My CMV Story

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Who Am I?

-I had suffered congenital CMV infection.
-My condition was diagnosed very early following birth.
-I was treated daily during infancy and frequently during my childhood.
-Because of this support, I overcame many obstacles.

My interest in CMV started when we were asked to write a paper for an English class about anything we wanted.

- -I was in my freshmen English class at Gallaudet University.
- -I am now a junior majoring in Communications and Government (double degree).
- -For the paper, I researched books, online and performed two required interviews.

My CMV paper

- -To gain insight into CMV biology and disease, I interviewed Dr. Anamaris M. Colberg-Poley (CMV virologist) and Dr. Roberta DeBiasi (Pediatric Infectious Disease Physician) at Children’s National Health System in Washington, DC.

For the paper, I wanted to know

- What are the symptoms?
- Am I still contagious?
- Who can get CMV?
- Could it affect my sex partner?
- Is it a genetic disease?

- Once I decided which questions to ask, I spoke with Drs. Colberg-Poley and DeBiasi.

What I learned

- -CMV is the leading viral cause of congenital birth defects in the US.
- -CMV does not draw the public awareness that it should.
- -The way I was infected during my mother’s pregnancy.
- -CMV is commonly detected in urine of young children, who can infect seronegative mothers during pregnancy.
- -I am no longer producing infectious CMV so sexual transmission is a minimal concern unless I become immunosuppressed.
- -I was stunned to learn that there is no effective CMV vaccine to prevent CMV disease in children.

What?? …no effective CMV vaccine yet?

How was I affected by CMV?

- -I don’t know all the effects of CMV infection on me because it was a closed record adoption.
- -I was very tiny and had to stay in the hospital for a month.
- -I had:
  - -weak muscles
  - -a cyst in my brain
  - -an enlarged liver
  - -yellow jaundice
  - -hearing loss
- -My birth parents made the decision to put me up for adoption.

How I was treated

- -Because my legs were affected, my doctors treated me with casts, braces, and finally hip surgery to improve my self-mobility. I used to fall often and had to use a wheelchair and crutches following the surgery.
- -I took physical therapy during school hours to help my muscles get strong.
- -Now I can walk without assistance.
- -When I was in third grade, I got my hearing aid to improve my hearing.

Emotional effects of growing up with CMV disease

- -Because of my size and appearance, I was always picked on.
- -At first in elementary school, I felt isolated.
- -In middle and high school years, I felt more accepted.
- -Emotional as well as medical support is crucial to enable the child to develop well given the circumstances.
- -My parents always told me to follow my dreams and helped me to do so.

Overcoming CMV Disease

- My parents and health providers gave me:
- -a safe home
- -excellent medical care
- -emotional support
- -and the motivation to keep me trying

- -I was never told no, my parents let me do anything that I wanted.

- -This made me realize that I could wish for greater things.

Beating the Odds

- -I am currently a junior at Gallaudet University.
- -Planning to graduate with two degrees in May 2016
- -I have made the Dean's List for 4 semesters in a row.
- -I am an intern at the US Capitol.
- -I work for a Louisiana State Senator.
- -I work on Gallaudet News crew.

My future is looking bright

- -A condensed version of my freshmen English paper got published in *Viruses*: Recent CMV Research (Dufrene et al., 2014)!
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- -For community outreach and medical education, I will be speaking with first year GWU medical students in December as part of their Medical Microbiology classes.

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Preface

Preface of the Special Issue: "Recent CMV Research"

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Printed Edition of the Special Issue Published in *Viruses*

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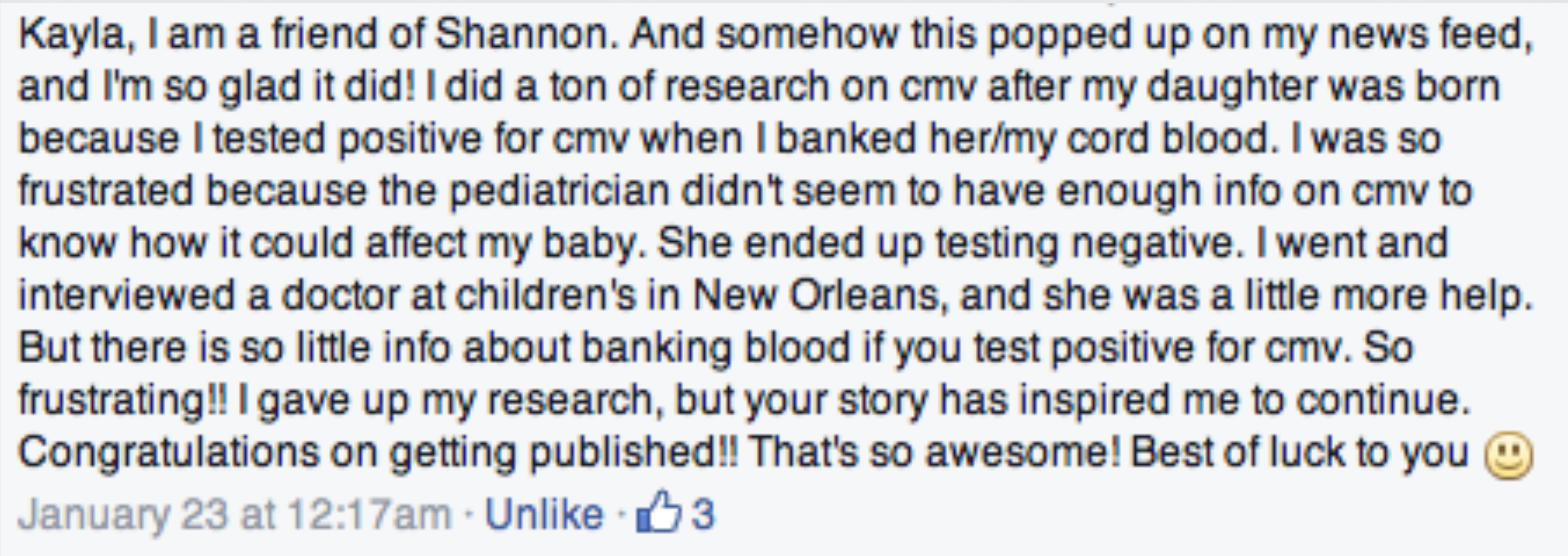
The **Viruses: Recent CMV Research** is in print by MDPI publisher.

