



CMV UPDATES

Winter 2014

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IN THIS ISSUE



'Tis the Season to Make Changes



congenitally infected newborns have silent CMV infections, these children have consequences of their congenital infection, including progressive sensorineural hearing loss that can occur in 10 to 20 percent of births.

Make this holiday one of joy and change, don't let another year go by without spreading CMV awareness.



As the year winds down and the holidays arrive, we are grateful for the support we continue to receive year after year from supporters like yourself. For that reason we would like to say thank you and send you and your loved ones warm wishes this holiday season!

After years of hard work the CMV Team and devoted CMV advocates we are getting closer to changing the way cytomegalovirus is viewed by medical professionals, politicians and the community. The fight against congenital CMV is not over, the number of infected newborns remains high. In the United States alone one out of every 100 to 150 babies are born congenitally infected and of these 10 to 15 percent have symptoms as a fetus or newborn. The remaining

USA CMV INITIATIVE UPDATE

Thank you to everyone who participated and shared letters and heartfelt stories with congress for the CMV initiative in Utah and Connecticut, H.B. No. 5147 and H.B. 81. Illinois was another state who fought to create new CMV laws with the H.B. number 4199.

Even though H.B. 5147 and H.B. 4199 did not go into law we will continue to advocate for more CMV awareness.

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CMV Updates is produced by the National Congenital CMV Disease Registry Research and Clinic at Baylor College of Medicine and Texas Children's Hospital. The newsletter is written to provide a medium for information, discussion, and exchange of ideas for parents of children with congenital CMV.

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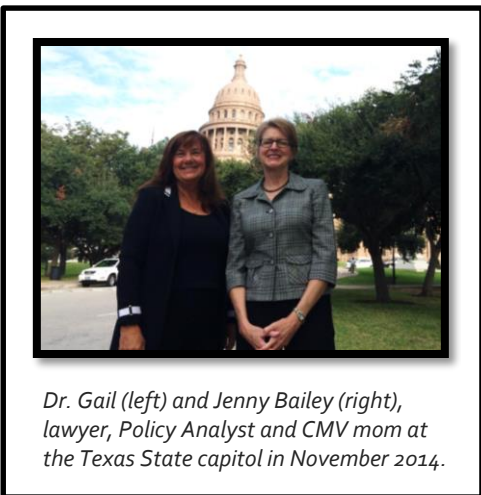
Let's Make Texas CMV Aware!

The state of Texas will soon be joining Utah, Connecticut and Illinois on the fight against congenital CMV. The CMV Texas Team and active supporters are in the early stages of introducing a CMV bill to provide education to pregnant mothers, healthcare professionals, providers and testing and screening newborns for congenital CMV.

to share their CMV stories and speak about the statistics of contracting congenital CMV disease in utero.

Help us make a difference by reaching out to your senators, representatives and share your CMV story. Don't forget the many lives this disease has impacted. It is time to make a change and help prevent another innocent baby from this silent killer.

Three Texas moms (Jenny Bailey, Farah Armstrong and Sandra Salerno) reached out to



Dr. Gail (left) and Jenny Bailey (right), lawyer, Policy Analyst and CMV mom at the Texas State capitol in November 2014.

Donating Smiles

In January 2013 we received a generous donation from Our Savior Lutheran Church and School in Grafton, Wisconsin. The staff, students and their families collaborated together to donate two large boxes filled with stuffed animals to the CMV Research Clinic in memory of Braydon Matter who lost his battle against CMV in 2012 and Jackson Radant who suffers from a congenital heart defect.

The toys were meant to bring a smile to the children suffering from congenital illnesses and to impress upon the students in Grafton, Wisconsin to help others in need as well as to teach them the meaning of noble acts.

Since we received the toy donations the CMV Clinic has provided services to many children including 45 of whom were confirmed as having congenital CMV and therefore received a stuffed animal.

All 45 children received follow-ups regularly with Dr. Demmler Harrison in the CMV Clinic at Texas Children's Hospital. A collage was created of the children who received a toy and was presented this past September at the CMV Public Health Conference held in Salt Lake City, Utah.

The families and staff of Our Savior Lutheran Church and School brought many smiles to the children that received a toy.

Once again thank you to the families and staff of Our Savior Lutheran Church and School for your kind donation and support.



Dr. Gail shows the toy collage at the September CMV Conference in Utah.



(L-R) Dr. Gail, Nick Mater, Holly McBride & Kendra Matter at the 2012 Fourth Congenital CMV Conference, San Francisco, CA.

