"How a Parent Can Raise a CMV Prevention Message"

by
Lisa Saunders
CMV mom, author and
parent representative of the Congenital CMV Foundation
Written September 15, 2014

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My CMV Story

- **Ran a licensed daycare center** in my home and had toddler of my own (many states STILL DON'T have CMV prevention in daycare licensing material).

- **Had miscarriage** on Christmas Eve of 1988—I was offered no blood test to help determine cause.

- **Pregnant three months later** and very happy. I had no idea what lay ahead…

Elizabeth Ann arrived on Dec. 18, 1989

- Her head was small, misshapen.
- She had difficulty breathing.
- Purple skin splotches on cheeks.
- Diagnosed with congenital CMV.
- We didn't tell her big sister Jackie for months that her little sister was born with a severely damaged brain.

As Elizabeth grew

- **Stayed developmentally at three months old**
- Profoundly mentally impaired
- Severe Cerebral Palsy
- Progressive hearing loss
- Cortically Blind
- Non-verbal
- Central and structural apnea
- Developed epilepsy
- Could only eat pureed food and wore diapers
- Surgeries: spinal fusion, hip reconstruction, hamstring lengthening

Despite all this, she was extremely happy and adorable -- to us anyway!

Big, formerly homeless dog keeps Elizabeth company

Elizabeth (at 15) and Jackie on N.J. boardwalk on last family vacation together

Elizabeth died during a seizure at 16

"I WILL DWELL IN THE HOUSE
OF THE LORD FOREVER"
PS 23:6

"THEN WILL THE LAME LEAP
LIKE A DEER AND THE MUTE
TONGUE SHOUT FOR JOY"
IS 35:6

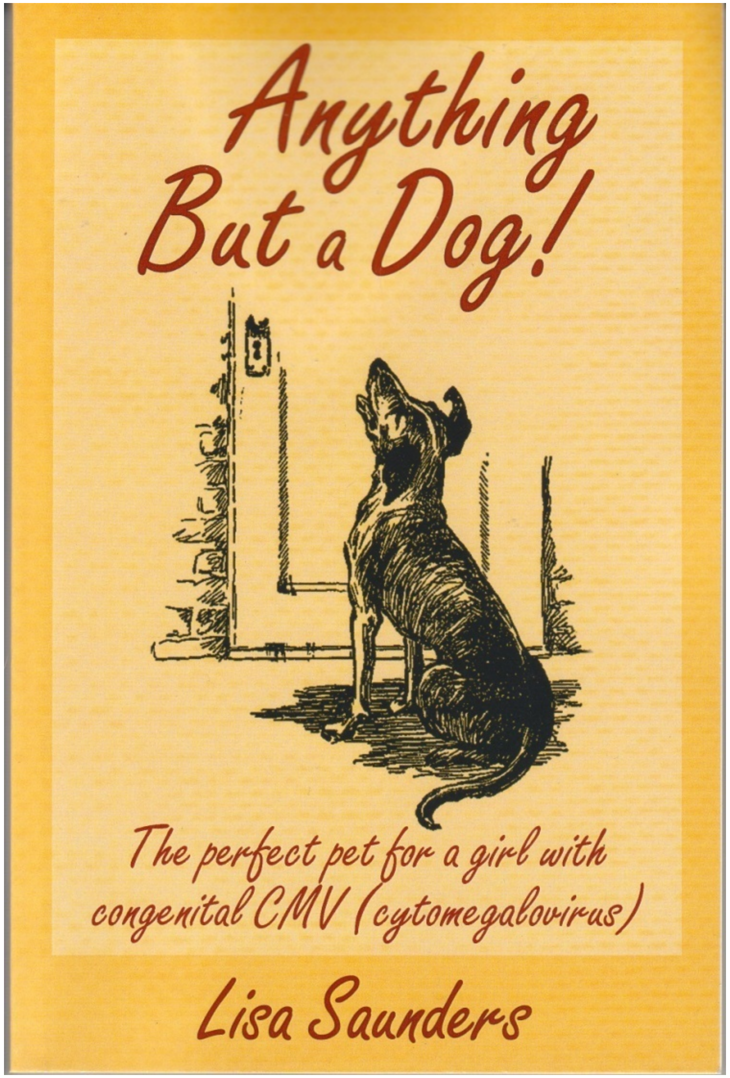
CMV Awareness Among Women

- After Elizabeth died in 2006, I began researching CMV awareness.
- Shocked only 22% had

heard of it.

