

Prevention and Early Intervention Through Policy: A Mother's Story

Cytomegalovirus Public Health & Policy Conference

Salt Lake City

September 26, 2014

Jenny Meeden Bailey, J.D.

cCMV Mom

Historian and Policy Analyst

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“...Something as simple as always washing your hands...could have prevented a child from being born with CMV.”

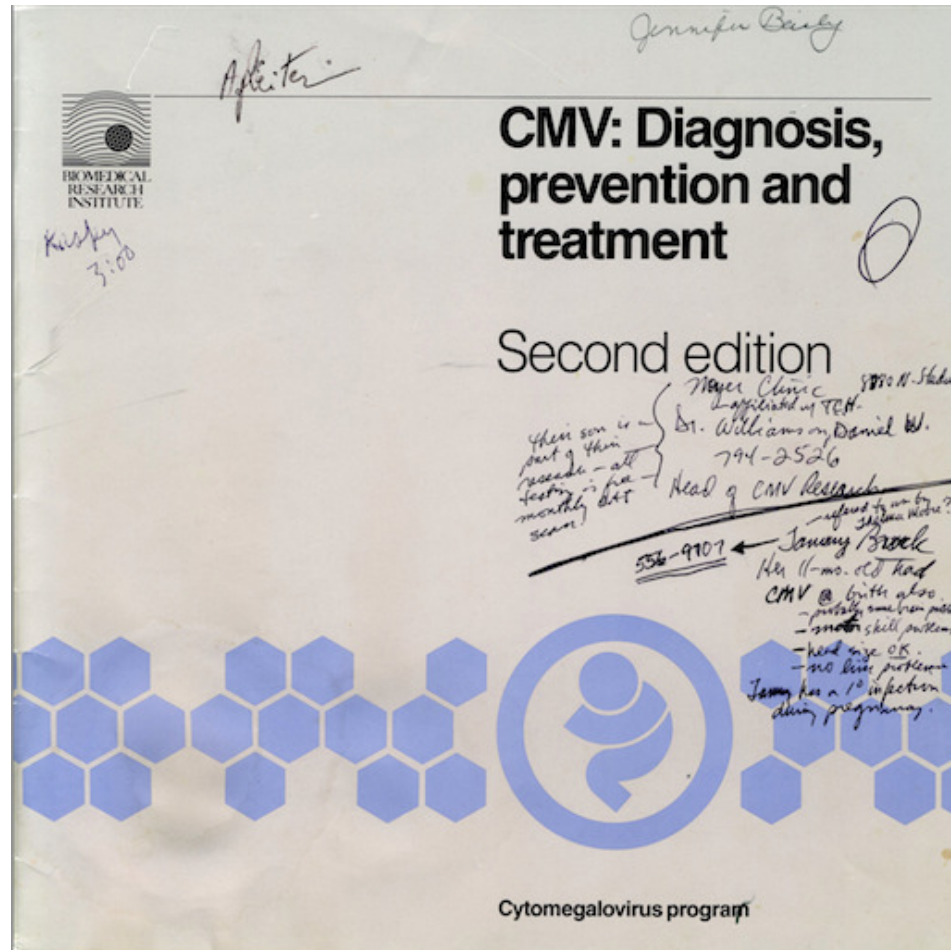
“A child like me, maybe.”



December, 1989



CMV: Diagnosis, prevention and treatment. Second edition. 1989.



“Is there a way to prevent CMV?”

“Hygienic precautions, such as handwashing and limiting contact with body fluids, are effective in reducing the risk of CMV infection.”

CMV: Diagnosis, prevention and treatment, p.12.

Caroline Recalls Her Prognosis

“There was a strong possibility that I would not live very long. How terrifying it must be to hear that your child could die shortly after birth; or if I lived, they could have a daughter... with several severe handicaps. I’ll never know just how tough it was for my parents to go through that experience, and I hope I never do.”