5th Congenital CMV Conference

Location: Brisbane Convention and Exhibition Center, Brisbane, Australia

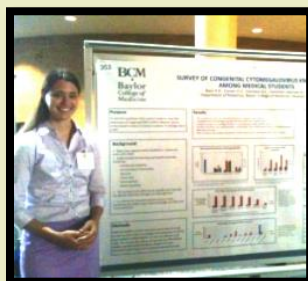
Date: April 20-24, 2015

Website:

<http://conference.qimberghofer.edu.au/>



Dr. Gail presenting her award winning CMV TCH BLOG at the CMV Public Health and Policy Conference in Utah, September 2014.



Dr. Hannah and Dr. Gail (not shown) at the Baylor College of Medicine's 2013 Academy of Distinguished Educator's, Annual Showcase of Educational Scholarship in 2013.



(L-R) Dr. Caviness, Nurse Griesser, Dr. Gail and Dr. Noyola at the 2012 Fourth Congenital CMV Conference in San Francisco, CA.

32 years of CMV Research

CONGENITAL CMV RESEARCH

To this day the Houston Congenital CMV Longitudinal Study cohort is one of the longest studies available. The study screened 32,000 newborns for CMV from 1982 to 1992. Newborns found to have CMV in their urine, and therefore found to be congenitally infected with CMV, whether or not they had symptoms at birth, were invited to enroll in a multidisciplinary study. The study was focused on the long-term effects congenital cytomegalovirus has on growth, neurodevelopment, hearing and vision.

OBSERVATIONS AND FINDINGS

The common prevalence of CMV in congenitally infected newborns in Houston was 0.4 to 0.8 percent per year screened. Fifteen percent of the asymptomatic newborns tested experienced a progressive and permanent sensorineural hearing loss during childhood. Of these, 80 percent experienced unilateral hearing loss and 20 percent progressed to bilateral hearing loss. The findings also have indicated that children with symptoms at birth from a congenital CMV infection are at much higher risk of disorders of growth, development, hearing and vision problems.

Details of results of the decades of research have been presented at scientific meetings and are in preparation for publication.

Would you like to donate to CMV Research?

We would like to give our sincere thanks to everyone who have donated to the congenital CMV Research Fund and CMV awareness over the many years. You are the reason why CMV research and CMV Updates is a possibility. Listed below are 2014 donors who have made contributions to the CMV Research Fund.

Thank you for your support!

We are also thankful for our CMV contributors through the decades: Children’s Hospital National Institutes of Health NIH – MOI RR 001-88-33; Mental Retardation Research Center at Baylor College of Medicine National Institutes of Health NIH – CHHD5—P30 HD 24064; Research to Prevent Blindness, Inc. New York, NY;

Deafness Foundation, Houston, TX; Vale Ashe Foundation, Houston, TX; Centers for Disease Control (CDC); Cooperative Agreement FOA IP 10-006, CDC Contract number 009280120/8454RU92, CDC Contract Number 0009184031/ 8403R491, CDC P3S Contract Arrangement; APS-SPR Summer Student Research Program by National Institutes of Health (NIH); Texas Children’s Hospital Clinical Research Center, as well as the donations of the time and talents of the numerous volunteers and professional colleagues in the BCM and TCH Departments of ENT/Audiology, Developmental Pediatrics, Ophthalmology; and the dedication of the “CMV Kids” and their families and physicians.

RESEARCH FUND DONORS 2013-2014			
Alan J. Bert	Ellen Kirchberger	Mary K. Zitzelberger	Richard Tate
Amanda Dawson	Hidden Fields Condo Owners Association	Microsoft Matching Gift Points	Robert & Barbara Norsworthy
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Craig K. Martin	Kayla Hancock	Our Savior Lutheran Church and School	
Donna Orozco	Lisa D. Slaughter	Pricilla Mata	
Edward S. Summers	Martin & Kay Den Braber	Richard & Darlene Rogers	

ATTENTION MEMBERS!!

We need your help to keep the parent registry up to date. Please give us an update of your child and update your member information.

CONTACT US:

E-mail: cmv@bcm.edu
 Phone: (832)824-4387
 Website: www.bcm.edu/pediatrics/cmregistry/

MAKE A DONATION

Online: <https://connect.bcm.edu/cm>
Mail:
 Congenital CMV Disease Research, Clinic & Registry
 Feigin Center, Suite 1150
 1102 Bates St.
 Houston, Texas 77030

SAVE A BABY TODAY FAMILY FUN RUN/WALK



SAVE A BABY TODAY 5K | 10K
 First Annual 5K | 10K competitive run
 Family fun run | walk
MARCH 7, 2015 | KATY, TX
 Benefitting Baylor CMV Research

Cytomegalovirus (CMV) is the least known but most common viral cause of permanent disabilities in newborns. Learn how to protect unborn babies from this PREVENTABLE virus.