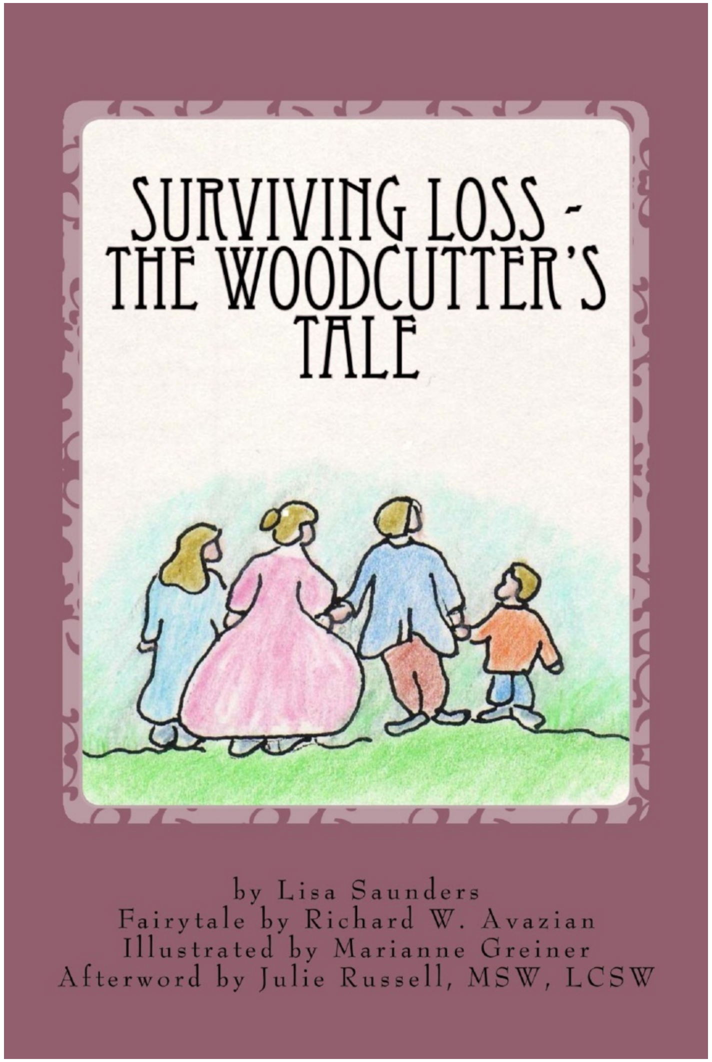
- I had a tormenting dream about

parents wondering why I didn’t do more to warn them about CMV



I wrote my memoir, *Anything But a Dog! The perfect pet for a girl with congenital CMV* , which includes interviews with CMV experts. I sent press releases and called magazines/ newspapers telling them about it and CMV prevention. Got some TV and newspaper coverage, but it wasn't enough to prompt doctors and health organizations to make CMV education mandatory.

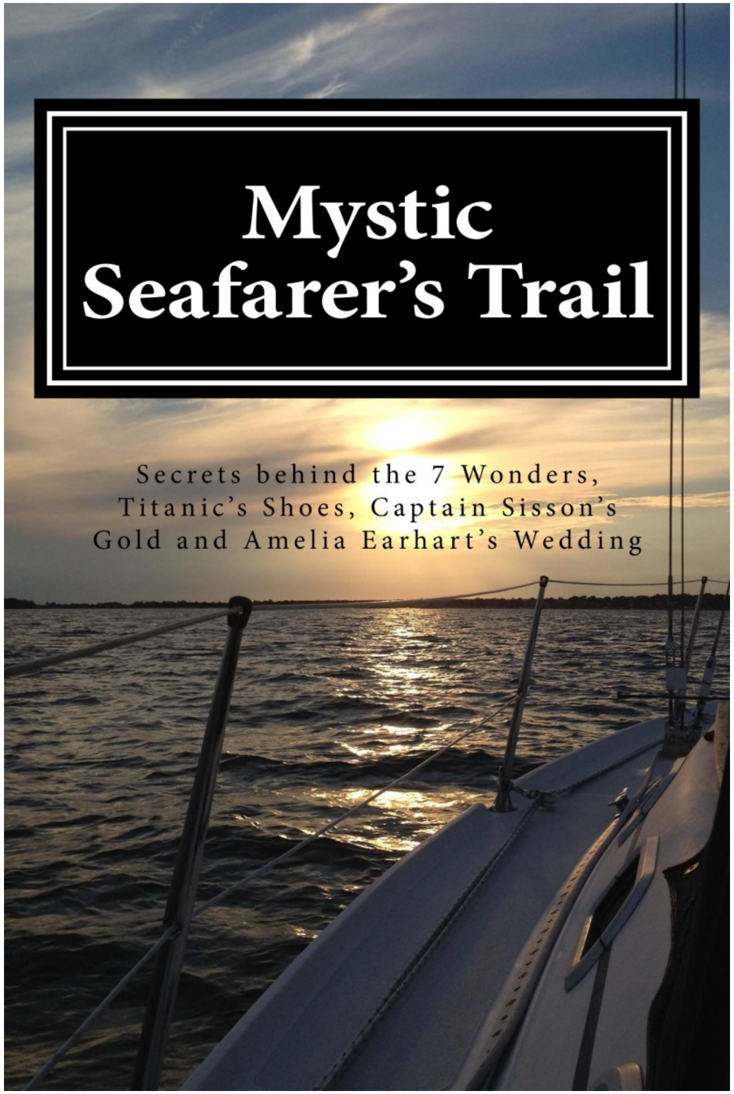
Surviving Loss: The Woodcutter's Tale. Available as a free e-book (& in softcover), this fairytale is about surviving the loss of a child and raises CMV awareness.



SURVIVING LOSS -
THE WOODCUTTER'S
TALE

by Lisa Saunders
Fairytale by Richard W. Avazian
Illustrated by Marianne Greiner
Afterword by Julie Russell, MSW, LCSW

Mystic Seafarer's Trail is my latest travel memoir where I try to get thin and famous like Amelia Earhart (who was secretly married near my home in Mystic). Eerhart used her fame to advance women's issues. I figured if I got famous, people would listen to my CMV prevention message (so I tried an epic voyage with a blind sailor). STILL NOT ENOUGH TO ENCOURAGE CMV EDUCATION FOR WOMEN OF CHILD-BEARING AGE.



What happened in Connecticut

- **Moved to Connecticut from New York in 2010. Started promoting CMV education in my new state when a grandmother contacted** me saying her daughter-in-law just gave birth to a child severely disabled by cCMV. She had interned in a Connecticut daycare center where there was no CMV prevention message. STILL, VERY FEW LISTENED TO ME.
- **Last year, it happened--I received a "Google Alert" that Utah passed a law making congenital CMV education mandatory.**
- I finally found a way to raise CMV prevention in a big way: Utah's bill—and CMV folks across the U.S.-- helped me launch campaign in Connecticut.
- **I asked Connecticut to replicate Utah's bill. This led to CT's *House Bill 5147*, which was unanimously passed by the Public Health Committee, then the House of Representatives--but the Senate did not bring it to a vote by the end of the session on May 7, 2014** (I was told probably because of funding issues--it was attached to a very costly testing of another disease). The CMV portion was estimated at $40,000 year for first year and $26,000 consecutive years for brochures, etc. (My daughter's public school education alone was $40,000/ year).
- Although crushed it didn't pass, many politicians thanked me for raising this issue. They also told me to get in touch just prior to the next session because they wanted to work even harder to see it pass.