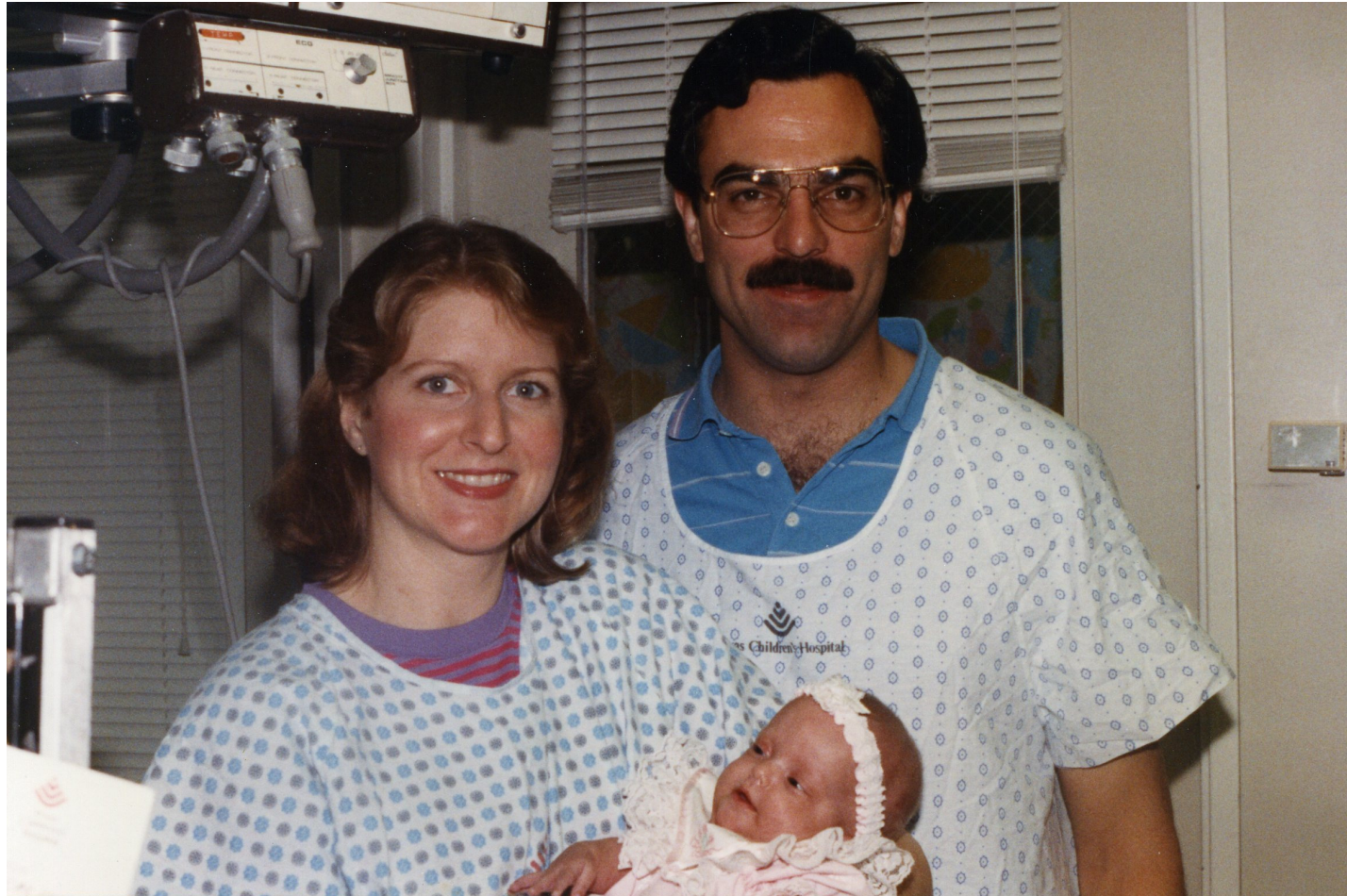
Caroline Bailey, 2014.

