



CMV UPDATES

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

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New CMV law in the state of Texas!



Group photos from left to right: Photo from the Texas CMV Dream Team and supporters at the State Capital in Austin, Texas. Photo of the Texas CMV Dream Team with Senator Lois Kolkhorst (R), author of SB 791, outside of Senate Committee Chambers. Photo of the CMV Dream Team with Representative Myra Crowover and Representative Dr. John Zerwas, House Sponsor of HB 2174.

The tireless efforts of supporters like Jenny Bailey, Farah Armstrong, Sandra Salerno, Peyton Stephens, the Houston CMV Research Team and others who continue to advocate for CMV awareness were instrumental to passing the new CMV law in the state of Texas.

In June, a revised version of one of two proposed bills (SB 791 & HB 2174) passed Texas legislation with bipartisan support and was amended into law. The bill was sponsored by Senator Lois Kolkhorst (R), co-sponsored by Senators Judith Zaffirini (D) and Carlos Uresti (D). The bill also received support from Representative John Zerwas, MD who sponsored the bill in the House of Representatives.

September 1st, 2015 was the effective date for Senate Bill 791 also known as the Madeline Leigh

Armstrong Act. The new law has two main parts that focus on public awareness and education of CMV. SB 791 directs the Health and Human Services Commission to develop a public education program to inform on CMV to expecting mothers, women of childbearing age and healthcare providers about CMV, the transmission of CMV, symptoms, preventative measures and the methods of diagnosis available to individuals.

You can view the bill archived proceedings. The files include bill stages, bill text and the committee hearing video. Please visit the archive pages of the Texas Legislature Online website at:

<https://legiscan.com/TX/bill/SB791/2015>

Congenital CMV Awareness Map



Map shows five US states, in blue, that approved CMV legislations between 2013 and 2015.

Spread CMV awareness!

In the United States 5 states have CMV laws in place. The first state was Utah with HB 81, effective 2013. Subsequently, Connecticut (HB 5525), Hawaii (HB 792), Texas (SB 791) and Illinois (HB 184) followed in 2015.

The five CMV laws share a common goal to direct state officials to provide individuals with public education programs, congenital CMV infection information, preventative measures as well as



Enstin Ye is a fourth year medical student at the University of Texas at Houston Medical School. Enstin is a CMV awareness supporter and has educated others about congenital CMV.

methods of diagnosis. Some states like Utah and Connecticut have included targeted testing for CMV in newborns with congenital hearing loss.

The congenital CMV registry turns 25!

The National Congenital CMV Registry turned 25 years old this 2015!

The registry started as a voluntary pilot surveillance system in early 1990. After 48 reported cases were identified the first year from 19 participating centers, the pilot was expanded to include all center in the US and Canada. The registry included clinical information obtained at the time of birth or near the time of birth of babies with symptomatic congenital CMV infections.

The goal was to characterize trends overtime, to identify risk groups, and to pave the way for evaluation of future intervention programs. To this day, the information from the registry has helped define congenital CMV disease.

After 25 years, we continue to see congenital CMV disease reported. However, there are still many cases that are missed.

CMV registry forms are available for physicians upon request. If you would like information

CONTACT US

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1102 Bates St,
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E-mail: cmv@bcm.edu
Phone: (832)824-4387
Website: www.bcm.edu/pediatrics/cmvregistry/

about the registry or the registry forms please contact us.

33 years of congenital CMV research

Houston Congenital CMV Longitudinal study

After 33 years, the Houston Congenital CMV Longitudinal study continues to investigate the long-term outcome of congenital CMV infections. The study includes a total of 237 study subjects who regularly participate, many have completed the follow-up evaluations, tests and procedures. The remaining study subjects continue to follow up with us. We currently have a total of 198 study subjects who are now young adults.

The congenital CMV longitudinal study is possible because of the ongoing support and commitment of participants, their families, our donors and grantors. Thank you!

Collaborating around the world


On 2015 Dr. Gail Demmler Harrison and Jerry Miller, PhD attended the 5th International Congenital CMV Conference located in Brisbane, Australia to collaborate and present new CMV research findings. The conference focused on the novel treatment strategies for CMV-associated diseases and also included informational sessions for the public.