How I—and you—can start the process in your state:

- **FIRST STEP:** Find out how to start the process of getting a CMV bill passed in your state. I started by visiting my Town Clerk, Betsy Moukawsher. (Town Clerks are voted into office so yours will be interested in helping you, plus they will be interested in the issue when you tell them about this low-cost way to prevent birth defects through education). Also, Town Clerks usually have friends and family in the Senate and House of Representatives. Tell everyone about the bill because you never know, they may have political connections.

- **Contact your local representative.** My Town Clerk told me who that was along with other representatives who care about health or children's issues. I could have found out who my representative was online, but she gave me my rep's home address (it's public record).

- **I went to my representative's house and dropped off a copy of Utah's bill, a page from Utah's health department showing how they are enforcing it, and gave her my book,** Anything But a Dog! The perfect pet for a girl with congenital CMV (you could send your representative your child's photograph or you can use my daughter's information).

- **I contacted several politicians,** particularly those interested in health and family. In the end, after a few conversations, it was my local representative who came through.

Sample letter asking your representative for bill similar to Utah’s.

Dear [Local representative},

I am your constituent [voter] and was wondering if you would introduce a bill similar to the one passed in Utah in 2013 to protect babies from the #1 birth defects virus, cytomegalovirus (CMV). It calls for educating women of childbearing age how to prevent contracting CMV, which causes more disabilities than Down syndrome. Congenital CMV is also the second leading cause of deafness after genetics. The bill also calls for testing a newborn for the virus if they fail a hearing test two times.

Less than half of OB/GYNs surveyed said they counseled their patients on how to prevent CMV infection despite these U.S. statistics from the CDC:

- Congenital CMV causes one child to become disabled every hour.
- About 1 in 150 children is born with congenital CMV infection each year (approximately 30,000).

According to an article co-authored by the CDC’s Dr. Cannon, “The direct annual economic costs of caring for these children are estimated at $1-2 billion…by missing prevention opportunities, we in the medical and public health communities are washing our hands of the congenital CMV disease epidemic.”

It has been estimated that the first year of educating the public will cost $40,000 the first year, then $26,000 each year after that. The cost of NOT educating the public about cytomegalovirus is much higher than spending the money on brochures and public service announcements. After my daughter Elizabeth died at age 16 from complications of congenital cytomegalovirus, I calculated that her special public school education--estimated at $40,000/per--plus spinal fusion, hip reconstruction and other surgeries came to $700,000. I have no way of estimating what all her additional therapy services and emergency room visits cost the state for 16 years.

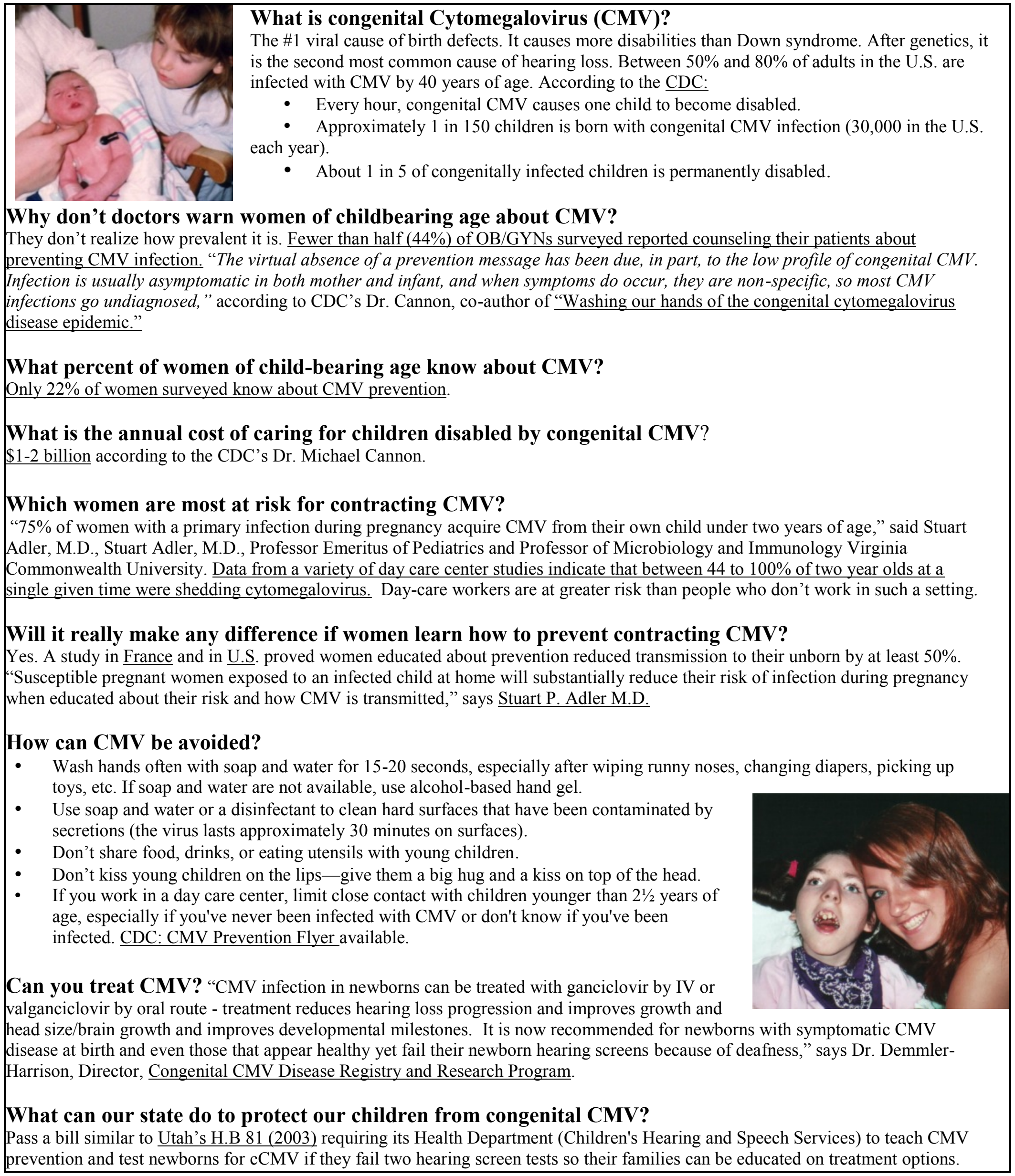
Utah passed a law making it mandatory for their Health Department to educate the public on how to prevent congenital CMV. The following is the link to the bill: http://le.utah.gov/~2013/bills/hbillenr/HB0081.pdf. The following is how Utah's Health Department (Children's Hearing and Speech Services) is abiding by the terms set forth in the bill: http://www.health.utah.gov/cshcn/CHSS/CMV.html

Thank you in advance for any guidance you can give me. Please see attached fact sheet.