Birthday

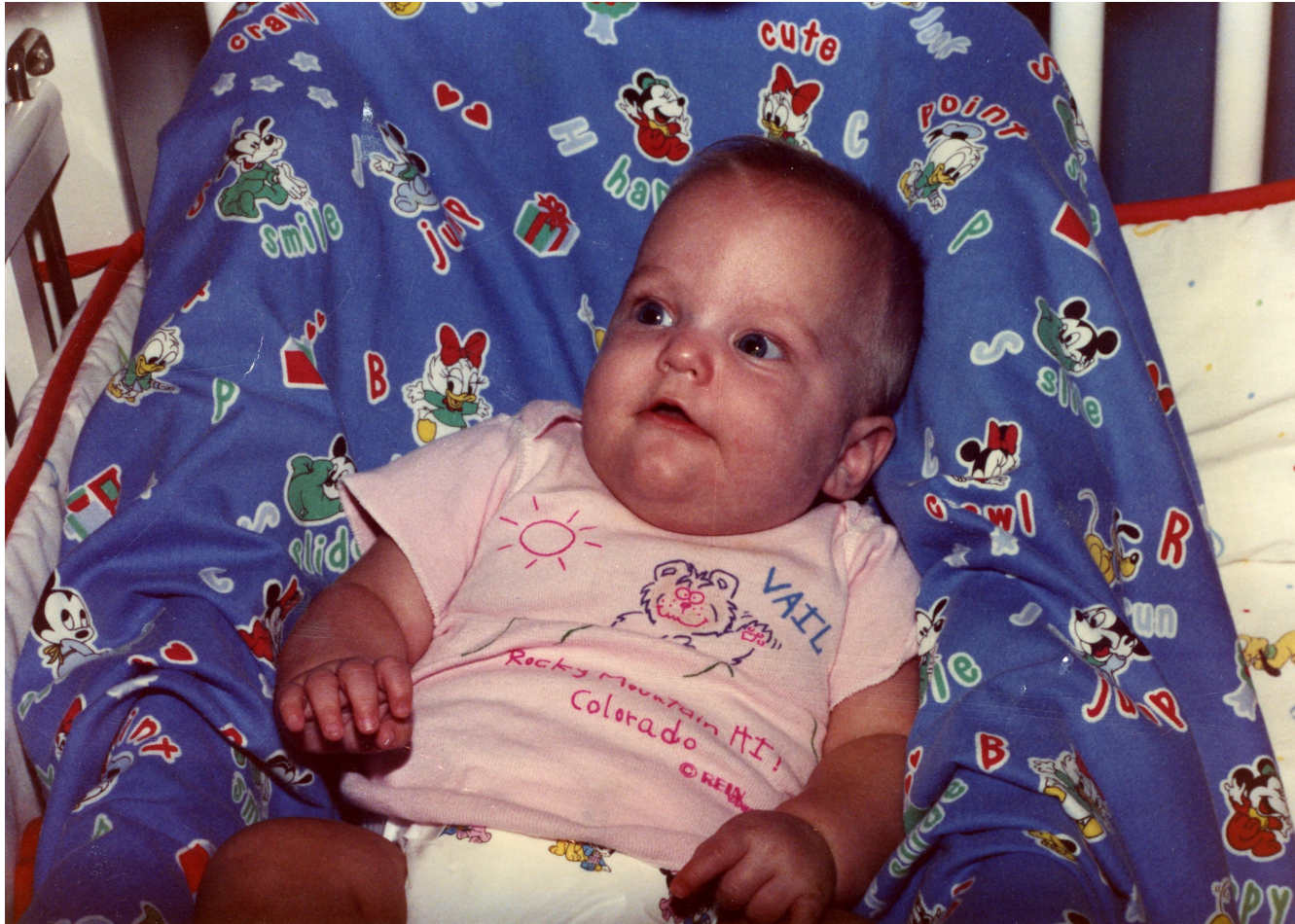
March 11, 1990



Caroline Smiles Because She Feels Better!



Cause: Ganciclovir
Effect: Healthy Baby



A Life Full of Challenge



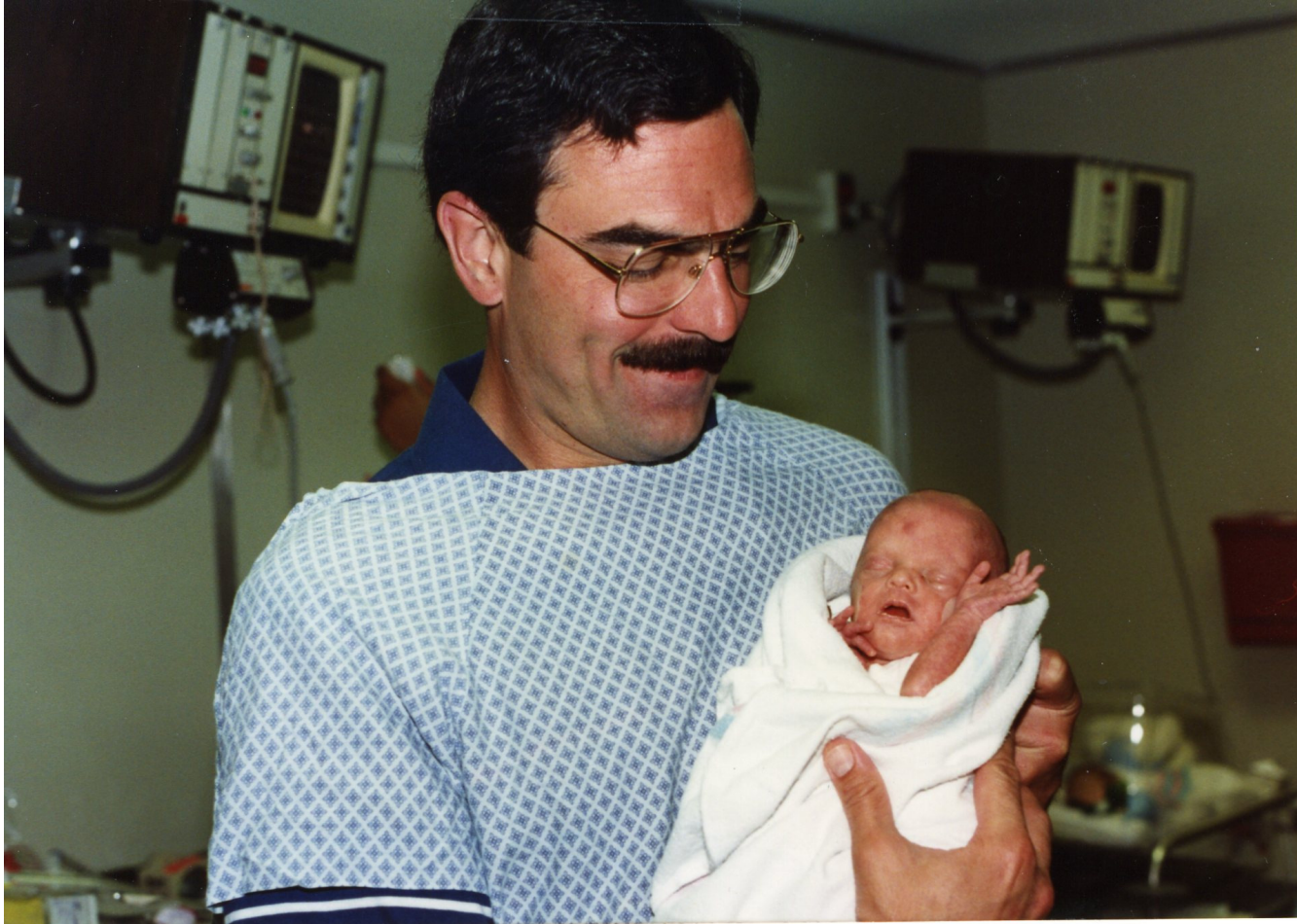
Zesty Determination



Excellent Medical Treatment Dr. Gail Demmler-Harrison



World's Best Dad



Supportive Brother



cCMV Mom

Image courtesy Memorial High School, Houston Texas. Emily Schwabenland, author. 2015.