Dr. Gail also collaborated with physicians and scientists in numerous conferences throughout

the year. Some of the work presented in 2015 are shown below:

1. Lanzieri T, Chung W, Flores M, Blum P, Miller J, Caviness AC, Bialek S, Demmler-Harrison G and the Houston Congenital CMV Longitudinal Study. 18-year Audiologic Follow-up of Children with Asymptomatic Congenital Cytomegalovirus infection. 2015 Scientific and Technology Meeting of the American Auditory Society (AAS), March 5-7, 2015, Scottsdale, AZ.
2. Chung W, Lanzieri T, Flores M, Blum P, Miller J, Caviness AC, Bialek S, Demmler-Harrison G and the Houston Congenital CMV Longitudinal Study. 18-Year Audiologic Follow-up of Children with Symptomatic Congenital Cytomegalovirus Infection 2015 Scientific and Technology Meeting of the American Auditory Society (AAS), March 5-7, 2015, Scottsdale, AZ.
3. Demmler-Harrison G, Lanzieri T, Flores M, Blum P, Caviness A. C, Chung W, Miller J, Bialek S. R, Houston Congenital CMV Longitudinal Study Group. Hearing Device Interventions in Children with Congenital Cytomegalovirus Infection (cCMV) and Sensorineural Hearing Loss (SNHL). 5th International Congenital CMV Conference and 15th International CMV/Betaherpesvirus Workshop. April 20-24, 2015, Brisbane Convention and Exhibition Centre, Brisbane, Australia.
4. Lanzieri TM, Demmler-Harrison G, Chung W, Flores M, Blum P, Miller J, Caviness AC, Bialek SR, Grosse S, Houston Congenital CMV Longitudinal Study Group. Sensorineural hearing loss (SNHL) in children with asymptomatic congenital cytomegalovirus infection (AcCMV) identified through newborn screening followed for up to 18 years. 5th International Congenital CMV Conference and 15th International CMV/Betaherpesvirus Workshop. April 20-24, 2015, Brisbane Convention and Exhibition Centre, Brisbane, Australia.
5. Lopez A, Bialek S, Lanzieri T, Claussen A, Abedi G, Vinson Sellers S, Turcich M, Iovino I, Voigt R, A Chantal Caviness, W Daniel Williamson, Demmler-Harrison G, The Houston Congenital CMV Longitudinal Study. Cognitive outcomes of children with asymptomatic congenital cytomegalovirus (AcCMV) infection: Houston Longitudinal Cohort Study. 5th International Congenital CMV Conference and 15th International CMV/Betaherpesvirus Workshop. April 20-24, 2015, Brisbane Convention and Exhibition Centre, Brisbane, Australia.
6. Demmler-Harrison G, Lyons C, Johnson J, Flores M. Global Response to CMV Awareness through a Pediatric Hospital BLOG. 5th International Congenital CMV Conference and 15th International CMV/Betaherpes virus Workshop, April 20-24, 2015, Brisbane Convention and Exhibition Centre, Brisbane, Australia.

UPCOMING CMV MEETINGS & EVENTS



European Congenital CMV Initiative. San Servolo, Venice.
April, 24th-26th, 2016
www.cmv2016.eu

Congenital CMV Public Health and Policy Conference.
Austin, Texas.
September, 26th-27th, 2016
<http://www.cmvconference.org/index.html>

6th International Congenital CMV Conference / 16th International CMV/Betaherpesvirus Workshop
Noordwijkerhout, The Netherlands
30 April 2017- 04 May 2017
<http://www.escv.org/>

The Texas Children's Hospital CMV Clinic is almost 10!

The Houston CMV Research Team follows hundreds of children from Houston and surrounding areas in the state of Texas that have been diagnosed with a congenital CMV infection at birth or around the time of birth.

The Texas Children's Hospital (TCH) CMV Clinic offers a multidisciplinary team approach that include Pediatric Infectious Disease Physicians, CMV expert Dr. Gail J. Demmler-Harrison,

ophthalmologists, audiologists, neurologist, nutritionist, developmentalists, mobility experts to optimize the care for children diagnosed with a congenital CMV infection.

The CMV Clinic also provides treatment with antivirals and other interventions to children with symptomatic congenital CMV, as well as infants and children with unusual or serious manifestations of CMV infections. We work

alongside the Hospital's birthing center Pavilion for Women to test newborns for CMV if they fail their newborn hearing screen.

We continue to actively promote CMV awareness through education of the medical community, public community and healthcare workers.

Parent to Parent Support Network

Every year we welcome new members to our Parent to Parent CMV community. This year we have a total of 689 registered members; 600 in the US and 89 reside internationally.

For parents who are interested in joining the Parent to Parent Support Network and are reading about it for the first time, the parent network database was created to link families who have been affected by CMV.