This is what politicians and the media really want to know—(PREPARE SINGLE-PAGE CMV FACT SHEET OR USE MINE)

- What is Congenital CMV & how many children are disabled?
- Why don't doctors warn women of childbearing age how to prevent CMV?
- What is the annual cost of caring for children disabled by congenital cmv?
- What percent of women of child-bearing age know about CMV?
- Which women are most at risk for contracting CMV?
- How can CMV be avoided?
- Does it really make a difference if women learn how to prevent CMV? Won't they just catch it anyway from their toddlers?
- Can you treat congenital CMV?

Congenital CMV Fact Sheet (You may use my daughter's photo if you wish)



What is congenital Cytomegalovirus (CMV)?

The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. According to the CDC:

- Every hour, congenital CMV causes one child to become disabled.
- Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year).
- About 1 in 5 of congenitally infected children is permanently disabled.

Why don't doctors warn women of childbearing age about CMV?

They don't realize how prevalent it is. Fewer than half (44%) of OB/GYNs surveyed reported counseling their patients about preventing CMV infection. *"The virtual absence of a prevention message has been due, in part, to the low profile of congenital CMV. Infection is usually asymptomatic in both mother and infant, and when symptoms do occur, they are non-specific, so most CMV infections go undiagnosed,"* according to CDC's Dr. Cannon, co-author of "Washing our hands of the congenital cytomegalovirus disease epidemic."

What percent of women of child-bearing age know about CMV?

Only 22% of women surveyed know about CMV prevention.

What is the annual cost of caring for children disabled by congenital CMV?

$1-2 billion according to the CDC's Dr. Michael Cannon.

Which women are most at risk for contracting CMV?

"75% of women with a primary infection during pregnancy acquire CMV from their own child under two years of age," said Stuart Adler, M.D., Stuart Adler, M.D., Professor Emeritus of Pediatrics and Professor of Microbiology and Immunology Virginia Commonwealth University. Data from a variety of day care center studies indicate that between 44 to 100% of two year olds at a single given time were shedding cytomegalovirus. Day-care workers are at greater risk than people who don't work in such a setting.

Will it really make any difference if women learn how to prevent contracting CMV?

Yes. A study in France and in U.S. proved women educated about prevention reduced transmission to their unborn by at least 50%. "Susceptible pregnant women exposed to an infected child at home will substantially reduce their risk of infection during pregnancy when educated about their risk and how CMV is transmitted," says Stuart P. Adler M.D.

How can CMV be avoided?

- Wash hands often with soap and water for 15-20 seconds, especially after wiping runny noses, changing diapers, picking up toys, etc. If soap and water are not available, use alcohol-based hand gel.
- Use soap and water or a disinfectant to clean hard surfaces that have been contaminated by secretions (the virus lasts approximately 30 minutes on surfaces).
- Don't share food, drinks, or eating utensils with young children.
- Don't kiss young children on the lips—give them a big hug and a kiss on top of the head.
- If you work in a day care center, limit close contact with children younger than 2½ years of age, especially if you've never been infected with CMV or don't know if you've been infected. CDC: CMV Prevention Flyer available.

Can you treat CMV? "CMV infection in newborns can be treated with ganciclovir by IV or valganciclovir by oral route - treatment reduces hearing loss progression and improves growth and head size/brain growth and improves developmental milestones. It is now recommended for newborns with symptomatic CMV disease at birth and even those that appear healthy yet fail their newborn hearing screens because of deafness," says Dr. Demmler-Harrison, Director, Congenital CMV Disease Registry and Research Program.

What can our state do to protect our children from congenital CMV?

Pass a bill similar to Utah's H.B 81 (2003) requiring its Health Department (Children's Hearing and Speech Services) to teach CMV prevention and test newborns for cCMV if they fail two hearing screen tests so their families can be educated on treatment options.

If you use photos of my daughters, if possible, please include photo info: Elizabeth Saunders and her big sister from memoir: *Anything But A Dog!: The Perfect Pet For A Girl With Congenital CMV (Cytomegalovirus)*

Helpful Articles/Flyers to link to as Backup Info.

- **CDC CMV prevention brochure:** http://congenitalcmv.org/CDCbrochure.pdf
- Article, **"Washing our hands of the congenital cytomegalovirus disease epidemic,"** co-written by CDC's Dr. Cannon. Article states: "The virtual absence of a prevention message has been due, in part, to the low profile of congenital CMV. Infection is usually asymptomatic in both mother and infant, and when symptoms do occur, they are non-specific, so most CMV infections go undiagnosed.": See: ttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1182379
- **"Knowledge and Practices of Obstetricians and Gynecologists Regarding Cytomegalovirus Infection During Pregnancy** --- United States, 2007": www.cdc.gov/mmwr/preview/mmwrhtml/mm5703a2.htm
- **Article quoting OB/GYN why CMV prevention isn't discussed** in Fit Pregnancy Magazine, June/July 2008 issue: "The list of things we're supposed to talk about during women's first visit could easily take two hours and scare them to death." From Protect Your Baby From A Tot-Borne Virus or visit: www.fitpregnancy.com/yourbaby/babycare/40723077.html?subsection=baby_health_development
- **"Knowledge and Awareness of Congenital Cytomegalovirus Among Women,"** 2006 PubMed Central article, http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1779612
- A study in done in France concluded that a prevention message reduces the chances of a pregnant women passing this debilitating virus onto her unborn by 50%. See: http://www.journalofclinicalvirology.com/article/S1386-6532(09)00419-3/abstract
- A study done in the U.S. showing effectiveness of teaching CMV prevention: **Prevention of child-to-mother transmission of cytomegalovirus among pregnant women.** See: http://www.ncbi.nlm.nih.gov/pubmed/15480372
- Study: **Group day care and cytomegaloviral infections of mothers and children:** http://www.ncbi.nlm.nih.gov/pubmed/3018892