losing her eyes as the I.V. is injected into her wrist, freshman Caroline Bailey squeezes her mother's hand as a tear rolls down her cheek. Surrounded by her family and the pastor of her church, Bailey nervously awaits her surgery to insert cochlear implant.

After struggling with a hearing disability for 14 years, Bailey was given the opportunity for a cochlear implant to increase her hearing

capacity.

Bailey was born with CMV (Cytomegalovirus), which she contracted during her mother's pregnancy.

"She was in the hospital for ten

Bailey said.

When Bailey was four months old, she received her first hearing aid.

"With her hearing aid, Caroline could hear a small amount of sound, but she relied more on lip reading and books for communications," first grade teacher Marsha Looper said.

The cochlear implant that Bailey received last July allowed her to hear a wider frequency of sounds than she could ever hear before.

"While hearing aids are amplifiers, the cochlear implant actually delivers the electrical impulses of sound directly to the brain," Bailey's mother

said.

Th activ start face: chall

activ bein; new neve only hea; encr over Baile Ni mor impl to sour hear bird frier of a



weeks with all sorts of problems," mother Jenny

impulses of sound directly to

David Groom
Brian Guarino
Kyle Guest
Edith Guevara
Brennan Guldner
Ashley Gunter

Cameron Guthrie
Kary Guthrie
Liliana Guzman
Chelsea Hanson
Evan Harche
Charles Harding



Friends and Extended Family



Medical Research

Photo courtesy Texas Children's Hospital , Houston, Texas



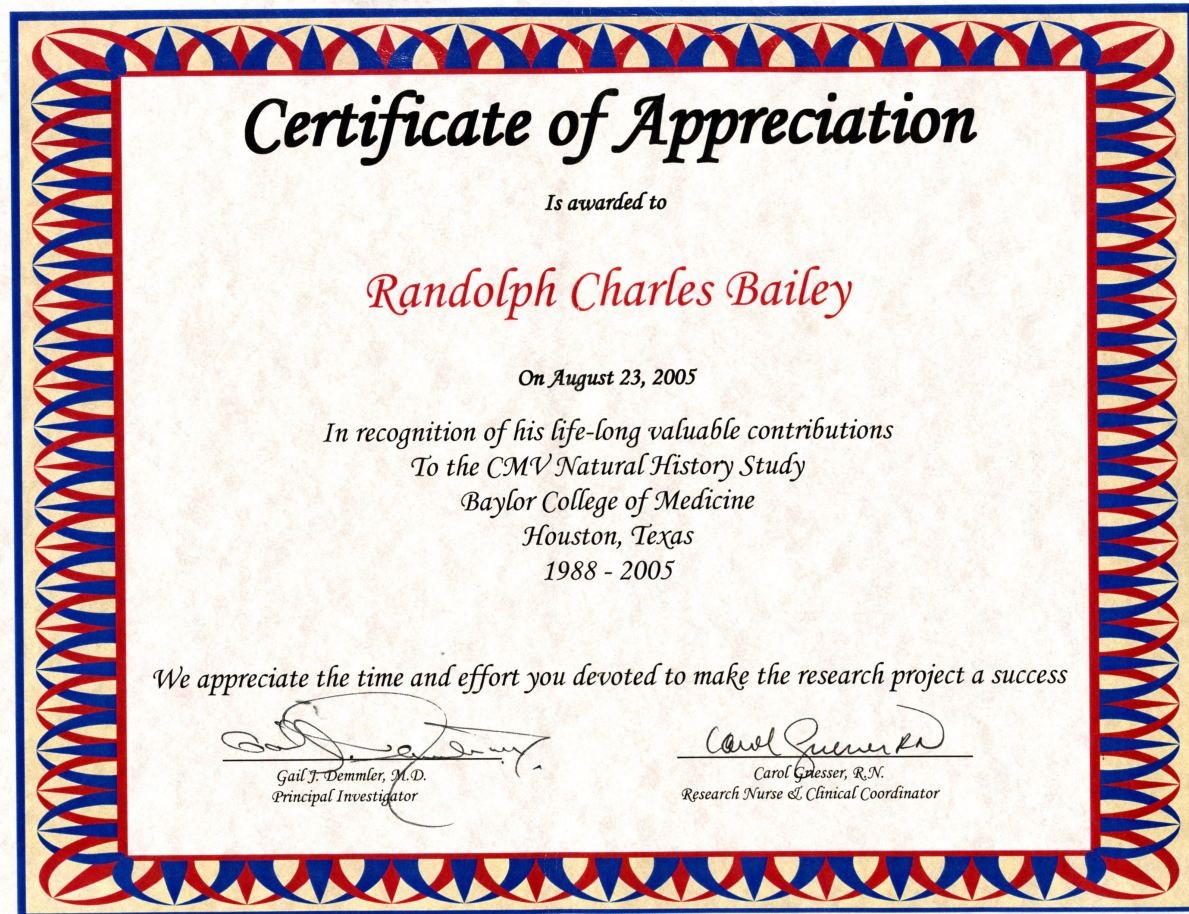
Caroline and Dr. Demmler sign "apple" during an enjoyable moment of reading together.