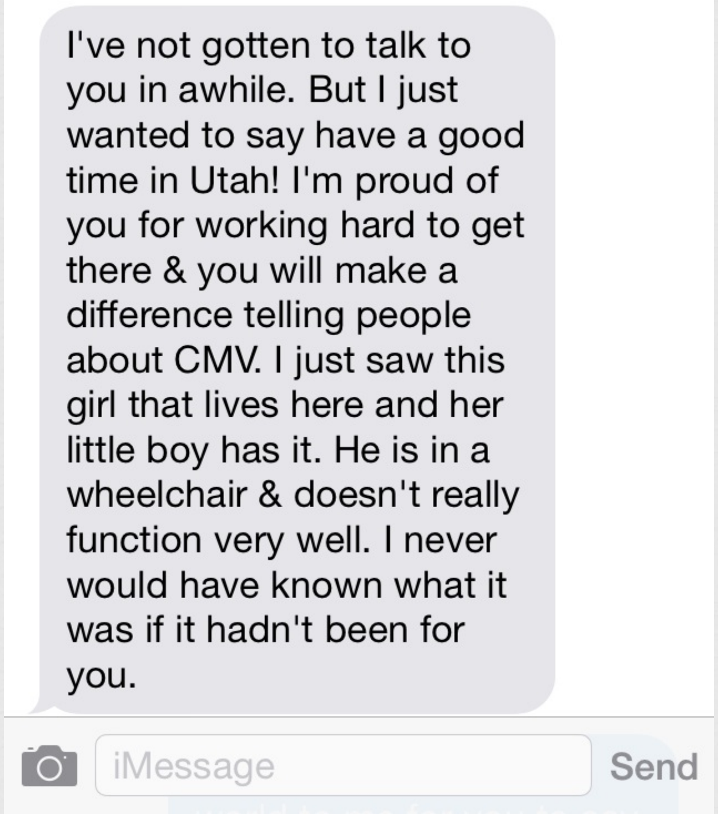
The CMV book provides articles of interest to (i) those affected by CMV disease (parents, caregivers, physicians) (ii) CMV investigators and (iii) virologists and cell biologists.

For more information: http://www.mdpi.com/journal/viruses/special_issues/recent_cmv_research



Kayla, I am a friend of Shannon. And somehow this popped up on my news feed, and I'm so glad it did! I did a ton of research on cmv after my daughter was born because I tested positive for cmv when I banked her/my cord blood. I was so frustrated because the pediatrician didn't seem to have enough info on cmv to know how it could affect my baby. She ended up testing negative. I went and interviewed a doctor at children's in New Orleans, and she was a little more help. But there is so little info about banking blood if you test positive for cmv. So frustrating!! I gave up my research, but your story has inspired me to continue. Congratulations on getting published!! That's so awesome! Best of luck to you 🙂

January 23 at 12:17am · Unlike · 👍 3


I've not gotten to talk to you in awhile. But I just wanted to say have a good time in Utah! I'm proud of you for working hard to get there & you will make a difference telling people about CMV. I just saw this girl that lives here and her little boy has it. He is in a wheelchair & doesn't really function very well. I never would have known what it was if it hadn't been for you.

I encourage:

-Parents, caregivers, nurses and doctors know that more CMV infected children can (given the right treatment and support) overcome many of the conditions caused by congenital CMV infection.
-Don't to give up on children congenitally infected with CMV, they need you and your dedication.

-For CMV investigators, press on to find better treatments for CMV disease and more effective CMV vaccines.

Special thanks to my parents, caregivers, nurses, and physicians who improved the quality of my life and helped me strive for greater goals!