Next Steps

- **Tell your representative you are prepared to publicly testify** (everyone is allowed to testify) when the bill comes to the floor (or that you can send your relative/close friend to testify). Ask your representative to send you a copy of their letter to the Public Health Committee asking them to propose the bill. Tell them that Connecticut estimated the first year's cost to be only $40,000 for brochures, etc. Each year thereafter was estimated to cost $26,000. Tell them the approximate costs (or services) your state is paying to help you care for your child.
- **Contact your state's** EHDI (Early Hearing Detection & Intervention) Coordinators and tell them what you are doing and ask for their help and advice. Ask them to put you in touch with your state's EHDI Chapter Champion (who will be a doctor). cCMV is a major cause of hearing loss so they are very interested in getting this bill passed.
- **Learn online specifically how a bill become law in your state** (in CT: www.cga.ct.gov/html/bill.pdf). I WAS SHOCKED THAT IT HAD TO BE VOTED ON THREE TIMES. 1: Public Health Committee; 2: House; 3: Senate.
- **Contact your local media and tell them you are trying to get a CMV education law passed.** My story was covered in a local woman's magazine. I sent the article to my representative. She thanked me for the reminder, and, because the timing was right, she immediately sent in a letter to the co-chair of the Public Health Committee stating what I wanted and why, and she gave the co-chair a copy of Utah's bill.

Step 1: WHAT TO DO WHILE YOU WAIT

- **Find doctors and parents in your state** who care about CMV. Ask them to contact their reps asking for this bill. Ask your friends throughout the state to contact their reps with a copy of Utah's bill. One of the reps is bound to follow through!
- **To find doctors in your state**, contact your state's EHDI (Early Hearing Detection & Intervention) Coordinators and ask them to put you in touch with your state's EHDI Chapter Champion. See also states with contact info in the study: "A Randomized Trial to Prevent Congenital Cytomegalovirus (CMV)." Contact **Dr. Demmler-Harrison** of the National Congenital CMV Disease Registry.
- **Find cCMV parents in your state through Facebook and join forces with cCMV non-profits such as:**
  - National Congenital CMV Disease Registry
  - Stop CMV - The CMV Action Network
  - Utah CMV Council
  - Brendan B Mcginnis Congenital CMV Foundation
  - CMV Help/ Buck Buck Foundation
  - Congenital CMV Foundation
  - Guiding Guardians CMV Family Advocacy Foundation
  - Maddie's Mission

Gather Politician/Media e-mail addresses

POLITICIANS

- **Visit your state's government website site to figure out the e-mail address** of everyone on the Public Health Committee and all of the rest of the House and Senate for the entire state—it takes a lot of digging because they would rather you used those time-consuming contact forms.
- Having direct e-mail addresses saves you and your supporters time—you will need to make it easy on everyone if you ask then to write to their representatives.
- When in doubt of an e-mail address, government emails usually follow a formula.

MEDIA—prepare contact list for you state

- Other than the media you are familiar with, find other Newspapers/Magazines at: http://www.usnpl.com/ or *http://www.50states.com/news/#.U6mS9cJOVkg*
- *Radio: Radio-locator.com*
- Call your state's Associated Press ph. # as they don't give emails.

Step 2: WHAT TO DO WHILE YOU WAIT

- **Contact organizations that would WANT the CMV bill passed** (such as pharmaceutical companies or hand sanitizing/soap manufacturers). They may have a government relations employee willing to give you advice.
- **Call your representative's aide.** They are very helpful and will give you a lot of advice on the best way to proceed. If possible, go to their office at your capitol so you can get to know them in person. In regard to networking, in person is best; calls, second best; e-mails are OK and will become necessary.
- **Once your rep sends in the letter** to the public health committee, it can be heard and voted on with very little warning. I only found out because my state's EHDI (Early Hearing Detection & Intervention) coordinator, who I was in touch with, told me (so please get in touch with your EHDI coordinator!).
- **Prepare your "Letter of Testimony"** for when the bill will be heard by the Public Health Committee. (It will be similar to the letter you gave your representative). Your state will probably have its own guideline, but here is what Connecticut states to do to prepare: http://www.cga.ct.gov/asp/content/yourvoice.asp. **CT only gives three minutes** to present public testimony, so it will take time to get your wording right (I would also mention medical professionals in your state who are in support of the bill in your Letter of Testimony).

Excerpt of My Letter of Testimony

Representative Johnson, Senator Gerratana and distinguished members of the Public Health Committee:

I am Lisa Saunders of Mystic, Connecticut, parent representative of the Congenital CMV Foundation, and author of *Anything But a Dog! The perfect pet for a girl with congenital cytomegalovirus.**

I am in support of H.B. No. 5147, “*AN ACT CONCERNING NEWBORN SCREENING FOR GLOBOID CELL LEUKODYSTROPHY AND CYTOMEGALOVIRUS AND ESTABLISHING A PUBLIC EDUCATION PROGRAM FOR CYTOMEGALOVIRUS.”*

I am a parent who didn't know how to prevent congenital cytomegalovirus (CMV) until it was too late for our daughter Elizabeth. The moment she was born in 1989, my first thought was, “Her head looks so small—so deformed.”

My doctor told us, "If your daughter lives, she will never roll over, sit up, or feed herself." Elizabeth's birth defects were caused by congenital CMV. I was given literature stating women who work in daycare, or have a young child in daycare, are at higher risk for catching it as preschoolers are the majority of carriers. Mothers must wash their hands after handling toys and should not kiss their toddlers around the mouth.