Research Follow-up Appointment

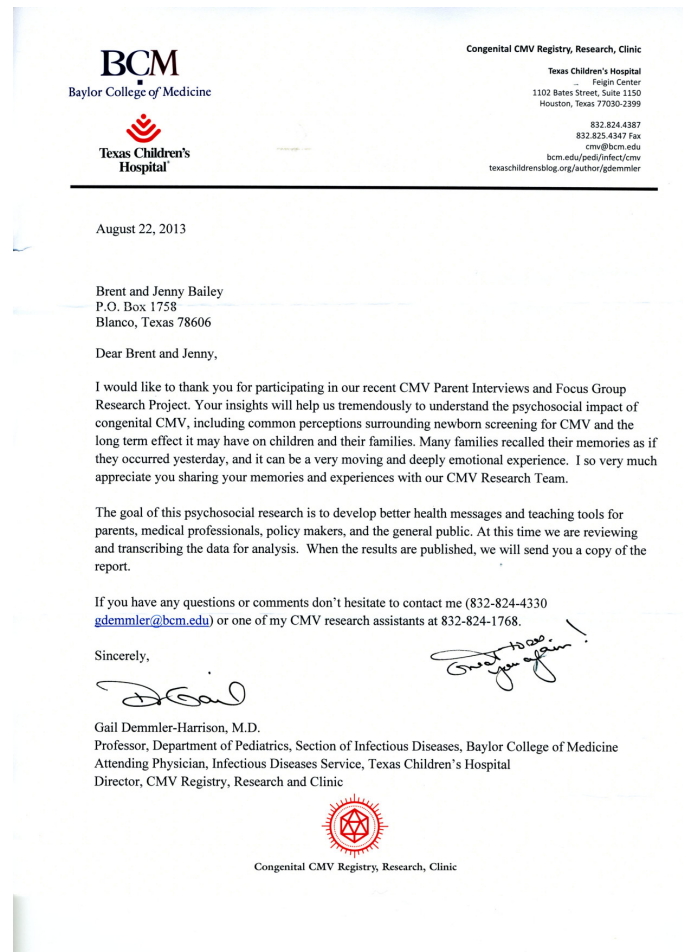
Photo courtesy Texas Children's Hospital, Houston, Texas.



Control Subject



Parent Subjects



Excellent Public School Teachers



Signing Flower Girl



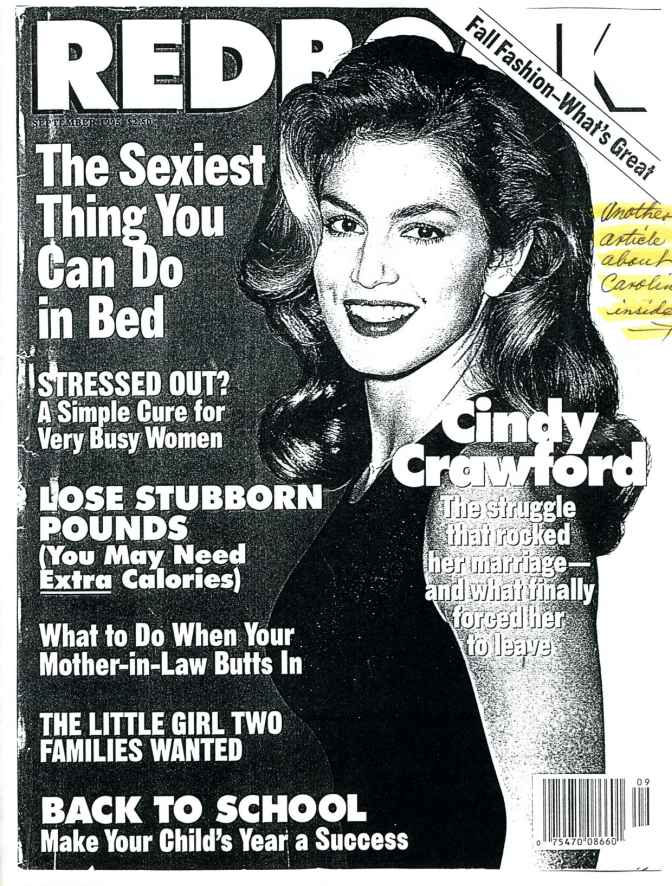
Spreading the Word About CMV and Ganciclovir

Watch image courtesy Texas Children's Hospital, Houston, Texas



1995: Our Story in *Redbook*

Image courtesy *Redbook*.



Cute, Cuddly and Contagious

Article courtesy Texas Children's Hospital. Houston, Texas.

Next Steps
{Toddlers}

ON THE WEB
Visit our Web site and search for siblings for more helpful tips.