For details and updates visit us at: www.maddiesmission.org

REGISTER:

<http://www.maddiesmission.org/>

SAVE THE DATE: MARCH 7, 2015



(L-R) Sandra, Lillian & Farah register participants for Maddie's Fun Run.

Fun Run For Bryson

Ashley Galaviz became an active promoter of CMV awareness after the loss of her baby boy Bryson. Bryson Charles Bryant lost his battle against congenital CMV at 3 months of age. To honor her baby boy Ashley organized a 5K Fun Run on July 13, 2013. All proceeds were donated to our Congenital CMV Disease Research program in Houston, Texas.



Ashley's story does not end there, soon after the race she enlisted in the US military and has been serving our country ever since. Thank you Ashley!



Parent To Parent Support Network

This year we welcomed several new members to our CMV community. We have a total of 656 registered members; 572 in the US and 84 reside internationally.

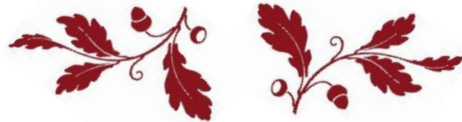
We are happy that families in the network from all over the globe continue to provide support to new members by regularly updating their contact information and the new resources available to parents and their families in surrounding areas.

The goal of the parent network is to create an updated database that links families who have been affected by CMV.

This is a safe place to provide support to others by sharing concerns, feelings, advice and other useful information.

If you are the a parent of a child who has CMV and would like to help a family affected by CMV, please call, write or E-mail us.

Share your CMV story with us and remember that you are not alone, together we can beat CMV!



DONATE TO CHANGE LIVES

Make a tax-deductible donation to support CMV research, CMV Clinic and CMV Registry programs at Baylor College of Medicine and Texas Children's Hospital.

DONATE ONLINE:
<https://connect.bcm.edu/cmvr>

DONATE BY MAIL:
 Congenital CMV Disease Research, Clinic & Registry
 Feigin Center, Suite 1150
 1102 Bates St.
 Houston, Texas 77030

TOTAL PARENT-TO-PARENT FAMILIES WHO RESIDE IN THE US: 572



PARENT-TO-PARENT FAMILIES WHO RESIDE OUTSIDE THE US

Arab Emirates	1	Canada	21	France	5	Italy	1	Nicaragua	1	Scotland	1
Australia	8	Chile	2	Indonesia	1	Japan	1	The Netherlands	2	Slovenia	1
Belgium	2	El Salvador	1	Ireland	3	Kenya	1	Portugal	2	South Africa	1
Cambodia	1	England	17	Israel	4	Mexico	2	Scotland	1	Spain	4



**Congenital CMV Disease Research, Clinic & Registry
Feigin Center
Texas Children's Hospital
1102 Bates St., Suite 1150
Houston, Texas 77030**



Texas Children's Hospital



**CMV UPDATES, NEWSLETTER SUBSCRIPTION
AND PARENT SUPPORT NETWORK
INFORMATION MAILING ADDRESS CHANGE**

I would like to be added to the **CMV Updates E-mail list**.

E-mail: _____

I would like to be added or have an address change (check one) to the **CMV postal address list**.

Name: _____

Address: _____

Switch us from the CMV postal address list to the email list.

Name: _____

Address: _____

Please add to the CMV Updates emailing list.

I would like to receive information about the **Parent-to-Parent Support Network**.

CMV RESEARCH DONATION

Enclosed is my \$ _____ donation to continue research on congenital CMV disease and infection. Please make check payable to the "CMV Research Fund," which is affiliated with Baylor College of Medicine and Texas Children's Hospital, Houston, Texas. All donations are tax deductible.

Donation in honor of: _____

Name: _____

Address: _____

Phone: _____

Email: _____

I would like to receive information about the **Parent-to-Parent Support Network**.

Detach and mail this form to:

Congenital CMV Disease Research, Clinic & Registry · Texas Children's Hospital · Feigin Center, Suite 1150 · 1102 Bates Street · Houston, Texas 77030-2399
Telephone: 832-824-4387 · E-mail: CMV@bcm.tmc.edu