Why hadn’t my OB/GYNs warned me about this—especially since, according to the CDC, congenital CMV causes more disabilities than Down syndrome? While I was pregnant with Elizabeth I had a toddler plus ran a licensed daycare center. Nowhere in the licensing literature was there a CMV prevention message. In milder cases, children may lose hearing or struggle with learning. But Elizabeth's case was not a mild one…

Continue Your Own cCMV Work With Health Department

- **Your state does not need a law to educate the public about congenital CMV.** While you are waiting for the bill to be heard and/or passed, ask your health department to follow the intention of Utah's law. See how Utah's Children's Hearing and Speech Services is implementing the intentions of the law. You can find your state's similar department at: http://www.infanthearing.org/status/cnhs.php.

Contact the following groups. Offer yourself as a speaker or tell them you would be willing to send information. These groups care:

- Nursing organizations
- Women's Groups
- Mother Groups
- Clubs you belong to (Daughters of the American Revolution members wrote their representatives and asked me to speak to their other clubs about CMV).

Utah CMV Council Will Help You

Message from **Sara Doutre,** co-founder of the Utah CMV Council: “While having the backing of the law and the State Department of Health is doing wonderful things for CMV in Utah, there will always be a need for more public education. Things take a long time to trickle down from the top. The Utah CMV Council works bottom-up to raise awareness and promote prevention of CMV in conjunction with the Utah Department of Health. We participate in health fairs, distribute materials developed by the Department of Health, and share our stories to make CMV personal in Utah. We also want to empower CMV family and friends to do the same in their states and share our experiences broadly.”

https://www.facebook.com/UtahCMVCouncil

http://www.utahcmvcouncil.org/

Sara Doutre, co-founder of the Utah CMV Council, is mom to Daisy, who has congenital CMV, and daughter to Representative Ronda Menlove, the woman responsible for leading Utah to passing and enacting the first CMV awareness and testing legislation in the United States in 2013. Sara is a former special education teacher, US Dept of Education employee, and has a Masters degree in education policy studies. Sara is currently a private special education and early intervention policy consultant and has worked in states across the country. In addition to being a parent-member of the team responsible for passing and implementing the Utah CMV law, Sara had unique behind-the-scenes access to her legislator and the work required in getting legislation passed. Sara Menlove Doutre, President and Education Policy Consultant at Doutre, sara@doutreconsulting.com

Other Contacts

Ronda Menlove, Utah House of Representatives and Senior Vice Provost, Utah State University. Grandmother of Daisy affected by congenital cytomegalovirus: ronda.menlove@usu.edu

Stephanie Browning McVicar, Au.D., CCC-A, DOCTOR OF AUDIOLOGY (worked tirelessly to pass the Utah bill), Specialty Services Program Manager, State EHDI Director, State of Utah Department of Health, Children with Special Healthcare Needs, Children's Hearing and Speech Services, (801) 584-8218, smcvicar@utah.gov

When you learn the cCMV bill will be heard by Public Health Committee

- **You may only have a few days** to make plans to attend the hearing. Call your representative's aide and tell them you plan to testify. Ask for advice.

- **Contact all your supporters and ask them to send in a letter of testimony** in support of the bill. Your state's website will tell you where to send these. They will get posted on the website and the Public Health Committee will read them, or at least a summary of them. I was surprised they also published backup material.

- **Contact the media** to let them this bill is being heard and why it's important.

Excerpt of "Letter of Testimony" for your friends to send in:

Dear Representative or Senator,

I write this letter to show my support of HB 5147 (or whatever your bill is called) to increase awareness of congenital CMV (Cytomegalovirus).

You may not currently have a pregnant daughter, daughter-in-law, niece, granddaughter, neighbor, or friend, but chances are you will at some point in your lifetime. No mother should have to find out after giving birth that they had passed a preventable virus to their baby before birth.

According to the CDC, this heartbreak is experienced every hour . You have the ability to help mothers of unborn babies to be educated about congenital CMV so that they can avoid this devastation. By passing HB 5147, Connecticut is setting an important precedent for every other state in this country (Utah is the only other state to pass a similar bill). The only way for change to occur is one step at a time, and I believe this is an extremely important step for CMV awareness.

Congenital CMV is a preventable virus and women should be properly educated about the simple hygiene precautions they can take while pregnant. Medical studies have proven that following three simple hygiene precautions can reduce the chance of catching the virus by 50%...

Letters of Testimony in Support of CT's cCMV Bill (there were 85)

Sample letters to help you get started:

- 02/28/2014 Sara Doutre
- 02/28/2014 Gail Demmler, MD
- 02/28/2014 Janelle Greenlee, President and Founder, Stop CMV
- 02/28/2014 Farah, Armstrong
- 02/28/2014 Stuart Adler, Emeritus Professor of Pediatrics and Chairman, Division of Infectious Disease
- 02/28/2014 Jenny Meeden Bailey
- 02/28/2014 Eugene Shapiro, M.D., Professor of Pediatrics, Epidermiology and Investigative Medicine, Yale University
- Here is my "Letter of Testimony": 02/28/2014 Lisa Saunders, Parent Representative, Congenital CMV Foundation

The day I testified in Hartford

- **I was the only one** because the other CMV mom's child was ill.
- **I read my three-minute** prepared statement.
- **Politicians were talking to each other** and eating their lunch—the rest of the room was noisy too. As I read, the audience gradually fell silent.
- When finished, the co-chair of the committee said they were sorry for my loss and **announced to the committee that 100 people wrote in letters of testimony** (even though many were from out of the state).
- **It was there I met Connecticut's Early Hearing Detection & Intervention (EHDI) American Academy of Pediatrics (AAP) Chapter Champion,** who came to watch: Dr. Brenda Balch of Mystic. Although it was too short notice for her to prepare to testify, she became a huge voice with politicians. She also appeared on T.V. three times with me to discuss congenital CMV and the importance of testing an infant for CMV after two failed hearing tests. Dr. Balch says, "I am looking forward to the day when the residents of Connecticut not only understand what CMV is, but also how to prevent the spread of CMV to those most vulnerable." **(Her involvement was a huge relief to me because I no longer had to feature all the facets of cCMV and the bill--that's where a doctor's help comes in. In regard to a parent's testimony, politicians can't argue about what our lack of CMV education did to our baby. To find out who your state's EHDI AAP Chapter Champion is, visit the AAP.org site).**

While waiting for Public Health Committee to vote

- **Write to everyone on the Public Health Committee**. Call their aides, tell them about the CMV bill and ask if their politician needs anymore information. Ask them to tell the women in their lives about cCMV.
- **Ask your friends and family living in your state to write everyone** on the Public Health Committee. Give them sample letter and emails.
- **Ask your local community access TV station** if they have any hosts who might be interested in interviewing you. Tell them you will bring your own flashdrive and upload the file they give you to Youtube in case they don't do it.
- **Write letters to the editor of your state's magazines or newspapers** (can only be 200 words). People read those.
- Contact the media.