Did you know?
Research on congenital CMV at Texas Children's Hospital has been going on for over 25 years. Dr. Gail Demmler and Carol Griesser, R.N., work closely with many Texas Children's physicians to follow more than 200 families in the world's only long-term longitudinal study on babies with congenital CMV. Dr. Demmler also founded The National Congenital CMV Registry, the only one of its kind, with the late Dr. Martha Yow. This national surveillance program tracks congenital CMV and provides a parent support network. To find out more, visit [www.bcm.edu/ped/infect/cmv](http://wwwbcm.edu/ped/infect/cmv) or call 832-824-4387.

Cute, Cuddly and Contagious

Toddlers are anything but silent, yet they are major carriers of a "silent virus" that unknowingly infects 40,000 newborns each year:

Caroline Bailey, a high school junior, has spent an exciting summer in New York City taking college prep courses at Barnard College. No one could have predicted such a bright future when she was diagnosed in utero with congenital cytomegalovirus (CMV) 16 years ago.

CMV, a virus that silently infects most people at some point, can feel like flu and be just as short-lived. It is found in bodily fluids and spreads through person-to-person contact, blood transfusions and organ transplantations—or from a pregnant woman to her unborn baby. Approximately 10 percent of CMV-infected infants have symptoms or abnormalities at birth.

CMV causes only minor illnesses in healthy children but can produce devastating, long-term effects in unborn children. Newborns born with symptoms of congenital CMV may suffer deafness, blindness, developmental and motor disabilities, and severe damage to the liver, kidney, spleen, lungs and bone marrow.

"We were told that Caroline would probably die, and if she lived, she'd have multiple severe, debilitating handicaps," says Jennifer Bailey, Caroline's mom.

When Caroline was born, she displayed numerous symptoms attributed to the disease, including skin lesions, an enlarged liver and spleen, fluid in her abdomen and bilateral nerve deafness. She immediately was referred to Dr. Gail J. Demmler of the Infectious Diseases Service, director of the Diagnostic Virology Laboratory at Texas Children's and professor of Pediatrics at Baylor College of Medicine.

After a careful evaluation, Caroline became the first newborn at Texas Children's to be treated by Dr. Demmler using a new antiviral drug, ganciclovir. Caroline responded immediately. All of her CMV-related problems receded, with the exception of profound deafness in both ears. Caroline's development since then has been healthy.

Vaccines to prevent CMV infection are in the research and development stage. Until a vaccine is available, pregnant women can take steps to reduce their chances of contracting the virus and control the spread of germs by toddlers, who are common carriers of the virus, in these ways:

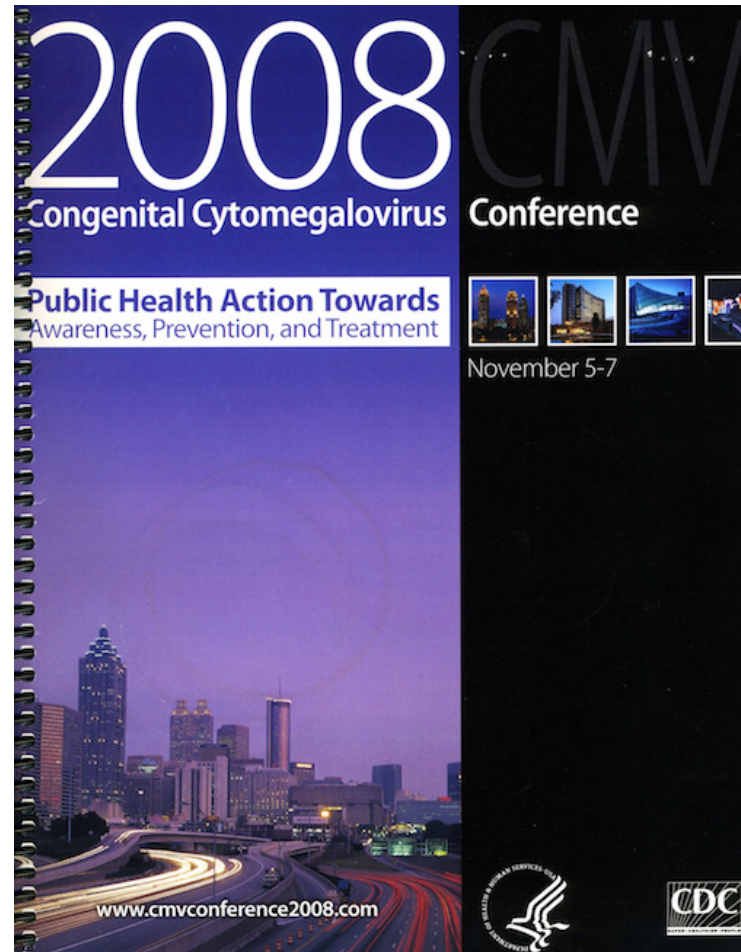
- Wash hands often—yours and your youngster's;
- Give young children a big hug or a kiss on top of the head instead of a kiss on the mouth or cheek;
- Avoid sharing food, drinks, utensils or toothbrushes; and
- Wash toys with soap and water, then rinse.

