrison:

“This bill simply supports programs for education that will provide ‘an ounce of CMV awareness’ and valuable knowledge about ‘three simple hygienic precautions’ that may save the life and well-being of an unborn child.... In addition, it provides for testing newborns for congenital CMV who fail hearing screens.... Treatment in randomized clinical trials shown to be beneficial is now easily available ... and covered by medical insurance policies.”

In early 1990 my husband and I were enjoying our 17-month old son and looking forward to the birth of our daughter. My obstetrician tested me for CMV early in the pregnancy but did not tell me anything about CMV or that I was CMV seronegative (*i.e.*, I had never had the virus before). I should have been told that women who contract CMV for the first time when they are pregnant can pass multiple profound life-long disabilities to their unborn children and that I could massively reduce this risk with simple precautions such as not sharing food from my plate or fork with other people and sticking to good hand-washing habits. This information was not provided to me. As a result, I was ignorant of CMV and my baby was vulnerable to its devastation. Simple counseling could have prevented the odyssey I am about to describe. An ounce of prevention could have saved a pound of cure.

A sudden weight gain when I was about 32 weeks into the pregnancy led to an ultra sound that revealed the baby’s abdomen was severely bloated with fluid. I was referred to a high-risk obstetrician who, through testing of a fetal blood sample, gave our family the diagnosis and grim prognosis of severe symptomatic CMV. We consulted many experts who all warned us of death and/or multiple severe handicaps and painful conditions for our baby.

Although it is impossible to describe how my husband and I felt, I can say we were in a pit of despair and we grieved for our daughter before she was even born. We were distressed about the toll our constant absence at appointments and emotional turmoil would take on our son, still in diapers.

Our high-risk obstetrician told us about the in-utero therapy available at the time to improve the prognosis. Twice he performed a procedure to drain the fluid in our unborn baby’s abdomen with an amnio needle that penetrated first my skin, then the baby’s. The procedures were not painful to me and both enabled my body to carry the baby to 35 weeks when the already severe problems would not be compounded by extreme prematurity and reduced the pressure the fluid was causing on all of the baby’s still-developing organs.

Just a few short weeks after we first heard of CMV, our daughter was born. She had petechiae all over her body, an enlarged liver and spleen, kidney disease, and swelling of the brain. One doctor advised me not to bond with my daughter because she would die shortly.

We received mostly bad news during the first week of her life, and I remember being so weak and grief stricken, barely able to stand by her incubator looking at that poor little sick baby and thinking about what life would be like for her.

But our high-risk obstetrician referred us to his colleague at the Baylor College of Medicine, Dr. Gail Demmler-Harrison, a CMV expert. I will never forget sitting in Dr. Demmler's office with my husband five days after our daughter's birth and having her tell us "there is hope". Dr. Demmler told us about the experimental ganciclovir study. Only 15 babies had ever been treated with ganciclovir, and all in the previous six months. Our daughter would be the first baby in Houston to receive the treatment. Improved outcomes were seen in the previous 15 babies, but at that point the experts thought a higher dose was needed for real effectiveness. Higher effectiveness could come with increased toxicity and terrible side effects. Dr. Demmler also told us about therapies available for the many conditions our daughter could have as a result of the CMV.

Over the next three weeks, our daughter continued to be very ill, was not gaining weight, was shedding high levels of the virus and there were pockets of the virus in her brain with evidence of some calcifications. It appeared that her brain damage was in fact minimal at this point but if the disease progressed severe damage would happen. A medical situation like we were in has cascading repercussions to all members of the family and all aspects of life. Emotional, financial, spiritual and other forms of upset came to our family, but we were offered and accepted help that ranged from meals from neighbors to the doctors' explaining to our insurance company the necessity of the experimental treatment for our daughter that we were soon to embark on.

Within days of starting the ganciclovir treatment, our daughter started smiling, gained weight, healed from all of the conditions the disease had been ravaging on her little body, and the virus became undetectable in her system. There were no ill side effects from the drug, except for a brief drop in her white blood count. Our daughter went through many tests during her hospital stay and after, but the only problem that was revealed was her deafness. After everything that had happened, we really were celebrating. I don't mean to minimize the hardship and challenges that being deaf has brought to our daughter's life, but to escape severe

symptomatic congenital CMV with only that problem is something we are thankful for.

Our daughter has diligently gone for follow-up exams for the CMV and ganciclovir studies her entire life. Her brother volunteered as a control subject around the age of 13 and went for intensive annual testing.

At the age of 14, our daughter underwent cochlear implant surgery on her left side. While the implant gives her some hearing, the surgery comes with risks and can take over four hours. It is not a simple outpatient procedure that some people believe it to be.

Our daughter is now 23 years old, has an amazing compassionate heart for other people, is a college graduate and has embarked on a career. Intervention during my pregnancy and early in her life saved her life and spared her from other severe and painful conditions.

But, if I had had proper counseling early in my pregnancy like all women should, I could have taken simple precautions that would have prevented my infection with CMV, her deafness and all of the medical therapies and special training she has endured. I can hardly believe that 23 years after our CMV story began, women are still not being told about CMV prevention and therapies.

PLEASE PASS THE BILL!

Sincerely,

Jenny Meeden Bailey

P.O. Box 1758, Blanco, Texas 78606