CONTACT THE MEDIA ABOUT THE PROPOSED BILL

- **Call, e-mail or send them a press release giving them the basic facts** about the proposed bill plus the links to the bill and CDC's webpage about cCMV.
- **Include a few sentences of your story** and offer medical professionals they can contact for a quote (list names at the end of your press release, which is marked by a ###).
- Specific examples of cCMV press releases I sent can be found on my website www.authorlisasaunders.com

Sample Press Release:

Mom Asks Connecticut to Become Second State to Stop #1 Birth Defects Virus

House Bill 5147 includes Cytomegalovirus (CMV) Public Education Program

Mystic, Conn.— Lisa Saunders of Mystic didn't know how to prevent contracting CMV (cytomegalovirus), which causes more disabilities than Down syndrome, until it was too late for her daughter Elizabeth born with a severely damaged brain.

On March 25, Connecticut's Public Health Committee voted in favor of **House Bill 5147**, which includes a cytomegalovirus (CMV) public education program. At present, **Utah is the only state** that requires their Public Health Department to provide CMV education (Utah's law went into effect in July 2013).

Saunders, the parent representative of the **Congenital CMV Foundation**, is now asking legislators to make Connecticut the second state in the Union to prevent the leading viral cause of birth defects by passing **HB 5147**. Congenital CMV can be prevented if women of childbearing age learn the precautions to take, which includes refraining from kissing their toddlers around the mouth…

Sample letter excerpt to politicians after I testified:

Dear [House/Senate member]

I am Lisa Saunders of Mystic, Conn., and came to testify in favor of HB 5147, in particular cytomegalovirus (CMV) education, on Feb. 28 (my daughter suffered and died because I didn't know how to protect her from it when I ran a licensed daycare center). A similar bill was passed in Utah last summer. Connecticut women still don't know the precautions to take in a **daycare center as Connecticut** doesn't require those working--or seeking a license--in daycare to be educated on that matter.

CMV is the #1 birth defects virus and causes more disabilities than Down syndrome, yet most women aren't educated in how to prevent it. **Less than half of OB/GYNs surveyed** said they counseled their patients on how to prevent CMV infection, despite these U.S. statistics from the CDC:

•Congenital CMV causes one child to become disabled every hour.

•About 1 in 150 children is born with congenital CMV infection each year (approximately 30,000).

According to an article co-authored by the CDC's Dr. Cannon, "**The direct annual economic costs of caring for these children are estimated at $1-2 billion…**" After my daughter Elizabeth died at age 16 from complications of congenital cytomegalovirus, I calculated that her special public school education--estimated at $40,000/per year--plus spinal fusion, hip reconstruction and other surgeries came to $700,000. I have no way of estimating what all her additional therapy services and emergency room visits cost the state for 16 years.

As time wore on, several representatives jumped on the proposed bill as co-sponsors:

Co-sponsors of HB-5147

Rep. Emmett D. Riley, 46th Dist.
Rep. Michelle L. Cook, 65th Dist.
Rep. Kevin Ryan, 139th Dist.
Rep. Elissa T. Wright, 41st Dist.
Rep. Peter A. Tercyak, 26th Dist.
Rep. Mitch Bolinsky, 106th Dist.
Rep. Noreen S. Kokoruda, 101st Dist.
Rep. Rosa C. Rebimbas, 70th Dist.
Rep. Hilda E. Santiago, 84th Dist.
Rep. Gerald M. Fox, 146th Dist.
Rep. Michael L. Molgano, 144th Dist.

Prepare interview questions a TV host/reporter can ask you:

Give the interviewer the cCMV Fact Sheet plus questions such as:

1. Knowing what you do now, what would you do differently before becoming pregnant and during pregnancy? I would have a blood test to determine if I had an active infection or if I had immunity to the disease from a prior infection. If I had an active infection, I would wait for a doctor to clear me before getting pregnant. If I had never had it before, I would not work with young children in daycare and I would be careful not to kiss my toddler around the mouth or share food with her. I wish I had not first heard of CMV *after* the birth of my child.

2. Everyone has heard not to change the kitty litter when pregnant. Is CMV the disease you can catch from that? No, that disease is **toxoplasmosis.** The prevalence of congenital toxoplasmosis is estimated to be between 1 of 12,000 live births [based on Massachusetts newborn screening data-the only state or one of the few states that screens for toxoplasmosis at birth] to as high as 5 per 1,000 births in the U.S. It is MUCH LESS frequent than congenital CMV infection and congenital CMV disease.

3. Can you treat congenital CMV? "CMV infection in newborns can be treated with ganciclovir by IV or valganciclovir by oral route - treatment reduces hearing loss progression and improves growth and head size/brain growth and improves developmental milestones. It is now recommended for newborns with symptomatic CMV disease at birth and even those that appear healthy yet fail their newborn hearing screens b/c deafness. Valganciclovir is recommended by CMV experts for symptomatic newborns now, it is well tolerated, with side effects of low blood counts in 20% that is monitored for, and is covered by most insurance plans and Medicaid now. CMV infections in other patient with immune dysfunction can be treated as well," according to Dr. Demmler-Harrison.