"Give young children a big hug or a kiss on top of the head instead of a kiss on the mouth or cheek."



Our Own Awareness Increases

Image courtesy Centers for Disease Control.



2013: Utah Capitol

Image courtesy <http://www.utah.com/culture/capitol.htm> .



2014: Maddie's Mission

The Armstrongs

Article and photo courtesy Chronicle. <http://www.houstonchronicle.com/news/health/article/Awareness-of-little-known-virus-is-goal-of-5281484.php>

Awareness of little-known virus is goal of 'Maddie's Mission'

By Kyrie O'Connor

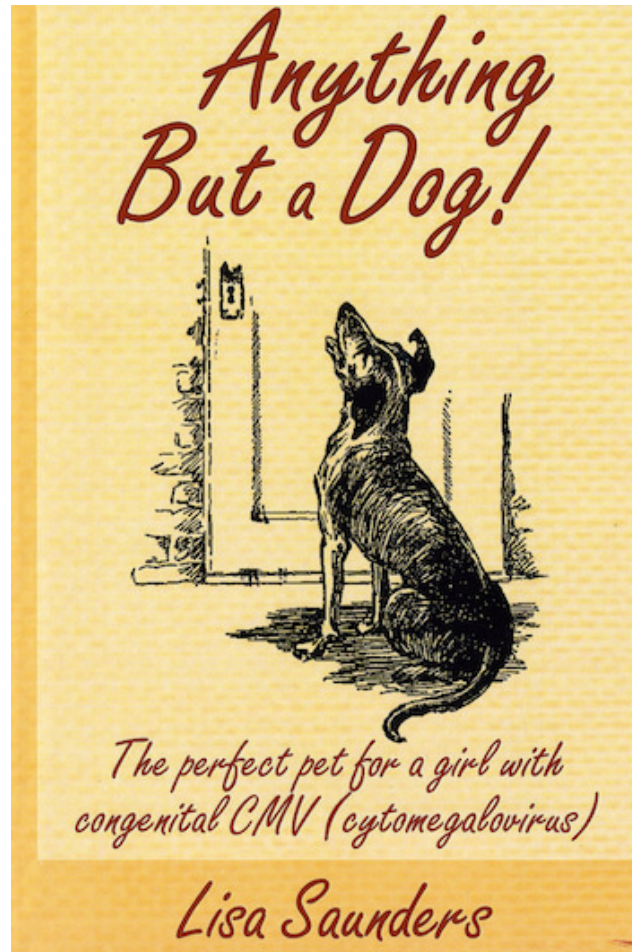
March 1, 2014

Farah Armstrong woke up, bustled around and got set for work. She readied her little blond 2-year-old, Sophie, for day care and drove to her obstetrician's office for her 8 a.m. appointment. It was Jan. 30, a day just like any other for a woman in the 38th week of a pregnancy that had been textbook perfect - the 20-week ultrasound had shown a robust little girl. Her due date was Valentine's Day.



2014: Connecticut

Image courtesy Lisa Saunders and the Baylor College of Medicine.



Death and Disability

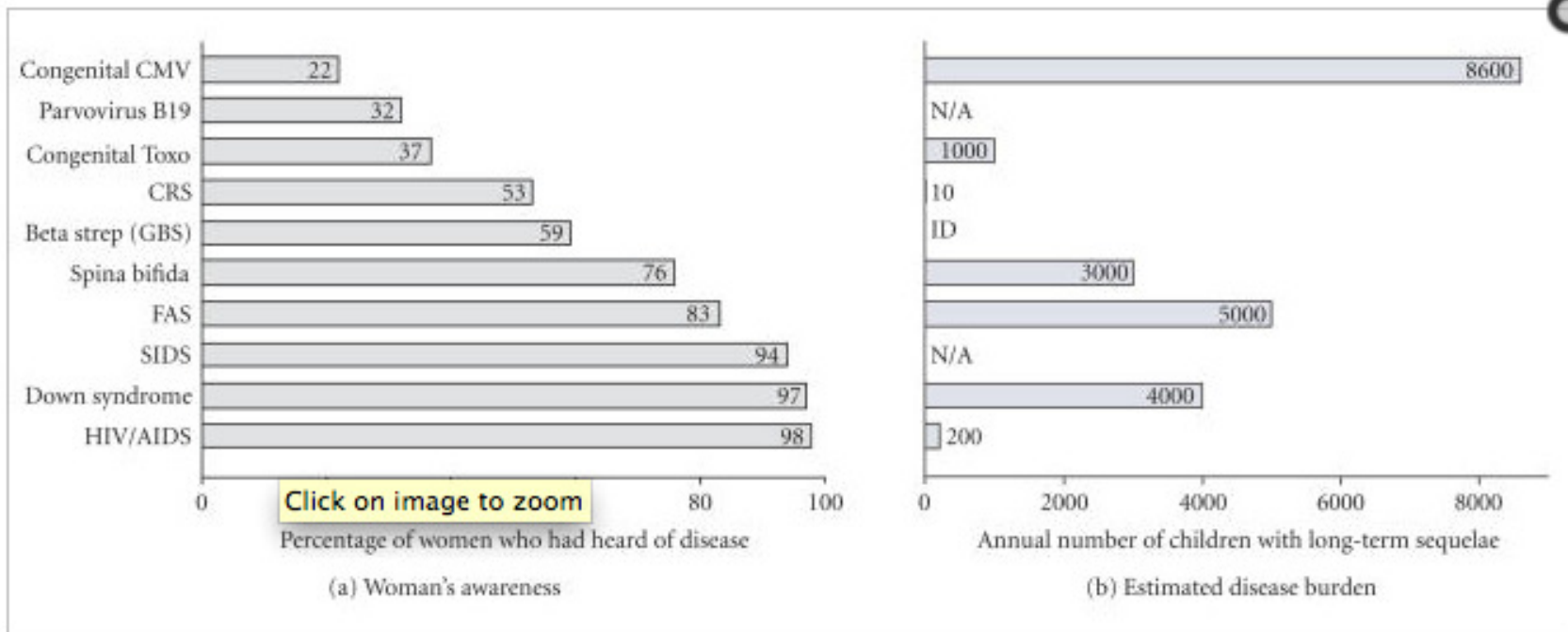
- 40 infants die and 800-1000 newborns are permanently disabled each year in Texas
- This is greater than the total number of newborns (600) diagnosed annually with all the core disorders on the Texas newborn screening panel combined.