Members are encouraged to reach out to one another, share concerns, feelings, advice and other useful information.

For our current members we ask to please continue to provide support to new members by

updating the contact information and resources available in surrounding areas.

The information provided to the Parent-to-Parent Network is confidential and is only accessible to members.

If you are 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!



ATTENTION MEMBERS!!

Remember to update your Parent-to-Parent Network information.

CONTACT US:

E-mail: cmv@bcm.edu

Phone: (832)824-4387

Website: www.bcm.edu/pediatrics/cmvregistry/

NETWORK NEWS!

We received news that Maddie's Mission, Stop CMV, and the Utah CMV Council have joined forces to form the **National CMV Foundation**.

You can visit the website at: www.nationalcmv.org

TOTAL PARENT-TO-PARENT FAMILIES WHO RESIDE IN THE US: 600



PARENT-TO-PARENT FAMILIES WHO RESIDE OUTSIDE THE US											
Arab Emirates	1	Canada	22	France	5	Italy	1	Nicaragua	1	Slovenia	1
Australia	9	Chile	2	Indonesia	1	Japan	1	The Netherlands	2	South Africa	1
Belgium	2	El Salvador	1	Ireland	4	Kenya	1	Portugal	2	Spain	4
Cambodia	1	England	19	Israel	4	Mexico	2	Scotland	2		



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**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 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

Thank you for your ongoing support!

Every year we make time to thank all our donors who have made contributions to the CMV Research Fund. This year is no exception.

We want to start by sending a heartfelt thank you to the Smithberger, Jones, Steadman and their loved ones for making donations to the CMV Research Fund in memory of Mr. Andrew Smithberger.

Mr. Smithberger was the great grandfather of Evelyn Steadman who was born with a congenital CMV infection. The Houston CMV Team will continue to work hard to provide

continuous research on treatment and the prevention of CMV disease. As well as to raise awareness of the life-long impact it may have.

We also would like to thank our ongoing donors who continue to support and share our mission to stop congenital CMV.

Listed below are the names of donors who have contributed to the CMV Research Fund for the year 2015.

Thank you for your support!

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

CMV RESEARCH FUND DONORS 2015		
Farah Armstrong	Charles J. & Barbara D. Gallagher	*Mr. and Mrs. Kramer
Cathy L. & John A. Badeusz	Kelia Hayes	G.J & J.R. Kromer
*The Cline family	*Angela Hutter	*The Matter family
Joseph & Anne Cornille	Mr. Robert Jones	*Kathleen Michals
*Amanda Dawson	Sandra Jones	Loddie Naymola
The Den Braber family	Robert A. (III) & Kathleen Jones	Gregory & Stephanie Reed
*The Duff family	Andrew Kamphuis	Debra Wert
Randall Dyk	Robert D. & Connie L. Kamphuis	John & Beverly Winters

* indicates ongoing supporters



Making a difference on 2015

On March 7th, 2015 Farah Armstrong and members of Maddie's Mission organized a successful fundraiser, the Save A Baby Today event, to raise funds for congenital CMV Research and CMV awareness. The event was held in memory of Madeline Leigh Armstrong who lost her battle against CMV at twelve days of life. People from Houston and surrounding cities like Katy, The Woodlands, Cypress, San Antonio, Denton, Arlington, Bryan and College Station joined the cause.

Proceeds from the event were donated to the congenital CMV Research program in Houston, Texas. A check worth \$40,119.81 was presented to The CMV Research Fund at the Check Presentation Event in Baylor College of Medicine on June 5th, 2015.

Some of the event supporters who are known for their philanthropy include Memorial Hermann in Katy, Katy Women's Care, The Shape of Behavior, Arrow Science and



Group photo from the CMV Check Presentation event held on June 5, 2015.

Technology, Lennar/ Village Builders, Kidstown Dental, Elements Massage in Katy, Katy Funeral Home, Nails of America in Katy, Proxy Realty, Renee Jones Interiors.

Top fundraising teams include Team Super Cooper and Dr. Gail's CMVDoc team. Also, Miles for Maddie, Team Brooks, BP Speedy Subsea, BP PFR Power, Spring Branch Bunko Babes, Anchored Hearts, Mithanis For Maddie, So More Will Be Like Sawyer, Team Bailey, Love for Lillian Grace Salerno.



Members of Team Super Cooper at the Save A Baby Today.



Runners at the Save A Baby Today event, March 7, 2015.



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