Medical professionals who may be willing to be quoted:

- **Gail J Demmler-Harrison** MD, Professor, Pediatrics, Section Infectious Diseases, Baylor College of Medicine, Attending Physician, Infectious Diseases Service, Texas Children's Hospital, Director of Congenital CMV Disease Registry and Research Program. Contact: 832-824-4330, gjdemmle@texaschildrens.org. The CMV Registry supports CMV research, disseminates information and provides a parent support group.
- **Lenore Pereira**, Ph.D., Founder of Congenital CMV Foundation and Professor, Cell and Tissue Biology Department, University of California San Francisco. The Congenital CMV Foundation raises awareness about maternal testing for first infection during pregnancy, newborn testing and the need to develop a vaccine. lenore.pereira@ucsf.edu, or visit www.congenitalcmv.org.
- **Stuart Adler, M.D.,** Professor of Pediatrics, Microbiology and Medicine and Director of Infectious Diseases at the Children's Medical Center, Virginia Commonwealth University Medical Center. Dr. Adler has specialized in CMV infections among women and children for over 28 years and has published extensively on this topic. sadler@vcu.edu
- **Michael Cannon, Ph.D.** mrc7@cdc.gov, is a research epidemiologist at the Centers for Disease Control, Atlanta, Georgia. Dr. Cannon is particularly interested in developing strategies to prevent congenital CMV infection through public awareness and education.

Contact politicians again…

- **If you get news coverage, write to the Public Health Committee (or House or Senate depending on what stage the bill is being voted on)** and tell them the proposed bill was featured in the news. Send them the link to it or snail mail/drop off the newspaper/magazine article.
- **Visit political offices** if possible and leave cCMV fact sheets
- **Write thank you emails** every time the bill is voted "YES," Some politicians became so engrossed in the passing of this bill, they contacted me the morning after it failed to get voted on by the Senate. When my representative called, she tried to comfort me as I cried! She reminded me that a lot was accomplished already in regard to education. She said if reelected, she would try again next year.
- **REMEMBER: No matter what happens in your state** during the voting session, your efforts will educate a lot of people. If you are grateful along the way, politicians will want to see this passed the following year because it the right thing to do.

Quote from my representative about Connecticut's 2014 Proposed CMV bill—after the Senate failed to vote on it:

"It was my pleasure to co-sponsor and successfully advocate for legislation in Connecticut this year designed to increase public awareness of cytomegalovirus, or CMV, a virus that can cause brain damage, deafness, and other birth defects when women inadvertently transmit the virus to their unborn child during pregnancy.

"The legislation, which also required screening for CMV in newborns who fail already required hearing tests, was a very good bill in the best interest of children and families.

"Although our bill passed unanimously in the House of Representatives, it failed to make it through the State Senate. Mounting this effort and the legislative process itself, however, helped educate women and healthcare providers about the virus and the impact that it can have on unborn babies whose mothers become infected during pregnancy.

"I thank Lisa Saunders, whose daughter suffered from CMV and died at age 16, for sharing her story with me. I look forward to the opportunity of working with her, and other advocates, on future legislation to address the potential dangers during pregnancy of this otherwise common, usually harmless virus."

– Elissa Wright, State Representative, 41st Assembly District

I offered this quote to my representative for her re-election campaign (this will give cCMV even more visibility as it will go in every mailbox in her district!):

"Elissa listened to me. She learned about the #1 viral cause of birth defects, cytomegalovirus (CMV), which debilitated my daughter. Elissa proposed legislation for prevention education including certain precautions necessary around toddlers. I trust her to continue to fight for the health of our children."

– Lisa Saunders, Mystic, parent representative of the Congenital CMV Foundation

Samples of my CMV coverage

- Fox CT Dr & Mom
- Dr. Balch, Saunders, Barry on Health Watch
- Mystic River Press
- Grace Magazine features Elizabeth & cCMV
- Lisa on USA 9 News
- Hartford Courant
- Lisa's Youtube PowerPoint Presentation
- **What every pregnant woman needs to know**
- CMV memoir--Anything But a Dog! The perfect pet for a girl with congenital CMV
- Lisa's PowerPoint on congenital CMV (you may use the slides if you like).

In Summary: How a Parent Can Raise a CMV Prevention Message

1. Parents Have a Valuable Voice
2. What to Say to State Representatives
3. What to Say to the Media

As a result of the State of Utah passing a bill requiring congenital cytomegalovirus (CMV) education and testing of newborns who fail the hearing screen twice, parents now have a template to follow in their own states to raise congenital CMV awareness among women of childbearing age. This presentation describes how to find one's local representative, what to ask for, which cCMV facts to present, and how to write and submit press releases to get media attention to move politicians to pass a bill similar to Utah's. Other important ways to raise awareness is through "Letters to the Editor“ and offering oneself as a speaker. A state's Early Hearing Detection & Intervention (EHDI) American Academy of Pediatrics (AAP) Chapter Champion can be a major help in this process. "Parents can inspire doctors, media and politicians to work together to save future children from the suffering caused by congenital CMV," says Lisa Saunders, parent representative of the Congenital CMV Foundation and author of a book, "Anything But a Dog! The perfect pet for a girl with congenital CMV." She coordinates the blog, congenitalcmv.blogspot.com, which specializes in reaching the general public with news about cCMV and how they can help raise awareness.

Summary Steps

- Learn CMV facts: http://www.cdc.gov/cmv/index.html (site has CMV prevention e-cards to send family.)
- CDC CMV prevention brochure: http://congenitalcmv.org/CDCbrochure.pdf
- Tell state representatives, family and friends about congenital CMV and Utah's law to prevent it.
- The blog, http://congenitalcmv.blogspot.com, and cCMV non-profits have all types of flyers for posting.
- Write to magazine/newspaper editors asking them to feature cCMV.
- Write to producers about you willingness to speak on T.V. about congenital CMV.

About Lisa Saunders

Lisa Saunders is the mother of Elizabeth, born with congenital CMV in 1989. Elizabeth died during a seizure at the age 16 in 2006.

Lisa is the parent representative of the Congenital CMV Foundation and author of the memoir, Anything But a Dog! The perfect pet for a girl with congenital CMV. She also published a tender fairy tale written by her father after Elizabeth died in *Surviving Loss: The Woodcutter's Tale* .

Lisa lives with her husband in Mystic, Connecticut, and works as a freelance writer, publicist, and TV talk show host. Contact her at LisaSaunders42@gmail.com, 845-222-8593, or visit www.authorlisasaunders.com