H.R. Baer, *et al.* Survey of congenital cytomegalovirus (cCMV) knowledge among medical students. *J Clin Virol* 2014; 60: 222–242. Abstract accessible at <http://www.ncbi.nlm.nih.gov/pubmed/24794398> Last accessed 7/20/2014.

Texas Department of Health Services website. https://www.dshs.state.tx.us/newborn/faqs_nbs.shtm Last accessed 7/20/2014.

CMV: Disease Burden is High Awareness is Low

z Image Jeon, Jiyeon, *et al.* Knowledge and awareness of congenital cytomegalovirus among women. *Infect Dis in Obstet and Gynecol* 2006 80383. Accessible at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1779612/> Last accessed 7/20/2014.



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Capitol Complex Information

July 20, 2014 Launch: Letter to the Legislature

Re: Alleviate Human Suffering Caused by Congenital Cytomegalovirus Infection through Education and Newborn Screening

Hon. Senators and Representatives,

We are three moms with stories spanning a quarter-century, but with the same message:

Most people will contract cytomegalovirus (CMV) at some point in their lives. Many people experience no symptoms, never know they have been infected, and are unharmed by the virus. But, for the unborn, CMV can be devastating and even deadly:

Personal Stories Plus Reliable Data

- Congenital (present at birth) CMV is the most common congenital infection in the United States and causes death in an estimated 400 infants and permanent disabilities in 8000-10,000 newborns each year.¹
- This translates to 40 infant deaths and 800-1000 permanently disabled newborns each year in Texas, greater than the total number of newborns (600) diagnosed annually with all the core disorders on the Texas newborn screening panel combined.²
- Congenital CMV has a greater disease burden than does Down syndrome, spina bifida, sudden infant death syndrome, fetal alcohol syndrome, or congenital toxoplasmosis.³
- CMV is spread through contact with bodily fluids including saliva and urine. Simple hygienic precautions when carefully practiced by pregnant women reduce the number of congenital CMV infections.
- The Centers for Disease Control and Prevention (CDC) and the American College of Obstetricians and Gynecologists (ACOG) both recommend CMV counseling for pregnant women.⁴
- Less than half of obstetricians counsel their patients about CMV⁵, and only about one in five women are aware of CMV.
- Congenital CMV is treatable if diagnosed early. Antiviral drug therapy can aid normal brain development and help prevent hearing loss.⁶
- In 1999 the Institute of Medicine ranked the development of a CMV vaccine as a highest priority because of the lives it would save and the disabilities it would prevent, but CMV has eluded vaccine development efforts.⁷

The “Ask”

- **“Thousands of other CMV families have been telling their stories, too, but CMV awareness is still abysmally low. It is time for policy to increase prevention and increase early intervention when infection occurs.”**
- **“We are looking for authors and sponsors of a CMV education and universal newborn screening bill for the 84th Texas Legislative Session.”**

Happy Birthday Song Hand-washing and cCMV-safe XO!

- Sing the *Happy Birthday* song using “babies” as the name while washing your hands with soap and water. This lengthens the washing time
- Rather than kissing young children on the face, which is so natural for mothers, they should give their toddlers a cCMV-safe XO, a kiss on the top of the head and a big hug

July 28, 2014

Eight Days After Launch

Photo courtesy Farah Armstrong.



Change Behavior through Education

Image courtesy Texas Children's Hospital, Houston, Texas



Cute, Cuddly and Contagious

Image courtesy Texas Children's Hospital, Houston, Texas

**Cytomegalovirus (CMV) warning
for Pregnant Women: Danger!**



2013
ANNUAL REPORT

**Do not kiss this cute baby on
the mouth. Those saliva
bubbles may harbor CMV
which may cause birth defects
and death in the unborn.**



A Clear Message Thank You Utah!

<https://www.facebook.com/UtahCMVCouncil>



Texas Capitol, Here We Come!

